DISABILITY, TECHNOLOGY & POLITICS:
THE ENTANGLED EXPERIENCE OF
BEING HARD OF HEARING

Ph.D thesis

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ACKNOWLEDGMENTS

Then of course I want to thank the protagonists of my research, the people who live and work with hearing disability and whose input has shaped and substantiated the research project. Firstly, I could not have written a dissertation about hearing disability had it not been for Steinar Birkeland at HLF and Kees Twilt at NVVS. I have benefited immensely from their extensive knowledge and commitment to disability politics. They were the perfect gatekeepers to the hard of hearing community. I am also grateful to the audiological professionals who let me into their practices and patiently explained the fascinating world of audiology, especially Dik van der Kloet, Annema Boberg, Nina Farstad and Stephan van der Hersch, and Gunn Irene Suhr at Statped who got me in touch with informants at home, in Finnmark. Finally, my utmost appreciation goes to the hard of hearing people who generously have told their wise, witty and brave life stories. During interviews we shared thoughts, laughter and some tears while documenting the often utterly unjust experiences of being hard of hearing. It has been a true joy to get to know all of these people, places and practices! When having turned their words into text, I can only hope that it will evoke in the reader what these largely marginalized voices induced in me; a new recognition of difference.

With regard to the last, strenuous months of writing I am forever grateful to Margunn Aanestad at the Department of Informatics. She took me in when I needed it the most, allowed me to finish the thesis *and* introduced me to a new and exciting research project: Flexibility in Integration Process in Public Sector (FIPP). As a FIPP researcher I traveled with my family to Barcelona as a visiting scholar. We had three fantastic summer months for which I want to thank Daniel Lopez Gomez, Mariona Estrada Canal and Israel Rodriguez Giralt at the Universitat Oberta Catalunya. They gave us the friendliest welcome, showing us the pleasant Catalan way of life. I am also grateful to Kevin Brandt and Marianne Lien for correcting my English, and to my colleague Miria Grisot, who helped give the thesis a touch of Italian style.

Looking back, I can honestly say that I would not have endured PhD life, had it not been for my amazing friends. I admire each and one of them for their highly diverse and colorful lives. They have been my great escape when my own life became frightfully dull, filled up with stressful work. Thanks a million Stina, Tanya and Irene, Renathe, Marianne, Erlend and Anki, Johanna and Bart, Silje, Janne and Christian, Johanne and Tor for being who you are, living the lives you do, and for meaning so much to Lars and me.

In my research I have been interested in how different people develop a sense of identity. My own steady rock in life is my family. Because of them, I am always close to happiness, comfort, challenges, wisdom and togetherness. All the things I hold as true and good are

reflections of them, and so is my 'analytical gaze'. My late granny Bergljot taught me something important about storytelling, how to listen beyond the individual and recognize the societal and moral implications of people's stories from everyday life. Following the Nazi's scorched earth tactic, my late grandfather Reidar and his generation literally re-built the Finnmark that I grew up in. When weary of the theoretical texts and talk, it was refreshing to go home and find a very different inspiration in my grandfather's commitment to community and work, to practice. My grandmother Olga has been active in local government, sports associations, and the international feminist movement, just to mention some. Her life-long engagement with politics and issues of international solidarity has inspired me to try to find my own way to contribute to the cause of social justice. My father Kurt and my mother Helene are not only the wisest and kindest people that I know, they are also great fun! Always up for exploring new people and places they have traveled around the world with my brother Hallvard and me. And when in their home, we live in a house with doors eternally wide and ceilings endlessly high. In Oslo, I am fortunate to have my 'little' brother Hallvard living around the corner. He is patient and calm, knowledgeable and witty; what is more, he is among my best friends and our Sunday dinners are the perfect end to the week.

It would not have been possible to explore empirical material from both Norway and the Netherlands without Lars, my better half. We met during my graduate studies in Maastricht, and all the sudden my interest in Dutch politics increased… With Lars, I got a new family to care for and be taken care of. Thank you so much Betsy, Jan, Ingeborg, Gerard and El, for being so lively and warm. You always make me feel at home in Sweikhuizen! It is also true, that it would not have been possible to sustain a four years long-distance relationship had it not been for my cross-country research. With the growth of my research, grew my love for Lars. These entangled relations have produced some remarkable effects! The book you now hold between your hands, but more importantly Nora, our perfect little girl. Thank you both for making my heart smile every day!

Oslo, 9th of February 2010

SUMMARY OF THESIS

Following the 2006 UN draft Convention on the Rights of Persons with Disabilities, disability has undergone a radical conceptual shift in international policy making. Disability is no longer a purely biomedical condition. Instead, it is a matter of cultural difference and social justice. It is no longer the disabled individual that needs compensation to integrate into normal society. Instead disabled individuals should be included as normal members of the multicultural society. But how does one go from here to secure social justice for disabled people? What is disability anyway, who are disabled people, and what expectations do they have for societal inclusion and participation?

Focusing on the largest and, arguably, least visible disability group, *hard of hearing*, in this thesis I investigate the processes of putting policy into practice. Working with empirical material from the Netherlands and Norway I explore how visions for the inclusive society are sought realized in practice. I study how the new policy objectives manage to translate into empowering audiological encounters, enabling technical aids, inclusive material surroundings and respectful social interactions in everyday life.

Mobilizing the notion of entanglement as a framing metaphor, the ambition guiding the study has been to move beyond, but not ignore, the split between a medical versus sociocultural models of disability. In this thesis, hearing disability is not either a biomedical condition or a sociopolitical issue; it is both – and more. I approach hearing disability as a complex phenomenon in which elements of academic reflections, policy making, professional practices and everyday life entangle to give rise to the diversity of experiences of hearing disability. Detailing these relations, I investigate the enactment and ordering of hearing disability in practice. I study how material and discursive elements are combined to make up the conditions of possibility for hearing (dis-)ability, subjectivity and agency. What this means is that this thesis is not about *the* lived experiences of hearing disability, rather it is adding to the knowledge and reflection about relations between people, things and material surroundings that produce a diversity of such experiences. Based on these descriptions, I discuss expectations for, and experiences with social justice among hard of hearing people.

The research project is positioned in and between two interdisciplinary research traditions; Disability Studies and Science and Technology Studies (STS). With Disability Studies, hearing loss is de-naturalized and politicized and, as a culturally complex and socially situated phenomenon, made operable for social science analysis. With analytical tools from STS, Actor Network Theory in particular, I explore the material enactment and ordering of hearing loss in practice.

In line with the material semiotic tradition that has inspired this project, I have not attempted to map and tell *one* large and coherent story about hard of hearing. Instead the thesis consists of several, different stories from various societal domains. The methodological approach has been explorative and multi-sited. Empirical material was generated through literature review, qualitative interviews and participatory observations. Throughout I have established three loci for the study; 'disability policy', 'audiological practices', and 'lived experiences'. Juxtaposing the material from these partly connected sites and situations I enact hearing disability as an entanglement of disability, technology and politics. I follow policy to practice, technology from design to use, and hard of hearing from the clinic and home. Throughout, I move in and between the ideals and objectives formulated in policy discourse and the handling of hearing loss in practice. I explore the conditions of possibilities for hard of hearing subjectivity and distribution of agency throughout processes of putting disability policy into practice. The political ambition has been to locate research in the mundane practices of everyday life to help make visible an invisible disability, and to politicize practices and relationship often screened into a so-called private realm.

The empirical findings are structured in three thematic parts. In *Disability Policy*, I consider how disability is constituted in the context of European political debates on economic globalization, political liberalism and individualization of care. Then I introduce two country specific analyses in which I discuss ideological shifts and drivers in the disability field. I analyze disability policy as discourses; a space for the enactment and ordering of hearing disability that works to frame the 'problem' of disability and what is considered legitimate and effective 'responses' in the context of Dutch and Norwegian aural rehabilitation policy. The analysis focus on the discourse on solidarity underlying the welfare systems, the conceptualization of disability, the disabled subject emerging in political debates, and the outlined geography of responsibility between individuals, technology and society.

In *Audiological Practices,* I study the design and distribution of hearing technology in professional settings. Hearing aids are the most common intervention in aural rehabilitation programs and, thus, play an integral part of many hard of hearing people's lives. Comparing two different approaches to design and distribution of hearing technologies I reject technological determinism by showing how technology can become an active element of the order-building surrounding hearing disability. Moving from design to distribution of hearing aids, I study what happens when people enters into rehabilitation programs and submit their hearing to professional tests, assessments, and treatment with hearing aids. Working with empirical material from participatory observations in audiological clinics, centres and dispensers, my concern is with the relation between

objectification and agency throughout the process of extracting, multiplying, reworking and replacing elements of hearing fundamental to the professional attempts to reconstruct of hearing.

In *The lived Experience of Being Hard of Hearing,* I work with empirical material from a user study in which I have asked how hearing loss is sought ordered in the context of people's broader identity projects. With five individual case studies I explore what hearing disability is made to be through the optics of those living with a hearing loss. I focus on three key issues in today's political debate on disability; *empowerment* in audiological practice; *activation* through hard of hearing careers; and *the equality-difference dilemma* inherent to international policy making on disability. Throughout, I go in-depth on five hard of hearing people's stories. I conclude the thesis by using these individual experiences and viewpoints to reflect on the politics of disability in the light of a broader debate on social justice.

LIST OF CONTENT

PART I – THE RESEARCH PROJECT

CHAPTER 1: INTRODUCING THE ENTANGLED EXPERIENCE OF BEING HARD OF HEARING

> When the declaration was finally approved, there was not only applause, there was shouting, screaming and hugging. Some people even cried, tears of joy. Disabled people had human rights, just like everybody else. Of course I always knew, but now we had it black on white on United Nation paper.[1]

In August 2006 the UN draft Convention on the Rights of Persons with Disabilities was finalized. Following the lead of other social groups, like children and women, disabled people were included in the international legal framework on human rights. The Convention marks a radical shift in the conceptualization of disability in international policy making. The legal framework is expected to become a powerful instrument in the struggle for access to equal rights and dignity for disabled people. Following years of advocacy work by disability activists and disability scholars, disability is no longer a purely biomedical condition. Instead, it is a matter of cultural difference and social justice. It is no longer the disabled individual that needs compensation to integrate into normal society. Instead disabled individuals should be included as normal members of the multicultural society. What follows is an international commitment to promote the inclusion and participation of disabled people throughout society as a whole.

But why did it take such a long time, and how does one go from here to secure social justice for disabled people? What is disability anyway, who are disabled people and what expectations do they have for societal inclusion and participation?

With an academic background from policy studies, I have had the chance to nourish my fascination and respect for deliberative processes: The extensive probing and negotiations foregrounding decision making, and the inspiring atmosphere and expectations following resolution. This time around, I will do it differently. Rather than studying the deliberative processes leading up to the formulation of disability policy, I intend to trace transitions between policy and practice. I will study how visions for the inclusive society are realized

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[1] The quote is from the weblog of Marianne Kroes, member of Dutch delegation to the UN.

in everyday life My focus is on one of the most widespread and, arguably, also the most invisible disability groups; *hard of hearing*.

If you are hard of hearing, you are among the estimated 10 % of a population who have a hearing disability. To be hard of hearing is not the same as being deaf. When you are hard of hearing you have a hearing loss of a more moderate character and you use speech as the primary mode of communication. In addition, hard of hearing people have a historical and cultural background that is distinct from Deaf people.[2] The majority of hard of hearing people are not born with a hearing loss; they sustain it late in life. In general, hard of hearing people do not use sign language or Cochlear Implants to support communication, but they may use a hearing aid. As a social group hard of hearing people are organized around other interest political programs that have not claimed recognition as a linguistic and cultural minority in the same way Deaf people have. While there exists a relatively large academic literature on Deaf culture, the social science literature on hard of hearing is rather sparse.[3]

Partly, the lack of social science studies on hard of hearing is probably due to the fact that traditionally, hearing loss has been the domain of rehabilitation professionals such as audiological experts, designers of technical aids and social workers. From these professional disciplines we learn that a hearing loss usually begins gradually and is found more often in men than women because men normally have greater exposure to environmental noise. If lifestyles include significant outdoor or open window conditions, these exposures over time can reduce the ability to hear. Physical trauma may lead to damage either to the ear itself or to the brain centres which process the auditive information conveyed by the ears. People who sustain head injury are especially vulnerable to hearing loss and/or tinnitus. Exposure to very loud noise (90 dB or more, such as jet engines at close range) can cause progressive hearing loss. Exposure to a single event of extremely loud noise (such as explosions) can also cause temporary or permanent hearing loss. Personal electronic audio devices, such as MP3 players can actually produce powerful enough sound to cause a significant induced hearing loss. A hearing loss can also be inherited. In addition, diseases such as Measles or Meningitis may damage the auditory

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[2] There are those who argue for the strategic advantages for hearing disabled people to address common information and communication needs related to living in a hearing society (see i.e. Valentine and Skelton 2008). However, taking serious people's complex identity projects, I have chosen to limit my study and go in-depth on hard of hearing experiences of disability, technology and politics. Danermark and Gellerstedt (2004) make a similar argument with regard to recognizing difference. Of course, this limitation has meant that a range of interesting topics are excluded form this study, CI, sign language, Deaflympics are but some.

[3] I refer here to the academic literature on Deaf culture already existing both within Disability Studies (See. i.e. Corker 2002; 1998) and the separate field of Deaf studies (Deaf Studies is organized through teaching in UK and US, and takes the form of publications in journals as i.e. the Oxford, Journal of Deaf Studies and Deaf Education or the *American Annals of the Deaf*).

nerve or the cochlea. There are also some medications that cause irreversible damage to the ear. But the most common cause of a hearing loss is 'Presbyacusis' which is deafness due to loss of perception of high tones. It is considered by some to be a degenerative process, although there has never been a proven link to aging. Nevertheless, the incidence of hearing loss rises sharply from the age of 65. Hence, the number of hard of hearing people is growing significantly with the 'greying of the population'.

Aural rehabilitation, the process instigated once a hearing loss is identified, has traditionally been a field dominated by the medical model, a type of knowledge and practice that conceptualizes hearing disability as an impairment of normal body function that requires rehabilitation. Rehabilitation professionals typically address questions about how to eliminate the disability and how to normalize and integrate the hearing disabled person into society. Accordingly, a compensatory process is instigated, commonly entailing the use of technical aids. The role of research within these domains has primarily been to produce knowledge that can be useful in relation to medical and rehabilitation practice. There is a striking lack of explorative and biographical literature on the topic, literature that could work to delegate agency and voice to those living with a hearing loss. In addition, more overbuilding perspectives and descriptive studies are given less space. Next to none academic publications offer reflections on the role of hearing technologies, research and practitioners within the field, nor in relation to broader debates on social justice.

Perhaps this homogeneity should come as no surprise. In our modern societies we have come to accept a fragmented culture in which it is possible to reduce a complex human being to body parts and welfare categories in order to enable legitimate and efficient responses to the 'problem' of disability. However, faced with such a unitary body of knowledge my curiosity was evoked. Can we really turn to audiological text books to learn all we need to know about hearing loss? And if not; *what could be different?* While the rehabilitation literature offers extensive knowledge about hearing loss as a somatic condition, its causes and populace, the ambition guiding this study has been to open up a field dominated by rehabilitation experts, to go beyond conventional understandings and practices and look for alternative stories to be told.

Taking the recent shift in international disability policy as a starting point, I will investigate how the new policy objectives translate into empowering consultation procedures, enabling technical aids, inclusive material surroundings and respectful social interactions in the everyday lives of people living and working with hearing loss. To do this, I mobilize the notion of entanglement as a framing metaphor that opens up hearing disability. In this thesis, hearing disability is not either a biomedical condition or a sociopolitical issue; it is both – and more. I study hard of hearing as a complex phenomenon in which elements of academic reflections, policy making, professional practices and everyday life entangle to

give rise to the varied experiences of hearing disability. Detailing these relations, I investigate the enactment and ordering of hearing disability in practice. I study how material and discursive elements are combined to make up the conditions of possibility for hearing (dis-)ability, subjectivity and agency. What this means is that this thesis is not about *the* lived experiences of hearing disability, rather it is adding to the knowledge and reflection about relations between people, things and material surroundings that produce a diversity of such experiences. Based on these descriptions, I discuss expectations for, and experiences with, social justice among hard of hearing people.

In line with the material semiotic writings that have inspired this project I will not attempt to map and tell *one* large and neat story about hard of hearing. Instead, the thesis consists of several stories from different sites and situations. I use material that go beyond national and disciplinary borders as I follow policy to practice, technology from design to use and hard of hearing from the clinic and home. Throughout, I move in and between the ideals and objectives formulated in policy discourse and the handling of hearing loss in practice. Working with these multiple, partly connected stories I try to learn about hard of hearing as an entanglement of disability, technology and politics. The political ambition is to locate research in the mundane practices of everyday life to help make visible an invisible disability, and politicize practices and relationships often screened into a so-called private realm. Following this, the thesis explores the conditions of possibilities for hard of hearing subjectivity and distribution of agency throughout processes of putting disability policy into practice.

The upcoming chapters comprise material on the enactment and ordering of hearing disability in academic writings, policy making, audiological clinics and everyday life. The findings are reflected in the structure of the book. I will introduce hearing disability as a matter of theory, policy, audiological practices and lived experiences.

Part 1 started with chapter 1, *Introducing the Entangled Experience of Being Hard of Hearing,* where I proclaimed hearing disability as a research project. In chapter 2, *Theoretical Framework*, I present the reading that has inspired the analysis. I introduce two interdisciplinary research traditions rooted in the postmodern project; Disability Studies and Science and Technology Studies. I discuss how they enact issues of disability, technology, and politics. Then I suggest combining resources from these two fields in order to get an analytical grip on matters of subjectivity and agency in the process of ordering hearing disability. In chapter 3, *Research Design*, I discuss the project's methodological stands and the research design. I establish three loci for the study of hard of hearing; 'disability policy', 'audiological practices', and 'lived experiences' and detail my explorative approach to data gathering, analysing and reporting.

Part 2 introduces hearing disability as enacted in public policy. In chapter 4, *Mind the Gap,* I contextualize European Disability Policy. Then I move on to the country specific analyses. In chapter 5, *The Emergence of the Elective Consumer*, and 6, *The Emergence of the Hybrid Welfare Citizen*, I analyze disability policy as discourses that works to frame the 'problem' of disability and what is considered legitimate and effective 'responses' in the context of Dutch and Norwegian aural rehabilitation policy. Based on the review of official documents and interviews with actors influenced by and influential for disability policy, I give an introduction to country specific policy strategies, including historical background and underlying discourse on solidarity. Through these storylines, I discuss ideological shifts and drivers in the field. In the analysis, I focus on the conceptualization of disability, the disabled subject emerging in these political debates, and the geography of responsibility drawn out between individuals, technology and society. In chapter 7, *Two Divergent Geographies of Responsibility,* I contrast the findings from the two countries and draw out further research questions.

Part 3 introduces audiological practices and looks at the design and distribution of hearing technology in professional settings. Hearing aids are the most common intervention in aural rehabilitation programs and, thus, play an integral part of many hard of hearing people's lives. In chapter 8, *Designing Disability*, I problematize the notion of technological determinism by comparing two different approaches to design and distribution of hearing technologies. Based on the analysis, I argue that technology can become an active element of the order-building surrounding hearing disability. In the two following chapters, 9 *Reconstructing Soundscapes,* and 10, *Positions in the Soundscape* I focus on the audiological encounter. I study what happens when people enter into rehabilitation programs and submit their hearing to professional tests, assessments and treatment with hearing aids. Working with empirical material from participatory observations in audiological clinics, centres and dispensers, the chapters analyse how professionals and hearing technologies enact subject positions and distribute agency in the lives of hard of hearing people. My concern is with the relation between objectification and agency throughout the process of extracting, multiplying, reworking and replacing elements of hearing, a process fundamental to the professional attempt of reconstructing hearing. In chapter 11, *Lost in Translation*, I summarize the findings and give some concluding remarks on audiological practices.

Part 4 introduces hearing disability as a lived experience. I analyse empirical material from a user study in which I have asked how hearing loss becomes ordered in the context of people's broader identity projects. With five individual case studies I explore what hearing disability is made to be through the optics of those living with a hearing disability. I focus on three key issues in today's political debate on disability; *rehabilitation*, *activation,* and *the equality-difference dilemma*. Going in-depth on these themes, I mobilize the five stories

as critical cases in which the experiences and viewpoints of individuals are used to reflect on broader challenges and opportunities for the politics of disability. Chapter 12, *Empowering Users,* focuses on aural rehabilitation systems, chapter 13, *Hard of Hearing Careers*, focuses on activation, and chapter 14, *Enacting Difference,* focuses on recognition and redistribution. In chapter 15, *Rethinking Social Justice,* I conclude the thesis by reflecting on the empirical findings in the light of a broader debate on social justice.

CHAPTER 2: THEORETICAL FRAMEWORK

INTRODUCTION

In the introduction to this book I argued that the normalizing medical gaze has worked to silence and suppress other ways of talking about and doing hard of hearing. My concern is with opening up the hearing disability issue to look for different accounts. In particular, I am interested in the sociomaterial conditions of possibility for hearing disability and the way which they emerge in policy and practice. Through my research I have tried to capture and describe as many as possible aspects of hearing loss. When I now turn to theory it is to find resources to explore and to make sense of the sometimes coherent, sometimes contradicting realities that I have encountered during research. In this chapter, I present the intellectual resources and debates that have enthused, motivated and troubled my engagement with the empirical material.

Disability in general has not been much problematized within Science and Technology Studies, while technology on the other hand, has not been a prevalent topic within Disability Studies.[4] Yet, it is exactly the complex relationality between social and material elements – their entanglement – that is at the crux of my exploration into hearing disability. Therefore, I have chosen to combine theoretical insights and methodological sensibilities from these two interdisciplinary research fields to gather and analyse the empirical material. For me, such an active 'pluralogue' with the theories and practices that I have met with has been necessary to reflect the complexity of the empirical material, to avoid reductionism. On the whole, it is possible to trace the common origin of these two research traditions in the postmodern project.

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[4] There are important exceptions, which without my own project would not have been possible. See i.e. Wynance 2006; 2008; Galis 2006; Diedrich 2005; Struhkamp 2004; Moser 2003, 2005, 2007; Goggin and Newell 2003; Moser and Law 1999, 2002; Blume 1999.

A POSTSTRUCTURAL ATTITUDE

This book is inscribed in a postmodern tradition that questions the grand narratives of Enlightenment.[5] From the postmodern point-of-view, modernism is defined by its belief in objective knowledge, or at least in the possibility of objective knowledge, and by its assumption that such knowledge refers directly to an objective reality which would appear in the same way to any observer. A further characteristic modernist assumption is that knowledge is a product of the activity of the individual mind, fashioning its ideas or mental schemas to correspond with this objective reality. Postmodernism, on the other hand, argues that what we call knowledge is a special kind of story, a *discourse* that assemble words and images in ways that appear meaningful to a particular culture, or even just to some relatively powerful members of that culture.

My approach to hearing disability is what might be termed poststructuralist. Poststructuralism does not represent a unitary theory, but rather a foundational idea about how the meaning surrounding nature and society emerges through discursive practice, rather than being discovered in its essence. 'Discourse' is itself a concept with manifold applications.[6] Bacchi (2000:46) has argued that it is not possible to provide a unified and concrete definition of discourse; 'because the whole idea of discourse is that definitions play an important part in delineating knowledge'. I share this understanding of discourse – the objective of this thesis is to scrutinize different discourses on hearing disability, not to replicate them. However, I find it useful here to define discourse as an *analytical* concept and discuss how it can be utilized as such in the context of this thesis.

In French, the word 'discourse' means 'language'. Yet, it is also in France where discourse analysis came to mean something different than linguistic analysis. A leading figure in this regard was the poststructuralist Michel Foucault. Foucault was not concerned with discourse in its linguistic form as much as its function in the social processes and political practices of modern society - the politically constituted nature of discourses. He argued

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[5] The postmodern framework is often referred to as four interrelated phenomena: the increasing incredulity toward meta-narratives, the growing awareness of new problems wrought by societal rationalization, the explosion of new informational technologies, and the emergence of new social movements together constitute what Stephen White (1992:4) describes as; 'an uncertain mixture of challenges, dilemmas, and opportunities that form a distinctive context for contemporary ethical-political reflection.'

[6] Wetherell et al (2001) have two definitions of discourse analysis. It can be seen as the study of language use which is a simple definition where discourse is what is written or said. This is often referred to as an American discourse analytical tradition focused on 'speech acts'. Or it can be understood as the study of human meaning-making which is a much broader definition that does not focus only on language use per se but, for instance, also includes meaning making frames and technologies which involves very little talk or writing. This latter approach is linked to the school of French poststructuralists which I follow.

that what we see as a phenomenon is grounded in the historical and cultural context we see from, and our knowledge about that phenomenon is entangled to the social power to define, categorize and describe nature and culture (Frostad, Solvang and Söder 2000). With his discourse theory, Foucault sought to disrupt the certainties of the present and allow new perspectives to emerge, including those of previously marginalised groups.

HOW TO TELL THE TRUTH ABOUT HEARING DISABILITY

Discourses, Foucault (1972; 1984) argued, are institutionalized forms of power and knowledge, that is, the aggregation of statements that embody rules for the constitution of specific subject positions from where individuals or groups can speak meaningful and with authority and legitimacy about certain things – concepts, objects, and subjects. In *Truth and Power*, Foucault (1980:131) neatly summarizes the theoretical shift in emphasis:

> 'Truth' is to be understood as a system of ordered procedures for the production, regulation, distribution, circulation, and operation of statements. 'Truth' is linked in a circular relation with systems of power which produce and sustain it, and to effects of power which it induces and which extends it into a 'regime of truth'.

In this understanding, discourses are practices that carry and legitimise the worldviews and the actions of individuals and institutions. They operate in discursive fields where accounts are 'circulated, exchanged, stifled, marginalized or, perhaps, come to dominate over other possible accounts and (are) thus marked as the 'definitive truth' which is assumed to be outside the realm of social construction, either already known or self-evident or discoverable through scientific inquiry' (Scott 1988:16). Since a discourse defines the limits for what can be understood and what is possible, things outside the discourse cannot be described: they are silenced. Discourse thus has consequences for the 'realities' which can be known and hence also what is seen as an issue in need of action. In these games of truth *being* is historically constituted as experience; as something that could and must be thought. The discursive meaning is, in other words, not understood as fixed or universal, but as meaning in continual construction. 'Meanings are locally contested within discursive fields of force and the elaboration of meaning (may) involve conflict' (Ibiden 1988:35). This entails that the power to control the truth about disability resides in claims to knowledge embodied not only in writings but also in disciplinary and professional organizations, in the audiological clinic, the job market; and in social relationships between hard of hearing people and their colleagues, between the user of hearing aids and the technical audiologist, between policy makers and professionals. Discursive practice is, thus,

profoundly political; power struggle occurs both in and over discourse and is the spring of social change and transformation.

Given the rejection of objective 'truth', discourse analysts are much more interested in studying the process of construction itself, how 'truths' emerge, whose interests they serve, how social realities and identities are built and the consequences of these, rather than working out 'the authentic story'. The object of research is not hidden behind the discourse. The object is the discourse, how discourses are perceived and shaped in a given context and how it enables and disables specific truths and realities. Herein lies the nucleus of discourse analysis: What matters is not why history takes its turn, but *how*. 'How is the social world, with its objects and subject, constituted through discourse?' What are the 'conditions of possibility' for knowing, and for reality?

Foucault's discourse theory introduces a novel understanding of power. Traditionally, power has been taken to inhere in specific agents such as individuals, interest groups or the state which regulate political life in purely negative forms, as a question of law and prohibition, something that agents execute on passive subjects through a political structure, a government, a dominant social class, or the like. In his lecture series at the College de France, *Society Must Be Defended*, Foucault (2003) argued that rather than seeing structures and agents as the primary entities, we should focus the analysis on the inseparable relation between power and knowledge; we must 'cut the king's head off'. Rather than being centralized and executed top down, power, or to be precise, relations of power, are everywhere, dispersed throughout the heterogeneous everyday practices in which they constitute discourses and subjectivity. Power, Foucault argued, is implicit to our everyday activities; it is exercised in the ways in which we gather knowledge of others. Thus, through audiological research, studies of work place relations, the production of official statistics and the like, 'truths about a 'disabled population' are generated. At the same time, new techniques of power are developed on the basis of these knowledge(s) - such as 'activation policies', 'technical aids', and 'legal frameworks' - suggesting the interrelated and reciprocal nature of power/knowledge. What this implies, is that power is not merely repressive, it is also a constructive force in discourses, a positive condition for the social. With power our social worlds are created, and concepts, subjects and objects are distinguished as characteristic in relation to one another.

Since power is always related to knowledge, Foucault's point is that systems of power produce the subjects they subsequently come to represent, the subjects we are and the objects it is possible to know something about. It is a form of power that makes individuals subjects; subject to someone elses control and dependence, and tied to its own identity by a conscience or self-knowledge. It is a form of power which applies itself to everyday life, categorizes the individual and marks it off as different, attaches it to its own identity, and imposes a law of truth on it that it must recognize and have others recognize in it. What

constitutes the specifics of these power relations is that it does not define power as a mode of action which acts directly and immediately on others. It is a form of individualizing power, which acts upon people's actions: a conduct of conduct, on possible or actual future or present actions (Foucault in Rabinow and Rose 1994).

GOING ABOUT IN THE MATERIAL

Foucault's antiessentialism has been interpreted by some to mean a rejection of reality, as a claim that i.e.? hearing disability does not exist. However, the problem is absolutely the converse. It is a question of knowing how a social phenomena, such as hearing loss, under the various definitions it is given, is at a particular time integrated into one or several institutional fields that can assign to it a specific place and status in systems of policy making, rehabilitation program, or in everyday life. Exposing the contingency of dominant logics should not be read to indicate that reason itself is in a process of collapsing or disappearing. Instead Foucault paved the way for a concern with the multiple transformations, the endless creation of different forms of rationality (Foucault in Rabinow and Rose 1994). For him, the main problem when people try to rationalize something is not to investigate whether or not they conform to principles of rationality, but to discover what kind of rationality they mobilize and what resources they have available when enacting themselves as rational beings. Foucault maintained that such truth games do not arise in some abstract space of thought, a discourse is not merely language. In order for discourses to endure or change they must be maintained in practice, they do not have an essential or objective existence outside the social, they are both constitutive for, and of, the social. A discourse represents actual or potential 'apparatuses' for the production of the social and the biological, it is a heterogeneous grouping composing elements of the said and the non-said, social and technical, human and non-human (Foucault in Rabinow and Rose 1994). The apparatus itself is the network that can be established between these elements. To study discourses, then, means to study the survival and change of these coherent and active set of heterogeneous elements and locate them in specific everyday practices.[7]

HEARING DISABILITY AS DISCOURSE

In her reading of Foucault, Shelley Tremain (2005) argues that his framework can help us identify how it is that the disabled subject is gradually and progressively discursively

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[7] On this, Rabinow and Rose (1994) emphasize how the notion of apparatuses introduced a difference into a field of social sciences predominantly working with notions of institutions, classes and culture, and in terms of ideas, ideologies, beliefs and prejudices. The new problems and relations that came into view, precisely because of the level of detail at which they are described, offered scholars and activists new and powerful rooms for intervention and change in institutions ordering social life.

produced through a heterogeneous arrangement constituting the modes through which human beings are transformed into subjects: the intellectual and practical instruments and devices enjoined upon human beings to shape their ways of being disabled. Refusing an essential human nature does not mean that disabled identities do not exist or that it is an invention of medical doctors and policy makers serving some dubious cause of repression. Something more is involved, however, than the simple observation that its contents vary with time and space. It means that one must investigate the conditions that enable people, according to the rules of true and false statements, to recognize a subject as hard of hearing or to arrange that a subject recognizes itself as disabled within a specific modality of disability that are also practices of power.

Drawing on the discourse analytical framework, I will investigate the modes ordering how people think about themselves when they become hard of hearing, speak about hearing loss, use hearing aids and enter the job market. I am interested in what resources people mobilize when they come to see themselves as disabled individuals and how these discourses are embedded in everyday practices: specific times and places, materials, relations and routines that link people and things together in complex webs of the said and non-said. What this implies, is that disabled people are not passively subjected to dominant discourses. Instead they are the active co-producers of those discourses and are, themselves, an object in it. This process is coupled to knowledge. If what you know of a hearing disability is that you should go to the doctor to get a hearing aid, and thereafter sign up for a welfare program, that is also what you see as your possible actions once you sustain a hearing loss. You become the active carrier of the discourse and it is through your actions that you subject to the position which the discourse assigns you. In this way, discourses contribute with a frame of understanding, or cultural knowledge, that individuals relate to.

Thus when I, in the upcoming analysis, refer to the ordering of hearing disability, it is a study of how the interplay between power and knowledge, the heterogeneous relations between disability, politics and technology, are understood and practiced as 'truths' that people navigate and negotiate with when they actively create their own positions on hearing disability. This means that I am not looking for an essential or authentic way of understanding or doing hearing disability. Rather, I study political reforms, audiological practices and everyday life to try to show how disability is, in itself, a concept undergoing sociopolitical transformation. A process, in which the very meaning of disability, the people referred to as disabled, and the things society surrounds them with, is being constituted.

DISCURSIVE RELATIONALITY

A main criticism of Foucault's discourse theory has been that he, in his empirical work, tended to overemphasise discontinuity and to identify *one* and only one discursive order in each and one historical epoch. Within the discourse analytical field, this monolist idea has to a large extent been replaced by a more pluralistic and conflictual image where different discourses co-exists or compete for domination (Winther Jørgensen and Phillip 2002). Today it is considered equally important to recognize continuities as well as ruptures in our ways of thinking about the social world. Arturo Escobar (1996) i.e.? has argued that discourses do not represent a linear sequence or series of stages in the social history of any phenomenon. They coexist and overlap. Moreover, they co-produce each other; like cultures and identities, they are relational. Discourses themselves may change when they are challenged by other discourses that hold different representations of the phenomenon the discourses are conceptualizing, or by the participants that have not naturalized the specific discourses. Recognizing the plurality of discourses means that it is possible to politicize the discourse analytical approaches.[8]

The notion of discursive relationality is a key premise for my engagement with Disability Studies. As I later discuss in more detail, there are different discourses related to disability in society. Discourses are thus the subject of tensions and contestations. Each of them attempts to provide a coherent 'truth' about disability in different ways. Each has its own idea of what progress means. As a result, each has its own instruments with which hearing disability may be ordered; biomedicine, meanings, policy, hearing aids, knowledge and identities may be important in all of them, although with diverging intensities and configurations. Given that individuals and collectives hold various discourses on disability in tensions, what matters is examining their mutual articulations and contradictions - the ways in which they vie for control over the social and the material. Here then, the notion of discursive relationality can allow us to understand how experiences of disability varies, and to study the politics between them.

The notion of discursive relationality also responds to another main critique of Foucault's work concerning the lack of human agency implied in monolism (McNay 1992). The idea that a discourse determines human affairs is countered by being sensitive to the multiplicity of 'truths' about hearing disability. While discourses take part in shaping the practice, subjects and objects of which it speaks, this does not mean that we have to consider individuals (exclusively) as compliant bodies that passively submit to discursive instructions. In and between different ordering attempts, there is room for critical judgment and social change. By bringing agency back in, poststructuralists open up the

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[8] Influential here is the work of Ernesto Laclau and Chantal Mouffe (1985) on hegemony; and Nancy Fraser (2000) on recognition and redistribution.

possibility for new routes of action and maintain: *things can always go, or at least could have gone, differently.*

This emphasis on change and dynamic in current discourse analysis has been interpreted as an argument for 'anything goes'. However, the meaning and relations within a discourse will always be associated and led by a context in which certain possibilities appear possible, while others remain hidden. To accept change is not identical with dismissing any stabilizing factor. The objective character that a discourse achieves will also limit possible actions, in other words there is no total relativism. Rather the point is to reject a society interpreted with essentialist theories while at the same time remaining alert to how the social and material resources for collectively inventing identities are unevenly distributed.

Thus far, I have discussed the broad theoretical framework that the project rests upon with an emphasis on discourses as heterogeneous practice, the productive and regulative effects of power, and the discursive ordering of concepts, subjects and objects, and the possibility for individuality and social change brought about by the notion of discursive relationality. Echoing the debate on poststructuralism, scholars within the field of Disability Studies and STS have called for new conceptualisations of the body, technology, and identity, and the relationship between them. In the following, I introduce some of these analytical resources and discuss how they relate to my analysis of the empirical material.

DISABILITY STUDIES - OPENING MULTIPLICITY

'Bring back the lived experience of disability'. The claim was made as the international disability movement mobilized against what they saw as the 'disablism' of society, the discriminatory, oppressive or abusive behavior arising from the belief that disabled people are inferior to others (Oliver 1990). The feeling of belonging to a representative category of human identity brought about the struggle for civil rights through the disability rights movement and the struggle for a new discourse on the experiences of disability through Disability Studies. Disability Studies came to provide a common ground for political activists and theoretical scholars whose aim was to politicize disability. As a result, much of the early work within the field was produced by people who themselves had experiences of disability, and who were able to offer personal reflections of marginalization and discrimination. In academic as well as political life disability was personified and politicized in opposition to the medical gaze. Juxtaposing a notion of the lived experience of disability with the medical model, the disability movement sought to articulate a more authentic and just version of disability that could be fused

into academic writings, medical practices and political life. What resulted was the social model on disability.[9] While the medical model has become the main target for critique of the discrimination and repression experienced by disabled people, the social model has been the trope for political mobilization and claims for justice.

CLASHING MODELS

Historically disability has been viewed as the domain of medical sciences. Consequently, the concept of disability has been built upon a (bio-) medical terminology which, according to Social modelists, casts the issue of disability as an individual matter, a personal tragedy following damage or disease. Disability is reduced to impairment, a dysfunction of a particular body. Ideas of the 'normal' body and its 'normal' functions are the point of departure to identify disabled people; those who deviate from normal curves of IQ, faculty of vision, hearing, mobility, and other bodily capacities make up the disabled population, those in need of correction and treatment. Normalization comes by following expert advice and adapt to the biomedicine, technical aids or welfare support made available. As a result, the medical model puts the burden on the disabled individual to adapt to the environment; disabled people can function in society only to the extent that their impairments can be 'normalized'. Practitioners of the medical mode sincerely assume heartfelt, that improvement in functioning will prepare the individual to lead a more successful and fulfilling life. And often it does. However, in more philosophical terms the problem with the medical model is this: How can we create a society in which the equal status of all citizens is paramount when some citizens are assumed to be lesser?

The first generation disability scholars built their theory on a critique of the medical model and its view on disability as personal tragedy in need of a cure or fix. Most disabilities are not curable. They are an integral and durable part of disabled people's lives. Thus, people reacted to being treated as patients when they were not sick, they reacted to being reduced into body parts and impairment categories in matters with profound and complex effects on their lives. People reacted to the asymmetry practiced in rehabilitation systems where the knowing and active experts provided treatment to a vulnerable and needing patient, a system in which the experience, knowledge and aspiration of disabled people did not count. As a response the social model was advocated, according to which disability is located at the interface of particular bodies with

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[9] The social model is the formalized articulation of a set of principles that a group of UK activists advanced in 1976 in order to counter individual or medical conceptions of disability (Union of the Physically Impaired Against Segregation 1976). Important references are Barnes 1991; Oliver 1990; Finkelstein 1980. With regard to the work being done it is common to distinguish between a North American and a British tradition. The British writings stemmed from a historical materialist, or neo-Marxist origins traditionally mainly concerned with material factors, social relations and political power. The US approach had its roots in social constructivism and focused on history, culture, literature and other aspects of discourse and meaning. In the North-American tradition, scholars have not gone so far as with the British 'social model', to conceptualize disability as a form of oppression, but instead developed the notion of people with disabilities as a minority group, within the tradition of US political thought. Key references are Lennard Davis 1995 and Rosemary Garland Thompson 1997.

particular societies. This model attempts to establish disability as a normal aspect of life, not a deviance, and thus rejects the notion that disabled people are in some inherent way 'defect'. With the social model, disabled people could make a distinction between their physical impairments and the experiences of being excluded from societal arenas, the experience of disability. The distinction was made to recognize, understand and alleviate the discrimination and oppression that seemed to be, but did not, inhere in particular impairments. The locus of attention thus shifted from somatic impairment to socially constructed disability. The key question became how to deconstruct normative attitudes and conventions and start to reconstruct the social and material world to better enable the participation of disabled people.

The constructivist approach underlying the social model worked to loosen up the dominance of the medical model by deconstructing its claim of universalism and objectivity, simply demonstrating how things could be different.[10] With the rise of the disability movement followed greater awareness of disability and protection given to the rights of people with disability through national and international legislation and policy instruments. Shakespeare (2002:5) has distinguished two main ways in which the social model has been important for the disability movement. Firstly, it enabled the identification of a political strategy, namely barrier removal as a mean for inclusion of disabled people: 'If disability could be proven to be the result of discrimination, then campaigners for anti-discrimination legislation saw civil rights as the ultimate solution.' The new model thus had the advantage for advocacy of diverting attention from what *happened* to disabled people as individuals to what *happens* to them collectively as a result of unnecessary economic, material, social and cultural restraints. Secondly, the social model was liberating for disabled people themselves, as a way to avoid unitary identification with a stigmatizing and subjugated role as defect patients in a medical system: 'Suddenly, people were able to understand that they weren't at fault: society was. They didn't need to change: society needed to change. They didn't need to feel sorry for themselves: they could be angry.' Rather than the demeaning process of relying on charity or goodwill, activists had found a common ground from where to empower, mobilize, organize and work for equal citizenship.

Since its emergence in the UK in the late 1970s, the social model has more recently received international attention, i.e. taking hold in the creation of the *Disabled People's Internationals* and the adoption by international organisations (UN, ILO and Council of Europe). But whilst the social model became an important basis for a political movement, concerns have surfaced whether it is an adequate grounding for social theory. In particular, two issues have emerged; the resurrection of the body and sensibility towards difference (See i.e. Shakespeare 2006; Tremain 2005; Diedrich 2005; Corker and Shakespeare 2002; Morris 1991).

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[10] A seminal work, often used to back up the social constructionist argument is Groce's (1985) study on the high prevalence of Deaf people on Martha Vineyard; Everyone Here Spoke Sign Language.

DISABILITY - A BODILY MATTER?

A key feature motivating the social model was its distinction between impairment; as the bodily deterioration, and disability; as the disadvantage which is imposed on top of one's impairment. Social modelists see disability as caused by a contemporary social organisation that takes little or no account of people with impairments and which therefore excludes them from participating in the mainstream of social activities (Oliver 1990). What the social modelists rejected was the uni-causal linkage between impairment and disability (Priestley 2003). The thus far; 'unchallenged dogma: that possession of impairment leads to social vulnerability (Finkelstein 1996:29).' Oliver argued that impairment neither equals disability nor causes it. In the more extreme cases, authors even denied the existence of impairment, there was only disability, societies disabling of bodies that stood out from the socially constructed standards and norms. While medical sociology could stick to the study of bodily impairment and medical interventions, Oliver (1996) and Barnes (1998) declared that the focus for Disability Studies should be disability, the social and political responses to disability in society.

In retrospect, scholars have criticized social modelists for downplaying the importance of the disabled body in order to develop a strong argument about social structures and social processes (Shakespeare 2006; Tremain 2005). This critique of the neglect of body was countered by social modelists who argued that the effect of considering individual experience and impairment was to dilute the effectiveness of the social model (Finkelstein 1996). Echoing earlier debates in the feminist movement the body became a contentious issue.[11] Jenny Morris (1991) and Liz Crow (1996) argued that the body could and should not be ignored in social theory and political strategy. The lingering question was whether the social model - with its insistence that disability was mostly, or even only (the strict constructivist version) a social construction of physical anomaly – had the unfortunate and ironic effect of effacing the body. In effect denying individuals the pain and suffering often related to the lived experience of disability. Keen to escape the medical gaze and refusing to take into account the embodied dimension of disability, Williams (1999) criticized the social model for relegating the body to the field of medicine and rehabilitation. Scholars like Tom Shakespeare (2006) argued that a strict antagonistic position to the professional system as a whole offered little ground for disability activists and scholars to become active agents on bodily matters, in result, closing down a potential avenue for bottom-up intervention into medical policy and practices. If so, the social model is not without risks.

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[11] Butler (1990) i.e. argued against the 70s distinction between sex and gender for creating a dangerous dualism of social gender and biological sex. In abandoning the sex/gender distinction *Butler* does not return to the traditional idea that woman's being is biological, instead, she observes that sex itself is alread*y social.*

Although its intent was to empower people with disabilities, to define their conditions as oppression risked characterizing them as passive victims rather than bodily agents. The worry is that with the social model critique of biomedicine, the pendulum has swung too far in the opposite direction, dissolving the discourses on nature into a sociological solvent that left nothing solid behind, leading to sociological reductionism.

The question that confronts both Disability Studies and social theory is how to overcome this impasse without reverting to a naive naturalism that entails its own form of reductionism such as socio-biology; how to bring the body back into the theorizing on disability without opening up to a re-medicalization of disability (Moser 2003; Tremain 2005; Crow 1996). While an antiessentialist approach insists that there is no inherent way to deal with hearing loss that does not mean that we should not recognize and do something about the negative effects of disability. On this, Shakespeare (2006) has developed the critical realist argument that to avoid turning the back to biomedical expertise, disability scholars should reintroduce impairment into their analytical frameworks. While I share with Shakespeare the interest in bodies and medicine I find it awkward that he does not attempt to problematize the somatic body on its return. The poststructuralist response would be that reclaiming the body is not merely a matter of reintroducing the natural body of medicine, but rather, on its return, to denaturalize and politicize the body. What is needed is a way to theorize the body without falling back on the assumption that there is *one* inherent and objective way to deal with disability, and that the biological should in any way determine the subjective experience of disability and its sociopolitical responses.

DISABILITY – A MATTER OF IDENTITY?

> People dwelling in a particular soundscape know the world in fundamentally different ways from people dwelling in a different soundscape (Smith 1999:47).

The social model is used by scholars who try to bring forward the voice and agency of disabled people as authorities on their own lives. The aim is to theorize personal experiences and bring these into the professional literature and develop new and different political insights into the meaning of disability. In taking such an approach, writing about disability reflects the feminist principle that one's personal experiences do not take place in isolation from wider social, economic and political structures. The personal must also be theorized, the personal is political. Following this emphasis on the lived experience of disability, the question emerges; what subject figures in the writings of social modelists?

Shakespeare (2006) has noted that the social model was developed and promoted by disabled people in the context of identity politics. Alliances were formed between scholars and activists in order to challenge the biologisation of difference in the same way in which feminists, black people and gay people had done before them. What is pivotal about the 'identity' of identity politics appears to be the experience of the subject, especially its experience of oppression, and the possibility of a shared and more authentic alternative. Thus, identity politics rests on unifying claims about the meaning of politically laden experiences for diverse individuals. Concern about this aspect of identity politics has crystallized around the transparency of experience to the oppressed and the uni-vocality of its interpretation. Experience is never, critics argue, epistemically available with a singular meaning. Rather it requires a theoretical framework — implicit or explicit — to give it sense (Scott 1992). Moreover, if experience is the origin of politics, then the risk is that what Kruks (2001) calls 'an epistemology of provenance' will become the norm: on this view, political perspectives gain legitimacy by virtue of their articulation by subjects of particular experiences. This closes off the possibility for critique of these perspectives by those who do not share the experience, which in turn inhibits political dialogue and coalition-building.

While recognizing the effort to bring the lived experience back into academia, critics are concerned with how, in identity politics, the understanding of the subject makes a single axis of identity stand in for the whole (Shakespeare 2006; Danforth 2001; Chapell 1998). Disability, as most social categories, is inherently reductionist. The medical model stresses difference over commonality by drawing attention to impairments or individual experiences. The social model, in contrast, opposes this individualistic approach by stressing commonality, at the expense of difference in the collective experience of discrimination and oppression among disabled people. But how representative is the disability movement for the heterogeneity of its constituency? Leaders within disability rights groups have primarily been persons with physical disabilities and the current scholarship in the field of Disability Studies frequently provides the perspectives of persons with physical and sensory disabilities. Yet there is nothing intrinsic to the word 'disability' that suggests physical rather than i.e. intellectual disability. Analytically, it is clear that different disability types impinge in different ways. That is, they have different implications for health and individual capacity, but also generate different responses from the broader cultural and social milieu.[12] The looming question surrounds the degree of social equality and inclusiveness within a movement that attempts to unite persons with a wide variety of conditions and diagnoses. The concern is that politically coherent and symbolically potent

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[12] For instance a wheel chair user may trigger social responses like people staring on the street, while an invisible disability as a hearing loss may not. A hearing loss, on the other hand may cause loneliness and isolation, because of the way it hinders communication.

representation may work to reify and diminish the space for enactment of a plurality of disabled identities, an order in which difference is suppressed. To the extent that identity politics urges mobilization around a single axis, it will put pressure on participants to identify that axis as their defining feature, when in fact they may well understand themselves as heterogeneous selves with multiple identities and political goals (Spelman 1988).[13]

Closely related to this first form of essentialism is a second: generalizations made about particular social groups in the context of identity politics may come to have a disciplinary function within the group, not just describing but also dictating the self-understanding that its members should have. Thus, the supposedly libratory new identity may inhibit autonomy, as Anthony Appiah (Appiah 1994:163) puts it, by replacing 'one kind of tyranny with another.' Shakespeare (2006) fears that the social model may lead to reification of the disability movement in the sense that it has lead people to evaluate ideas on the basis of their conformity to social model orthodoxy. The concern, echoing earlier discussions in feminist theory, is that the lack of internal differentiation between dissimilar experiences of disability may foster essentialism through the denial of differences: different disability groups, different experiences and different attitudes to theory and politics. In result, allowing little leeway for alternative accounts and analysis.[14] Following the critique of the identity politics some recent work in Disability Studies may signal a new approach that might be understood as postmodern, simply pointing out that it cannot be taken for granted who the disabled subject is (Davis 2003; Corker and Shakespeare 2002; Shakespeare 1996; Chappel 1998; Thomas 1999, Wendell 1996; Morris, 1991):

> Disability is the quintessentially postmodern phenomenon, because it is so complex, so variable, so contingent, so situated. It sits at the intersection of biology and society and of agency and structure. Disability cannot be reduced to a singular identity: it is a multiplicity, a plurality (Shakespeare 2002:19).

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[13] Blume (1999) has illustrated this problem with the dispute over Cochlear Implants. The procedure has been embraced by hard of hearing organizations, who organize people with increasing hearing loss and therefore are potential candidates for surgery, and who also sees CI as a bridge to potential members from the Deaf community. In the Deaf community the reception has been far more critical. CI has been seen by Deaf organizations as a threat against their long fought struggle for cultural recognition

[14] As Chappel (1998) has pointed out, presenting the argument about lack of internal diversification should create a sense of déjà vu. A reading of the history of second-wave feminism makes it clear that the first feminist literature which emerged in the early 1960s, with its idealist emphasis, claimed to articulate the experience of all women. However, the experiences of white women are often quite different from the experiences of ethnic-minority women. To treat them as one, has merely worked to ignore the experiences of these minorities, and relegated them the status of 'the Other'.

Postmodern critics are not arguing for disaggregating disability and referring solely to clinical diagnosis, but for recognizing that the different major groupings of disabilities, because of their experiential impacts, cannot be reduced to a singular experience. Besides, there is more to a disability than disability. The authors point to the great diversity among disabled people on the basis of age, gender, class and sexuality, differences that have not always been well treated in the literature addressing 'disability' as a unitary phenomenon.

PROMISINGLY DIFFERENT

In her account of Disability Studies, Ingunn Moser (2003) refers to this postmodern turn as a second generation disability scholars. They stand for a form of writing that is no longer that strongly linked to the agenda of the disability movement, in particular the advocacy of the social model. Instead, these scholars have moved towards a broader approach to cultural studies of disability. While this cultural turn is marked by multiplicity with regard to topics, theories and methodological approaches, Moser also points to commonalities. In particular, the theoretical interest in poststructuralism and feminist theories, and the topical interest in the body, identity, individual/subjective experience of disability and the importance of discourse to the social ordering and regulation of disability:

> What this adds to earlier work on social constructions of impairment and disability is that disability is studied as a cultural and discursive phenomenon which is not only produced in social interaction and institutional arrangements. It is also produced in cultural and representational practices. Further the focus is no longer simply on the production of disability and its regulation, confinement, and exclusion. The focus is on the relation, and more specifically, on the dependence, between the cultural constitution of disability and ability, the deviance and the norm. Disability is seen to be *internal* to the configuring of the abled, the norm, and the culture from which it is marked off and expelled (Moser 2003:11).

Criticizing the normalizing ideology, scholars started to deconstruct the binary in which disability had been placed. Rosemary Garland Thompson (1997), in particular, has been an influential figure. She conceptualizes disability as an exclusionary system – a form of intolerance – that produces the 'disabled' as well as the 'able-bodied' through shifting, interrelated web of linguistic, legal, medical, political, social, economic, *and*, material and technological structures. Structures holding in place a hierarchy of bodies in which some were valued, other denigrated. The refusal to accept binaries is important also because it challenges the social model's status as a kind of meta-narrative on disability.

In the clash between the medical model and the social model, the social modelists appear to behold of the 'real', 'true' logic of disability, that of social oppression, which has been masked behind the false consciousness of medicine. In this struggle over truth the social model evokes a sense of essential end of history. It is as if all the sociopolitical barriers

encountered by disabled people were removed, disability itself would cease to exist. Discourse theorists are critical to the structuralist underpinning of this argument (see? i.e. Tremain 2005). They refuse to reduce disability to oppression and instead deconstruct the binaries which set someone out as 'the Other' in the first place. Being positioned in opposition to the medical model, the social model has constructed its identity as inherently different from the medical model. As a counter model, we could say that the social model is defined by its dependence on the medical model. Every attack is also an account of the medical model's power. The antagonism of the social model, in effect, works to reinforce the dominance of the model it tries to break down. The identity of each model is the result of discursive articulations - with biological, social, and cultural couplings - that take place in an overall 'field of discursivity' wider than any particular model (Laclau and Mouffe 1985). That means that by enacting the division between the medical model and the social model one risks reducing and silencing alternative accounts. With discourse theory, scholars instead aim to break down the dichotomy between the medical and the social model by opening up for a radical difference in the discursive field. Rather than explaining disability in terms of meta-narratives, such as that of capitalism and modern assumptions of 'truth' and 'reality', disability is seen as constituted in and through specific sociomaterial arrangements. In this framework, one studies how discourses on disability are dispersed throughout societies in fragmented, hybrid ways. The framework enlarges the conventional notion of disability to include attention to how the disabled subject is produced by the discursive practices in which disability is enacted.

Lisa Diedrich (2005) has suggested that we problematize the received history of the disabled body, disrupt the notion of a continuous development of ideas and images, and shift the focus to competing, fractured, and discontinuous discourses culturally embedded in particular historical periods. In this framework, it is important to recognize continuities as well as ruptures in our ways of thinking about the social world. While the social model might have gained influence in certain policy circles, faith in rational science and the ability to ameliorate or manage social problems with technology endures in diverse areas of culture, including the disability field. The social model does not replace the medical model. It introduces an alternative, among presumably many more. What persists is a multitude of modes of ordering disability and the relationality between them. Rather than taking the antagonism between the dominant and suppressed as the starting point for analysis, poststructuralists refuse to speak in terms of fixed identities. Instead they strive to be sensitive towards the several routes towards being disabled. They look for how people hold different realities in tension, which shapes their identities in hybrid and fluid ways. On these grounds multiplicity and openness - to not yet imagined difference - seems a better option to explore and reflect upon the politics of disability. For Moser (2005) it is important to argue that this introduction of difference and new alternatives in itself

contributes to making visible what normalization has made invisible, disarticulated and stood in the way of.

And here my engagement with Disability Studies starts, in search for new analytical tools with which to revisit the disability issue as an entangled experience emerging in the various, complex arrangements of subjectivity, bodily senses and materiality.

THE MATERIAL MATTERS

> Whether in the home, at work or leisure, technology plays an important role in the lives of people with disabilities, and also in the way disability is conceived, experienced and framed in society (Goggin and Newell 2005).

Technologies are widely implemented as technical aids in aural rehabilitation programs. As users of hearing devices, hard of hearing people are enrolled in webs of relations that consist not only of hearing aids, wires and batteries, but also of people, formal procedures, organizations and work. Users become part of an intricate geography of responsibility in which the social and the material rely upon one another to work.

In public discourses on disability, technologies are often enacted as problem solvers. As Goggin and Newell (2003) make clear, the dominant thinking is that the more and newer technology, the better for disabled people. Consequently, political analyses of technical aids tend to focus on their quantitative aspects; who have access to how many devices, and at what cost However, one of the strong points of the social model was its focus on how technologies and the material environment can also become barriers for the inclusion and participation of disabled people. Hence, it is important to maintain an analytical space for the recognition that technology represents possibilities both to improve and exacerbate problems encountered by disabled people. Thus, rather than make deterministic assumptions about technology's effects, positive or negative, we should instead engage it and study it in practice. Acknowledging that sociomaterial arrangements have the power to enable *and* disable people, we must also ask how exactly this is done. Inspired by Ingunn Moser's (2003) material semiotic approach to disability, technology and the politics of everyday life, my interest is in what subjectivity and agency hearing technologies enact through use, and what is made of disability in these heterogeneous practices.

Despite the wide variety of approaches and topics, surprisingly few works within Disability Studies has dealt with technology. Indeed, most of the Disability Studies literature has not

had an account of the materiality of the social world and identity projects in it. This void might be understood in the light of the social modelists' aspiration to move Disability Studies out of the medical gaze. With the attempt to understand and analyze disability outside of the medical model the focus went from science, technology and medicine and towards social and cultural processes in the quest for an alternative discourse on disability (Diedrich 2005; Moser 2006b). As with the body, technology too became relegated to the domain of technical expertise. This is problematic since, clearly, models and discourses on disability have material as well as social consequences, and we should scrutinize their relations and effects. To interrogate and bring together those complex worlds of disability and technology, I mobilize and combine the critical insights from Disability Studies with the material semiotic sensibilities of Science and Technology Studies (STS). The aim is to add to the understanding of the (dis-)abling effects of materiality.

STS provides a conceptual register to make sense of the messy, inequitable process through which the production of science and technology becomes entangled with human subjectivity and social orderings. At its core lays the rejection of technological determinism by pointing out contingencies; *things can always be different*. Rejecting determinism, STS researchers instead thrive on their sensibility for the multilinearity of design, distribution and use of technology. STS, in Foucauldian terms, represents an anti-positivist approach to science and technology. Critical interventions in the politics of science and technology have been at the crux of the field since its early beginning.[15] Rather than conceiving of technoscience as engaging in some pure practice of discerning facts about things apart from 'interest, justice and power', STS demonstrates that the knowledge of things and human politics and forms of power cannot be separated from each other. According to Bruno Latour (1993), STS is always attempting to retie the Gordian knot by crisscrossing, as often as we have to, the divide that separate exact knowledge and the exercise of power – let us say nature and culture. Over the years STS has grown and become a highly diversified field with a multitude of approaches.[16] For this project, I mobilize a material semiotic approach concerned with use, users and the politics of practical ontology.

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[15] Asdal, Brenna and Moser (2007) explain how STS grew out of an interest in the difference made by science and technology, and the possibilities for making science and technology differently. From being seen as an inherently neutral, progressive and prosperous human project, in the 1960s in the wake of the atom bomb, the Green revolution, DDT and other pesticides, people's faith in science and technology became mixed with scepticism. As a result, demands and attempts to democratise science and technology were being made, and critiques and analyse were developed of the social relations and contexts of science and technology.
[16] For an introduction to STS see i.e. Asdal, Brenna and Moser 2007; Sismondo 2004; Jasanoff 1995

ACTOR NETWORK THEORY

> The commitment to relationality makes it possible to explore strange and heterogeneous links and follow surprising actors to equally surprising places (Law 2007).

The material semiotic route towards surprising places started out in the late 1980s as scholars in STS became interested in developing a poststructural approach to the study of science and technology.[17] These scholars brought with them the fundamental idea that the work of science and technology is not fundamentally different from other sociocultural activities. However, keen to avoid the sociologism inherent in some earlier work by sociologists studying scientific knowledge, scholars wanted to develop analytical tools based on an antiessentialist attitude towards science, technology and society.[18] What emerged was Actor Network Theory (ANT). ANT privileged neither natural (realism) nor cultural (social constructivism) accounts of scientific production. Instead, John Law (1987) asserted that science is a process of 'heterogeneous engineering' in which the social, technical, conceptual, and textual are puzzled together and transformed.

Despite its name – Actor Network *Theory* - ANT is not really a theory at all, rather it is an ethnomethodological approach to study science and technology.[19] Acknowledging the built nature of sociotechnical networks and with a predisposition to exemplary case studies scholars like Madelein Akrich (1992), Michel Callon (1986), Bruno Latour (1987) and John Law (1987) approached the sites where science and technology were being done; laboratories, design work shops, computer labs and medical institutions to examine the taken for granted.[20] [21] They applied the methodological principle stated by Latour for

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[17] It would perhaps be more accurate to trace beginning of ANT already back in the late 1960s when Sociologists read Kuhn and created a sociology of scientific knowledge (SSK). Their key idea was that a paradigm can be understood as a culture. In other words, science was a social construct (Barnes 1974). SSK thus deposited scientific knowledge from the pedestal upon which positivism had put it. SSK asserted that scientific knowledge should be treated as any other form of knowledge, and thus, that it too is subject to social control and social interests. The connection between knowledge and power could then be thematized together with ethical questions and issues concerning social change. In this way of thinking the absolute truth of a theory is irrelevant since there is no independent way of knowing it. This led to a methodological dictum, the so-called 'principle of symmetry': true and false knowledge, it was said, need to be explained in the same terms (Bloor 1976).

[18] Notwithstanding its originality at the time, SSK was also criticized for being too narrow in its focus on science in terms of social interactions. The problem was that it dematerialized the study of science, and tended towards sociological reductionism (Pickering 1995). ANT, in part, sprung out of this critique of SSK.

[19] According to Law (2007; 1997), advancing a single set of principles is seen as counter to the desire to sustain ANT as a diverse and dispersed set of practices with transformative properties.

[20] Law (2007) has explained that this preference for exemplary case studies is another borrow from Kuhn who said that scientists work through cases, exemplars. Knowing formalism is not enough. You need to know what they mean in practice. Knowledge lies in exemplars and words are never enough.

analysing science as practice; 'follow the actors', in order to identify the ways in which they associate the various elements that make up their social and natural worlds.[22] Asking in what way materiality is influential for the ordering of social interactions, they developed a research agenda evolving around the notion of a practical ontology. They studied *how* different realities are being built and sustained through sociomaterial practice. Simultaneously they described the making of knowledge, the epistemological.

MATERIAL SEMIOTICS

> This is a *material semiotics* in which facts, artifacts, nature and objects are treated not as given categories lying outside culture or society, but as effects of interactions, relations and order building. One investigates what something is by asking what it is made to be and how it emerges. One traces what its – materially heterogeneous – conditions of possibility are, what relations it emerges from, how it is done in practice and with what effects (Moser 2007:376).

ANT started out trying to understand 'technoscience' as the creation of larger and stronger networks.[23] [24] The notion of a network stems from semiotics, which treats meaning as an effect of relations between signs and traces the unfolding of order building. But while poststructuralists focused on how   is constructed and understood through language and discourse in social context, ANT extended the semiotic approach by adding materiality to the networks it studied. To get a practical grip on discourses, Law (1994) suggested that we understand material semiotics as an empirical version of poststructuralism. He proposed to cut the Foucauldian discourses down to size, and understand them as actor-networks or 'modes of ordering.' His point is that despite the

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[21] Other scholars within STS working under the same ethnomethodological guidelines, but not within the analytical framework of ANT, were Karen Knorr-Cetina (1981), Michael Lynch (1985), Steve Woolgar (with Latour 1979), and Sharon Traweek (1988). Their common goal was to understand 'science in the making' rather than knowledge that had been judged by history and been 'black boxed' (Asdal, Brenna and Moser 2007).

[22] Latour (1987) draws this principle from ethnomethodology and from Hughe's (1983) slogan 'follow the actors' and injunction taken up by Callon (1980) and then by Latour to explain science in action, followed scientists and their work practices, as well as the specific practices of representation with which they describe the world.

[23] 'Technoscience' is Latour's terminology (1987) since, according to him, science and technology involve the same process. As an antiessentialist movement, ANT does not differentiate between scientific knowledge and technology.

[24] The ANT analysis can be seen partly in analogy to traditional analysis of power politics; just as the political actor strives to put together alliances that allow him to maintain power, so do scientists and engineers (Sismondo 2004).

contingency of real life, recognisable ordered patterns are still discernible. A kind of coherence emerges and works to order interactions, practices and materialities.

On this, Moser (2003; 2005) explains that ANT should be understood within the tradition of empirical philosophy that investigates the specific and localized conditions for both knowing and realities. This reflects the influence of Foucault, and his attempt to understand present realities by tracing how they emerge and become what they are. The material semiotic tradition takes quite literally the Foucauldian definition of 'discourse as *a strategy in material* and traces it in local, situated practices and a wide set of relations and arrangements (Law 1994 in Moser 2006a:376).' Rejecting essentialism and meta-narratives, instead one; 'investigates empirically the conditions of possibility of facts and truths as well as objects and realities' (Moser 2003:27). The argument is that the networks of the social come in a variety of material forms, for instance, people, texts, machines, architectures. Order then, can be understood as constituted through practice, which in turn arise out of mundane and routinized ways of acting and interacting. To study ordering one follows practice, because practice connects knowing with doing, the power to act. The analytical task is to draw out different ordering attempts and convincingly demonstrate how they work in the specific materials and interactions which one studies.

ANT proponents do not subscribe to the division between society and nature, truth and falsehood, agency and structure, context and content, human and non-human, micro-level phenomenon and macro-level phenomenon. Binaries between nature and society, subjectivity and structure, fact and fiction are all treated as effects of semiotic relations. This 'relational materiality' or 'material semiotics' presupposes that all entities achieve significance in relation to others (Law 1994; 1999). It assumes that what is produced, together with whatever goes into producing it, secures its significance, meaning, or status. Not because it is essentially this way or that, but rather because of how everything interacts. Concepts, subjects and objects are all produced in circumstances that are materially heterogeneous. These materials are not given in nature; they are more or less precarious ordering effects which express themselves in different ways, including that of durability. This means, that the distinctions between ideas and objects, between knowledge and infrastructure are enacted rather than given in the order of things (Law 2007).

With the semiotic toolkit, the network elements were deprived of their essential character, demoted and treated as the effects of semiotic relationality. The distinction between these entities is of little analytical importance except in terms of their practical performance, their semiotic effects. But, as Law (2007) crucially emphasizes, this is not to say that they are not real – they may indeed be *made* real in practice - but they offer no framework for explanation. Relations need to be repeatedly performed or the network will dissolve. Social order is, thus, seen as an effect caused by the smooth running of an actor network, not as an

essential feature of the network; it is the dual process of complexity unfolding and ordering in the making.

This theoretical insight was expressed in the methodological principle of 'generalized symmetry (Callon in Law 1986).' One should not make a priori distinctions between the natural and the cultural. Even the boundary between human and non-human dissolved when all elements were approached symmetrically. People, as well as things were treated as relational effects. Any 'actant', whether person, object or organization, is equally important to a social network and capable to act upon one another.[25] What emerges is an interest in the productivity of practice. One should start out with as few assumptions as possible, to learn about *how* realities are being built and sustained through sociomaterial practices, *how* the elements of material-semiotic networks come together to act as an apparently coherent whole. The focus for analysis is thus the relations and interactions, or the heterogeneous practices, that carry and (re-)produce relations. Hence, Law (1994) describes ANT as a contingent sociology of verbs, not nouns. Realities exist but they are brought into being by ordered arrangements of specific actors and practices. If the arrangements are lasting, some verbs may end up acting for longer than others. Some may even look like nouns for a while, depending on the actors' ability to produce stability.

THE FEMINIST INTERVENTION: DIFFERENCE AND POWER

Throughout the latter part of the twentieth century and into the twenty-first ANT was increasingly criticized. The critique which has given most momentum to the material semiotics approach came from feminist theory and mainly evolved around two concerns; the issue of women's invisibility in (historical) accounts of technology, and a conceptual lack of difference and power.[26] ANT was attacked for its almost exclusive attention to experts and producers (mostly men) and for the preference given to design and innovation in understanding sociotechnical change. Critics targeted the distribution of agency, and accused ANT of 'managerialism'; for excluding and silencing the accounts of marginal positions, and the tendency to:

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[25] Through this insistence on methodological symmetry ANT caused turmoil in the scientific community. Criticism of various aspects of such disposition has been expressed particularly in terms of normative worries and accusation of political abdication. See i.e. Collins and Yearley 1992 for a critical comment and contributions in Harbers (2005) for more positive, yet critical, discussions of the normative and political implications of this post-humanism.
[26] That women's relation to technology earlier was relatively 'invisible' can be explained by how women's artefacts were not considered to be 'real' technologies, and thereby not considered to be interesting enough for STS researchers compared to the dirty and noisy machines we find in spheres dominated by men, for instance in industry (Lie 1998).

> … approach any object of study from above, from a position of control. And of studying only strong, heroic male actors, and so also colluding in making these men even bigger and more heroic while the rest of the world is performed as silent and passive (Moser 2003:30).

Much early ANT work centred on key figures, heroic scientists and technologists, or of failed heroes. It was as if the world revolved around these powerful *men*. This obsession with powerful actors paid less attention to non-standard positions, including women's voices. Such narratives did not say anything about the entities that were excluded from the actor-network. Susan Leigh Star (1991) argued that ANT analyses tended to make invisible the efforts, practices and functions of less powerful entities. The managerial approach implicitly assumed a specific type of power relations between i.e. users and designers in which designers are represented as powerful and users disempowered relative to the experts. Feminist scholars like Lie and Sørensen (1996) suggested instead that the distribution of power and agency in sociotechnical affairs should be approached as an empirical question. Additionally, they were critical to the notion of human relations put forward in early ANT studies. Moser (2003:30) has argued that they were; 'disturbingly Machiavellian-Nietzschean'. The development and spread of technoscience was interpreted and described as an entirely cynical and strategic enterprise, a power game among actors who saw the world of science and technology as a battlefield. There was no room for chance, collaboration and care.

The feminist approach is instead focused on 'the Other' - on everything that is not necessarily represented in the technology – and from there observes the conditions for use of technology. This type of attention reminds us that technology is not neutral, but strongly political – it marginalizes certain actants and limits participation. Judy Wajcman (1991) suggested that focusing on users and use rather than on engineers and design would enable historians to go beyond histories of men inventing and mastering technology. Similarly, Susan Scwartz-Cowan (1987) urged STS scholars to choose the user, rather than the artefact or the technologist, as a point of departure in analyses of technology. This would enable a conceptual shift, in which users were not seen as passive recipients of technology, but as active and competent consumers. Feminists emphasized the diversity of users and, thus, encouraged STS scholars to pay attention to differences in power relations among actors involved in the development of technology. The feminist intervention, thus, aimed to avoid silencing invisible actors and to include power relations explicitly in the analysis of sociotechnical relations. The project was to give voice, agency and relevance to the trivial, mundane and understudied. With the turn towards users and everyday practice, a new avenue of STS studies emerged.

STS scholars were no longer merely occupied with the invention and impact of technological artefacts and the societal regulation of these. Rather than viewing technology and users as separate objects of study STS scholars started to look at the relationsbetween them. The idea was that a study of technology in use in everyday life contexts could improve our understanding of the unanticipated consequences of technology in the hands of the users (Schwartz Cowan 1987). A new branch of STS studies emerged which focused on users and their different roles for technological discourses, deliberations and decision-making, design and development strategies, and appropriation of technological artefacts and systems in work life and domestic settings (see i.e. contributions in Oudshoorn and Pinch 2003; Rohracher 2005). What these studies revealed was how different groups involved in the design of technologies may have different views of who the user might or should be, and these different groups may mobilize different resources to inscribe their views in the design of technical objects.[27] As Oudshoorn and Pinch (2003:6) have noted; 'the very act of identifying specific individuals or groups as users may facilitate or constrain the actual roles of specific groups of users in shaping the development and use of technologies'. Studying technologies in their context of use – the society and the web of other elements within which technologies are always embedded - a core finding of these studies was that there is no one essential use that can be deduced from the artefact itself.

The emergence of User Studies was further important because it entailed a conceptual shift in the view of the user. Users went from being seen as a passive receiver to become active subjects interacting with technology trying to fit it into their everyday lives. Studies of users revealed how they partake in the continuous order building surrounding the multilinear shaping of the meaning and practices surrounding technology. With the turn towards everyday practice, use and users STS researchers could analytically access science and technology as lived experiences and make visible the politics of technology as enacted in everyday life. The approach also opened for an analysis of the role of technology for enactment of different social identities and relations between technology and humans. With the new figures and sensibilities brought about by feminist scholars and User Studies, STS broadened the scope for analyses of the politics of technology. Not only did these new writings draw attention to the involvement of users in technology, but in the later years, as the field has grown and more empirical research has come about, a more critical view on user involvement has developed, considering also the barriers and limitation for user involvement (Rohracher 2005).

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[27] Inscription refers to Madelein Akrich's (1992) material semiotic concept of a 'technological script' introduced to illuminate how technological design could become a disciplining force in the relations between humans and their machines. The concept draws attention to users as represented by designers rather than users as individuals or groups involved or implicated in technological innovation. I will use this concept in chapter 8, *Designing Disability*, where I study the design of hearing aids.

ANT differentiates itself from other sociologies with its sensitivity to the materiality of our social worlds. However, critique was raised that it did not seriously engage in the materiality of the cases it studied. Especially the early ANT studies, with their emphasis on construction, were accused of reproducing the social deterministic ghost of the past (see i.e. Grint and Woolgar 1997; Barad 2007). Here the feminist and ethnomethodological oriented studies of science and technology have contributed to develop a further sensitivity to things, details and specificity which has given rise to an approach that might be called 'post-constructivist'.[28] In the assemblage of research which makes up today's material semiotic approach the core of ANT persists, the interest in knowledge, practice, heterogeneity, process (*hows*), and relations. What is new is a focus on performativity and the multiplicity of ordering.

Linking a postconstructivist attitude up with the performative tradition, Annemarie Mol (2002) has pointed to the important metaphorical and explanatory shift that has taken place in the new material semiotic studies.[29] We are no longer dealing with construction in any form. The centred and strategic subject is gone, there is no social or individual to construct anything. Thus, the metaphor of construction is no longer useful. Rather we are dealing with 'enactment'. 'In this heterogeneous world everything plays its part, relationally. All the heterogeneous elements gather and together enact a set of practices that make more or less precarious realities. Any coherence, if it happens at all, is a momentary achievement' (Law 2007:13). Here, the focus has shifted from the centred construction of networks towards the multiple enactment of intersecting modes of ordering. As before, 'ordering' calls up a process: it suggests that the activity of ordering involves a continuous effort, and that it may always be frail. 'Modes' is a plural: it invites a comparison of different ways of thinking and acting that co-exists in a single time and place. There is no single enactment of reality, but the possibility for multiple realities. What then emerges is an interest in the politics between them (Mol 2008).

Crucially, Moser (2003:47) has noted that this does not mean that everything flows and anything goes. Things tend to remain the same, or appear impossible to change because they are enacted in the same way, to the extent that they become naturalized and appear as

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[28] For STS related research on postconstructivism see i.e. contributions in Mol and Berg 1998 on Medicine; Asdal 2003 on Environmental history; Barad 2005 on Physics

[29] Karen Barad (2007:28) juxtaposes performativity with 'representationalism' – the idea that representations and the objects (subjects, events or states of affairs) they purport to represent are independent of one another: 'Performativity is an alternative to a constructionist approach (which much as their scientific realist counterparts, are based on representationalist beliefs). The move towards performative alternatives to representationalism changes the focus from questions of correspondence between descriptions and reality (e.g. do they mirror nature or culture?) to matters of practices or doings of actions'. For other STS studies dealing with performativity see i.e. Callon (1998) on economic markets; Mol on the medical body; Markussen (2005) on research.

given: 'In order to simultaneously explore and describe the dynamic and unstable character of reality *and* the naturalized character of ritualized, embodied and materialized practices, realities are better understood as enacted and re-enacted into being, that as constructed and reproduced.' Using the term 'enactment', material semiotic researchers not only seek to reveal the meaning of the world from the point of view of its actors, but what is actually produced in these sociomaterial practices.

With the new line of ANT studies followed a topical expansion with an inwards move towards the users, consumers, citizens and other configurations of subjects and bodies that are made along with the facts and objects of science and technology, opening for new domains of study. While early ANT sat out to de-naturalize science and technology, the new generation ANT scholars moved from 'outer nature' to 'inner nature', from design workshops and power plants to bodies and subjectivity. Moser, influential for introducing the material semiotic approach to Disability Studies, refers to Bruno Latour (1999:22-23) who concluded that; 'inner nature is no less inner than outer nature is outer'. Instead, with the new material semiotics emerging, they are all:

> … expressions or manifestations of materially and discursively heterogeneous relations, the interactions that carry and produce these relations, and their ordering. There is no clear dividing line, at least in principle, between the technological, the social and indeed the human. This means also that ability and disability are located neither within people nor society, but in the particular sociomaterial arrangements of relations and ordering of practices that simultaneously produce the social, the technological, the embodied, the subjective and the human. Any of these entities as well as their character, composition and boundaries are thus understood as relational effects, and as effects of ordering work (Moser 2006a:376).

In her work to understand what happens when one becomes disabled, Moser retains the link between discourse analysis and ethnomethodology and extends it into the study of disability as an emergent sociomaterial practice.[30] She combines the notion of order building with the question of how disability is done in everyday life; the character of the modes of ordering that emerge in these practices; how this ordering is achieved; how disability is done in different material forms, and the nature of the relations and interferences between these ways of becoming disabled. In this framework, disability is not

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[30] The question is inspired by West & Zimmerman re-conceptualization of gender as 'a routine accomplishment embedded in everyday action' (1987:125 see also West and Fenstermaker 1995). Their analysis of differences from the standpoint of ethnomethodology turns the focus away from individual characteristics. Instead, they are understood processually as emergent properties of social situations which simultaneously produce systematically different outcomes for social groups and the rationale for such disparities.

a role or individual property, but a product of sociomaterial relations. In these relations it is not only the meaning of disability, but disability itself that is created. Disability is something that one *enacts*, and enacts recurrently in interaction with others. This means that we need to investigate *how* exactly disability is made in social interactions and *how* it comes to matter in people's lives, and *how* technology is involved in such processes.

The notion of enactment is promising because it can be used to surpass the antagonism between the medical model and the social model on disability. Basically, enactment states that phenomena only have an ontological reality in the doing. Disability is neither a biomedical condition nor a social construct. Rather it is enacted and emerges as material semiotic effects in which bodily, social, and material elements entangle in specific ways. Disability is what it is made to be, in practice. No model on disability is real before it is enacted into being, through the relations of concepts, subjects and objects such as policy documents, hard of hearing individuals, hearing aids, audiograms, visiting hours, and work environments. No mode of ordering hearing disability is dominant before it becomes routine, materialized and socialized in practice. What this means, is that I approach hearing disability as an enactment without an essential quality, but nevertheless real and with social consequences. Rather than treating disability as free-floating discourse and psychology, the material semiotic approach offers an opportunity to engage with experiences of hearing disability with a sensibility for how it is actually being done, how the process of doing hearing loss is ordered, what the regulative and productive elements of this are. To deconstruct these ordering modes is to explore how the various elements together make certain practices appear as natural, given truths about hearing disability, in turn, revealing the politics of disability. It is these processes that are the conditions of possibility for hearing disability. In these processes disability becomes real and the hard of hearing subject emerges.

HEARING OUR MULTIPLE SELVES

How then to analytically access the lived experience of disability? Both social modelists and scholars working with the material semiotic approach have run into problems when attempting to conceptualize subjectivity and agency. Within Disability Studies, the problem was the tendency to suppress difference. Equally problematic was early ANT and its flight between, on the one hand, a posthumanist extremity, and on the other hand, the centred, cynical and strategic subject pulling the strings from the top of the networked world.

Looking for fresh analytical resources with which to study processes of subjectivity in relation to disability, Moser (2006a:377-8) has suggested combining material semiotics with poststructural identity theory. The idea is to start out with as few theoretical assumptions as possible and instead approach the question of subjectivity and agency as an empirical matter, to be traced locally:

> …my interest and concern is with what subjects are enacted in interaction with material arrangements, as well as *how* they are enabled in practice. For this I adopt the notion of 'subjectivity' in its semiotic and poststructuralist usage, as referring to a location of consciousness, knowing, thinking or feeling. This is a very open definition that makes few assumptions about where or what kind of location this is, and so provides me with an undetermined framework for tracing the making, shaping, embodying and delineating of subjectivities empirically.

In the poststructural framework, subjectivity emerges in relation to available subject positions that individuals can try to identify with, change, avoid or even ignore, or have others identify them with.[31] Subject positions as i.e. woman, hard of hearing, and mother, belong in modes of ordering gender, disability, and family life, which ascribe meaning and room to position. We identify with subject positions because they explain and give norms and rules and directions to humans living in society. Subject positions offer us viewpoints and classificatory schemas to think and act with in concrete situations (Laclau 1996; Laclau and Mouffe 1985).

On this, Foucault (1988) argued that the increase in knowledge, as attached to specific subject positions with which one identifies, does not mean solely that one becomes more enlightened but also that one becomes subordinate to the discourse's expectations on what is normal, acceptable and working. The knowledge arrived at through discourse, about the world and about oneself, both disciplines and makes possible. This productive dimension imbues the concept of subjectivity with a political sense. As we identify with and use

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[31] Caroline Williams (2002) has noted that it is hard to pinpoint the exact origin or position of poststructuralist thinking on subjectivity. Partly because the field embraces such diversity of thinkers who adopt markedly different positions upon the concept of the subject, and partly because their points of references are closely related to other, even competing theoretical positions. Nevertheless, William refers to four key figures inspiring contemporary poststructuralist work on subjectivity Althusser, who conceptualize the subject as a function of ideology, Derrida who sees the subject as being opened up by *differance*, Lacan who argues that the subject is an imaginary caught up in a linguistic relation, and Foucault, who focuses on the subject as a modification of power relations. While diversified in their theoretical positions these poststructuralists thinkers are unified by the mode of questioning of and pre-occupation with the concept of the subject: What does it mean to be a subject to be constructed according to certain presuppositions rather than others? What moreover, are the philosophical and political effects (and costs) of the construction of the subject?

subject positions we take part in the (implicit) meaning struggle on what kinds of identity forms and world views should be considered as natural and truthful in particular situations (Shapiro 1992). Subject positions, thus, give us guidelines for deciding what one should consider in specific cultural contexts where one seeks to act as sanctioned, normal and desirable as distinct from prohibited, deviant and repulsive (Sarup 1996).

Subject positions are more or less easy to access or avoid as there are some we cannot avoid, some we cannot reach, and a whole spectrum in between, which are open for negotiation. The way positions are activated must always be recognizable within the existing discursive frames in order to be accepted and they must somehow relate to other subject positions identifying the individual. This means that subject positions cannot be freely chosen. What is of particular interest then is the manner in which positional limits are constructed. These limits allow certain positions to be constituted as outside the differential system of interaction. This boundary work involves a political judgment. Since ordering modes are multiple and without essential justifications there is always room for difference and social change.

The material semiotic approach adds to the contingency of identity theory by investigating not only the discursive, but also the material space for such positioning. In this framework, disability does not inhere in the individual, but in the modes of ordering disability in which individuals interact, the sociomaterial arrangements that make available certain ways of enacting the world, of positioning as hard of hearing. To understand how experiences of identity vary, Moser (2003) insists that one engage with the multiplicity of modes of ordering disability that are active in a given empirical material while also being open to how experiential variation stems from the multiple subject positions held by individuals and their mutual influences. This means that hard of hearing people may occupy a range of subject positions within social relations. Positions that may be donned or shed, muted or made more salient, depending on the situation. One may be a friend, spouse, professional, citizen, and many other things to many different people - or to the same person at different times. What is clear is that if we are to understand how experiences of hearing loss vary, we must allow for complexity of the life stories, wherein disability is one, out of several subject positions and must be negotiated as part of an overall identity project.

Asking how differences are made, interacted and come to matter in people's lives, Moser (2005) introduces the concept of 'interference' to the study of disability. She explains that not only are people made up of several subject positions, these subject positions also come to matter to each other. Sometimes they work together sometimes they seem to work against each other. And other times, they are simply made irrelevant. Thus, we should study the enactments of different differences and the relations and interactions between them. Such theorizing on the subject, what it *is*, or how it *should* be conceptualized, is not to

be made *a priori*. Instead, Moser insists that we engage with these processes in practice, deconstruct the social and material components to carefully explore what it takes to become a subject and what kind of configurations this builds or seeks to achieve.

BETWEEN SOCIAL ORDER AND INDIVIDUAL FREEDOM – THE QUEST FOR AGENCY

In the poststructural framework, disabled subjectivity arises out of the discursive and material structures in which people interact. The subject cannot be assigned either origin or essence and thus must lose its status as sovereign power and source of knowledge (Williams 2002). This claim has (somewhat superficially) been taken by some to mean that poststructuralists deprive the subject of its source of agency and its capacity for self-determination. Such critics insist upon the 'death of the subject' in poststructuralism and have, in my view, contributed to strangle discussions of the political implications of analyses of subjectivity. Whatever their particular perspective, poststructuralists thinkers by no means abandon the concept of the subject. Rather they infuse the subject with new meanings and new theoretical possibilities. Discursive structures are both productive and regulative, but that does not have to imply that they are deterministic. As argued by Laclau and Mouffe (1985), we cannot ignore the agency of the individual, however, limited, suppressed or condemned, the way we all in different ways and to different degrees strive to shape our own destiny. Given that subjectivities emerge in and between different modes of ordering hearing disability, and that hard of hearing people have access to a variety of subject positions, there is a (limited) room to position strategically in the meeting with different ordering attempts. This dynamic attribution of agency assigns room for critical thinking and guarantees the possibility of human individuality.

In this framework, agency too becomes an empirical matter. Analyzing the enactment of subject positions can show how people use ordering modes as resources to constitute themselves as meaningful agents in the stories of their lives. By positioning in and against different ordering modes, people can make a critical space for themselves to oppose dominant ordering modes and negative subject positions through a process of differentiation. People can enact an understanding of a specific mode of ordering disability, say the medical by going to get a hearing aid, and still attempt to construe a counterargument to medicalization by undoing and disputing its categorizations, story lines and positioning. In arguing instead i.e. for a social model on disability, the attempt is to move the disabled subject out of the patient position, and into the position as a citizen. By expressing one's own position, one also criticize and oppose the counter position. Key to the analysis is therefore to become sensitive to how people look for ways to thrive on the creative tension between social orderings and subjective experiences of disability.

Again the material semiotic literature adds specificity to the analyses of these processes of identification and agency. Concerned with action, Moser (2003) and Moser and Law (1999) have explored the question of (dis-)ability: how people become able or disabled to act. In these studies, they find that agency derive from a chain of material semiotic relations that distribute actions between people, things and material surroundings. Disabled people are what they are and can act the way they do because they are linked to technical aids, devoted family members, accommodated work places, and so on. Moser and Law, conclude that we are all enabled and disabled in different and specific ways, because we are all made (dis-)able through the sociomaterial arrangements in which we are positioned.

Summing up then, the assumption is that hard of hearing peoples' experiences do not spring uncontaminated from an essential inner disabled way of knowing, but is structured within and in opposition to material semiotic relations through which experiences are constructed. In the empirical chapters, I explore the details of this 'order-building'. 'Enactments' are the focus of analysis because these are the processes that produce and move ordering modes. These are the practices that make a difference. The importance of 'subject positions' in this context is that they can explain similarities and differences between people with reference to the modes of ordering from which they emerge. Agency too is studied as an *effect* of these sociomaterial arrangements, dispersed throughout the material semiotic relations in which subjects are (dis-)abled to act.

Turning to the empirical material, I will investigate the modes of ordering hearing disability that makes different positional strategies appear more or less feasible. I study these to learn about how things can remain stable and some people choose to submit to negative ordering attempts without being irrational. What people perceive as options depends on what positions they perceive as (im-)possible and what social and material resources they can mobilize to reach them. Studying these conditions of the 'real' can tell us something about what truths about disability exist, are contested and/or changed through people's active positioning in relation to ordering modes. By identifying different positional strategies, I study what realities on hearing disability are being fought over, which ones are taken for granted, and which need to be justified. This also goes for hard of hearing identities. I am interested in which identities are accepted and understood and which ones are contested or rejected.

INTRODUCTION

My research interest is in exploring the sociomaterial conditions for hard of hearing subjectivity and the distribution of agency in transitions between policy and practice. My concern is with how the ideas and visions enacted in documents on disability policy translate into enabling technologies, inclusive material surroundings, and empowering social interactions. Opting for an explorative approach meant that I wanted a research design that could give room for uncertainty, unpredictability, and theorizing about relevant relations and phenomena that were not defined in pre-formulated research questions, but instead evolved through my interaction with the field. But where exactly is *the hearing field*, and who, and what belongs in it? Obviously, my use of the notion of a 'field' is strictly metaphorical. Fields do not present themselves as pre-given objects that can just be entered. They *emerge* during the process of research design, and they must be localized. Analytical approaches to theoretical concepts such as *enactments*, *modes of ordering* and *positional strategies* require an empirical construction in order to become qualitative research domains. Therefore, in this chapter, I account for and reflect on the work with gathering, selecting and analyzing empirical material on hearing disability as an entangled experience.

Practices dealing with hearing loss are dispersed throughout a multitude of locations and involve numerous actors. Policy makers draft anti-discrimination laws, disabled people take part in the job market, and designers make hearing aids. Broadly speaking, my research approach was developed as a two-step design. First, I reflected on issues of disability, technology and politics as I encountered them in my studies of research literature and public policies on disability. Then, I moved from policy to everyday practice, from formalized deliberation to situated practice in order to study what happens when policies on hearing disability are to be translated into dynamic relationships between hard of hearing people, professionals, and technologies.

To bring out the complexity of hearing disability, I have gone beyond national and disciplinary boarders and across sites and situations. I have followed policy to practice, technology from design to use, and hard of hearing individuals from the clinic to their homes. In the analysis, I bring this diversified material into the same frame of study and

discuss how these different practices relate in complex ways.[32] Interacting with documents, people, and technologies, my aim has been to learn about how different modes of ordering hearing disability emerge and relate and give rise to a multiplicity of experiences of hearing loss.

When gathering empirical material, I have tried to get a range of views on hearing loss. When writing, however, I have not strived towards depictions of what is normal or general in the hard of hearing community. I have been interested in nuances and understanding rather than explanation. The material that I present, aims to introduce difference to the field; different ways of writing policy, different ways of designing technologies, different forms of practicing audiology, and different ways of being hard of hearing. More specifically, I have looked for accounts that represent what Bent Flyvbjerg (1994) has called 'critical cases', cases that can have strategic importance in relation to general problems. Contrasting policy with practice I have not looked for material that can confirm what we already know, but rather selected cases that made me re-think and then re-define dominant knowledge, cases from which new learning can be derived. Flyvbjerg's point is that those few interviewees or observations that produce a radical different or contrasting material can often be central to modifying theoretical and political assumptions and attitudes. Atypical or extreme cases often reveal more information because they activate more actors and more basic mechanism in the situation studied. From an explorative perspective it is often more important to try to detail the complex processes leading up to a given problem and its consequences, rather than merely describe the symptoms of the problem and how frequently they occur. In the light of this, critical cases are selected to make visible challenges and opportunities for fulfilment of policy objectives, the idea being that if these do not occur here, they probably never will. However, when objectives fail to realize, despite specific preconditions being present, there are lessons to be learnt.

Throughout, I have defined the objects of study through several different techniques, but the research has had three loci; hearing disability as 'policy matter', 'audiological practice', and 'lived experience'. While the choice of a multisited approach has offered a rich source of empirical material this unavoidably also lead to a problem of limiting the data collection. Not all sites are treated by a uniform set of participatory observation practices of the same intensity and qualities. In the following I detail what sites and situations have been investigated; what methods and techniques were applied; and how choices were justified.

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[32] The approach is inspired by the ethnographic work of George Marcus (1995), pioneering the multi-sited methodology. Marcus has argued that the value of this methodological strategy lies in its capacity to make connections through translations and tracings among distinctive discourses from sites to sites

DISABILITY POLICY

> More so than conventional approaches, a postmodern policy analysis offers the opportunity to interrogate assumptions about identity embedded in the analysis and making of public policy, thereby enabling us to rethink and resist questionable distinctions that privilege some identities at the expense of others (Schram 1993:249).

Norway and the Netherlands adhere to the same international framework on disability policy, the UN declaration of Human Rights and the EU Framework on Equal Citizenship. As I will show in the empirical analysis, both countries identify similar structural challenges and opportunities for disability policy. In addition, both countries are pluralist democracies with strong corporative traditions. Yet their disability policies diverge. While the Dutch have opted for a market-oriented policy reform, the Norwegians maintain their welfare state model. As a result, the countries enact two very different responses to the issue of disability.

In the light of this difference, my curiosity was triggered, not by the fact that policy diverge, this has been well documented in the political science literature. Rather, what evoked my interest is the question of *how* such divergence comes about, and with what implications for the entangled experience of hearing disability. To explore the emergence and performance of country specific disability policies, I have not been interested in the type of research resting on methods of benchmarking, regression or typologies. Rather, I have been interested in what policy does, in the lives of those working with and using health care and rehabilitation systems. What does it mean for you and me when policy establishes a holistic approach to aural rehabilitation, how does one go from being a patient to becoming a health care consumer? These are the types of questions that have given my project momentum, questions which the modernist oriented policy analysis had conspicuously few answers to. So if not a policy analysis in the traditional instrumental sense, what type of policy analysis have I conducted, and how did I go about?

ON THE MATERIAL

In the analysis of national policy making on disability, I approach policy as discourse. The basic assumption is that policy is constitutive of the reality against which it is directed.[33] The empirical material underlying the analysis is gathered through reading of political documents and 16 interviews with people in and around the Dutch and Norwegian political-administrative systems

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[33] A fundamental acknowledgment guiding postmodern policy analysis (see i.e. Schram 1993; Hawkesworth 1988; Stone 1988).

that in different ways have been influenced by and influential for the development of policy on hearing disability. These include representatives from user organizations, professional organizations, industrial actors and governmental representative. In the analysis, I identify and discuss the key concepts, subjects and objects of Dutch and Norwegian disability policy. The aim is to trace similarities and differences in lineage and configuration of contemporary policy.

My approach is limited both in theoretical and methodological scope. Empirically speaking, I have chosen to focus my policy analysis on the health care and rehabilitation sector, which also means that I have had to exclude other important areas for disability policy, e.g. educational and human rights issues. My study is further limited with regard to timeframe. The written material I have analyzed has been released during the last ten years, and interviews have focused on contemporary developments. What is more, which I discuss further below, when gathering material I have chosen to focus on a few key documents and actors to go in-depth on these. What this means, theoretically speaking, is that the study is limited to a descriptive oriented analysis of a few concrete texts and interviews, rather than constructing a complete account of meaning, power and institutions in a political field.[34] Since my research design involves multisided qualitative work in two countries, in which policy analysis is seen as *one* out of several rooms for the enactment of disability, such a comprehensive methodology has simply not been feasible within the framework of this PhD project. Surely, focusing more broadly on *one* country or *one* institution would have given me more detailed empirical material to support my analytical discussions. It is, without doubt, a long step from exploring how a few policy documents and interviews enact policy, to arguing how, or to what extent these actually shape politics. On the other hand, as argued earlier, the advantage of multisided research is its ability to present a multiplicity of enactments of disability and analyzes their relations.

Then, once an empirical domain was located, how did I identify and make its active discourses operable for analysis? With a broad interest in problem representation concerning disability in the context of national policy making there were many potential data sources. Politics is not only shaped by actors, but influenced by other material forms, documents, newspapers, procedures and legislative frameworks. In the process of gathering material, I have located discourses on disability as they are represented in policy documents and in the 'talk' produced during interviews. In the empirical chapters, the focus is on the documents, and what was said during interviews, not on the actors and institutions expressing them. This is not an analysis of the politics of user organizations, political parties or specific welfare agencies. Rather it is an analysis of their (various) influences and relations as emerging in the policy documents and interviews which I study. This does not mean that these actors are not important, but that they are not the central units for analysis, and such empirical data is not explored in a systematic way.

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[34] The latter form of analysis is proposed by Neumann (2001) who emphasizes discourse analysis as a method consisting of several steps: Identification and limiting of a discourse (including revealing its genesis and institutionalization through the review of a broad swath of relevant literature), uncovering the discourse's key representation and social hierarchies, the discourse's material forms (what social, material and institutional conditions the discourse is produce under), and investigating the discursive effects, including power relations.

The material from the interviews has been helpful in identifying key documents, actors and for elaborating on the underlying models on disability which were presented in the texts, and in introducing me to the broader historic and sociopolitical context for disability policy in the two countries. In addition, the interviews gave me insight to the workings of the aural rehabilitation systems, the flow of users, the technologies made available, and the expertise involved. The conversational-based form of the interviews allowed me to probe theories, analysis, arguments and concepts, by entering into a dialogue with the participants, inviting them to take part in the analytical process and verify my data (Andersen 2006). Structure and meaning was then constructed in common by the interviewee and I. During interviews, notes were made by hand and later transcribed.

From the array of written material on disability policy, I have selected a few, key documents as entrance points to the analysis of how the 'problem' of disability and legitimate and effective 'responses' are designed and represented in political discourse. These specific documents have been selected because of their availability: they are all accessible online, readable in English, Norwegian and Dutch, and the function they have; they are key political documents conceptualizing disability and giving concrete guidelines for aural rehabilitation in their respective national context. They are documents which have been released to signal that a government wishes to focus on a specific policy area and therefore aims to give a coherent overview of this field. Strategically speaking, these types of official documents can be read as an attempt to lay down the discursive frame for the policy, and are important points of reference for public debate and scholarly work on disability policy. What is more, the documents I have analyzed result from the collaborative writings of politicians, professionals, and interest organizations in the disability field and therefore are a good source of key problem definitions on disability from the intersection of professionalism and politicization. Next to official documents, I support my analysis on the work of other researchers and their work within the field. All sources are listed in the literature list.

FROM DATA TO ANALYSIS

My approach is close to Carol Lee Bacchi's (1991) 'What's the Problem?' method. Bacchi builds on discourse analysis in her approach to policy analysis.[35] Her method involves a conscious shift in focus from analysing policies as attempted 'solutions' to 'problems', to the analysis of competing interpretations (or representations) of policy problems and the political issues underlying them. An implicit connection is thereby made explicit: how we

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[35] I discuss the theoretical foundation for Bacchi's method in part II, *Disability Policy*, here I focus on her methodological approach to policy discourse analysis.

think about something will affect what we think ought to be done about it. The prescribed method is to start out with a broad and explorative research question, and through the detailed engagement with the empirical material and the main themes one identifies develop more specific research questions for further analysis. This explorative method stands in contrast to the more common found ideal in policy analysis – starting the analysis with a clearly defined and limited research problem. The point is that in my study of disability policy, the object of study is exactly how problems are constructed in the empirical material. Too narrow, theoretically grounded assumptions of how this is done would potentially get in the way of the analysis. By this, I do not mean that the analysis started from an objective position, that I, as a researcher, was somehow an unbiased reader of the material. Rather, the analysis was built on an ambition of positioning as open as possible to a limited empirical material, to thereafter develop analytical categories through the engagement with the empirical material.

Key to Bacchi's method is the contrasting between alternative, competing problem representations and different policy outcomes that can be taken from the debate itself, or be suggested by the researcher, critically examining their effects. This analytical grip works to de-naturalize discourse. Such de-naturalization can occur by shifting theoretical perspective, by tracing debates over time, and by comparing debates across sectors. Stenvoll (2003), and Sirnes (2001) suggest that international comparison is particularly well suited for such de-naturalization purposes because a comparable debate in another country provides the researcher with the opportunity to move beyond the national discourse and in this way uncover *doxa* (Bordieu 1977). This perspective has been important for my own choice of research design. In the gathering and analyzing of the empirical material I have strived for a certain balance. I have selected documents of key strategic importance in both countries and interviewed informants representing similar types of institutions. Nevertheless, given the difference in structure and variable access to the field, the material from the two countries is by no means comparable in a systematic way.[36] Rather, the material has been collected according to a contrasting approach, to illuminate similarities and differences between the two countries' policies.

In the analytical chapters I use the empirical material to move in and between the two national contexts in order to reveal different ways of dealing with disability in policy making, and the assumptions underlying these. Since my aim has been to construct a critical room for reflection about current practices the 'What's the problem' approach seemed appropriate to illuminate the contingency of disability policy; how hearing disability is conceptualized, what is considered legitimate and effective responses, and the

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[36] For instance, I have conducted interviews in Norwegian among the Norwegian actors, while in English with Dutch only as a support language among the Dutch actors.

status of the hard of hearing subject. In order to structure the method, I present the reading of the material as main storylines on disability in national policy making, stories that order a set of problem representations. In my view, each of these storylines contains and structures the discursive drivers and shifts leading up to current problem representations regarding disability in the two countries. In the analysis, I investigate the causality presented in the storylines, how disability is conceptualized as a social phenomenon in need of policy intervention, the constitution of the disabled subject and the geography of responsibility between individual, technology and society. Throughout the analysis I also focus on the specific policy aims and objectives enacted in the texts and discuss other political effects of different problem representations. The assumption is that disability policy plays its part not only for the redistribution of welfare, but is also a key distributor of identity. As distributors of identity, discourses have consequences for the shaping, but also the experience of disability policy.

The presentations of national disability policies in the book are of course reworked and shortened understandings that I, as a researcher in a field with which I had no prior knowledge, have developed based on the limited empirical material I have collected. They are by no means exhaustive descriptions or analysis of disability policies and rehabilitation systems since the data I use were gathered from specific sites at a specific time. This is the nuisance of writing empirically oriented analysis; while this text freezes, the field keeps on moving. On this subject, Torfing (1999) argues that the validity of discourse analysis lies in the eyes of the reader, based on their assessment of its scientific robustness and whether it manages to bring on new knowledge not delivered by other forms of theoretically grounded analysis. For a quality check of my analyses, I have looked to the empirical domains that I have studied. I have participated in informal and formal events organized by research communities, user organizations, professional groupings, and policy makers. I have met with the people who, in different ways, animate disability policy in their everyday lives. They have given hours of their time to let me present my arguments in text and speech, before commenting and discussing these critically with me. Based on these encounters I have had the chance to revise and develop my analysis further.

TECHNOLOGICAL DESIGN AND AUDIOLOGICAL PRACTICES

> In fact, we still know very little about actual design practices and the use of technology. Since these practices are now at the centre of almost all professional, domestic, and leisure activities, we might as well say that we know very little about what people really do (Vinck 2003:203).

Hearing tests, functional assessment, and treatment with hearing aids are common responses to hearing loss. What is characteristic of these activities is their professional underpinning. Professionals consist not only of technical audiologists, but also special educators, dispensers, engineers, and marketers; people who through their jobs enrol people into aural rehabilitation programs. To learn about these processes in which hard of hearing people are introduced to hearing aids I have studied audiological practices.

But why would I want to study audiological practices when this thesis is an attempt to make a difference in a field hitherto dominated by professional knowledge? The answer is that aural rehabilitation is part of the entangled experience of being hard of hearing and, as such, should be part of the project of opening up the hearing disability issue. In doing this, I follow Annemarie Mol's (1999) plea for social scientists to abandon the simple taking of positions *for* or *against* medicine, and rather to engage in a serious dialogue with practitioners and practice. In line with the new material semiotic studies of medical knowledge and practice (see i.e. contributions in Mol and Berg 1999), my attempt has been to position as an engaged and negotiated insider, rather than an oppositional outsider.

Arguing against the tendency in social model writing to silence and suppress professional practices to escape the medical gaze (Oliver 1999), Davis (2000) makes a similar argument from within Disability Studies. Drawing on Rabinow (1986), he claims that to engender social change, we need to study people in positions of power. Rehabilitation professionals are often being accused for inhibiting the empowerment of disabled people. To learn about the structural and cultural pressure that professional practices relate to, I have visited different sites and professionals that people encounter as service users. I have done this to try to understand how professionals, technologies, and systems may themselves experience a limited room for manoeuvring in the cross-pulls from different ordering attempts. These are conditions which may invite and/or inhibit social change. Therefore; 'the role of the researcher should not simply be to confront oppressive practices, but also to unpick both the pillars upon which these practices are built and the vested interests which sustain them' (Davis 2000:200). The argument is that by valuing all respondent's (disabled

and non-disabled) experiences and viewing them as inter-related, this form of research overcomes Olivers' (1999:187) concern that from the outset researchers create a set of social relationships in which 'we designate disabled people as inferior'. Instead, the key is to view all actors as possessing the potential to contribute to constructive professional-lay relationships. Investigating audiological practice might thus, in some modest way, trigger reflections on the professional ordering of hearing loss, reflections that can lead to new developments in the field.

With this methodological stand, I have gathered material to trace transitions between aural rehabilitation policy and practice. In the light of the ongoing attempts to de-medicalize aural rehabilitation by shifting power from the professionals to clients I have investigated how audiological professionals are influenced by the developments in disability policy, and how professionals influence disability politics. In the empirical chapters, I use the empirical material to explore how audiological professionals deal with hearing loss. Then I contrast the findings with the objectives found in disability policy. In part III, the findings are structured in two thematic sections, *Designing Disability* and *Audiological Encounters.*

ON THE MATERIAL

I have gathered and present empirical material that describe a typical audiological trajectory. I started out by studying the design of hearing aids, asking how hearing aids become inscribed with social order and with what material and discursive effects. When hearing technologies are developed they are moved out of the workshops and into the clinics and dispensers. Following hearing aids from design to distribution, I have studied the processes in which they are introduced as ordering elements for hard of hearing people's lives. Data were gathered from several sources in Norway and the Netherlands. I have visited workshops, seminars, and conferences on technical aids. I have reviewed written material from producers and dispensers of hearing aids. I have interviewed representatives from five of the world's largest hearing aid producers and 16 representatives from professional groupings. Finally, I have been a participant observer during consultations between professionals and clients.

For participatory observations four different sites were selected that represented the institutional variety of the Dutch and Norwegian aural rehabilitation systems. Visits were approved by management following a letter that informed about my research, my institutional affiliation, the purpose of the study, and how I planned to gather and handle data. I started out by making a list with questions that served both as interview guide and as a guide for participatory observation. The idea was that using the same questions in interviews and during participation could make me more aware of the implicit and non-verbal elements of practice. The ethnomethodological point is to study not only how people

see things, but how they do things, studying practice. The point is not only to access meaning, but to observe how social orders become enacted (Silberman 1963). Each visit lasted for three working days, during which I followed the staff around and observed their routines. During consultations with clients, the staff would introduce me as a student studying use of hearing aids. I would be placed next to the professional, in order to see them operating their computers. At times would I ask the professional to demonstrate and explain their use of a specific tool. These interventions led to reflexive in situ discussions where I got viewpoints not only on what was actually being done, but also what could have, and perhaps should have been done under different conditions. During breaks I took part in discussions among staff on the political and organizational framing of aural rehabilitation. During observation, notes were made by hand and later transcribed. When I use empirical material in the text, I describe contexts and situations in some detail. These extracts serve as starting points for analytical discussions. Staff and visitors are then given fictional names. A 'quick and dirty' study, such as this, does of course not produce a proper ethnographic note book with sufficiently numbered stories to give a thick description of the entire range of practices included in the field of audiology. It has, nonetheless, enabled me to bring out some of the differences in audiology.[37]

FROM DATA TO ANALYSIS

The promise of a material semiotic approach is its ability to bring out and juxtapose different ways of knowing and practicing the sensorial, subjective, technological, and material realities of hearing loss. To go from the theoretical ambition of breaking down binaries to locating sociomaterial relations in practice I have tried to follow Latour's (1990) 'strategy of deflation'. He asserts that in order to understand the dramatic effects of technoscience, it is best to avoid large explanatory systems and instead focus empirically on its mundane practices. Latour claims that it is only by examining carefully the things professionals do with bits of paper, tables, traces, instruments, reagents, and the like that any understanding can be gained of science's abilities to manipulate and produce the material world.

With these analytical sensitivities, I have entered audiological practices to study some of the processes involved in making hearing operable for audiological intervention. Through a close engagement with the details of audiological practices, I have tried to obtain empirical descriptions of the practices in which the social and the material become entangled. I use this descriptive approach to explain how audiological knowledge and practices are made

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[37] For a similar approach, studying food to make an argument for an ethnography of daily care, see Harbers et al 1999.

possible and implemented and with what effects. In the empirical chapters, I try to report symmetrically on my findings by detailing the heterogeneity of practice, paying attention to material settings and technologies at work, as well as professionals and service users. Such descriptions made the tools of professionals ordinary and the objects of audiology accessible for study. To detail these heterogeneous interactions that enable people and technology to act, work and circulate underlies the importance of material semiotics as a methodological sensibility that explores relations (Law 2004). The idea is that the identities of the people and things involved - who are a technical expert, what is an enabling technology, what is an efficient system, etc – are created in and by relations. Studying hearing technology in use discloses the material semiotic relations involved in making it work. Otherwise the only thing that seems to work is technology, and the remaining efforts stay invisible and under-acknowledged.

'Observing' is not an innocent or neutral activity, it is creative work. The activity of participatory observation creates and co-creates its object as well (Mol 2002). In the analysis of the material, I mobilize this mode of seeing to intervene in audiological practice and stir up and trouble the sometimes over-rational, other times naïve assumptions that I encountered in policy documents, audiological text books, and marketing material on hearing aids. Assembling fieldnotes, interview transcripts, and materials that I have gathered during research, I try to use the empirical descriptions to tell political tales. In the empirical chapter, I gather and structure the presentation of data according to the textbook audiological trajectory. By this, I do not mean to enact audiology as a coherent whole. On the contrary, I try to theorize on professional knowledge and practices by exploring the multiple modes of ordering sound and by critically discussing the gaps and frictions between ideals and practice which professionals and clients have to deal with. Inspired by Annemarie Mol (2002), I try to move beyond description to speculate and theorize about the operations of audiology and its relationships to everyday forms of (embodied) hearing and subjectivity. Detailing the tensions which professionals and users of rehabilitation systems experience, I try to bring out the sociomaterial conditions for realizing political goals. According to Mol (2006:412), this is the modest contribution of research; 'we unravel tensions, articulate them, and cast them in words that allow them to travel so that they may be more widely reflected on'.

USER STUDY

> Disability Studies are both about achieving a better deal for people, but also about establishing the stories people tell about themselves and having them listened to (Shakespeare 1996:17).

As researchers we play a (limited) part in framing the field, the issues at stake and the relevant actors. In the introductory chapter I stated my interest in revisiting the lived experience of disability, but not to listen to 'the authentic voices from the field', or describe that which is general or representative for the community as a whole. My aim is to bring out new and challenging accounts of hearing disability, technology, and politics from a field hitherto dominated by professional knowledge. It has been important for my understanding of hearing disability not only to rely on what audiologists take hearing loss to be or their demarcation of their field of work to other professionals or from experiential knowledge of those living with the disability. I have wanted instead to provide analytical assistance and credibility on behalf of hard of hearing people. This means that they are given much more credit than is usually the case in the standard scientific literature. But while the official systems, bureaucratic or industrial, have their communicative practices to follow, rational, economic or technocratic, hard of hearing, as lay people, are often not in the position or do not have the capacity, to make their voices heard and counted for in expert forums.[38] Yet, these are the individuals living with the disability, they are the ones being affected by policy, and they are the users of the hearing devices. As such, they are important sources of knowledge and their viewpoints carry moral weight. Providing new and challenging descriptions to people both in and outside social science, research can be influential in opening up for multiple realities on hearing loss. I believe demonstrating such variation might work against stereotyping and discrimination and, possibly, enable people to respond differently to their environments.[39]

ON THE MATERIAL

The core of the research project has been the user study where I have asked hard of hearing people to tell their stories of disability, technology, and politics. Empirical input for this part of the research stems primarily from interviews with people from the Netherlands and Norway.

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[38] This argument for a methodological asymmetry is developed within STS by Scott, Richards and Martins 1990. For commentary on their argument see Collins 1991 and Martin, Richards and Scott 1991

[39] The degree, extent and measure of such changes are of course minimal. Whatever the researcher means and communicates, and however agreeable this might be in interviews and meetings, this is a highly contextualized interaction, where my issues for discussion and the following research questions are treated in a relative isolation to the rest of the universe that the participant is obliged to consider in their daily work. In the broader context there are other, maybe conflicting concerns, interests, priorities, and needs that should be taken into account.

I started out with an e-mail based questionnaire in order to gather data from which an interview guide could be extracted. The questionnaire was distributed on Dutch and Norwegian e-mail lists for hard of hearing people. 11 people responded and in broad terms identified what topics were relevant for their experience of hearing loss. The answers were structured into seven broad themes for the interview guide: 'biography', 'type of hearing loss', 'experiences with service provisions', 'support network', 'education and work', 'societal status and disability politics', and 'use of (hearing) technologies'. With this guide, I visited eight Norwegian, and six Dutch people to conduct in-depth interviews and observe their use of hearing technologies.

Participants were recruited through several channels; the Norwegian and Dutch user organisations, e-mail lists for hard of hearing people, people I met during participatory observations, and people who got in contact with me because they had read about my project on line. When I got in touch with potential participants I sent an information letter where I described my project, the interview and how I would use data in analysis. I asked the participants to read through the letter and to take some time to think though whether they wanted to participate or not. After reading my information letter all agreed to meet and talk with me, but one person cancelled the appointment due to the loss of a family member.

The majority of the participants were severely hard of hearing. Some also had additional medical diagnoses related to their hearing loss such as tinnitus and psychological problems. The participants differed with regard to gender, age, geographical belonging and professional occupation. Some were born hard of hearing, but the majority sustained their hearing loss later in life. To protect anonymity, I use pseudonyms for participants and disguise or omit potentially identifying information in the text. I introduce informants by their fictional first name, not surnames. Partly this has to do with a Norwegian research tradition in which formal titles and family names are not commonly used. It also has to do with my engagement with the participants of the study. I wanted to get to know the people I interviewed; I spent time on getting close to them and their stories. Arguably, addressing people in an informal fashion has given me different data than I would have obtained if I had addressed people by surname. Using first name in the text is not meant as a lack of politeness, but an attempt to give the reader the same feeling of personal engagement with their stories.

At the onset of my meetings with participants I emphasized that the interview was to be an arena for them to express their experience and viewpoints. Meetings with the participants could last anything from one and a half hours up until a whole working day. I met some of the participants several times. Many of them I kept in touch with after the interviews through e-mails and phone calls. The interviews themselves were more limited in time; they lasted from an hour and a half to four hours depending on the development of the

conversation. All interviews were recorded and later transcribed word-by-word. Transcripts were sent to participants for comments and corrections. In addition to the interviews participants often provided me with other type of material, i.e. texts they themselves had produced for newspapers, court case material, letters, media scraps, commercials, small technical innovations they were working on and so on. This material became a source for the rich descriptions of everyday experiences of hearing disability.

Prior to the user study I was anxious to know what arrangements would be necessary to interview hard of hearing people. To prepare I asked a social worker and a special educator for guidance on how to provide a good interview situation. Advice were to ensure good lightning, get rid of background noise, articulate clearly, not interrupt, and make sure to take breaks since verbal communications is particularly demanding for the hearing disabled. These were valuable tips, but the issue of accommodation brought on a methodological dilemma. On the one hand, I wanted to make the participants feel comfortable so that they could focus on our conversation. On the other hand, and following my non-essentialist understanding of disability, I was also interested in learning about when and how hearing disability was enacted. To accommodate meant minimizing the chance that I would get to observe this. To get around this problem I made a point out of meeting participants in their homes, workplace, cafes, university, or other sites they traversed in their everyday lives. While I took care to accommodate communication during interviews, when being on the move, I observed barriers to communication as they occurred. By making the meetings into an ethnographic site I got material not only of verbal accounts of disability, but also of disability as embedded in everyday action. While my primary interest was in exploring the enactment of the subject position 'hard of hearing', these interactions also enabled me to explore other possible subject positions related to their hearing loss. Similarly, I obtained information on the participants' use of technology. Material that includes the measures taken by the participants attempting to domesticate the technology, as well as contingencies and provisions for use of technology, not only proposed use(-fullness).

FROM DATA TO ANALYSIS

I have studied hearing disability by investigating how it becomes enacted in different practices in different locations. My accounts of hearing disability, hence, derive from detailed descriptions of individuals and the environments in which they interact. I give much room for the empirical material in the analysis. The choice has to do with the relatively limited knowledge we have about the sociomaterial ordering of hearing disability. Little is written about hearing disability in technology studies, and technology has not been a common topic in studies of hard of hearing. The data I have gathered are therefore rather unique. Since I also have spent a lot of resources on gathering it, I believe

that it is correct to present it in such details and give the reader a view on the dynamics in the field.

I approached the empirical material with a list of analytical questions that I wanted to try to answer. The questions stemmed from my theoretical reading and evolved around questions of translations between policy and practice, tracing active ordering modes, and investigating the costs and benefits of different positional strategies people enacted through their stories about disability, technology and politics. These were not questions that I asked informants in interviews, but analytical optics during the reading of the material. The questions also gave structure to the writing and helped me develop the material from data to analysis. I use the empirical material to show how different ordering modes are enacted and relate within and between individual stories. In the analysis I link this multiplicity to the discursive relationality in the field. The key is to investigate how certain ordering modes constitute disability, technology, and politics in specific ways. I do not approach individuals as passive media for the different orderings to be played out in. Rather, I show how the hard of hearing actively mobilize different discursive and material elements, and combine them to enact versions of themselves. In these stories different modes of ordering disability merge with elements from other subject positions the hard of hearing have access to, sometimes in harmony, other times with considerable friction. To demonstrate such multiplicity and contestation some, critical, cases have become central, while other accounts are left out. However the analysis rests on assessments that extend what is immediately visible in the text, which means that all the interviews play a part in forming the broader background picture for the analysis.

THE RELATIONSHIP BETWEEN VOICE AND EXPERIENCE

When we listen to the voices of hard of hearing people how should we hear them? When I speak of the lived experience of disability, it is because that is how I enact it in my writing. But both researcher and interviewee take two very specific, yet various and changing positions during the research situation. In other situations the participants would perhaps have had a different opinion or framed and formulated the answer in a significantly different way. What are the implications in methodological terms, if not authentic voices, then, what is the status of the interviews? The issue here is the relationship between the 'voice' of participants and the 'experience' they report. Can we, as analysts, take everything informants say as an accurate reflection of what really happened or even as an accurate record of their perspective or account of what really happened?

The view that interview data are (more or less) reflecting the interviewee's reality outside the interview has undergone a lot of critique from feminists and poststructuralist who cast doubt on the project of giving voice as a channel to 'authentic', 'true' or 'factual' experiences

(Rapley 2004). From this perspective it is inappropriate to talk about the 'validity', 'reliability' or 'accuracy' of talk. What disabled people say should not be taken as evidence of their experience, but only as a form of enactment, an account or repertoire that represents a cultural available way of packaging experience. In this way experience is never 'raw' but is embedded in a web of interpretation and re-interpretation.[40] It is fundamentally entangled. Disabled peoples' experience does not spring uncontaminated from an essential inner disabled way of knowing, but is structured within and in opposition to material semiotic relations through which our experiences are constructed. For the interviews, this implies that there are all sorts of actions going on other than simply 'topic talk'. Interviews are inherently interactional events that are locally and collaboratively produced by the interviewee and interviewer. The talk in the interview is not only about the topics of the interview, but might as well be about the person producing herself/himself as an adequate interviewee or as 'a specific type of person in relation to this topic'. In this sense the interview data may be more a reflection of the social encounter between me and the participants than it is about the actual topic itself. The cases presented in the book are also restricted in the way that they are my selections, interpretations and presentation of interviews conducted with a limited selection of people, during a limited time, talking about a limited part of their experiences. However, all this does not mean that the findings are not valid, but they are not valid for all people at all times and in every situation. Which does not mean that a focus on interview-talk as locally and collaboratively produced does not deny that the talk is reflexively situated in the wider sociocultural arena. Rather the point is that interviews do not provide any form of direct access to the 'truth' of interviewees' actions, experiences, feelings and thoughts.

What then is the relationship between the data and the conclusion we as researchers draw about the lived experience of disability? I interpret the interviews as participant's attempts to make sense of themselves and their everyday life experiences. The interviews offered them a chance to position as active agents in the story of their life. The interviews provide evidence for the material semiotic relations through which disabled people represent their experience, rather than offering a direct route to that experience itself. This does not mean that I consider the interviews meaningless, rather that they bring on some perspectives,

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[40] The same goes for the listening. What i.e. do we, as researchers, do with the voices we do not want to hear, because they contradict our own theoretical or political beliefs? Do we then treat it as a result of false consciousness? If disabled people do not report being oppressed do we then take this as evidence of the depth of their oppression? Few of the participants reported that their exclusion in the job market were cases of discrimination, some downplayed the importance of being excluded, or internalized the cause of their problems. Some participants also did not want to be identified as disabled but preferred to think of themselves as sick, in need of expert intervention. Rather than dismissing these accounts as false consciousness I think it is important to try to understand why these hard of hearing people do not interpret their experiences through the disability political lens and what the costs and benefits are for hard of hearing people struggling to make sense of their lives.

not *the* perspective. This means that this book is not about *the* lived experiences of hearing disability, rather it is adding to the knowledge and reflection about material semiotic relations that produce such experiences.

Since the participants have many positional belongings and the interviews seek to explore a multiplicity of these, the material shows how specific and sometimes contradictory 'truths' are produced, sustained and negotiated. Rather than dismiss the contradictions and (apparent) irrationality that often appear in the course of an interview, I try to utilize them as a source of data. I argue that disabled people have access to a range of different modes of enacting and ordering everyday life experiences, some user driven, others expert driven, some directly related to their hearing loss, others focusing on other subject positions. Hence, disabled people, through their talk, can also participate in and reproduce the very systems they oppose. The point is to make them into 'subjects/agents', as active contributors in the knowledge production process. More than simply being done to, they are also doers. Service users are part of forming the authoritative knowledge of medicine. Only when the individuals fulfil their expected roles, in collaboration with the audiologist, the hearing aids and the application form is the system stable. But what are reflected are processes of order building, not an internal psychological state. What is criticized is socially available discourse, not the individual availing of it (Gavey 1989).

What should be clear from all this is that I do not make a truth claim on behalf of my data, rather I present these data to problematize other claims for truth. This thesis is about enacting difference. I want to add to the academic literature critical cases that do not seek to confirm existing knowledge, but instead question established truths and contribute to make visible a multiplicity of accounts of hearing disability. Analytical concepts are introduced to explore the empirical material and develop arguments, not to test theory. The aim is to bring new examples and ideas and surprising links that, in whatever modest way, leads us to question dominant assumptions about disability, technology and politics, thus, broadening the basis for political reflection.

PART II DISABILITY POLICY

INTRODUCTION

On the 13ᵗʰ of December 2006, the UN Convention on the Rights of Persons with Disabilities and its Optional Protocol was adopted.[41] The Convention has been signed by Norway and the Netherlands. The Convention does not include a definition of 'disability' as such. However, the preamble recognizes that; 'disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others'.

Consequently, the notion of disability is not fixed, but instead conceptualized as a relational phenomenon, a product of the interaction between individual impairment and societal barriers. What is more, disability is not considered merely as a medical condition, but rather as a result of the relationship between the somatic condition of a particular person and negative cultural attitudes or an unwelcoming material environment, a form of discrimination. By dismantling attitudinal and environmental barriers - as opposed to treating disabled people as problems to be fixed - those persons can participate as active members of society and enjoy the full range of their rights. The Convention marks a shift in attitudes and approaches to disabled people. It takes to a new height the movement from viewing persons with disabilities as 'objects' of charity, medical treatment and social protection, towards viewing persons with disabilities as 'subjects' with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society.

Following their commitment to the Convention and to the UN declaration of Human Rights, which grants disabled people the status as equal citizens, the Netherlands and Norway have developed country specific strategies to try to ensure disabled people the same rights and opportunities as any other citizen in society. The way these two countries organize,

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[41] For more information on the Convention see: http://www.un.org/disabilities/

manage and finance welfare and health care for disabled people share some common principles: universal access to care and insurance, solidarity in the distribution of costs, and a good standard of care. However, while considerable similarities exist in policy issues there are also significant differences in the way they seek solutions. Each national policy system has been created in its own particular way, influenced by different opinions about what strategies are most effective in order to achieve equality.

In this part of the book, which I have called *Disability Policy,* I tackle the question of how policies for disabled people are developed within the context of national health care and aural rehabilitation systems. Disability policy matters because policy creates (a limited) space for the enactment of hearing disabled subjectivity and the accompanying geography of responsibility between individuals, technology and society. My investigation into disability policies, thus, seeks to illuminate underlying assumptions with regard to the modes societies seek to respond to, and order disability.

Part II consists of four chapters. In chapter 4, I consider how disability is constituted in the context of European political debates on economic globalization, political liberalism and individualization of care. Before moving on to the two country studies I introduce a discourse analytical approach to policy analysis. In chapter 5 and 6, I present and discuss the empirical material from the Netherlands and Norway, material that shows how nation specific 'truths' about disability accelerate certain policy paths and depoliticize others. Finally, in chapter 7, I contrast the findings from the two country studies and extract research questions for further analysis of the politics of disability in practice.

INTRODUCTION

National welfare systems can be seen as the institutional expression of solidarity (Stjernø 2005; Meulen and Jotterand 2008). However, in an age of individualism, the idea of solidarity seems to be threatened and on the defence in many European countries.[42] As outlined in an EU paper on the future of European social policy, a series of changes related to public service provision have emerged within European welfare states (MinVWS 2004). The well-known rationalization is that governments are concerned about the financial and social sustainability of their welfare systems, as well as the efficiency of their health care systems. Behind the concern is the proportional increase of the ageing population, the emergence of new and expensive medical innovations, and citizens' growing expectations regarding the quality and availability of healthcare and demand-driven healthcare provisions. Consequently, many European governments are seeking ways to make the system more efficient so as to reduce pressure on public budgets. The critique of the welfare system has stimulated discussions about which services and facilities should rightly fall within the government's purview and what tasks might be better left to the market. As a response, many nation states have made adjustments seeking to match the global economy, for instance by moving in a marked-oriented or neoliberal direction. The suggested institutional changes have to be seen not only as demands for improved efficiency. They are also connected with comprehensive political and ideological changes. The triumph of capitalism and the expansion of markets and market ideology make collective arrangements and the ideas on which they are founded more precarious.

Increased individualism and, in particular the emphasis placed on the personal freedom to choose and mould one's own destiny also challenge the traditional value of solidarity and

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[42] In particular in its Keynesian version. The period between 1945 and up until the 1970s was a period of economic stability and prosperity for western nations. This Keynesian/Fordist settlement between capital and labour, of mass production and mass consumption, was reinforced and supported by welfare state provisions. Notwithstanding the specifics of the national circumstances and traditions, the common objectives of public policy were broadly to ensure 'the general maximization of welfare within a national society' (Cerny 1990:205).

thereby the foundation of the welfare state. Coupled to the political liberalism is an increasing professional interest in the individual recipient of health care. In later years, neoliberal arguments from policymakers seeking to make health care more cost-efficient and service-oriented have joined with a protective concern regarding patients' rights. In the liberal western ethics, one of the most important values is the respect for the individual's autonomy regarding her or his health, body, treatment, and life. This moral principle emphasises the rights of the patients to be protected in situations where they are in an asymmetrical position vis-à-vis a powerful professional. Today it is widely accepted that health care and rehabilitation programs should be organised and integrated around the patient's needs in order to make care more 'patient-centred'.[43] Patients, in turn, should be educated and supported to make 'informed decisions' concerning their treatment and care. Arguments such as these shape the public image of care as well as the expectations and demands with which professionals and lay people enact rehabilitation practices.

A new discourse on health and disability has emerged in which the patients are constituted as emancipated citizens who have the right to speak up for themselves and who are treated on an equal basis. Citizens can assert their interests, either individually in situations of treatment and care, or collectively through the influence of consumer-oriented patient organisations. The call for individualization of care is also advocated by disabled people themselves. As a reaction to the paternalistic practices experienced by disabled people as uses of rehabilitation systems calls for individual choice and independent living have become key elements in the political demands of the international disability movement (Morris 2005).

A DISCOURSE ANALYTICAL APPROACH TO DISABILITY POLICY

In the next three chapters, I study how nation-specific disability policies are shaped in the context of these broad European debates on economic globalization, political liberalism, and the individualization of care. Rather than discussing what disability *is,* as a given entity,

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[43] Rita Struhkamp (2003:18) traces this protective concern in relation to health care from the period after WW2; 'when people with mental disabilities and prisoners were enrolled in medical experiments without their consent. After these practices had been disclosed, critics made a strong claim for self-determination and respect for the person's autonomy and bodily integrity in medical experimentations. Formulated first in the Nuremberg Code in 1947, these principles were acknowledged as fundamental human rights and formally endorsed in the declaration of Helsinki in 1964. In the decades after the declaration, the principle of personal autonomy developed into one of the key moral ideals of medicine and health care. Respecting a person's self-determination was not only important to protect patients from unwanted interference in experimentation, but also in regular treatment practices'.

the objective is to discuss *how* disability is enacted in Dutch and Norwegian policy making on health care and rehabilitation and with what consequences for the direction of policy making. To study the constitutive role of policy making means that I approach policy as discursive arrangements that carry and are carried by different modes of ordering disability.[44]

Inspired by Foucault, Carol Bacchi (1991:40) defines discourse as 'practices that systematically form the objects of which they speak; they do not identify objects, they constitute them and in the practice of doing so conceal their own invention.' She argues that within policy discourses, various interpretations of an issue co-exist and compete with each other; this implies that political discourses are struggles over interpretations rather than over pre-determined issues. It is an essential feature of political conflicts that their interpretation – and not only their status within the political realm – is a political stake. Since it is not possible to separate 'solution' from 'problem definition', within this discourse analytical framework, the task of policy analysis is not to identify how to do problem definition better, but to reveal the assumptions about the nature of the problem in any postulated solutions. Thus, whereas traditional policy analysis sees policy as an answer, a solution to objective problems, policy discourse analyses aim instead to evoke critical reflection on established 'truths'.

In this framework, disability policy is involved in the enactment of the disability it tries to abolish. What this means for my study of Dutch and Norwegian disability policy, is that I focus on the conditions of possibility for policy, the ordering practices which leads up to the

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[44] The approach should be seen in the light of the growing dissatisfaction with the limitations of the rationalist mainstream of instrumental policy analysis. Modernist perspectives in social thought take the material constitution of society as given. The discursive practices in which state actors are centrally implicated are not seen as important factors in producing and reproducing that reality. The task for modernist inspired policy analysis is to count and categorize the occurrences of specific phenomenon to enable effective and efficient intervention. The problem is that these efforts underestimate the extent to which policy does not just create its own politics and does not just become its own cause, but contributes to constitute the reality against which it is directed. Postmodern researchers (see i.e. Parsons 1995; Yanow 2000; Gottweis 1998; Stone 1998; Roe 1994; Schön and Rein 1994; Schram 1993; Forester 1993; Bacchi 1991; Hawkesworth 1988) have instead approached policy making as discourse and established a 'post-positivist' position in policy studies. Their interest has been in how certain relations of dominance are structured and reproduced in policy making. Poststructuralist scholars, (see i.e. contributions in Finlayson and Valentine 2002; Petersen, Barnes, Dudley and Harris 1999; Connolly 1991) exploring the inter-linkages between political discourse and democratic theory, have expanded this discourse analytical approach by bringing into the domain of policy research the question of how public policy discourse work to construct and maintain personal and collective identities. Rather than aiming to facilitate efficient and effective state action, these analysts advocate a form of research in which academics are to fulfil an independent role as public intellectuals addressing public problems, not necessarily in alignment with the state. Such analysis is part of what Connolly (2005) sees as the democratizing potential of 'critical histories of the present', or what Foucault (1984 Nietzsche, *genealogy, history* in Rabinow and Rose) called 'genealogy'.

formulation of a specific policy issue. Importantly, this is not the same as claiming that disability does not exist, or that that disability policy is without effects.[45] Discourses on disability have real consequences for the execution of power which shape experiences of disability. Policy documents and interview talk within this framework *enact* power. Texts, legislations and debates describe and legitimize geographies of responsibility between individual, technology and society. They construct a room in which hearing disability is ordered and the disabled subject positioned within. It is these theoretical insights which justify and give weight to the study of policy making. Applying this sensibility to the study of disability policy, I aim to highlight how policy discourses themselves are implicated in the enactment and maintenance of hard of hearing identities in ways that have profound implications for the allocation of scarce resources. With this as the analytical starting point, the aim is to trace cross-country similarities and differences in lineage and configuration of contemporary disability policy and, thereby, to de-naturalize those discursive processes, and leave them open to contestation.

Chapters 5 and 6 present storylines on the development of Dutch and Norwegian disability policy and the way these influence the organization of national aural rehabilitation systems. In chapter 7, I contrast the findings from the two country studies so as to highlight the contingency of the disability issue; how disability is conceptualized, what is considered legitimate and effective responses, and the status of the disabled subject emerging in policy making.

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[45] Bacchi (1991), drawing on Foucault's (1980:196) notion of discourse as embedded in a larger 'apparatus' of the said and non-said, argues that stressing the productive quality of discourse does not entail the relativity of interpretations. Rather, an emphasis on the limits of discursive construction draws attention to the sociomaterial embededdness of discourses. Although the approach understands policy problems as discursive constructions that do not simply reflect reality and although there is no objective truth by which to test them not all constructions are equally valid and possible. On the contrary, interpretations are limited by factors internal and external to the discourse. Interpretations might be limited due to structural factors, such as the power of institutions and individuals to shape policy making, as well as to limits that are due to the availability of discursive resources within a society.

INTRODUCTION

'Hoorwijzer' is an online, step-by-step, self-assessment guide provided by the Dutch organization for hard of hearing people. The guide helps you choose a hearing aid. The guide helps you single out what is important so that you will choose an instrument that fits you, and gives you tips for how to use it. The guide advices you on other technical aids that you can use in addition or instead of a hearing aid. It guides you through the world of specialists, practitioners, and devices. The guide is built on input from people that themselves use hearing aids and is therefore independent, objective and reliable.

Through the website you can also share experiences with other hearing aid users. This is beneficial for you, and it provides NVVS with a tool to gather consumer knowledge. We will use your feedback in our collaboration with producers, dispensers and insurance companies, actors whose importance has increased in the wake of the new Insurance Act. The aim of 'Hoorwijzer' is to stimulate the empowerment of patients in health care delivery. In this context, the self-assessment guide will give you as a hearing aid user a platform to voice your concerns and have them listened to by producers and distributors of technical aids.[46]

Contemplating on the future of NVVS, in the 100-years anniversary address the director states that recognition of hard of hearing people as a social group, respect for the individuality of the members and reliable information have been at the core of the organization for more than a century (Beleen 2008). While the core values have remained the same, the strategies for realizing these have changed historically. Today 'Hoorwijzer' symbolizes the future of NVVS. The online self-assessment guide is a tool to help hard of hearing people become informed and critical consumers. The guide is designed to provide objective and reliable advice, empowering people to make rational choices and participate in aural rehabilitation on equal terms with experts. The idea is that people should no longer act as compliant patient in the meeting with experts. NVVS envisions a future in which

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[46] Retrieved, translated and modified from http://www.hoorwijzer.nl/over-de-hoorwijzer.html on 25.06.09.

people are critical health care consumers. They demand high quality, and they want guarantees that service providers are competent and diligent. In short: People want value for their money. Therefore, NVVS is rapidly developing into a form of consumer organization. Using the 'Hoorwijzer' website to gather consumer feedback from hearing aid users, NVVS envisions a strong position for themselves in collaboration with service providers, audiological specialists, hearing aid dispensers, and insurance companies. In this chapter, I introduce the Dutch welfare system and trace its origin in a Christian democratic discourse on solidarity. Then, I explore the discursive drivers and shifts prompting the new focus on consumers, competition, and choice. I show how these changes relate to the introduction of a new market-oriented health care reform that attempts to de-medicalize hearing disability by turning it into a consumer issue.

THE DUTCH WELFARE SYSTEM

The Dutch welfare system has been inherited from the period of 'pillarization' (verzuiling) in which the vertical societal divisions (based on denominational or ideological lines) were at their peak (1920–1965), and the subsequent era during, while the Christian democrats dominated political life in the Netherlands.[47] The system is founded on two constituting principles. First, the principle of 'subsidiarity' implies that what can be managed in the private sphere should not be undertaken by government. It was Pope Pius who said that; 'it would be wrong to take from the individual and entrust to society what may be managed by private initiative, it is an injustice, a sin, and a disturbance of the right order if larger and higher organisations usurp functions that might be provided by smaller and lower instances' (Stjernø 2005:66). The principle of subsidiarity limits public interventions and gives non-state actors an important role in social policy. The state has some responsibility,

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[47] From the 1917 to about 1970 a stable civic equilibrium was achieved through governmental power sharing of the elites of four so-called pillars of Dutch society, the Catholics, the Protestants, the Socialists and the Liberals. For the member of the pillar its ideology was the main locus of social identification. The elite accommodation of these subsystems in society linked political power, social organisation and individual behaviours and aimed to promote competition as well as cooperation with other social and political groups (Cox 1993). The process of de-pillarization started in the 70s and drastically changed the Dutch political landscape and did away with the peculiar 'social apartheid' of the pillars (van der Hoek, 2000:389). But the open and near proportional Dutch electoral system continues to make coalition building a political inevitability, and Parliament a place for unspectacular deliberation rather than fierce debate. When it comes to ideological polarisation at the level of concrete policy making the picture is one of mutual accommodation rather than polarisation of positions. Dutch political life remains consensualist at heart (Gier, Henke and Vijgen 2003).

but only when the individual, the family, voluntary organisations and local communities are unable to fulfil their obligations.

The second, related principle is that of 'volunteerism'; social solidarity on an organized basis, actively supported by the government. Kramer (1981) has argued that volunteerism builds on a set of values that can be fulfilled through citizen participation in policy making, planning, advocacy, administration, fund-raising, and in freely giving oneself to directly help another person or group, and is an integrative element of the Dutch welfare system. Stjernø (2005) links the notion of responsibility to the Christian discourse on charity which emphasises God's love of humankind, a precondition of the admonishment to love thy neighbour, again closely associated with the concept of charity, the expression of the highest form of God's love. In a charity discourse, benevolent people who feel the responsibility to ensure that everyone's basic needs are met, provide care. Giving individually to charity is, thus, seen to be in the interest of all those who are able to give.

This discourse on solidarity has given much attention to the role of informal care in the Netherlands. Houten and Jacobs (2005) estimates that currently, there are more than 300.000 volunteers in the health care sector alone who provide practical assistance and social support for the elderly, disabled, and chronically ill. Over 1,3 million people provide informal care for family members, friends and neighbours.

DUTCH DISABILITY POLICY

The Dutch policy for disabled people is found in documents, statements and legal acts issued by various ministries. However, the Ministry of Health, Welfare and Sports has the coordinating responsibility for policy making in the field. In public documents, disability policy is aimed at 'people with a disability' or 'clients' when referred to as users of care. Disabled people are defined as limited in their functioning as a result of physical or intellectual impairment, which is of a lasting or permanent nature and threaten the individual's capacity for personal development (MinVWS 2004:1). According to the Dutch Constitution and the Universal Declaration of Human Rights, the principal foundation of the Dutch government's policy for people with a disability is that they are full citizens of the Netherlands and have the same rights and duties as anyone else. The Dutch policy is based on the respect for disabled people's wish to make their own choice and to take their own responsibilities. This means that they should be able to decide where to live and work and spend leisure time. It also means equal rights, being able to have your say and a society that

offers enough opportunities and support to allow you to be genuinely independent and self-sufficient. Policy in this area is aimed both at society as a whole and disabled people themselves:

> Society must be encouraged to take its responsibility and to make room for people with a disability. People with a disability must be given opportunities to allow them to act on their personal responsibility for giving shape and substance their own lives. They have to demand their place in society. Their own strength of character and support from their direct social network is extremely important in this regard. In addition, they need to be given access to sufficient information, expertise and, where necessary, support. This involves ensuring that facilities are physically and socially accessible (MinVWS 2004:3).

In 2002, parliament unanimously approved the Equal Treatment on the Grounds of Disability or Chronic Illness Act. Raising disability as a sociocultural issue, the law prohibits discrimination against disabled people in the field of employment, training and transport. However, when it comes to the responsibility of the state, the government tries to be a facilitating government rather than a directive one. It is recognized that, in the best case, legislation can provide the necessary conditions for a more inclusive society, but it will not change society. Houten and Jacobs (2005:650) have pointed out that; 'this legislation is complaint-driven, and ultimately puts the onus on those who experience discrimination to take action.' Until legal actions are taken, according to the new law, institutions and employers are merely encouraged, not obliged to accommodate disabled people's needs and aspirations.

Following the principles of subsidiarity, the state does not intervene in social practice, but leaves it to the actors in the private sphere to effectuate its policy. In general, the government encourages disabled people to be as independent as possible. Disability is defined as a private issue that can best be solved at the community level by mobilizing the resources of the disabled individual itself and the volunteer efforts of family, friends and neighbours. Disabled people should, when and where possible, be able to participate and integrate in society by utilising existing public services and facilities. Special facilities are required only where this is not doable. The goal is an inclusive society with as few as possible separate policies for the disabled In reality, however, it is recognized that disabled people often are marginalized. This is considered not only to be due to impairment, but also due to societal barriers. As a result, the government encourages facilities and services aimed to let disabled people compensate for their disability. When it comes to means for compensation, medical devices with freedom of choice for the client are highlighted. This means that Dutch disability policy, on the large, is deliberated, administered and implemented as a health care issue with the Ministry of Health, Welfare and Sports as the

responsible coordinating body. Hence, in the following, I focus on the development of a new market-oriented health care policy.

THE DUTCH HEALTH CARE SYSTEM - FROM PILLARS TO MARKET

The Dutch health care system can best be described as a hybrid system of public, private and professional elements. Constitutionally, the Dutch state is responsible for the accessibility, quality and efficiency of health care. However, the government's role in the actual provision of services is minimal. The principle of subsidiarity has resulted in a dominant role for private organizations in the formulation and implementation of social policy. During the reconstruction period of growth in the welfare system a national health care scheme was constructed. The scheme was predominantly financed by public means while the delivery of health care was private. A hybrid system emerged in which national associations of health care providers, insurers, trade unions, and employers played an important intermediary role (Lieverdink 2001; Hemerijck 1993). Private, for profit initiatives have always been treated with some suspicion, so while most health care providers were private parties, they tended to be either ideological or religiously inspired, as opposed to profit oriented. There is, therefore, an array of actors involved in the development of health care policy and practice, some of which are for profit organizations, such as the insurance companies, others are non-profit, while others again represent professionals in the sector. As a result, the Dutch health care sector does not have a single power centre that can interfere unilaterally in the organisation of health care. The state has delegated public regulatory authority to the various associations of providers, insurers, trade unions, employers, and a number of volunteer organisations. The parties are mutually dependent on each other and have traditionally collaborated under the label of corporatism known as the 'Polder model', which emphasises cooperation over conflict.[48]

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[48] The polder model is used to describe the unhurried decision making process, in which all parties have to be heard, which has been characteristic for Dutch politics. In all major socio-economic policy areas government consults social partners. Such consultation has been highly institutionalized and prescribed in the standard process of policy making and has given the Dutch a long tradition of consensus. Abrupt changes in government policy have thus been quite rare. Opposition to forthcoming policies have been neutralized at an early stage because this way of communicating made sure that the stakeholders were involved in the process of formulating and executing policy, and contributes to make actors take ownership of the decisions made (Grinten 2002).

Given the considerable size of the disability movement, an estimated 17,5 % of the disabled community is organized, Dutch disability scholars are puzzled that disability has failed to manifest itself on the political agenda as a social problem (Houten and Jacobs 2005; Houten and Bellemaker 2002). Part of the problem is put down to the reserved approach of the disability movement in the Netherland. Disability organisations are part of the corporative decision making structure, but the development of Dutch disability policy is driven by policy makers, corporations, charity organisations and professionals rather than by disabled people.

The 1970s heralded the start of the patient's movement in the Netherlands, with particular initial emphasis on mental healthcare, and particular attention to the patient-doctor relationship. The debate first centred on criticism of the defining powers of professionals in charge of the healthcare system. The main issue was the emancipation of the patients. Mental care patients opposed to the residential model of care, its medicalization of social life, and its social exclusion of disabled people. Inspired by the social movements of the 1960s, patients started demanding a say in their daily lives. The movement was supported by a group of professionals who proposed a different way of functioning. This so-called anti-psychiatry movement demanded the formulation of patients' rights. The approach also came to influence the disability movement. Mobilizing a notion of full citizenship, disabled people were no longer prepared to be treated as patients and demanded to be accepted as citizens. What was brought to the fore was the lived experience of disability. Contacts were developed among fellow disabled people and this helped develop a sense of community based on self-esteem and pride. Together people started combating what they experienced as dependency cultures, welfare systems which deconstructed and reduced the complexity of their lives into welfare categories based on the logic of policy making. Houten and Jacobs (2005) describe these movements as flat and informal with some strategic contacts with local officials and professional workers. Their target was local municipalities and other local institutions.

In the 1980s power was organized at a national level and in 2001 the national councils of disabled people and chronically ill people merged to form the Dutch Council of the Chronically ill and Disabled people. However, while local initiatives have been critical in demanding change, the umbrella organisation has generally tried to avoid words such as oppression and discrimination and has thus been criticized for its reluctance to exert political pressure. Rather than focusing on barrier removal, the disability movement has been keen to facilitate conditions that can enable disabled people to reduce the negative impact of such barriers. Despite its institutionalized contact with the other stakeholders in the field, the Council has not managed to produce and promote a critical alternative to the policy of officials, professionals and private sector actors. Arguably, this is because the

representatives from the disability movement have been too concerned with speaking the language of policy makers and avoiding strong political statements. On this, Houten and Jacobs (2005:648) have argued that the Dutch disability movement is riddled by the Polder model, and caught between the paradox of struggle vs. cooperation: 'In the Dutch polder model of political decision making, with its emphasis on harmony and compromises, loud voices and demands can easily disturb this harmony.' The authors understand this imbalance to be a result of an unintended consequence of the success of centralization of power within the Council. Participation in the corporative decision making structure has demanded a more bureaucratic form of leadership and some degree of specialisation and division of labour. The drawback of growing large and powerful is that critical experiences are suppressed and potential for improvement ignored. The charge is that the Dutch disability movement has prioritised centralization, mainstreaming and growth over critical consciousness and direct action to such an extent that ordinary members feel that they are no longer represented by the Council and do not recognize themselves in council policies. The social movement has been transformed into an oligarchy, a rule by few.

PRESSURE TO REFORM

Following a rapid growth in the reconstruction period, towards the end of the 1970s the period of collectivisation and solidarization of the Dutch welfare system came to an end. With the oil crisis the economic optimism of the 60s evaporated and further expansion of the welfare state lost its appeal and was replaced with caution, followed by pessimism and what was ultimately to become a deep economic crisis by the end of the 70s and early 80s. Following economic stagnation, distrust in Keynesian politics increased and with the growing influence of the neoliberal ideology the state has moved towards retrenchment and the system has gone through a gradual market-orientation. In a national report on health care and long term care the Ministry argued that:

> The post-war primacy of the government in health care has contributed to the lack of financial stimuli promoting efficiency. The lack of efficiency this has led to is becoming a larger and larger problem, and is aggravated by the rising costs of medical technology, social pressure to increase health care packages and the consequences of an ageing population. In an ageing society, a relatively small group of people has to bear the costs of providing (health) care to a growing group of expensive patients (MinVWS 2005:7).

The main objection of politicians and policy makers against the model of collective solidarity has been its anonymity. The national and collective nature of the system was seen to undermine individual responsibility and to promote calculative behaviour by all

actors involved, be it citizens, workers, employers, unions or companies. Schuyt (1995) coined the term 'modern carelessness' to explain how moral hazard, broadly defined, came to be seen as the core problem of the model of collective solidarity. In this view, the main reason for the still high demand for protection and the high expenditures is an obscure failing structure of responsibilities and obligations allocated to the different actors involved. Based on this diagnosis, market elements were introduced such as freedom of choice and risk differentiation, which in essence were aimed at re-introducing individual responsibility, by way of confronting all actors more directly with the costs of social protection.[49]

Plans for reform started already in the 80s, but due to the consociational system, the reform was not introduced until 2006. During the end of the 90s public discontent over waiting lists and the call for more autonomy by individual providers and insurers strengthened the alliance in favour of de-regulation. In 1994 a new governmental program was launched to investigate the potential for de-regulation and market reform of previously sheltered sectors. In addition, the new government revised the corporatist decision-making structure itself by reducing the number of advisory bodies, disentangling their advisory and monitoring tasks, and terminating participation by interest groups. Moreover, the role of corporatist organizations (i.e. the interest organizations of hospitals, medical specialists, the sickness funds) also declined because individual insurers and provider organizations became powerful independent actors as a result of a rapid consolidation process.[50] The system was seen to offer little or no choice for insured parties, and was considered ineffective due to a lack of competitive incentives for insurers and had little or no pressure on suppliers to achieve better performance. In addition, there was an external pressure stemming from the EU and its new stringent Competition Act, which was adopted by the Dutch in 1998 under the responsibility of the Ministry of Economic Affairs.

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[49] The diagnosis is also the starting point for 'activation' market, which comprises extended policies aimed at the (re-) insertion of disabled people into paid, and even, unpaid work.
[50] Many sickness funds and private health insurers not only merged but both types of health insurers also joined forces in a limited number of insurance holding companies. In 2001, the five largest holding companies had a combined market share of more than 60 percent of total health insurance premiums. These large holding companies have become powerful actors in the policy arena and pursue their own interest independent of their interest organizations.

Responding to the political and financial pressure, in January 2006 the Dutch government introduced a new market-oriented health care policy reform. The reform seeks to combine the introduction of competition elements with the realization of a right to health to make care more efficient and affordable. With the new health care policy, the government remains responsible for the accessibility, affordability and quality of health care, but gives the parties in the market more freedom and responsibility to compete for the business of the insured. Following the shift in health care policy, the public, non-for-profit funds have been privatized and entered into competition with other insurance companies that now also offer social health packages. In addition, de-regulation is thought of as an incentive to provide quality services and implement effective care purchasing processes, and stimulate competition between health care insurers. According to the Ministry, a key objective has been to decrease the power of care providers:

> Care providers have always occupied a very dominant position within the care system in the Netherlands. They would determine to a great extent the care that was provided, as well as the quality of care; there was hardly any incentive to improve and measure performance (MinVWS 2006:14).

With the new health care policy reform, a shift of power is attempted from the medical professionals to parties in the market. The neoliberal reform is based on a belief that de-regulation and competition will increase consumer choice and quality of service provisions. On the supply side, the implementation of the reform is sought through efficient use of new medical technologies both aimed at curbing ailments and at the reduction of staff needed to care for patients, introduction of incentives to the market, stimulating competition between care providers and de-centralization of management responsibility. In order to foster the efficiency of medical care, price regulation is reduced and health insurers are given the freedom to contract with selected providers and to differentiate the terms of the contractual arrangements. As emphasised by the Ministry, coupled to the commercialization process is the changing role of the recipients of government programmes from 'users' to 'consumers':

The customer has to become a critical care consumer, and should be encouraged to make responsible choices. Insurers should compete in price, service and quality, and health care providers should be stimulated to provide efficient and effective health care. Governments will have an important role in guaranteeing quality, accessibility and affordability of health care. However, the foundations of the current Dutch health care system have to be renewed, taking into account the current political insights, by putting responsibilities with the persons and institutions that are involved (MinVWS 2005:9).

In the new health care policy, the recipient of health care is constituted as a consumer that will act as a critical and autonomous agent in the market place. To encourage the shift from patients to consumers, the principle of cost sharing is introduced as an incentive for consumers acting as responsible and quality oriented agents in the market place. The professional is no longer the expert who decides what is good for the patients, but becomes an equal partner who informs the consumer about the health 'products' and 'services' that are available. Given appropriate access to information, the belief is that the informed consumer will make the 'right' or 'rational' choice. Contrary to the pillar model, in which people were born into a pre-determined package of provisions, insurance companies can no longer expect their clients to be loyal. The exit option that now becomes available is thought to stimulate suppliers to compete for a market share and be more open for consumer demands.

The advance of the consumer order does not only imply a growing orientation to the market, but also a growing popularity of economic metaphors and management rhetoric in general. This has opened the door for another key element of the market-oriented discourse, the urge to control by quantifying, measuring and comparing social phenomena through statistics, and performance analysis (Grint and Dolfsma 2002). With the idea of product differentiation and the exit option, policy makers have evoked a need for quantifiable and objective information about health care to enable the consumers to make rational choice in the health care market.[51] According to the Ministry (MinVWS 2004:5), the aim is to create; 'a situation in which the care supplied takes the wishes and needs of the client into account, so that clients are in a position to give shape and substance to their lives.' In addition, there has been a strengthening of legal protection enabling disabled people to file law suits when experiencing discriminatory practices. The assumption is that citizens who display critical behaviour will provide an impulse for insurers and care

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[51] Consequently, the leading Dutch magazine,' Elsevier', part of Kluiwer Publishers that has a strong profile in medicine, started rating hospitals. For a critical analysis of the increasing urge to manage through counting, control and calculations see Power (2004)

providers to provide good quality care for a reasonable price. As critical consumers patients are expected to help maintain the competitive market system.[52]

Since the Ministry of Health, Welfare and Sports act as the coordinating body for disability policy, the shift in health care policy has had consequences for hard of hearing people too. Following the change in health care policy, a consumer oriented mode of ordering hearing disability has emerged. In policy documents hard of hearing individuals are described as active and rational consumers that, equipped with the right of choice, plays the role of regulators in the new market for hearing aids.

THE ELECTIVE HEARING AID CONSUMER

In the swirl of the market-oriented health care reform, a demand-driven system for hearing aid distribution is sought by de-regulating the distributive system and de-centralizing responsibility from the state to the market, assuming that the market is more receptive to the demands of the user, as argued in the 2005 Action Plan from the Ministry:

> The policy on aids is aimed at making necessary care facilities available and accessible so that disabled people can function and participate in society as normally as possible. Fewer rules and a decentralized approach bring the responsibility for providing aids much closer to the parties directly involved. This offers more opportunities for demand-driven care and coordination of the different provisions (MinVWS 2005:10).

Following the shift in health care policy, a new model for hearing aid prescription for adult hard of hearing people with moderate and uncomplicated hearing loss has been planned and tested. The new system is based on a protocol developed by the national committee for audiological assistive technologies (NOAH) and the assessment and implementation project, 'Adapted Care System Hearing Impaired' AZOS. Prior to the reform, the trajectory the hearing aid user had to follow was clearly regulated. In order to receive reimbursement

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[52] The notion of consumer sovereignty is reflected for instance in the recent introduction of personal budgets. This has the objective of increasing the transparency of costs. Consumers choose their own provider, which can be a person or an organization, and enter into agreement. In the process of 'economization' experiments started to provide people in need of care with a budget to allow them to make choices about how they would like to be cared for.

for a hearing aid, the patient had to visit an ENT doctor or an audiological centre to be diagnosed and get a prescription for hearing aids. Then the client went to a hearing aid dispenser who selected and fitted a hearing aid based on this prescription. To have their costs reimbursed, the insurance companies then required that clients went back to the audiological specialist, to have the fitting approved.

In the new system the distributive procedure has been de-regulated. The goal has been to develop a system where dispensers are able to perform rehabilitation with hearing aids without intervention from an audiological specialist. In the new system, the three central entities responsible for hearing aid fitting are still the ENT doctor, the audiological clinics, and the hearing aid dispensers. The change is that the hearing aid dispensers are now delegated 1st line responsibilities and the required specialist control on hearing aid fitting is lifted. Through initial screening the dispensers are responsible for assessing whether clients need treatment from a medical doctor or audiological specialist, or if they can simply follow a commercial route. The new system, thus, seeks to transform the geography of responsibility in the Dutch audiological field by de-medicalizing the distribution of hearing aids. As regulation is lifted, the government anticipates that competition will rise among dispensers. Competition, in turn, is expected to lead to lower prices and increase the quality of service provision. Following de-regulation, the commercial routing has become the standard route for the majority of hearing aid users. In the process, the hard of hearing shift from patients to consumers, and patient organizations to consumer organizations as the distribution of hearing aids is moved out of the audiological clinics and into the hearing aid shops. Sociopolitically speaking, with the reform towards a more demand oriented care system, the consumer becomes more central in the care process. Key here is the focus on consumer choice. As costs are now increasingly covered by the hearing aid users, they should also have a choice of caregiver, hearing aid dispenser, and hearing aid. Increasingly, consumer organizations are expected to become important collaborative partners for providers of care, insurance companies, and the government (AZOS 2006).

What emerges is a Dutch aural rehabilitation system driven by competition, consumers and choice. It is a system primarily focused on rehabilitation as the distribution of technical aids., assuming that these enable hard of hearing people to function and participate in society as normally as possible. In the upcoming parts of the book, I trace this 'normalizing' policy in practice and study the opportunities and challenges involved with trying to enact the elective hearing aid consumer in practice.

CHAPTER 6: NORWAY - MOBILIZING THE HYBRID WELFARE CONSUMER

INTRODUCTION

It is 10th of June 1947. In Bergen the founding meeting of what is to become the Norwegian organisation for hard of hearing people (HLF) takes place. Signe C. Bjerke enters the floor. She is about to deliver the Work Program Speech. One of her aims is to convince the assembly that the new organisation should work to have the government reimburse costs of hearing aids. At that time such support was only given in Oslo and Trondheim. Bjerke also argued strongly against the common practice of those days: women applying for reimbursement were commonly rejected on the grounds that they were 'merely' housewife and, thus, hardly in need of such sophisticated technology as hearing aids.

Perhaps she was too radical for her days because the following day, when the general assembly gathered to elect their first president, Bjerke was not among the election committee's candidates. Instead, professor Odd Opheim, an ENT specialist at the Norwegian national hospital won the position. Bjerke was nominated through a motion from the floor, but many saw her as unfit for the position, given her severe hearing loss and vast communication problems. The choice of Dr. Opheim reflected the general attitude in those days: trust in professional expertise was larger than confidence in members of the electorate, regardless of their experience (My translation and modification from Nielssen 1997).

Today, 60 years, later much has changed. HLF has grown from 1,200 to 40,000 members, and is today the largest organisation for disabled people in Norway. Trust in medical expertise has eroded; today it would be unheard of to have medical experts as elected representatives. As an interest political organisation HLF remains true to the international disability movement's slogan: 'Nothing about us without us'. What is more, it would be unthinkable to exclude people from the welfare scheme because of geographical belonging or gender. The state reimburses expenses for hearing aids for all its citizens. These changes relate to the development of an egalitarian welfare state. In this chapter I introduce the Norwegian welfare state system and trace its origin in a social democratic discourse on solidarity. Then, I discuss the entwined process of developing a comprehensive policy for

disabled people. I show how Norwegian disability policy is currently influenced by an attempt to modernize the public sector. From claims for democratic participation *and* demands for more efficient service provisions emerges the welfare-consumer. Focusing on the notion of 'user-involvement', I show how this hybrid figure is enacted in relation to hearing disability by the attempt to develop a holistic model on aural rehabilitation.

THE NORWEGIAN WELFARE STATE SYSTEM

In the early post-war period of national reconstruction, all political parties expressed a joint commitment to develop a comprehensive legislative framework to cover important life contingencies. This started a 25-year process of planning, design and implementation of an encompassing scheme. The Keynesian politics laid the ground for what is now known as 'the Scandinavian model', and relates to the way in which the Scandinavian countries have chosen to organize and finance their social security systems, health services and education. In the Norwegian case, typical features are the corporatist mode of government, the strength of the rural district and the periphery, the egalitarianism and deep structure of social democratic norms across the political spectrum (Østerud 2005; Stjernø 2005; Seip 1994).

'Equality' and 'egalitarianism' have always been core values in the social democratic tradition and a strong force in the normative fabric of Norwegian society in which the welfare system is rooted. The social democratic concept of solidarity is linked to a concept of freedom that is somewhat different from a traditional liberal concept of freedom. It not only refers to individual political rights, but directs attention to the material basis for freedom as well, and therefore emphasises redistribution as key to fulfilling justice. Accordingly, the development of the Norwegian welfare system is based on an underlying principal of universal entitlement to social welfare services. The intention of the National Insurance Scheme ('Folketrygden') is to secure income for individuals, compensate for expenses and help people to help themselves, so that they can manage on their own in personal and work related situations. To ensure that these objectives are met, the state has taken on the responsibility for the different programs and is involved in financing and organizing the welfare benefits available to the citizens to a far greater extent than in other European countries. Partly because private and voluntary arrangements are not considered comprehensive enough, in turn due to a lack of resources, and partly because of a more general ideology, seeing social care as a public responsibility. In addition most of the social

welfare tasks are undertaken by the state or local authorities and only to a limited extent by actors in the third sector. However, organizations and professionals partake in the policy making process. In the Norwegian corporatist system representation is seen as key to the process of governance at all levels. The idea is that policy making and the quality of public services would be enhanced when citizens are represented in separate bodies.

In general, the welfare system has been widely accepted by Norwegian citizens and political parties, at the same time as cultural acceptance or trust in the state institutions has been relatively high. Currently, however, pressure against the universal welfare system has increased due to a large influx of immigrants and refugees and an ideological shift in favour of the liberal party (FrP). In the modern egalitarian discourse, the collective orientation of solidarity has weakened and individualism has surfaced on the political agenda (Stjernø 2005). Whereas freedom in the past referred to collective freedom through political rights and the development of a material basis for freedom through social security and equality, the connotation of freedom today is increasingly the individual freedom to choose in the market, and to realise individual interests and personal development. As I will discuss in more detail below, individualisation and flexibility are key drivers underlying the ongoing project of modernizing the welfare state and also for current political debates on disability. Notwithstanding these ideological changes, the political coalition supporting welfare is supported by the petroleum fund, and there are no signs of an early demise of the welfare state in its current form.

NORWEGIAN DISABILITY POLICY

The general objectives for the Norwegian disability policy are found in the public White paper NOU 2001: 22 *From User to Citizen - A strategy for the dismantling of disabling barriers* and in governmental Green Papers on disability. In these documents, it is recognized that a policy for the disabled is ultimately a question of democracy. This is in line with the Norwegian commitments to the International Human Rights which grant disabled people the right to participate in society, on the basis that all people are equal.

The White paper recognizes the concept of 'impairment', which refers to the loss of, injury to, or deviation from the normal psychological, physiological or biological functions of the body. When the concept of disability is applied to persons, it refers to people whose practical living is limited due to the gap or discrepancy between their impairment and the demands of the environment – with regard to those functional abilities that are vital in

order to establish and maintain independence and a social life. With this definition, the political rhetoric has gradually moved away from a medical understanding of disability and towards a sociocultural understanding. Disability is no longer seen as a product of individual qualities, but according to a relational approach, as a result of the interaction between the individual's impairment and society's lack of accommodation to the diversity of the population. With this shift follows a policy focused on society's responsibility to dismantle barriers for an equal status and full participation in culture and social life. Full participation implies the opportunity to participate on your own terms in a society where there is room for different ways of functioning. This policy requires that society adapts to the variation in the requirements of its citizens.

Despite broad agreement on these general objectives it is not given how they are to be realized. In policy, the focus is on the responsibility and opportunity to combat the discrimination experienced by disabled people through a universally shaped society. The aim is mainstreaming disability issues, so that these are included in the planning and actualization of all societal projects. But thus far, this policy has not taken effect. In reality, the main arena for disability policy is still the welfare state and the distribution of technical aids.[53] Within the welfare state framework there is a notion of a conceptual progression in the view on disabled people. From earlier being perceived as passive 'clients' of welfare they are now mobilized as active and contributing 'citizens'. This involves a changing geography of responsibility between the disabled subject and society, a relationship which throughout the years has been negotiated and institutionalized through regulations, institutional norms and practices.

ORGANIZING DISABILITY: FROM CHARITY WORK TO INTEREST POLITICS

In the Norwegian corporative tradition, the disability organisations have been actively involved in the negotiation and development of a Norwegian disability politics in the period from 1960 until today.[54] Disability organisations early on identified with the labour unions claims for recognition and redistribution and demanded influence and participation in all issues that involved disability. The state became the important

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[53] In the White 2001 paper, the government concluded that there is in fact a gap between ultimate standards and the reality. Accordingly, in November 2002, the Government appointed a legislative committee to investigate the need for legislative and judicial measures to strengthen the legal status and protection against discrimination of persons with disabilities. Their conclusions are found in NOU 2005: 8.
[54] Anne Lise Seip (1994) has studied the historical development of the Norwegian welfare state. According to her, it is only from the beginning of the 1960s and onwards we can talk of a comprehensive policy for disabled people, with aims and instruments that involve several groups and several different areas of society. Before that, the poor relief, the church or the family had been the only solution for the 'blind and crippled'.

regulator and arena for interaction. Policy makers were the main target group and the struggle was for social rights and public budgets. This new rights-based approach led Norwegian disability politics out of a charity discourse and towards interest politics. The demands from the organisations for increased political influence grew out of a political climate in the 60s and 70s where the goal was to expand the democratic participation. When interest organizations started to make an impact on governmental decision making processes they were also seen as participating in collective state-led effort: to build the Norwegian welfare state.

'User involvement' - the right that the concerned parties of a process or decision should get to influence the decision-making process - was meant to ensure political participation by groups that otherwise did not have the opportunity to participate in democratic processes due to societal barriers and became a key instrument in the new rights-based approach to disability policy.[55] But user involvement is not a self-evident concept and cannot be understood in isolation from the institutions and norms that exists where one seeks to implement the policy. In the 80s, the Norwegian political climate changed. In the wake of a liberal-conservative wave ('høyrebølgen') the opposition to the welfare state started growing. There were large cuts in the public budgets, and the increased focus on individualism came to influence the way user involvement is practiced within Norwegian disability policy.

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[55] Tone Alm Andreassen (2003) has traced the development of user involvement as policy and practice in the Norwegian disability field in two influential reforms. First, there is process of moving the distribution of technical aids out of hospitals and the medical domain, and into Assistive Technology Centres, the domain of other health professional groupings and technical competence. Secondly, there is a program for modernizing public sector collaborations. In the process, the user is constructed as a person with relevant knowledge, insight and resources, and capable of making assessments of importance for the problems they bring with them. That meant that professionals were to acknowledge the shortcoming of their professions and knowledge. User involvement was also seen to add benefits to the system since it was recognized that the user has a fundamental and important knowledge that is necessary to build on if one is to develop a rational, efficient health care service with high quality standards.

> User involvement is a democratic right which entails that individuals take part in the decision-making processes that regards their life situation (individual level) or where representatives of organizations takes part in the shaping of public service provisions and measures (system level). User involvement is a working method that implies a quality assurance of public sector services, by transferring experience-based knowledge to policy makers and administrators. It is also a strategy to reach the objective of a society for all (NOU 2001 ch.19:1).

In the 2001 White paper on disability a distinction is introduced between user involvement on the individual level and user involvement at the system level. At the system level, the aim is to facilitate formalized collaboration between the user organisations and the government administration, in other words, continuing the corporative tradition. What is new, is the strong focus on the individual level; that is the influence the users have in relation to the decision making process and the shaping of the service provision that they are users of. Along with the activation of the individual, a new rationale for user involvement emerges. User involvement is no longer seen merely as a channel for democratization. For the government, the activation of the user is now also considered crucial for the modernization of the public sector:

> User involvement is the modern expression for the ability of the population to influence the development of public sector services. Conceptually, user involvement is linked to the modernization of public sector and to the goal of a more user-oriented service (NOU 2001 ch. 19:3 my translation).

Following extensive critique of what was experienced as an outsized and rigid welfare system, a tendency among service providers has been to seek more flexible solutions in order to increase the quality of services and make the welfare system more efficient. The call for efficiency has fostered political action plans in which disabled people are mobilized as active participants in service provisions. As the state looked around for ways to activate the users and their individual resources, the 'welfare consumer' emerged as an efficiency instrument (Alm Andreassen 2003). As consumers of welfare services, disabled people are seen as valuable informants. They know where the shoe pinches and are, thus, able to contribute with insight and experiences that can be used to improve the system. According to modernization policy, the development of the welfare system should no longer be a one-

way affair - an active state providing welfare to passive recipients. Instead, welfare provision is now considered a collaborative project. As informed welfare consumers their autonomous choices should form the basis for the service provisions. As the state aims to develop a more flexible system, more amenable towards the demands of the user, it is also expected that the users should take on more responsibility for the development of these services.

This shift, towards involving the individual user in the development of flexible rehabilitation programs is in line with the demand from disabled people. The Norwegian disability movement has, for a long time, insisted that individual needs and aspirations become the starting point for service provisions (Frøstad and Ravneberg 1991). But the shift should also be seen in the light of the broader neoliberal turn in Norwegian social policy. With the demand for a more efficient public sector the egalitarian underpinning of the social democratic system is challenged. However, due to the country's prosperity, based on oil and gas, such reforms have commenced later in Norway than in many other European countries. What is more, scholars have noted that neoliberal reforms are of a peculiar form in Norway (Christensen 2005; Østerud 2005). While countries like UK and the Netherlands have opted for privatization and de-regulation by pulling health care and welfare services out of the public system, Norway has instead incorporated market principles into public administration. The choice has been to reform existing systems by focusing on efficiency schemes, stronger management by objectives, and structural de-centralization within the public sector.

In the case of disability policy the shift is evident as user involvement goes from being a channel for democratization of the welfare state – a democratising element of the social democratic discourse on welfare, to *also* becoming an instrument for the modernization of the public sector – a rationalizing element of a neoliberal discourse. Emerging with a new welfare policy which emphasises universal rights *and* individualization of service provisions, the new service user is, thus, best described as a hybrid; a 'welfare-consumer'.[56] In what follows I move from the general disability policy, to a focus on the enactment of this hybrid figure in the context of aural rehabilitation programs.

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[56] A typical example is the 'Brukerpass' reform, a free pass which gives the user of assistive technologies the ability to steer the process of trying, changing, servicing, and repairing their assistive technologies. While the user is delegated more control over the process, it must simultaneously take on the work that used to be done by a rehabilitation professional (Olaussen In Asdal and Moser 2008).

Norway has a public support network for the hard of hearing which disperses responsibility for aural rehabilitation throughout the central, regional and municipal level. The state, through the National Insurance Scheme, covers expenses related to rehabilitation, while the municipalities have the overall responsibility for developing and executing service provision. In order to attain a hearing aid, which is distributed as a lifelong loan, users follow a medical route. Audiology is practiced in audiological wards located at public hospital or by ENT specialists in private practice. In either case, an ENT doctor shall conduct a thorough medical examination, followed by several hearing tests, preferably done by an authorized technical audiologist. Official guidelines emphasize that the assessment should include both the persons hearing loss and functional abilities. According to test results, one tries to find a hearing aid that can be fitted to match the subjective hearing; the relationship between measured hearing loss, and the lifestyle of the hard of hearing. The process shall proceed in continuous dialogue with the user who also has the right for a probation period before deciding what hearing aid to use. Throughout the process, service users should be given information on alternatives and complementary devices. As for other assistive technologies, supplemental to hearing aids, these are distributed from regional Assistive Technology Centres with coordinating responsibility for distribution of technical aids to public institutions and individuals. Their main objective is to contribute to equal and comprehensive solutions for people with disabilities – at home, school, and work. When a choice is made for a hearing aid or a technical aid, an application is written by a professional and sent to national insurance administration for processing. When the application is approved and an aid distributed, the professional who has recommended the device is responsible for the follow-up, instruction and training in using the device, and for evaluating function together with the user to ascertain whether the device actually solves problems and/or whether further adjustment is required.

REALIZING THE RELATIONAL MODEL

Until the mid-20th century, schools for hearing disabled people were in charge of rehabilitation in the Scandinavian countries. Then audiologists brought aural rehabilitation into the hospitals and made it a medical matter (Lieth 2002). The use of hearing technology was considered part of medical audiology. Thus, traditionally, aural rehabilitation has followed much the same pattern as in other disability fields, where rehabilitation is considered a health issue and patients and health authorities have focused primarily on bodily function and repair. In order to make a change, in 2002, the government released an

Action Plan for aural rehabilitation (SHD 2002).[57] The document came after extensive pressure from user organizations and professionals that expressed a grave concern with the scantiness of existing services and the continued medicalization of hard of hearing people. In the call for a user-centred rehabilitation, which is adequately sensitive towards the complex needs of individual users, users and professionals argued that interdisciplinary collaboration is needed to break down the uniform and reductionist approach built into the medical model on disability hitherto dominating the rehabilitation system. Eva S. Falkenberg, a leading Norwegian scholar on aural rehabilitation argued that:

> Rehabilitation can no longer be limited to the repair of physical functional deficiencies or, more generally, to what the health sector does. The individual must receive assistance to be able to achieve the greatest possible interdependence and to participate in society on his or her own terms on par with others. This means that other sectors, in addition to the health sector, must be brought on board to help the individual (Falkenberg 2007:79).

The Action Plan asserts that Norway has an extensive and expensive aural rehabilitation system, but despite its benevolent aims and objectives, service provisions are experienced as haphazard and fragmented. Part of the challenge identified through policy has been to clarify and carry out lines of responsibility. One of the main areas considered in need of improvement is the distribution of hearing technology. Since normally the same people who use hearing aids are the ones who need access to technical aids, the distribution of responsibility between different instances in the systems had brought challenges for the collaboration needed with regard to the individual user. The problem identified is that users who clearly need other solutions than hearing aids often are not given information and access to such because of the lack of collaboration between the audiological wards and the assistive technology centres. This, together with the local authorities failing to develop local rehabilitation programs and oversee the services provided to individuals, has meant that in reality, for most people, aural rehabilitation ends with hearing aids.

Responding to these challenges, the Action Plan sketched out the contours of a holistic rehabilitation model as part of the effort taken by the government to dismantle the societal barriers for disabled people.[58] While the plan identifies and seeks solutions to practical problems such as waiting lists and unused hearing aids, the underlying agenda is a discursive shift from a medical model on disability towards a social-contextual model on aural rehabilitation. The effort is an attempt to translate the general objective for

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[57] The Action Plan was developed in a typical corporatist fashion. Through committee work and public hearings user organizations, professionals, public agencies and private companies in and around the aural rehabilitation system were invited to report on their experiences and suggest improvements.
[58] Such a holistic rehabilitation model is not confined to aural rehabilitation, but figures in rehabilitation work in general, see i.e. Normann, Tveit, Sandvin and Thommesen 2004; Schwandt 2004.

Norwegian disability policy, based on the relational understanding of disability, into concrete policy instruments. The holistic model developed in the Action Plan challenges the medical model and tries to establish a new practice based on an interdisciplinary approach to hearing disability with user involvement as the key element. A technical fix is considered insufficient for rehabilitation. Instead, the aim is to empower the hard of hearing to participate in and contribute to the content and progress of the program and to develop a sense of self-coping. The holistic model does not abandon professional expertise, but changes the geography of responsibility in the aural rehabilitation system. While the medical model on disability was characterised by a relationship where the expert knew best and gave advices for the hard of hearing to follow, the new holistic rehabilitation model is concerned with the user as a knowledgeable actor in service delivery. The power of the expertise is to be reduced in order to ensure a more symmetrical meeting between the professionals and the hard of hearing. It is considered important that users have access to professionals that can perform specialized rehabilitation. However, rehabilitation should develop in dialogue between the hard of hearing and the professional. The policy is built on the recognition that hard of hearing people are the experts on the context for the rehabilitation process, their own lives. Their opinions and views are essential elements of a successful rehabilitation. The aim, thus, is to develop a system where the knowledge and aspirations of the user is the starting point for service provision, and programs are tailored accordingly.

On completion, the Action Plan was signed by two ministers, the Minister for Social welfare and the Minister of Health. The document was to become a key policy instrument for the development of a coordinated and coherent aural rehabilitation system. The holistic rehabilitation model constitutes the foundation for the government's work with improving the public rehabilitation service for hard of hearing, both with regards to systemic improvements and development of competence and services directed towards the individual user. However, such Action Plans tend to abound with good intentions and references to somewhat idealistic goals. As a processual concept, user involvement brings challenges both to the system and the individual. The critical question, which I go on to explore in upcoming chapters, is how well equipped is the rehabilitation system in meeting with these new expectations for user-centred rehabilitation?

WHAT'S THE PROBLEM?

What is the problem driving policy discourse, what assumptions underlie problem representation, and what implications do such conceptions have for how to shape solutions? These were the questions brought on by scholars approaching policy as discourse. With this analytical starting point, I have investigated Dutch and Norwegian disability policy as a space for the enactment and ordering of (hearing) disability. Both countries develop their disability policy in reference to a European context of economic globalization, political liberalism, and individualization of care. Yet, what is perceived as challenges and opportunities for policy in the hearing field was shown to diverge according to each nation's specific history, political tradition, sociocultural formation and economic situation. What emerged were two aural rehabilitation systems with different definitions of disability and belonging geographies of responsibility between individuals, technologies, and society.

In order to open a room for critical reflection, in this chapter, I will summarize and discuss these similarities and differences by means of a set of analytical questions inspired by Bacchi's (1991) 'What's the Problem Approach'. These questions relate to problem representation; the effects produced by policy in terms of systemic responses; the construction of subjects; dominant voices; and areas left unproblematic.

PROBLEM REPRESENTATION

The prime objective of Dutch and Norwegian disability policy is to ensure equal citizenship for disabled people. Yet, in a European context, both countries have been relatively slow to adopt an anti-discrimination legislation for disabled people. With regard to the model on disability underlying policy, none of the countries have gone as far as to include the social model on disability in their policy. Both countries recognize the concept of impairment, but also the social-contextual element of disability. A key difference hinges on the geography of responsibility; should the individual or society adjust? With its relational model, Norway has gone farthest in recognizing society's responsibility for constructing disability and for

the dismantling of its disabling barriers. The Dutch model tends to emphasis the responsibility of the individual rather than the social context, and does not go so far as to demand societal accommodation, but instead encourages it. However, both countries struggle with the gap between policy and practice. Neither the Dutch nor the Norwegians have managed the transition to a universal society or the mainstreaming of disability issues. Faced with this gap, both countries assign an important role to their redistributive systems.

SYSTEMIC ORDERING

Bacchi (1991:9) has argued that policy is a strategic and political process in which the battle is not simply fought on the level of 'wanting or resisting particular policy initiative, but at the level of constituting the shape of the issues to be considered.' Given the assumption that every problem representation incorporates causal assumptions, it is only by investigating the postulated solutions to 'problems' that the presumed problems can be revealed. Then, what solutions do the different conceptualizations of disability lead to in the two countries.

In the Netherlands, following its placement as a health issue within the larger context of a new health care reform, disability is sought ordered in a market-oriented mode. The disability issue undergoes a process of de-medicalization as the market emerges as the key redistributive arena. In Norway, which has a more coherent disability policy, reforms continues within the state system, and is cantered on the notion of holistic rehabilitation with continuation of the state as the main redistributive actor. Democratic principles of equality and participation continue to be pivotal in the planning and implementation of service provisions. The difference is that they are now joined by an instrumental logic that has emerged in the wake of a public sector modernization project.

When it comes to the actual apparatus for implementation of the country specific policies, technical aids play a pivotal role in both aural rehabilitation systems. Technical aids are implemented because they – in different degrees and forms - are believed to compensate for disability, enabling hard of hearing people to participate in society, they are tools implemented in compensatory systems geared towards normalization. On this, both Dutch and Norwegian policy making envisions a development more responsive to user needs and preferences. Here, the different modes according to which disability is sought ordered are constitutive for the way the countries envisions results. The Dutch approach opts for the responsiveness of the market to consumer demands. The Norwegian approach emphasizes the dialogue between professionals and users as key for assuring user driven technological solutions. However, it is worth noting that while the act of distributing technical aids is a

contentious issue, the design and development of technical aids and the social order they are inscribed with is not discussed.

Arguably, the placement of disability policy, one independently, the other as part of an overall health care policy, has consequences for the way disability policies are exposed to broader political trends. As an integrated part of a broader health care policy, the Dutch disability policy forms part of a high-status field, more exposed to political competition than (hearing) disability issues normally are. This means that Dutch disability policy is subject to the same neoliberal pressure to reform as the health care sector as a whole. As a separate policy area the Norwegian disability policy operates more sheltered from the broader political debates over the welfare system. The difference between the two countries, in this regard, is augmented by the economic situation in the two countries. Due to its oil reserves, cost efficiency has not been as high on the political agenda as in the Netherlands. This allows Norway to consider other objectives in the shaping of their disability policy, such as those outlined in the international framework of human rights and social justice and the principals of user involvement emerging from the social democratic discourse on solidarity. However, with its focus on equality, the Norwegian system struggles with a different challenge. Where the Dutch system is of a hybrid kind, with institutional expressions differing according to regional and local demands, the Norwegian centralized system has been riddled by ongoing conflicts between state and periphery. The charge being, that in a fragmented and haphazard system, service provision depends on the economy of the municipality and the goodwill of providers, rather than national quality standards.

SUBJECT POSITIONS

Drawing on Foucault's dual concept of power, Bacchi asks questions about the effects related to the discursive modes of subjectification.[59] In the analysis of national disability policies I have focused on how people are categorized within the problem interpretation and the ways in which policy discourses position different people as experts, hearing aid

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[59] Bacchi (1991) is also concerned with a third effect, which focuses on lived experience. Here she draws the attention to the limitation of strategies which focus on discursive interventions solely as social construction; i.e. that because what we think about things is delimited by social constructed meanings, we only need to challenge those meanings. Bacchi acknowledge that there are real bodies and real people who are living the effects of discursive conventions and that it is vital to attend to the harms they experience. In the light of the critique of the social model's indifference to the embodiment of disability, her caution is particularly pertinent. I go on to explore the lived experience of disability policy throughout the next two parts, where I approach disability as audiological practice and everyday life experience. In this, however, I focus on the general status of the hard of hearing in the context of policy documents and interview notes.

users, commercial actors etc. I argued that such positioning contributes to set limits for what can be said, thought and done. That is, which subject positions the discourses create for the subject to be legitimate and understandable. The focus has been on the subject positions that become available in the policies, programs and activities that are the target of national disability policy in the context of health care and rehabilitation. I noticed a transformation of the disabled subject in both countries. From being the passive receivers of charity and welfare they are now mobilized as full citizens. However, how such citizenship is conceptualized depends on the mode of ordering disability it is enacted within. What both systems have in common is a turn towards the individual in the planning and implementation of service provisions. Following the Dutch market-oriented health care reform, hard of hearing people are now constituted as consumer in relation to the (de-regulation of the) hearing aid market, and assigned new capacities and challenges related to the key concepts; consumption, competition and choice. In the Norwegian welfare state system, hard of hearing people are constituted in relation both to the modernization of the welfare state and the democratic system, this constitutes the hybrid consumer-citizens figure. Further complexity is added by the focus on holistic rehabilitation following which the hard of hearing individual is expanded and has become a socio-contextual being with a subjective hearing.

DOMINANT VOICES

The analyses of disability policy, the concepts, objects, and subjects enacted in policy discourse, the meaning assigned to them, and the heterogeneous practices they make room for, is also an analysis of the power relationships constituting modes of ordering disability. An important part of the national storylines I have presented dealt with the inclusion of voices in the policy making processes. Since discursive change involves social change, I am interested in what discursive resources are available in the disability field, and which interests they support. This meant that I was interested not only in how interpretations changed throughout the debate, but also who are able to push their interpretation on what grounds and against what background. A particular concern was how the voices of disabled people are accounted for in the formation of disability policy and rehabilitation programs.

Norway and the Netherlands are both pluralist democracies, but with different corporative traditions. The divergence emerged by tracing the process of making disability policy and designing of aural rehabilitation systems. In the Norwegian case, representation has taken the form of user involvement. Drawing on the experience of the labour movement, disability policy has been developed according to an interest political model rooted in demands for democratic participation. According to the Norwegian corporative model, disabled people themselves, through their user organisations, have been directly included in policy making processes. In the Norwegian context, the mobilization of the disabled peoples organisations and their inclusion in the corporative decision making structure has

worked to set the standard for the patient rights movement (Alm Andreassen in Asdal and Moser 2008). In the Netherlands the mobilization was reversed, from patients' rights to disability rights. Dutch disability policy has developed according to professional interest representation and a strong third sector with its roots in the Catholic principal of subsidiarity rather than through the mobilization and representation of the disability movement.

Next to the disability movement, another influential driver for the development of Dutch and Norwegian disability policy making is researchers working with social policy issues. Disability research in both countries is typically practice-oriented, often commissioned by the government or health care institutions operating in the field. Research plays an important advisory role and underpins policy decisions and reforms. Explorative or critical policy research into the disability issue is, however, comparatively scarce. Most research is descriptive and/or evaluatory and refrains from problematizing the underlying models policies and practices are built upon. The aim of research is not to provide critical alternatives, but to contribute to the reform of the existing system. The lack of independent research together with the corporative decision making structure, which links stakeholders together, may in part explain why, in neither of the two countries, Disability Studies has not been established as a separate field and there have been few advocates for a critical disability discourse among the disability organisations.[60]

AREAS LEFT UNPROBLEMATIC

According to Bacchi, the importance of a contrasting policy analysis lies in its capacity for opening room for critical reflection. What is seen as self-evident in one national context might be contested in another. This goes to demonstrate the contingency of the disability issue. I have presented two countries whose welfare systems have been dominated by two political parties and their respective underlying discourse on solidarity, one social democratic, the other Christian democratic. The focus on equality is what makes the social democratic tradition stand out as different from the Christian democratic discourse. In the Norwegian political tradition the social democratic party has defined equality as reduced social difference. The premise is that freedom presupposes a 'just distribution' of resources and cannot exist if social and economic differences are great. Solidarity, in the Norwegian case, implies a strong state with the will to distribute resources to guarantee freedom and security. This means that in Norway solidarity is mainly expressed egalitarian through the institution of a welfare state. In the Dutch Christian democratic discourse, which builds on the principles of subsidiarity, volunteerism is social solidarity on an organized basis, as an

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[60] For an argument on the Norwegian case see Moser 2003; and for the Dutch case see Kool et al 2006; Gier, Henke and Vijgen 2003

alternative (or complementary) to the welfare state. The Dutch disability policy explicitly acknowledges, and justifies, individual capacities as a result *and* source for sociocultural differences. In other words, policy acknowledges the individuals right to be different, and the individual responsibility to cope with such differences. There is no welfare state in place to redistribute resources. Instead, it is the responsibility of each and every citizen to be insured, and utilize personal capacities in the pursuit of goods. The role for the state is to provide a fair playing field; to stimulate competition among market actors and engender rational market behaviour among hard of hearing people.

With the current market-oriented shift in Dutch health care policy, the differences between Norwegian and Dutch disability policies can be understood, in broad terms, as a division between a liberal and a social democratic policy tradition. In the Netherlands, a Christian Democratic discourse adhering to a principal of subsidiarity merges with a political liberalism built on a newfound trust in the market, producing a system in which individualism is sought maximised and state intervention minimized. The market works as the redistributive actor, based on principles of competition. The Norwegian social democratic tradition emphasizes redistribution of resources through the welfare state and incremental public reform. Interest politics is institutionalized through user involvement. The state is *the* redistributive actor in aural rehabilitation program. The role of market actors is minimized and relations between users and producers of hearing technology are subject to strict regulations.

CONCLUDING REMARKS

In the analysis of Dutch and Norwegian disability policy I have explored how Dutch and Norwegian policy makers talk about, plan and intervene in relation to hearing disability. I have investigated how disability comes into being in a public space, how it links up with broader societal issues, stabilizes and transforms. I have traced discursive drivers, shifts and relationality in order to uncover the role of policy in defining problems and effective responses to hearing loss. As a space for the ordering of (hearing) disability, policy making constructs a legitimating geography of responsibility on hearing loss; what can and should be done by whom about what. What is noticeable, in this respect, is the ongoing shift in expertise in the disability field. Introducing the elective consumer and the holistic user, Dutch and Norwegian policy makers attempt to redistribute power away from audiological professionals and towards the recipient of aural rehabilitation programs. What emerges is

a notion of empowered service users, prompted to make individual choices regarding assessment and treatment of hearing loss.

While policy is an important room for the constitution of hard of hearing subjectivity, it is not the only site in which hearing disability is enacted and ordered. Public policies give guidelines for the desirable society, one envisioned possible. At the same time, policies are also ideal descriptions; they indicate the way we have to go to realize that society. Principles and objectives enacted in policy documents and interview talk should not be accentuated as reflections of 'reality'. They still have to be translated into routines and norms in everyday life. I am interested in what ideals of inclusion and empowerment are made to be and how they come to matter in practice. How congruent are the aims and objectives developed in policy making with the experiences of people working and living with disability?

To trace the transition from policy to practice, in the remaining parts of the book, I depart from the study of policy as discourse and mobilize analytical resources from the material semiotic tradition for the ongoing study of disability, technology and politics in practice. A material semiotic approach acknowledges the 'reality' of policy as principles and ideals inscribed in documents and debates. However, the point is to simultaneously recognize the multiplicity of principles and ideals, some enacted through documents and debates, others, and potentially contradicting, complementary or convergent, inscribed in clinical routines, technological artifacts, and everyday life interactions. Thus rather than seeing policy as deterministic, the material semiotics approach urges sensitivity to the way different modes of ordering disability are activated and come to relate in practice, and the space for the disabled subject to position in and between these heterogeneous ordering attempts. In the light of this, the shift in policy opens a new line of inquiry; how is the changing geography of responsibility in the disability field experienced by the people who deal with hearing loss in practice? To investigate this, I turn to two new sites for the enactment and ordering of hearing disability. First, I study how hearing disability is done in audiological practices. Then, I ask how people experience living with hearing loss in everyday life.

PART III: AUDIOLOGICAL PRACTICES

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You're a banana, the dispenser says. A banana..? I'm not sure how to
react. I have just concluded a hearing test at a Beter Horen store in
Maastricht. Now the dispenser reviews my results and gives me the
diagnosis. I am – a banana. Pointing to the paper with my test
results, the dispenser explains. Hearing is depicted in an audiogram.
Frequency is depicted on the horizontal axis, from low frequencies on
the left (250 Hz) to high frequencies on the right (8.000 Hz). The
amount of hearing loss is shown on the vertical axis with the higher
numbers indicating a greater degree of hearing loss. When we connect
the dots indicating your test results in the different tonal areas, we
have your hearing curve. Now note the shape and position of your
graph, it curves like a banana in the upper middle part of the
audiogram. We call this area the 'speech banana' because it represents
the frequency area of speech. Your hearing lies within this area,
which means you are able to recognize speech. So when I say you're a
banana, it means you have normal hearing (Fieldnotes Beter Horen,
Maastricht 2005).
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The ability to hear and interpret sound is important for several reasons. Sound gives you a sense of being in an environment. You are able to locate people and situations by following sounds. Sound also gives a sense of security, since you are warned about approaching objects. Sound and language can give you a feeling of belonging to a community. By chatting and being able to pick up on the subtle nuances in talk you can reveal irony and share a joke. Hearing enables one to stay informed and communicate a response that enacts you as rational in social interactions. These are the elements of subjectivity at stake when sound is lost. This is why hard of hearing people enter audiological clinics, centres and dispensers to have their hearing assessed and treated with hearing aids. They consult with technical audiologists to get help with reconstructing sound, to be enabled to hear again. To have one's soundscape reconstructed means repositioning as a social, secure, humorous, and rational being.

In this part of the book, which I have called *Audiological Practices*, I investigate the design and distribution of hearing technologies in professional settings. Audiology is performed in workshops, clinics, and dispensers, and is a practice marked by the interplay between humans and solid materials. Cables, measuring instruments, computers, software and hearing aids are integral parts of the job. For the service users, a hearing aid is the primary, and often the only rehabilitation service they receive. Therefore, it has also been striking to note the lack of critical perspectives and debates on the technological innovations implemented in audiological practice. The dominant view found in policy documents and

audiological text books is that digital hearing technologies, so-called 2nd generation hearing aids, are objective and neutral tools to realize efficient and user-centred rehabilitation programs.

My own intervention into the field of audiology started from a rather different premise. I have not assumed that technology will inevitably empower service users and prompt the efficiency of audiological organizations. Instead, my position has been to remain alert to the productive potential of technologies without making too many prior assumptions about the extent and nature of their use and relationship to any specific ordering mode. This means that I approach hearing devices as sociotechnologies, and seek to demonstrate how these are relational effects without any straightforward 'trajectory'. I do this by detailing the specific materially heterogeneous 'arrangements' at work in audiological practices - the interactions between material surroundings, technologies, professionals and users, including the work people do to make technology work.[61] Engaging with the empirical material, I ask whether it is indeed able to reconstruct hearing, and, if so, what the material and discursive conditions of possibility for such achievements are. What is more, I am interested in what options arise for hard of hearing subjectivity and agency throughout these audiological interventions.

The questions are inspired by, and seek to contribute to a new line of material semiotic research that builds on, and extends Foucauldian analyses of medical discourse as heterogeneous practice (Mol and Berg 1999; Thompson 1998; Mol 2002; Moser 2003). For Foucault the rise of modernity signified the rise of new technologies for normalizing the body and self, especially by means of new regimes of ordering through technologies of disciplinary knowledge. In this *early* work, medicalization is a main theme. Foucault (1973) described medicalization as a process through which the *medical gaze* defines the objects under its scrutiny. The phrase is used to describe both literally and figuratively the sense in which patients become subject to medical inspection. In the process individuals yield control of their bodies to medical expertise and are, in this sense, de-centered from their bodies: they become objects of others. My concern is with the question of subjectivity and agency in these processes of objectification. Is objectification always and necessarily a threat to personhood?

What the new line of material semiotic studies (of medical practice) attempt to do, is to move beyond the implied monolism of the medical gaze - the totalizing and reductionist effect of medicalization on subjectivity - by remaining sensitive to the multiplicity of ordering modes at work, and the distribution of agency in and between them. Charis

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[61] The reference to *arrangement* is taken from Moser (2003) who approaches disability as constituted in and through specific sociomaterial arrangements, which leads one to study the discursive and material elements that go into the ordering of disability.

Thompson (1998), particularly influential for my work, argues against the position from which objectification is theorized as an important part of understanding modern personhood, but still metaphysically opposed to subjectivity, the idea that medical interventions inherently objectify patients and thereby strip them of their agency. Her concern is with the philosophical implications of how much feminist and Foucauldian inspired analysis tends to equate objectification with lack of agency. Thompson argues instead that objectification does not have to lead to alienation, nor does it always and necessarily stand in opposition to subjectivity or personhood. Instead, drawing on empirical studies from fertility clinics, she shows how agency is not only compatible with objectification, but sometimes *requires* periods of objectification. The key is to combine a radical theoretical openness with detailed empirical work: 'To understand this interdependency it is necessary to look at the local achievement of identity, without deciding beforehand what may or may not be an element in that achievement' (Thompson 1998:169).

Hence, leaving the question of subjectivity and agency in the clinical encounter open, I engage with empirical material from interviews with rehabilitation practitioners and participatory observations from audiological clinics and dispensers to learn about how hearing loss is enacted and ordered in professional practices. To set off discussion, I use empirical extracts to describe and discuss three routine elements in the ongoing efforts to reconstruct soundscapes; design of hearing aids, hearing tests and hearing aid fitting. The findings are structured into four different, but partly connected chapters. In chapter 8, *Designing Disability,* I use Akrich's (1992) concept of 'technological script' to problematize the notion of hearing aids as neutral tools with unilinear effects. Analyzing two different design projects, I argue that technological artefacts are inscribed with social order and should be approached as active elements in the order-building surrounding hearing loss. Then, I move from the process of designing hearing aids and into the sites and situation in which hearing aids are introduced as ordering elements of hard of hearing people's lives, the audiological encounter. In chapter 9, *Reconstructing Soundscapes*, I introduce the hearing test and the fitting of hearing aids. The focus is on the process of extracting, multiplying, reworking and replacing elements of hearing that foregrounds intervention with hearing aids and the reconstruction of soundscapes. In chapter 10, *Positions in the Soundscape*, I use the notion of 'synecdochical relations' (Thompson 1998) to investigate how links between ear, hearing aid and everyday life are maintained throughout increasingly automated processes of hearing aid assessment and fitting. Finally, in chapter 11, *Lost in Translation*, I draw on the findings from the empirical chapters to discuss some tensions between policy and practice in the audiological field.

INTRODUCTION

Devices and systems based on ICTs are widely implemented in aural rehabilitation processes, among which the hearing aid is the most common. A hearing aid is an electronic, battery-operated device that amplifies and changes sound to allow for improved communication. Hearing aid sales are worth an estimated $2.9 billion a year in Europe alone (Thompson and Thomas 2005). Still this is considered a low market penetration because despite the fact that clear benefits to their use have long been recognized the majority of hard of hearing people do not have or use a hearing aid. People often wait seven to ten years after sustaining a hearing loss before they get their first hearing aid, and even after procurement, many refrain from using them. Due to the greying of the population there is a growing market for hearing technologies and strong incentives to generate solutions that can decrease negative effects of hearing loss. From a commercial viewpoint, this is an incentive for finding new ways to increase access to, and use of hearing aids. In addition there are also audiological arguments for increasing use. Without audio stimuli the brain forgets how to interpret the meaning of sound. The longer people wait before they attain a hearing aid, the harder it is to rehabilitate hearing with hearing aids. Consequently, producers and audiologists are now targeting younger users.

With the significant amount of resources that go into the making of technical aids it becomes interesting to ask how designers enact hard of hearing subjectivity and agency in the process of shaping hearing aids. To explore the mutual shaping of hearing disability and hearing aids, I introduce two design projects. Both set out to tackle the problem of social stigmatization in relation to use of hearing aids. In the case of the ReSoundAir, the designers enacted a medical model on disability and pursued a normalization strategy. In the HearWear project, the designers took as their starting point a sociocultural model on disability and opted for an aspirational strategy. The two projects further differed in their approach to user involvement, distribution of roles and responsibilities, and in their view on distributive networks. However, it is not only the different design strategies that make them interesting for comparison, so do the asymmetry between them.

The first case, the ReSoundAir project is conducted by the world's largest producer of hearing aids, GN Resound. Their approach is representative for the industry as a whole. Hearing aids are not national innovations; they are the products of large multinational companies operating within

a centralized Reseach and Development (R&D) structure. What is striking about this global industry is that despite the heterogeneity of the hard of hearing community, hearing aids marketed by different hearing aid producers look and do the same. Next to their auditory functionalities, the idea driving hearing aid design reported in my interviews with producers and dispensers is to make them 'near invisible'. The variation among hard of hearing people in terms of age, gender, etc, seems not to matter for the design of hearing aids. There is indeed ample evidence of an industrial lock-in on design approaches geared towards normalization through minimization. How then to make the politics of design visible in the analysis? To open up a discussion on design of hearing aids, I use HearWear as a critical case (Flyvbjerg 1994). This design project is not a commercial project. The products that were designed and the design teams behind them are not to be found in today's market for hearing aids. Nevertheless, with its radically different design philosophy, the HearWear project highlights the dominant industrial politics, while at the same time opening room for critical reflection by making visible the politics between them. Contrasting the two design projects, thus, offers an important opportunity to reflect on the importance of technological design for the ordering of hearing disability.

EXPLORING THE DISABLED SCRIPT

A useful analytical concept for highlighting the mutual shaping of hearing disability and hearing aids is the concept of a 'technological script', as developed by Madeleine Akrich (1992). Akrich rejects a conventional, technological-determinist conception of technological impacts according to which technologies 'impinge on' societies and brings about changes. Instead, she adopts a conception of consequences as resulting wholly or in part from social interpretation and negotiation, rather than (just) from intrinsic features of the technology in question. The concept of script highlights how technological objects enable or constrain human relations as well as relationships between people and things. To explain how the scripts of technological objects emerge, Akrich draws our attention to the design of technologies. She suggests that innovators 'inscribe' a specific vision about the world into the technical content of the new object. Comparing technologies to film, she has suggested that like a film script, technical objects define a framework of action together with the actors and the space in which they are supposed to act. Akrich suggested that in the design phase, technologists anticipate the interests, skills, motives, and behaviour of future users. The user may be represented in terms, for example, of presumptions in relation to their skills, their identities (e.g. in terms of age, gender, class, or disability) and the activities that may be seen as appropriate and inappropriate. Subsequently, these

representations of users become materialized into the design of the new product, which results in a script (or scenario) for use.

The concept of script indicates two processes at work in the mutual shaping of hearing disability and hearing aids. First, a technical aid can cement a certain mode of ordering disability because innovators anticipate the preferences, motives, tastes, and skills of the potential users, and the cultural norms in society at large. These views subsequently become materialized into the design of new products. Secondly, artefacts are inscribed with and enact modes of ordering disability that can shape the agency of hard of hearing people. Due to the norms and values that are inscribed into an object, technical aids can attribute and delegate specific roles, actions, and responsibilities to their users. By inscribing programs of actions into a piece of technology, the technology works to impose its inscribed program of action on its users, defining roles to be played by users and the system. As a result, implicit or explicit assumptions about what competencies are required by the hearing aid users and the system are being made. Hearing aids may thus create new, or transform or reinforce existing geographies of responsibilities in the hearing field.

I mobilize the concept of script to intervene in the design practices in the hearing field. I am interested in how different modes of ordering disability are sought materialized in the form of hearing devices. The assumption is that hearing aids are not objective, neutral tools designed to meet pure aural needs. As active participants in the shaping of hearing aids, designers enact modes of ordering and contribute to frame and discipline understandings and practices surrounding hard of hearing subjectivity and agency. Technologies are approached as elements of identity projects that may stabilize or destabilize dominant social orders. By studying how hearing aids are inscribed with modes of ordering hearing disability I want to contribute to improve our understanding of how technical aids invite or inhibit specific enactments of hearing disability through their use.

DESIGNING SOLUTIONS

In March 2005, a seminar addressing the future design of hearing aids took place in Oslo. The event was organized by the Norwegian design council, GN ReSound and the Norwegian organization for hard of hearing people (HLF). Social stigmatization had been identified as the main cause for people's non-use of hearing aids, and the organizers wanted to discuss whether better design could work to diminish stigmatization and increase use. Two design projects had been invited to present their design philosophies; their view on hearing loss

as a social problem and their perception of design as a solution. First was the ReSoundAir, a hearing aid introducing an innovative open ear plug system that had come to set the standard for similar devices from all major producers. Next was the HearWear project, wherein several top British designers had been invited to design hearing technology for the future. I apply the concept of a technological script to try to illuminate how these two projects materialize two very different responses to hearing loss. Following closer investigation I explain these differences with reference to underlying modes of ordering hearing disability, which again influence design philosophies and the inscribed distribution of roles and responsibilities.

'RESOUND AIR'

With their new ReSoundAir system GN Resound targets a new market segment.[62] Their product is promoted as an answer for the younger user group from 45 years old with a commencing hearing loss. People who do not wear hearing aids because they think they are too young or because they have tried out a device but experienced it as uncomfortable, or they want a smaller and less visible solution. The device is designed to tackle the common problems associated with fitting high frequency hearing losses such as occlusion and feedback that cause problems with recognizing the sound of your own voice and excessive whistling. The product is acclaimed for its novel venting design that keep the ear canal open to reduce the plugged-up sensation. The new Mini-Behind the ear fitting system replaces the traditional ear molds with very thin tubing and a dome. The open solution also allows fresh air to reach the ear, providing additional wearing comfort. ReSoundAir has won several prestigious prizes for its design. For the Red Dot price, the jury commented:

> The product reflects thorough analysis of the needs of the target group – an analysis that has led to an optimum and impressive expression in the capacity, specifications and design of the finished product (http://en.red-dot.org/2797.html).

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[62] GN Resound is the largest international manufacturers of technology hearing instrument, extensive information about the company is posted on their website: http://www.gnresound-group.com/. It is also possible to read more about the ReSoundAir on: http://www.resoundair.com/

Then, what needs were identified and what solutions inscribed into the ReSoundAir? To investigate this, I turn to the material from the seminar where Henrik Nielsen, GN Resound's chief designer, presented the design philosophy behind their ReSoundAir device.

ENACTING DISABILITY AS NORMALIZATION

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Nielsen: Social stigmatization related to hearing disability became
a main driver in the project and minimization the key to our
success. In the design team we were puzzled by the disparing
acceptance level between glasses and hearing aids. Glasses have
throughout centuries been a symbol for knowledge and intellect that
through widespread use and design developments has become an
artefact that brands the vision disabled user positively towards
what is considered to be normal and acceptable. Hearing aids,
however, are still seen as icons for aging and loss of physical and
cognitive abilites. When we started researching, we found that
hearing disability has isolated people for thousands of years. In
the Roman Empire, the Senators lost their right to vote and their
sociopolitical influence when they lost their hearing - they became
stigmatized!

Imagine yourself how it must be to walk around with this negative
stamp on your personality for 16 hours a day, every day! Throughout
the history of hearing aids people have been profoundly creative in
order to find ways to hide their hearing aids, using clothing,
hairstyle and disguising their aids as glasses or other instruments.
With our minimal ReSoundAir we have solved this problem for the
user. We have succeeded to such an extent that it's virtually
invisible, even to those looking directly at your ear (Fieldnotes
Design Council Seminar, Oslo 2005).
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Despite the many innovative technical features of the ReSoundAir it is the cosmetic features that are used to promote GN Resound's new hearing aid. In the seminar, their chief designer enacted hearing disability as something inherently negative for a person's identity. A hearing loss is presented as a condition that causes social misfit and isolation. A shameful condition that should, and increasingly could, be fixed through technological design. Instead of scrutinizing and/or criticizing the norms underlying the stigmatization, disability is individualized and its sociocultural causes mystified. As a deficit of the hard of hearing person, it is an individual responsibility to seek compensation that can normalize the situation. Normalization comes through buying the newest and best technology available. In the normalizing order, the main functionality of a hearing aid, next to amplification of sound, is to conceal disability and to help hard of hearing people to avoid the social stigmatization they would otherwise be exposed to. In this normalizing ordering designers play an important role in diminishing stigma surrounding hearing disability by

designing invisible hearing aids. As Moser (2003) has noted, by compensating for and hiding away disability, they perform a Cartesian split between the subject and its shameful body.

DESIGN PHILOSOPHY – THE MINIMIZATION STRATEGY

> Nielsen: Before designing the ReSoundAir we engaged in extensive mapping of users and their demands. Mainly we used surveys to try to get an objective idea of user requirements. Users are generally very subjective; they refer to their own, specific situation and needs. They are not able to give general advice that we can use in the design for a larger market. In my experience participatory design approaches in earlier phases of product development is futile because users are not capable of providing us with valuable feedback until in the later stages of product design. When we have an actual prototype we involve users. We do usability tests, we ask them to assess wearer comfort and we ask for advice on the cosmetic features (Fieldnotes Design Council Seminar, Oslo 2005).

In order to map the preferences of their users, GN Resound relied on questionnaires and surveys. When asked what was important for them, hard of hearing respondents commonly ticked out cosmetic aspects and wearer comfort. However, by rejecting substantial user involvement in the early, creative phase of product development the designer argues for a technologist driven development. This means that it is the designers, based on their view on disability and what is technologically possible, that are seen as capable to decide on the development of technical aids. In this ordering mode, hard of hearing people are not capable of contributing with valuable input on technological function; that is what solutions are sought for what problems. The end user is enacted as technically incompetent; incapable of articulating social aspirations and linking these to specification for design. Users are, however, seen as capable of contributing when it comes to the minor modifications of nearly ready-made products. By that stage, however, many design pathways have already been closed and users are confined to a 'yes or no' choice regarding the cosmetic aspects of hearing aids.

Goggin and Newell (2003) have argued that the idea that this particular consumer knowledge from that specific consumer group may be dismissed as 'uninformed' or 'ignorant' or 'subjective' only shows a lack of understanding that all people bring knowledge to encounters between users and producers. What follows is that rather than situating design in the everyday contexts of users, innovation is driven by a synthesis of surveyed ideas of user needs, which points to a shortcoming in the design of assistive technologies. Part of the problem with special devices is that so often the design and

changes recommended comes down to designing for particular abstracted disability needs, rather than ensuring an engagement in the process of design and implementation with people with disabilities and the complex realities they bring with them. Such systematic exclusion of the life experiences of disabled consumers can lead to a restricted technological script. While in principle the use of hearing aids seems well fit to address the communication problems of hard of hearing people, it is hardly sufficient to merely focus on the technical possibilities in a lab setting and apply those principles in a social setting. That would imply a deterministic approach to design, and may have the unfortunate effect of forcing users to adapt their lives to technology, rather than designing technologies that are robust enough to tackle the social realities of the users.

In the history of hearing aids there have been few radical innovations in design. The development has mainly cantered on minimization. While the technology inside the devices is progressing, the design is not. Hearing aids from all major producers are locked-in on more or less the same form and function, as if the user group were one homogeneous mass, with disability as their only subject position. Such a design philosophy, focusing on somatic impairment and how to 'fix' it by hiding it away, impounds the enactment of different forms of hard of hearing identities and compels all hearing aid users to adhere to the same materialized ordering of disability, that of normalization. Given for instance that there is no gendered design of hearing aids, it is worthwhile recalling the point made by Tom Shakespeare (1996) about how disability has the power to transcend other identities. For example it has the power to de-sex people, so that people are viewed as disabled, not as women and men. People rejecting such a reductionism might be the cause for people choosing not to use technological devices just as much as the fear of social stigmatization.

DISTRIBUTION OF ROLES AND AGENCY

> …interpret the hearing aid as an integral part of modern lifestyle. This is materialized through an elegant appearance. The device is hardly visible and is understood as a fashionable accessory - just like a mobile phone fitting, a headset or an MP3 player. It integrates a fully digital hearing system with high sound quality dynamics and a high performance processor that enables signal processing that keeps in touch with the modern world. Therefore, the ReSoundAir is thought suitable also for young people with hearing problems (GN Resound 2005).

In the case of ReSoundAir, disability is enacted as a condition that can be remedied by technical intervention. How then, are subjectivities and agency inscribed by this normalizing ordering mode? The extract above is taken from a marketing brochure for

ReSoundAir. The text targets the modern, technologically mature consumers who lead an active lifestyle and are experienced and demanding when it comes to technological design and functions. People who use MP3 players and mobile phones do so not only for their function, but also view them as status symbols. These types of gadgets are often designed to cater to the users' desire to control and manage technology, thus, they often contain an element of learning. To become a user you must build competency on the device and its use. This is not seen as a downside to the products, rather it is part of their attraction, as use signals technical competence. However, while marketing material enacts a competent and avant-garde consumer, the user role inscribed into the device itself is more ambiguous, which became apparent in the designer's presentation at the seminar.

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Nielsen: We are also pleased with the user friendliness of the
ReSoundAir. In this little device, you will find the latest
technology available on the market. The device has a closed system
which runs on intelligent software. Once a hearing aid is fitted by
an audiologist it will automatically adjust programs following the
user's movement through various soundscapes. The device runs by
itself, there are no complicating buttons (Fieldnotes Design Council
Seminar, Oslo 2005).
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Notwithstanding the impressive technological possibilities, there is also a different message to be read from this kind of 'intelligent design'. Trough automation agency is delegated from users to experts and from humans to artefacts. An active user role is restricted by the closed design of the ReSoundAir. Apart from changing the batteries, the device does not encourage competent and active ownership. For elderly users with reduced vision and/or stiff fingers automation might be advantageous. However, the point is that this specific device is not designed for the elderly; this device is targeting modern and young users.

The passive user role is further reinforced by the distributive system the hearing aids take part in. In order to adjust and control the device hard of hearing people must seek professional assistance in a system that enact them as dependent persons in need of help and assistance. Through automation and a closed system, the script of ReSoundAir enacts the hard of hearing user as incapable on technological matters and dependent on professional assistance. On this Goggin and Newell (2003) assert that while technical aids are potentially liberating, they are also inherently controlling. The technoscience world of assistive devices is inherently controlling when looked at from the perspective of people being required to meet standards defined by professionals and regulatory groupings before gaining access to a particular technical aid, and when their devices must be adjusted, controlled and repaired. In fact, most hearing products on the market today emphasize

user friendliness in terms of simplicity of use. The result is closed systems without much possibility for user modification and devices that must be programmed by an audiologist by means of special software

The marketing of ReSoundAir fortifies the division of power and control between users and experts. Information material is not only, or even typically, targeting hard of hearing people, but rehabilitation professionals. Through brochures and websites the information targeting professionals is on technical functionalities, here the user is referred to in the third person, positioned as the passive beneficiary of professional services. On the occasions hard of hearing people are targeted directly, the information regards cosmetic and comfort aspects, the hearing aid's 'invisibility' and open venting system. Rather than ascribing the user status as dynamic, modern and gadget oriented, in marketing material the hearing aid user is again enacted as technically incompetent or uninterested and ashamed about their disability.

So what where the reactions among the participants of the seminar? The presentation awoke an outcry among representatives from the user organization and welfare professionals. The minimization strategy promoted by the GN designer was criticized for undermining the disability movement's struggle for awareness and acceptance of hearing disability. Professional representatives reacted to the attempt to demarcate the social from the technical. To sell hearing aids as a technical fix to more complex problems was regarded as counterproductive to the attempt to realize the holistic aural rehabilitation model currently advocated in policy making and professional teaching. Official policies and text books on aural rehabilitation emphasize how the social and technical is interrelated and successful rehabilitation requires a mutual and balanced strategy (Normann, Tveit, Sandvin and Thommesen 2004; Schwandt 2004). Hard of hearing people should be made aware that technology alone only offers limited results, since a hearing loss cannot be compensated for by hearing aids. Successful communication still requires social accommodation from the user and surroundings. To facilitate communication conversational partners need to be aware that the person they are talking to have a hearing loss. Trying to camouflage hearing loss undermines such adjustment and often feeds misunderstandings that may cause further social isolation. Met with the critique, the GN Resound designer maintained his stand.

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Nielsen: Surely there are shortcomings to portraying technology as a
complete solution to the more complex social problems of hard of
hearing people. But in our experience, the response to the social
stigmatization surrounding hearing disability is best framed as a
design issue. People are really satisfied by our device. I think
that better design can play an important role in helping these
people, and eventually eradicate the whole stigmatization problem. I
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do not mean to underestimate the need for sociopolitical accommodation. However, this is the responsibility of policy makers and user organizations. It is way beyond my job as a technologist. What we have tried to do in this project is to provide our customers with what they want. They want smaller devices. This was well-documented in our pre-design questionnaires. What is more, it has been confirmed by our remarkable sales result. You really cannot argue with that! (Fieldnotes Design Council Seminar, Oslo 2005)

The response leaves the underlying cause of social stigmatization unchallenged. But then, what is the role of engineers and designers in the hearing field? The dominant practice in the design, production and marketing of technological objects is to follow existing trends in society. Designers often explain their choices in terms of 'we do what the consumer wants.' On this, Oudshoorn et al (2002), in their study of gendered scripts, note that designers can be seen as 'culturally naïve' because they reproduce, strengthen, and legitimize dominant sociocultural stereotypes of the preferences and skills of specific users. Through its minimization strategy, the ReSoundAir design works to reinforce rather than challenge the social stigmatization related to hearing disability. Enacting hearing loss as a shameful condition, the ReSoundAir device might, in part, offer a solution to the actual discrimination and stigma hard of hearing people experience in societal life. However, the solution is deficit since it leaves aside the need for social accommodations. On a collective level such solutions might even work to reinforce stigmatization as hearing disability remains invisible and technical intervention mystified. But are engineers necessarily culturally conservative, or can they act as reflective agents of change? In the next case, the HearWear project, the objective was to act as a catalyst for change.

'HEARWEAR'

Thomas: The first thing we did was to stop calling it hearing *aids*. We work with hearing products. We want to challenge the perception of hearing devices as medical tools and instead try to demonstrate that it is as any other consumer product you find in the high street these days. For us, this is a way to tackle the stigma it is attached with. A hearing loss is a common phenomenon, why make it so special? (Fieldnotes Design Council Seminar, Oslo 2005).

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This is how Neil Thomas, head of product design with RNID introduced HearWear, a design project in which 20 of Britain's leading designers were invited to redesign the way we hear and create new products to enhance, protect and augment our hearing.[63] The display featured radical new designs for hearing products, all exhibited at the Victoria and Albert Museum in London. Concepts ranged from jewellery such as a sleek necklace, glasses incorporating a hearing aid, and sparkling in-the-ear devices, to completely new concepts including devices to boost your hearing in noisy bars and products which 'cancel' noise, enabling you to control your sound environment by blocking out unwelcome sounds.

ENACTING DISABILITY AS DIFFERENCE

> Thomas: Mainstream design of hearing aids remains locked-in in on the desire to naturalize and miniaturize the product, while advertisement for a hearing aid, surprisingly, rather than talk about the assets these products can offer, are likely to talk about how small the product is; 'so discrete nobody will know you're wearing it'. This negative marketing tells the users that hearing loss is first and foremost a disability, and something to hide, and does little to improve the image of the actual product. Arguably, this approach creates a closed loop where the customers are forced into seeking smaller and smaller products. When this is what people are told is the future, what they understand as progress, and what they are offered by way of a development, it might not come as a surprise that is what they seek.
>
> The starting point for HearWear was that disability is a widespread social phenomenon. Thus, rather than hiding it one should be open about it. Technology plays a role in this, as a way to communicate disability as an element of one's identity. In the HearWear project we tried to use design to establish hearing disability as a normal aspect of life not as a deviance and, thus, rejected the notion that persons with disabilities are in some way 'defect'. Instead of trying to 'fix' disability, our ambition for their project was dual. First, we wanted to design a wide range of devices to expand access to the latest technological solutions that could decrease the negative effects of hearing loss. Secondly, we wanted to create a positive buzz about hearing loss to increase the social status of hard of hearing people (Fieldnotes Design Council Seminar, Oslo 2005).

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[63] The Royal National Institute for the Deaf (RNID) is the largest volunteer organization working for deaf and hard of hearing people in Britain. For more information see: http://www.rnid.org.uk/. To learn more about the HearWear project visit: http://www.designboom.com/contemporary/hearwear.html

Both design projects aimed at tackling the problem of social stigmatization. But while GN Resound adopted a minimization strategy, HearWear made the critique of such a strategy the core of their project. Their argument was that; 'it, in part, sustains a silence and lack of everyday understanding about a condition which many of us will experience at some point in our lives'(Thompson and Thomas 2005:19). In the HearWear project the solution to this social blind-spot was framed as better design, products more pleasing to the eye, greater awareness of users' taste alongside better marketing, branding, and distribution.

Herein lies a bigger lesson about technology and innovation – one which encourages new thinking about the body and technology. According to Susan Livingstone (2005), the hearing-aid industry has fallen into a trap where one single-mindedly is seeking to stimulate the human body – to make technology appear as natural and the body as unaided as possible, to 'normalize' the condition of the deviant body. However, she asserts, the great breakthroughs in technology often do the opposite. Frequently, they turn the body and its capabilities on its head. They show that real innovation does not always come from seeking to mimic nature, but rather from thinking beyond it and, in a positive way, transforming it.

A basic objective of the HearWear project was thus to challenge the 'culturally naïve' design approach. Rather than just being a case of 'giving the customer what they want' the HearWear project indicates that mainstream hearing aid design and their following marketing apparatus is important for creating that demand, and thus, also plays a part in maintaining the stigmatization of hard of hearing people. HearWear began by asking; 'What if hearing aids could be desirable, aspirational products in their own right, rather than an aid to compensate for impairment?' The project investigated how the hearing aid industry could be opened up for new, and different stream of design and innovations – and how it might be a market in which more mainstream consumer electronics manufacturers could get involved. In sum, calling for a new design philosophy to hearing technology.

DESIGN PHILOSOPHY – THE ASPIRATIONAL APPROACH

Two men walk into a bar. It's Friday night. It's busy. The music is loud, and the atmosphere is buzzing. Matt and Dave come here regularly for a few drinks and a chat. Matt fancies a girl who works behind the bar. People are standing in groups, shouting to be heard over both the incessant beats. It might be worth pointing out at this point that Matt is a bit deaf. He blames it on his brief career spell in the Army five years ago. It doesn't really bother him – apart from when he's at a party and the background noise is too loud. It's another reason why he likes this bar – he knows as long as he can get a table it's somewhere he can have a proper conversation. Hold on... He's hard of hearing and he goes to this particularly crowded, noisy bar because he can hear? Yes, and so do a lot of his friends, because this bar has a clever system installed called Table Talk – it's one of the main reasons it gets so busy in the first place. Designed by IDEO, Table Talk is an amazing new range of furniture that helps people to hear in noisy situations. The tables look just like ordinary tables, but they have a built-in microphone system linked to a conductive strip running round the edge. If it's really noisy all

you need to do is go to the bar and buy a little blister pack of ear buds for a fiver or so, and share them out around the table. The ear pieces, working with the technology in the table, amplify local sounds, so whatever conversation is going on around the table is crystal clear. The ear buds look cool too – very iPodish.[64]

The above extract is from the brochure following the HearWear exhibition at Victoria and Albert museum in London. Here the scenario behind one of the devices, the 'Table Talk' was explained. In order to develop such user scenarios the design teams engaged in extensive multivariate approaches to profile consumers, using ethnographic methods, interviews, surveys, observation, engaging lead users, and drawing on the experiences of professionals and researchers in other areas of electronics. The design teams considered it as critical to have a plurality of methods and to work together with users in all phases of the design process. By engaging with users' everyday life context one hoped to learn what would trigger their desire for products. Their starting point was that it was not to be a restyling exercise. The designers needed to fundamentally re-address what a hearing device could do and how it could be integrated with other technologies just as much as how it could look. By pinpointing problems and situations related to hearing loss they could create product proposals that would be an attractive proposition not only from a usability point of view, but also – crucially – from the point of view of the potential consumer positioned in a sociocultural context of use. The idea was to demonstrate what a shift of design approach – from that of minimalization towards an aspirational approach – could achieve. The designers wanted to augment and experiment with the way people hear, to develop products that were stylish and desirable and that people want to pay for. Technology was seen not as a fix for a functional problem, but as an element of identity construction projects.

Disability scholars and activists have challenged the stereotyping of disabled people by describing and advocating the diverse experiences of being disabled in our society today. With the call for sociocultural conscious design HearWear articulates a perspective on user-technology relations which emphasizes the role of technological objects in creating and shaping social identities, social life and culture at large. What follows is a rejection of rehabilitation professionals' attempt of objectifying disabled people as one homogeneous group, making disability a unitary subject position that can determine their choice of technical aids. The HearWear project aimed to respond to this critique on two accounts. First of all, their design situates the users in a sociocultural context. Secondly, the project emphasizes choice by designing a variety of products for a heterogeneous user group. On an analytical level, the project can be read as an attempt to escape medicalization by

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[64] Retrieved from http://www.vam.ac.uk/vastatic/microsites/1498_hearwear/player.php on May 6th 2006

ordering disability as a consumer issue in which consumption of hearing products becomes a site for the enactment of disabled identities.

Distribution of Roles and Agency

Thomas: When targeting a market segment we emphasized how generations advance. The people who have grown up in a world saturated with branding and consumerism will be the ones with the spending power. They will also have lived their whole lives in the information age, and will be – for the most part – thoroughly comfortable with the idea of new technology, and personal electronics. All this adds up to a future where older generations will be demanding products of an entirely different nature than the ones they have today. We wanted to create hearing devices that create awareness about hearing disability, gadgets that can be shown in fashion magazines, portrayed as desirable objects, not something to hide and be ashamed of (Fieldnotes Design Council Seminar, Oslo 2005).

As with the ReSoundAir team, the HearWear designers took as their starting point the increased threshold for augmenting our hearing with technology through mobile phones, iPods, and blue tooth systems. And so, they asked what scope is there for new products that increase the users' control over their own hearing. In contrast to the ReSoundAir, this user configuration went beyond marketing and became central to instructions for use. User friendliness was defined as a possibility for user intervention and control. The product design allowed for user modifications through, for instance, changeable parts, accessible control buttons and integrative possibilities with other gadgets. In this way the designers wanted to facilitate an active user role, based on their vision of the users as competent and knowledgeable about technology and confident and open about their disability.

The designers involved in the HearWear project did not have prior experience from the disability field. Rather than working with technical aids, they were invited to design desirable technological gadgets for mainstream consumers, products that could be fitted into a modern, mainstream context of distribution and use. The intention was to establish hearing disability as a varied enactment wherein the user is delegated control through consumer choice. With a focus on consumer goods, brands, marketing and distribution in the high street the HearWear project mobilizes consumption as a way to challenge the enactment of disability as a shameful bodily condition. As with any ordering mode, the consumer order constitutes its own normativities; inclusions and exclusions. The products that emerged from the project targeted a user segment with particular knowledge and

interest in technology. People who can afford to stay up to date with the newest of the newest. Users that are confident about their disability and the attention their gadgets attract. This type of conspicuous consumption indicates that the HearWear gadgets might not be an answer for all. Since markets tend to create differences, what could result is a social divide between those that can afford the advanced technology and those having to settle with the discount chain.

Then again, the idea behind HearWear was not that everybody should buy into it. Rather, the project wanted to serve as a critique of dominant practices. They wanted to enact difference to escape the current lock-in on minimization. Linking the recognition of hard of hearing people as a heterogeneous group with the acknowledgment that people consume technology, not merely as enabling tools, but also to reflect their broader identity, the project aimed to demonstrate how multiple design solutions can materialize in the form of a multitude of products, fit for different personalities and contexts. Through a broad product range and accessibility in the high street, the HearWear project sought to open up for the enactment of differences to allow the plurality of disabled identities to 'come out'. Insistency on plurality and choice was seen as key to materialize and visualize manifold ways of being hard of hearing, which again was seen to counter stigmatization. With a new way of thinking, and appropriate changes in marketing and product development, HearWear wanted to demonstrate that there is a vast potential for new solutions to encourage more responsible, experimental, and positive attitudes to hearing disability, and towards the potential for audio enhancement.

CONTRASTING REMARKS

How can it be that two design projects sharing problem definition; how to increase use of hearing aids, and targeting the same user group; modern, technologically adept people can come up with such different technical solutions? In both projects, hearing disability is seen to induce special needs: a need for amplification of sound and a need to combat stigmatization. However, the mode according to which disability is sought ordered differs, which also influences the materialization of solutions; their technological scripts.

The ReSoundAir project enacts hearing disability as normalization. The underlying question is how to conceal physical impairment by minimal design that avoids stigmatizing attention. The HearWear project challenges this design strategy. Embedding the distribution and use of hearing products in a broader consumer culture, hearing disability

was enacted as sociocultural difference. Their message was that by increasing the social status of hearing products, wearing them as fashion gadgets, one may tackle the prejudices that lead to stigmatization in the first place.

The case studies illuminate the difference between a technological script designed to conceal impairment, and another trying to move away from a deficit approach to hearing disability by attempting to situate the technological script in a more aspirational sociocultural context. By materializing these two differing ordering attempts, technological design become active agents in the enactment of hearing disability. Yet, notwithstanding the differences in design philosophy and materialized result, on an ontological level, the question of disability remains. All hearing technologies are, in some way or another, designed to compensate for a loss of hearing. Thus, they invoke, of necessity, a script of normalization and a repair of a damaged body. At a fundamental level, there is no difference in substance between the two design projects, they both enact normalization. The difference between them, I suggest, hinges not on disability, but on their theory of the social: The 'normal' society with which technical aids are to enable the hard of hearing to blend in.

In my reading, ReSoundAir enacts the rational, modernist, society in which science and technology is applied to fix all divergences and deficits. HearWear enacts the complex, postmodern society in which individuals actively consume identity. In the latter case, technical aids still enact normalization through compensation, in addition, they also cater to the multiple self, users' desire to reflect positions such as gender, class, trendy, and technologically adept. Thus, while technical aids are inscribed with different social orders, the need to order hearing disability by use of technical aids remains the same in both cases. What this means, with regard to subjectivity, is that whether or not people are able to move into an aspirational position on disability, depends not so much on hearing loss itself, but the ability to mobilize other subject positions in the consumption of technical aids. In this case, as already argued, the HearWear project might indeed open for the enactment of difference, but on the cost of increasing social divisions within the group.

My argument is not that technological design is capable of solving all problems related to hearing disability; there can be no promise neither of a technological nor social fix! Hiding away disabilities does not eliminate the causes for social stigmatization. Developing a plurality of hearing products will not necessarily lead to a free choice when it comes to enacting disability. Discrimination occurs in fundamental arenas such as schools and work places which are not only influenced by the form and function of artefactual design. The extent to which things structure and determine human behaviour is an empirical question and may be different for different technological objects and users. If the scenarios for use that the designers make do not fit with the actual context of use, the resulting script can work excluding. When I use the term 'exclusion', it seems to suggest that users are static

entities who are influenced by the script in a particular way. This suggests a technological determinist view on technology. Of course, people in society and technologies constantly change, mutually influencing each other. The experience of disability in our societies may change, ideas about technology evolve, barriers may vanish while new barriers appear and groups of people who were formerly excluded get included while others are excluded again. Thus, while the concept of a technological script is fruitful for the study of sociomaterial relationships, it is limited by its preference given to the perspectives of designers which lead one to ignore the potentially transformative force of users (Stewart and Williams 2005).

Users, by their different ways of interpreting, using and talking about technologies further contribute to the shaping of technology. In order to understand technology as a relation element, it is necessary to ask how users of hearing devices experience the producers' scripts and how they construct their own. Users define whether things are stigmatizing or aspirational when it comes to enacting subjectivity. This does not exclude the argument that hearing technologies play their part in shaping the conditions of possibility for the enactment of these identities. Rather than interpreting non-use as a deficit on the part of the user group, i.e. in terms of social stigma or lack of knowledge about existing products, the concept of a script highlights how technological design itself might work to include/exclude potential user groups. What agencies users have to re-interpret scripts is an empirical matter. Thus, in the next two chapters, I move from the design philosophies driving the materialization of hearing technology towards the professional practices in which these technologies are introduced to their users; the audiological encounter.

INTRODUCTION

Exactly who visits the technical audiologist varies from place to place. In Norway hard of hearing people are those who have a functional disability lasting more than two years. In the Netherlands, visitors are those with a verifiable loss of 35 decibel or more. When people enter the office of a technical audiologist, whether in Norway or the Netherlands, they typically find it furnished with a desk and some chairs that position patient and professional facing one another. On top of the desk there is a computer and a phone. On the wall are posters displaying the inner ear and calendars sponsored by hearing aid producers. In shelves and drawers there are earmolds, tubes and batteries of various colours and sizes, and an otoscope to look into the ear. What is most striking is the collection of cables hanging on the wall, like spaghetti. Each hearing aid model has two cables, a red for the right ear and a blue for the left ear. There is no industry standard, which means there is quite a bundle. The cables go into an adapter that transmits digital information between hearing aid and computer. The latter is the hub of the office. On the computer the technical audiologist keeps journals, audiograms, test programs, and fitting software that structures their interaction with visitors. As clients enter, they submit their hearing to professional tests, assessments, and treatments with the aim of reconstructing soundscapes.

When I use the word 'reconstruct' it is to highlight how soundscapes, after having been extracted, multiplied, reworked and replaced, might not be the same which was originally lost. It means being open for the possibility of something new coming about, something that needs to be adjusted to and accepted by the hard of hearing. This indecisiveness is intended to give room for analyzing not only how synecdochical links are maintained, but also how rifts can come about, alienating humans from their machines, the hard of hearing and their hearing aids. Which begs the question; what is done in audiological practices to maintain the link between ears, hearing aids and subjective hearing?

In Norway, audiological clinics are sited at the regional hospitals. 'Ahus' is located just outside Oslo. The hospital hosts an audiological clinic that offers services to the regions 340,000 citizens. Visitors first take a seat in the waiting area in the hallway. From here, two doors lead into the clinic. One door is for the ENT unit, this is where new patients start out, to eliminate medical complications and remove ear wax. The other door is for the department of technical audiology, this is where hearing tests and hearing aid fitting are performed by the technical audiologists. This is also where I am, paired up with 'Heidi', a technical audiologist, to study the work routines in which hearing aids are introduced into the lives of hard of hearing people. In the empirical extracts below, Heidi consults with a new client to assess her needs for hearing aids.

PASSING THE TEST - EXTRACTING AND MULTIPLYING ELEMENTS OF HEARING

Heidi asks 'Mrs. Sørensen' (60) to tell her about her problems hearing. Mrs. Sørensen is nervous. She explains how she started asking over again, and went to see the nurse at her work about it. The nurse had done a test and concluded that she was hard of hearing. Mrs. Sørensen: "I was shocked. I didn't want to think about it, but, it's become impossible to ignore. I lose information and… and my daughter insisted that I do something. She drove me up here today". Heidi: "I'm glad you came. I'll try to help you, but you have to keep in mind that hearing aids won't give you your normal hearing back." Mrs. Sørensen: "I know, but I want to give it a go. I am not getting any younger you know..." Heidi nods then she starts to explain the procedure. First they are going to do a hearing test, to get an idea of Mrs. Sørensen's hearing and then they will discuss her options for hearing aids. Heidi explains that she won't get hearing aids today. They have to be ordered from a dispenser, and an imprint of Mrs. Sørensen ear has to be made, in order to make earmoldes. When all the parts are ready, a new appointment will be set up to fit the aids. Mrs. Sørensen looks confused. Mrs. Sørensen: "I thought I would get them right away?" Heidi: "Are you motivated for that then?" Mrs. Sørensen: "Well, I do think that I'm a bit young… but in some situations, like in the theatre I could need it, but not all the time. Like now, I have no problem hearing you. Can't I start little by little?" Heidi: "It doesn't work like that, when you start with hearing aids, there won't be an effect over night. Suddenly you will hear a lot of new sounds that you have to get used to. It will take some time. Often one-to-one situations when you're not stressed and can hear reasonably well are the best to start practicing, even though that's when you feel like you don't need aids. Now, let's first have a look at your hearing. When we know more, we can discuss your options."

The empirical extract introduces a typical first time consultation at the clinic. For Heidi, the professional, this is routine. When she meets with Mrs. Sørensen she follows a standard procedure which she repeats every day, several times a day. It is an operation she, as all Norwegian technical audiologists, has trained for during a three years' college bachelor program. She goes through a testing phase and she introduces some of the possibilities and challenges involved when becoming a hearing aid user. For Mrs. Sørensen, the encounter is far from standard. She describes the hearing loss as a shock; it has turned her life around. She has come to the clinic to find a solution to her problems, but she does so hesitantly. During the consultation she acts restless, nervous, even annoyed. However, she asserts that the hearing loss cannot be ignored, she must face her problems. Therefore, she takes the position as the patient, seeking professional advice from Heidi, which also means complying with hospital schedules, testing procedures, and a stranger telling her to adjust her daily routines.

Before Heidi can start to work on Mrs. Sørensen's hearing, her disability must be verified and made operable. For this, Heidi initiates a sequenced process, an order which disentangles an objective measure of loss from the subjective experiences of (not) hearing. Mrs. Sørensen is unfamiliar with the procedure. She thinks her story about miscommunication is sufficient to verify her disability, she wants hearing aids immediately, and she wants the technology to adapt to her lifestyle. She only wants to use the aids when *she* thinks she needs them. But Heidi intervenes to discipline her; 'first we do a hearing test, then we discuss your options'. A border is drawn for what is relevant in the consultation and what should be left out. A sequence is established in which the hearing test becomes the foundation for further action. Mrs. Sørensen needs to recognize the positionality in the consultation if order is to be established. Heidi knows the routine, she is the expert. Mrs. Sørensen is the patient and must allow herself to be treated.

MAKING HEARING VISIBLE

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Mrs. Sørensen is seated in the midst of the soundproof test room.
She is about to start the tympanometry test, to measure the
flexibility of Mrs. Sørensen's eardrum. From the wall Heidi gets a
set of cable which she attaches to a pair of red ear plugs. The
cable goes into the computer, the ear plugs into Mrs. Sørensen's
ears. Heidi: "Try not to move or speak." Then Heidi applies air
pressure changes, and measures how sound bounces back. It is
essential for the hearing ability that the eardrum is flexible and
allows sound to pass through into the middle ear space, and from
there into the inner ear. If the eardrum is too rigid (i.e. if there
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is fluid behind it), the sounds bounce back off the eardrum instead of passing through.

Next Heidi does a pure tone test to get an idea of the hearing loss in decibels. She opens a blank audiogram on her computer and instructs Mrs. Sørensen. Heidi: "I want you to put on the headset and position with your back towards me. Then you let me know every time you can hear a tone by pushing the button." Heidi uses a machine called an audiometer to generate sounds of different degrees and frequencies, high and low, bass and treble. By decreasing the level of the sound, she can work out the quietest sounds Mrs. Sørensen can hear. When Mrs. Sørensen doesn't respond to a tone, Heidi marks it off in the audiogram. When she has run through the entire audiogram, the computer connects the dots into a graph, which is Mrs. Sørensen's hearing curve.

Heidi: "Ok, good. Now we just have one more test left, and then we're done. I'll play a sequence over the loudspeakers. I want you to repeat the words you hear. The sound will gradually become lower." Mrs. Sørensen: "Horse – Horse, Seven – Heaven, Two – Two, Clothes – Clouds… No, no, wait I don't know." Mrs. Sørensen concentrates. Then she becomes frustrated, unable to determine the meaning of the sound. They try some more, but the limit seems to have been reached. Heidi finalizes the test. According to Mrs. Sørensen's answers, she gets a percentage score which indicates her ability to recognize and discriminate words.

Heidi saves the results and presses print. Out comes two diagrams with each their graph, right and left ear. She turns to Mrs. Sørensen and starts to explain the figures. Heidi: "You see here is your hearing, which is a bit less than normal on the right ear, but on the left you have a more distinct loss. It's not very complex, no problems in the middle ear. It appears to be an age related loss, here in the treble area, the area for speech understanding, very typical." Heidi walks up to a poster of the inner ear. She points to the cochlear, depicted on the poster, curling up like a snail house. Then she explains how the beginning of the cochlear is the high frequency area, the treble. This is often were people first sustain their damage. It can go inwards, but most people only loose sound in the treble area. She returns to the desk and the print out. Heidi: "These numbers in your audiogram indicate how loud the sound must be for you to hear them. You see you start with 20 dB and end with 40 dB on the treble. It's only a moderate loss, but, if you want to try hearing aids I think you should. I will try to amplify the sound in that area with hearing aids. However, with a moderate loss, it's really important that you're motivated. If you believe you can manage without aids, then that's what you're going to do. Then you want take the trouble getting used to them." Mr. Sørensen looks from the poster to Heidi. Mrs. Sørensen: "I want to try. I have this image of my dad. He couldn't understand what went on around him, still he wouldn't dream of seeing a doctor about it. I don't want to end up like him!"

For Heidi to get an idea of Mrs. Sørensen's hearing, means seeing it. To make the hearing loss visible she starts to break it down into readable parts. For this a test room is made available. Sounds are sent through cables from Heidi's keyboard, through the computer, across the soundproof room, and into the headset. Responses are made through the button on Mrs. Sørensen's stick, back into the computer. Sounds are transmitted between humans and machines. Sounds ears detect or ignore. Sounds which produce responses that are monitored and coded into a readable test result. The computer sends the results to the printer that produces a graphical image of the audiogram on paper. In the process, Mrs. Sørensen's ability to hear is extracted and depicted as percentage scores and graphs, visual images and diagnostic categories that objectify her, and makes her hearing readable and operable. This process of using technology to make hearing visible is what constitutes the audiological profession. The technical audiologist depends on methods of viewing and arraigning hearing spatially and temporally. During the audiological encounter patients are produced in forms that can be worked on, of proportions that can be scanned, read or recalled rapidly during consultation.

To produce an efficient view on hearing involves disentangling the objective from the subjective according to a sequenced order. Certain elements are singled out as relevant, others are excluded. It is Mrs. Sørensen's physical ear that is the focal point of the test. Mrs. Sørensen's attempt of self-diagnosing - referring to her everyday life experience of being unable to hear - is not what counts; it is the visible test result that verifies the loss and sets off action. When Heidi initiates the procedure; 'let's first do the test', she adheres to an order in which diagnosis and treatment is based on graphically displayed test results rather than face-to-face interaction. In fact, Mrs. Sørensen is asked to sit with her back towards Heidi and the computer to avoid her from 'cheating'; to use her eyes to see when Heidi transmits sounds. The procedure enacts Mrs. Sørensen's subjectivity as suspect, possibly interfering with the reliability of the test result. A form of patient is assumed in which the visual images, numbers and graphs, are privileged and personal accounts of symptoms and experiences are relegated, even distrusted in the gathering of evidence. The objective audiogram replaces Mrs. Sørensen's subjective account of her experience of disability and her active involvement in the interpretation of results. Technology, in the context of audiology, provides images of hearing which represents it in new ways, allowing for new forms of interventions. The hearing problem is disentangled from Mrs. Sørensen's tangible, physical body and the sentient of human being, becoming an object that can be moved through computer networks, in situations across space and time. The audiogram is trusted to tell the structuring narrative, based on objective measures, without subjective disturbances, it is seen as a key enabler of effective intervention. And it is efficient indeed. The whole procedure is over in 15 minutes.

The test result quantifies Mrs. Sørensen's hearing loss in decibels and shows how it spreads across the different tonal areas. The audiogram depicts her hearing in an audiological language, that of percentages, graphs and curves, which makes it readable for a technical audiologist. Making hearing visible gives Heidi a view of Mrs. Sørensen's soundscape, how she hears the world. In this sense, as noted by Latour (1986), the main quality of visualization is not to be 'objective' in the naive definition realism would claim, but rather to have optical consistency. Because, once extracted, Mrs. Sørensen's individual graph can be compared to a standard graph, that of people with 'normal' hearing. Based on the divergence between the graphs, Heidi identifies abnormalities, which she classifies into specific types of hearing disability; 'flat loss', 'pool loss', 'ski slope loss', 'age related loss', etc. The divergence assigns room for intervention; it tells Heidi what areas of the audiogram can be worked on to try to reconstruct Mrs. Sørensen's ability to hear. Once extracted, Heidi can upload the audiogram onto her computer and initiate a fitting program which can read and adjust graphs. The software communicates with a hearing aid, which is then programmed to amplify sound in the tonal areas Mrs. Sørensen is unable to hear. Sound can then be replaced in Mrs. Sørensen in a reworked form, in the form of hearing aids. What is important here, as noted by Latour, is not only visualization, but its linkage to cognition. What is needed is more than visible objects, but a mode of ordering that sets these objects in relation to one another, which mobilizes their material relationality. Within a normalizing order, elements of hearing, hearing aids, welfare systems, audiological procedures and patient roles stand in a logical relation to one another. On its own, the hearing curve does not mean much. The audiogram needs to be viewed according to specific mode of seeing to produce measurable results and enable intervention.

The reference to 'normal' hearing means that Heidi works on the assumption that there is a typical hearing, one that allows audiology to construct standardized classificatory systems that define 'normal' and 'abnormal' ways to hear. Within this binary the enabled body is indisputably the norm. The hard of hearing subject has all the body parts as that of somebody with normal hearing; they are simply deformed, so the disabled ear is the inferior enabled ear. The latter thus becomes the object of reproduction and extensions by the technologies of disciplinary-based knowledge. Audiology as a physical process of reconstructing hearing depends on the social process of maintaining categories of disability and ability that are sustained culturally. Categories that are used to read hearing curves and to decide whether the problems that people, like Mrs. Sørensen, experience are uncomplicated or serious enough to justify intervention with hearing aids. To a greater or lesser extent, society draws on medical knowledge to set the standards for normality and to decide how people should behave to meet these standards and so maintain an able body. In practice, physical hearing is fundamentally entangled with social norms about how to hear.

What this means, is that the audiological encounter builds on, and adds to an order of 'normalization'. A normalizing order enacts disability as something inherently negative, a problem to be managed and solved for individual as well as for society, a discernment which triggers a (moral) responsibility to act. Expectations linked to normality allow technical audiologists to diagnose, prescribe, and decide when to intervene and what advice to give, to offer prognoses, and to use their discretion in such a way that the particular case of hearing is seen to be managed effectively. This becomes collectively experienced as well, i.e. through disability policy that, in preserving standards of public health presumes to secure individual health through aural rehabilitation programs.

ENACTING ALIENATION AND VICTIMIZATION

In the process of testing, assessment and consultation, Mrs. Sørensen's hearing is broken down into isolated parts, extracted from her subjective state, and studied and evaluated by the professional who, in the end, also makes a recommendation on her behalf for how to normalize what has been categorized as deviant and problematic. When Heidi has assessed Mrs. Sørensen's hearing loss she concludes that it is not a profound or complicated loss. Nevertheless, she recommends that she starts using hearing aids. Heidi thinks they will be of help to her, conditioned that she uses them according to her professional instructions; 'change won't be over night'. To benefit from hearing aids requires adaptation on the part of the user, senses have to be rediscovered and daily routines have to change. Although this is not quite what Mrs. Sørensen had in mind when entering the clinic, she decides to enrol into the aural rehabilitation program.

Here, then, the clinical gaze is viewed as a composition of professional and institutional power. That which, in this case, gives Heidi the authority to decide homogenously and absolutely what is normal with regard to hearing. This entails handing over power to define problems and propose solutions of technical as well as social forms; hearing aids and their 'correct' use. By leaving the categorization of 'normal' or 'abnormal' hearing to be carried out by only one voice, that of Heidi, the professional, a homogenously fixed order is produced rather than a multiplied exposition of different approaches to the audiological encounter. This ability to produce homogeneity is what, according to (early) Foucault (1973), makes the clinical gaze efficient.

Foucault's work on normalization has inspired STS scholars in their studies of medicine and medical technologies. Brown and Webster (2004), i.e., argue that with new medical technologies, the body has become subject to the power of medical classification, supervision and regulation, a site through which the regulation of disability and ability, the process of normalization, can be secured both at societal and subjective levels. Similarly, and with reference to Foucault's dual concept of power, Mort et al (2008:8) argue about

medico-technical interventions that, 'constructing such systems or schema is part of a dual process of objectifying and subjectifying (and governing) individuals, characteristic of modernity. The point brought forward in these STS studies is not that medical systems crush subjectivity, but that they act to produce it and to shape it.

Also scholars within Disability Studies (see i.e. contributions in Tremain 2005; Goggin and Newell 2003) have been inspired by Foucault, which has given rise to a body of work in which patients are paradigmatic to the objectified patient, supposed either to be helpless and saved by the technologies, or to be victimized by them. In these studies, objectification is seen as alienating, with technology in imminent danger of disciplining personhood. Given the apparent pacification of Mrs. Sørensen during the testing procedure; the rejection of her everyday account of disability - her positioning with the back towards us, and the instructions for how to change her everyday life - it is tempting to describe Mrs. Sørensen's meeting with the audiological expertise in either terms.

In the first story, Mrs. Sørensen's status is that of the helpless beneficiary of an audiological rescue operation that works to restore normalcy in her life. Since the patient has no agency on this view, all the value and virtue accrues to Heidi, the professional and her technical tools. In the second story, that of victimization, Mrs. Sørensen takes the stigmatizing position as a welfare client and enrols in a rehabilitation program which forces her to adapt her life in order to conform to an order of normalization. On this view, she is turned into an object of study, tested, assessed and treated, reduced to a mere physical presence in the name of procedures that can only assist, not compensate her hearing loss. Since Mrs. Sørensen has no agency in this case either, all the criticism and debunking accrues to Heidi, the professional and her technical tools. In both interpretations, Mrs. Sørensen is thought of as someone who has no say in the shaping and application of the technologies. She is at best someone who benefits from her objectification in the clinic by being more enabled in her hearing, and by being recognized as someone who acts in compliance with the dominant mode of ordering disability and seeks help from the aural rehabilitation program.

During the audiological consultation an order is established. Mrs. Sørensen seems content, even relieved. Her social problem is singled out as a typical case of age related hearing loss. She has seen it on the poster on the wall, the audiogram, and her percentage score on the speech recognition test, it makes sense. Her condition is one perfectly recognizable and operable within audiological practice. By objectifying herself according to measures of physical normality and abnormality, Mrs. Sørensen's hearing can be, if not repaired, at least ameliorated with hearing aids. Hearing aids become the intermediate through which not only clinical but also social abnormalities can be contained, rationalized and managed. During the consultation personal chaos is replaced with audiological order.

However, this framework is not without problems. In particular, I am concerned about the monolism implied in Foucault's (early) work. Having moved in and between different audiological sites I have observed different modes of ordering hearing in practice. Yet, a basic premise for the efficiency of medicalization is its homogenous totality, and the lack of alternative ordering modes. On an analytical level, the problem with enacting this totalizing medical gaze in analysis is that it works to silence difference and opposition, in effect, leaving the hard of hearing individual trapped in normalization. The only course of action for Mr. Sørensen is to subject to the discursive instructions of Heidi, which in this framework is taken to imply that she either willingly or by force accepts this ordering mode as truth. The medical gaze leaves no room for the multiplicity of ordering modes and the strategic positioning in and between them. With elements of objectification and normalization at work, surely medicalization is a plausible reading of the audiological encounter, but is it the only possible interpretation?

REENACTING AGENCY THROUGH THE MULTIPLE SELF

Charis Thompson's (1998) work suggests another reading of the audiological encounter. Hers is enabled by a sensibility towards the temporal and spatial multiplicity of webs in which hearing disability is enacted, which are also constitutive for subjectivity as multiple. According to her, the multiple objectified patient does not have to entail neither being helpless nor a victim. Instead, she suggests that the patients' objectification involves their active participation, and is managed by themselves as crucially as by the practitioners, procedures and instruments. The point is that the activities occurring in treatment settings are not only incompatible with objectification, but they sometimes *require* periods of objectification. Thompson's report from the fertility clinic is about how patients use their multiple selves and their sociomaterial surroundings in the ongoing construction of agency. Key to her argument is the notion of *synecdochical mechanisms*; denoting how a part of something is used to refer to the whole thing, or how a thing (a 'whole') is used to refer to part of it. She applies the term to the study of distribution between subject-status and object-status in clinical settings. This denotes the process in which patients allow body parts to stand in for them during treatment because this may help realize aspirations for long termed self. By emphasizing the enabling role of objectification, Thompson is concerned to show how *de-centring* may be crucial to cantered control. And conversely, that accomplished centring may lead to motivating de-centring. On this, John Law (2007) argues that the strain then, is not necessarily towards 'drawing things together'. Or if it is, then it is about how drawing things together is intimately related to a contrary process of

taking them apart.[65] That making a coherent subject may work by attending to disparate organs. Thompson (1998:192) refers to this process: 'of forging a functional zone of compatibility that maintains referential power between things of different kinds as *ontological choreography.*

In addition to this spatial notion, Thompson introduces a temporal dimension in her work. She is concerned not with simple movements through time or the creation of irreversibility. Instead she attends to people's prospective/retrospective interpretations, with the possibility for reflexive repair of indexicals. Thompson's understanding of agency entails that what it is to be a subject changes in ways that are the result of, and simultaneously the proof of a person's agency. This is what, according to John Law (2007), makes Thompson's work so groundbreaking. In arguing that ordering is momentary, temporally and spatially, her work has no problem with inconsistency. What is objectifying in one situation can be ordered differently at some other time, in other places. What this means, is that Thompson, in contrast to those who view the objectification inherent to the clinical encounter as a threat to subjecthood, locates alienation not in objectification per se, but in the breakdown of synechdochal relations between parts and the whole that make objectification of various forms into associated forms of agency. Medical ethics and accountability, she argues, need to be founded not in the figure of the rational, informed citizen but in the conditions for the maintenance of those crucial relations that configure identities and selves, and that might allow them to be reconfigured in desired ways.

Relating this to my empirical material, I noted how people coming to the audiological clinic go through many positions. In Mrs. Sørensen's case, she is the mother complying with her daughter's concern for her hearing. In the waiting area she is a generic patient. After the testing procedure she becomes a graph in an audiogram. Following assessment, she will return to be the private person who has to fit hearing aids into her daily routines. Within the context of audiological practices, it is the operations performed by professionals and their tools that allow these ontological variations to be realized and to multiply. By passing through them hard of hearing people embody new options for their long-termed selves. The key here is to see ordering as momentary. In her life, Mrs. Sørensen enacts disability in several places and many ways. The clinical setting is just one of these, her everyday life is another. This multiplicity of ordering is the source of her multiple self. Going from home to

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[65] Here Law refers here to Bruno Latour (1986) who analyses technoscience as the mutual process of visualization and cognition, a process in which the centered actor (engineer, scientists) plays a crucial role in drawing immutable entities together in the mobilization of strong and large network. According to Law, Thompson's ontological choreography, with its notion of spatiality and temporality, stands out from the work of early ANT. Spatially by emphasizing de-centering, temporarily by extending early ANT's interest with simple movements through time or the creation of irreversibility. The argument is that with Thompson's framework we may move beyond the early ANT concern with centering, towards notions of multiple, loosely connected webs, opening new possibilities for agency.

the clinic, is to move in and between ordering modes, which also means opening a passage between her multiple self. The audiological encounter is at the same time isolated and connected to the ordering of her everyday life. The clinic is isolated because it is limited in time and space; it is only a short visit to a place far away from home. At the same time, it is connected because coming here means complying with her daughters wish, and gaining access to treatment that can be of help in her everyday life.

In this reading, Mrs. Sørensen objectifies her body to bureaucratic routines, medico-technical procedures, and an asymmetrical positionality that make her body operable for intervention in the form of hearing aid because this objectification promises to bring about the desired changes in her identity. This is an aspect of the 'synecdochical mechanism', in which patients make a part of their body stand in for the subject position as a patient. Mrs. Sørensen allows Heidi to focus on her ear, and extract elements of sound. She agrees to sit with her back against her and to exclude her subjective opinion in ways that would never have been acceptable in other contexts because it enables her to enact rationally exactly in these other contexts. Thompson's argument is that people's multiple subject positions are temporarily irrelevant whilst they are being examined by the professional. At some other moment things will be ordered differently, thus, there is the option for reflexive repair. Based on the temporary objectification taking place in the clinic a new and transformed identity is available for Mrs. Sørensen in her everyday life. Back home she can reposition from a social misfit to a rational hearing aid user and that is what *really* matters and what justifies a momentary de-centring. In this sense, the audiological encounter is a dual process where objectification in one context can enable subjectivity in others. By allowing Heidi to objectify her body to exam and make decisions for her in the context of the consultation, Mrs. Sørensen can re-emerge as an active agent in other contexts of her life, a person who, compared to her dad, acts on her hearing problems and takes responsibility for her life.

To recognize the interdependence of objectification and agency means to position against the view that the use of medical technologies necessarily and always entails a loss of agency following the objectification of patients. While Thompson does not deny the possibility that technologies may discipline and subjugate their users, her argument is that the various forms of objectification are not, per se, anti-ethical to personhood. She argues instead that this process of objectification, of turning the patient into an array of objects that are, at least in some instances, disembodied, intersects positively with construction of the subjectivity of the patient: the notion, in the case of Mrs. Sørensen, that it is important to do something about her hearing disability, to seek professional assistance and try to become a hearing participant in social life.

There are pertinent political implications to this analysis. In the theoretical chapter, I argued the problem with much work within Disability Studies has been its tendency to

alienate users from medicine and medical technologies. In my view, Thompson's framework enables a different, more constructive reading of the audiological encounter. Paying attention to the specificities of technologies in setting may re-open the room for critical politics in use and development that was relegated by social modelists in their attempt to escape the clinical gaze. This is not the same as to embrace audiology and the hearing technologies that professionals put to work uncritically. The rendering compatible of themselves with the instruments, routines, and material surroundings holds the possibility of transforming visitors of the audiological clinic, but it is not inevitable. Rather, the argument is that any evaluation of patients' actions has to take into account their multiple identities and the way they objectify to treatment because of effects it produces outside the clinical realm. The experience of agency relates to the extent to which the encounter manages to maintain the synecdochical link between ears, hearing aids, and everyday life.

The hearing aid users I present in this part of the book were people that I interacted with only during consultations. During which they were prepared to orient themselves as objects of study and intervention. They willingly subjected to the expertise of the technical audiologists and their tools, to the bureaucratic routines of rehabilitation systems, and to the material setting they saw as appropriate for acting on their bodies. This willingness must be seen on the grounds that people were interacting in active treatment, they were aspiring candidates for hearing aids. They were there because they hoped hearing aids would become a solution to their hearing problems. If however, the visitors went home only to learn that their aids did not function as expected, that their abilities were not improved, or the costs of making them work were simply too high, then there is the risk they would feel alienated from their bodies by the treatment. They would be stranded at the phase at which they had undergone lots of procedures but had nothing to show for it. A loss of subjectivity and agency in this case, recurs after the procedure has failed, which replaces the functioning synecdochical relation with an ontology in which there is a rift between the patient as a subject and the patient as object. Then, the objectification is indeed alienating.

Since ruptures may not be immediately apparent, but manifest themselves further down the rehabilitation process, a qualification is in order on part of my analysis. Since I have not followed the visitors out of the clinic, I can make no claim with regard to whether they experienced agency or alienation.[66] I can, however, point out that the objectification of hearing involved in the audiological encounter is not inevitably opposed to human agency. Not being able to establish whether or not agency was indeed resulting from the encounter

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[66] In part IV, I investigate everyday life as an important setting for the enactment of hearing disability, but the people I introduce there are not the same people that I interacted with at the clinics.

between hard of hearing and professional does not prevent me from proposing the analytical argument that synecdochical links can neither be ignored nor taken for granted beforehand. They are maintained in practice, and must be investigated empirically. For now, I will continue to study issues of subjectivity and agency in clinical settings as I move on to the next phase in the treatment cycle, the hearing aid fitting.

Thus far, I have focused on audiology as material practice. I have discussed how, the otoscope, cables, hearing aids, computers, software and the like are an integral part of the job. So is the ability to interpret materials and images produced by these technologies, when, during a hearing test, hearing is locally and temporally extracted from the physical body and becomes represented through a series of visual images; dots, graphs, curves, and numbers. Here visualization is an important part of the audiological encounter. Making hearing visible through hearing tests, audiograms, and fitting software is what makes the hard of hearing operable for intervention in the form of hearing aids. Missing from this partial list, and arguably less evident at first glance, is the ability to know how to talk about sound in ways understandable to hard of hearing people.

Working with empirical extracts from hearing aid fittings, I have learned how sound poses a specific challenge to the audiological encounter; how to render audiological phenomena concretely in language.[67] The analytical task is to show how sound is enacted, and with what implications for the ordering of hearing disability. Exploring empirical material on the interactions between professionals and their client, I have found that there are several ways to enact sound – lay, medical and technical – in the audiological encounter. In the light of this multiplicity, and without fixed descriptors for sound, I am interested in the relationality between them; how is multiplicity handled in the context of a hearing aid fitting, and what are the conditions of possibility for a reconstructed soundscape to emerge? To explore this, I introduce empirical material from a hearing aid fitting. Combining resources from ethnomethodological studies of professional audition (Porcello 2004) with a material semiotic approach to the mode of ordering of disability (Law 1994; Moser 2003), I investigate how professionals and clients talk about sound. Based on the findings I argue that the ordering of sound inherent to the reconstruction of soundscapes can be understood as a form of situated action that involves elements of *probing* subjective senses*, translating* between different ways to enact sound and a process of *persuasion* with regard to the effect of hearing aids.

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[67] As Porcello (2004) has argued, the problem of representing sensorial phenomena through language is not, of course, unique to sound. Wine tasting for example, raises the problem of how to make taste accessible to others in language, and attempting to describe perfume does much the same for rendering the sense of smell.

Eindhoven audiological clinic is a regional institution offering interdisciplinary services through a team of physiotherapists, audiologists, social workers, secretaries, technical audiologists, volunteers, special educators, psychologists, and ENT doctors. People who come here have been referred by their GP or dispenser because they have a medical condition and/or a complex hearing loss. In addition to having their ears checked and hearing aids adjusted, people can visit the technical showroom to try out assistive devices such as alarms, phones, or listening devices. I am here to learn about hearing aid fitting from 'Jelle', the clinic's senior technical audiologist. In the empirical extracts below, Jelle consults with Mrs. Hoof, an experienced hearing aid user who has a large and complex hearing loss.

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Jelle asks his client to tell him about the problems she has had
with her new hearing aids. Mrs. Hoof: "Well, when I'm at parties or
in big crowds, I can't understand a thing. Also, they whistle a lot,
and my own footsteps sound like thunder. I think there is something
wrong about the fitting, because the sound better is a lot better on
the right ear." Jelle: "Well, that's how it will always be, because
your right-hand ear is better. But we'll work on your hearing rest
to optimize the effect of the hearing aid and try to make it more
balanced." Mrs. Hoof:  "That's good, because I like the devices. I
just think they need some adjustment. The dispenser tried. Twice I
was back, but the last time she said she couldn't help me, and sent
me here." Jelle looks at her and asks her whether the earmoldes are
comfortable. Mrs. Hoof nods. Jelle glances through her journal.
Jelle: "I agree, I think this model can be really good for you, we
just need to do a thorough fitting. But you know they want give you
your normal hearing back." Mrs. Hoof nods again. Then Jelle takes
his otoscope and use it to look into her ears. He says everything
looks fine and tells her to put the hearing aids back on. Then he
gets some cables from the wall and connects the hearing aid to the
computer. He sits down, opens the fitting program and retrieves Mrs.
Hoof's audiogram.
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Mrs. Hoof has gone through all the tests. Her hearing has been extracted, depicted in her audiogram, saved as a computer file that is now downloaded to Jelle's computer. After breaking her disability down into readable parts it is time to use what hearing she has left to try to reconstruct what has been lost. For this Jelle initiates a fitting software that allows him to operate on the divergence between Mrs. Hoof's audiogram and the 'normal' hearing

curve. During the fitting procedure Jelle tries to manipulate the sound produced by the hearing aids so that they can work as an intermediary between the elements of hearing that were extracted and diagnosed as dysfunctional and Mrs. Hoof's experience of sound.

The first generation analogue hearing aids only amplified sound. For persons with a flat loss who have lost sound equally in high frequency, low frequency and middle tone area, amplification might be sufficient to reconstruct hearing. For Mrs. Hoof, whose treble, bass and middle tones are differently affected, amplification alone wont do. Ten years ago, people with this type of complex hearing loss would have been socially deaf, even with hearing aids. But with today's digital hearing aids sounds in different tonal areas can be adjusted independently, allowing new experiences of hearing to emerge. With today's devices, Mrs. Hoof can take part in conversations at home, in a restaurant and over the phone. But first the hearing aids must be fitted according to her loss. Mrs. Hoof is not satisfied with her new hearing aids and she does not think it is right when she has paid so much for them. Jelle will try to fine tune the devices to optimize the sound. During the fitting process Jelle works to maintain the synecdochical link between the audiogram, hearing aid, ear and everyday practices. The aim is to adjust the hearing aids in a way that allows Mrs. Hoof to recognize herself in the elements of hearing that are now to be reworked and replaced.

PROFESSIONAL AUDITION

As Jelle moves the cursor across the screen, information windows pops up with specification for the hearing aid; functionalities and parameters that can be adjusted. While operating the software, he asks Mrs. Hoof to describe the sounds. Mrs. Hoof: "Too hard, now it's too soft… It's so difficult to describe..." Jelle: "Yes, there are no words, but don't worry, we'll take our time. Just try to describe how the sound is. Your own voice, does it sound natural?" Mrs. Hoof: "No, it's like it is somewhere outside of me." Jelle: "But if I adjust some more on the left ear, how is it then?" Mrs. Hoof: "My voice is better, but now your voice sounds a bit... eh... mechanical..?" Throughout the fitting process Mrs. Hoof struggles to put her hearing into words. Jelle senses her frustration and encourage her to articulate the sounds. While she probingly puts her hearing into words, Jelle looks from the screen to Mrs. Hoof, then back at the screen, while he manoeuvres around the software adjusting different graphs. A little less echo, some more bass, amplification in the middle level. Jelle: "Hmm, what is most important for you, is it the comfort or the sharpness of the sound?" Mrs. Hoof: "What do you mean..?" Mrs. Hoof looks frustrated.

Jelle prints out her audiogram and bends over the table. Jelle: "You see here, this graph here shows your hearing loss. You see that you can hear reasonably well in the bass area, but you have lost a lot

of sound in the treble. When I adjust the hearing aid I want to add
a little bit bass, while I want to turn the treble sound as far as
possible towards your hearing curve. The problem is that if I turn
it too high, it gets uncomfortable, that's when your footsteps sound
like thunder and the aids starts to whistle so we have to find your
threshold level. Let's try some more, you just try to describe to
me, how the sounds are." Jelle grabs his pen and drops it on the
table. Then he picks up a newspaper and crunches its pages between
his hands. He stands up and talks to Mrs. Hoof with his back towards
her. She responds to the sounds he sends through her hearing aids.
<u>Mrs. Hoof</u>: "Wait, wait, it is too loud, it cuts through my ears."
Jelle manoeuvres on the screen again and puts the sound down. <u>Mrs.
Hoof</u>: "Oh, that's better, now it's soft and natural." <u>Jelle</u>: "Ok,
let's focus on my voice, how does it sound to you, is it also
natural? Say if I tell you about the beautiful weather we have
outside today, can you understand that?" <u>Mrs. Hoof</u>: "Your voice is
fine, it is very clear. It's amazing how well I can hear you! But my
own voice is a bit weird; it is like… like I'm inside a tunnel..?"
Again Jelle manoeuvres on the screen. They keep on talking, until
Mrs. Hoof says she is content with the sound of her own voice.
<u>Jelle</u>: "Good, I think we have a basic fitting!"

The interaction between Jelle and Mrs. Hoof illustrates a key challenge in the audiological encounter; how to render experiences of hearing understandable in intersubjective terms, how to speak of sound. Mrs. Hoof is frustrated, both by the unnaturalness of the sounds coming through the hearing aids and the difficulties she has explaining to Jelle why they are wrong. Yet, throughout the consultation between Mrs. Hoof and Jelle something happens that allows him to conclude that they have 'a basic fitting'. Mrs. Hoof goes from being frustrated by her inability to hear and communicate sound, to sharing with Jelle a sense of order in the making. How does this happen? How is a synecdochical link established between Mrs. Hoof's ear, the hearing aid and her experience of sound?

It has been difficult for me to get an analytical grip on sound as an intersubjective phenomenon. On the one hand, this project is all about sound; the inability to hear. Yet a lot of the material I work with relates to effects of sound. I read about aural rehabilitation programs, I describe hearing aids, and I listen to the life stories of those unable to hear. Given my material semiotic approach, perhaps this is to be expected. I am, after all, interested in how things emerge through relations, not in their essential being. But the fieldnotes from the audiological sites troubled me. Would not analyzing policy and technology, the sociomaterial effects of a hearing, while avoiding sound itself, reproduce a representationalist view on hearing disability? What more is there to be said about sound than pointing out its relativity and the political implications of closure? What more is there to do than criticizing hearing aids for being reductionist and policy strategies to be inapt What to do with all the transcribed pages with *talk*? The challenge is accentuated by the primacy of vision in scientific work, STS is no exception. Over the last two decades some of

the most prominent work within STS has focused on the minutiae of the visual practices and techniques of scientists (See i.e. Lynch & Woolgar 1990 and Latour 1986). Diagrams, drawings, graphs, photographs, and pictures are at the heart of the technoscience enterprise. The world of the scientist and the technologist and indeed the world of those who consume its ideas, products, and innovations tend to be treated as a visual world. Scientific instruments are often designed to render the world visually, to provide what Lynch (1990) has called the 'externalized retina' that guides scientific inquiry. What gets visually represented in what form and by what means, and how such visuals are read and transformed are key questions. What we might call the 'visual paradigm' has come to dominate STS and the humanities and social sciences in general. As noted by Bijsterveld and Pinch, the visual is the known, there are ways to deal with it, talk about it and study it. The auditory is the unknown, the unfamiliar, the new.[68]

How one hears is seldom problematized in everyday life. People tend to think of sound as something either inherently subjective, so individual that it cannot be shared, or, conversely, people take sound for granted and assume that one can hear and understand the same things as the person one is interacting with. [69] But while descriptors like 'amazing', 'clear' and 'jazzy' might be appropriate vague metaphors for discussing music among friends, they are insufficient as linguistic tools in an audiological work place defined by sound-identifying, -creating and -manipulating technologies where the goal of work is to control and craft sounds with great precision. In the field of audiology sound is important for its own sake and so is the ability for professionals to, on the one hand, understand it in finely detailed ways and, on the other hand, discuss it with clients in a colloquial manner. Then, what analytical resources do we have to talk about what we hear?

Thomas Porcello (2004) mobilizes analytical resources from social studies of technology at work to study sound engineers in music studios. Coining the term 'professional audition' he conceptualizes the fundamental relationship between language use and knowledge of the profession. Drawing on ethnomethodological analyses, he suggests that we approach professional audition as a form of 'situated action' (Suchman 1987; Garfinkel 1967). He argues that professional audition entails an ability to shift between different ways of speaking of sound, to deploy different discursive registers when developing a sense of

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[68] As a reaction to the primacy of vision Bijsterveld and Pinch (2004) introduced Sound Studies in a special issue in Social Studies of Science under the slogan; 'Sound and listening matter!' The authors behind the volume suggested that STS's engagement with the auditory dimension can be thought of as an extension of the field's continued examination of the detailed material practices that constitute technoscience. However, little sustained scholarship has followed.
[69] DeNora (2000:47) has suggested that the 'ostensibly 'private' sphere of music use is part and parcel of the cultural constitution of subjectivity, part of how individuals are involved in constituting themselves as social agents'

shared listening. Porcello's approach to discourse is primarily linguistic. In addition, I am interested in the relations between discursive and material elements of sound. Thus, in order to get a grip on the heterogeneous shaping of soundscapes, I have combined the notion of professional audition with the material semiotic concept of ordering modes. Analyzing the ordering of hearing as enacted by Jelle and Mrs. Hoof, I argue that fitting procedures involve more than opening a direct link between hearing aid and ear. The process of reconstructing soundscapes rely on a process of probing sound to rediscover senses, the professional's ability to translate between different ways to enact sound, and (dis-)ability to persuade the client of the effect of hearing aids. Presenting this work on the ordering of sound, I want to contribute to extend the material semiotic sensibility, thus far preoccupied with visualization, towards issues of sound and hearing.

THE ORDERING OF SOUND

In analyzing the interaction between Jelle and Mrs. Hoof, I focus on the audiological encounter as a site for professional audition. In this framework, an important part of becoming a professionalized 'expert' is gaining the ability to speak authoritatively as an expert; acting like a technical audiologist entails learning to speak like one. The discursive conventions attendant to the work of technical audiologists are, in large parts, about becoming familiar with a kind of classification system of like and unlike concept, objects and subjects, and, more importantly, classificatory actions taken by learning and applying the classifications made by others. Audiologists do not only learn how to hear sounds when studying the sensorial and technical principles underlying audiograms and hearing aids, not only do they learn how sound waves are modified and their effects on achieving a different ability for speech recognition, they do not simply memorize information about electrical current flow and software components. They also learn a complex audiological discourse – a way of talking about and hence enacting, the relevant phenomena – then translating them into significant communicative resources to be deployed in consultation with clients. Such socialization matters because it is pivotal to professional identity (marking oneself as a technical audiologist with rights to speak authoritatively in the profession) and competence (getting the hearing aid fitting done - thoroughly).

Porcello argues that dealing with sound is particularly complex because of the heavy reliance on competence in managing a wide range of metaphoric discursive conventions. The metaphoric dimension means that no act of classification is absolutely correct, and successful application of terms of classifications are not independent of previous applications of that term. As metaphors map one domain of experience onto another, they leave room for negotiation of collective judgments about classificatory terms and actions for sound. These negotiations can have important residual traces in subsequent classifications. In other words, there are no 'correct', 'objective', or 'universal' terms to

describe what you hear. Thus, the process in which the meaning of sound goes from being incommunicable to become shared is highly interpretive.

The encounter between Jelle and Mrs. Hoof can be seen as a form of 'situated action' in which one consequence of the indexicality of language is that a mutual understanding is achieved on occasions of interactions with reference to situation particulars, rather than being discharged once and for all by a stable body of shared meanings. Unable to draw on readily available and fixed descriptors, Jelle and Mrs. Hoof try to build an intersubjective sense of sound through probing different descriptors. While Mrs. Hoof struggles to describe her soundscape, Jelle struggles with 'seeing' a territory unknown. 'There are no words', Jelle says, comforting his frustrated client. However, the apparent void of a common language does not mean that there are no structuring elements in the ongoing interaction. The audiological encounter is highly standardized. The aim is to enrol Mrs. Hoof as a hearing aid user. The procedure depends on Jelle's ability to turn subjective descriptions of sound into standard technical terms, a precondition for making it operable within the fitting software. The linking of skills and technology is the basis of the organization of audiology and establishes the audiologist as the source of knowledge. It is essential to maintain the link between the audiogram, hearing aid, ear and everyday practices in order for Mrs. Hoof to recognize herself in the reconstructed soundscape and avoid becoming alienated her from body and technology.

TRANSLATING ON THE MULTIPLICITY OF SOUND

Following the probing attempts to describe sounds; '...your voice sounds a bit... eh... mechanical...', comes the challenge of translation that, I argue, is an essential element in the reconstruction of soundscapes. First, the translation between senses, what is heard needs to become visible, this was the result of the testing procedure. But there is also another, more subtle, translation going on. The audiological encounter can be seen as a situation where different modes of ordering hearing disability become linked together. There is the (generally) non-technical ordering of Mrs. Hoof, 'footsteps like thunder', 'at parties I can't hear a thing'. There is the normalizing order in which these contingent subjective experiences of disability are categorized and compared according to constructed audiological standards for hearing. And there is the technology structuring conversation by asking for articulations that are translatable in terms of software commands. When Mrs Hoof says that the sound is 'too high', Jelle must be able to translate that spatial metaphor for hearing into a corresponding technical concept, also expressed via metaphor; 'too much treble', which translates sound into assignable numbers; frequency, or Hz. Inside the world of this second metaphor, Jelle can turn to an equalizer in the fitting software and increase or diminish the specific frequencies to alter the sound, take away or add some Hz, and retranslate into a spatial metaphor: 'your voice is now softer'. To be an effective technical

audiologist, one must be able to move comfortably among all these metaphors and across their level of technicality and be able to relate them proficiently to the subjective hearing in question; Mrs. Hoof's soundscape.

In order for hearing to re-emerge in a modified form, in the form of a working pair of hearing aids, the parts that are extracted during the testing procedure needs to be replaced and linked to the rest of Mrs. Hoof to make her whole again. Here, part of the technical audiologist's job involves what Thompson (1998:192) refers to as; 'forging a functional zone of compatibility that maintains referential power between things of different kinds.' This means that Jelle has to translate a subjective account of hearing into an operable command in the software, in order to adjust her hearing aids according to the divergence depicted in her audiogram. The different modes of ordering hearing disability are enacted through arrangements of sociomaterial elements that (seemingly) straightforwardly represent set auditive realities. The ongoing interaction between Jelle and Mrs. Hoof illustrates how there are a multiplicity of ways to speak of and order hearing disability. The audiological language is not totalizing, nor is the subjective account decisive. Different auditory realities must be linked in order for a tolerable soundscape to emerge. The process is one, not of reducing multiplicity, but of ordering the relationship between different ways of enacting sound. Multiplicity gives room for interpretive flexibility, which in this case implies that elements of probing, learning, and interpretation are involved in the process of reconstructing soundscapes.

Through training, technical audiologists learn the terminology and techniques specific to the professional ordering of sound, and they also learn how to deploy and interpret that sociotechnical knowledge skilfully. Learning an ordering mode is, technically speaking, a matter of acquiring language and skills. Someone learning to become a technical audiologist may be thought of as essentially memorizing technical user manuals. How to conduct a hearing test, read graphs and interpret their divergences, and operate fitting software. But knowing technical tools is not the same as possessing the ability to deploy them correctly particularly when it comes to the social conventions that inevitably surround their use. Therein lies the crucial distinction between professional acquisition and socialization.[70]

Translation between different modes of ordering hearing disability is essential when fitting hearing aids. Translation entails shifting between modes of enacting and ordering hearing disability. Nuances of soft and sharp, good and bad must be translated into technical descriptors with corresponding commands in the fitting software, commands that control

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[70] I discuss the distinction between professional acquisition and socialization further in chapter 10.

parameters of sound, echoes, amplification, bass, treble, etc. As Mrs. Hoof probingly describes what she hears, Jelle rearticulates the description in 'correct' technical terms, and translates from subjective experience to objective standard. If 'weird' means 'echo' and 'too loud' translates to 'too much treble', sounds are also adjustable in the fitting software and allows for reconstruction following standard parameters.[71]

Translation is what links different ordering modes and enables Jelle to intervene in, and shape, Mrs. Hoof's subjective experience of hearing and her (dis-)abilities. Translation enables action, and the ability to act, to do something about the hearing loss, is what makes the professional ordering of sound effective. Mrs. Hoof's hearing is extracted from her ear, translated and transferred into the software, where it becomes amendable in a computer program. Hearing is actively moved into a technologically mediated, relational space in which sounds becomes meaningful inasmuch as they are juxtaposed with linguistic metaphors, verbal performances and simulated listening environments (crumpling newspaper, pens dropping, parties simulated). These sociomaterial arrangements enable hearing to make sense; they render sound socially and individually meaningful. When things make sense the professional ordering is successfully enacted. But with a multiplicity of ways to enact sound, how do Mrs. Hoof and Jelle come to agree on acceptable translations, how is order negotiated?

PERSUASIONS OF SOUND

> Jelle draws Mrs. Hoof's attention to the computer screen. The fitting software has a cartoon feature depicting various listening situations. He asks her to identify the situations that are difficult for her. She looks fascinated at the screen, then she starts to chuckle. Jelle laughs himself, and makes some comments on the childish cartoon appearing on his computer screen. Mrs. Hoof: "That one, parties, those are hopeless, but the next one-to-one conversations, they're ok. Traffic, I can't handle, I just turn them off. Oh, I would love to be able to listen to music again." Mrs. Hoof points to the screen while articulating enthusiastically. Then Jelle explains that her new hearing aids have different programs for the listening situations she just identified. When Mrs. Hoof finds herself in those difficult situations, she can turn on the corresponding program and the hearing aids will adjust to that

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[71] On this, Lucy Suchman (1987) has noted that the significance of an instruction for action inheres not only in the instruction itself, but crucially in the relationship between the instruction and the followers who act in the situation. The same is true for diagnostic fitting procedure, as many of the conversations in the consultations that concern 'good' and 'bad' sound might be best characterized as diagnostic language, itself generally a prelude to an instruction for how to fix the problematic hearing, it is not merely anchored in, but in large measure constitutes, the situation of use.

specific listening environment and give her some extra help. Jelle
tells Mrs. Hoof that he will fit the different programs according to
her hearing loss and starts the simulation. <u>Jelle:</u> "You'll hear
music, people talking and shouting, and traffic. While you listen we
repeat the fitting procedure, we talk and you have to give me
feedback on the sound." The search for words continues; weird,
unnatural, clear, echo, metallic, loud…

<u>Jelle:</u> "I think we have come as far as we can with these hearing
aids. Before you go I want to do a speech recognition test. I will
play sound over the loudspeakers. I want you to listen to the words
and try to repeat them for me." Jelle instructs Mrs. Hoof, who
listens and replies. Mrs. Hoof: Supper – Supper, Cast – Cart, Wine –
Wine, Song – Wrong, Red – Red..." When the test is done, he prints
out the result and goes through it with Mrs. Hoof. <u>Jelle:</u> "See here,
the audiogram tells us what you hear without hearing aids. Now, this
graph on top of your hearing curve indicates your ability understand
words with hearing aids, you see it's a 20 % improvement. That's
very good. I know you can't hear everything, but considering your
loss, it's certainly a big improvement." <u>Mrs. Hoof</u>: "Yes, yes it is
definitely sharper now. It's not like I'm expecting miracles, but
the old fitting was unbearable. All the sounds cutting through my
ears… By noon I was exhausted." Mrs. Hoof asks Jelle for a copy of
her audiogram, she writes the date on it and puts it into her purse.

Thus far, I have argued that the process of reconstructing soundscapes centres on
developing a shared language between hard of hearing, professional and technology at
work. It is a process in which the professional actively translates between different ways of
enacting and ordering sound. But the translation between humans and machines, hard of
hearing and hearing aid, is not flawless; the reconstruction only works to some extent. Part
of the challenge with a hearing loss, is that sound is so much more complex than i.e. vision.
While glasses are seen as compensatory devices, hearing aids are only assistive devices;
'they won't give you normal hearing'. What use people have from hearing aids depends
among other things on where the hearing loss is, whether it is in the area of the soundscape
well mapped by audiology, or sits in more unknown territory. The treble area where
speech understanding lies, and where Mrs. Hoof has a large loss, is considered the most
complex, where to few coordinates exists. So while Jelle can offer Mrs. Hoof a position in an
improved soundscape, it is nevertheless a restricted position. She will not be able to hear
everything; she still has to deal with lack of sound, and sound that is weird and unbalanced.
She is still hard of hearing.

Without a technical fix, the normalizing professional order is incomplete. Mrs. Hoof's
hearing aids cannot fully compensate for her loss of hearing. Thus, following fitting, part of
the work Jelle performs to maintain synecdoche is to rationalize gaps and construct links
between the audiogram, hearing aid and Mrs. Hoof's subjective experience of sound.
Because it is not only the hearing aids that need adjustment to ensure that Mrs. Hoof

experiences a successful fitting. Mrs. Hoof herself must be adjusted too. The successful ordering of sound depends not only on the effectiveness of the hearing aids; equally important is Jelle's ability to adjust her expectations towards the effect of the hearing aids and persuade her to accept the limits of his translation.[72] This involves negotiating sound. Since what is heard can not be shared aurally, in common, Mrs. Hoof and Jelle engage in a highly interpretive ordering over verbal references to hearing. What is heard is verbally expressed, but individually imagined by these interlocutors, even as it comes to be constituted through communication between them. Since there are no fixed and shared standards for sound, there is room for persuasion, for influencing the subjective experience of sound (generated by hearing aids). What gets to count as effective interventions is negotiable.

To speak for the effectiveness of the hearing aids, Jelle does not rely on Mrs. Hoof's subjective hearing alone, he offers visual 'proof' of their improvement. Jelle takes her through a speech recognition test to quantify the effect of her hearing aids and prints out the results for her to view. He allows her to *see*, not only hear, their effectiveness. A 20 % improvement is a concrete and 'objective' measure that is hard to argue with. While she might have expected more, Mrs. Hoof is induced to accept the result. She is aware the aids will not give her normal hearing, but she is persuaded that the improvement is worthwhile. Persuaded about its effectiveness and informed about its limits, Mrs. Hoof consentingly enrols into the normalizing order; 'It's not like I expect miracles…', she says and puts the audiogram into her purse. Within this audiological encounter, geared towards normalization, an important aspect of the relationship between hard of hearing and audiologist is the need to compensate for a biophysical condition, to deal effectively with hearing disability through use of hearing aids. Mrs. Hoof, enacting normalization by accepting Jelle's fitting, becomes someone who takes action and does something to minimize the negative effects of her hearing loss.

ENACTING PROFESSIONALISM

Mrs. Hoof has come to the audiological clinic because she is not satisfied with the fitting done by the dispenser. She feels alienated by her hearing aids. She says she does not;

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[72] The argument can be seen in analogy to Latour's (1986:13) ethnomethodology on the construction of facts. He claimed that facts are not discovered, what is to be considered a fact is socially constructed. He also illustrates the importance of visualization in his seminal article *Visualization and Cognition*; 'What is so important in the images and in the inscriptions scientists and engineers are busy obtaining, drawing, inspecting, calculating and discussing? It is, first of all, the unique advantage they give in the rhetorical or polemical situations. "You doubt of what I say? I'll show you." And, without moving more than a few inches, I unfold in front of your eyes figures, diagrams, plates, texts, silhouettes, and then and there present things that are far away and with which some sort of two-way connection has not been established'.

'recognize my own voice', and she hears; 'my own footsteps like thunder'. What is more she feels the hearing aids restrict her capacity for action; 'at parties I can't hear a thing.,' 'traffic I can't handle,' and 'I would love to be able to hear music again'. Based on her complaints Jelle works to re-establish links between ear, hearing aids and everyday practices. When it is not possible to automatically translate between different ways of enacting sound, Jelle does not trust the technical instructions alone; he also activates Mrs. Hoof in the assessment of sound. Ears, hearing aids, and subjective experiences must *become* 'in tune', links must be maintained through probing audition between hard of hearing, professional, and technology. This translation process assigns an important role to the situated action between hard of hearing, professional, and technology. Mrs. Hoof has objectified her hearing to tests and delegated hearing to her hearing aids, but she is not without agency in the encounter. The reconstruction of her soundscape depends on her ability to speak up for herself; 'how does it sound', and make choices; 'what's most important for you?' But to point out that Mrs. Hoof is actively involved in the maintenance of synecdoche is not the same as to say that the audiological encounter is symmetrical.

Jelle enacts professionalism which distinguishes his from lay behaviour. His status as a professional is deeply tied into his competence with multiple modes of ordering hearing and the ability to switch between them. To fully mark oneself discursively as a professional, one must have exposure to learning relevant codified metaphors and one must be further confident about their appropriate and accurate use in interaction. Learning how to speak about hearing positions one as an 'insider', and is therefore fundamentally implicated in the matrix of social and technological practices that constitute the profession. The process of socialization, linking linguistic knowledge and technical skills to performance, allows professionals to distinguish themselves as different from their clients. The proper use of ordering materials marks one's status as a professional insider or outsider.

The extracts from the consultation between Mrs. Hoof and Jelle reveals how the technical language of audiology can reinforce hierarchies between the professional and the hard of hearing. To get an image of Mrs. Hoof's hearing problems and how to solve them, Jelle must construct an intersubjective experience of sound. He must encourage Mrs. Hoof to describe what she hears to get coordinates to her soundscape that he can use when navigating the software. Mrs. Hoof, on the other hand, struggles simultaneously with learning to sense anew - interpreting the sounds coming through her hearing aids - and finding a language to make sense of the soundscape. When Mrs. Hoof adapts to the strategy of Jelle, allowing him to translate her subjective experience of sound into objective parameters in the software, a geography of responsibility is enacted between professional and client. In this situation, Mrs. Hoof provides the raw material for the professional work, the subjective, non-technical descriptions of sounds. Jelle needs these descriptors to perform his translation

work. On its own Mrs. Hoof's description is of no value, it makes no sense in the fitting software before it is translated into a technical language. Jelle is the translator between ordering modes. With access to different registers of descriptors for the same sound, he can take the central position in the interaction. Such discursive resources are further embedded and structured by the technologies at work. As the beholder of 'correct' technical terms Jelle possesses the translation key that can make things happen. Metaphors develop codified meanings that are easily translated into specific actions taken in the realm of fitting software. In this sense, the technologies also structure the work, since the digitization of sound implies the ability to code and read data, sound and perceptions of sound need to be translated into a readable language. When Mrs. Hoof probingly describes her subjective experience of sound, Jelle is the beholder of the 'correct' technical terms and can interpret and act on instructions. His technical knowledge enables him to mediate sound between human and machine, between the subjective and the objective and take the position as the expert in the audiological encounter.

As Mrs. Hoof struggles to find words, and fails to understand the difference between discomfort and volume she reveals her unfamiliarity with the deployment of the audiological vocabulary and techniques. She is not educated to order her subjective experience in technical terms. When she speaks of hearing it is in associative terms, i.e. the inability to hear in parties, which is to speak of its social function. Therefore, she depends on Jelle to make sense of her hearing in technical terms. She needs him to translate her social problem into an operable command in the fitting software. Jelle as the professional understands her problems hearing in associative terms. In addition, he understands the work and technology behind the sound. When Mrs. Hoof says she has problems hearing in parties, he can activate the hearing aids' program for background noise.

The ordering strategy of technical audiologists is a recurrent resource. It is part of the discursive repertoire of audiology – codified, repeatable descriptions of hearing used across multiple audiological sites in a relatively conventional fashion, to generate relatively predictable responses. Every day technical audiologists, in Norway and the Netherlands, follow this standard procedure of categorizing and intervening in various kinds of hearing loss. The professional ordering objectifies subjective experiences and rationalizes difficult life situations. Established practice and standard routines are also a politically potent arrangement. Strategies can be used or withheld, recognized or misunderstood, by clients. Strategies can be offered up in order to clarify or obscure, to parade one's own knowledge while, directly or indirectly, pointing to another's ignorance. They assign social positioning in the audiological encounter. During the consultation, Jelle takes the time to explain some basic audiological insight to Mrs. Hoof. He prints out her audiogram, points to graphs and percentage scores, and makes her familiar with the fitting procedure. The

sharing of knowledge from professional to hard of hearing is informative, but it also establishes the asymmetry between them. By explaining his procedure, Jelle does not merely enlighten Mrs. Hoof, he also ascribes her position in the professional order. By being informed on the audiological procedure Mrs. Hoof gets a glimpse of expert knowledge. Rather than positioning her as equal, the information makes visible the distance between them, her dependency on him. In this sense, insight into sociomaterial ordering is pivotal for communicating asymmetry between professional and hard of hearing. Then, why does Mrs. Hoof choose to submit to the asymmetrical positionality enacted in the audiological encounter? Considering Thompson's caution not to automatically assume that objectification inherently leads to a loss of agency, how to interpret the fitting process as more than the passive, submissive participation of patients in the skilful hands of the knowing and active professional?

ENABLING AGENCY - EXPANDING CAPACITIES FOR ACTION

Within material semiotics, the question of agency concerns how action is made possible and defines actions and (dis-)abilities as emergences of heterogeneous links (Moser 2003; Law and Moser 1994). Mrs. Hoof enacts hearing disability as the synecdochical rift between such heterogeneous links; the ear, hearing aids, and everyday practice. She finds her capacities for action restricted by the current soundscape which is described as a 'weird voice', 'footsteps like thunder', 'inability to function in traffic', 'not being able to listen to music', and 'exclusion in social gatherings'. Restricting her ability to enact subjectivity, the hearing aids work to alienate her from her own hearing. Because the current hearing aid fitting decreases her capacities for action - the places she can go and the things she can do - the aim of the new fitting is to reconstruct a soundcape that can expand her possibilities for action in everyday life. Since hearing aids cannot compensate for hearing loss, the process also involves a re-conceptualization of self, where Mrs. Hoof will have to get to know herself anew, rediscover sound and hearing abilities.[73] In this sense, the fitting process is also about transforming the everyday life in which she is included, giving rise to new restrictions as well as novel possibilities for the enactment of her multiple self.

Jelle and Mrs. Hoof's negotiation over sound illustrates the indecisiveness of this process. Nobody knows this soundscape in advance. Elements of hearing must be tried out, senses rediscovered, and expectations adjusted through a process of probing, translation and persuasion. The new soundscape is the emergent achievement of interaction that involves Mrs. Hoof, Jelle and the technical tools. First, as the fitting proceeds, Mrs. Hoof must try to assess and articulate what she hears. In focusing on hearing, she assesses which sounds she can get used to and which are alienating. Probingly she describes whether or not sounds

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[73] This is the point made by Myriam Winance (2006) in her conceptualization of wheelchair adjustment as the 'mutual fitting' of user and technical aids.

are bearable, improved and enabling. At stake here is the rediscovery of her senses. Mrs. Hoof must focus on some parts of her, and allow her hearing to be objectified by the professional so that she can rediscover herself, a subject capable of communication. Secondly, the reconstruction is made possible by the professional translation between the different modes of enacting and ordering hearing – lay, medical and technical. Jelle assesses the quality of the sound according to his professional opinion of whether they manage to converge towards the norm. Finally, the different experiences of sound are confronted with the adaptability of the hearing aids. The technology at work assesses sound according to whether it matches the parameters in the software. And when Jelle concludes that; 'I think we have come as far as we can with these aids...' he indicates the possibilities and restrictions of the technical aids and establishes an important element in the assessment of the reconstructed soundscape.

During the consultation, a link between ears, hearing aids and everyday life is opened. The fitting is the work on the links that shape the person and the device, what they are, and what they will be able to do. First, Jelle and Mrs. Hoof test and question how she hears with her hearing aids. In other words, the links between the ear, hearing aids and subjective hearing are opened to assess which ones works and which ones must be reworked. Secondly, Jelle and Mrs. Hoof try to restore and make new links by reprogramming the aids. Through this mutual fitting process both the devices and the person are transformed; a new soundscape emerges, potentially enabling Mrs. Hoof to regain access to subject positions that were lost with hearing.

The fitting process not only tests the links between ears and hearing aids. Through the simulation program, Jelle and Mrs. Hoof try to define the everyday life in which she wants to be included. That is, the social and material elements that compose it and the relations that are established between those elements. Jelle asks Mrs. Hoof to identify situations that are difficult for her. Based on this, he maps the current restrictions on her capacities of action. With the simulation program, Jelle adjusts sounds and probes how Mrs. Hoof can act with the hearing aids in these simulated contexts. The promise of the fitting Jelle performs is that her everyday life will again be composed of the listening situations identified as problematic; 'traffic, parties, and music...' He thereby redefines actions and (dis-)abilities as emergences of maintained links between ears, hearing aids, and subjective hearing.

What the process of reconstructing soundscapes actually promises, is the transformation of the person, what Mrs. Hoof is able to do, how she can identify herself and become identified by others through the subject positions she can access in everyday life, be it in relation to parties, traffic, music, or socializing with family and friends. Little by little, through the probing, translation and persuasion involved in fitting hearing aids, the synecdochical links between ear, hearing aid and subjective hearing are being maintained to give rise to a soundscape in which Mrs. Hoof can come to recognize herself with hearing aids. The

hearing aids become part of her, in the sense that they modify how she hears and positions herself in everyday life. The mutual fitting between her and the hearing aid produces a distribution of competencies and a transfer of action. The action is partly realized by the person and partly by the hearing aid. Thus, in the case of Mrs. Hoof and her hearing aids, a soundscape is reconstructed between them, the hearing aids that produce sound and Mrs. Hoof who interpret sounds through hearing. This is the material semiotic argument. Agency is not an essential property of the disabled person surrounded by devices. Action is distributed and delegated between humans and non-humans.

For Mrs. Hoof, the goal of the fitting is not to produce sounds that can converge towards a constructed norm. Nor are hearing aids devices to amplify sound, but mediators of action. Through the fitting process listening situations are simulated, potential actions emerge, actions whose subject is Mrs. Hoof. It is a process of repositioning as a subject capable of acting, enabled to go to parties again, to enjoy music, and feel secure in traffic. These actions are possible in so far as Mrs. Hoof feels that her hearing flows between her ears, hearing aids and subjective hearing. The hearing aids have to transform from being devices that created alienation and put restrictions on actions to become a medium expanding her possibilities of action in everyday life. Simulating the renewed Mrs. Hoof in these social contexts and pointing to the percentage score indicating the improvement of Mrs. Hoof's soundscape, Jelle persuades her to accept the effectiveness of the audiological intervention. Thus, as Mrs. Hoof objectifies her body to professional assessment and treatment, allowing elements of hearing to be extracted, reworked, and replaced, it is not the ongoing interaction itself, the asymmetrical positionality between her and the professional that determines her experience of agency. Agency arises from the promise of expanding her capacity for actions in other places and at other times. If the fitting process is successful, both devices and person are new, with the links between them re-established their attachment is a source for enabling actions and maintained synecdoche.

LOCATING AGENCY IN THE SHADOW OF THE NORM

Shuttling between empirical extracts and analysis, in this chapter I have described and discussed two routine audiological procedures; the hearing test and the fitting of hearing aids. I set out to explore whether technical audiologists are indeed able to compensate for loss of hearing, and if so, what are the discursive and material conditions of possibility for the reconstruction of soundscapes. To explore this, I introduced some recent work within

material semiotic studies of medical knowledge and practice that re-conceptualizes subjectivity, agency and our capacity for action, from something inherent in individual actors, to an effect of intimate relations between humans as well as non-human.

The first section, *Seeing is Believing*, introduced the hearing test and illustrated how the procedure relies on making hearing visible in the form of numbers, dots, and graphs. Visualization, in turn, is key to optical consistency which enables comparison. During consultations, subjective experiences of hearing are translated into objective measures of loss that can be compared to the hearing curve of an assumed normal hearing. I argued that this process of objectification is fundamental for making elements of hearing operable. The measured divergence assigns room for intervention and enables intervention in the form of hearing aids. Based on the audiogram, hearing aids are fitted to compensate for the hearing loss and normalize the individual.

Moving from the hearing test to the hearing aid fitting, in the next section, *Speaking of Sound*, I discussed how technical audiologists try to reconstruct soundscapes by reworking and replacing elements of hearing with hearing aids. The analysis of the interaction between professional and client illuminated a key challenge in the audiological encounter, given the multiple modes of ordering sound, how to render experiences of hearing understandable in intersubjective terms? On this, I argued that the professional takes a key position in maintaining synecdochical links between ears, hearing aids and everyday life. This means that the effects of hearing aids cannot be assessed with reference to sound alone, but has to consider whether they enable users to expand their capacity for action and enact subjectivity in contexts beyond the clinical realm.

To re-establish synecdoche means to reconstruct capacities for action that enable subjective repositioning and allows people to recognize their materially situated selves with hearing aids. In this process, links making soundscapes are tested and transformed, but they are also defined, shaped and formed. The hearing aids enable some action, making others impossible; the sound was unbearable, now it is better, but it is not perfect. Hearing abilities and disabilities are not only enactments and results of distribution and adjustment of sound between people and machines. They are also the result of processes of probing, translation and persuasions of sound, a process in which the possibilities for agency are shaped. The argument was that soundscapes emerge not only through sounds but also through adjustment of expectations and shaping of selves.

Thus, in the process of reconstructing soundscapes; hearing tests, instruments, software, and hearing aids take on some of the hard of hearing person? by standing in for the parts diagnosed as not working. In these encounters the client is objectified. Sitting with their back towards the professional and their machines, or having their subjective hearing translated into 'correct' technical terms, people are positioned asymmetrically in relation

to the active and knowing experts. The question is whether objectification as such, inevitably poses a threat to personhood? Drawing on Charis Thompson's analytical framework, I argued that the question of agency has had to be assessed according to sites and situations beyond the audiological encounter.

In everyday settings, hard of hearing people complain about the social effects of their hearing loss. In these cases hearing disability is dispersed across situations and sites, invisible to the eye. When entering the audiological clinics, patients experience being objectified by audiograms, software, hearing aids and professional diagnosis, their hearing disability is localized and isolated from the rest of them. This might appear alienating, but such objectification may also offer a sense of relief. Rather than the experience of being unable to participate in social interaction, hearing disability is made visible and located in the ear, it takes the form of a test score and an audiogram, which gives it a new form of concreteness that can help distance what people fear from who they *really* are. It is not the subject, it is the ear, and it can be worked upon in the form of hearing aids. Mrs. Sørensen and Mrs. Hoof allowed themselves to act and be acted upon as body parts because, in time, this could make them into whole subjects again. In this sense, they submit to objectification because it is a step towards the achievement of a long-termed self.

Now, this process can also be reversed. Thompson's argument is that accomplished centring may lead to motivated de-centring. Through their consultations, Mrs. Sørensen and Mrs. Hoof were offered a set of sociomaterial elements to use when re-entering their everyday lives and if a need to rationalize experiences of communication failure should emerge. The hearing aid Mrs. Sørensen choose to use, the audiogram that Mrs. Hoof puts into her purse, these enact expertise-based verifications of their hearing problems. They are elements of ordering to be applied in social settings where disabilities emerge. According to the normalizing order mobilized in these audiological encounters, to wear hearing aids enact the users as responsible individuals doing their part to normalize difficult interactional situations. Hearing aids, as applied within a normalizing order, make visible the dysfunctional body, and enact the Cartesian split between body and mind. By enacting disability as a somatic condition and wearing hearing aids, the moral responsibility for failure to communicate, is averted from the subject, the 'real' self.

In this sense, the audiological encounter is about how 'drawing things together' is intimately related to the converse process of taking them apart: making 'whole subjects' may work by attending to disparate organs. Agency may require periods of objectification. It is the professional extraction, reworking and replacing of elements of hearing that may enable Mrs. Sørensen and Mrs. Hoof to hear again and that offers them a rationale for when they cannot. Following the processes of objectification, hearing aid users may re-emerge as rational beings in the context of their everyday life.

The material semiotic framework was applied to illuminate the agency of hard of hearing people in the context of the audiological encounter, agency which has not been recognized in the scholarly literature enacting the homogenous and totalizing medical gaze. I argued that the objectifying and normalizing aspects of audiological practices might very well be an important element in people's experiences of hearing loss. Hearing disability, however, is not reducible to this. Agency can also be located by remaining sensitive to the multiplicity of modes of ordering hearing disability, their temporal and spatial diversity, and the possibility of agency in and between them. Juxtaposing the positionality enacted in the audiological encounter with the everyday life objectives articulated by the clients, I argued that objectification can lead to desired changes in long-term self. The analysis rationalizes individuals who subject to the powers of professionals and their tools. But what kind of politics does this alternative analysis enact? Thompson, in her work on the fertility clinic, has chosen to accept the desire of women to become mothers. She does not question the norm linking female bodies to reproduction. Her framework, in other words, does not allow for problematization of the politics underlying the maintenance of synecdochical links.

In the theoretical chapter, I showed how Disability Studies grew out of the conflict over what kind of role medical knowledge and practices are fulfilling in the relationship between disabled people and society. In this framework, technical aids have been interpreted as a means of excusing wider politics from its responsibilities to inclusiveness. Related to this, Brown and Webster (2004), STS researchers inspired by Foucault, have pointed out how technical aids enclose a relationship between the disabled and society. What they propose is that we see technical aids as an important axis in the 'technological contract' between disabled people and society. Hearing aids, according to their analyses, reflect in artefactual terms many of the conventional features of the enabled-bodied world. Materially, they reflect not only able-bodied limbs, ears and cognition, but also architecture, practices, design and communication conventions. All those elements inscribed with normalization, enacting some people as normal, while others become disabled, deviant, and in need of compensation. The logic of medicalized disability, these critics of normalization argue, is to identify a deficient body as that which needs re-engineering for better integration into the world.

And it is indeed something strikingly individualizing about the audiological encounter. At the clinic it is Mrs. Sørensen, or more accurately, her ears and extracted elements of hearing, that are in focus. Assessment and treatment occurs without leaving the context of the clinic, without talking about social accommodations and coping strategies. Similarly, Mrs. Hoof's problems hearing in parties and during walks around the city is as much caused by people's lack of accommodation and the way we allow traffic noise to pollute our social space, as by her hearing loss. However, these are obdurate structures to change. It is

considered easier to change the individual. In one sense, the issues hard of hearing people bring with them into the audiological encounter are individual problems, but they are also problems enacted through and by the normalizing society that create expectations for abilities. The normalizing order assimilates hard of hearing individuals without integrating any concerns for their needs and aspirations. There is no need to change disabling environments when individuals carry the burden of adaptation. In these contexts, the normalizing order does not eliminate hearing disability, the individual responsibility to adapt to the use of hearing aids is that which constitutes disability. Thus, rather than bringing out and problematisizing a disabling world, 'the world' is brought into the clinic. Simulation programs with cartoon sequences invite Mrs. Hoof to rehearse her performance in a disabling society. Meanwhile society can remain the same. Thus, when trying to normalize the hard of hearing through compensating for hearing loss, the professionals are involved in the execution of social control. They engage in mechanisms which achieve people's adherence to norms of appropriate behaviour and they help regulate what identities are socially appropriate.

Analyzing the material from hearing tests and hearing aid fitting, I have argued that technical audiologists enact and order hearing disability as normalization. Much in line with the medical model on disability, technical audiologists work on the divergence between clients' audiograms and 'normal' hearing curves, the bodily defect, trying to reconstruct elements of hearing through interventions with hearing aids. A main objective of Dutch and Norwegian disability policies has been to move away from the medicalization of disability and instead provide solutions in which hard of hearing people are in focus and control of service provision. In this context, hearing technologies are surrounded with a special promise, that of enabling an audiological encounter which is both user-centred and efficient.

Following the digitization of the hearing aid, so-called 2nd generation hearing technology is now introduced in aural rehabilitation. Digital technology allows for quick and convenient micromanipulation of sound. Within the audiological field, developments are seen mainly in two, interrelated, areas; product and process innovation, hearing aids and assessment and fitting software. With the digitization of the hearing aid, the hearing aids have become smaller and more advanced. It is now possible not only to amplify sound, but also differentiate between frequencies which make it possible to program the hearing aid according to various listening situations. Digitization allows technical audiologists to break sound down into pieces of data, which is represented by numbers and stored in digital mediums, computers, hearing aids and software. These numbers are related to waveforms by a convention arrived at in inter-corporate negotiations and established as an industry standard. Since these numbers, like all such data, are arbitrary – related to their referent only by social convention – it is in principles possible for the user to treat them as anything. There is no physical linkage between the original sound and the information worked on in the software. Once brought into the numerical domain, practitioners can read the hearing aid into a computer, manipulate the data with programs reading it as graphs and numbers, and retranslate it into sound, to reconstruct soundscapes by means of a new range of

products. But digital technology has brought on new opportunities not only with regard to the programming of the devices. A great number of process innovations are developed to facilitate the consultation process. While the software works by manipulating the digital code as data, practitioners work with visual displays of frequencies, tonal areas and speech recognition abilities. The focus is on interactive assessment protocols and efficient handling of clients. The software follows a pattern of development that has fostered a growing individualization and commoditization of health and its delivery, while the body has become – as a site for audiological intervention – more available, accessible, mobile and dematerialized. The promise of these digital tools is that they will give room for new and different experiences of the audiological encounter for both hard of hearing and professional; that they will help realize the shift towards the flexible service provision envisioned in policy. But can technology deliver on its promises? To explore this, I introduce two case studies, with empirical material from two new audiological sites. The shift of locations is illustrative for the specific structures of the Dutch and Norwegian aural rehabilitation systems, one based on decentralization of public services, the other on de-regulation in the market for hearing aids.

In the Norwegian case study, *Under Surveillance*, the challenge is to effectuate a centralized disability policy through a regional and local rehabilitation system. From the regional hospital located in the central part of the country, I move into a specialist centre located in the rural area of Norway. The case study takes as it's starting point the 'empowered' service user, an informed and active participant in the audiological encounter, enacted in policy documents and public debates. Analyzing a consultation between client and professional, I question the assumptions underlying this new figure. First, I ask whether all hard of hearing people are willing and capable of participating in an informed and critical way and what happens to those unwilling or unable to meet the standards of the configured user? Secondly, I investigate what room and resources are made available for the realization of user involvement in practice. In the consultation that I study, the technical audiologist introduces a new surveillance technology that works to automate parts of the process of hearing aid fitting. Through digital tools, the audiological encounter becomes a site for work on sounds and hearing completely outside the patient's body. As elements of hearing are extracted, multiplied, reworked, and replaced the user is left out of the interactional loop and the critical question surfaces - how is synecdoche maintained, and what happens to the politics of empowerment in this process of automation?

In the Dutch case study, *Better Hearing,* the challenge is to manage a new stream of hearing aid consumers as the distribution of hearing aids is relocated from the clinics to the market following the introduction of a market oriented health care policy reform. To study the ongoing transition, I move from the audiological clinic providing specialist services, to a

local dispenser in the high street. Beter Horen profile themselves as an innovative chain of dispensers. During my visit I had the chance to observe one such novel fitting technology in use, 'Amplifit'. The software promises to facilitate an interactive assessment process in which the lifestyle of the client is decisive for the choice of a hearing aid. In addition, the dispenser takes use of user friendly software that allows for layered fitting of hearing aids. These new technologies bring out new entities in a treatment zone that is composed of links of instruments, technicians and objectified patient. The tool enables efficient fitting, by automating the technical calculations needed to assess parameters of sound. The critical question, which I investigate in this case, is what happens to the professional position as technologies take on a more prominent role in the translation between hearing aids and subjective needs, between the lay, medical and technical ordering of hearing disability. How is synecdoche maintained when parts of the fitting process is automated?

UNDER SURVEILLANCE

The most northern of the Norwegian audiological clinics, is not really a clinic at all, it is a specialist centre located in the Norwegian Sami capital, Karasjok. The centre hosts a cardiac unit and a team providing aural rehabilitation for the county's 72,000 citizens. The centre is located in a three storey high wooden building. The staff consists of two technical audiologists and a secretary. They have still not found a replacement for the ENT doctor who left two months ago. I am here to go to work with 'Siri', one of the two technical audiologists, and also the manager of the centre. In addition to operating the centre she and her colleague ambulate to the county's two regional hospitals twice a week. The empirical extracts below, introduce the consultation between Siri and an experienced hearing aid user who has come to the centre to get new hearing aids. I am interested in how he is introduced to the new technology.

Mr. Loppa (84) has travelled far. First by boat from the island where he lives, then by bus to Alta, and from Alta to Karasjok he has joined two other patients for a three hours long cab ride. He wears a dark suit and offers us a formal greeting. With him he has his old hearing aids in a plastic bag from the local grocery store. They stopped functioning half a year ago, but he has managed because he borrowed a friend's spare set. While Siri takes a look into Mr. Loppa's journal, he tells me he had to extend the tube on his friend's hearing aids because they were a bit too short for him. The hearing aid is patched together with scotch tape. Even though he

assures me the aids have been working just fine, he seems a bit worried, looking over to Siri. Mr. Loppa: "But maybe I can get a new pair now?" Siri: "Of course today you're going to get brand new hearing aids," Mr. Loppa: "That's good because my eyes are not what they used to be, I really depend on my ears and I got to return the spare set to my friend."

During the fitting, Siri shows me the different functionalities in the fitting program. The program has an experience curve, from one to three. Siri tells me that for first time users she normally put it on level one or two, because that gives them a softer sound. She explains that Mr. Loppa's loss is bigger and he is an experienced user, therefore he needs much sound. Siri adjust his hearing aid to level three in the program and tells me the sounds will be sharp, but not more than she thinks he can handle. Siri: "Mr. Loppa, how is the sound now, ok?" Mr. Loppa: "It's ok, but…" He folds his hand around the hearing aid while looking confused. Then Siri stops him. Siri: "No, there's no whistle. These new hearing aids cut off the high tones, you want be bothered with the whistling sound." Mr. Loppa: "But how can I know it is on?" Siri: "You just have to try it out, get to know them. Then, Siri asks Mr. Loppa to remove his left aid, so she can explain how the hearing aids work.

Siri: "These new devices are automatic, they change program according to your hearing needs, but you can also adjust it yourself. This aid has three programs you change with this little pin sticking out, see it?" From his plastic bag, Mr. Loppa gets a magnifying glass while Siri continues her instructions. Siri: The first program is 'normal', which you use for everyday listening. The second is for noisy backgrounds. The problem is that the device can't separate between noise and voice, but it has a directional microphone system. That means that you have to position actively, stand towards the speaker to get a good result from your hearing aids. Then the device amplifies the sounds in front of you, the person talking, and lowers the sounds from behind you, the background noise. The third is the 'T' switch so you can listen to TV through a loop system. But don't use it otherwise then you will have to listen to the noise from the light bulbs. You have to go through program two and three to get back to one. Go ahead try it out." Mr. Loppa maneuvers his magnifying glass and the hearing aid. Then he asks Siri if he can get the manual in case he forgets something. Siri puts it into his bag. He fumbles with the aid and mumbles, more to himself than us. Mr. Loppa: "Well, I guess the aids were getting old there was nothing more to get out of them."

Brown and Webster (2004) note how, within the context of ICTs, the ready availability of medical information via the internet has begun to destabilize the professional boundaries of medical knowledge itself. By means of ICTs, the internet in particular, people have access to new information from a much wider range of sources than in the past. Along with the analysis, emerges the configuration of a 'new' or 'future' user of health care services; the 'informed patient', potentially empowered by its access to information. In the analysis of Norwegian and Dutch disability policy, I traced the emergence of such visions for patient-

centered care. In the Dutch context, the empowered service user figures as the elective consumer. The surrounding order is that of consumerist medicine, reflected in the growth of private medical insurance, and the increasing demand from consumers for a wider range of choice of medical treatments that should be available. In the Norwegian case, the dependent welfare user is to be replaced by the autonomous welfare-consumer. The surrounding order is that of a modern public sector in which services are developed and delivered based on principles of user involvement. In both cases, with access to information and prompted by the shift towards patient-centered care, hard of hearing people are envisioned to enter into an equal partnership with the professional. They are capable of assessing complex information and make rational decisions on complex audiological matters. What is more, they are eager to get hold of, and use the newest and, implicitly, best technology available.

But how relevant is the configuration in the case of Mr. Loppa? Dressed in his best suit, there is not much in his behavior that reminds one of a critical approach to the audiological profession. He has come to the clinic for advice that he intends to follow. Rather than being covetously eager in the meeting with the newest digital hearing technology, he hesitates. New technology implies new routines to be learnt and old ones to be dis-learnt. Besides, living on a secluded island in the North of Norway also means he has no direct access to the service of dispensers and support of user organizations. An access implicitly assumed in the policy of governments, user organizations and private companies in their demands for better choice of ever more advanced technological products and services. For Mr. Loppa, more technology means more dependence on a system remote from his everyday life. Dispenser and meeting rooms he does not traverse and a professional expertise on a daytrip's distance. And what about the hearing aid, are more functions, smaller devices and shorter lifecycles necessarily and always an improvement for the user? Does such innovation reflect a technology driven or a user driven development? The majority of hearing aid users are elderly. With age, many experience poor vision, stiff fingers and a slippery memory. How do they become active contributors in the rehabilitation process? How do they deal with the rapid technological development? My aim here is not to construct a technological age divide, but to ask what happens when the real user does not meet the standards of the configured user.

PRAGMATIC SUBJECT POSITION

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     Siri injects silicone into Mr. Loppa's ears. The imprints will be
     sent to a laboratory that makes earmoldes. While we wait for the
     silicon to dry I ask Siri about the instructions, did he get it? She
     shows me one of the new features in the fitting program on her
     computer and explains that the new hearing aids automatically change
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program according to the auditive environment of the user. This specific model also has a function that monitors these shifts, the frequency and conditions of use. When Mr. Loppa comes back for his control the software extracts information from the aids and compiles a report, a graphic illustration of his pattern of use. Looking at which program he activates, and how he adjusts the volume will give Siri an indication of his hearing needs. Siri: "See here, a patient from yesterday; this graph indicates his sound environment. He is spending 70 % of his time in a very quiet surrounding, probably alone inside. He told me the hearing aids were uncomfortable because they amplified all kinds of sound, newspaper, coffee cups, and the radio in the background. He had to constantly adjust the volume. Based on his log, the program suggests that I increase the comfort level, so he doesn't get tired listening to sharp sounds, then he doesn't have to be so active on the hearing aid, it is more in tune with his lifestyle. With Mr. Loppa I'm not sure, he needs a lot of sound, but on the other hand, he lives on an island… I want to use the monitoring so when he comes back I can see if he's pleased with my fitting or needs adjustment. I also want to see if he can manage with all the programs. Some patients get confused. They end up on the 'T' switch and can't hear a thing. They think there's something wrong with the aid. From the user log I can get an idea of what I need to teach him and whether he uses all the programs. If not, I can suggest a less expensive and simpler model that is easier to operate."

Siri removes the silicon from Mr. Loppa's ears into an envelope. Siri: "I will send the new ear plugs in the mail along with some extra tubes and batteries. You don't have to pay anything for these hearing aids, consider them a loan from the State. But you're going to have them for six years, so you should take good care of them. When the aids need service you contact the dispenser. The phone number is in the box." Then Siri asks Mr. Loppa if he has any questions. Mr. Loppa: "No, I can't think of something right now, I'm just so focused on the sounds." Siri: "Don't worry you'll get used to it. When you're back home, I want you to take notice of your use of them, what sounds are uncomfortable so I can adjust them for you at the control. If you have problems you just call me, ok."

Bodies have long been extended beyond the boundaries of peripheral skin through connections to external prostheses. We find ourselves increasingly presented with options and possibilities for substituting our unsatisfactory body parts with those stemming from elsewhere, with innovations shaped at the juncture between medicine, machine and bodies. Hearing aid producers and dispensers target new user groups, hospitals launch prenatal aural screenings and Deaf people are presented as candidates for cochlear implantation. In this context, 2nd generation hearing aid technology presents an option for extending the self, for molding new operable versions of hearing loss. As a result of digitization, Mr. Loppa's hearing can be abstracted out of context, extracted from its subjective state, and integrated into software interpreting and working on sound as data. In order for Siri to assess Mr. Loppa's hearing she does not have to be where he is, she uses the surveillance

log to trace its workings in different contexts. In order for Siri to work on his hearing, she does not need to ask him about his hearing, she can monitor it through the surveillance software. His pattern of use leaves electronically based traces in the form of digital codes. Data, that Siri later can transfer into her computer. By means of fitting software she can translate the digital codes to information to use when further adjusting his hearing.

Mr. Loppa enters the centre dressed up in his best suit. Not only is he willing to accept objectification to a medical ordering mode, he is an active contributor. Meeting the expert is not an everyday event, and he has great expectations to the audiological encounter. As an experienced user, he knows he can take use of hearing aids, even though it means a lot of work getting to the centre, and it will involve more work to get accustomed to new aids. Nor is the meeting symmetrical on his account. Mr. Loppa depends on Siri to gain access to the means that can improve his life. He is severely hard of hearing. With his vision getting poorer he says he depends on his aids. Thus, for him, it is important to appear as a good candidate for treatment. So he dresses up. He formally shakes Siri's hand, and obediently follows her instructions because for him, a lot is at stake. It is reasonable to expect patients to take an active interest in their own presentation as objects of treatment; to remain in good relations with the professional, to listen attentively to instructions and follow expert advice. Mr. Loppa, although seemingly passive and helpless, in fact, works hard to establish and maintain the link between subjective needs and aspirations and enabling technological solutions, solutions that are attainable through the audiological encounter. He seeks to fulfill his part in maintaining synecdoche between social needs and technical solutions. Experienced users, like Mr. Loppa, know that it is not merely enough to get hearing aids. To get good sound, hearing aids must be optimally fitted and ear molds perfectly shaped. The link between hearing aids and good sound is not readily available, in the form of hearing aids. First a thorough hearing test is necessary in order to map subjective hearing. Then hearing aids must be adjusted to these hearing needs. For this, he depends on the professional's abilities and diligence during the adjustment of the aids.

Importantly though, subjecting to such power relations might not necessarily imply the acceptance of the asymmetry. Given Mr. Loppa's dependence on Siri, as the gatekeeper to hearing aids, one could also interpret his objectification as a pragmatic adaptation of a subject position, where he intentionally subordinates his will to the structural power of another person or organization in order to achieve some overarching goal. The power is not something that simply resides in the professional or institutions, however, as this notion tends to suggest. The technical audiologist, in this case, is an obligatory point of passage through which access to the hearing aids and welfare schemes is mediated. On this, Thompson (1998:178-9) argues that; 'the visitors do not so much let themselves be treated like objects to comply with the audiologist as comply with the audiologist to let themselves be treated as objects.'

The surveillance technology allows Siri to monitor disability without herself having to be present. The technology abstracts hearing from context, lifts it from the specificities of time and space, and makes it viable for control and operable for intervention. Following its extraction, elements of hearing are made compatible with audiological techniques and tools which can operate on them. By means of technologies, the internal constitution of the auditory sense is reconstructed through substitution in the form of hearing aids. In the process, hearing does not anymore stay confined inside Mr. Loppa's physical body, it is extracted, multiplied, reworked, and replaced. New digital hearing technologies and the medico-technical ordering modes they travel with can be understood to be reordering the internal substantive nature of the body, in such a way that any sense of the commonsense boundaries separating inside from outside, internal from external, becomes open to question. The passage goes in both directions and has several lanes. The first means that hearing goes in both directions, elements of sound and hearing are extracted, reworked *and* replaced. The second claim is, perhaps, more difficult and involves the multiple elements of hearing.

Mr. Loppa is seated right next to me in the consultation room, his ears filled with silicon. Siri makes sure he sits still while the silicon dries. It is important to get a good imprint to avoid whistling sounds and friction causing irritations to the skin. Meanwhile, his hearing is also being worked at on the computer screen in front of us. Siri adjusts the hearing aids according to the audiogram on the screen. In addition, she turns on the user log and starts monitoring Mr. Loppa's pattern of use. This will give her one more element of hearing to work on when she later assesses the fitting. This multiplication of hearing enables several, singular operations to be performed simultaneously. This ontological split implies that there is no longer *one* hearing in the audiological setting, there are multiple elements of hearing at work and they give rise to different practices, they are enacted, which is what makes them real.[74]

Thompson has argued that to speak of ontology on this matter is not to say that these body parts become more real than they were all along, or in the parts suddenly becoming relevant because I, as a researcher, in some way open the body's black box, revealing its 'true' content. The different versions of hearing circulating in the audiological setting become real only in the sense that they are enabled to display properties in their own rights. And they are made more relevant only in the sense that they are rendered as functional stages to which hearing aids can be fitted. Thompson notes how the clinical

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[74] It is Annemarie Mol (2002) who has suggested that realities are enacted and that multiple practices entail multiple realities.

setting draws out the body parts into a new metaphysical zone consisting of many perceptible functional stages where treatment can be focused. In the case of Mr. Loppa, this multiplicity of hearing is enacted through the ears filled with silicone, the audiogram on the computer screen, the user log in the hearing aid. During the audiological encounter these elements of hearing come onto the scene of action of his future chances of reconstructing soundscapes by becoming connected to new and different things. Procedures, such as the hearing test, make the body operable and render it accessible to a treatment zone which mobilizes an arrangement of new entities composed of links of instruments, techniques, audiologist, and objectified patient. A link is opened from subjective hearing to the fitting software to the hearing aid. When producers launch new functions in their fitting software, such as the user log, new links are made and new elements of hearing enter the zone of operability. Siri gets more and different information to work on when adjusting the hearing aids. There are different realities to adjust to; Mr. Loppa's subjective opinion, the audiogram, the user log and the shape of his ear canals.

During the audiological encounter, visitors are locally and temporally extracted and multiplied into a series of bodily functions and parts, ears and graphs. The aim is to forge a functional zone of compatibility that maintains referential power between these different elements of hearing with means of audiological intervention. In the process, the tests, instruments, software, and hearing aids take on some of Mr. Loppa by standing in for the parts diagnosed as not working. The treatment is a series of interventions that seek to turn personal chaos into audiological order. However, the process of the rendering compatible of the hard of hearing and the hearing aids does not itself guarantee seamless and successful solutions to hearing disability. The objectified elements of hearing must not lose their metonymic relation to the whole person, and neither must the instruments lose their acquired properties of personhood in virtue of which they fix, bypass, or stand in for the stages in the process of reconstructing soundscapes. But if hearing can be multiplied, what is the link between different realities, the different elements of hearing at work? How is synecdoche maintained when elements of hearing are extracted, multiplied, reworked and replaced?

The audiogram, the user log, the hearing aids, they are all part of a package sold by a hearing aid producer. When installed on the computer a software translates between the different incoming and outgoing pieces of data, making the hearing aids, cables and fitting procedure compatible with one another. Siri has chosen this specific product, she is trained to use it, and she has integrated its operations into her daily routines. In doing so, she has made herself compatible with the technology. She monitors the numbers and graphs, makes sure links are maintained between the operations she performs in the software and the way the hearing aid is programmed. What troubles me is the position of Mr. Loppa.

In the process of extracting operable elements of hearing, Mr. Loppa is de-centered and made redundant. He is represented and mobilized through particular types and forms of knowledge and data. The user log gets to stand in for him in the consultation, enacting his hearing needs. The surveillance function configures a position *for* Mr. Loppa. For Siri, the user log is his disability; this is the element of hearing she works with when she adjusts the hearing aids. All Mr. Loppa has to do is to go home and use the hearing aids according to Siri's instructions and then come back and have them fine-tuned. In fact, with the surveillance function it is possible to leapfrog the consultative part of the audiological encounter, the strenuous process of finding workable descriptions to construct a shared soundscape. Mr. Loppa can effectively be positioned outside the interactional loop. The information Siri needs to perform the audiological *modus operandi* is simply extracted from him without consent or objection, without any complicating factors. The user log speaks for him. Siri does not have to translate his subjective experiences into technical terms. The graphical image and suggestions for programming speak directly to Siri in a language she reads and can respond effectively to. With automation the consultative work involved in maintaining the link between subjective report and technical solution is suspended. There are not three orders at work, as we saw in the case of Jelle and Mrs. Hoof. With Mr. Loppa out of the interactional loop, the lay mode of ordering hearing is effectively excluded from the consultation.

Drawing on Thompson, I have argued that such operations are not always and necessarily a threat to the patient's personhood. As long as these links of actants-in-the-setting flow back to the patient, the synecdochical links between elements of hearing and the patient are maintained. Mr. Loppa willingly objectifies his hearing. He allows it to be extracted, multiplied, reworked, and replaced, because he believes the intervention will reconstruct a soundscape in which functional links between his social needs and technical solutions are opened and maintained. He objectifies his hearing to professional intervention because his ability to take part in social interaction depends on his access to good working hearing aids. As long as the hearing aids enable Mr. Loppa to hear better, synecdoche is maintained, but how can we know whether or not this is the case?

Leaving users out of the interactional loop gives rise to an interpretive problem related to the subjective experiences of the hearing loss. In the case of Siri's patient from yesterday, her goal was to adjust the fitting to better match his asocial and immobile lifestyle. The question, however, is whether current lifestyle - what the user log depicts - is what should be enabled or disabled? Withdrawal from social interactions due to inability to hear is a common problem related to hearing disability, for most, that *is* the disability. In that case, Siri's intervention to facilitate current pattern of use reinforces disability by promoting a passive and isolated lifestyle. Perhaps what is needed, in this case then, is not further isolation, but psychosocial coping strategies, with hearing aids and a training program

fitted accordingly. When current use is translated with desired use the extracted graphical illustration of use pattern may indeed enable an efficient fitting process. But with the user out of the interactional loop, the key question remains: Does the graphical illustration indicate problem or preference? The promise of 2nd generation hearing technologies is that they will enable more efficient and user-centered services. However, technologies such as the surveillance function, also give rise to tensions between goals. Basing the fitting on an extracted element of hearing allows for efficient handling of client, but the user log does not given any insight to the way this sound is subjectively experienced. With the user left out of the interactional loop, automation risks creating a synecdochical rift between the user as an object of the user log, and the user as a subjective experience of disability.

In the Norwegian Action plan for a holistic aural rehabilitation, user involvement is a key concept to ensure that the subjective aspects of hearing are integrated in aural rehabilitation practices, analytically speaking, to maintain synecdoche. How then is the position of the user enacted in an audiological encounter driven by technology and professionals?

ROOM AND RESOURCES FOR AN INFORMED USER POSITION

Siri: "In general, there is little knowledge of audiology among the GPs, so when people come here they are not informed and prepared for our questions. They just know that they might be hard of hearing. Some have a relative with aids who they can relate to, but for most it's a shock. We try to assess whether the patients are motivated to start using hearing aids.

The time schedule is based on 15 minutes intervals. New patients get an hour. Adjustments are also an hour, well, unless it is an experienced user, then we only need half an hour. A hearing aid control takes about 45 minutes. Then, in addition to consulting with the patients, the time is also used to read through their file and prepare before they come in, and write a report after they leave. We don't have much time for each patient. With our hearing tests we make the patients audiogram and fit the aid, but the most important test is when patients try out the aids at home on their own. When they come back for the control, they are experienced and can ask questions.

There is no fixed procedure for the consultations, but a lot of the job is psychology, trying to understand needs and help people feel secure about wearing aids. Sometimes, when people come and go for a whole year without finding an aid we have to ask them to make a choice. But I guess that the truth is that they have different needs. They need help to overcome psychosocial barriers to hearing aids. There is really a need for that kind of follow-up. I wish we had some more of that in our education. Kids are enrolled in habilitation programs, but for grown-ups there's nothing. Clearly

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different people need different treatments, we see that, and we see
that many need more than technology. For example, we have applied
for an audiological educator, someone to give lip reading courses.
We also want to become a user training centre ('Lærings og
Mestringssenter') with peer consultation and next of kin
involvement, but right now we don't have the competence and we're
not quacks."
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In the last chapter, I argued that display of professional knowledge may work to objectify patients. Certain facts about the body, about one's own body, and about the treatment options become the things one is told, expected to know, or comes to know. This generation of epistemic standards in clinical settings also helps constitute the practitioners as experts in the procedures as reliable, and facilitates the flow of authority and accountability. For Thompson, such epistemic disciplining is not automatically a threat to agency. In her study of fertility clinics she finds that, as in other circumstances where rational informed citizens are produced, participation of the educated is enhanced. Patients are better able to participate in their own care because they have been initiated into the epistemic environment of the clinic. According to her findings, dissemination of knowledge might actually work to strengthen the synecdochical link between subjective aspiration and technical solution, enabling the users to optimize their treatment by participating actively in it. For Thompson, epistemic agency consists to the extent to which the patient is a rational health care consumer who makes decisions in their own interest because they are well informed about available options. In the fertility clinic, which Thompson has studied, the patients are the objects of expensive treatments paid for through private insurances. The clinic emphasizes education of their patients. Through brochures, lectures and seminars, patients are made into informed users of fertility technology. In addition, professionals actively encourage their patients to contribute as expert witnesses. Patients are treated as sources of knowledge and information about their bodies. How, then, do the visitors to the public audiological centre, in an, arguably, much less high-tech and prestigious field, become learning and coping hearing aid users?

In the interview extracts I present above, Siri argues that both among practitioners and clients there is a general lack of knowledge about hearing. The information that actually does circulate tends to be of a haphazard kind, dependent on who you know and the time available during consultations. During consultations, the professionals explain the procedure to their clients. They offer insight in the process of testing, fitting and maintenance, they inform their clients what needs to be done in relation to the public insurance system. However, there is not much information or training for how to become a critical user of hearing aids. As Siri explains, for the majority of the clients, it is their first meeting with the professional, they are unfamiliar with the procedure, they have never worn a hearing aid before so it is hard to assess the fitting because they do not know what

to expect. Experienced users too find it hard to contribute critically in this setting. When Mr. Loppa is asked whether he has more questions, he replies; 'I can't think of something right now, I'm just so focused on the sounds'. Perhaps no surprise then, that during my participatory observations, I observed no visitors who participated in the consultations in a critical way. People tended instead to listen attentively to the professionals' explanations and advice.

In the Action Plan for a holistic aural rehabilitation, the aim is to give room for the client as a complex individual with differentiated needs, situated in social communities with family, friends and colleagues. But with 30-60 minutes for each client, next to testing, fitting, and instructions, the room for professionals to conduct holistic assessments and for clients to position actively is highly restricted. There is not much time for psychosocial treatment, coping strategies, and technological learning. Consultations follow a standard format, based on procedures driven by the professional. In fact, through technological solutions, like the surveillance function, the patient may even find themselves left out of the interactional loop. The problem, as articulated by Siri, is that certain things tend to fall out of consultation when relying mainly on technology. There is no opportunity for Mr. Loppa to get to know and articulate his hearing needs. There is no subjective hearing to adjust hearing aids according to. The mutual process of reconstructing a soundscape is leapfrogged as technology becomes the translator of needs. Here then, technology, as implemented in an order of efficiency, does not support, but interferes with the visions of the empowered user. Technology plays its part in producing a gap between policy and practice. In a practice framed by bureaucratic standards geared towards normalization, user involvement as a political and practical project, as a means for empowering users and improving service provision, is relegated.

CONCLUDING REMARKS

During my visits to the audiological sites, in lunch breaks and between clients, technical audiologists often brought up the gap they experienced between policy and practice in their daily work. With the growing awareness surrounding needs and demands for social accommodation prompted in policy making and by educational institutions the concern is that technology alone is not enough to tackle the complex challenges of their clients. Yet, during consultations there is no talk of psychosocial coping strategies. Given the restrictions put on assessment, fitting and training according to subjective hearing in consultations the responsibility with regard to making technology work is distributed to the user. The 'real' test for the hearing aids is delocalized from the consultation to patients' homes. Siri emphasizes that when Mr. Loppa returns for a control, he will have the experience that enables him to participate in an active and critical manner during the fine-tuning of the hearing aids. However, when configured users meet real users in the context

of everyday life we know little about what happens because there is little attention to the report on such interaction.

There is no denying that everyday life - the actual context of use - is the important testing ground. But what I find striking is the limited room hearing aid users have in consultations for realizing the empowered user position, and the lack of resources they get access to when sent home to domesticate the new technology. There are no protocols or technological tools developed to enact hard of hearing people as informed and critical users before, during and between consultations. Prior to controls there is no notification of the content of consultation, how to communicate subjective hearing in words, or become aware of needs and aspirations for hearing aids. When an aid is fitted, there are no procedures for domestic assessment, like what to expect from a hearing aid, how to identify potential obstacles for optimal use and room for further improvements of its programming. Most of the information and tools existing in audiology target the professionals, not the end users. In this setting, the potential for epistemic agency - users taking informed ownership and control over their own rehabilitation - is not realized. Thus, an opportunity to maintain links between social needs and technical solutions are neglected, which potentially threatens the synecdochical relationship between ear, hearing aid and everyday life experiences.

Among staff, there is a will to position differently. However their ambitions are restricted by time schedules, limited budgets and lack of interdisciplinary competence. To work as a technical audiologist, means operating as a double buffer between the complex sociotechnical needs of clients and a bureaucratic system whose main concern is efficiency. Caught in the middle of orders, one that prompts efficiency, the other emphasizing holistic rehabilitation, the surveillance function comes to be seen as a viable option. Siri emphasizes that it gives her an idea of what programs are used and what needs to be taught, it gives her the chance to fine-tune the hearing aids, according to pattern of use, and it is convenient and fast. In this regard, the technology promises to increase efficiency *and* deliver tailor-made solutions when there is limited time to consult with the user.

However, the individual hearing assessed through the user log is of a different kind than the subjective hearing conceptualized in aural rehabilitation policy. The technology monitors shifts in sound alone, not the context. The software assesses hearing needs, but without considering the preferences and priorities of the user. Fitting according to a monitored depiction of use involves users, but they are enacted in an objectified inactive and non-informed manner. All this is in stark contrast to the holistic approach to aural rehabilitation envisioned in policy. The basic premise underlying policy is the *intrinsic* value of user involvement. The process of informing, activating and empowering service users is advocated not because it prompts efficiency or secures an optimal hearing aid fitting (although it might do that as well). User involvement is a process with value in itself,

because it can help people become aware of needs, because it helps them develop a coping strategy to deal with a hearing loss, and because they can become active participants in their own rehabilitation. In the process, it is not only hearing aids that are to be adjusted, user and professional should adjust too, and, from that dialogue, a rehabilitation plan should emerge. User involvement is seen as necessary to maintain a robust and reliant synecdochical link between subjective hearing and technical solution, and to know when there is a need to open other links to different treatments, of social, psychological, organizational or political kinds.

To position as a responsible member of staff is to enact an order of efficiency. Yet, Siri and other practitioners realize that the technical solutions are, after all, insufficient. Their clients also have different needs. Thus, to deploy technology as a technical fix means to create and live with the tension between different goals. Reducing complexity may foster efficiency, but leaves little opportunity for the holistic rehabilitation program envisioned in policy. The lack thereof is particularly grave when for most people the hearing aid is the only rehabilitative support they receive.

BETTER HEARING?

Stephan: "For us being in the hearing aid business is about a lot more than technical products. When we recruit people we look for candidates with people-skills. I would describe our organization as a pyramid. On top we have sales, we are a sales organization, marketing is also important. Then, at the lower levels, is the staff with technical competence. We try to have this expertise represented also on the upper level of the organization, but sales are dominating.

Today, only a third of the estimated 1.500.000 Dutch hard of hearing people has hearing aids. There is a large market potential here. I think the great percentage of non-user has to do with the social stigma related to hearing aids. You don't have to go many years back before shops like ours were not to be seen, they existed, but not in the high street. Hearing disability wasn't something to talk about, and hearing aids weren't something to promote. If we're going to tackle stigma a shift in attitude is required. Therefore, we're building a new marketing strategy. Traditionally, our customers have come here with a prescription from their GP. Nowadays, we try to attract people that are curious about their hearing but haven't talked to their doctor about it yet. By opening shops all over the country and using the type of marketing materiel that we do, we try to become more visible to get the customers in directly from the street. We're not merely content with reaching people after they've

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had their hearing loss confirmed. We also run preventive measures,
like our free hearing tests."
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With the new stream of hearing aid consumers there has been a significant growth in the number of hearing aid dispensers in the Netherlands. Today there are around 300 stores nationwide. According to policy, it is proverbial that the market is closer to the customer, and in a better position to know their desires. To explore how political de-regulation influences the work routines at the dispensers, I visit Beter Horen, Maastricht. Beter Horen is located in the high street and looks different than the audiological clinic in Eindhoven. On the pavement there is a poster advertising free hearing tests. In the windows products and posters with young, good looking models wearing them are on display. Inside, the decoration is in fresh colors and the staff all wear orange. Once you get into the consultation the rooms, the décor is more familiar. There are the computers, cables on the wall, and shelves with plugs, tubes and batteries.

In the, extract above, Stephan van der Hersch, regional market manager at Beter Horen, explains how the de-regulation of the Dutch distributive system works to rearrange forms of expertise at the level of the dispenser. Sales and marketing skills become more important drivers in a field earlier dominated by audiological expertise. At Beter Horen, a focus on sales is coupled to a focus on service and what the market manager calls the 'human factor'. In the recruitment and training of staff, they emphasize the social evaluation as the most important part of consultation. In the course of training, they are not primarily occupied with the technical side of the job, but the human side; how to deal with the clients. 'Kim', the dispenser that I am teamed up with, finds this the most interesting part of her job.

THE HUMAN FACTOR

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Kim: "Many people come here and they are in tears, it is hard for
them to accept that they need hearing aids, they feel ashamed. It is
something from the old days. People tend to link hearing aid with a
lack of cognitive abilities. If you wear glasses, people think of
someone with their nose in a book. You might not be popular, but at
least you're smart. If you wear hearing aids you're dumb. When you
cannot hear, you often misunderstand things. If you're not open
about your hearing loss, people can think you misunderstand because
you're less intelligent, weird or arrogant.

I like to be able to help. But often when people come here they're
not ready to talk about their problems. No one is happy about having
to start with hearing aids. So first I have to make them relax, talk
about other things and make jokes so they open up. Then I can talk
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> about our solutions. I introduce the pros and cons of hearing aids.
> I let them try one, to get used to it in here. But it also happens
> that people walk out of here without an aid because they simply
> can't go ahead with it."

Along with the call for cost efficiency, rapid technological development is often pointed out as an important justification for the de-regulation of the distributive system. The aim is to reduce pressure on specialist services. GPs are no longer seen as able to give expert advice on hearing aids because of the complexity of the technology involved. Therefore, a lot more of the consultation and detailed assessment with regard to finding hearing aids for the customer is now assigned to the dispensers. They have the time to do it, and they claim the competence. The insurance companies seem to be for it because they see that a consultation for a hearing aid fitting takes time, an hour in general. The doctors are already pressed for time and their time is more expensive than the dispensers. There has been a shift in expertise. But, what type of technical service does the new 1st line of service offer?

THE TECHNOLOGICAL FACTOR

The focus on social interaction does not mean that there is no technology at work. On the contrary, the entire process of getting an appointment, the hearing test, fitting a hearing aid and administrating the client journal is all conducted by means of technology. In fact, even the social evaluation is technology driven. At Beter Horen they have their own computer based evaluation tool, the 'Amplifit'.[75] The dispenser sits down with the clients and guides them through the assessment of their social needs. As needs are identified they are registered in the program. The result is an auditory profile and a suggestion for a hearing aid. It is all about software now, Kim explains.

> Kim: "We have all the A-level brands here, but I don't go through
> all of them in a fitting. In general, I try out two, and then I have
> pretty much covered what's technically possible. If I haven't found
> something then, there isn't much I can do." Today Kim has found
> something she thinks will work for Mr. Jongen (62). He sits next to
> her with his new hearing aids on. They both face a large screen on
> the wall. The room has a powerful surround set. Kim has opened
> Amplifit. On the screen a set of movies are played out with various
> everyday life situations: home, recreation, work, transport, nature,
> for a total of six types of sounds: normal speech, speech in noise,
> speech with reverberation, weak sounds, strong sounds, musical
> sounds. Each clip lasts about 30 seconds. Following the clips there
> are sets of questions for Mr. Jongen to answer. According to his
> answers, a sequence is chosen that shall reflect his soundscape. The

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[75] For more information see the amplifon website: http://www.amplifon.com

software asks whether he visits the opera, whether he watches TV alone or with his wife, whether he has grandchildren, whether it's hard to follow conversations over the counter, whether he enjoys hiking, and so on. Kim records his answers in the program. The answers are calculated and his score drawn into a graph. The result gives an overview of his hearing needs and suggests the appropriate hearing aid fitting.

For Kim, the assessment tool is a complete solution. She explains that they chose to implement this based on experience. Kim: "We saw that if we didn't do a thorough lifestyle assessment, customers would come back with complaints. Like first we provide hearing aids and then, a month later the client comes back because he needs something to watch television with. A month later he comes back again because he needs his hearing aids adjusted to the sound environment at his work. This took more time than conducting a thorough assessment to start with. With Amplifit, we can also give the clients advice for training and use according to the specific situations relevant for their hearing aid use."

At the level of the dispenser, hearing aid fitting is increasingly about the ability to engage with clients' life situation to assess their social needs. Kim does not sit down and talk to Mr. Jongen about technical details. Her job is to operate the interface and guide him through the assessment of social needs to uncover what he wants to use his hearing aids for, his subjective hearing. The promise of the technology is that it can produce individual assessment and tailor-made solutions. The program calculates Mr. Jongen's score and suggests an adequate hearing aid. Kim fits the aids according to the auditory profile compiled by the program, and helps Mr. Jongen become comfortable with it's use.

Within the health profession, there has been some vocal effort at curbing excessive scientific and technological zeal and 'treating the patient as a person'. Katz (1984) has argued that the practice of patient-professional communication has been given short shrift in this age of science, in the expectations that treatment only requires silent scalpels, wordless monitors, and mute pharmaceutical agents. Often, hard of hearing people feel they lack a language to communicate their experiences of disability, the technical terminology of medicine seems unfit for social talk, and their hearing aids, they are often told by advertisement, is something to conceal. What may ensue is a cultural void of gestures and words that communicate experiences of disability in everyday settings. Lack of public awareness and social understanding necessary for the sociocultural accommodation of disability may prevail. The incommunicability of disability may work to isolate individuals and strip them of cultural resources, especially the resource of language. It is therefore, worth noting that according to research and studies on service provisions

among dispensers, user satisfaction is high.[76] Dispensers believe that the satisfaction is due to their focus on the human factor: the time and space they offer for a thorough assessment of needs and aspirations. It seems the language and interaction oriented toward the client as a social person and the work done on making people feel comfortable as hearing aid users is hitting the target with consumers. However, in conjunction with the focus on the human factor, technical skills are downplayed.

DISLOCATING DECISION-MAKING

> Kim: "Everything I've learnt, I've learnt here at my work. Then we learn a lot from the producers of course. They travel around and demonstrate new products. That's the most important source of new knowledge."

Given that practitioners' reliance on technology is increasing, how do the dispensers acquire their technical knowledge? New hearing aid models and fitting software are introduced on an annual, sometimes biannual basis. The rapid technological development is a challenge for practitioners in the field, who struggle to keep up with the specialized developments. In the Netherlands, there are institutions offering audiological education both at a vocational and higher level, but formal training is not a requirement for a position at a dispenser. Without educational standards there are different practices for hiring and training of staff. Most dispensers offer some sort of internal training with recruitment, but the length and content of these courses varies considerably. In interviews, practitioners like Kim, favored in-house training offered by producers. Following the increased complexity of the fitting procedure dispensers have made it a strategic choice to rely on the producers and their software when handling the technical aspect of the hearing aid fitting. Thus, as a consequence of rapid technological development, producers become the beholders of the knowledge that is considered relevant and desirable among practitioners in the field. It is their user configurations that are transformed into assessment schemes and fitting procedures. In fact, the rapid technological development makes it hard for practitioners to follow the technicalities of hearing aid fitting, it is preferable to use an interface, considered more accurate, safe and efficient. And the producers follow up by designing user-friendly fitting software that allows for rapid adaptation by practitioners and gives an efficient answer to the administration of a growing customer base. While the

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[76] For more information on this study (only available in Dutch) see:
 http://www.oorakel.nl/shownieuws.php3?id=740

standardized assessment software reduces the complexity of the fitting procedure the dispensers can focus on the consultation part, the psychological and human aspects related to becoming a hearing aid user. Paradoxically, the same argument about the rapid and complex technological development that was earlier used to legitimize the key role of the dispensers in the new distributive system is now also used to justify the dislocation of technical decision-making from the same practice. Kim does not see technical nor audiological knowledge as her foremost competence; it is her social skills that are essential for her work.

As sales becomes de-coupled from audiological competence, how are the links between the social assessment of needs and the technical solutions maintained? Can technology deliver on its promises of subjective assessment and tailored-made solutions? As in the case of Amplifit, is the hearing aid fitting done by the dispenser compatible with the auditory profile generated through the interactive assessment process? Again I return to the question of synecdoche following the technological extraction, multiplication, reworking and replacement of elements of hearing.

CONFLICTING LAYERS

When producers launch a new hearing aid, software for fitting follows. Such interfaces come with different layers in which the dispenser can choose to operate. The layers have varying degrees of complexity with regard to what kind of adjustments can be done on the hearing aid. In the simpler layers you upload the client's audiogram and adjust volume accordingly. The procedure is fast and simple, but there are also limits to such fittings, which has led to unexpected and undesirable effects in the Dutch system. Back in Eindhoven, Jelle articulates the problem.

Jelle: "A common problem we have with the fitting done by the dispenser is that they adjust the volume, but not the discomfort level. Clients go to the dispenser complaining they can't hear; 'could you please turn up the volume'. Then dispensers give the customer what the customer demand. But with a high frequency loss people can't hear the vocal sounds which are important for our speech understanding. Then adjusting volume alone will not improve hearing. You need to fine tune the hearing aid, try to optimize the fitting according to what hearing the client has left. To fine-tune hearing aids one must use the advanced layers in the fitting software where other parameters than volume are adjustable.

At the dispenser they only do pure tone tests, they don't measure speech understanding or discomfort level. They lack the equipment and expertise. In general, they base the fitting only on the audiogram. People without an audiological education are not trained

to operate the advanced interfaces because they demand an understanding of the interrelatedness between different elements of sound. So while a user-friendly interface might be an efficient tool, it is crucial that one is aware of its limitations. It's important to be able to interpret the client's social problems in technical terms so you know when to use the more complex layers.

In some cases, when dispensers can't optimize the technical potential of the hearing aid they pass the moral responsibility to adapt on to the client. People who come here are frustrated because they can't get their hearing aids to work and they think there's something wrong with them. They have been told by the dispenser that they have to be more active in their listening, position closer to the person speaking, use all programs, and control volume. That's unfortunate, because then the dispensers try to make their clients compensate for a poor fitting job."

Because of long waiting lists many clients are content with the possibility to make an appointment directly with the dispenser. In addition, the consultation does not take much time because the dispenser only set the audiogram. The risk is that the quality of the fitting is reduced. But for most clients it is hard to assess the quality of the service they receive. The dispensers are seen as the experts and the clients trust them to be competent. In order to manage a growing customer base, and without formal requirements for training, dispensers have chosen to adopt assessment and fitting programs that are designed to evaluate and systemize the human factor and reduce the complexity of individual cases so their characteristics can be translated, quick and convenient, into a suggestion for hearing aids. The software allows more clients to get service, but also compromise the opportunity for fine-tuning of hearing aids. What is more, when clients are not satisfied with the hearing aids bought from the dispenser, it is they who are given the moral responsibility to adapt.

The problem is that of maintaining links between the different elements of hearing at work in the audiological encounter. While digitization increasingly allows the dispenser to extract, multiply, rework, and replace body parts, these operations do not inevitably maintain synecdoche between ear, hearing aids and subjective hearing. The elements of hearing depicted in the different layers of the fitting software do not automatically overlap according to an internally organized logic. Different elements of hearing represent different possibilities for intervention and effects, sometimes overlapping, other times contradicting. Adjusting a hearing aid only according to the audiogram in the simpler layer of the program, may disturb the fine balance between volume and discomfort operable in the more advanced layers and produce synecdochical rifts which lead to new experiences of hearing disability.

The novel products emerging with digitization also reorder audiological practice. Analyzing the process of constructing soundscapes, in chapter 9, I argued that to participate fully, knowledgably, and with authority in audiological conversations – as one who produces and interprets situated language as a professional – requires competence in knowing the technical tools. Professionalism also involves being socialized into what constitutes their appropriate and inappropriate use within both the professional community and the particular situated context. Without knowing the rules that govern the proper use of technology one will remain an outsider.

Jelle acknowledges that a user friendly interface might be an efficient tool, but he also warns that it is crucial that the operator is aware of its limitations. He uses the layered fitting software to illustrate the critical role of the professional in maintaining synecdochical links; 'It is important to be able to interpret the client's social problem in technical terms so you know when to use the more complex layers', he says. Here he acknowledges that there are different ways of ordering hearing; the social and the technical, and a hearing aid fitting; the adjustment of volume and the fine tuning. The task of the practitioner is to try to make these different elements of hearing compatible. The operator of the fitting software must, on the one hand, be able to translate between different ways of speaking of sound, and, on the other hand, manage the operation of different software layers. Based on this, I have argued that to translate between elements of hearing is key to maintaining links between ear, hearing aid and subjective hearing.

With automation the 'speaking of sound' part is leapfrogged. This was my argument about the surveillance technology that worked to position Mr. Loppa out of the interactional loop. Now, in the case of Kim and Mr. Jongen, I argue that this process of exclusion is taken one step further as the professional is also made redundant. In the case of Amplifit, the technology, not the professional, becomes the translator between social needs and technical solutions, between the ear, hearing aid, and everyday life. The technology is radically changing the position of the practitioner. With automation, the practitioner goes from being a translator to becoming an operator. There is no critical mediator at work in the process of reconstructing Mr. Jongen's soundscape. The translation is not unproblematic, evident in situations such as 'the problem with the fitting done by the dispenser'. Here Jelle talks more about the problems he experiences following de-regulation.

> Jelle: "The software gets more and more advanced. I mean both its user friendliness and what you can actually do with the fitting. It is quite impressive. Yet, sound is so complex that even with all this technology we can't give our clients' their hearing back. The technology isn't perfect. I still think my best instrument is my

ears. When a client has problems putting something into words I link
myself on to the hearing aid. With the stethoscope I try to listen
if maybe I can catch what's wrong. I use my eyes, I observe the
client and I take the time to talk to them, try to find out what
their problem is and what solutions are best for them. It's not just
about sound and technical things, hearing is subjective. I ask the
clients questions and look at their reactions. Some are shy, they
don't want to complain. But it takes time to find a good hearing
aid, and to adjust it properly. Then again, it is better to spend
some time on it than having the client go home and put the hearing
aids in the drawer."

Audiology, according to Jelle, is not merely about knowing how to operate software, it is equally important to be sensitive towards the situated action generated by consultation. The situated action assigns for how to translate between different elements of hearing and ways to order hearing disability, the human and the technical, professionals and clients. It is not enough to master the technology, it is equally important to know how to critically evaluate instructions before following them. The ability to perform such modal shifts is what constitutes the audiological professional. It is a process analogue to the shifts between the different layers in the fitting software. The ability to translate between different modes of enacting and ordering elements of hearing is equivalent to knowing how to diagnose a social problem arising from the inability to hear, translate it into technical terms, and adjust it in the more complex layers of the software. The problem following de-regulation is that the majority of the practitioners distributing hearing aids are not educated to do so. Without knowledge of the technicalities behind the interface, the dispensers are only able to do a basic fitting. In other words, they are able to sell hearing aids, but they cannot operate the advanced functions needed to fit the hearing aid optimally.

Jelle implements his formal training and professional authority as he switches between modes of ordering hearing, between the interaction with his client, his audiological knowledge, and the fitting software. He rejects the notion of audiology becoming a fully automated practice. Dismissing the characterization of his field as 'wallpaper matching', he criticizes the oversimplification of the fitting process which replaces face-to-face consultation in the process of constructing a soundscape. Jelle rejects the idea that it is possible to substitute the time and skills needed to consult with clients with an ICT mediated assessment and fitting software. He explains that he applies a wider range of resources when technology is insufficient to deal with situations emerging locally. He mobilizes embodied instruments, his ears, eyes and communicative abilities. With his stethoscope, he literally connects to the link between technology and user to assess the quality of the sound.

The knowledge and skills Jelle verbalizes in the audiological encounter is at odds with the way a dispenser, without audiological education, and more reliant on technology,

demonstrates. While Kim sees the packaged assessment software as a complete solution, Jelle, equally impressed with what is technologically possible, still maintains a room for professional judgment and critical use. For him, the interactive assessment tools do not manage to reflect the complexity of hearing. Jelle's rejection of automation, his insistence on observing and talking to his patients can be interpreted as work to maintain synecdoche between hearing aid and user. Relying single-handedly on the software is to objectify the client without maintaining synecdochical links, without making sure the clients subjective hearing are in tune with the technologically mediated sound. In this interpretation, not to speak of sound during the process of reconstructing soundscapes is to risk causing a rift in the synecdochical relationship between ear, hearing aid and subjective hearing. Replacing a hearing aid that is not optimized according to hearing needs, to the client's everyday practices, is to install a technology that may alienate hard of hearing people from themselves.

Related to this, Brown and Webster (2004) argue that the more medicine depends on high-tech science, the more its tacit, bedside, discretionary knowledge is under threat. The tendency is found in audiological practice, where aural rehabilitation is becoming more and more defined in technical rather than in professional terms. The software is technically accurate, but ignores the tacit knowledge and embodied skills linked to professional audition. What gets lost is sensitivity for the ongoing and mutual shaping of linguistic resources and the situated activity of work that yields specific context-dependent representations of sound. Against the replacement of the patient to software categories, audiology itself is reduced, and so the professional practicing audiology. It is, in other words, not only the complexity of the patient which is reduced through implementation of assessment and fitting software, also the audiological gaze, talk, and listening is made redundant. The process of de-professionalization through automation, prompted by an order of efficiency replaces tacit, embodied audiological know-how with technological standardization.

As technological, political and industrial changes reconfigure routes of entry to audiological practice, means of acquisition of practical knowledge necessary for professionals have changed the way knowledge is practiced in the audiological encounter. Apart from presenting a potential decrease in the quality of audiological service provisions, such shifts can be interpreted as a challenge to the cultural status of audiological work, a de-professionalization of expertise and a threat to clinical autonomy and judgment. Given the pressure for efficiency dominating current health care practice, professionals are increasingly encouraged to embrace the new opportunities related to digital technologies, especially their potentially greater efficacy. When implemented within an order of efficiency, technology has the effect of displacing the traditional role of professionals as primary observers and instead projects the observer into a complex world of technical and resource dependence. The dislocation of decision-making is highly paradoxical. What has been used to justify the role of technical audiologists and

dispensers, the rapid technological development, is also threatening to dis-empower the professionals in the field. Yet, the more dispensers and technical audiologists promote the accuracy and efficiency of technology, the less they behold of this expertise themselves. They, in fact, take part in the de-professionalization of their own field.

CONCLUDING REMARKS

In this case study from Beter Horen, I set out to explore how political de-regulation influences the work routines at the level of the dispenser and how the technologies at work interfere with policy shifts in the context of the audiological encounter. Analytically speaking, I was interested in synecdoche as work practices become automated and technology takes on a more prominent role in the translation between ears, hearing aids, and subjective hearing.

While the new Dutch health care policy emphasises competition, consumers, and choice, the growing number of dispensers, and the competition between them, has not yet influenced the design of hearing aids. Within their range of models producers offer more or less the same technical possibilities. For producers it is, thus, crucial that the dispensers like their software if they are to sell their hearing aids because, as Kim explained, if she struggles with the fitting software, she can simply choose another brand without losing out on the range of technical possibilities. Therefore, producers also invest a great deal in developing user-friendly software. With regard to knowledge and control in relation to the new software, dispensers do not need to understand the audiological assessment behind the suggestions for a hearing aid and its fitting since these are done automatically by the program. In the wake of de-regulation the dispenser has shifted focus from the technical aspect of hearing aid fitting, towards accessibility, positive branding, and the assessment of social needs. Following de-regulation, the technology at work has become an active contributor to the tension between standardization and flexibility, between profiting on a growing customer base and offering high quality service provisions. By designing different layers for hearing aid fitting, producers actually invite a shift in the quality of service provision.

Ironically, as a consequence of the de-regulation policy, which aimed to reduce pressure on specialist service, consumers like Mrs. Hoof who start up in the commercial routing end up in the specialist system because of the lack of technical expertise at the level of the dispenser. What is further thought provoking is that the new system, thus far, has not contributed to cost-efficiency as predicted by policy makers. According to the AZOS (2006) evaluation report, the cost of hearing aid distribution is today the same as before the de-

regulation, while the quality of service provisions has decreased slightly. The difference is that consumers are now increasingly made to cover the costs.

While I have proposed that the two dominant drivers in the de-regulated Dutch aural rehabilitation system are rapid technological development and increasing demand for (cost) efficiency, it is also my supposition that these cannot be seen in isolation. They are mutually constitutive elements of the emerging system. Technology is not inevitably leading to less local knowledge and control. However, when intensively used as an administrative tool in a commercial system where the priority is sales and personnel that can attract customers, then lack of knowledge and local control may be the result. Emphasizing the human factor, assessing a hearing aid fitting according to lifestyle and individual preferences and the context of use at first seems a progressive move in the direction of a more user driven development. However, the administrative framing involved in implementing a standard assessment tool risks dislocating expertise and decision-making. The user friendly interface reduces complexity by allowing the technology to make suggestions and decisions on behalf of the practitioner. As a result, dispensers may weaken their sensibility for the ongoing social interaction with clients. Here then, the entangled effects of shifts in technology and industry structure, together with a policy of de-regulation, make their way into a locally situated audiological practice. The de-professionalization of audiological practice can work to threaten the synecdochical relationship between social needs and technical solutions.

A key objective in Dutch and Norwegian disability policy is to realize efficient and user-cantered service provisions that can replace much criticized professional paternalism. In this context, 2nd generation hearing technologies are promoted as tools to enable interactive consultations in which practitioners and service users find solutions in common, tailored to subjective hearing. However, within one and the same field various actors are involved in the definition of user needs, and configurations occur at many levels and take multiple forms. Rather than assuming that technology, in some pre-determined way, can increase efficiency and enable user-cantered care I have remained critical to the professional ability to reconstruct soundscapes. I have followed the policy on empowerment into the workshops where hearing technologies are designed, and into the audiological sites where hearing disability is assessed and hearing technologies distributed. Through analyses of audiological practices, I have found that the technological hopes and visions formulated in policy might necessarily be the same as those 'inscribed' in technological devices and systems, or those emerging from their professional use.

The demand for efficient service provision has led to two apparently opposite tendencies in the Netherlands and Norway. In Norway, due to tight time schedules and lack of interdisciplinary resources, the technical audiologists report that they feel they are too focused on the technical dimension of aural rehabilitation when, evidently, there is a need for holistic treatment. In the Netherlands, the sentiment is that dispensers, due to increased commercial competition, downplay their technical skills for the sake of sales and personnel that know how to operate the human factor. As a result, the quality of the hearing aid fitting has decreased.

Ordering hearing disability according to a bureaucratic and/or a commercial mode implies having to meet demands for efficiency. In these ordering modes, the configurations of technology, professional and hard of hearing are not primarily aimed at developing user-cantered care, but at organizing standardized public services and generating profit. Prompted by demands for efficiency, technological tools are increasingly implemented to translate complex social needs into workable technical solutions. New digital technologies have opened for novel and efficient ways to reconstruct soundscapes. The object of maintenance and care is no longer simply the individual body. The representations or traces of bodily senses can increasingly be extracted from the individual and distributed

across vast webs of information and data management and disciplinary expertise in which hearing is tested, logged and treated to enable reconstructive interventions with hearing aids. Along with the new technological possibilities, the intricacy of the fitting process has increased. Therefore, producers invest a great deal in developing user friendly interfaces for their fitting software. The technology helps map soundscapes and finds coordinates when the course towards an optimal fitting is to be drawn out. The ideal seems to be a form of distant control, enabling an efficient ordering of disability rather than interactive engagement. To some extent, these types of technologies manage to extract experiences of hearing from clients when access to a shared language is scarce. Instead of relying on the patient's (ability to) report, or their own technical skills, practitioners turn to software, providing elements of hearing that are considered reliable and workable. By isolating fragmented representations of hearing (audiograms, percentages, logs, and lifestyle indicators), subjective expectations and experiences become orderable.

But while these technological innovations open up new and exciting possibilities for reconstruction of soundscapes, at the same time, as technology is implemented to increase efficiency, ontological connectedness is hard to maintain, technically and morally. Such requires maintenance work based on the active participation of technology, professional *and* service user. But with an increasing demand for efficient service delivery, a tendency is to try to replace human participation with technological automation. The technology assigns and structures available positions for professional and user in the audiological encounter. Despite aiming for a patient-cantered care, the interaction promoted by hearing technologies is framed around existing professional procedures. The assessment and fitting tools are developed to enable the professional to assess needs and preferences for hearing aids. They are not facilitating a user-cantered and, potentially, very different, report. In practice, it is the professional who is the prominent user of the technology at work. It is the active position of the professional, their ability to define and decide that the technology is designed to support. The hard of hearing are seen as users of service, not technical systems or intervention vehicles.

There is a striking lack of room and resources available to realize the empowered user. Rather than shifting power relations, hearing technologies reinforce the asymmetry between professional and service user in new and intricate ways. What is more, in situations where the professional lacks education and critical judgment, surveillance technology and standardized assessment and fitting software work to dislocate decision-making further from local practice. In result, making technology, not service users and their needs and aspirations, the main decision maker in the audiological encounter. The technology monitors patterns of use, proposes what questions to ask, calculates answers and decides what the correct hearing aid is. Based on this, I argue that technology, as

inscribed with an order of efficiency, interferes, not only the political objective of patient-cantered care, but also with the enactment of audiological professionalism.

It would be premature to make decisive conclusions based on my limited research, but there are reasons to warn about the development. Surveillance technology, standardized assessment and fitting software, suggestive information pop-ups, and cartoon features are effective translators in the audiological encounter. However, when the hearing aid user is left out of the interactional loop and/or the professional's role is reduced, things tend to get lost in translation. When the synecdochical links between the heterogeneous actors involved in the audiological encounter are not maintained the objectification hard of hearing people submit to when entering the audiological clinic can come to stand in opposition to aspects of personhood. Oppositional tensions between objectification and agency alienate people from technology. It is the ubiquitous possibility of this alienation resulting from synecdochical breakdown that explains the customary ambivalence towards the benefits of technology and, perhaps, the high frequency of non-use. Thus, not forgetting, or taking easy on the criticism rehabilitation professionals have been met with for tendencies of paternalism and arrogance, given the unexpected and unwanted effects of technology in practice, perhaps we should not turn our backs to expertise just yet?

This, however, entails that professionals too engage in reflections about the professional enactment and ordering of hearing loss, hearing aids and service users. By automation, the service user is left out of the interactional loop, which means that professionals risk alienating resourceful users. In this situation, the question is how long the experts can maintain their privileged status as the gatekeepers to welfare services. How long before, service users start seeking alternative routes towards rehabilitation with hearing aids. Seen in relation with the ongoing automation of testing assessment and treatment procedures and the tendencies towards de-professionalization of technical audiology, I want to suggest that there may be unseen connections between service users and professionals. What is more, I believe that professionals may have aspects of their professional status that can be appealed to in order to facilitate change towards more user-centred practices. Perhaps rather than perceiving the empowered service users as a threat to professional status, dialogue, recognition and co-understanding can be achieved in a way that enables different people to grow through mutual exchange of viewpoints. To take seriously the complex and variable aspirations and abilities of service users could be a first step towards forming a new alliance that legitimises a new professional status and re-professionalize the field.

While design teams and audiological professionals are important actors in shaping the initial forms, functions, use and meanings of hearing technologies; their influence is not deterministic. While scripts follow technologies, the question remains, will users follow the script? Obviously, identities do not develop solely in the relation between people and their

hearing aids. The experience of hearing disability is shaped in other powerful contexts too, in the job market, in family life and through the venues of popular culture. These are the relations I go on to explore in the next part of the book, *The Lived Experience of Being Hard of Hearing*. Here I study how, outside the clinical encounter, hard of hearing individuals are assigned other subject positions in different status hierarchies. In their everyday lives people can regain social status, they have (various) power to reject, oppose, change or adapt to the sociotechnical solutions prescribed by their audiologist. A crucial question is how the professional enactments and orderings are received differently among different people and how other active ordering modes influence the experience of being hard of hearing.

PART IV: THE LIVED EXPERIENCE OF BEING HARD OF HEARING

INTRODUCTION

In this part of the study, I revisit the issues of hearing disability that I have found in social theory, public policy and professional practice and engage them as they emerge in stories from people's everyday life. Now it is the voice and agency of hard of hearing people that is brought to the fore as I investigate how hearing loss is enacted and ordered in the light of broader identity projects. In the theoretical chapter, I argued that disability is neither a structurally determined subjectivity which can be read off from biology or production – as some versions of modernity would have us believe, nor free-floating and freely chosen through consumer life-styles – as some interpretations of postmodernism would have it. Instead disability is constituted in and through sociomaterial relations that create cultural hybridity. Disability is one of those positions that cannot be chosen; always there, but never appearing in an essential way. Disability is not to do away with, but negotiable. What matters, then, is the varying access people have to sociomaterial resources to enact disability in aspirational ways.

To investigate this, I draw on the poststructural notion of subject position and combine it with analytical resources from material semiotic studies of the ordering of disability. Here, in particular, the work of Ingunn Moser (Moser 2003; 2005; 2007) has been important. She has developed an approach that traces and locates the politics of disability in everyday life. Her point is that despite the initial openness following a hearing loss - how people enact and order their disability, how they draw on an entire repertoire of subject positions, materials, and environments - there seems to be a more limited set of doing disability. Patterns are discernable that seem to build different orders. Subjectivities, embodiments, the collectives they are part of and (dis-)abled by, the elements and relations, practices and materials they are enacted in, all become ordered in specific ways.

The subsequent questions, with which I explore the empirical material, are what these are, what kinds of ordering they enact and what they make of the disabled subject. The assumption is that people do not passively conform to discursive instructions. People contribute actively by accepting, rejecting or changing the ways society attempts to order hearing disability, they enact agency. The aim of the case studies is thus to contribute to our understanding of what ordering modes are active in the society hard of hearing people live

in, how people find their own position in these order-building processes, and what social and material resources they have available in realizing these positional strategies. What is important about the forthcoming analysis is not alone what is being said or done, but the conditions for these enactments, what subject positions people conceive as possible in the space in and between different ordering modes and the costs and benefits of realizing specific positional strategies.

In her empirical material Moser discerns *normalization*, *passion* and *fate* as three modes of ordering disability and describes and discusses their particularities and interrelations. In the analysis I use Moser's analytical framework as an inspiration for the exploration of hearing disability. However, a qualification is in order. While I bring out and discuss how elements of normalization, passion and fate are at work in my empirical material, I have not used Moser's heuristic framework in the thorough comparative manner that she does. Instead, I use her work as analytical starting points to discuss how different experiences of hearing disability emerge. Differences that stem from disability *and* from the other subject positions people identify with. Based on such relationality, the aim is to build on and extend the material semiotic approach by discussing how ordering modes can produce similar and different effects to those traced by Moser.

The chapters go in-depth on five individuals and their stories about disability, technology and politics. I present each story individually and in empirical detail by use of a wide range of material from the user study; observations from audiological encounters, interviews with professionals and policymakers, and interview transcripts and fieldnotes from my interaction with the participants in the user study. This is because I consider details to be of the essence when exploring exactly *how* experiences of hearing disability emerge and the specific conditions of possibility for these enactments. The findings are structured into three thematic sections that reflect key issues in today's political debates on disability; chapter 12 is on 'empowerment', chapter 13 is on 'activation', and chapter 14 is on 'the equality – difference dilemma'. In my view, each individual story is interesting not only because it tells us something about the sociomaterial conditions for hearing disability in society. As critical cases they are also *useful* in that they reflect challenges and opportunities for theoretical reflection, policy making and professional practices in the field. Presenting these case studies, I want to stimulate fresh thinking about the politics of disability. Therefore, in chapter 15, *Rethinking Social Justice,* I reflect on the findings from the user study in the light of a broader debate on social justice.

INTRODUCTION

'Empowerment', or patient autonomy has gradually replaced professional paternalism as a political ideal, a key to the lay-professional relationship.[77] Yet, in a clinical context, more knowledge is needed about what should be an appropriate understanding of empowerment: who has the power to define what empowerment should be and how are such ideals transformed into practice? In the Dutch context, policy makers have turned to the market as a responsive mechanism. Here 'empowerment' is defined as consumer choice. In the Norwegian public system, 'empowerment' is defined as user involvement in the design of holistic treatment programs.[78] The disabled subject figuring in these policy documents is equally transformed. Departing from the much criticized patient role, hard of hearing people are now constituted as autonomous actors engaging in 'equal partnerships' with professionals. In disability policy it is recognized that different people have different needs and aspirations for rehabilitation. Hence, flexible forms of service provisions have become the ideal model for organizing audiological practice. In the light of this, the professional challenge is to recognize the realities hard of hearing people bring with them to the audiological encounter and find ways for these to get to have repercussions on the design of rehabilitation programs.

In the previous part of the book, *Audiological Encounters*, I analysed how hearing disability is enacted and ordered in professional practice. I used Charis Thompson's (1998) notion of synecdoche to show how audiological interventions opened possibilities both for objectification and agency for hard of hearing people. I argued that the outcome of such interventions could not be determined in advance, but had to be seen in light of the broader identity projects service users bring into the audiological encounter. To investigate this, in this chapter, I introduce two hard of hearing people, Reidar and Bart, who in interviews

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[77] Community empowerment has increasingly been identified as critical to health and well-being and is central to the WHO definition of health promotion (WHO, 1986).

[78] In part II, I discuss how consumer choice emerged as an empowerment strategy in the wake of a 2006 market-oriented health care reform in the Netherlands and I show how user involvement emerged as an empowerment strategy in the Norwegian disability field in the 1960-70s.

talked about their expectations for and experiences with 'empowerment' in the context of aural rehabilitation. Working with the extracts from these interviews I explore how elements of disability, technology and politics combine to enact conditions for subjectivity, as well as *how* agency is negotiated in the meeting between hard of hearing, professional, and technology. Both Reidar and Bart consider their relation to technology a strong point of identification. As they enter into rehabilitation programs they are keen to participate actively and they have the resources to do so in a competent manner. As such, they are ideal candidates for the new user-cantered rehabilitation models. However, the analysis shows that despite the conditions being in place, both experience considerable problems activating the empowered position in practice. Hence, as critical cases, their stories can contribute to improve our understanding of the multiple, and sometimes unanticipated effects of aural rehabilitation practices.

Staging the analysis is the recent shift in Dutch and Norwegian disability policies and the dynamic involved in enacting the empowered service user in practice. The underlying assumption is that in order for flexible service provisions to become real, policy objectives and legal documents must be translated into local practices where a heterogeneous constellation of actors, potentially involved in various other modes of ordering hearing disability, struggle to define what should count as legitimate and effective responses to hearing disability. Exploring the transition from policy to practice, the analytical task is to answer what modes of ordering hearing disability are activated during the audiological encounter and how people negotiate subject positions and agency within this.

To investigate the mutual constitution of order and subject I mobilize Michel Callon's (1986) concept of an 'obligatory point of passage'. Callon has described the process during which an actor network is built and the identity of actors, the possibility of interaction, and the margins of manoeuvre are negotiated and delimited. He highlights how the actors involved in the translation try to become indispensable to other actors and insert themselves as an obligatory point of passage. A key element of Callon's (1986:216) concept is the need for the obligatory point of passage to succeed to speak for others and; 'to speak for others is to first silence those in the name we speak'. Drawing on Callon, I identify the Dutch and Norwegian gatekeepers to hearing aids, and the way these seek to order hearing disability, technical aids, and the hard of hearing subject. Translation, in this case, involves the process of transforming the rehabilitation client into a health care consumer (NL), and a holistic user (N). Within the two systems for hearing aid distribution, several actors, on different grounds, struggle to become part of the obligatory point of passage and partake in the constitution of the new service users. To be a constitutive actor means being an indispensable actor, thus justifying and strengthening one's own position in the emerging orders. Bearing in mind the call for 'empowerment', the pivotal question thus surfaces; who speaks for the hard of hearing and with what voice?

THE HOLISTIC USER

In the call for a user-centred rehabilitation the 2002 Norwegian Action Plan for aural rehabilitation singled out two interrelated concepts; *subjective hearing* and *holistic rehabilitation* (SHD 2002). During audiological consultations hearing is to be assessed individually and treatment designed involving psychosocial as well as technical elements. Rejecting the idea of hearing aids as a technical fix, the holistic model challenges the medical ordering hitherto dominating the Norwegian rehabilitation system and tries to establish a new practice based on an interdisciplinary approach to hearing disability with user involvement as the key element. In the light of this policy shift, I develop a critical analysis of the process in which hard of hearing people are to change from patients in an expert driven rehabilitation system to individuals in a user driven rehabilitation system. In the analysis, I focus on the activation of the 'holistic user'. With a critical eye to the notion of user involvement, I seek to problematize the empowerment of users as predicated within the context of holistic treatment. Rather than an abrupt discursive shift, the analysis of current practice illuminates a modal clash between medicine and holism. To explore this, I will present *one* hearing aid user - 'Reidar Sørensen' (54), situated in *one* discursive context - the first time consultation at a rehabilitation centre. In the analysis I am interested in what kind of agency Reidar seeks and how his expectations for empowerment are met during the audiological encounter.

MEETING REIDAR

Following an accidental fall five years ago Reidar sustained Tinnitus and a one-sided hearing loss.[79] Now he uses an in-the-ear device that is a combined hearing aid and Tinnitus masker. He is trained as a civil engineer and has worked most of his life as a manager of an energy company. After the accident, he decided to make a career change and started teaching natural sciences at the local high school. Reidar lives in the northern part of Norway together with his wife. Their two adult children have moved out. In his spare time, Reidar is acting chair of a sports club. He has earlier been involved in regional politics. I have looked forward to meet with Reidar. He is the first engineer I interview. I am curious

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[79] Tinnitus can be perceived in one or both ears or in the head. It is usually described as a high pitched in a variety of forms, ringing, buzzing, screaming, etc. Tinnitus can be intermittent or it can be continuous in which case it can be the cause of great distress.

about how his professional background and familiarity with the public system have influenced his views on technical aids. According to policy documents on the situation for hard of hearing people in Norway it is the resourceful service users that manage to get through in the system and get help:

> The common feature is that person with persistence and insight in the public system will be able to maintain their rights, while those that are not in possession of such qualities will not get what they need. The system benefits the strong while it fails the less resourceful (SHD 2002:13, my own translation).

But is this always and necessarily the case? In the 2002 Action plan, help is defined as access to specialists and technical aids. Yet, the most resourceful among the participants of the user study (that is the informants with higher education that in the course of our meetings demonstrated technical skills and familiarity with the public system) were also the ones least satisfied with the support system. My idea is that their discontent stems from the clash between alternate modes of ordering hearing disability and the positionality between professional and service user which these enact. While professionals enact and order hearing disability as a biomedical condition, these specific service users expected to receive holistic service provision that recognized their multiple selves. To explore this further we shall follow Reidar through what I have distinguished as two phases. In the first part Reidar reflects on his consultations with the audiological specialists. We will learn that this was a particularly negative experience for him. But this is not just a story about loss and subjugation. Hence, in the next part I introduce interview extracts in which Reidar talks about learning to cope. Here he mobilizes other ordering modes in which for him, the desirable subject position as capable on technological matters is available.

A MODAL CLASH

> Reidar: "The GP sent me to the specialist centre. I was quite disturbed by the system that I met. The whole consultation was just so paternalistic. All I got was the message that according to my audiogram this was the hearing aid I needed." Researcher: "Did you try different types of hearing aids then." Reidar: "No, there was no talk about alternatives; the choice was made for me. I got a hearing aid and that was it. No discussion about other possibilities." Researcher: "How long did the consultation last?" Reidar: "About fifteen minutes. I drove for five hours to get to the rehabilitation centre and all they had for me was fifteen minutes... I remember how frustrated I was. I discussed it with my wife when I came home. I was quite astonished since this was supposed to be a specialist service. A place built on competence about hearing and

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rehabilitation. I would have appreciated it if the ENT doctor had
taken some time to discuss with me, involve himself a little bit in
my situation. But he said that was not something that they did."
Researcher: "But did he ask questions about your life style, what
you needed your hearing for, and how to accommodate these needs? Was
there any talk about your work situation, did he suggest a loop
system?" Reidar: "No nothing like that…"
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Reidar was not born with a hearing loss. He had no position on disability before he became hard of hearing. Until then, he experienced his identity as stable, grounded in a career, family life and the multiple positions he had chosen to take in activities surrounding sports and politics. Following the accident and loss of hearing, Reidar experiences what Ingunn Moser (2003:38) has referred to as being; 'quite violently displaced from one mode of ordering to another. Being placed into disability'. After having been to the rehabilitation centre for treatment Reidar is stunned. As he explains, it was not so much what the specialist said, but the way it was said. Reidar reacted to the paternalism of the audiological encounter, being treated like a patient, like he was sick, not able to take care of, or answer for himself. He reacts to how his life situation did not count, only impairment.

Reidar describes the audiological encounter as a clash between expectations and realization with regard to the content of a specialized service and his position in it. For him, a specialized service means a service that covers all aspects of hearing, a service with a holistic approach to his disability. For the professionals, specialization appears to mean partial knowledge and isolated treatment. The technical audiologist initiates the normal objectifying procedure; measure his hearing disability with a tonal test, draws the result into an audiogram, then attempts to compensate for his loss with a standard intervention, prescribing a hearing aid. Reidar, however, expected to meet a specialist who would 'involve himself a little bit in his situation'. What Reidar looks for is someone who can help him understand and cope with his hearing loss, including its psychosocial effects. He considers the medico-technical approach inadequate and reacts to the idea that it is possible to separate the physical part of him from the rest, his 'situation'. He cannot understand why there are no questions about his domestic or professional situation. He expected the consultation to include a plan for how to assess and accommodate his subjective hearing. Importantly, such questions might have assigned Reidar a competent and active position, allowing him to contribute with knowledge from his area of expertise, his own life.

When Reidar's agency is hindered, the meeting between him, professional and technology takes the form of a modal clash. The medical ordering enacted by the professional interferes with Reidar's expectations for holistic treatment. For him, the consultation develops into a conflict over identity and expertise: what is to be considered relevant knowledge in the set up of a rehabilitation program, and who get to have a say in this.

Reidar insists that treatment must be related to his life situation. With reference to everyday life as the important contextual setting for rehabilitation, he can legitimately assume the position as a knowing subject. But the specialist does not recognize the notion of subjective hearing. What is more, it is in direct conflict with the medical ordering enacted by the specialist. His focus is on the somatic condition. He looks into Reidar's ear, reads his audiogram and – simultaneously - dismisses life situation as a relevant element for treatment.

In the 2002 action plan on aural rehabilitation, service users are no longer bodies with a biomedical condition. They are transformed into complex individuals situated in social milieus, with identities that should matter when hearing is assessed. In policy, it is recognized that outside consultations, hard of hearing people engage in more complex and active modes of ordering their hearing disability. They are more fully present as socially and culturally situated, thinking, feeling people, with their own ideas on their disability and opinions and possible criticism of audiological interventions. In a holistic model hard of hearing people are allowed to present their full selves. But the system Reidar meets with is unable to realize this ideal. Reidar's subjective experiences from living with a hearing loss are left outside of the interaction between him and the professionals. Instead, his story is about a rehabilitation practice in which the service user continues to be construed as a purely biomedical entity, that is, an impaired hearing wanting a label for what is wrong and a technical fix to put it right. In the medical order enacted by the specialists Reidar finds himself positioned as a passive participant to the audiological encounter.

THE USER AS EXPERT

Reidar: "You see the thing is that I have a background from filter technology. I graduated specializing in this field. It is something that I really know a lot about. I tried to discuss the technology with the technical audiologist. But I soon realized that she didn't have a lot of technical know-how. I asked things about the hearing aid but she was incapable of answering even the most fundamental, but for me, crucial questions. Like when I wanted to know how many filters they had she just had to make a guess. Well, I guess the technical dimension to my questions made her uneasy in some way. I got brushed off.

Later at home, I read on the Internet that the device had six filters. I also found that the frequency area of my hearing aid goes up to 6400 hertz and that above this the hearing aid cannot capture the treble. That's where I've got most of my loss. Around 6-7000 hertz the treble just disappears. Since most of the information lies in these frequencies I can hear what people say, but I can't understand it. I hear sounds, but I misunderstand words and meanings. I have learnt some techniques of course, not to ask over all the time, it's too tiring."

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Researcher: "But, was there no talk about referring you to a speech
therapist?" Reidar: "No nothing like that. I was told to come back
for a control to adjust the hearing aid that was all. I guess, I'd
gotten what they had to offer, but what I was looking for was some
guidance in the process, not to be entirely left by myself in a
difficult life situation. Training, information about other
technical solutions and the social adjustment, all these issues I
have had to cope with on my own. I told myself that ok I've been
given a technology that helps me a bit on the way so I should use
it, but I was frustrated. I mean it's my situation. I want to know
what my options are, the kind of practical information that enables
me to handle the situation. I would like to control my own life, not
being controlled by others! Well, it was just a lousy start for my
part..."
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It is not Reidar who is the central actor in this audiological encounter. He only gets to take part through representations of hearing. The focus for assessment and treatment is impairment, as observable through the audiogram. From his hearing curve the professionals attain the information they consider useful for their work. Reidar, who considers his technological competence to be a strong point of identification, is discontent with being positioned passively within an area where he himself holds expertise. He expresses a need to understand and take an active part in the situation, because it is *his* situation. Reidar tries to position as an equal partner in the meeting with the expertise, but in the medical ordering enacted by the specialists his technical experience does not seem to matter and his opinion does not count.

The geography of responsibility inherent to the medical order is signified by a gap of competence between the one seeking help and needing treatment, and the active rehabilitation professional providing treatment and having the knowledge that can be of help. It is this gap in competence that justifies the asymmetry inherent to the medical ordering mode. The one providing treatment is the responsible one and the service user can trust the provider to be competent and to take responsibility. This exclusive professional knowledge has, hitherto, justified the powerful position of experts and the equally docile position of service users. Those in need of help are not seen as capable of knowing their own good, to assess the causes of their hearing problems, or know the interventions needed to solve these. Therefore, experts have been assigned a key position in speaking and acting for service users in the design of rehabilitation programs. Professionals have traditionally been given broad authorities, both in policy and practice, based on a trust of their attitudes, competence and professional knowledge. In this ordering mode, the interest of the service user is ensured by handing over power to the professionals, allowing them to assess and make decisions on their behalf on matters regarding their health and well being. Based on their exclusive and esoteric knowledge, professionals are trusted to make competent end-means assessments and to use their

professional knowledge in the realization of the societal objective of normalization; the rehabilitation of hard of hearing people through hearing aids that will allow them to re-integrate in normal societal life.

When Reidar complains that he was; 'not given any choice, the choice was made for me...', it is the geography of responsibility inherent to the medical order that is contested. Reidar does not have unreserved trust in the audiological expertise and their judgments. Rather, he is concerned with the professional's lack of technical knowledge. Reidar is familiar with the technology at work and, thus, particularly able to position as the capable service user. He does not accept the medical ordering of his hearing disability – as impairment for which can be prescribed a technical fix – and his position in it – as incompetent and passive on matters of rehabilitation in relation to the knowingly and active professional. Instead he tries to mobilize a subject position in which agency arises from his ability to bring into the audiological encounter relevant knowledge of different spatial and temporal kinds. Reidar mobilizes a notion of subjective hearing and holistic treatment. From his point of view, he has access to a dual expertise; he knows the technology *and* its context of use. With reference to his life situation and professional background Reidar can claim agency on matters linking ear and hearing aid with everyday life. Agency, for him, is linked to the ability to use this resource to *do* something to gain control over *his* life. For Reidar, this is *empowerment*, to have his everyday, subjective experiences recognized as valuable for rehabilitation. To make his voice heard and his resources utilized. Referring to his formal training on filter technology and his ability to locate relevant information and ask 'crucial' questions, he seeks to justify his active participation in the consultation.

But Reidar's claim for agency - his attempt position as capable and coping - interferes with the medical ordering of the professionals, and becomes a problematic element of interaction. When Reidar initiates a technical discussion with the technical audiologist to move out of the passive position, his attempt is actively ignored; 'brushed off'. By refusing to answer his questions and labelling his input as extraneous the technical audiologist lets him know that his behaviour is out of order. When the technical audiologist enacts the asymmetrical relationship between him, the service user and her, the provider Reidar is re-positioned as passive and medical order re-established. She can continue to perform a fitting based on the objective audiogram, without his subjective involvement.

It appears that it is not technical know-how *per se* that is at stake here. Reidar, the service user, demonstrates that he has equally, if not more, competence than the professional with regard to the technology at work. Still he finds that there is no room for his active participation. Expertise does not flow unreservedly in and between settings. Technological competence and abilities are not (merely) dependent on expertise within the specific field. The position as capable on technological matters is contingent on the mode of ordering activated in the audiological encounter. Ordering modes assign geographies of

responsibility. As a professional engineer in an occupational setting, Reidar would have been enacted as an expert in relation to filter technology and the status as a competent and active contributor to problem solving process would have been readily available. As a manager in the private sector, he has been used to assessing complex situations, compare alternative solutions, and make decisions. In the audiological encounter, his agency is delimited. As a user of rehabilitation services choices are being made for him. He is not invited to assess, discuss and decide for different options, his choice is to accept or reject. As a result, he expresses frustration, even bitterness, as if the experience has degraded him and his capabilities.

Following the audiological encounter Reidar's position on technology changes too. The idea of becoming a hearing aid user was, at first, thought of as a solution. Technology was a familiar tool that would bring opportunities in a difficult life situation. Now Reidar talks about how using technology as prescribed within the rehabilitation system implies dependency and constraints on his life. Hearing aids are not autonomous elements of rehabilitation. As part of aural rehabilitation systems they emerge in and by relations to the other elements of the sociomaterial arrangement in which they are activated. These sociotechnical arrangements shape the specific use and effects of technology, and the distribution of agency and expertise on technological matters. Presented with technology as an answer to disability, Reidar is asked not only to accept a technological solution to his hearing problems, but an entire geography of responsibility in which he comes to depend on the judgments and interventions of audiological professionals. Therefore, for Reidar, the technology poses both opportunities and challenges in more than a functional sense. Enrolling as a service user means accepting the aural rehabilitation system and its medical ordering as an obligatory point of passage towards rehabilitation with hearing aids. To use technology in this situation causes different subject positions to conflict. He is faced with a subjective dilemma; to accept a technology that can diminish the negative effects of his hearing loss means accepting a loss of agency on matters of his own life. Reidar finds himself positioned in an audiological encounter which de-centres and alienates him from his own body, a setting which he experiences as threatening to his identity. Paradoxically then, in a situation where the rehabilitation system is meant to support the hard of hearing the result is the opposite because the service user, in this case, is trying to get involved in his own rehabilitation. Instead of feeling supported, Reidar articulates a feeling of loss – a double loss: First the loss of hearing, then a loss of social status.

> Reidar: "A month later or so I was called in for a new consultation, it was strange because the note I got did not specify what type of control it was. I thought about it, five new hours in the car, a whole day gone from work... if it was going to be another fifteen minutes session without further consultation... well, you get the picture... I called them at the rehabilitation centre to get some more information, but they were not able to give me an answer. I had to talk to the technical audiologist and she was not in that day… I think that as users we should get some more time to prepare. We ought to be informed on what sort of control we are in for so we know how to contribute in dialogue with the experts. I think we should be informed about what they want to know, what type of questions we will get, alternatives. The kind of information that we can use to optimize the consultation, not just deal with it in an *ad hoc* fashion."

Ordering modes not only work to regulate human behaviour in a negative manner, they also make concepts, objects, and subject possible, they create realities within to act. Then, what goods results from Reidar's consultation at the rehabilitation centre? From the point of view of the medical order, the audiological encounter was a successful one. Reidar's complaint was handled efficiently - in fifteen minutes, and effectively - through distributing a technical fix. Hearing tests were done, an aid was fitted, which made rehabilitation possible through compensation. With the hearing aid, Reidar has access to a rationale on his hearing loss. As an element of a normalizing order the hearing aid can be used to direct attention away from him as a lacking individual and instead locates the problem in a dysfunctional body part, lending some of medicine's prestige and making the problem easier to handle.[80] In this ordering there is no need for Reidar to take an active position, the audiogram defines his problems and the specialists decide on a solution. The problem is that certain things tend to fall out of the consultation when merely focusing on disability as impairment. In this ordering mode, any hearing related problems Reidar experiences when using the hearing aid become the misrecognized elements of disability. Through the active rejection of the specialists, they are ordered exterior to the consultation, deemed irrelevant for audiological practice.

For Reidar, there is more to disability and rehabilitation than physical loss and a technical fix. He talks about the responsibilities that are individualized when they are not recognized by the rehabilitation system. Without a holistic treatment, it is Reidar who is responsible for managing the disabling elements that the hearing aid cannot do away with or compensate for. He reacts against not being given any further guidance. He feels like he is being 'entirely left to himself in

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[80] See Solvang (2007) for a critical discussion of the goods and bads of the medical model on disability.

a difficult situation'. But in the medical order, disability can be normalized by adapting a technical fix. When society has fulfilled its part of the bargain, distributing technical aids, it is the (moral) responsibility of the individual to cope with the remaining issues such as social, psychological and pedagogic strategies. The medial ordering constructs a dichotomy between the objective and subjective in the distribution of responsibilities and actions. The specialists do the job of producing an objective categorization of the disability. They set the audiogram and deliver the aids to remedy the condition. But the responsibility to make the solution work, in a specific setting, is individualized. Failure to do so becomes a failure of the individual to mobilize the sociomaterial resources to cope.

But why is this troublesome, Reidar seeks agency in the rehabilitation process. The answer lies in the peculiar distribution of responsibility. Reidar is not reluctant to take on responsibility; on the contrary, he seeks an active position on technical aids. Yet, he experiences that the system stalls his attempts to deal competently with the task. The routines and agendas of the professionals are not made transparent and works as a barrier for the position as informed. To begin with user involvement is excluded in the appointment note from the rehabilitation centre. The letter contains no information for Reidar to prepare for the consultation and there is no assistance available over the phone. Thus, while policies mobilize the involved service user, at the same time, the rehabilitation system Reidar consults limits his agency by denying him access to information that he needs to externalize his subjective competencies and position as a capable and coping service user. Paradoxically, he becomes dependent on the arbitrariness of the rehabilitation system, its people, routines, and procedures. The denial of Reidar's agency is enacted by the entire continuum of the hybrid collective that makes up the aural rehabilitation system. Closed devices, non-transparent routines, paternalizing professionals, and asymmetrical consultation procedures, all do their part in disabling action and cognition, enacting barriers to empowerment. But what should we make of this resistance to an active user role?

A CHALLENGING PERSPECTIVE

The Norwegian sociologist, Tone Alm Andreassen (2003; 2008), has investigated the introduction of user involvement as ideology and as a work tool in the Norwegian disability field. She has argued that through user involvement transparency is introduced as an ideal for the rehabilitation system and public insight enters a part of the public sector which has until now been subject to professional control and sheltered for lay scrutiny. This challenges the professional status because once service users are to define problems and take part in finding solutions their viewpoints tend to point to solutions that go beyond the established health care service, in particular the specialized service. User involvement commonly instigates a rehabilitation process that includes other everyday life arenas such as education, work, and family and community life. In the process, an understanding of the professional intervention as the *real* treatment is challenged by a perspective in which aspects of rehabilitation which today is seen as framing, subjective hearing as situated in an everyday life context, gets to become a part

of the treatment. Simultaneously audiological treatment is made into one out of several elements in an extended process where efforts from other parts of the welfare system, the users themselves, and their next of kin contribute to rehabilitation. The holistic model, thus, decreases and limits the professional knowledge in such a way that it now only represents *one* out of several sources to knowledge when user needs and aspirations are to be identified. This challenges the exclusive position of audiologists in defining problems, and makes it hard to maintain the dominance of professional knowledge in rehabilitation services.[81] Expert knowledge is no longer considered esoteric and exclusive, it has become transparent, accessible and open for scrutiny. The professionals are no longer in a position to legitimately speak on behalf of hard of hearing people.

Perhaps it should come as no surprise then, that the new user-centred policy has been met with charges of being un-scientific, anecdotal and subjective, a critique, based on the construction of a gap between the professional knowledge and the everyday experiences of the service users. When critical users mobilize alternative modes of ordering their disability to confront professional experts the system reacts with rejection because alternatives threaten the stability and inner order of the audiological order, depriving it of its exclusivity. The irony is that user involvement does not have to mean a reduced faith in medicine and audiological technology and its abilities to bring about solutions to hearing problems. As in the case of Reidar, the importance of expertise is not challenged. If anything, it is the lack of access to professional knowledge that causes Reidar's disbelief. He is keen to learn more about technical aids and audiological procedures. What he contests is the exclusive position of professional expertise in interpreting problems and defining solutions. Because, as Alm Andreassen also points out, to believe that professionals can provide solutions is not the same as to say that any solution proposed by a professional will solve the problem. When user involvement is introduced as an ideal for audiological practices, professional authority is confronted with the experiences of the service users themselves. Reidar seeks access to expertise, but he wants professional assessment and treatment that is contextualized and applied according to his individual case. That is, 'he wants the specialist to involve himself in his situation'. He seeks information and advice that is relevant to his life style and a plan to help *him* take control over his own life.

But if not always and necessarily a threat to professional knowledge, why is it so difficult to realize the user-centred policy in aural rehabilitation practices?[82] Alm Andreassen locates the problem with realizing user-centred policies in the ambiguity of the policy making. While policy makers have been eager to discuss the content of expertise, they have been more reluctant to challenge the dominant position of the expert in recognizing social context as important for

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[81] The argument is also made by Mol and Berg (1999) who have noted that the powerful position of medicine rests upon its ability to project an image of internal unity and stabilization outwards, and to enact as a provider of clear-cut definitions (categorization and diagnosing of impairment) and working (technical) solutions.
[82] Falkenberg (2007) documents the problems of realizing the holistic model in practice.

rehabilitation. Reidar's story is illustrative. In order for subjective hearing to become an issue of user-professional interaction, it must be invited as a topic. The technical audiologist can recognize and address psychosocial issues by asking Reidar questions about his lifestyle, but instead he is told; 'that is not something we do here...'. Thus, as long as professionals are in the position to define what is important and relevant in the consultation, all issues that they interpret as being outside their area of expertise, are silenced and left untreated. Provided that the professional route remains the obligatory point of passage towards aural rehabilitation it remains a professional privilege to conceptualize hearing problems and formulate solution. As long as the medical ordering mode continues to dominate rehabilitation practices, problems that cannot be defined in biomedical terms are not recognized as a hearing problem; they are not 'real' diseases or loss. Thus, while policy opens for an alternative understanding of rehabilitation, the audiological professionals are still in the position where they can choose whether to accept or reject the holistic treatment model and the empowered position the service user holds in it.

In Reidar's story, the problems with realizing the user-cantered policy are not merely about the interpretive privilege of the professionals. Reidar is also concerned with the way barriers to user involvement are enacted in material forms. In his story, the asymmetrical geography of responsibility between service user and professionals is entangled with materials and routines at work, elements that also are involved in the distribution and deprivation of agency during the audiological encounter. The holistic rehabilitation model becomes real when hard of hearing people are enacted as having subjective hearing and involved in the set up of treatment programs. Instead, Reidar is not being informed on the process. The technology at work leaves him out of the interactional loop. The specialist only has 15 minutes for consultation. And he is not given further information about additional services or support groups that could help him to cope as hard of hearing in his everyday life. Without sociomaterial conditions being in place, there are no conditions for the holistic service user to emerge. Thus, while the empowered service user is introduced in policy, in practice Reidar is still positioned as the passive receiver of a technical fix.

Herein lies the ambiguity of today's welfare policy, a policy that seeks both to reduce and is dependent on professional expertise. While the holistic rehabilitation model aims to limit the power of professionals, experts are still delegated the task of certifying user needs. As gatekeepers to societal resources they are in a position to decide on the legitimacy of individual needs in relation to welfare political objectives. These are aspects relating to the tasks policy distribute expertise, and not about the content of expertise based knowledge. While the content has been an issue for discussion, the professional position is an issue that policy makers and user organisations have hesitated to discuss. In this situation, audiological professionals incapable of meeting demands for user involvement work to reproduce paternalistic practices, counter-productive to goals of empowerment and rehabilitation. The same goes for the technologies at work and the bureaucratic procedures; they too take part in the disempowerment of service users. The lack of interactive artefacts and transparent routines limits the professionals' ability to

involve service users in treatment programs. Rather than being exposed to critical scrutiny, material elements tend to be de-politicized in professional literature and policy documents, thus, enacting an invisible and incontestable barrier to empowerment.

Reidar, entering the rehabilitation system, does not merely want a hearing aid, a technical fix. He looks for other, more cantered forms of control. He talks about the need to reconstruct himself. For him, subjectivity is at stake. But the specialists are unwilling to recognize subjective hearing as an element of professional practice, and the audiological encounter becomes a site for the struggle over identity. Positioned between policy and practice Reidar faces a subjective dilemma. With reference to the shift in disability policy, he is entitled to holistic treatment. Yet rehabilitation clinics, audiological specialists, and technical aids enacting the medical order remain the obligatory point of passage for rehabilitation with hearing aids. His access to a hearing aid depends on his ability to enact and belong to this medical order. So what does Reidar do? He cannot ascribe to the patient position and refuses to align with the medical geography of responsibility. Unable to inform himself on the purpose of the next consultation, he decides not to go back to the rehabilitation centre. He withdraws from the rehabilitation program. He is determined to continue to use his hearing aid, but engages sites and situations beyond the audiological encounter to regain agency and become an informed and active user of hearing aids. I return to the empirical material to investigate how this is done. This part of Reidar's story I have called the reconstruction phase, a process in which he revives the positions as a capable user of technology.

LEARNING TO COPE AND ENACTING RESISTANCE

Reidar: "I guess I've been too passive... But I really thought that I would get the help that I needed, that it was an existing service. Maybe that was the wrong attitude, but it also had something to do with my life situation. It's been hard on a personal level. With a hearing loss it's hard just to make it through the day. At the rehabilitation centre there was no talk of a coping plan, so I have had to teach myself some tricks. Like in social settings, I make sure to position myself so that the good ear is turned towards the speaker. Things like that I've learnt, but it has taken time and it's been tough. It has changed my life in a way. I guess it's all right. My problems are not *that* big... But it would have helped if I could have discussed this with the audiologist, not only the technical things, the audiogram, but also how to take care of the social aspect, what my limitations were and how to cope with my life again. Looking back I wish the process had not been so demanding. If I'd gotten this information from the start of, I wouldn't have had to use years of my life to figure it out on my own, with all the frustrations that came along. Getting the foundation back in place as fast as possible - how cope in everyday life - that's just so important. From there you can start to redefine yourself."

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The 2002 Action plan promises an empowering audiological encounter by involving service users in the rehabilitation process. But while disability policy explicitly prioritize user involvement in changing conceptions of rehabilitation, this notion of empowerment becomes much harder to locate once the rhetoric is problematized. Reidar, the 'empowered' service user encounters problems when attempting to exercise power, becoming almost immediately deprived of agency on matters of treatment and technology. When he attempts to introduce elements of subjective hearing and holistic treatment, his move is subject to mechanisms of social control, his subjectivity and agency is actively ignored. As the obligatory point of passage towards rehabilitation with hearing aids, hard of hearing people continue to be routed through a support system in which hearing disability is ordered as a somatic condition for which there can be prescribed a technical fix.

But Reidar also talks about the process in which he starts to rebuild, for him, a more positive identity as hard of hearing. Describing how he deals with his hearing loss, he takes a position on his disability that identifies him as learning and coping, in control and making decisions. For him, the route towards empowerment – regaining the position as capable and coping on matters of technology – bypasses the aural rehabilitation system and goes through his access to another subject position, his professional status. Mobilizing his engineering background, technology too resurfaces and is rehabilitated. Reidar speaks enthusiastically about 'the digital revolution' and sees user involvement as the crucial ingredient of progress.

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Reidar: "Now as the digital technology enters its adolescent and new
possibilities open up it's crucial that we don't let producers alone
control the development. Users should get to participate in the
definition of needs. As engineers we were always told that it
doesn't matter if we create the most amazing programs and systems.
As long as they're not what clients specify they won't be used.
That's why it's important to have a dialogue with users and let them
define working solutions. The role of the experts is to present
possibilities. Standards are also important so that we do not end up
in a situation where the producers all make their own, incompatible
things. Just think about MS DOS. Open standards allowed programmers
to link up and contribute to the development of ICT. With open
source people from all over the world with ideas about how to solve
things could collaborate because they shared a language, the same
codes. The same principal goes for the hearing aid industry. The
expert regime that I met with should be something of the past. It is
hopelessly outdated when hearing aid users are not allowed to
participate and contribute to the solutions." Researcher: "Are there
possibilities for such interventions in the device you have now?"
Reidar: "No, no. It's a closed device. All I can do is to adjust the
volume and change between programs. You need software to program the
hearing aid. I miss that possibility, being able to adjust the aid
myself. I have the technical training. I wouldn't have had problems
running the program."
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When Reidar goes to the rehabilitation centre to get a hearing aid he has faith in the audiological expertise as problem solvers; 'that he would get the help he needed'. Following the negative experience at the specialist centre, he starts to construe a counterargument to the medical ordering enacted by the professionals. Talking about digitization, open standards, and user driven innovation processes he mobilizes a different mode of ordering technology to make available an alternative to the patient role he was positioned in at the rehabilitation centre. Rhetorically, he uses the case of the software industry to demonstrate how the medical mode, with its asymmetrical patient-expert relationship, is outdated; something that we need to move away from. As an analogy for a more user-centred mode of ordering rehabilitation Reidar talks about MS DOS and the open source community. In this alternative mode materials and organization – codes and standard interfaces – enable dialogue and blur the border between users and producers. Similarly, referring to his own engineering training, he enacts an alternative geography of responsibility between service user and expert, a relationship in which the task of the expert is to present options, while the service user makes decisions based on their subjective needs and aspirations. Criticizing the dependence on professionals inherent to current patterns of hearing aid usage, Reidar talks about local access and devices open for user intervention and control. As reference points to existing alternative modes of ordering technology, these differentiations work to open up and challenge audiological practice by demonstrating possibilities for change.

What I suggest is that Reidar's story is an attempt not only for him to regain agency on matters of technology, entangled with this it is also an attempt to rehabilitate technology. If technical aids go from being fixed, expert driven solutions, to becoming flexible, user driven projects, Reidar, as competent on technological matters, gains access to a new position in the audiological encounter, an active participant in the design, distribution and use of technical aids. Mobilizing an alternative mode of ordering technology and disability, Reidar puts his negative experiences from the rehabilitation centre in perspective and proposes an alternative. The differentiation makes room for resistance, a form of action that Reidar uses to regain agency - as having, and exercising choice. Identifying as an engineer he makes available a different position on technology, as a decision-maker, able to analyze his individual experiences in a broader sociopolitical framework. Mobilizing his professional background, Reidar can speak with authority, his arguments should count. He can take the position as the expert; he can make strategic recommendations, he can teach others something. But this agency is not experienced in the context of the audiological encounter. To differentiate the patient role to his 'real' and positive identity Reidar looks to sites and situations beyond the audiological encounter. Key to this process is the construction of 'others'.

Reidar: "To use assistive devices makes my disability visible. It's not always easy. It's like I'm walking around reflecting my functionality. It's been a process. But I've concluded that if I, who am strong, can't do it, then who can. So I decided to go ahead as a good example. If there is someone that thinks that it looks bad, thinks that I am stupid, or less worth because I use a hearing aid, well then there's nothing to do about it. You see I use technical aids to make my life easier, but, at the same time, it's not easy. I do understand that some people want to hide it. I guess it's because... how should I put this... I guess it's something about not being a complete human being. If you wear hearing aids people might think that there are other things wrong with you as well.

I can imagine if I was young today and, say I was on a date. Then it wouldn't have been so easy. In a setting like that, where first impressions are so important it must be difficult. However, I'm a mature, married man. I can be more laidback. I don't care if some people think I' less of a human because of my hearing. Then it's their problem, not mine. If there really are people *that* narrow minded then I want nothing to do with them… I guess you can say that I've taken a defence position; I build my own prejudices on those of others'. Then again, I think it's important to play a part in diminishing stigma surrounding hearing disability. So I tell students about my hearing loss. In the beginning I gave a long explanation. I told them about the accident. I guess it was a kind of defence mechanism. I wanted to say that there was nothing wrong with *me*; I had just been unfortunate to fall. Now I don't. I just say that I have a hearing loss. I don't try to explain why. I guess it is all part of a maturing process. Then what I do is that I step forward as a role model for colleagues and students that are, or will be disabled at some point. I try to use the hearing loss in my teaching. I make small lectures in physics, mechanics and mathematics where I talk about frequencies and how hearing changes with age. I try to explain how important it is to take care of your ears."

Reidar sustained his hearing loss as an adult. As an adult he has moved within and between many social networks with distinct ordering modes and different processes of identification. Positioning himself a family man, engineer and teacher, Reidar has built a strong identity as a decision-maker, a role model, a problem-solver. So far the agency acquired through these subject positions have been more or less overflowing, seemingly evident. For someone who has identified strongly as a competent user of technology the meeting with the rehabilitation system is a turning point, a fragile moment when it becomes clear that his identity is not essential or self-evident, but an object of negotiation in which limitations to overflow are decided by the relationality between ordering modes. In Reidar's story, the different geographies of responsibility between medicine and holism

appear irreconcilable. A modal clash results when Reidar, a resourceful and competent service user, is positioned passively and deprived of agency in the audiological encounter. Reidar, who cannot identify with the patient position, speaks from other subject positions to escape the detrimental patient position and stabilize a new meaning for, and about himself following the hearing loss. Given his multiple subject positions he *can* take a strategic position in the meeting with what he experiences as a harmful ordering. From the position as an engineer, family man, and teacher he can relate differently to hearing disability and distance himself from the medical ordering enacted by the audiological specialists. By positioning in and against ordering modes, he opens a critical space to oppose negative subject positions through a process of differentiation. This dynamic attribution of agency to the subject opens the possibility for critical thinking and enables Reidar to regain some social status on disability as well as on technological matters. By simultaneously referring to himself as similar and different to others Reidar negotiates and clarifies his own positions. First, with reference to hard of hearing as a social group, Reidar shares a disability with these, but he is also different from them. There are 'other' disabled people that do not come forward with their disability. Reidar does, in his story that sets him out as a role model. Secondly, Reidar also positions himself against the general public, where the 'others' comes to mean 'people with prejudices'. He does not care about ignorance and narrow-mindedness; such does not deserve his attention. It is an attitude he seeks to embed in practice, like in relation to his teaching where he positions himself as someone who uses his experience of disability and his personal strength for the common good.

But there are also limits to Reidar's positional strategy. While he might try to use his multiple self to regain agency on disability and technology outside the audiological encounter, currently in Norway, there is no alternative route towards rehabilitation with hearing aids. As he points out himself, hearing aids are closed devices and fitting software is under professional control. Thus, while Reidar may reject the professional system as an obligatory point of passage, to continue using a hearing aid he is forced to take a position in the medical order when his hearing aid needs adjustment or renewal. Rather than empowering him, he is made dependent on an ordering he objects. Without an alternative route towards rehabilitation with hearing aids, his agency is delimited.

CONCLUDING REMARKS

As the user-centred policy is sought implemented among professionals and service users, policy ideals are to be transformed into concrete practices and confront established modes of ordering hearing disability, hearing aids, and hard of hearing subjects. According to policy plans, professional knowledge is to meet with the experiences of the service users and reposition expertise. As a critical case Reidar's story highlights some of the challenges involved with

realizing the holistic model for aural rehabilitation. In his story, the user-centred policies fail to translate into new organizational routines, consultations procedures and technological innovations. Through the audiological encounter hard of hearing people meet with clinical sites, audiological specialists, and technical aids that enact hearing disability as a somatic condition that can be normalized with hearing aids. The medical order persists to dominate audiological practice.

Drawing on a poststructuralist conceptualization of identity and combining it with a material semiotic interest in agency as a derivate of sociomaterial relations I have criticized this medical ordering for its absolute approach to categorization, diagnosis and treatment. I argued that this practice may lead to arbitrary exclusion. I analyzed the exclusion of Reidar throughout the audiological encounter as of a systemic, technological and social kind; obscure routines, closed technological script, and objectification through standard assessment procedures and technical solutions. Based on this, I argue that dominant audiological practice artificially divides identities into exclusive and excluded cases and, thus, cannot reflect the complexity of a hearing loss, or the heterogeneity of the user group. The concept of subject positions illustrated that it is important in this context to view each identity not as a total, fully formed position, but as de-stabilized by its multiplicity. This approach could avoid the exclusion inherent in unitary identities and invites the possibility of negotiating between subject positions, a framework that allows for the acknowledgement of different (idiosyncratic) user roles. Following the analysis, it is my assertion that existing practice does not utilize the existing (limited) resources that exist among hard of hearing people. Reidar's competencies on technology and his will to participate actively in the rehabilitation process is being denied when the consultation is strictly framed around impairment and other relevant positions he holds in the multiple sociomaterial relations which he is part of are not utilized.

The user-centred policy has in some ways opened up and seemingly democratized the service user's experience of rehabilitation. The medical order, its subject and objects and its distribution of agency is no longer exclusive when people enter the rehabilitation system identifying as hard of hearing. By introducing user involvement through policy, hard of hearing people can legitimately claim to be recognized as multiple selves with a subjective hearing. Through this enactment of difference the bads of the medical order are made visible and can be challenged. Holism deprives medicine of its exclusive position, decreases the social status of the expert, and reveals the ineffectiveness of the technical fix. A holistic approach to aural rehabilitation challenges the dominant medical order because it is an understanding of rehabilitation as the service user's process and effort more than the systems and the professionals. Holism inspires one to look to situations beyond the audiological encounter for resources with which to cope with a hearing loss. In this critical space, service users, such as Reidar, *can* engage in reflexive processes that allow them to distance themselves from unwanted subject positions. Access to, and mobilization of alternate ordering modes *can* open for new perspectives and aspirational

identities. In this critical space, the hearing aid user *can* become an agent, possibly activating oneself i.e. at home, on line and through work. Whether, and how, critical spaces are mobilized and come to matter for the individual is dependent on their access to subject positions outside the audiological encounter. However, if the aim of rehabilitation is social redistribution, then this is problematic. Then the Norwegian rehabilitation system is indeed a system which benefits the resourceful and persistent service users, those able to mobilize and re-emerge as agents. The irony is that such empowerment does not occur as a result of service users' ability to access the rehabilitation system and its medical ordering, but rather on their possibility of escaping it.

THE ELECTIVE CONSUMER

In the following, I develop a critical analysis of the process in which hard of hearing people shift from patients in an aural rehabilitation system to consumers in the hearing aid market. In the analysis, I focus on the activation of the 'elective consumer'. With a critical eye to the notion of choice I seek to problematize the empowerment of consumers as predicated within the context of the newly de-regulated distributional system for hearing aids in the Netherlands. Rather than an abrupt discursive shift, the analysis illuminates an emerging practice in which consumer issues and a medical model on disability intertwine to produce new and powerful ways of ordering hearing disability.

To investigate the ongoing discursive shift I introduce 'Bart Winstra' (51). Bart was born hard of hearing and has always used hearing aids. He is experienced with other hearing technologies too, alarm systems and solo equipment. Focusing on his active approach to technology, I have followed Bart as he makes the leap into the new consumer position. Together we visit 'Oorakel', a consultative service for deaf and hard of hearing people.[83] Oorakel seeks to become an obligatory point of passage in the new consumer-oriented health care system. In alignment with the focus on rational choice, they present themselves as a site where the user can become an informed and active consumer. In the analysis I present material from the interview with Bart. I also introduce material I have gathered from the people and places which Bart identified as important for his relation to technology, his identity as hard of hearing. This material includes an interview with the Director of the Dutch organisation for hard of hearing people (NVVS), interviews with Oorakel representatives, and field notes from the meeting Bart and I had at Oorakel.

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[83] Oorakel has a website (in Dutch) with extensive information about the Dutch aural rehabilitation field. The site can be accessed at: http://www.oorakel.nl/

I meet Bart through the Dutch user organisation. He lives in Haarlem where he has bought a large, old house. He was lucky, he says, bought it when the prices were still low and had his brother who could help him with the renovation. Nowadays, Bart is unemployed. He used to work as a librarian at the University of Utrecht, but during major cut downs, he was among the first who had to go. It is like that, Bart says, disabled people are vulnerable in the job market.

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Bart: "In Holland, there are now about 500,000 unemployed. It's
difficult for people to get a job, especially for people with a
handicap. You are put into what we call 'Sociale Weerkplaatzen',
where you can earn your welfare, not an income. That is a pity,
because people have to work under their level, they have studied a
lot and then they get a very simple job with no career
perspectives."
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Bart wants a job where he can use his degree in Informatics, but it is hard to find something new. He tells me he must have sent about 100 application letters, without a positive result. Meanwhile, he works as a volunteer for NVVS. While he finds it meaningful, it does not provide him with an income. So now he is on welfare, and he has taken in a tenant, a student. He needs the money, because he worries that he will not be able to pay his mortgage and lose the house.

The first time I meet Bart is in April 2005 at the train station in Utrecht. From there we travel, a lot. Bart takes me around. He introduces me to people and posts information about my project on web forums to help me recruit informants. He sends me information material and he makes sure I understand the Dutch rehabilitation system. He has grown up in it, and he takes pride in knowing it inside out. Now he talks about the changes that are on their way. In 2005, when we first meet, the Dutch were deliberating a new marked-oriented health care policy reform. In January 2006 the new health care insurance act was introduced. As the government attempts to de-medicalize the distribution of hearing aids Bart, as the majority of the hard of hearing population, is no longer a patient in the rehabilitation system. He becomes a consumer in the health care market.

The consumer position differs from that of the patients 'involuntary' admission. In the emergent consumer discourse, as seen against the medical ordering of disability, the

consumer is rational, where the patient was irrational the active consumer clashes with the passive patient. The informed and empowered consumer towers over the docile patient. It is as if the sociological deficiencies in the medical model of disability have informed the construction of the health care consumer. This then begs the question of what function this consumer rhetoric fulfils.

IDENTIFYING THE LEAD USER

> Researcher: "What does it mean to be hard of hearing?" Bart: "It depends on a lot of things, like what you want to do with your life, what kind of job you want. Also there is a difference between people who have been hard of hearing their whole life, and those who get it later. While I identify as disabled, people who get it late in life, they often think of themselves as patients, and they look for a cure, not an identity. But, the most important thing is your hearing loss, and how you cope with it. Like me, I hear people say; 'you are very hard of hearing'. Then I ask what do you mean? Ok, I have a 70 Db loss, but now as we are sitting here I can hear nearly everything."

> Bart: "A hearing loss is not like a mobility disability. As hard of hearing you can still move around, you do not need to communicate to do that. Actually, that is the real problem, that people can do things without communicating. People cut off their contacts, and we all need contact as human beings! If you can't see you can have contacts, you still can communicate with people, but if you can't hear, you cannot directly communicate with people. It's easier to avoid the problem by cutting off your contacts, but then you become isolated. You see it as a personal problem and since it is possible to live without dealing with the problem, people develop shameful feelings. We have a lady who is a board member of our local club in Haarlem. I visited her one day, and I asked whether she had a loop system installed in her house, then she told me she didn't have anything, no alarms no loop system, nothing because she doesn't think it looks good. And she is in our board! She should be acting as an example. It's a shame, but it just shows how difficult it is. There is still much prejudice around. I think that many people think of hard of hearing as we are hearing; …if they just tried a little harder..."

Bart does not have much hearing left. Even with top notch hearing aids he has problems hearing. For Bart his hearing disability *is* his identity. He was born hard of hearing and for him that means something compared to sustaining a hearing loss late in life. Bart has always related to his hearing loss, he has built his life accepting it to be a part of him. In this way, Bart's story is different from others in this book that became hard of hearing late in life. Their stories are about the process of becoming hard of hearing, of shifting from one ordering mode to another, from 'normal' hearing into hearing disability. That does not

mean that Bart's experience of hearing disability is stable. In the context of the new health care policy reform, meaning and practices surrounding hearing disability are changing, which call for Bart to change too.

Bart tells me how his hearing loss differs from a mobility or vision disability and he identifies the difficulties with communicating as the most pressing problems you face as hard of hearing. For him it is important to take action to avoid social isolation. For Bart the solution lies in the aural rehabilitation system; the professional routing and the support offered by the user organisation. These are important contexts where Bart takes responsibility for his hearing loss, and his life. As a child he went to a special education school, he has always worn hearing aids and he is an active member of NVVS. The hard of hearing community is where he has most of his friends. His social life is built up around activities in the user organisation.

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Bart: "In the Netherlands we used to only have a young group which
is for people up to 30 years old, and we have the group for elderly.
After 30 years people leave the organization, and only a few fools
like me joined the elderly organization. But, about ten years ago,
we started a group for the middle age people. We do social things
together, last time we went parachuting. Well I didn't, I watch some
other members do it from a safe distance! We don't meet often, and
there are not that many members. It is mostly single people like me
who go there. I like it because I meet friends. For example, on the
16th of April, we have a walk near den Haag for nine kilometres. I
know how that works, it's only nine kilometres, but walking for a
few hundred meters, talking walking on for a few hundred meters,
stop to talk again, so we are busy the whole afternoon. And
afterwards we go to eat and drink together. It is nothing big, but
nice."
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The user organisation is a context for positive self-identification. While a Sunday walk might appear trivial, for Bart it offers a chance to be hard of hearing among people who understand and respect him. In a society in which social stigma is still prevalent these meetings give room for an alternative and positive experience of disability. Organizing extreme sports people get the chance to do something unachievable for most. In the organization hard of hearing people develop a feeling of coping and a shared sense of community. The NVVS is also an important carrier of ordering modes. It is a place where the members can come to know their hearing disability and learn how to do deal with it. In the wake of the policy shift towards consumption, competition, and choice, Joop Beleen, Director of NVVS, talks about their efforts to transform into a consumer organization.

Beleen: "For the years ahead our focus is on becoming a consumer organization. We want to highlight the individual rights of our members. There is not much awareness on these issues and with the new insurance system we really need to watch the development carefully while also ensuring that our members are equipped to meet the new system. We need to make sure that they know about the alternatives and their rights. Just take a fundamental thing as the right to try out different hearing aids; most people are not even aware there is more than one brand. The shops may have agreements with different producers and they only recommend this brand to the customer, despite the fact that it might not be the best choice for that person."

Here the NVVS Director substantiates the current market-oriented policy, and talks about how the organization for hard of hearing people adapts its strategies accordingly by becoming a consumer organisation. For Bart the organization is an important arena for the enactment of his hearing loss. He identifies with the new consumer discourse and the strategy of NVVS.

Bart: "Now, as people have to pay more for their hearing aids, they are also more concerned about price. The shops follow, and that creates a kind of class divide. The big group is those who become hard of hearing around the age of 65. They don't know what happens. They just need something to improve hearing. They are simply glad that they get a hearing aid. Like my mother when she was going for her first hearing aid. She had seen that TV commercial with Carry Tefsen.84 In the commercial she goes to the store and asks to try the new super small hearing aid. And then as she walks out of the store we hear a voice saying: 'Don't forget to give the hearing aids back'. Like they are so small you forget you have them on… In my opinion this commercial only reinforces stigma, saying that a hearing aid is something you must hide. My mum, she sees that advertisement, and when she went to the shop, she too was preoccupied with the looks; she chose one of those in the air devices. The man at the shop then gave her a choice, 'you can get this hearing aid for 500 Euros or that hearing aid for 700 Euros, which one do you prefer…' My mum lives on her pension, so of course she wanted the cheapest option. She didn't know that the one for 700 Euros was better because it had a T-switch. No one in the shop told her. Now she cannot use a loop system in her house. The new users just don't have the knowledge of what the shops can offer.

The hearing aids I have now were about 3000 Euros, they are digital. Not everybody can afford that when the most that you get from the insurance is 900 Euros, but I needed them for my work. Without hearing aids I don't understand anything. Since I'm active in the organization I know what I can get. I was born hard of hearing, I

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84 Dutch actress and singer.

Both for the NVVS director and for Bart, *knowledge* of hearing disability, the aural rehabilitation system and the proposed solutions are a pre-requisite for health care consumption. Additionally, the ability to *act* upon this knowledge is a necessary pre-requisite for health care consumption. Implicit in the consumer ordering of hearing disability is an informed and active service user, a rational agent who can make decisions in his/her own best interest in relation to the services they receive. For Bart, that is empowerment. The solution to Bart's communication problem is hearing aids. To act means to enter the market for hearing aids, this requires competence on the relationship between quality and price. Being knowledgeable on what the market can offer and demanding it for a reasonable price, that is what counts. For Bart to deal effectively with his hearing loss within this ordering mode, to be a 'rational' hard of hearing individual, means acting as an informed and critical consumer.

To develop a new norm for good or rational user behaviour, also means constructing a divide between those that live up to the norm and those who fall outside it. Above, Bart distinguished the experience of hearing disability from that of other disability types. Now he explains how experiences of disability differ also within the hard of hearing community. An important difference relates to when in your life you sustained your hearing loss. Here Bart constitutes two groups of hard of hearing. First, there is the group who has been hard of hearing their whole life and can draw from experience to take an active approach to their disability. Then, there are those who sustain their hearing loss late in life and either are ashamed about their disability or lack technological insight. In comparison to a fellow club member with shameful feelings or to his inexperienced mother, Bart can take the position as a highly competent hearing aid consumer. By describing what his mother is, he establishes what he himself is not. His mother comes to stand for the ignorant user who cannot optimize from technology because of her lack of knowledge and experience. Bart, on the other hand, knows the system and the products and he can take an active approach when buying hearing aids. In the case of his mother, technology enacts her as a victim of her own ignorance in the meeting with a profit seeking dispenser. In the case of Bart, technology enacts him as a lead user who uses his experience to negotiate good service. Bart's ability to get and use technology is an important element of his positional strategy and sets him out as different from the majority of hard of hearing.

In Bart's case, this differentiation is possible because in the new system there has been a shift in expertise. Rehabilitation with hearing aids is no longer merely a medical issue, following the de-regulation it is primarily a consumer issue enacted between cost-responsible consumers and competing dispensers. Becoming a rational consumer depends not only on the consultation and getting a hearing aid. To live up to the norm demands a process of self-learning in which users have to learn to trust in their own abilities to make the right choice among competing products and services. This part of the work required to operate the new technology illustrates how hearing technologies shift responsibilities and agencies to the users. The consumers have to cope with a hearing loss and its social consequences for coping with work and family life, while at the same time master the new technology. As the control with an audiological expert is lifted, there is no professional system in place to assess the quality of aural rehabilitation according to 'objective' audiological standards. Instead, hard of hearing people have to safeguard their own interest in the meeting with dispensers.

As Bart articulates, users need confidence and competence in order to look past the commercial message. He is concerned that hard of hearing people will choose hearing aids based on cosmetic aspects or price, rather than technical qualities. The new ordering of hearing aid distribution gives rise to a potential social antagonism, a class divide. On the one side, there are those uninformed or ignorant about their needs and rights. On the other side are people who benefit from experiences, know where to get information and use it. The differential system Bart mobilizes is not innocent. By differentiating his position in the consumer order to that of inexperienced users, as his mother, he becomes the rational consumer, a position from where his social status increases in comparison to that of the negative others.

To gather information and become a rational consumer Bart takes use of the surrounding support system, user organizations and professional agencies. But how does a system in which Bart traditionally has been constituted as the passive and needy patient meet his attempt to position as a rational and active consumer? What are the consequences of the shift in terms of the geography of responsibility for the support system? To explore this I make a contextual shift. I introduce empirical material from a visit Bart and I made to Oorakel.[85] Bart comes here, not merely to get practical information, but also because the active search for information enacts him as a lead user, a competent carrier of the consumer order.

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[85] The name Oorakel has a double metaphorical meaning. First, the extra 'o' in Oorakel makes up the Dutch word for ear 'oor'. Second, the reference to Greek mythology and the Oracle of Delphi, reflects the ambition of Oorakel to be an all encompassing consultative service for the hard of hearing.

The current health care policy is geared towards ensuring that the entire chain, from the need for devices to their distribution and use, operates efficiently and affordably. In order to achieve this, it is considered important that; 'clients have enough choice in the device market, the level of regulation is reduced and existing problems are removed' (VWS 2004:3). The focus is on supporting clients in making their own choices and in subsequently expressing and realizing these choices. Pivotal to the ability to make rational choice, is the need for 'objective' and 'reliable' information. The Ministry has committed to make such information available by supporting actors and systems that; 'gives specific information at every turn to enable readers to arrive at rational choices' (VWS 2004:5). Oorakel is one such actor, working to disseminate information about hearing disability. They promote use of hearing technology and are concerned with the lack of technical knowledge among their clients. Here, the Oorakel chief director, Gert Stolk, illustrates the worry with a story of a client:

Stolk: "She didn't feel that she needed an alarm system until one day she saw a fire brigade outside her house. It turned out she was the only habitant left inside the building because she hadn't heard the fire alarm. Only then did she come here. In my opinion she should have come ten years ago! Now as ICTs are becoming more and more important in our society why should the hearing impaired be, or let themselves become, excluded when there are all these devices to help them!

In general, we see that most people wait too long before they take action on their hearing loss, meanwhile their impairment increases. People often downplay their problems instead of doing something about it immediately. Now, there are changes on the way. Before people had to go through the specialist to have their hearing checked, now everyone can just drop by one of the shops. With the commercial market developing we have a better chance of reaching new users at an earlier stage.

Before, the shops could not charge the customer for service so they were also reluctant to offer any, but people did not really care, because it was all paid for by the insurance so they bought things anyway. With the new insurance system there is a limited coverage for the hearing aids and people have to pay for service. Now they need a good reason for buying something. That means that the shops have to become better to attract customers. I think this will improve services.

One of the problems with assistive devices today is that there is no real competition. Therefore it's important for us to be there to push the market. Take modified telephones, there are plenty of models, but most users are not aware of these choices, they come here and they do not even know there exists something like a modified phone, how can they be critical consumers? In the shop they'll meet a sales agent who has an agreement with a producer and

Oorakel was originally established with funds from a catholic charity group that also runs schools for Deaf children. Their mission was to serve parents who needed information on assistive technologies. You cannot buy things at the Oorakel, but they show the different equipment, except for hearing aids which is the domain of the dispensers. In addition to the showroom, they disseminate general information on hearing disability and assist clients with application procedures within the health insurance system. Today the affiliation with the Deaf schools is weaker and Oorakel struggles with funding. In light of the turn towards consumer, they are now trying to re-define their rationale in order to justify their existence in the new health care system and attract new sponsors. Incorporating the policy shift, the Director promotes the idea that cost sharing, competition and choice can improve the quality of service provisions. But he also evokes the notion of an information gap, a need for objective and reliable information. As a consequence of public cut downs less devices and services are offered through insurance. For what is still covered, the users' own contribution to the cost is getting higher. Many, i.e. people living on their pension alone, cannot afford to experiment; they need sound information on which to put their money, information that Oorakel claims to provide. In the wake of the commercialization of aural rehabilitation, where opportunities and responsibilities are distributed to the private companies, Oorakel claims to be unique. They are among the few organizations in the system that has the resources to operate preventive and informative services. According to the Director, this is work that is scarcely financed by the government, not seen as profitable by private business, and that GPs, pressed for time, do not prioritize. For Oorakel to succeed in filling the information gap and becoming the provider of reliable information means to become an 'obligatory point of passage' in the stream of consumers in the new hearing market.

Stolk: "We're in agreements with the shops that if customers have
questions about assistive devices not offered at the shop the sales
agents send them to us. Our relation with the other actors within
the field, audiologists, GPs, producers, sales agents, and the NVVS
is very important. We depend on creating a flow between the actors.
We need them to tell their clients about us, give them our brochure,
and encourage them to come here."

Instead of serving parents of Deaf and hard of hearing children, Oorakel now serves hearing aid consumers. To provide information is no longer just an end in itself, it has also become a means for increasing competition. But to adapt their rationale according to the new health care policy is not enough. To become an obligatory point of passage they must link up to the flow of consumers. Oorakel depends on a good working relation with dispensers and audiological clinics. They need audiologists and sales people to inform their clients about Oorakel, to do that, dispensers must first trust Oorakel to guide the customers. But what happens with consumer rights when the focus is on creating flow and enabling consumption? Are consumers, like Bart, still encouraged to use their experience and become critical and empowered agents in the market for hearing technology?

AGENCY DELIMITED

Bart is keen to see Oorakel's technical showroom and invites me to come with him. We have scheduled a meeting with an information consultant, 'Rob Verdonk'. When we arrive at the Oorakel office Bart and I have a look around in the showroom. The room is filled with telephones, blue tooth systems and different conference and alarm systems. The equipment is provided by the producers and dealers. The companies consider it an opportunity to market their products. They come to install the equipment and give the staff instructions for use. From there onwards the Oorakel staff is responsible for demonstrations and maintenance. I ask Bart what he has, whether he uses FM equipment. He nods, he has a Smart Link that he got for work, but he does not use it often.[86] He explains that it improves the quality of his communication, but it is so tedious to always remember to charge it and bring it along. Besides he has problems making it work.

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Bart: "It's like they have made it thinking that the only thing I'm
going to do is use the device. The microphone is really neat it has
a multi-directional function so you can capture sounds from the
whole room or just from one person. It works fine with the sound,
but when I'm at a bar, or at a party, I have the beer in one hand
and the microphone in the other, and then what do I do when they
serve the bitterballen..?[87] It only works properly if you use it
exactly the way they want you to. Life isn't like that. You can't
always control the situation. It's very seldom you can actually, so
then I forget about bringing it. Today I should have; it would have
helped me, but..." Rob: "It's not very user friendly all this
equipment. It is not made for people with a normal life. They forget
that hard of hearing people are also biking and walking around in
traffic. The designers live in their own little world and see things
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[86] http://www.phonak.com/consumer/products/fm/smartlink.htm
[87] 'Bitterballen' is a typical Dutch party snack.

> from their narrow perspective. They think that devices can be
> transferred directly from the workshop to real life, of course it
> can't."

Bart points out that his Smart link lacks the robustness to tackle the complexity of his everyday life. Despite technology being an integral part of his positional strategy, there are times when he chooses not to use it. Part of the problem with technical aids is that often the development comes down to designing scripts for particular abstracted disability needs rather than ensuring an engagement in the process of design and implementation with disabled people and all the messy realities they bring with them. With design strategies built on medical models of disability, the charge is that engineers are too much oriented towards the 'technical fix'. They see technical possibilities instead of taking the social context of the users as their starting point. They think what is discovered in the lab can be transferred and applied in a social setting. They ignore the social factors distorting and restraining the effects of technology, and the effort that goes into making it work.

Latour (1986) has observed that what goes on in the laboratory is more than testing of hypothesis and theories; it is artefactual. Nature is carefully shaped to make it susceptible to analysis. Latour's observation has relevance for our understanding of the relations between technology and disabled people. In abstract terms Bart's Smart link may be regarded as an aid to communication, however, it is only when the real world is designed to enable equitable communication for people with hearing aids that the device works as an effective enabler. The Smart link only works with necessary social accommodation; when he remembers cables and charger; when there is no background noise; and as long as no one serves food. Without these adjustments the smart link as a system has different meanings and effects, it inhibits his spontaneity rather than supporting it. For Bart the choice is to make the social world more like a laboratory, or just leave the technology at home.

How, then, can the realities and aspirations of hard of hearing people come to have repercussions on the developments of products and services? Perhaps if one asked hard of hearing people what problems they have in their everyday life and what types of accommodation they want, technical and non-technical, the product design might be different? Such a shift demands that one relinquish the view on of the user as a passive consumer and instead position hard of hearing people as competent agents who can play an active role in the shaping of products and services. In this regard, the consumer ordering is promising; a basic tenet in the new health care policy is the desire to bring the market closer to the consumer and enable more critical exchange. The idea driving de-regulation is that proximity in the market will stimulate a more demand driven technological development. The question thus arises, how receptive is the new market-oriented system

towards constructive feedback from users? As an obligatory point of passage, Oorakel is a potential site for reception, translation and mediation of such feedback. Bart and Rob seem to agree that there is room for improvement. However, they disagree on what to do about it.

Rob: "We try to push the market. When we started up we only had two phones. I told the dispenser that there's a market potential here. Now we have ten. But they all look the same! When the dealers come to install devices we ask them to have a look at their products, whether it's something they would want to have in their home. Like the phones. When people see their huge digits they react of course, they're not blind. They look like a device for a disabled person. Nobody has such phones." Bart: "Yes, and people don't want to be different, they don't want devices that make them look handicapped." Rob: "We ask the dispensers to think more about design. The devices should have the same design and the same functions as other products. Just imagine if hard of hearing people could use their mobile phone as a conversational device. Then they don't have to bring more equipment than anyone else, and they don't have to look any different." Bart: "I would really want my phone to be integrated with my hearing aid, maybe even with my laptop." Rob: "Yes, but the problem is that the market is too small; there's not enough money for product design and no competition among the producers, they don't need to improve." Bart: "Well, there is about 1, 5 million hearing disabled people in the Netherlands. You can't say that the market is too small!" Rob: "But that doesn't mean that there are 1, 5 million who are interested in using technical equipment, and the same particular device. It's more like a Catch 22 situation, no one produces, no one asks for it…" Bart: "Well, they have never asked me what I want. If anything, I'm asked to test readymade devices."

Researcher: "What about Oorakel, do you involve end-users in your work to be able to give relevant advice?" Rob: "It's important for us to be professional, since we're dealing with policy makers and specialists, so we don't. To be honest, I find user involvement problematic. There are some very dedicated users out there, and they can feel offended when we come in and are professional about it. They feel like we enter their domain, because they have organized, they have gotten hold of information, they are calling and arranging meetings and so on, so we have to be a bit careful… I think the NVVS should be more active here, but it's really hard to change the system." Bart: "Users, especially volunteer, are often difficult people. They are subjective, they talk about their experiences, and these are not necessarily valid for the rest of the group, besides they are tempered." Rob: "And we are not just promoting technology like that. When new equipment comes in we measure it to make sure it works. We drop things on the floor and test the battery capacity. We also rely on the feedback from our clients. If 9/10 says the product is good we, decide it is. I have many hearing disabled friends that I talk to and I learn through that. I mean we do give a critical explanation of the devices. We tell the visitors about product functionalities and potential problems if they decide to give it a go. We are honest about flaws and faults. But keep in mind that it

Bart has knowledge of the rehabilitation system and experience with hearing technology. He looks to technology for solutions to his communication problems, but he is also critical. He has experienced that technology is not a fix to his social problems and he has concrete suggestions for improvement. When he articulates his viewpoints in the meeting at Oorakel the response is paradoxical. While the user undeniably is the one with hands on experience, Bart's knowledge is rejected. Actually, it is exactly his experience with use that deprives him from having a say. Both Rob and Bart engage in this process of disablement. In their conversation hard of hearing people are constituted as too 'subjective', 'ignorant', 'poor' and 'unorganized' and effectively denied agency on technological matters. The idea that this particular consumer knowledge from that specific social group may be dismissed as 'uninformed' or 'subjective', only shows a lack of understanding that all people bring knowledge to such encounters. Yet, the dominant assertion seems to be that hearing aid consumers are only capable of being involved in the consumption phase, and not in any wider or more substantial process of technological development and distribution.

Within the consumer order hard of hearing people are to be empowered by choice, however, the choice is limited to a 'yes or no' to an already existing product range. Then who decides what there should be to choose from? While the de-medicalization of hearing products may decrease the threshold level for use that does not determine an appropriate technological development or solve the practical problems involved in making them work. Appropriate solutions and systems still need to be shaped according to the complex and variable needs and aspirations of the users. Bart argues that there might be a market for a different range of hearing technologies, but his opinion is rejected. Rather than being seen as socially shaped, the development of hearing aids is naturalized, with design changes driven almost entirely by technologists and markets. Such ideas conceal the social forces at play influencing the direction of the technological development and design. By drawing a rigid boarder between users and producers technology is assigned to the domain of the expert. Consequently, the potential for sociopolitical intervention that could lead to a more user driven development is limited and the asymmetry of the medical order reproduced. Because at the same time as hard of hearing people are constituted as incapable of providing constructive feedback on technological design, Oorakel positions as a spokesperson speaking on their behalf. When Rob asks friends and clients for opinions their feedback is no longer subjective, it has been translated by the professional and re-

emerges as solid information. Similarly, and contradicting his earlier critical remark about laboratory driven developments, Rob now argues that even trying out devices in their offices gives more reliable results than listening to Bart who uses the equipment in everyday life. On its own, users' assessment of technology is of no value; the reliability of the information is ascribed on its passage through the professional system. User experience must be translated and mediated by professionals before it can serve as valuable information.

In the ongoing mediation between the consumer and the producer, the consumer gets to have little or no say in what 'choices' are possible. When choice is only to be made at the point of consumption, within the frames of existing product range, clients should not have too high expectations to devices and their use. At Oorakel they are; 'honest about the faults and flaws of devices.' Rather than building system critique, their clients' critical feedback is sought translated into more 'realistic' demands. By moderating the expectations of consumers one avoids clashes between what the consumers demand and what the market actually can offer. The problem is that despite the awareness of its lacks, Oorakel, as a spokesperson, does not, in any substantial way, try to challenge or improve the existing system. Oorakel is no longer positioned on the side of the users. Their current identity is that of a double buffer in between the market and consumers. Their main objective is to create flow, avoid friction, and push the market to stimulate more competition. While Rob recognizes the shortcomings of today's hearing technology and claims to give reliable and user-centred advice, he nevertheless continues to promote technology as a solution to the social problems of his clients. Ordering hearing disability as a consumer issue, Rob portrays technology as outside the realm of social constructivism and deems efforts to politicize the technology and the market in vain. I ask him whether there could be alternative, more user driven ways to organize the development and distribution of hearing aids.

> Rob: "Well, to be honest, it sounds all good, but it is not very realistic is it? It's more important to disperse basic information. That's what we're really working with here; informing the people so that they can make the right decisions. I would love to be more critical, but I am split in two. One side is the more political one, which asks the same critical questions as you. The other side works here, dealing with the reality of it. You have to remember we started out from a very practical point of view, today we are quite unique, we run the only place where you can come to compare all the technical stuff and we are really objective, because we do not sell anything."

The conditions of possibility for hard of hearing people's active agency appears highly delimited in the emerging consumer oriented mode of ordering. Oorakel aims to provide

hard of hearing people with objective information that enables them to make rational choice in the market for hearing technologies, this is done by informing alleged 'ignorant' consumers and dispatch them through the system. But Oorakel does more than providing reliable information to an allegedly pre-existing group of ignorant clients. By evoking the image of hard of hearing people as incompetent on matters of technology and in need of basic information they also take part in constructing the client group they claim to serve. This works not only by bringing forward the stories of those ignorant of choice, but also by deleting feedback from critical clients, such as Bart. By reinforcing the image of hard of hearing people as ignorant and incompetent, they may strengthen their own position as an obligatory point of passage. However, by silencing their clients' critical technology assessment they relinquish the opportunity to make available an alternative and more aspirational position for hard of hearing people in the rehabilitation system. Oorakel is not the only actor carrying this negative perception of hard of hearing as a social group. The NVVS Director articulates an equal lack of confidence in his constituency.

Beleen: "There's still a lot of stigma attached to hearing disability. Often users are either very shy about their disability or they are very aggressive, there's nothing in between. I believe issues can only be solved by communication, but that's at the heart of the problem for the hard of hearing, their shyness and aggression stands in the way of solutions. The majority of our members are 60 plus. They have grown up in a generation where you should be thankful if you got something at all. They lack confidence and they are not critical. Most of them are interested in finding a social community; they are not here to be politically active. They look for a place where they can have fun as hard of hearing, an arena where the social activities are accommodated to their needs. Also NVVS is marked by this. We're not very demanding. Instead we're used to being grateful for what we get.

At the political level, NVVS was not so popular just five years back. We were not considered a professional organization. There was no secretariat, all the people worked on a voluntarily basis so it was not easy to take on responsibilities, the whole organization of daily tasks and the priority setting was rather random. Today we have grown, and we have become more professional. We have staff working full time. We seek to become a representative actor in the field, an actor that is accountable and can be included in policy making. We want to be an actor that the industry can talk with, take seriously and listen to. We have grown into an 'adult' partner in the public sphere. Now it's important not to be critical and hostile towards the industry, but instead try to be a cooperative partner, to work on improving instead of just rejecting the products that come out on the market. Of course it's important for us to keep a certain distance as well, to have room for critique and opposition. We seek a balance here, but I think most of our members are simply happy because they hear better with hearing aids."

Here the NVVS director articulates the goods of the consumer order. Hearing products are worth promoting because they help people communicate. Underlying the argument is also the potential de-stigmatizing effect experienced by the actors. Bart, NVVS and the Oorakel staff talk about the discrimination towards disabled people in Dutch society. How hard of hearing people avoid talking about their hearing problems, refrain from using hearing devices, and have problems making demands because they harness shameful feelings to their disability. In the light of this, the consumer order may recast the meaning of technology and open for new identities and relations among the actors in the hearing field. The promise of consumption is its positive effect on the social status of hard of hearing people, both as individuals and as a group. To move the distribution of hearing aids out of the clinics and into the high street is an attempt to de-medicalize hearing disability by turning it into a consumer issue. The shift may support hard of hearing people in moving up the social hierarchy. In the new distributive system they are not constituted as patients, they are consumers. Their hearing loss is no longer a medical defect, but a matter of choosing the right device based on taste for price, design and usability. Compared to the passive recipient of welfare, hard of hearing people become agents who make rationale choices between hearing gadgets, not technical aids.

Also for hard of hearing people as an organized group, the consumer order reorders the room for manoeuvring, opening new possibilities for positioning. Following the policy reform, NVVS has seized the opportunity to shun their reputation as an unprofessional actor and re-emerge as an accountable player in the policy making field. For producers and dispenser, a consumer organization is a potential medium between the demands of the consumers and the offers of the dispensers, thus, an actor well worth listening to. However, the role as a consumer organization also means making priorities and inner division. In order for NVVS to appear as a palatable player among policy makers and industrial actors, they have chosen to de-politicize the grass root level, which creates an internal split within the organization. While members at the local level are organized around social activities, the central level strengthens its professional profile outwards, i.e., by hiring people from outside the constituency, people who are not so 'subjective'. The problem with regard to such professionalization has been pointed out by Houten and Jacobs (2005); prioritising centralization, mainstreaming and growth over critical consciousness and direct action may lead to a gap in viewpoints between organizational leaders and their grass root constituency. But the organizational also offers its goods. For Bart it is indeed important to have the organization as a social arena in which he can enact a positive identity as hard of hearing. A place where he does not have to struggle to be normal, included, accepted, but can be himself among other hard of hearing people. But is this social function necessarily excluding the potential to develop and execute a critical technology policy? Why are these

two orders, the political confrontational and the harmonious socializing enacted as mutually exclusive? In the following I argue, that the reason is that, despite its promise of empowerment, the consumer order has not abandoned, but integrated the medical order.

MEDICINE MEETS MARKET, A PRODUCTIVE ENCOUNTER

The consumer discourse has its origins in policy, particularly policies concerned with the empowerment of service users (McLean 1995). Stemming from the neoliberal debate on deficits of care, the creation of the health care consumer, in a policy context, functions to provide a subsidiary pathway out of care deficits. Rather than mobilizing collective or public resources to solve the health care deficits, the problems are relocated into the market. This occurs when the dominant medical order is sought replaced by market principles with notions of self-determination and successful satisfaction of health needs and aspirations. However, in practice, the emerging consumer position is ambiguous. In policy hard of hearing people are called forth to become informed and critical consumers, yet the system Bart meets is unable to meet his expectations of empowerment. Instead, he is enacted as the passive receiver of an expert driven technical fix. What is the condition for this paradox?

I suggest that the answer lies in the interference between medicine and market. The consumer order does not challenge the notion of a technical fix inherent to the medical order, but looks for ways to profit on it. The actors do not question normalization, its value and the possibility for its improvement. Hearing aids and rehabilitation services are the dominant means instigated to bring about achievement of normalization as a collective social ideal. In the rationale for the market-oriented policy shift medicine, dispenser, audiologist and other professional identities which had been regarded as capable of fulfilling the modern rational objectives of normalization were seen to have failed. Crucially, however, their practices of cure and fix are not challenged - Bart is still encouraged to visit the audiologist and buy a hearing aid to diminish the negative effects of his hearing loss - rather only the way in which they are organised is confronted. Once the health care sector became classified as inefficient and expensive the space opened for the consumer order to emerge and introduce competition and choice to bring about the desired order. But it takes more than discourse and re-organization to create social change. As long as hearing technologies remain the same, designed according to the same normalizing order, and as long as institutionalized relations are reproduced, the medical order is not replaced, it co-exists with the consumer order, reproducing the asymmetries of the past.

Through commercialization of hearing aid distribution, disability is turned into an individual matter that can be managed and dealt with in the market place. Apparently,

rather than challenging or replacing the medical model on disability, thus far, the idea of hard of hearing people consuming a technical fix is incorporated in the emergent consumer order; the market continues to sell the same hope of compensation and cure. As such, it works for the consumer, but only to an extent, with limitations and within professional boundaries that do not adequately allow for the problematization of a sole reliance on medical and technological intervention. In this potent mix of medicine and market, the enactment of service users as passive consumers of solutions and cures is reinforced, and the knowledge that disabled people propose rejected. Technology's role as a problem solver remains undisputed while the activation of the critical consumer and their intervention in technological development is forfeited. Despite opening for competition and choice, actors such as Oorakel and NVVS essentially continue to individualize the issue of hearing disability. What is more they contribute to render hard of hearing people as incompetent on matters of technology, enacting them as a passive and needy consumer who cannot in any substantial way contribute to the inherently political process of technological design and development. At Oorakel the empowered consumer meets the medical ordering of disability, and the class divide Bart earlier positioned within, is reversed. Those seeking basic information do not stand to lose; it is the realities of the experienced users that become misrecognized.

INHIBITING POLITICS

The mix of medicine and market is effective because, in Foucauldian terms, it conducts conduct, it enables people to act as rational consumers, and it is powerful because it is conceived as the only realistic alternative. However, it is also inadequate because it deletes political resistance. The analysis in this chapter indicates that the consumer ordering does not in any meaningful or significant way re-allocate power. Instead, the consumer order passes the onus to service users themselves, to take steps to address their rehabilitation needs and aspirations. The consumer order functions to re-locate the empowerment debate from a resistive political arena back into the non-political, non-resistive market-oriented context. What is more, consumer power only extends as far as the state and the professionals will permit. In practice, the consumer order, and its rhetoric of consumer empowerment, is more reflective of a drive to de-politicize service users.

Grace (1991) has argued that the health care consumer dissolves resistance and centres concern on the market relations rather than political challenges and struggles. The demands of the consumer can only be met by the market, not by political resistance. Whilst the consumer order is constructed upon notions of empowerment, it fundamentally and fatally contradicts itself by failing to engage in any type of political struggle. If talk of empowerment is taken to mean the re-allocation of finite power resources, this process could then be characterized as a political process. However it would appear that the market

oriented health care reform does not necessarily cede power from the professional to the consumer; rather the site of re-allocation is from the professional to the market.[88] In its extreme, it might be argued that this position functions to disempower both the consumer and the professional, and functions only to empower the state and private corporations. The findings in this chapter support that position and highlight the process involved in the turn to commodified provisions rather than politicized utilization. This change impacts directly upon service users who are being offered an empowered choice from a new and improved range of products and services. In this situation, the consumer order and its primary concern with price and competition obviates critique of the medical ordering of disability. Concern with competition between different assistive technologies within the same line of expert driven medico-technical ordering of disability only works to draw attention away from more pluralistic ordering modes in which technology is one, out of several possible interventions. Even more so when the consumer oriented policy is legitimated by state, user organizations and other bodies in the disability field. Adapting to the language of the market, NVVS, Oorakel and other spokespersons for the hard of hearing take part in limiting hard of hearing peoples elective agency. Choice becomes a strictly bounded notion where the range of choice is predetermined to a range of products and services which are being developed on the basis of an approach to disability as curable and fixable. Through consumption hard of hearing people (often implicitly) have to accept this dominant medical ideology, where only certain types of interventions are seen as legitimate and effective. This process functions to maintain the dominance of the medical model whilst at the same time prioritizing commercialization, in effect leaving hard of hearing people with the increasing responsibility, both with regard to the price and quality check of the rehabilitation provisions they receive.

The consumer order promises an audiological encounter in which hard of hearing people can become rational actors in the process of aural rehabilitation. But Bart encounters problems when attempting to exercise that power, becoming almost immediately deprived of agency on matters of technology consumption. While the current Dutch health strategies, underpinned by models of choice, explicitly prioritize consumerism in changing conceptions of health care this notion of choice becomes much harder to locate once the rhetoric is problematized. The empowered consumer, informed about technology and service provision, is still bounded by the structure of the medical order.

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[88] The acceptance of consumer ordering of health care services requires that a new meaning be given to a number of pre-existing and available signifiers, such as 'the audiologist' who becomes not a self-sacrificing and all-knowing expert but a fallible and over-powerful worker.

WHERE DID ALL THE CRITICS GO?

Throughout the chapter, Bart's voice grows increasingly silent and submissive. Rather than challenging the disempowerment of hard of hearing people, he partakes in it. His self-suppressing voice troubled me. I knew Bart as an experienced user with sound views on technological design and development. It was important for him to have these recognized, to be able to take the position as a lead user. How, then, to make sense of his growing silence; what does it enact?

Rather, than eviscerating his voice from the analysis, in my reading, his lack of resistance is symptomatic for the current political situation in the Dutch hearing field. The silence links up with the lack of an alternative mode of ordering disability. It is a result of the dominance of the medical-market order prevalent in the social spheres Bart passes through. There seems to be a broad agreement among research communities, policy makers and umbrella organizations that the Dutch Disability field is lagging behind compared to other European countries when it comes to mobilizing research and activism aimed at empowering disabled people. While there are attempts to include a critical perspective on disability in research and policy, these attempts have so far lacked a structured platform. Kool et al (2006) argue that the lack of a structured attempt to instigate a disability discourse is a result of the dominance of the medical model in Dutch research and information campaigns. Here, disability is enacted as a medical condition, which means that efforts are made to adjust the individual expectations to functional level rather than engaging in more critical perspectives, including the social and political barriers disabled people may meet. The critique is that these studies of disability have taken as their starting point the individual and its loss and lack, instead of seeing them as equal citizens.

The delimited consumer order, predicated upon a normalizing ideology of technical fix which individualizes disability, combined with a lack of a critical alternative, means that Bart is unable to draw from a more political critique. Without access to an alternative ordering mode, the costs of resistance are high. His identification with the hearing field is strong. NVVS is the arena for his social life. This is where he has his volunteer work that gives his life meaning while unemployed. There are considerable costs involved in criticizing or choosing to stand outside the dominant order. To stand up for his critical viewpoint would mean challenging the entire discursive foundation of this social platform, it would mean having to fight to change it, or leave and build a new subject web. Well aware of the danger of social isolation he finds himself in a vulnerable position. Perhaps it is understandable, then, that it is easier to go with the flow. Bart needs the energy for his volunteer work, his social life and the pursuit of a new job.

In current Norwegian and Dutch disability policy, the 'empowered' service user is mobilized. Informed by the critique of the medical model on disability hard of hearing people are constituted as elective consumers (NL) and holistic users (N) and ascribed agency on matters of aural rehabilitation. Drawing on analytical tools from material semiotics and combining these with subject position theory, I have explored the predicated notions of 'empowerment' by extending the analysis of aural rehabilitation policies into practice. With Michel Callon's (1986) notion of 'obligatory points of passage', I approached the Dutch and Norwegian aural rehabilitation as systems that seek to align the diverse interests of hard of hearing people on a single issue; that of rehabilitation with hearing aids. I argued that this process involves the mutual constitution of order and subject, which begged the questions; what ordering modes are active in hard of hearing people's story about aural rehabilitation? What options arise for subjectivity in the meeting between professional, service users and hearing aids? And, finally, how is agency distributed between them?

Both Reidar and Bart considered their position on technology to be a strongpoint of identification. When entering into rehabilitation programs they aimed for an active position in the assessment and treatment of hearing loss. These aspirations are in line with the user-centred policies. The analysis, however, revealed that while the critique of medicalization is prominent in policy making its translation into audiological practice is more dubious. In both cases empowerment failed to realize. In the meeting with the professional systems, Reidar and Bart's competencies and subjectivities are ignored, as service users they are positioned as passive on technological matters. When hearing disability is enacted as impairment and hearing aids distributed as a technical fix, the identity of the aural rehabilitation system as a societal promoter of normalization is maintained and the medical order prevails. By operating this politically outmoded geography of responsibility, the aural rehabilitation systems work as barriers for the fulfilment of user-centred policies.

While Bart and Reidar shared a loss of agency in the audiological encounter, their stories differed with regard to how elements of disability, technology and politics entangled to produce their experiences. Their stories also differ with regard to the positional strategies they develop to deal with the ambiguities stemming from the relationality of orders enacted in the professional system. While Bart chooses to accept the medical ordering and obliterate system critique, Reidar rejects the system and withdraws to other ways of

enacting subjectivity. To understand the differing positional strategies I looked to their broader identity projects.

Reidar entered the rehabilitation clinic with a notion of subjective hearing and expected to get to take an active position in the audiological encounter. Here he experienced that it is impairment that is in focus for assessment and treatment, and he, himself, is being treated as a patient, as he was sick and unable to take care of, and answer for himself. For him, this gives rise to a subjective dilemma. To accept the medical ordering will give him; access to hearing aids and welfare services, this, however, requires that he accepts a loss of agency on matters of disability and technology, on matters of his own life. Reidar, who sustained his hearing loss late in life, has no experience with technical aids, nor does he identify with the hard of hearing community. Disability, for him, is a new position, hitherto unrelated to the other positions that he has access to; positions in which his agency and social status relate to him as an engineer and competent user of technology and as an influential decision maker with a broad professional experience. Trying to escape medicalization and regain agency in the meeting with the audiological experts, he mobilizes these subject positions from his professional and family life, positions from which hearing loss can be ordered in alternate ways. When the strategies are futile and he is unable to create overflow between his multiple self in the course of the audiological encounter, he decides to bypass the rehabilitation system and find other ways to become an informed and active user of hearing aids. Because of his multiply identity, the cost of resistance is conversely low. He can mobilize other positions to identify in aspirational ways.

Reidar's story can be read as a struggle over agencies and action, where modes of ordering are used to position and legitimize positions in the field. In the clash of orders a critical space emerges, in which Reidar can take an aspirational position on disability. Mobilizing hearing loss and hearing aids as elements of a broader identity project opens for new stories to be told about hearing loss, stories in which his subjectivity and agency differs from that of the medical ordering. To align with the medical ordering would be too risky, threatening his positions as an engineer and decision maker. For Reidar to enact resistance by becoming a hearing aid user on his own terms works to strengthen his identity as competent and capable on technology. Through resistance he is not a passive patient, he re-positions as an agent, he can make a choice and reflect on it in political terms.

Bart is well aware of the market-oriented shift in Dutch disability policy. He identifies with the consumer figure and the way empowerment is conceptualized in terms of having a choice among competing dispensers. He approaches the commercialized rehabilitation system determined to position as a lead user - an informed and critical consumer of technical aids. But while in policy documents hearing aid users are endowed with choice with regard to devices and services, Bart experiences that little is done to influence what is to be chosen from. Instead, technical aids continue to be designed and distributed

according to the same normalizing order as within the medical routing system. When Bart attempts a critique of existing products and practices in the meeting with the audiological experts his concern is rebuffed on the grounds of being too subjective. Not only is Bart effectively silenced, he also partakes in this process of disempowerment. How can Bart, on the one hand, enact himself as a lead user and, on the other hand, accept a loss of agency on matters of technology all in the same interactional setting?

To make sense of this paradox, I looked to Bart's broader identity project. Bart's identity is tightly built up around hearing disability. His experience with technical aids, the distributive system and the user organization identifies him as a lead user and ascribes his aspirational status in the hard of hearing community. The problem, however, is that the system that predicates empowerment through choice, is also the system that deems service users too subjective and ignorant to have a say on development and distribution of technical aids. What is more, in a situation without counter orders, the room for critique is highly limited. While Reidar moves through a variety of subject positions in negotiating his status as hard of hearing, for Bart such overflow is not available For Bart, his identity is tightly built up around the hard of hearing community. Enacting resistance means jeopardizing the discursive foundation on which he builds his social life. There is also another cost related to moving out of the (officially) legitimate consumer position to criticize the professional ordering. To resist the new market-oriented system as an obligatory point of passage means withdrawing from the mode of ordering that makes the aspirational position as a lead user available. Therefore, Bart aligns with the professional ordering, which also forces him to accept the (temporary) loss of agency.

Working with these two case studies I have tried to show how people simultaneously are restrained by, and use ordering modes as resources when positioning as meaningful agents in the stories of their lives. How Bart and Reidar deal with the medical ordering enacted in the aural rehabilitation systems relate to how they can draw on subject positions in contexts beyond the audiological encounter. Based on the analysis of their positional strategies, I suggest that illuminating unstable, multiple identities provides useful insight for policy planning to overcome some of the exclusionary practices within today's rehabilitation systems and develops the possibility of allowing social networks to develop, with the room for negotiation of identity representing the first step in an improvement of actual social status, from patient to empowered service user. However, my argument is not that social positioning can solve all problems inherent to the audiological encounter. On this, Bart and Reidar's stories extended a sociological analysis by offering critical insight about the material at work.

Sociological analyses of the clinical encounter have traditionally located the problem with realizing empowerment in the dominant position of professionals in defining the interests of service users.[89] In response, more collaborative rehabilitation processes are advocated, in which expertise and the expert still have a place, but complemented by the experiences of the service user. Furthermore, and crucially, professional knowledge is considered minor to what is important in the individual's life. Rehabilitation, in this social-contextual approach, is conceptualized as a meeting between different perspectives; the perspective of the professional and the perspective of the user, in which the latter should get to count. This entails that professional knowledge needs to be communicated to the individual and made relevant according to their life situation.

The argument is taken up in Dutch and Norwegian disability policy. The elective consumer and the holistic user figuring in these user-centred treatment models are constructed on the critique of the medicalization of disability. Yet, the analysis in chapter 12, *Empowering the Service User,* revealed two aural rehabilitation systems struggling to effectuate the policy objectives. Reidar and Bart's stories offer critical insight in that they describe how subjective experiences and user competencies become misrecognized elements of audiological practices. When trying to contribute to the audiological encounter with knowledge from his everyday life, Reidar experienced that his domestic situation and professional life did not get to count. Similarly, in the meeting with the professional system, Bart experienced that his critical feedback on technology was deemed irrelevant. Entering rehabilitation programs, Reidar and Bart were keen to participate as capable and coping users of technology, but in the meeting with the professionals their agency became restricted. Actions and decision-making were distributed away from them and were instead taken up by the professionals and technologies acting on their behalf. An audiogram came to represent Reidar in the assessment of hearing and a professional ignored his professional competence in the fitting of the hearing aid. When Bart reports that the 'labbish' design of his Smart Link limits his abilities to enact himself as a full social being, his critical feedback is silenced by the professional. Their stories enact the critique of

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[89] The anti-sentiment towards professionals is evident within the social model writing criticizing professionals for their text book knowledge approach to disability (Davis 1993) and the way they work to safeguard their own professional interests rather than the interests of the clients they are paid to offer service to (Oliver 1991). Shakespeare (2000), even though he later revising his position (2006), criticized the situation in which professionals are in the position to define the needs of disabled people. He went on to challenge notions of expertise, and the way technical language was used to control and exclude. Medical sociologists, for whom the encounter between professional and patient is one of the basic units of analysis, have been equally critical. Conceiving of medical practice as a dyadic encounter, defined by asymmetries of power, the negotiation of rational and authoritative scientific knowledge, and private, proximal, relations. For an example see i.e. May (2007) who from this problem definition goes on to argue that clinical consultation practices needs to integrate a social-contextual view on illness and disability.

professional paternalism and the lack of contextualization of expertise in clinical settings. As such, their stories align with the sociological critique underlying the construction of social-contextual treatment models inherent to current disability policy.

In the social-contextual approach the service user comes to the audiological encounter with a somatic problem arising with a social context for which the expert offers a technical solution. To consider social context, in this case, means to recognize individual differences by prescribing technical aids for the diverse individual needs in relation to work, TV viewing, phone conversations, etc, and by offering advice on how service users can adapt to the technical solution in their everyday life. Subjective hearing is assessed and treated by enabling lifestyle choices. While surely this social-contextual approach goes further than the medical model in recognizing subjective hearing, it is nevertheless, still the same technical fix being applied over again. What I want to argue is that choice, in this situation, is limited. In result, forcing service users to adapt their lifestyles to make the technology work by considering the context for application, with the help of more or less dominate professional advice. What is recognized as flexible and made into an object of professional-lay interaction is the service user and their everyday life. The use of standard audiological interventions, however, is not problematized. To conceptualize empowerment as a matter of adding a sociocultural perspective to the application of hearing technology means to consider issues of subjective hearing, but without relating to the material conditions of possibility for subjectivity. The effect of not problematizing 'objective' treatment is to exclude a critical appraisal of how technical aids are involved in the ordering of hearing loss by inhibiting or inviting specific enactments of hearing loss. By enacting technical aids as neutral compensatory tools the audiological encounter convey concealed ideological messages supportive of the normalizing order; the notion that whatever social context of rehabilitation, however different the users of hearing technologies, the same technical fix can be applied over again. What is more, while service users are ascribed some agency on matters important for the rehabilitation process, however, the division between expert knowledge - which is on technology and treatment, and user knowledge - which is on the social context for adaptation, remains.

In a material semiotic reading, the social-contextual critique of medicalization is problematic due to its implied perspectivism and the lack of sensitivity to the materials at work.[90] Rather than relegating technology to the domain of experts, the material semiotic approach extended the politics of hearing disability to include a focus on the material

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[90] Annemarie Mol (2002) has argued that we should suspend the idea of perspectivism. Perspectivism entails that we as humans gather around an object and look at the same thing from different positions and thus we see it differently, but essentially the object looked upon is a unified, coherent object with specific given properties. Instead, Mol develops the notion of multiple ontology, thus, expanding the room for political reflection and practice.

enactment and ordering of hearing loss in professional practice. In this framework, Reidar and Bart's critique of professional practice was not only about lack of social-contextualization. Their stories also illuminate how technologies and the routines they are surrounded with take part in the distribution of subjectivity and agency in the rehabilitation system. Reidar and Bart were concerned not so much with the lack of access to audiological treatment and technical aids. Rather they contested the politics these technologies enact. When Bart said he was critical towards the 'lab like' design of his Smart link, he argued that technical aids lack the robustness to tackle the complexity of his social life. Based on his experience from use, he had concrete feedback on technological design. He talked about integrative solutions and wireless devices and tried to justify his partaking in design of technology; 'not just the testing of prototypes'. Similarly, Reidar argued that users should take part in the specification of technology to ensure that solutions would be used. He wanted solutions that could allow him to control technology, to be able to program his hearing aid at home. In these stories, material practices deprived service users of agency in rehabilitation processes and contributed to inhibit social change. When rigid borders were drawn between users and professionals, technological agency was assigned to the domain of the expert and the asymmetry of the medical order was re-produced. Here, Reidar and Bart's critique goes beyond the application of technical aids and gets to have a deeper political meaning. Ultimately what is criticized is the social *and* material ordering of them and their hearing that constitutes them as passive and incompetent users of technology; in need of professional assistance, in need of a technical fix.

For Reidar and Bart 'empowerment' was not merely a matter of considering the social context in which to apply standard, objective assessment and treatment. Instead, I suggest that we read their stories as a claim for relational practice. In a relational practice, empowerment is not only about shifting perspectives, replacing the dominance of professional expertise with the more 'authentic' experience of the service user. A relational practice also recognizes that technology is not a fixed object that can readily be implemented in any subjective contexts. In a relational approach assessment *and* treatment emerge from the locally enacted meeting between professional, technology and service users. By politicizing the material, service users are ascribed agency on the *sociotechnical* handling of hearing loss.

REHABILITATING TECHNOLOGIES – EMPOWERING PEOPLE

While disability policies have undergone considerable ideological transformation towards individualized care, strikingly few material changes have followed to support the empowerment of service users. When empowerment is conceptualized in disability policy

documents and debates, the focus tends to be on humans and their social relations. The emphasis is put on assessment of lifestyle choices and individual adaptation of technical aids. The analysis suggests the limits of such an approach. While people can draw on their multiple selves to restore an aspirational identity, there are also material limits to such positional strategies. Text books and educational systems, assessment and fitting tools, invitation letters and consultation procedures, information pamphlets and marketing material, hearing devices and user manuals play their part in realizing the audiological encounter. Materials make things happen and coordinate actions among service users and professionals. To merely focus on empowerment as a matter of social positioning, and not include a critical appraisal of the material at work is to limit the room for intervention. When policy reforms are not followed up with material changes the audiological encounter continues to take place within professional boundaries that do not adequately allow for the problematization of a sole reliance on medico-technical expertise.

Reidar, who mobilizes his professional position to escape the aural rehabilitation system, will still have to take the abjected position as the patient every time his hearing aid needs adjustment or repair. Bart, who aligns with the consumer order, can choose between competing providers in the market, however, his agency is delimited as long as the industrial design remains locked-in on standard solutions geared towards normalization. In these cases, real change seems not to hinge only on the position of the service users, but as much on the material resources they can draw on to realize aspirational identities. While inter- and intra-group differences among disabled people are recognized in policy documents, professionals lack the tools to respond to this diversity in practice. In this sense, materials can be seen to have an exclusionary function, rejecting identities and hindering the development of social groups. Closed hearing devices and fitting software operated by professionals do not distribute agency and action to service users. Instead, these technological scripts leave the user out of the interactional loop. Non-transparent and inaccessible bureaucratic organisations that restrain service users' ability to enter consultations in an informed manner narrow the grounds for decision making. As hearing aid users, Reidar and Bart experience the tensions between different ordering attempts, social-contextual treatment models that apply a standard technical fix. Reidar and Bart are critical towards the current design and distribution of technical aids. However, talking about user involvement in design, distribution and use, they also reserve a room for change.

A shift to a relational practice entails relinquishing the view on material environments, including technology, as objective tools that produce universal effects. Instead, the key is to enact people as resourceful subjects whose agency is made possible or restrained through their relations with non-humans as well as humans. Importantly, this does not mean that people should simply demand access to more existing technologies, or that they should

downplay the importance of materials at work. Rather, the challenge is to stimulate thinking about the ways technologies and material surroundings contribute to the emergence and the transformation of social identities and human agency. Audiological tools and the interventions they make possible do not produce effects or impacts on pre-existing subjects. They actively participate in the production of identity. The material semiotic point is that service users who express their individual needs and aspirations are not isolated individuals but people caught up in heterogeneous relations. It is not through the liberation of the individual from its sociomaterial dependencies that people gain agency, on the contrary, it is exactly in and through these arrangements that empowerment can become experienced. Materials, technologies, institutions and internalized routines that currently work to restrain the empowerment of service users, can, with much effort, be changed into things and material surroundings that enable Reidar and Bart to enact themselves as capable and coping hearing aid users. This, however, requires that decision makers problematize the ways technologies are involved in the political enactment of hearing disability.

In a peculiar way then, material semiotics rehabilitate non-humans by the recognition that they have real competencies and an active role in action. Technologies matter because they take part in shaping geographies of responsibilities, link existing actors, and invite or inhibit the emergence of new and alternative ones. In the light of this, aural rehabilitation processes cannot be reduced to the individuals who constitute them, and they cannot be considered as pure associations of human beings who interact with one another. Audiological practices are not simple associations of humans mobilizing powerful and sophisticated technologies in order to reconstruct hearing. To conceive new technologies, services, and treatments, is not just a question of satisfying needs or demands expressed by well-identified human beings. Technologies, as currently applied in audiological practice, are already involved in the distribution of competencies and actions, of agency and social identity. To recognize the constitutive role of materials in shaping human subjectivity and agency means opening for the possibility of more human abilities and richer social relations. To recognize the materiality of audiological practice expands the room for political intervention into the ordering of hearing disability. A consequence of the rehabilitation of non-humans is, thus, the (potential) empowerment of humans.

In light of the problems with realizing the empowered service user, it might be tempting to construct a new subject position from which to speak. However, it is by no means clear that such nominal innovations will, in significant ways, re-order power relations in the audiological encounter. The problem seems not to be the eloquent formulation of policy objectives, but rather of enacting ideals in practice. While policy makers have been quick to re-write policies, they have been much more reluctant to intervene in the shaping of technical aids and in the design of rehabilitation programs. However, from the case studies

it becomes clear that political critique alone does not work to replace the medical ordering of hearing disability. Without material routines that enact service users as capable and coping participants of the audiological encounter, service users remain positioned as passive and needing patients. Change audiological text books, professional guidelines, and hearing devices and the hard of hearing subjectivity and agency changes too; what hard of hearing people can do, what competencies they are delegated, and their social status as service users. What I want to argue is that decision makers need to develop critical thinking around the ongoing material ordering of hearing disability in professional practices. In fact, I believe that a main challenge for disability policy ahead is to discuss which types of sociotechnical arrangements to design and experiment, or, in other words, which type of service users to develop. The consequence of *not* engaging in the politics of materiality is to reproduce the gap between policy and practice. As long as policy objectives are not translated into different things and material surroundings their effects on professional practice is limited and the elective and holistic user figures remain words in policy documents and debates.

By all this, I do not mean to imply that changing the audiological encounter in itself will lead to empowerment. Although professionals and the materials they work with may reinforce a negative ordering, a transition towards user-centred rehabilitation practices will not automatically create wider social change. Just as the audiological encounter is only part of the problem, their reform will constitute only part of the solution. What is more, an expansion of the audiological domain can lead to further professionalization of social problems. When the entire complexity of the service user is brought into the narrow realm of technical audiology, the risk is that professionals will medicalize a wide range of psychological, social, economic, and political problems. Perhaps, then, instead of asking how professionals and users deal with social problems, a more appropriate question is whether professionals always and necessarily should deal with social problems? As professional management of social problems has increased, the social roots of personal troubles become mystified and de-politicized. That is, by responding in limited ways to people's non-technical problems, professionals tend to shift the focus of attention from societal issues to the troubles of individuals with adjusting to the 'normal' world.

To engender change, professionals too must be engaged and urged to become more self-reflexive with regard to the materials they apply and the positionality they enact. Such self reflexivity may enable practitioners to heighten their sensitivity for the broader impact of audiological encounters on the identity of service users. However, although technical audiologists should recognize that service users are complex beings with individual needs and aspirations for aural rehabilitation, should the audiological encounter continue to be the key site for the realization of disability policy? People move through a variety of subject positions and material environments in negotiating audiological encounters. The

complaints they bring with them are linked to the enactment of subject positions in their everyday life, as colleagues, family members, or active in sports. Perhaps the inclusive society is better located beyond the audiological encounter, in the sites and situations where hard of hearing people seek to position throughout their everyday lives? In the next chapter, I make this move as I study the enactment and ordering of hearing disability in the context of work.

In this chapter, I explore how experiences of hearing disability emerge in the context of work. The education and job market is an important arena for self-realization and, regretfully, also for social exclusion and discrimination towards hard of hearing people (Eurostat 2001). The general pattern observed across Europe, is that disabled people have a relatively low educational level compared with non-disabled people. Disabled people are disproportionally congregated in semi and unskilled occupations. Disabled people are under-represented in professional and managerial occupations. Disabled people also experience higher levels of employment in jobs for which they are overqualified. Disabled people are over-represented in lower income jobs and under-represented in higher income jobs. In general, disabled people in employment work fewer hours a week, and receive lower wages than their non-disabled counterparts, women in particularly are disadvantaged.

In interviews, people shared stories that revealed severe difficulties in getting and keeping jobs where their competencies were acknowledged and fully employed, a problem accentuated in periods of economic hardship. Despite the difficulties related to positioning at work, people put high value on getting an education and having a job. Work was described as a form of self-realization, a social venue, and a way to get access to the financial resources needed to pursue other activities outside work. Thus, while their careers were challenging, given the choice, none of the people I interviewed would prefer to live on welfare alone. People expressed a need to contribute, to take part in society, to be valued for what they could do, not only what they were. Work, in other words, is an important arena for the enactment of abilities as well as disabilities. Given the strong sociocultural position work has in modern societies, it is not surprising that people put much value and effort into having a paid job.

Starting with Durkheim, sociologists have theorized the value of work in terms of social integration.[91] The prominence attached to paid work has endured through into more recent analyses that draw a clear line between citizenship and exclusion - the latter defined as the denial (or non-realization) of the civil, political and social rights of citizenship (Barnes and Mercer 2005). In other words, citizenship is associated pre-eminently with being an active economic agent, with the linked assumption that paid employment is privileged over other forms of work activity (Grint 1998). On this, Gorz (1999) argues that the specific definition of work in western societies is located in a market-based activity and largely ignores what others describe as 'socially necessary' labour. The wage-based capitalist society provides income, social recognition, citizenship rights, and a sense of identity so that those who do not work, for whatever reason, experience hardship and diminished social standing, in effect assigning them to the margins of society (Abberley 2002). For the large bulk of disabled people without permanent employment the implications are clear, they cannot contribute significantly to one of the most valued areas of life and, hence, are liable to be set apart as unproductive and 'in need'.

It should come as no surprise then, that access to work has been a main concern also in disability studies. Social modelists have criticized the medical model on disability for legitimating disabled people's exclusion from labour market participation.[92] Their argument is that the medical model on disability runs parallel to the characterization of work in capitalist industrial societies in terms of paid wage labour and profit maximization. Principles which work to place disabled people at a serious disadvantage because they are increasingly viewed as less productive in the workplace than their non-disabled counterparts. Since traditionally work has been associated with waged labour disabled people have experienced being systematically excluded from an important social integration arena, on the grounds that they were seen as unable to conform to the demands of the capitalist labour markets and its work discipline (Abberley 1987; Finkelstein 1980; Oliver 1990). In this context, Barnes (1991) has argued that the social model underscored the development of a 'materialist' account of the social creation of disability in industrialist societies, and the specific form of institutional discrimination experienced by disabled

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[91] Durkheim characterized social integration of pre-industrial societies by mechanistic industrialization, founding on overlapping roles in the social division of labor. With industrialization a more specialized and complex division of labor developed, with society now grounded in organic solidarity.

[92] Barnes and Mercer (2005) finds this to be a particular feature of capitalist production system in contrast to the many pre-capitalist and small-scale agrarian societies where work is organized around a different set of principles, such as social necessity and interdependence, and disabled people are more often included (albeit of necessity) than excluded. See also Gleeson 1999; Ingstad and Whyte 1995; Thomas 1999; Oliver 1990

people. This suggested a new target for disabled people's political campaigns; a focus on the removing of disabling barriers in work, and more generally.

ACTIVATION POLICIES

Social model analyses of disability have had a growing influence on international disability policy. The need to remove disabling barriers, of social as well as environmental forms, and include disabled people in the job market is broadly recognized by policy makers. While ideological rationales diverge and policy instruments differ, 'activation' is a key area of European disability policies.[93] Based on the observation that disabled people struggle to enter, stay in, and re-enter the job market, a gap has been identified and an arrangement of compensatory measures instigated in order to activate disabled people. The intention is that excluded groups should be brought into the realm of 'mainstream' society constructed around notions of independence and paid work. The compensatory arrangement includes a large body of research aimed at analyzing the numbers, causes, and potential solutions to the problem; regulative instruments launched to protect disabled peoples' equal rights in the job market; agencies stimulating disabled people to qualify, apply, and train for work; welfare allowance to secure a basis income for disabled people while unemployed; and rehabilitation systems distributing technical aids designed to enable disabled people to do their jobs. On the one hand, activation policy builds on the idea that work is better than passivity and welfare, and on the other hand, that the more people are in work, the better for society (Oorschot 2004). There is also a moral dimension in play; society should not be held responsible for people that are able to take care of themselves. Tax payers should be certain that all options are tried out before social insurances are paid out (Kildal 1998). Within this discourse paid work is not only interpreted as a right, but also as the first duty of the good citizen, except for disabled people for whom it has become both a 'duty and a right' (Williams 1999).

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[93] There are different ideologically informed purposes of activation policy. A distinction is often made between the solidaristic and liberalist tradition discussed in part II and the divergent geographies of responsibilities between society and individual. Liberalist policies are geared to promoting the competitiveness of labor market and the responsibility of the individual to compete. The solidaristic alternative will focus on the inclusive potential of labor processes and the shared responsibilities or loyalties associated with labor participation (Lødemel and Tricky 2001; Leibfield 1993).

ACTIVATION RESEARCH

Activation policies are firmly grounded in research. There exists a large academic literature dealing with the problem of providing opportunities for work for people with disabilities.[94] The dominant approach is to contrast nation-specific conceptualization of disability in terms of participation in the labour market, to count and compare disability statistics, and to critically discuss the various methods issued in controlling and reducing the number of people claiming disability insurance benefits. The empirical foundation is policy documents, statistical data and structured interviews with representatives of key government and implementing agencies and organizations of disabled people. Such quantitatively oriented research is crucial in illuminating the structural exclusion of disabled people from the labour market. However, as pointed out by the European Commission (2001) there is a critical lack of descriptive studies of disabled people in work.

Therefore, in this chapter, I go behind the numbers and in-depth on two hard of hearing careers. Rather than counting how many are included or excluded from the job market or what societal measures need to be taken to have more people integrated or compensated, I study how two hard of hearing people, Marianne and Anouk, become active in the work place. Both have their identities strongly linked up to their professional careers. In order to take a position at work they have developed two distinct strategies that, notwithstanding their differences, are both geared towards normalization. In the context of work, Marianne has chosen to try to pass as hearing, while Anouk has opted for adjustment. I work with their stories to study how hearing disability is enacted and ordered in the context of work, the sociomaterial contingencies of their positional strategies, and related costs and benefits in the light of broader identity projects. Drawing on Moser's (2003) material semiotic study of disability, I combine the notion of doing disability with an investigation of the conditions of possibility for the social undoing of disability, for 'normalizing' hearing disability in the context of work. I use the empirical material from my meetings with Marianne and Anouk to study how hard of hearing experiment with the flexibility of disability, how the making and unmaking of disability is done as part of explicit positioning strategies, and what it can tell us about the ontological status of disability.

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[94] Key references here is Hvinden on the Norwegian and Nordic literature, and Oorschot (), Oorschot and Boos (2000) on the Dutch, while Hvinden and Oorschot (2001) together have conducted large scale comparative studies between European welfare states.

> Marianne: "I don't want them to think of me as someone with a
> hearing aid that has made it, just someone who has made it."

Compared to mobility disability, it is not easy to spot a hearing loss. But while hard of hearing people may escape unwanted stares from people on the street they have other challenges. When talking about hearing loss, people often referred to it as an 'invisible disability'. Since they look and act so 'normal' people, even their close ones, tend to forget about their hearing loss and address them as hearing. The invisibility of their disability makes it necessary for someone hard of hearing to actively and continuously make people aware of their problems hearing and their information and communication needs. The invisibility also offers a chance to avoid stigmatization and discrimination by not making people aware of disability and try to 'pass as hearing'.[95] In order to explore how passing is done we shall meet 'Marianne Steine' (35). She has gone through much of her life, more or less deliberately trying to pass as hearing.

Marianne has read about my research project in the member magazine of the Norwegian organisation for hard of hearing people. She sends me an e-mail and tells me she is keen to participate. She has used hearing aids her whole life, and invites me to her home to talk about her experiences. After the interview we keep in touch through occasional e-mails. Marianne and her husband live with their two-year old son in one of the surrounding cities of Oslo. It is spring 2005 when we meet and Marianne is pregnant with her second child. She is at a turning point in her life. In our conversation she looks back and reflects on her career choices, while contemplating the future. I have looked forward to meeting and talking with Marianne about her experiences with technical aids. Marianne is not only hard of hearing. She is also a young woman, in the midst of establishing a family and a career. The new digital devices that have now come on the market target precisely the kind of active and social lifestyle that Marianne leads. I am curious about how technology works in this phase of life, at work and at home between husband and children. The more surprised I am to learn that Marianne does not use digital hearing aids, despite the fact that these by now dominate the Norwegian market. She tells me they are not for her and her lifestyle.

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[95] Goffman coined the term in 1968. Within the STS field, Bowker & Star (1999) have written about what happens in a society that sets standards, categorizes people according to these and values normality while consequently devaluing what falls out of this norm as abnormal, deviant and lacking. Using the case of South African apartheid regime, they have showed how black people born with a light skin color, in an attempt to avoid the unwanted stigma and discriminatory practices following being classified as black, tried to 'pass' as white.

Her response was for me counter-intuitive because back then, I was used to thinking of young hard of hearing people as technological optimists. Their challenge was getting access to the latest technology, not having to reject it. The meeting with Marianne was to become an important learning experience, one that made me re-think the complex relationship between subjects and their positions in a material world.

PASSING AS HEARING

> Marianne: "When I sat there, in the interview, I didn't know the people and they didn't know me. I was just thinking that the job was a great career opportunity for me. In the interview situation you are supposed to sell yourself. You don't want to portray your weaknesses, because the employer only concern is with finding the most competent candidate. If they don't know anything about how it is to be hard of hearing, why bring it up? Most probably, the only one they know who use hearing aids is their grandmother, and they would not give her the job, right. But I knew I could manage. So when the Human Resource Managers asked me if I knew any reason why the company should not hire me, I didn't say anything."

Marianne got the job. Since her graduate studies she has worked as a technical writer in a large international IT-company. She says the job is fast paced. There are constantly big deadlines and new people and departments to relate to. They work in project-based teams. That means that they move around in the company, according to which department needs their skills. The working language is English, and there is a lot of technical vocabulary that needs to be renewed all the time. Still Marianne feels that she copes well. Her job is largely text based. Instead of meeting or calling, people often use e-mails and instant messaging to communicate in and between the teams, even with their colleagues next door. Besides she is not in a managerial position. She does not have to lead meetings and report results. She does not have to be visible. Therefore, she did not say anything about her hearing loss in the interview and she has not told anyone later either. In fact, Marianne has never really taken an active position as hard of hearing. She grew up in a small rural town in the North of Norway. As a child her mum took her to an audiologist in Trondheim. They made some tests and gave her hearing aids. One summer she went to the school for Deaf children to learn to lip read. After that, there was never any talk of it.

> Marianne: "Of course, there were problems, but I got so used to it, I never really thought about it. There was never any special attention towards my hearing loss. I went to a normal school without accommodation where I was expected to learn the same things as the

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other kids. My mum always says that nobody ever thought about
treating me any special because I always coped so well. I liked to
hear that about myself, it gave me a kick."
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Since her childhood Marianne has not herself actively identified as hard of hearing. But what does Marianne do to enable her to (momentarily) pass as hearing, how does she unmake her disability? Obviously, it starts by her avoiding making people aware of her hearing loss. But to pass as hearing it is not enough not to position as hard of hearing, she also needs to do hearing.

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Marianne: "When I went to high school and later university I
specialized in languages. It wasn't easy with my hearing disability,
but I loved the subject and I was a really good student. I worked
hard to compensate. I memorized texts, prepared for potential
questions and rehearsed answers in front of the mirror. I always
went to class and paid attention to everything the teacher said.
There was so much to concentrate on. I had to choose many things
away, especially the social part. I was a nerd... I never went to
parties or to the cinema in the evenings because I didn't have the
time or energy. With that kind of prioritization, it's easy to
become good. I guess that's why they never thought of giving me any
special attention."
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Marianne's strategy is to put all her effort into the one subject position which she enacts in social encounters, as a pupil. That means she avoids the social interactions where she can be identified as hard of hearing; going to parties or the cinema. The same pattern is repeated when Marianne studies at university, and when she starts her new job. She starts by not mentioning it during the job interview. She knows she can cope, and it goes pretty well. They sit in offices with three people, and most of the interaction is one-to-one. After meetings she engages colleagues, asks them questions to make sure she got it. She makes two new best friends; e-mail and instant messaging. She takes full advantage of the text based communication culture that exists within the IT-company. In the beginning she goes to the canteen for lunch, but she soon got tired of hitting the wall down there, so she stops going. 'I guess stopping going has made me appear much more individualistic than I really am', Marianne says. Now she avoids the common areas and instead eats lunch at her desk. That is, she avoids what enacts her as hard of hearing, the noisy canteen and her colleagues' chit-chat.

NEW OWNERS, NEW STRATEGIES

Then the company is bought up by a Dutch firm. With the new owners followed a different work culture and a new office location.

Marianne: "They came in with their suits and formal attitude; you could tell they were more professional. In the same period the company also moved into a new building with an open office landscape. The architect was interviewed by a magazine saying that; 'it looks so stylish people want to dress up for work.' Norwegians gladly go to work in their slippers, but soon the whole work environment changed. Now I feel like working in 'Dilbert'.[96] If you are the right type, you thrive in this kind of environment. The foreigners at work, and especially the Americans, they're accustomed to those things, how to dress and act. They can be 'bitchy' as well if needed. That culture is too hard for me. I need time to build relations. I depend on people to understand how I need to work. I guess I'm lucky to have a niche competence. As a technical writer it's possible for me to have a well paid job in this type of a company.

In the new building we were moved out of our offices and into a common area to sit in teams of four. If the others are talking, I don't stand a chance to follow them. Then I just fade out. Someone has to call my name before I pay attention. Actually, I like to work when it's a bit noisy around me, so that doesn't bother me. But I hear from my colleagues that they enjoy sitting in teams, because then they can listen in on conversations. The management encourages us to actively share thoughts and ideas over the table, eavesdrop to pick up on project updates. That doesn't work for me. I rely on the project leaders to answer my questions and keep me informed, in writing if needed. With e-mails and messenger I still managed."

The new office environment reconfigures Marianne's hearing loss and disables her in new ways. It becomes harder to continue to pass as hearing. She has to develop new strategies. Because of her hearing problems she tries to ignore the small talk around the table. But Marianne is used to withdrawing from the social interactions, this is not new. Neither does she have any trouble working in this environment, she does not mind the buzz. The problem is that with the new material landscape follows another set of norms for how to be competent in the job. Now part of being a good employee is to share knowledge informally. With her hearing loss, it is impossible for Marianne to meet the new expectations. Instead she tries to stay informed through alternative channels. She relies on a good relationship with the project leader, and she clings to the text based communication. By actively

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[96] 'Dilbert' is an American comic strip written and drawn by Scott Adams, known for its satirical humor about a white-collar, micromanaged office featuring the computer engineer Dilbert as the title character.

compensating, Marianne continues to undo her disability, until the incident with the phones.

COMING OUT OF THE DISABILITY CLOSET

> <u>Marianne</u>: "When we moved into the new building, everything became fancier. We used to have stationary phones. They were compatible with hearing aids and I could easily adjust the volume. When we moved into that open office landscape, we were expected to be more mobile so we got these wireless phones. To not disturb people we had to bring the phone with us and take the conversation in a meeting room. These new phones did not work for me because they created a buzzing sound on my aids. I could not manage anymore. I told my boss and he arranged my old phone back. Because of this phone incident people understood that I had problems with my hearing… I sort of came out.
>
> Looking back at it, I think people understood something was wrong all along. I mean, there are certain ways you are supposed to react, when someone says something. But since I did not hear the nuances in their voices I didn't respond to that. I think people thought I was a bit weird because of it. That's why it hasn't done me any good to hide it. I regret it now, especially that my direct colleagues had to find it out on their own. But I just felt that it was so difficult to all the sudden tell them when I hadn't said anything to begin with.
>
> It's been tiring as well, always having to use my intelligence to try to reconstruct meaning. I got my hearing aids when I was a child, I've been compensating and adapting tactics my whole life. I managed but I've had to pay for that. Everything becomes tactics. I have to be careful about that, sometimes the tactics takes over. I get used to nodding and answering yes on the 'right' places. Every now and then you fail, you misread body language, answer people who are talking to themselves, or give a wrong answer. Then you really make a fool of yourself. Then I have to make excuses and explain about my hearing. It's humiliating..."

Marianne's story is analytically challenging and brings us to the core of the debate on the ontological status of disability. What is disability, how is it made, and can it really be undone? Starting her new job, Marianne does not tell her colleagues about her disability. This part is about undoing disability. I do not mean that she no longer has a hearing loss, her problems hearing, her hearing aids, they are still there. What I mean is that she does not activate a position as hard of hearing. Her hearing loss is not an evident part of her collegial interactions. What they do not see, that goes on behind the scenes, is her undoing of her hearing loss, the making of what most people take for granted - a normal hearing.

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Marianne, thus, conceals the work she does to avoid being identified as disabled. It is demanding. She uses all her energy during work hours to do hearing, which means that there is little time and energy left for informalities. The deletion of social life is key to Marianne's positional strategy. Lunch with colleagues is not part of her job, simply because she does not have the energy to cope with it on top of her work. So for a while her disability is imperceptible because of this process of undoing, doing, and deletion. For a while she can manage its appearances by performing invisible work to pass as hearing. However, the result is limited, abilities are limited. Hearing problems can be concealed or ignored, but do not cease to exist. Marianne might be able to hide her problems hearing, but she cannot avoid the work she does to pass as hearing. While disability is not an explicit topic during conversations or part of a work accommodation program, disability is still there. It is simply producing other effects. Actively undoing disability by doing hearing is also a mode of ordering disability. Marianne's positional strategy, her attempt to pass as hearing, is just another way of producing disability. That is the disability. Disability is not perfectly stable, nor completely flexible. It cannot be done away with, but with much work it can be reordered. Specific ordering modes might be deactivated, hid or suppressed, but are always latent according to specific conditions of possibility; the social and material elements that take part in the interaction. In retrospect Marianne acknowledges that her disability had been there all along. It is just that now she has to deal with it under the scrutiny of her colleagues.

There is much on Goffman's (1959) concept of onstage/backstage to be read into Marianne's story. Onstage Marianne puts up a play in order to pass as hearing, behind the scene she works to compensate. But there is also difference. First of all, it is not a play in which Marianne holds the part as the centred performer with the directive control of her audience. Marianne's problems hearing do not merely emerge from her body, they are not only the results of her individual role. Disability emerges in other relations; places and situations beyond her individual body and control. Despite her attempts to control her working environment, all the tactics and manoeuvres, situations emerge which make it impossible to continue to pass as hearing. A new office culture is instigated, introducing a new sociomaterial arrangement for performing work, an open office landscape and a new phone system. Following these changes in the sociomaterial relations at work Marianne is unable to cope in her job without accommodation. Her strategy breaks down, she is forced to identify as hard of hearing in order to maintain her professional position. The new phone system demands a new strategy. While in the interview, Marianne thought her hearing loss would exclude her from a position in the company, to reveal disability is now a premise for keeping the job. If she does not ask for accommodation, written messages and her old phone back, she risks being deemed incompetent and, eventually, sacked.

Here then, the material semiotic approach extends and complements the symbolic interactions framework by discarding the centred actor and the ongoing and situated interactions, the 'stage', to show how ordering modes also emerge in disembodied forms, in a loosely connected web, through a multiplicity of heterogeneous, dislocated and uncontrollable elements.[97] Disability is not evident, nor is what transpires with the situations obviously related to the disability. It is not an essential and isolated phenomenon, but appears and changes in relation to the sociomaterial elements it comes in relation with. Disability slips and slides throughout the day, emerging through the practices of work, without an essential being. Sometimes it emerges in relation to the material; the mobile phone without a loop induction system, sometimes in the social interactions; having to reject colleagues' invitation for lunch. Disability is socially *and* materially produced. So is technology. By changing from stationary phones, compatible with hearing aids, to mobile phones, without an integrated loop induction system, the phone goes from being a thing that enables her to do hearing, to something making her hearing disabled. Thus, not only is disability socially and materially produced, it is an entangled effect. In one sense, of course, it is individuals who do disability. It is Marianne who avoids the canteen, her attempt to compensate and cover over her problems hearing produces disability. In one sense, disability, and the unmaking of it, is an individual accomplishment, an achievement of situated conduct. But rather than the property of the individuals, disability is an emergent feature of sociomaterial relations in the work place, Marianne's' relation to people, canteens, phones and attitudes. Disability is a disembodied and distributed part of sociomaterial relations, an effect of the social interactional rituals at lunch and colleagues growing suspicion something is wrong. Here the material semiotic approach shifts the locus from matters internal to the individual towards the sociomaterial interactions where subject positioning occurs.

So far, I have argued that it is not possible to do away disability, but that, with much work, hearing can be momentarily done which leads disability into alternative ordering modes. I have also argued that disability is produced in the material semiotic relations in which it takes part. Then, what position does Marianne strive so hard to avoid? If undoing disability is just another way of doing disability, how can we make sense of her attempt to undo disability, what mode of ordering disability does her efforts enact? It appears paradoxically to talk of a hard of hearing positional strategy when Marianne does not identify as disabled.

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[97] For a discussion of the relationship between ANT and SI see Law 1994. I go on exploring this difference in terms of the technological enactment of disability later in this chapter. Here, I focus on disability as a de-centred, dislocated, relational phenomenon.

NORMAL WORK REQUIRING NORMALIZATION WORK

Listening to Marianne's story about growing up without special education, technical accommodation and a life with strict priorities it is fair to say she has worked to pass all along. Her hearing was never a topic among family and friends. Instead, it was made invisible and did not come to matter because Marianne in public was always totally focused. She was so successful in undoing her disability that people simply forgot. Again, and following the analysis above, this is not the same as to say that the disability ceased to exist. Her disability was always there, but it was not enacted i.e. through special education programs, welfare support, social accommodation, or peer awareness rising initiatives. Yet disability existed in Marianne's active effort to undo it. Thus, in practice, she was disabled all along, it is just that nobody noticed because of how she did hearing, because she alone carried and concealed the costs of being as everybody else. The part of her disability that Marianne could not delete or hide, her withdrawal from social life, became ordered and named in other modes. Since her asocial behaviour was not related to her hearing loss instead Marianne was seen as a nerd, an individualist and a loner, but not hard of hearing.

In her new job, Marianne continues to order her disability in this mode. Compensation, prioritisation and deletion, these are old and familiar strategies. Passing, for her, has become a sport; the satisfaction of succeeding despite it all. I too admired Marianne for being so successful, for managing studies, work, and family life with her severe hearing loss. But her story also bothered me. Despite the success, her experiences did not fit into a discourse on empowerment. Her story was not about the struggle for recognition as disabled in the work place. On the contrary, her struggle was about how *not* to be recognized as hard of hearing. Nor was her story about medicalization. There was no dispute over what means to intervene within rehabilitation, how to become cured with access to more and better technology. Then, this idea of passing as hearing, why was it so important for her? Where did it come from, this urge to eliminate her disability regardless of the costs?

Marianne did not want people to think of her as; 'someone with a hearing aid who had made it, just someone who had made it.' She wanted to be normal. Her struggles to avoid being set out as different, to pass as hearing, are all geared towards normalization. Then, why was it so hard for me to recognize the ordering at work in Marianne's story? In retrospect I realize that I got caught up in a dichotomy. I focused on how active Marianne was, her ambitions and how much she managed. Activity, aspirations, and coping were elements that I linked to the social model and the current active citizen debate (see i.e. Morris 2005). Connoting opposite descriptors to the medical model and its underlying normalization ideology made me blind for Marianne's strive to do normal. By making the social model into the story of the empowered participation of disabled people I made the

story of normalization into a story of disabled people's submissive marginalization. However, re-reading her story, detailing the processes that allowed her to take positions at work, instead of just focusing on the actual positions she was in, I realized that normalization, momentarily and with costs, can produce activity and success. Within the normalization order the disabled subject is enacted as someone that can become 'normal' by doing the 'normal' things that 'normal' people do. To make this happen, a compensatory arrangement is instigated. As hard of hearing one is taken to see the technical audiologist which gives you a technical fix, a hearing aid that shall compensate for the loss of hearing and enable you to take part in normal life, to pass as hearing. In hindsight, I realized that this, the normalizing order, had followed Marianne throughout her entire life. It started with growing up, being given hearing aids, and that was it. From there she was expected to cope as the normal kids, no special treatment, no accommodation, just passing. It continued at her work, where she did not want to stand out, be treated as special, did not want to ask for accommodation and appear needy. Marianne had ambitions. In a highly competitive business environment with a reverence for the profitable her efforts needed to be extreme, in order to compensate and pass as 'normal'. Therefore, normalization in the case of Marianne did not produce an inactive and marginalized subject. Instead it produced a successful career and the extra work she put into being as good as everybody else. From her story I learned that it takes a lot of work to be normal, to not position as hard of hearing is not only the passive act of not identifying as disabled, it is also the active work of passing as hearing, of *doing* hearing to be normal.

Normalization is a powerful ideological device which produces, reproduces and legitimates the choices and limits that are predicated on disable people. Because of the lack of an external societal actor promoting normalization, be it through a policy document, a rehabilitation program, or a medical intervention, Marianne's story stood out as different in comparison to the bulk of disability studies literature on normalization. There was no authority figure in place telling her to become normal. The active subject enacting normalization was Marianne. And the way she went about doing this was much more subtle and silent than the verbal, powerful, discourse found in the public welfare state arrangement, its work place programs, technical aids, and regulative frameworks. But Marianne's strategy is no less effective than the public machinery. What is produced is the same. It is the identification of a gap and the instigation of a compensatory strategy. Marianne thinking of herself as deviate compared to people with normal hearing. Marianne in need of normalization. Marianne doing extra work and withdrawing from social life. Marianne working to restore and make possible an order of the normal. Thus, in her case, normalization is not only the effect of medicalization, rehabilitation programs, and policy interventions. In her case, such control processes emerge as an internalized element of the hard of hearing individual; her urge and efforts to pass as hearing.

Obviously, the cost of normalization is high, both in terms of the invisible work needed and the (potentially) considerable tensions and difficulties of managing information and interaction involved in order to construct and control a narrative self. Thus, notwithstanding her successes, Marianne's story begs the question whether her ordering mode is psychologically or socially healthy or progressive? As well as expressing satisfaction about the ability to overcome, to succeed despite it all, her account also includes the worry of failure to come to terms, the stress and pain following the risk of 'being caught', embarrassments following misunderstandings, and the exhaustion following all the extra and invisible work that comes with 'passing as hearing'. A temporary 'compromise identity' may be developed, but it is frail, and ultimately has costs for personal happiness and security (Shakespeare In Barnes and Mercer 1996:7). To avoid the embarrassing moments following disclosure she has to be continually alert to actual or potential threats to the security of her position as hearing.

THE TECHNOLOGICAL ENACTMENT OF DISABILITY

What happens now then, when Marianne starts being open about her hearing loss at work, what difference does that make? For a start she gets her old phone back. In addition she gets conference equipment she can use to amplify sound during meetings from the Assistive Technology Centre. The equipment has ten different programs to fit different hearing needs, but Marianne has not really started using it yet.

Marianne: "I just don't think that I can take the time to test new things when I'm in the middle of a meeting. Then there are a lot of things going on all the time, I have to pay attention, I don't want to miss out on important information. Last time we had a meeting I brought it with me. When the projector started running, I realized I had the wrong program and couldn't hear a thing. I'd left the remote control in my office and I just thought; I'm not going to do this now, I rather just do it as normal. My colleagues are really ok about it. They have told me that we can slow down if it causes problems for me. They know I need to test the equipment. But it is more that I don't want to be bothered with it. We have a large deadline due in a week so meetings must be efficient.

Besides I don't like all the attention that comes with it. I have to tell people that the equipment I put on the table is there because I cannot hear what they are saying. I think it is embarrassing. I know I have to learn to be truthful, but it is just takes so much time sometimes. I just want things to go as smooth as possible. I want to be able to do my job and lead normal conversations without having to make people aware of my special needs all the time. I don't want to go around all the time feeling like I depend on goodwill. That's what the technology makes visible right, that I am special, that I need something extra. Throughout I have been more concerned about

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avoiding the whole 'goodwill thing'. I have compensated by being
double as good as everybody else, so that no one would have anything
to complain about. I mean even though I'm hard of hearing I'm still
ambitious. Anyway, I am soon going for maternal leave so I've put it
on hold. It's just not high on my priority list right now."
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First Marianne told us about the costs of passing, the risks and embarrassments, the compensating and her tough priorities. Now she tells us that there are also costs of coming out. She is reluctant towards using assistive technologies, she does not want special treatment from her colleagues, in reality, she still does not want to position as hard of hearing.

In the official script, technical aids diminish the negative effects of her disability and enable Marianne to work on par with her colleagues. But for her, the conference equipment is not only a means for overcoming disability, it also enacts disability. For Marianne to use technical aids while the rest of the people around the table do not have to use it is to draw on and exhibit the difference between them. What is enacted and re-enacted is not merely use of technology, but the material embodiment of disability, and derivatively, of abled and disabled conduct. Marianne experiences technical aids as a menace to her identity. They enact her as different and in need. Installing the equipment on the table, interrupting the meeting to get a remote control, to jeopardize a deadline are all elements producing disability. To make technology work, Marianne must fit it into an already busy working day and she rather avoids having to go through all that. To reject technology, means that she has to continue to compensate, listen extra carefully, ask people questions after the meeting, and so on. But for her, that is a preferable strategy compared to having to exposit disability openly, enacted and ordered as different from her colleagues and dependent on their goodwill.

I suggest that in this situation, with Marianne coming out, normalization is not replaced. Rather, there are several strategies aiming for normalization at work, with different understanding of disability. For the Assistive Technology Center and for Marianne's colleagues, disability is a bodily condition that can be compensated for by technical aids. In this ordering mode, distributing a high-tech conference equipment means providing Marianne with the chance to overcome her disability and become normal. But for Marianne, disability is not so much about the lack of sound, as it is about her social status among colleagues. For her, bodily function alone is not what is at stake. Lack of sound she can always tackle, she always has by working doubly as hard. What she fears is a double standard, one for her 'normal' colleagues, and special arrangements for her. The technology does not so much allow for the *representation* of her disability (Marianne is able to do her job) as for the making of that disability itself; Marianne needing special arrangements to do

her job. Hence, by not using the technology, Marianne does not escape her disability. She still has problems hearing and struggles to cope in her job.

What Marianne wants to escape is the negative position as 'the Other'. A position in which she is no longer enacted as normal, but disabled, different and in need. Thus, while the rehabilitation professionals, colleagues and Marianne herself agree that disability must be compensated for, to normalize Marianne at work, they disagree on what disability to overcome. For her colleagues disability is the problem hearing - a bodily condition - for which there exists a technical fix. They are ready to give her the room she needs to start using the conference equipment because, for them, the technical aids will enable her to participate in meetings on par with them. For Marianne, however, the technical aids enact her disability, which for her is not predominantly a lack of hearing – a bodily condition, but a matter of social status. She knows that the conference equipment is no technical fix, and that in addition, it attracts a lot of attention that deprives her of normalcy and enacts her as different. Her strive towards normalization take a different route and entails different costs. Her strategy enacts normalization by concealing difference through indivisible work.

But what are the goods of normalization, what makes it worthwhile to go through all the trouble to pass as hearing? If individuals strive towards positions in encounters with others, how does society instil the need to achieve it?

BUSINESS AS NORMAL

> <u>Marianne</u>: "It's not just me. I think there's still a lot work to be done with regard to disability rights. My boss is really nice, but not the Human Resource guy. It is almost like he despises people with weaknesses. I would never trust him with a problem. I'm sure he wouldn't believe in someone that isn't perfect. It's much because of him I chose not to be open about my hearing. But, I can sort of understand him as well. When you operate in a highly competitive market, I guess you need to bring in the best people. I know that I have the rights on my side. But I guess it is somewhat naive to think that they will believe in someone who acts nervous and reveals weaknesses, believe in people and give them the opportunity and conditions they need to realize their potential. Especially when there are 100 more people waiting in line for the job. They are in it for the money. They look for someone with abilities. They have a responsibility to generate profit, every day. Then it is hard, money-wise, to justify hiring people they know will need special accommodation, in order to one day, maybe, reach their potential. So I lied. I hid and I compensated. If I don't let people know that I'm hard of hearing they can't treat me like that. I try hard to avoid the group stamp. I have this enormous need for people to focus on me, who I am."

Marianne is hard of hearing. Marianne wants to be normal. She is ambitious, qualified and she knows she can manage. Her worry is that if she interrupts one too many meetings, or misunderstands one too many messages, than her colleagues will start noticing her weaknesses instead of her strengths. They will start to think her hearing problems disqualify her from the job. She worries that the position as disabled will lead to enact her as loss and lack, and all the things she cannot do. The fear is that being open about her disability will lead to a deep identification that violates all other aspects of her identity. To take use of technical aids means risking having her entire identity reduced to that one subject position as hard of hearing. The technical aids make her disability an overt object of the social interaction at work. This is problematic because in Marianne's understanding of others understanding of disability, a hearing loss is always and necessarily associated with weakness, special needs, and dependency, elements incompatible with a professional career.

By acting out of fear of prejudices and continuing to try to pass as normal Marianne becomes the carrier of a highly negative image of disabled people. But it is not all about disability is it? According to Marianne, there is also a different order at work. She refers to a business order in which disability is quite irrelevant as long as it does not interfere with the objective of the company; profits. Aware of her disability rights, Marianne also knows that business is about more than being political correct. In this setting, technical aids do not just enable hearing, they also enact disability. If business goes bad difference can easily translate to weakness and threaten Marianne's position in the company. Marianne supports her suspicion with a characterization of her Human Resource Manager. With him as a reference she anchors her fears in the reality of work, the business she is positioned within. It is from this position her urge to undo disability is derived. 'Knowing the world', she says, and justifies her continuous attempts to pass.

Then, do we cast opinions on Marianne's positional strategy, her enduring attempt to pass as hearing? Now that we, as a society, have introduced universal rights to promote the inclusion and participation of disabled people, do we also implicitly expect them to activate their rights, to actively identify as hard of hearing, as empowered and liberated citizens in every position they take? Should we expect disabled people to always act as political activists, to claim their rights? Why does Marianne accept all the cost and risks that come with trying to conceal her difference and become 'normal'? She is resourceful and successful, why does she choose the disempowering positional strategy? Why can she not instead step forward as a role model for other disabled people? Can we expect Marianne to act on behalf of the group in her choice of an individual career?

In her youth, Marianne was an active member in the Norwegian organization for hard of hearing people. She is well aware of the current disability policy debate, and the empowered citizen it constitutes. She has nevertheless chosen not to position herself within it. Instead, Marianne works hard to be a participant of a business culture with its own norms for good behaviour. Normalization is compatible with her position at work. In her view, there is no room for a disability discourse on inclusion and accommodation in this environment. To claim recognition for one's difference and demand special treatment may cause friction in what is supposed to be an efficient and lucrative business organization. Therefore, she individualizes and conceals the efforts needed to stay on top of the job. Then she does not have to expose her disability. Marianne's cautious moves are not ungrounded. There is still much work to be done in a society where disabled people are overrepresented in the unemployment statistics, also those clearly qualified for available jobs. While the public policy is full inclusion, it is employers who employ, and their priorities might be different.[98] Thus, Marianne says it is hard to be a spearhead, because when your real job is done, there is not much energy left. To politicize her position as hard of hearing means additional work and additional risk, it is a cost she is not willing to bear.

AN HONEST MOVE SHIFTING INTO FAMILY ORDER

> Marianne: "Everything that reminds people about the other role I rather not have. I just feel that, and I guess that is also why I haven't talked about my hearing at work, that I'm trying to get away from the idea of being a successful user.[99] I think that I try very hard to get away from that. Of course that influences my relationship with technology. It makes me want as little as possible. I don't want the technology as a reminder of what I don't want to be. I can't complain and ask people to treat me special all the time. The user role, where you are to be demanding accommodation and special treatment, just doesn't fit with all the other things I want to be. But then it is the necessity of things that makes me have to. I'm in a relationship where I need to function. I have a job where I'm required to be professional. I have a little son that I need to hear. I need to function relatively well."

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[98] In a statement on the problems of exclusion in the job market, the Norwegian Minister for Work and Integration, stated that only 46 % of all disabled people are employed, compared to 75 % of the rest of the population. The Minister went far in placing the responsibility for the situation on the employers (Aftenposten' Friday 2nd of November 2007). Related to this, Oorschot (2004) detects a shift in the traditional social contract in employment relations, with employers more prepared to take action against employees who are thought less productive

[99] Marianne's reference to 'user' mobilizes the political struggle of the Norwegian disability movement to be seen as an interest organization representing active and involved users of welfare services, not as passive patients. See part II.

I started by saying that Marianne's story had a transitional element, that when we met, she stood at a biographical turning point. When her passing strategy breaks down, Marianne does not mobilize an alternative ordering mode to manage her job as hard of hearing. She does not want to position as the empowered service user because this potentially threatens her position in the business order at work. Instead, when she cannot position herself as 'normal' at work she retracts into another discursive context, in which she has access to a different set of subject positions, whose importance increases. Earlier Marianne's first priority has been work. Now she chooses her family. To pass as hearing in the family is impossible, because her family confronts Marianne with her strategy.

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Marianne: "When it comes to the whole compensation issue… well I got
hearing aids when I was around five, so I know all the tricks. It's
difficult to change, to talk true. I have to dis-learn my tactics.
Since I got married, the questions have started coming; 'Hello, did
you just hear what I said or not?' And if I'm to be honest, then I
have to tell him that I didn't, it's just something I said because I
was busy with something else, or I did not want to bother with
asking over. So I have to learn to be true, but it's so demanding
some times."
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Marianne makes a choice. After the maternal leave, her life changes radically. In an e-mail she tells me that she has given up her job at the IT-company and taken her family with her and moved back up North. They are expecting their third child. She writes that it was the consideration for the children that in the end made her decide, and she has not regretted it. In their new town, she teaches Norwegian to immigrants. She has a temporary contract and works two days a week. She thrives in the new job. The town they live in is quiet and she has plenty of spare time. She is thinking about doing an internet based course to formalize her teaching competence and apply for a permanent position.

Here, it is not only what happens at work, the coming out, that leads to a change in Marianne's positional strategy. Subjects are created in complex sociomaterial relations inscribed with a multiplicity of social categories of difference. Marianne struggles to build coherence out of the multifaceted experience of diverse relations which will have disability as one of its components. And, as the analysis show, not even disability is a fixed position. The different identifications she makes bear differently upon disability depending on the context within which they are asserted and the meaning they have for her. Things change because Marianne gets a family and now have several interactional arenas in which she has to function. She mobilizes a new mode of ordering which evolve around her as a mother

and a wife, not primarily as a disabled individual or a career woman. It is not possible anymore to let work drain her energy and then go home to switch off and recharge. She has a family that depends on her, she has to become truthful. I write back and ask her whether she misses 'Dilbert'.

> Marianne: "That's just so long ago. I can't believe I used to live and work in such an environment. Here there's no stress, and that works for me and my hearing. It makes me calmer and more honest about my situation. I don't have a job to defend, no prestige to maintain, and that's all good. But I miss the action and the opportunity to use my competence. But with children you want to give them solid ballast. Right now that's my first priority. It gives me some time to think through what I want for myself. I guess I've understood that it is not so important where I live as long as my family is happy."

While Marianne is hard of hearing, that is not her entire identity. Her position as hard of hearing intersects with other positions, as mother and professional. In order to manage with her new life, Marianne has lowered her personal ambitions. She changes job, and she cuts down on working hours. This flexibility is what enables her to cope with work *and* family. Although she does not deny the possibility of change, at this point in her life Marianne experiences a sense of coherence. Behind the new positional strategy is not only a move of location, it is also a re-ordering of herself, from emphasizing her formal position at work, to her position in her family. As Marianne changes, technology changes too. From the position as mother and wife, technology acquires a new meaning in relation to the other elements of Marianne's new subject web. Technology used to be what enacted her as disabled, as negatively different from her colleagues. Today she speaks of; 'the necessity of it.' Technical aids are necessary for Marianne to be able to communicate with her family and to perform her teaching. Technical aids are no longer a threat to social status. Entangled in the family order, they enact her position as a dedicated and altruistic mother and wife whose prime interest is to give her children the best possible upraising. Here, Marianne mobilizes the traditional, socially prescribed, gendered subject position for women which is based on a moral ethics of care (See i.e. Ring 1994 and Haug 1992). The ordering of women as the caring ones has derivative subject positions including being a 'caring' and 'kind' young women, a 'loving' wife, a nurse, or a 'good' mother, to mention some. Such caring often implies the suppression of one's own needs, sometimes to the point of self-martyrdom. While the subject position as a committed mother allows Marianne to make priorities with regard to how to act, it simultaneously gives a moral guideline for how not to act. To be a self-sacrificing mother means being able to let go of the self-centred business career and the compensations and priorities needed to live up to the expectations at work.

Is Marianne's choice a downscaling? A product of the 'intersectionality' between two subject positions that puts her in a double disadvantage (Hill Collins and Andersen, 1995). Not only is her disability hampering her business career, in addition, as a mother and a wife, she *should* feel more committed to her family than herself and her job. On the intersection of these two subject positions, she is left with little other choice than to prioritise her family and downscale her career. This reading is plausible and, responds to the call made by disability scholars to include gender in our analyses of disability (See i.e. Barron 2004; Thomas 2002; Traustdottir 1991). However, as Jenny Morris (1996) points out, while it is important to include a gendered perspective on disability, it is also pivotal to avoid the notion of an automatic double discrimination when analytically approaching the intersectionality between gender and disability. Morris warns that the little analysis there has been on disabled women's lives has tended to be couched in terms of asking whether and how disabled women encounter a 'double disadvantage' because of their experiences of sexism and disability.[100] Usually these studies try to assess which is worse. Such readings do little to empower disabled women. And there are problematic aspects related to the intersectionalist reading of Marianne's story. First of all in that such analysis automatically assigns a negative social status to the positions 'woman' and 'disabled', and thereby diminish Marianne to a victim. Secondly, the demeaning reading of her positional strategy does not fit with the enthusiasm and pride she expresses about being able to teach refugees and with bringing her family with her back north. Marianne articulates a sense of having made the right choice, not only for her family, but also for herself, having chosen finally to be honest about her hearing problems. In this sense, Marianne's story is an important rejoinder to the intersectionalist argument, in that it urges us to look for other methods of making experiences visible, in ways that draws attention to difficulties, yet does not undermine disabled people's wish to assert self-worth. With this in mind, I have aimed to study the difficulties Marianne faces and the way she goes about ordering them in the context of her broader identity project, but without turning her into a passive victim either of patriarchy or disablism.

Rather than seeing Marianne's choice as a product of a double discrimination, her position as a mother and a wife can be seen as a resource she utilizes in order to interfere with the risks of normalization. The active citizen discourse promotes the full inclusion and participation of disabled people in society. Activation is a key instrument and the job market a key implementation area. In the case of Marianne, the discourse seems simultaneously too broad and too narrow. It is too broad because the instigation of universal rights implicitly carries expectations that not only should disabled people

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[100] An example is Carol Thomas (2002:48) who starts out with the assumption that; 'disabled women occupy different kinds of social locations to disabled men, because more than one system of oppression is in operation.'

participate as everybody else they should also do so with success and according to the same conditions and expectations as 'normal' people. The activation discourse is also too narrow. It is too narrow because activation is highly conditioned. There are certain activities that become recognized and valued and others – like a position in family life - remain hidden. For Marianne, family life is as important, and in the end more important than her career.

Of course order is never complete. Marianne's sense of coherence is temporary and seems tinted with a feeling of lack. She articulates a sense of guilt stemming from what she has left behind. Ideas of city life and a business career linger on. Sometimes she; 'misses the action and the opportunity to use her competence.' Yet, that is a priority she is willing to make. The other life and her positions in it can be deleted, at least for now, with youngsters at home. Here then, Marianne mobilizes her position in the family and its surrounding order, not built around her disability, but as a mother and a wife. The order of the family has its own demands and expectations for how to live a normal, good life. As a woman to mobilize the family order, and to point to responsibility in it, the need to make a personal sacrifice, to be there for her children is a viable option. The family order interferes with the unease caused by 'not using her competence' and works to draw attention away from Marianne's inability to live up to the expectations of work. This ordering liberates her from the judgments of normalization, ideas of downscaling and experiences of failure, lack and loss. She mobilizes something else instead, another way of positioning which gives her access to other expectations and a different status. The family order interferes with normalization and justifies Marianne's radical leap. The relationality between the ordering modes and her ability to draw on her multiple self to switch between subject positions is what generates a sense of coherence that allows her to escape the demeaning judgment of normalization.

By telling Marianne's story, I do not mean to imply that there is a simple way to a positive identity. It would not be accurate to trace a neat trajectory between being enacted as a category of otherness, and then being able to use once difference as a strength. There is nothing inevitable or determined about the process, and there are major difficulties with successfully and positively identifying as disabled. For Marianne her new solution is as energy demanding as her prior life in Oslo, perhaps even more. She has three toddlers at home, lives in a new place, and works as a language teacher for immigrants, a particularly demanding job for someone with a hearing loss. Why, then, does this new life offer more coherence? I think it is not merely a matter of energy alone. Energy is relative to what we choose to put our energy into, what return we get on our energy so to speak. In her interview Marianne already expressed doubts about the corporate culture she worked in, the sharp elbows and profit drive was not really her. Now, being a mother and working as a teacher is, on the other hand, meaningful for her. Our fragmented and multiple selves will provide multiple resource for doing disability under a diverse set of circumstances in

which disability appears and disappears, become actualized and significant or neutralized and irrelevant. Today Marianne identifies primarily through her family, and it is through this prism she now views the other positions, her disability, and the former life. From that position she mobilizes the extra energy to cope with her new and demanding life.

Later I return to Marianne's story in the contrasting discussion towards the end of this chapter. But first I introduce another hard of hearing career, 'Anouk de Jong' (57). Unlike Marianne, Anouk has not been hard of hearing her whole life. Her story starts with how disability became the springboard for a biographical turning point. Following a surgery gone wrong, she decides to take control of her own life and makes leap from one subject web to another. When talking about how she copes with the hearing loss, she articulates a strong sense of individualism. It is a positional strategy well grounded in the rehabilitation profession. Rehabilitation programs tend to start with the recognition of bodily impairment and seek to undo disability through individual adjustment. Through lifestyle choices the aim is to reintegrate the hard of hearing into 'normal' life. The aim is to make disabled individuals aware of their bodily limits and, on the basis of this, encourage them to make priorities for what to do with their lives. For Anouk, work becomes *the* arena for the realization of her new identity. At work she takes part in a social community. Here she is recognized as a competent and contributing colleague. For Anouk, that makes her a normal person. I will use the material from our meeting to analyze the way the normalizing mode of ordering, inherent to rehabilitation practices, becomes embedded in the context of work. As in the analysis of Marianne's story, I combine the condition of doing disability with an investigation of the conditions of possibility for the social undoing of disability, for adjusting to life.

THE POLITICS OF ADJUSTMENT

Anouk: "The head nurse told me it was extremely important that I lay down for five whole days after the surgery. But they had forgotten to write it down in my patient journal. After three days, there was a shift of staff and they insisted that I got out of bed so that they could clean it for me. At first I refused, but they insisted. Everybody was watching. It turned into a scene. I was still weak after the surgery and I didn't want to be a difficult patient. In the end I gave in and got up.

It was one of the worst moments of my life. I just took two steps, and then I had to sit down in the chair. Bells were ringing in my right hand ear and blood started streaming. I knew something was

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very wrong. I heard nothing and from that moment I was deaf. My
inner ear was destroyed. The balance centre is in the inner ear so
afterwards I experienced a lot of dizziness. I had to have more
surgery to fix it. I was in and out of the hospital for a year... a
whole year, going from big hope to becoming a completely handicapped
person."
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Anouk works as a researcher at the sociology department of one of the largest Dutch Universities. Twice a week she also teaches distance learning at a college downtown. Back in 1981 she was to undergo surgery for Otoschlerose.[101] The surgery itself was successful, but during recovery, something went wrong. In the course of a few seconds, Anouk becomes hard of hearing. She can literally feel it. Her story begins here, with what happens afterwards, the process of re-establishing a sense of self, a sense of coherence following the loss of hearing. Instead of feeling anger and lament, Anouk uses the hearing loss to become someone new. As part of the process of identifying as hard of hearing she escapes a life not wanted. The hearing loss becomes an element of a decision long sought as she makes a leap, from one subject web to another.

I travel to Rotterdam to talk with Anouk. We meet in her office at the University. I am keen to hear about how she has managed to reinvent herself after the surgery. I am also somewhat nervous. Knowing that she is a senior in my own field, makes me feel like a student again, like it is me, my conceptual framework and the research approach that is to be questioned and tested. Given Anouk's seniority, she surely will see through my questions about work, family life and hobbies and detect my underlying framework, my search for dominant, repressed and oppositional modes of ordering her disability. I am also curious. Given her sociological career and insight into processes of identity formation, I wonder how she reflects on her own story. To what extent has she used her sociological insight in the rehabilitation process? Has she mobilized her social scientific background to deconstruct (and challenge) the dominant individual model on disability. While the notion of identity as a social construct has been around in social sciences since Goffman, the idea of disability, a bodily phenomenon, being equally constructed has a genealogy much shorter. Has it taken hold?

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[101] Otoschlerose implies multifocal areas of sclerosis within the stapes bone and the middle ear. The ossicles (bones) become knit together into an immovable mass, and do not transmit sound as well as when they are more flexible, leading to a loss of hearing. Otoschlerose affects about 0, 5 - 1% of the population, more often women than men, and normally between the ages of 20-40 years.

Anouk: "Before the operation I only had a small problem hearing. However it wasn't nice, people made jokes about me. I repeated things that someone had already said and there were things I did not understand because I couldn't hear them. You know the comic 'Tintin'? In it there is a character called 'Professor Zonnenbloem'?102 He is the typical messy and eccentric character, like we used to picture professors back in the old days, and he's hard of hearing. When someone says something, he doesn't hear it, or he misunderstands and gives weird answers… Well, 'Professor Zonnenbloem', that's what my ex-partner used to call me. He said I was perfectly willing to hear if I just wanted to, I was just being difficult. And it took me some time to realize that I was hard of hearing. But my father wore hearing aids, so I had an idea and I went to see the specialist, who suggested the surgery.

I spent the year in and out of hospital to think about what I wanted to do with my life. Those things were linked together. The hearing loss made me think how long I could go on with my partner. I decided I couldn't do it anymore. When I got the divorce, I began to build a new social life for myself, without him. I moved and started a new job, picked up new social activities and got new friends. At that time I was working at another university and I was the feminist movement. I stopped all that. It was a big change.

It was not just about getting to know my senses anew. It was also about realizing that I got older. I had gotten something that was never going to be better again, something that couldn't be repaired. So it was important for me to get away from people who identified me as someone with a big loss. I mean people were really nice, but even years after they would bring it up; 'how is your hearing?' They knew it had happened and I just could not go on with that, it made me sick. I had to close that chapter and start over with people that didn't know me as someone that had lost her hearing. Instead I met new people, people that only knew me as hard of hearing."

Anouk already had a small problem with hearing before the surgery, but now it had gotten worse and she needed to find new ways of relating to it. In her story, many different elements entangle. The dramatic period at the hospital, the hearing loss, the problematic relationship with her partner, and her body getting older, feeling time was running out. All these elements finally pushed her into changing her life, a decision that involved both closure and a new start. After surgery, Anouk rejects the hospital's offer to meet with a

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[102] 'Professor Zonnebloem' is the Dutch name for 'Professor Calculus', who appear in the comic 'Tintin' by the Belgium comic book artist Hergé.

social worker. She was already seeing a psychologist about her relationship problems with her partner. He would also help her rehabilitate her hearing loss.

Anouk: "People were surprised that I did not sue the hospital. They couldn't believe I just walked away. But say if I did get some money, then imagine how many years I would have to spend telling people how terrible my life was. That would be a self-fulfilling prophecy. If you tell yourself, or need the story that you are so bad off, then that is how you feel. I did not want to blame anyone. I thought; this is my problem. I have to live with it. If I start to be resentful then I spend all my energy on hatred, and I have to work on my own future as a forever hearing impaired person. Then again, a year ago I was driving in my car and passed the hospital and I had to stop and cry… You ask me if it is possible to let go. Yes, it is possible, but that doesn't mean that you don't have feelings. In a way it was a rational decision not to hate the nurse, but instead use that energy on my own life. I think you do have a choice there. More than people think. I chose to move on. I said that; ok, not everything is lost. I just have to be patient and honest about what I can and cannot do, and I have to figure out what I really want to do."

Anouk is keen to avoid having her identity reduced to that *one* position as hard of hearing. She makes several moves to avoid the position as a victim. Since her old friends kept on reminding her about the loss, they too had to go. Since her partner could not respect her for it, she had to leave. Anouk needed a new beginning, to focus on her abilities not the disability. While some elements go, new ones are to be added, materials and people are re-arranged to build a new life. As Anouk contemplates how to re-define herself with a disability, she engages in an ordering, both of disability and of identity. Identity is constructed and it is changeable. Disability, on the other hand, is loss, something fixed that cannot be cured, something she has to learn to live with. It is the entanglement/relationality of these two apparently contradictory positions, one determined, fate, and the other construable, autonomy, that becomes the starting point for Anouk's reconstruction. On the one hand, there is the notion of being stuck with a disability that she is forced to relate to. On the other hand, there is a feeling of freedom and the power to build a new life. Anouk says that; 'as people, we have more of a choice of what to do with our life than we think'. People, here represents the orthodox idea of identity, as unitary and essential. She differentiates to the idea that identity is fixed and maintains that one can in fact reconstruct oneself, that we are capable of changing our lives.

ENABLING TECHNOLOGICAL RELATIONS

> Anouk: "A lot of things disappeared. When I went hiking with friends
> they would go; '…oh, listen to the brook running', but I couldn't
> hear a thing. So it was really a wonderful experience to get a
> hearing aid. I didn't have any problems getting used to it either.
> Everything became so clear. All the sounds that had been gone were
> back. It was like a miracle. That first summer, I sat for hours in
> my garden listening to the birds singing."

After all the surgery, Anouk gets a hearing aid for her left ear. With Otosclerosis hearing aids are often a great help. The loss is flat, which means you do not need help to discriminate between sounds; you just need a lot of it. Anouk becomes a 'gain addict' and she is really pleased with her aid, because she can control volume as she wants. Max it when she wants to hear, and turn it off when sound is disturbing. Both at her office and at home she has phones with integrated amplifiers which enable phone calls. Because Anouk does not want to give up her social life and her work, the adoption of technological devices is a crucial element of her new identity. Hence, when she found out about the Smart link, she was really enthusiastic.

> Anouk: "Everything that is more than 2, 5 metres away is very
> difficult to hear. When I got the new job here, I went to the
> university doctor to tell him about the hearing loss. He immediately
> suggested that they should try to do something for me. We contacted
> a firm and they came to install a loop induction system. Great
> sound, but these devices stay in the room. Later I looked at the
> website of the NVVS and there they had information about something
> like a handy-mic. I got one right away and I'm so pleased with! I
> use it to talk to people, at meetings, and to watch TV. It's like a
> gadget, it's handy to use and it looks good. I always put it on the
> table. Then people get curious and I tell them that I put my ear on
> the table so that I can hear them, then everybody laughs. It's
> completely accepted. People want to look at it. They think that it's
> really smart. Many say it's something they could use as well, and
> they want to know where they can buy it. I have to tell them that
> they need a hearing aid first.
>
> You know for many people who are getting older a hearing aid is a
> bad thing, but when they see this they just think it is elegant. In
> my social circle there are several persons who finally have gotten
> hearing aids after I started. I tell people that the sooner they
> start using hearing aids the better because when you become really
> hard of hearing it's hard. You need to use your capacity to hear to
> get used to a hearing aid."

In Anouk's story, technical aids are not only about the sound they produce. Technology is involved in the enactment of a hearing disability, but also other subject positions that Anouk aspires. A loop induction system is a collective solution which is considered supreme with regard to the quality of sound. However, it is a system reliant on technicians installing and maintaining it, and it is not mobile. Anouk is not always in the meeting room, when she needs to talk to several people at once she cannot always go into the accommodated room. She also goes to conferences, the canteen, or to the pub after work. She wants a solution that does not confine her abilities to a specific room. She wants a flexible solution that can follow her into the social contexts she moves in and between. The smart link is a fairly expensive solution that involves a lot of work in terms of batteries that need to be charged, wires being brought along, and a microphone that must be passed around. However, because the Smart Link belongs to and is operated by the user, it distributes agency to Anouk and extends her subject web, the places she can go and the positions she can take in social life. For her, this enabling effect outweighs the work involved in making the technology work.

But while the Smart Link works for Anouk, it is not technology alone that makes it work. The positive effect depends on a series of other elements. Anouk's position at the university enrols her into an accommodation program. There is the doctor who takes the initiative and discusses her options, signing a form and verifying that she needs technical aids. Then it is Anouk herself, who finds information about the smart link on a web site. A web site made by the NVVS. Because Anouk is a university employee she can afford to pay for the device herself. In addition, according to Dutch health care policy she is also entitled to reimbursement. Anouk's hearing loss and her relationship with it is similarly important. While she has a large loss, it is rather uncomplicated, equal on all frequencies. For her the amplification from a hearing aid works fine. What is more, Anouk has decided to be open about her disability. In social interactions, she always puts the Smart link on the table. The reception among people is positive. People's feeling for technological gadgets, their curiosity, acceptance, even admiration plays a role for the positive experience Anouk has with her Smart link. These are feelings also reliant on Anouk's position among her colleagues. She feels sage to make jokes and she is accepted as an innovative user. The ability to draw these different elements together; hearing aids, accommodation programs, collegial esteem, and funding are elements enabling Anouk's hearing and increase her social status.

ADJUSTING TO LIFE

> Anouk: "I need an alarm system and I need a new phone. I saw my
> neighbour's phone. He has a hands free solution with all kinds of

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possibilities for changing the volume. That would be perfect for me.
I know I get it if I ask for it, but the process… it's just a lot of
fuzz. Always extra, extra… I have to find out about it on the
internet first, and then go to the dispenser to buy it. Afterwards I
have to figure out which employer reimburses me. There's a lot of
paper work, but it is also about knowing where to go! It's
complicated so I don't want too many things… but of course, that's
my problem. Sometimes it can be… but that's how it works, you have
to fight for yourself. If you don't do it yourself, nobody will. I
think you always have to think that you're the one who's in charge.
You're the one who is paying, or who is having nothing. Well, so
it's just like an extra job, it takes energy from other things. And
even if you get hearing equipment it's very important to realize
that it helps you, but it doesn't mean that you don't have your
handicap anymore. So what are you going to do, how you are going to
learn to live with that. That's the social part of technology."

Policy documents and official information material on hearing disability tend to focus on all the things hard of hearing can, and have the right to do, with technology, at the work place, and in societal life. What is often under-communicated is the contingency of such accomplishments. It is as if technology or disability rights are a fix to the complex challenges facing hard of hearing people when seeking to position in society. As a result, many hard of hearing people experience disappointment when their expectations for full inclusion and participation are not met. Anouk acknowledges this. Although the new health care policy speaks of the empowered consumer, Anouk knows that consumer rights need to be activated and activation means work. Thus, while she is pleased with her hearing aid and the Smart Link, there are also technologies she chooses not to get because of the work involved in making them work. Besides, she says, hearing technologies are no cure for disability. Anouk articulates this as; 'even if…', a turning point for many hard of hearing. The realization that even if people wear hearing aids, even if they are legally protected against discrimination, even if they ask people to accommodate, they might still experience trouble hearing, unemployment, and social exclusion. And then what? At that point people start building coping strategies.

When the hearing loss decreases her ability to do things, Anouk is keen not to let it lower her life quality. Instead, she starts to prioritise; to conserve and release energy for the things that she actually can, and really wants to do. For her, work and colleagues are important. Contrary to many hearing disabled people who refrain from crowded social events, she invests much energy in going; 'I'm a normal person in that sense, I go every time'. But in order for her, as hard of hearing, to take part in, and enjoy what 'normal' people do, she adjusts her expectations according to the hearing loss.

Anouk: "I think that hard of hearing people have a tendency to blame others. They think people are rude when they don't talk louder. Because they don't have a clear position on their hearing loss, they don't trust others to understand it. Of course people forget, but then you have to remind them. They do normal and I am abnormal. Even if I tell everybody that I have an impairment it's still my problem. One just has to accept that. For me it's never been a secret. I've worked on accepting it as a part of my identity. Why should I conceal it, when I can never take it away from myself? That's what's unpleasant about it, that's exactly why it's a handicap; you're not the normal, you're different from the norm.

Especially in social life, people with a hearing problem feel isolated. But you have to learn not to isolate yourself, not to let it happen to you. Be there and accept that you cannot hear everything. I mean if you can hear 50 %, you can still be part of the community. Too many people think that they have to hear everything. In a lot of situations that's not possible. Say if people make a joke and everybody is laughing but you miss the point. Well sometimes that happens. In a lot of situations you just have to laugh and accept that you didn't hear it. It's not such a big deal. It's just a stupid joke. You can still laugh. You just embarrass everybody if you constantly ask them to repeat things. It's the laugh that's the thing, not the joke."

Anouk carries the idea that, as hard of hearing, she is different from and, somehow, worse off than 'normal' people. According to her, disability is an embodied condition for which there is no cure. Disability is inherently negative, a handicap and, essentially, her problem. There is no use in blaming others. It is her that has to change. To rehabilitate means to learn to live with it, despite it. To do so, she mobilizes her social resources to minimize the negative effects of hearing loss. By adjusting to, and trying to make up for disability, Anouk's efforts are geared towards normalization. The approach is well-grounded in the rehabilitation profession. Rehabilitation from its Latin origin presumes that a human being in some ways has lost or lacks a part of its ability to function and do certain activities that are considered normal and common for humans in the society they live in (Kerz, Werner and Wesser (1995). The individual and its surrounding notice this lack of ability and puts great value on trying to restore functions by adjusting to the 'abnormal' body to close the gap. Adjustment, in its Latin origin, is defined as the ability to adapt to a norm. Rehabilitation professionals' approach to disability is similar to that of medical professionals because they share a conceptual starting point. Disability is seen as a biomedical condition, as individual lack or loss. Yet there is also a significant difference between medicine and rehabilitation. While medical professionals pursue aims of cure or recovery, rehabilitation professionals deal with disabilities that are often irreversible and rarely curable and, thus, have to establish alternative aims for treatment and care.

Over the years, the field of rehabilitation has increasingly moved from a medical model towards more client-centred models of treatment and care (Barnes and Ward 2002). In general terms, rehabilitation scholars agree that rehabilitation aims to support a person with disabilities to mobilize resources to maximize physical, psychological, and social functioning to surpass barriers of a psychological and societal kind (Kerz et al 1995). Consequently there has been a shift in distribution of responsibility and expertise. Treatment is no longer to be expert driven, with a powerful and knowing professional providing standardized assessments and treatment to a passive and dependent client. Instead, treatment should include a subjective assessment of individual needs, where the client establishes and prioritises goals for the treatment process according to their individual life situation. In this client-centred model, professionals still play an important part in assisting the individual in the setting of goals and providing them with adequate information, advice, and support to help achieve these. Rehabilitation practices now focus on the assessment of what functions are feasible and how these can be achieved. Professional support might include the need for mourning, and coming to terms with loss, and helping the client to adjust by mobilizing individual and external resources to compensate or ameliorate for the lack or loss of function caused by disability. The rehabilitation professionals, in other words, assist in the re-assessment of functional conditions and consequent reframing of lifestyle possibilities.

!!To come to terms with the trauma at the hospital and her loss of hearing Anouk sought professional help. Through rehabilitation she has come to accept the hearing loss as an inescapable part of her, which has also meant recognizing her ability and responsibility to take control of her life. With the hearing loss as a fixed, somatic condition, Anouk has found a steady ground to build a positional strategy on. That offers her a sense of freedom. In the process of coming to terms with her hearing loss, she has made priorities for where and when to invest her limited energy, for what she can, and wants to do when it is no longer possible to do it all. In doing so, she takes a perspectivist position on her disability. While disability is fixed, the way she relates to her disability and how its effects can be controlled is subject to lifestyle choices; what relations she enters into, what it means to take part in a community, and what expectations she has to her own performance. She argues that unless you accept your disability and adjust your expectations accordingly there is going to be a lot of friction and struggle. She knows that she could get technologies and ask people to repeat things, but sometimes, instead, she instead just chooses to go with the flow. And when she does, when she cannot hear what is said, she does not feel excluded or marginalized because she does not expect to always be included and accommodated.

Anouk does not politicize her experiences of disability, instead she maintains they are her problem, and as the problem owner she can choose to ignore them. Thus, rather than challenging the normalizing medical model on disability, Anouk's story draws on, and

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combines the notion of disability as fixed with a view on identity as construable. With adjustment as a positional strategy, Anouk has created room to reflect on the relation between her hearing disability and the other subject positions that she aspires. It is a room to get to know herself and her abilities anew and of adjusting expectations accordingly. The notion of adjustment, thus, assigns an active role to Anouk and gives her a sense of control over her disability. With multiple positive and enabling positions available and the capacity to use these to reflect on, and adjust her own performance Anouk is able to minimize and downplay the negative effects of her hearing loss. She even allows herself to be excluded here and there, without seeing it as a threat to her belonging and position in the social community she traverses, without it appearing threatening to her identity. Adjusting to the hearing loss Anouk has made substantial alterations to her subject web. Marriage, technology, work, and social life are elements with a high degree of flexibility to her. Juggling these she copes with her hearing loss, without having to give up what is really important for her.

In Dutch disability policy (MinVWS 2004), society is encouraged to take responsibility and make room for people with a disability. In addition, the active citizen is brought fore. The individual responsibility to give shape and substance to one's own life is emphasised, for which individual strength of character and support from direct social networks is considered extremely important. Anouk's positional strategy is in line with this policy. She starts by articulating a view on disability as individual tragedy, a medical condition located in her body. Despite this, she is keen to participate in 'normal' societal life. She has implemented the proposed actions, she has followed the medico-technical route, she has taken use of assistive devices tailored to her individual needs, she has incorporated the notion of adjustment as promoted by rehabilitation professionals, and she is successful because, as emphasised in policy, she has taken up the individual responsibility to realize her potential, to succeed despite her loss. Because of that, she does not *have* to challenge the dominant order. The dominant order works for her.

Ostensibly, the notion of adjustment appears as a fruitful strategy, adaptable for system development. The process in which Anouk reflects on and adjusts to her disability exceeds the reduction of disability as objective and measurable degree of loss and rehabilitation as standard interventions. Adjustment, as a relational concept, promises to give room for subjective hearing. It requires user-centred consultations that invite professionals and service users to draw on personal resources in the design of coping plans. Yet, as I go further in to Anouk's story, there are also problems with adjustment as a positional strategy. It appears that it is only successful as long as disability remains like that, fixed inside her body, not in the people who do not talk louder, not in the design of an immobile loop system, and not, as we shall see, in poor quality subtitling.

When Anouk decided to start a new life, she also left her positions in the feminist movement. That does not mean that she does not care about politics, but that she depends on finding other contexts to enact herself as a politically interested person, like following the election campaigns on TV.

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Anouk: "The Dutch subtitling is really terrible. Especially live
programs like political debates are disastrous. On the screen you
see people talking for five minutes, but what comes out in
subtitling is no more than a couple of lines. You just know the
writers make their own interpretations of what they hear and you're
missing out. Obviously certain things can be done about it. The NVVS
could do something. They have to bring it up. I hope other people
are working on it because that is a political problem."
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Anouk's positional strategy has been to accept and reify her disability as an irreparable damage to the ear, while trying to make everything else fluid and changeable. The strategy depends on disability remaining fixed, confined in her body. When the quality of the subtitles interferes with Anouk's ability to stay politically informed, a new experience of disability emerges. Disability is no longer fixed inside the body, but emerges as the relation between a verbal based TV culture, poor subtitling technology, and loss of hearing. And there is nothing Anouk can do about it, because now disability emerges in sociomaterial relations beyond her individual control. She, alone, cannot improve the quality of the subtitling. Her individual efforts are restricted and a situation emerges which calls for collective efforts.

So, whilst the notion of adjustment promoted by rehabilitation professionals is different from the hopes of cure presented by medicine and the technical fix marketed technologists, a core supposition remains, the modernist assumption that enacts nature as objective. The body as representation of nature is a variable which is determined and which we can adjust our social world to. When accommodation is no longer a preferable solution, Anouk's positional strategy, in which disability is the pivot according to which all other subject positions can be adjusted becomes problematic. To understand how disability emerges, not only as a result of bodily impairment, but as a result of how hearing, TVs, and cultural norms are configured, adjustment wont do, we need a different vocabulary. The material semiotic approach challenges the modernist world view, and invites us to think of disability in radical new ways. The notion of disability as the result of social and material relations exceeds the notion of a fluid and changeable identity enacted by Anouk by allowing for an equally anti-essentialist take on disability in bodily and disembodied forms. In the material

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semiotic approach none of the elements making up Anouk's subject web are fixed. There are more or less durable ordering modes, but without any organizing centre. For Anouk this is problematic because she, herself, wants to be the organizing centre of her life. With the hearing loss as the fixed reality and all other subject positions flexible and open for control, she can adjust and be the agent, the source of order and a new identity. However, from a relational viewpoint, individual adjustment will never enable Anouk to do away with her hearing loss. Efforts may be successful for a while, as long as long as disability remains fixed inside the body, or in the individual's immediate control, or as long as the individual can mobilize resources to adjust to the bodily demands.

In response, Anouk could, again, adjust her expectations and ignore the fact that she has trouble following TV debates, or she could find other means to stay informed, in any case, or in the case the quality of subtitling improves, disability – Anouk's problem staying politically informed - would disappear. But, importantly, that does not mean that disability is fixed. It only appears to be for a moment, given the arrangement of social and technical efforts joined to confine it. The very act of having to re-configure practice to enable Anouk to view TV becomes disability. Adjustment and accommodation does not compensate for disability, technical aids, work place adjustments, awareness programs, they do not eviscerate disability, they simply enact it in different ways, orders it in other modes, drawing on a different sociomaterial arrangement. Hence, disability is not what Anouk manages to avoid by adjusting her lifestyle, disability becomes the very act of adjustment. The problem is that the issue of disability is reduced to societal regulation and lifestyle choices. The choice of a lifestyle, the possibility to counter the negative effects of disability through active adjustment, is highlighted, while the implicit notion of a bodily norm to adjust according to the body built into TV programs and work environments is not problematized. Thus, even by undoing disability, Anouk is engaged in doing disability, of producing difference. Then, how to deal with this inequality?

With her adjustment strategy, Anouk is open about her hearing loss and her use of technical aids, she has built a new and more aspirational life for herself, and she copes well in her job. But her way of ordering hearing disability depends not only on what she manages to enact and make visible. In order to normalize as hard of hearing, she has also engaged in a 'pattern of deletion' (Law 1994). She has overthrown her old life, she has lowered expectations, she has chosen to focus on the things she wants to do rather than those she is incapable or not interested in doing. Building order is, thus, as much about making sense of things as it is about trying to get rid of things that do not make sense. In this context, the subtitling issue is interesting, because the relation between poor subtitling quality and loss of hearing results in a disability Anouk is reluctant to ignore, and becomes a source of friction in her life. Friction emerges when the subtitle issue interferes with the normalization strategy Anouk has mobilized to order the hearing loss. Thus far, she has

talked about accepting her loss and adjusting expectations. Now a sense of opposition appears; an unwillingness to adjust to the disabling sociomaterial environment that fails to recognize her right to stay politically informed. She has already adjusted by leaving an active position in the feminist movement behind, now the position as politically informed is at stake. Unable to do something about the subtitling issue herself, she calls for organized efforts; somebody has to fix it, because *this* is a social problem. How are social problems to be solved when it is up to the individual, with the support of rehabilitation professionals, to order their disability by mobilizing subject positions that can be used to diminish its negative effects? What emerges in Anouk's story is the key problem with the individualization of disability - it leaves disabling material surroundings and cultural norms unchallenged. What can be adjusted are the individual and local conditions. Rehabilitation can only deliver normalization if individuals can shift between and use subject positions as resources to compensate for disability, and/or if they lower their expectations for life. For Anouk, who has access to multiple positions, this is a viable strategy, but it implies that those unable to draw on such personal resources are left with the moral responsibility for the failure to cope.

ORDERED BY FATE

> Anouk: "I'm not aware of other disabled people and their problems, but that's just life; 'every house has its cross', something that you have to pay extra attention to. But that's the nature of inequality. You can't take that away with any welfare system. Of course it's ok with disability rights. Disabled people should be able to participate, but then they also have to teach people to be that hard, to fight for oneself to get there. That's very important! You say that it takes a certain kind of person, well, I think you have to learn to be that person, because I wouldn't describe it terms of personally traits, it's just something that you have to add to your personality."

Anouk is positive to recognition and regulation. She is critical towards the market oriented welfare system, but does not reject it; she uses its products and services and is pleased with what she gets out of it. The point is that she sees the enabling effects of technical aids and accommodation programs as the result of her active management. Recognition and redistribution alone is not enough. To get there, she argues, people must take responsibility for themselves and their lives, individuals can, according to her, take control over their destiny and construct an aspirational identity. Anouk, thus, argues for a liberal individualism. Pluralism to her is individuality and difference, but without solidarity. In the individualist ordering mode Anouk has articulated hitherto, the autonomous and rational individual can freely construct its own identity and prosper; 'it is just something that you

have to add to your personality'. But why, then, are there some that do not? When I comment that perhaps everybody is not equally able to mobilize resources, that as a strategy, such individualism may foster inequality, Anouk concurs. Between us, as sociologists, she recognizes inequality as well as difference. Thus, while normalization is a strategy for dealing with disability, with the recognition of society's disabling barriers – the subtitling issue – bodily impairment alone cannot justify the social division that evokes the need for people to adjust in the first place. With marginalization as an overt topic between us, social inequality is hard to delete and the idea of free choice seems hard to defend.

Then something surprising occurs. 'Every house has its cross', Anouk says. Doing so, she does not follow the trail opened in the talk of subtitles. She does not politicize the disparity experienced by disabled people as oppression. Instead, she mobilizes a different ordering mode, that of religion and fate. By mobilizing fate, Anouk rejects structural explanations for disparity. Within an order of fate, disability needs no rationalization; 'that's just life', Anouk says. Thus, instead of evoking claims for redistribution, fate focuses on the individual's own responsibility to compensate for its unfavourable social position, and doing so enacts and, ultimately, justifies a social division among disabled people. It makes a division between those able to utilize individual resources and lead successful lives despite their disability and those unable to prosper, exactly because of their disability.

The mixture of accepting ones fate and carrying an individual responsibility for your destiny is part of a protestant mentality ingrained in Dutch cultural life. Anouk mobilizes this ordering mode when articulating the proverb; 'every house has its cross'.[103] According to the saying, no one is perfect, everybody has their burden to bear. But tied in with that descriptive statement is a normative imperative: 'So I must bear mine'. The proverb actually has a double metaphorical blend, importing structure and elements from two different 'source domains'.[104] The cross on the house refers to the medieval practice of marking a house with a cross when one or more members of the household had fallen victim to the Black Death. The marking of the house, the stigma, was intended to warn people passing not to enter here. The inhabitants of the house could not be helped anymore and should be left to die. Falling victim to the pest was a matter of ill fate, or the wrath of God. The second source domain is the crucifixion of Jesus. The cross Jesus was given to bear represented the burden of all the sins of the people. The pest maps onto Jesus' cross that he bears on his back when ascending Golgotha, and then is nailed to the people's burden, not his own. But Jesus accepts the people's sinful burden as his own, willingly. He suffers the torturing of his body and dies for the salvation of the people, to be resurrected three days

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[103] It was my Dutch supervisor, Ger Wackers, who explained the meaning of this proverb and pointed out its religious connotation and its importance within the Dutch protestant culture.
[104] Lakoff (1987) explains a source domain as a concept that is metaphorically used to provide the means of understanding another concept.

later and return to life, whole again. Jesus provides a role model that is projected into the proverb 'every house has its cross' from which the normative imperative of: '…so I must bear mine' derives. To accept ones cross means acting up to the ideal of Jesus Christ and doing so means that you can be rewarded and made whole again in the afterlife.

Within Disability Studies, Thomas G. Couser (2005) has studied the Christian discourse on disability as fate. In this discourse, disability serves as a trope for a moral or spiritual condition. Both notions of stigma and of fate are relevant here. The implication of the constituting disability as fate is that disability is largely, if not entirely, a function of lack of coping or a personality defect - in effect, moral failing. While the value ascribed to disability in the religious texts is not always negative - consider the notion of the blind as having second sight - Couser argues that the religious discourse always generalizes, stereotypes, and essentializes. It's cost, even when it is not inherently prejudicial, is that it erases individual difference within the group marked off as different. Disability as fate stigmatizes because it makes disability the master status of all those who possess it, reducing their complex identities to a single subject position. In representing one such individual, it characterizes them all.

While Couser traces the discourse on fate through studies of literature, Ingunn Moser (Moser 2003) has traced its ordering in everyday life. According to her, fate, as a mode of ordering disability, enacts disability as an outcome of circumstances and forces beyond anyone's control. (Dis-)ability in fate is left to chance, and so outside the reign of human rationality, mastery and management. Fate enacts disability as one's lot in life. Similarly to Couser, Moser also points to the individualizing effects of fate as a mode of ordering disability:

> Disability is more often than not constituted as 'tragic fate' and so suffering. And so the responsibility for caring for those who are destined to suffer a hard fate is often individualized, too and distributed into the realm of private rather than public matters (Moser 2003:276).

For disabled people fate can be a source of reconciliation in that it assigns a higher meaning to their position in life. It produces goods. But fate also has its limits in that it works to depoliticize the experience of disability. As subject to fate, one is expected to accept one's destiny and deal with it as a personal problem. In this process of dealing with the hearing loss, it is legitimate to seek professional help, but it is not legitimate to blame others for the problems one encounters. One should not point to societal causes for the marginalization and discrimination of disabled people because these are part of the burden one must bear, and the more one suffers, the more worthy one becomes.

When Anouk presents hard of hearing people as unfortunate, and says 'that's just life', she also disconnects and isolates their fates from the politics of disabling arrangements and environments and as politics of redistribution. Moser notes that, since within this order of fate, no one can be blamed or made responsible, it makes little sense to claim that one – society or state – should take action. Since there is nothing to be done about disability as fate, what is left for care is only to diminish suffering. Here, in contrast to Couser, Moser is not merely concerned with the costs of fate, she also points to its goods. From the perspective of society, fate tends to generate pity, compassion, and a protective charitable attitude and actions on the part of fellow beings and shapes the relations between providers and receivers of help in a particular way; the able as independent, the disabled as dependent. From the perspective of the disabled subject fate means that one does not have to politicize, rationalize, prioritizes, plan, manage, and answer for ones choices and actions. One does not have to demonstrate ambition, live up to expectations, prove something. There is no need to be competent and capable all the time. According to Moser, subscribing to an order of fate allows the disabled individual to accept and remain passive about its misfortune. Fate frees one from the, arguably, strenuous arrangement of normalization and allows one to leave one's destiny in the hands of higher power.

Misfortune and tragedy, de-politicization and individualization, stigmatization and charity - Anouk articulates these elements of fate. Yet, there is also more to her story. In her case, disability does not only produce stigma, it also becomes a symbol of her outstanding abilities. What is more, positioning within an order of fate does not work to enact Anouk as a passive and unambitious subject. Instead fate becomes the source of action and ambition.

AN EXCEPTIONAL INDIVIDUAL

I described my own reaction towards Anouk's fate with surprise. For a social scientist to rationalize disability and justify disparity with reference to a higher power was not only unexpected, it seemed outmoded. The medical model on disability, emerging with modernity, ultimately came to replace the dominant position of fate. Doctors and scientists sought to demystify, de-moralize, and naturalize somatic aberrancy, stripping away any supernatural or moral significance and insisting that human variation is a matter of a defect or irregularity in the individual body that medicine could prevent, cure, fix, or rehabilitate. Disability as fate was the mode of ordering that normalization sought to replace, and successfully too. Today fate is a discourse that has more or less disappeared from the public scene, as Moser explains, often considered a relic of the past:

> It finds little place in a worlds in which ambition, dynamism, progress, career and emancipation are highly valued goods - whereas accepting the situation as it is, without wanting or being able to move on, change and emancipated comes out as failure. It is the definitive bad. But accepting the circumstances, and the coincidences of the given

In Anouk's story, an order of fate appears and takes over when normalization cannot delete or explain disparity. Yet, as I will argue below, it is not fate in its pure form, as depicted in the writings of Couser and Moser. From the relationality between fate and normalization a difference emerges, which is not necessarily in contradiction to their arguments. Both authors acknowledge the dominance of normalization, but they also argue that normalization has not entirely replaced fate. Instead, these two modes of ordering co-exist. And they have continued to co-exist despite the enormous efforts put into normalization. The relationality between these two ordering modes - normalization and fate - is the source of Anouk's positional strategy.

For Couser, the main implication of disability as fate is its stigmatization of the individual. In Anouk's story, the metaphor adds a normative imperative to the stigma; the cross she must bear. She argues that the individual is responsible for taking control of one's destiny and can cope despite disability. In her story, she opens a space for resurrection, and a position for herself as someone actively and successfully dealing with her fate. From this position, disability can be enacted not as something inherently negative, but may also become a source of something good, of social admiration instead of condemnation. Here fate, as I read it from Anouk's story, also differs from what Moser finds in her empirical material. Moser traces a version of fate that produces a passive subject without ambitions. Fate then enacts a situation in which the individual can refrain from action and leave its life into the hands of a higher power. Fate for Anouk also refers to a higher power, to Jesus Christ. The difference to the first version of fate is that the protestant ethics Anouk mobilizes adds to the notion of tragic fate; a normative requirement for individual action. If Anouk is to become the worthy, she must actively deal with her disability. Anouk must accept her fate, but instead of passively accepting her disability, she must strive to become successful in life, despite her misfortune. People should learn to 'be hard, to fight for oneself, to get there', Anouk says. To earn a position in the afterlife one must first prove oneself worthy by being capable of earthly success. Evoking fate, Anouk not only seeks to explain for social disparity, doing so she constructs a social antagonism between those willingly accepting and proficiently dealing with their disability and those unable to deal with their disability, falling outside society, losing their jobs, feeling isolated or not benefiting from hearing technologies. Consequently, with reference to her own success, Anouk can position on the worthy side of this social divide.

Thus, in Anouk's story, fate does not inevitably set disability off as a negative difference, and fate does not always result in passivity. What is more, fate as a mode of ordering disability does not always and necessarily reject or oppose normalization. In the case of Anouk, fate is what fuels her will to succeed, what drives her to becoming 'normal'. To do what normal people do, have a normal job and partake in normal social life. Here then, fate is not the definitive bad of normalization. Instead, fate interferes with normalization and produces the exceptional individual. Anouk's is a story of remarkable success, in it disability is not a stigma, a negative mark, but symbolizes her ability to rise above. The positional strategy thus emerges from the relationality of two ordering modes, normalization and fate. On the one hand, Anouk's story enacts fate. Her disability is the tragic outcome of a surgery gone wrong, an incident beyond her individual control which has left her worse off than hearing people. The hearing disability is Anouk's cross, the burden she must bear. But because of her active positioning, Anouk's story is not one of personal tragedy and loss; on the contrary, it is a personal success story. Instead of growing hatred or becoming passive, she escapes a destructive relationship and uses her energy to build a new life for herself. In the process, she also comes to accept her hearing loss as something fixed that can be adjusted to. Anouk is determined not to be a burden for others. She wants to manage what hearing people do, so she subscribes to an order of normalization in which work becomes a key arena. Taking use of technical aids and making the priorities and compensations needed to enable her to perform on par with her hearing colleagues is what, according to Anouk, makes her normal. Thus while normalization is her main strategy, for Anouk, fate intervenes to take over when the logic of normalization runs short. Combining a multiple view on identity with the individualization of disability the story paradoxically contains both a sense of tragic fate and a notion of being in control of destiny. The individualization of disability underlying normalization is, in fact, reinforced through the meeting between fate and adjustment.

While this strategy works for Anouk, what does it do for the social status of hard of hearing people? The question here is not whether normalization (i.e. through medical treatments and assistive aids) or fate (i.e. leading to reconciliation) has done any good for people with disabilities 'in real life', which is undeniable, but what their implications are as 'modes of ordering'. Although they do not necessarily essentialize conditions, both medicine and fate may represent conditions in ways that are inimical to the best interests of those who have them insofar as it suggests that the problem resides entirely in a defective body. Both ordering modes, thus, put the burden on people with disabilities to adapt themselves to their environment; they can function in society only to the extent that their disability can be normalized. When, in addition, those who are not capable of such adjustments are deemed morally unworthy, themselves responsible for their lack of coming to terms with, and carry their 'cross', what results is a potent justification for the marginalization and discrimination of disabled people.

In part III, *Audiological Practices*, I discussed how technical audiologists work to reconstruct soundscapes according to an assumed normal hearing. The tendency to record differences, compare these to constructed standards, and find ways to close gaps is not only found in audiological practices, but prevails in other key societal institutions. In this chapter, I showed how a normalizing order became enacted in the context of work. With a material semiotic sensibility to the social *and* material enactment of disability, I worked with the stories of Marianne and Anouk to demonstrate not only the advantages, but also the efforts that goes into becoming 'normal' at work. The critical question surfacing from their stories is this; if, as predicated by activation policy, it is indeed possible to close the disability gap, what are the benefits and costs in the light of broader identity projects?

NORMALIZATION AT WORK

Marianne and Anouk strive to live 'normal' lives as hard of hearing. Both put high value to their jobs, not only as a means for income, but as a site where they can enact themselves as competent, contributing, and coping citizens. Marianne says she does not want to be seen as someone with a hearing aid who has made it, just someone who has made it. Anouk says that contrary to many hearing disabled people who do not mingle with colleagues she invests a lot of energy in being social because that, for her, makes her a normal person. For these two, going to work means taking part in normal life, work is a place where they can become like everybody else. But Marianne and Anouk not only go to work to be normal, they also work a lot to be normal.

Since there simply is not enough energy to cope with it all, attending work means having to make strict *priorities*. Marianne has prioritized studies and work all her life. She goes home exhausted from managing all the strategies she applies to conceal her hearing loss. When the working day is over, there is no any energy left for movies and parties. Anouk also makes priorities. She invests a great deal in her job, including the social events. Even though Anouk has great difficulties hearing in these situations, she has not stopped going to the canteen or the pub with colleagues. Her first priority is not to be able to hear everything that is said, but to take part in the social community at work. Next to their strict priorities, both Marianne and Anouk work a lot to *compensate* for hearing loss. Marianne works double as hard as everybody else. She is always well prepared, in addition she cross-checks information with colleagues to make sure she is up to date. Anouk gets much help from her technical aids. In addition, she takes advantage of her sociological sensibilities when mingling with colleagues. Despite their efforts', there are also things that cannot be

compensated for; messages that slip, a joke that is not heard, a meaning misunderstood. These episodes of miscommunication are part of their hard of hearing experience of living and working in a hearing world. Cautious not to expose their disabilities and maintain a status as normal, Marianne and Anouk choose to *ignore* and conceal their problems hearing. Marianne says she just want things to go as smooth as possible, she wants to be able to do her job and lead normal conversations without having to make people aware of her special needs all the time. Anouk is not always able to hear the joke, but when everybody else starts laughing, she laughs too; 'you just embarrass everybody if you constantly ask them to repeat things', she says. When Marianne and Anouk experience frictions, tensions, and interruptions, they try to conceal their hearing problems. They lower their expectations to social life, they work double as hard as their colleagues, and they ignore incidents of exclusion. Rather than to politicize their experience, Marianne and Anouk have developed two positional strategies that by way of compensation, prioritization, and deletion seeks to build and fix in place an order of the normal, and turn them into competent employees.

In the context of their careers, a competent colleague is someone who is not only formally qualified for the job, but also has the social ability to adapt to people and situations in highly relational, dynamic, and international work environments. A competent colleague is able to communicate in a highly flexible manner, to manage streams of talk, information, and decision-making flowing through the work place, seemingly effortlessly and without considerations for the bodily medium. Disability, what is sought undone, is constituted as a breakdown of the normal, like the inability to hear in meetings, inability to talk on the phone, inability to eavesdrop on colleagues in an open office landscape, and inability to make decisions during encounters in the hallway. Disability is frictions; slips, interruptions and misunderstandings. Disability brings communicative contingencies into view and forces people to become aware of, and adjust to their ears at work. Disability, in other words, is what interferes with the expectations towards being a competent colleague. Expectations that Anouk and Marianne strive to meet as they struggle to undo disability and become 'normal'. Normalization, in their case, means to find ways to close the communicative gap at work. It means for Anouk and Marianne to access the flow of information, communication and decision-making by adjusting to the way their colleagues speak. For this, not only technical aids are adopted. Their normalization strategies include social, psychological and environmental adjustments too. The fundamental aim is to integrate the disabled individuals at work. Integration means enabling them to do their jobs in a presumed 'normal' working environment. In this interpretation, disability is a property of Marianne and Anouk. Disability is their lack of ability to function and do certain activities that are considered normal and common for their colleagues. Integration comes by ways of compensation. But how innate and effortless are the communication abilities of their colleagues really?

Moser (2006a) has argued that agency, in our case the ability to contribute competently at work, is not an inherent property of particular and bounded human bodies. Applying semiotic sensibilities she argues that agency is always mediated. People are not actors. People are enabled to act in and by the practices and relations in which they are located. People become agents because agency is distributed and attributed in the routines we follow, and the expectations we strive to live up to, ideas of the normal, good life. What is more, such agency is also enacted materially. People become agents because agency is distributed and attributed in the materials we apply.[105] In this framework, the production of ability and, thus, also disability, is an effect not merely of social norms, stereotypes, political ideas, and working routines. Expectations about 'the normal' are built into materials and environments as well. Thus, we should scrutinize the role of material arrangements in (dis-)abling interaction.

Marianne and Anouk live and work in a hearing world. A world in which the ability to function in a noisy canteen, use a standard phone, and communicate on the way into a meeting, is taken for granted. Standard physical environments and technical equipment - such as phones, conference rooms, and open office landscapes - are readily in tune with 'normal' hearing. These environments and artefacts enable the smooth and effortless flow of information and communication between hearing people. This world is, quite literally, built on, and contributes to build expectations towards competence. Norms that hearing people fit into, communication standards at work that they can live up to, materials that enact them as competent colleagues. Since their hearing is compatible with the standard environments, there is no need for them between to be aware of, or adjust to communicative contingencies. The compatibility between material environment, technological artefacts, and hearing people grants them with what appears to be a natural capacity to act. The work environment enacts them as competent colleagues, versatile to the dynamics of auditory sites and situations. Within these walls, using these tools, their hearing, which their competencies and abilities rest upon, becomes invisible. Sociomaterial arrangements enable standardized bodies and subjectivities to disappear into the background and allow hearing people to appear as detached, independent, bounded and with inherent capacities for work.[106] Hearing is not a given, individual property, it is an achievement which emerges in and between the sociomaterial arrangements at work. It is a setting that produces abilities. It is also a world in which the inability to follow these standards sets one out as different and enacts special needs. It is a setting that produces disability as well.

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[105] Here Moser rests on the work of Susan Leigh Star (2000; 1999; 1991) who has developed a symbolic interactionism take on embodiment and standardization within STS.
[106] The 'abled bodies disappearing into the background' metaphor is taken from Moser (2006a).

When expectations about hearing are built into the physical environments and materials at work, friction results when these are entered and used by someone hard of hearing. Marianne and Anouk experience disability because of the clash between their non-standardized bodies and standard technologies and environments. Their hearing does not fit with the customary environments and tools that allow information and communication to flow seemingly effortlessly, without interruptions. Instead their hearing becomes a disturbing element of social interaction. To manage their bodily difference within a materially enacted order of the normal means having to adjust to standardized work environments and tools. In this situation, disability is not a given result of loss of hearing alone. Disability emerges in sites and situations beyond Marianne and Anouk's individual bodies and beyond their individual control. Material surroundings and technological artefacts that sometimes enable and other times disable Marianne and Anouk in doing their job on par with their hearing colleagues. Sociomaterial relations that enact them as different, problematic; in need of ordering, and give rise to disabilities that must be compensated for, tensions to be deleted, and priorities to be made. While Marianne chooses to leave her job at the IT firm, Anouk stays in her position at the university. In the following, I discuss the consequences of their choices in terms of the risks of normalization.

ENTRANCE FEE

To stay in her job, Anouk continues to make tough priorities and adjust her expectations to life in order to feel included in a social community that matters for her, colleagues and technical aids that enact her as a strong and positive individual. But there is also ambivalence to her positioning at work. The SmartLink produces expectations among her colleagues. For Anouk these expectations are a double-edged sword, simultaneously enabling and disabling. With technical aids, Anouk participates in meetings and social events. People believe in her gadget, it enacts her as a competent and coping member of staff. But even with technical aids Anouk has problems with hearing, but she does not want to ask people to accommodate because; 'that would just embarrass everybody'. What I suggest, is that concealment is not just done out of consideration for colleagues, but also plays a broader role in terms of her positional strategy. Adjustment as a positional strategy, builds on normalization, the idea that with technical aids *and* extraordinary individual efforts, it is indeed possible to undo disability. Within this normalizing order the subject position as the exceptional individual becomes available. The normalizing order, thus, becomes the source of her equal, if not superior, standing among her colleagues. Here then, the position as the exceptional individual comes to depend on people believing in and expecting a technical fix; that technology enables communication flows and compensates for disability. Therefore, when the strategy is to appear as normalized through adjustment - technological and social - in order to maintain the impression that the technology enables

her to participate on par, she cannot reveal her problems hearing. Instead, she must continue to accommodate a hearing world by adjusting her expectations to life, and by compensating for, and concealing disability. Colleagues cannot be aware of the limits of normalization, and she cannot ask people to consider her problems hearing, even with aids; because her strategy hinges on the chimera of normalization. For Anouk, what makes the costs of normalization worthwhile is the position as an exceptional individual, the idea that despite her hearing disability *she* can take part in normal social life.

Here then, normalization produces goods, but also costs. The problem with normalization is that it represents disability as an inherent property of the individual, an idea internalized by Anouk. In her story, it is her and her hearing that has to be adjusted to fit into a hearing world. She must be enabled to work on par with her hearing colleagues. As long as reality is built on the assumption that there is a universal, and so 'normal' body, non-standardized bodies will always come out as problematic and in need. It is not that society does not take its share, on the contrary; an entire arrangement of compensatory means is instigated to close the gap. Nevertheless, the responsibility for making the arrangement work is often individualized. It is Anouk who must figure out which employer to ask for reimbursement. What is more, contrary to the logic of normalization, technical aids cannot compensate for, or do away with disability. Technical aids do not produce 'normal' subjects. The gap is still there. What is also there, is a new set of expectations and demands; 'now as we have accommodated you...' leaving the individual with the responsibility to accommodate a hearing world. To have a hard of hearing career means having to live up to the expectations and demands of a hearing world. To become included at work means having to accept the prioritization, compensation, and deletion needed to make up for non-standard hearing. Yet, the invisible work hard of hearing people have to do in order to manage the functions, most take for granted, i.e. talking on the phone, taking part in meetings, are tasks that do not fit easily with the notion of work as any activity (whether paid or not) that involves the production of goods or services for consumption by others (Taylor 2004). Such invisible work tends instead to remain invisible, undervalued, and unpaid. These are costs of inclusion that disabled individuals have to carry alone, without recognition.

EXIT COSTS

When Marianne gets the conference equipment her colleagues tell her they will allow her time to test it, which implicitly means that they expect her to use it, and by using it, be enabled to work as normal. However, while the equipment might help Marianne hear better in meetings, installing it, turning it on, finding the remote, changing programs, all makes her disability visible and present in the situations. For Marianne this is worse than not being able to hear everything, because it is not lack of sound, but an inferior social

status that Marianne fears; that, for her, is disability. So while Anouk chooses to continue her hard of hearing career, Marianne's choice is different. Her's also entails risks, but these are different from the costs of staying in the job. Marianne cannot cope with the all the invisible work, the strict priorities and the deletion of social life anymore. Encouraged by the birth of her third child, she decides to prioritize her family, change career path, and move back home. With a different and reduced job she can do her disability in new ways. Marianne feels that she has done the right thing. For her this is an honest move.

Yet, there is also a friction in her story. An implicit premise of activation policy is the idea of work as the route towards the good life, the main arena for self-realization, a place to become normal. Normalization creates expectations. The expectations are that once Marianne is included in the workplace and has gotten technical aids, she should also be successful at work. To give up a professional career, to priorities family, to move away from urban life, these are elements that do not fit with normalization, in this framework her new life is a downscaling. When the individual fails to live up to the norm, new feelings of failure, lack and loss are produced. Disability is having to abandon your career and live with the feeling of not being able to cope because one can no longer prioritize work, all the extra work becomes too much, and the tension arising from the cross pull of subject positions is too strong to ignore. In this ordering mode, Marianne's choice to give up her career enacts a failure to activate her given abilities. By given abilities, I do not only mean the competencies and skills Marianne has acquired through education and work experience. I also mean the failure to live up to redistributed abilities, a failure to produce return on the inclusion and accommodation provided by society. It is Marianne who fails to meet the standards and expectations at work. Tied up with this, is an implicit acceptance of the invisible work, strict priorities, and, arguably, quite stern deletions Anouk performs in order to maintain her professional life. But here, as with Anouk, another order interferes with normalization. The mobilization of the family order works to draw focus away from Marianne's inability to live up to the expectations of work. It is an ordering which liberate her from the judgments of normalization, ideas of downscaling and experiences of failure, lack and loss. She mobilizes something else instead, an order of the family and another way of positioning, as a mother and a wife, which gives her choice a different status, assessed according to other demands and expectations. The relationality between the ordering modes and her ability to draw on her multiple self becomes the source of stability.

TIME TO WORK ON THE NORM?

In policies aiming at equality and inclusion, activation is a key instrument and the job market a key implementation area for the integration of disabled people. The aim is to facilitate disabled peoples' entry into paid work. Integration means closing the gap

between individual abilities and society's expectations and demands. To close the disability gap, universal rights are instigated to improve access to work and technical aids are provided to make up for bodily differences. Simultaneously, expectations are created that they can and should integrate as 'normal' people. In policy documents, European governments have accentuated its commitment to 'mutuality' or the rights and obligations of both society and disabled people towards each other. In reality, however, most of them have relied on variants of supply side and individual approaches (Hyde 1996; Martin et al 2004; OECD 2003; Roulstone 2000). These centre on education and training programs, distribution of technical aids, and various inducement schemes for employers to take on disabled workers. Overall, the focus has been on employability or making individual disabled people more 'attractive' to potential employers by enhancing their skills and further training. As Moser points out, the problem with the gap model is that; 'crucially, the gap or misfit is attributed to individual loss or lack of function, and identified as a condition in the individualized body rather than as a problem with the standards or requirements of the environment, which leads to produce disabilities all over again.

When technical aids are designed and distributed according to a logic of normalization, the strategy is to compensate and limit the consequences of reduced functions for the individual. As long as the focus is on the adjustment of the individual the core ideology continues to be normalization, and integration means the assimilation of disabled people into existing structures, practices and routines of society. The problem with compensatory strategies focusing on individual rights, technical aids, and lifestyle choices is that disabled people have to prove they can meet the requirements of society and not the other way around. Non-disabled people are seen as having natural abilities and competencies, while disabled people must be made into normal beings, they must be accommodated in order to work.

In this context, a material semiotic approach is important because it illuminates the material enactment of disability and, thus, points to disabling elements beyond individual control. In this framework the 'othering' of disabled people at work is linked not only to individual impairments, but emerge from sociomaterial arrangements at work. Physical environments and technological artefacts are built according to standard hearing and enact abilities as well as disabilities, they are neither neutral nor innocent, but take part in the ordering of disability in everyday life. It is the gap between this constructed norm and the deviant individual that technical aids are designed to close. However, when technology fails to produce normal subjects the work with making up for the enduring gap is individualized too. In practice, although with the support of governmental funds and services, the misfit is attributed to the individual loss or lack of function, and identified as a condition in the individualized body rather than as a problem with the standards or requirements of the

environment. This is because technical aids implicitly include an acceptance of the societal definition of 'normality' as a fixed given.

Through the analysis of two hard of hearing careers I have argued that sociomaterial relationships with the norm shapes disability and constrains disabled people by reducing their difference to that of something missing, something to be compensated for, situations to be normalized. In both cases, new experiences of failure, lack and loss emerge, demanding ordering. In the case of Marianne and Anouk, it is not so much society that accommodates the disabled individual, but the individual that works to accommodate a normalizing society. As critical cases, their stories revealed the work involved in accommodating the normal and thereby disturb the idea that it is possible, relatively cost free, to produce normal subjects, and thereby make it less acceptable as a (implicit) political strategy.

Two decades after the UN declaration of the Equal Rights for People with Disabilities it should evoke critical reflection to see that despite the avowed commitment to get more disabled people into employment through activation schemes the overall results have been disappointing and uneven. Indeed while most European countries have introduced policies to increase the numbers of disabled people in paid work, none has achieved the significant improvement anticipated (Martin et al 2004:23). Given that it is highly unlikely that one will be able to eradicate the environmental and cultural barriers that excludes disabled people from work perhaps it is time to consider whether employment should continue to be the place where disabled people 'discover' and 'realize' their central identities? How did we come to create and accept all these expectations as normal, after all, is it not the inability to live up to these expectations that create the feeling of failure, lack and loss? Obviously, by questioning activation policies, my argument is not that hard of hearing people should not work, or that they cannot have success in so doing. Nor is my argument that all hard of hearing careers involve extreme priorities, excruciating compensations, and inevitable experiences of exclusion. How disabled people manage and prioritize their lives around domestic labour, paid employments and other activities is of course a matter of choice, obligation and necessity. Rather the point of the analysis has been to provide a counterweight to the dominant notion that full inclusion and participation of disabled people in society is always and necessarily beneficial. When normalization policies fail to provide a social and technical fix and at the same time individualize and hide the struggle to fit constructed standards, disability is produced and legitimated all over again.

Despite all policy action against employment barriers, and despite all efforts put into accommodating work, Marianne and Anouk still struggle to enact themselves as competent colleagues. Based on this, all disabled people can or should not be expected to enter the conventional labour market. But in a culture that generally values work activity, it begs such questions as what sort of projects are available and what sort of 'security' is provided

for those who remain outside the paid labour market? And how are alternative lifestyles valued, the activities that normalization through work makes invisible, silences, and suppresses? While current disability policies invite us to include and celebrate difference, what room and resources are made available for positioning outside the mainstream? Both Anouk and Marianne strive to enact an order of the normal. Kari, whom we shall meet next, challenges the normal. When it is too tough to be included, she finds a different project to give her life meaning. In her case, I explore the costs and benefits of enacting difference.

INTRODUCTION

In the previous chapter, I discussed how employment, as a key area for the inclusion of disabled people, has given rise to a large compensatory arrangement aiming to integrate disabled people at work. Despite all benevolent effort that goes into bridging the disability gap, attempts to 'normalize' disabled people through policies, legislations, and technical aids have not yet succeeded in doing away with disability. Instead normalization strategies produce new costs and risks for disabled individuals. But what room and resources are there for positioning outside the mainstream, for alternative ways of enacting and ordering a hearing loss in the context of everyday life?

In order to explore this I introduce Kari whose life project differs from the rest. Whilst Reidar, Bart, Marianne and Anouk in some way or another struggled to get, keep, or change a position at work. Becoming hard of hearing late in life, Kari, instead, chooses to leave her job and her 'normal' life behind to indulge in sports. Drawing on Ingunn Moser's (2003) work on the ordering of disability, I analyse her choice as an enactment of passion. Working with the empirical material with Kari, I trace passion as a mode of ordering disability that enables the enactment of difference. I am interested in what subject is enabled through an order of passion, what elements go into its enactment, and what form of agency is made possible in these sociomaterial relations. What the analysis shows, is that it is not easy to escape normalization. For Kari, to enact passion depends on her access to the goods of normalization. In the light of this modal relationality, I discuss the costs and benefits of being positioned in between.

THE EXTREME SPORT OF LIFE

Kari: "I used to have an interesting and challenging job with much communication. After my hearing loss I couldn't manage anymore. I had to give it up. I knew from the moment I left my job that life was going to be very different. I guess I could have just sat down and said my life is over. Well, it hasn't been easy…But I'm an extremely competitive person. I have this urge to succeed. So it was

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really important for me to find new challenges. I looked to my other
big passion in life, sports. Sports has always been a part of me,
now it gives my life a new meaning. This time of the year I go off
piste skiing with friends. With the blue skies, crisp snow and the
sun shining, life couldn't be better!"
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Kari Sjoa (49) has read about my research on the internet and invites me to come spend a day with her to learn about her experiences as hard of hearing. She tells me that her life took a turn ten years ago when she was diagnosed with a double-sided progressive hearing loss. She became extremely sensitive towards noise, but unable to understand the meaning of words. At the time she lived in Trondheim, working as the headmaster of a high school. With her hearing loss she could no longer cope and had to leave the job that she had worked hard to get and thrived in, for a disability pension. With the hearing loss, the subject web that Kari used to function in changed. Positions that before felt safe and gave her life meaning and direction were now enacting her disability not her abilities.

Even though she loved Trondheim, the place she grew up and has most of her friends, her sensitivity towards traffic noise and big crowds made city life unbearable. When she lost the ability to talk on the phone she also found it difficult to stay in touch with friends. Kari could have given up, lived on her disability pension and done nothing, but instead she looked for an alternative life project. Unlike Marianne and Anouk, Kari does not look for ways to compensate for her disability in order to make it possible to restore a normal life. She does not try to accommodate a job and city life, nor does she live with a feeling of lack and loss, because she has another big passion in life. Outdoor adventures and sports had always been an important part of her life, now this has become the key to the realization of Kari's new self. She moves from Trondheim to Oppdal, a small, peaceful mountain municipality known as a paradise for outdoor sports. Here she can do all the sports she wants to; kayaking, skiing, paragliding, kiting, waterskiing, you name it. Summer or winter, land or water, as long as it is fast and requires a high level of skill Kari says she is out there to explore her bodily capacities. For Kari, passion is more than just the feeling of fresh air, sunshine and powdered snow. As she leaves her old life behind, passion also becomes a way of life, an alternative to normalization.

PASSIONATE ORDERING

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When we arrive at Kari's place, I enter a hallway full of sports
gear; skis, clothes, sneakers, a pair of rowing blades, a bicycle.
The apartment is quite shabby. Kari nods to a piece of wallpaper
coming off the wall and explains that it's an old student shack, but
located at the foot of downhill facilities it's perfect for a ski
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Ingunn Moser (2003) traces and theorizes passion in her work on the ordering of
disability. She does not find it so much in disability discourse, medical practices or
policy documents; here passion is not listed as an alternative to normalization.
Becoming disabled through an order of passion is not about ways of integrating
disabled people into society – but neither is it about disabled people as being outside
of society in the first place. It is not about disability as a social or political phenomenon
that must be recognized and redistributed – it is not even about disability as such. It is
rather about life as an individual project, and about the identification and realization of this
project. Disabled or not. Moser describes the passionate subject as dynamic and creative.
Passion thrives on the productive tension between activity and passiveness, the passionate
subject is simultaneously involved in setting up and letting go to passion. Passion produces
effects that can not be accounted for, and which, therefore, sits uneasy with normalization.

Normalization, rehabilitation and re-integration into work and city life is what Kari strives
to escape. But how is this done, how does one enact passion? What elements go into
building an order of passion? How does Kari become a passionate subject? For one, she
takes action. She says she could have given up. Her life could have ended there. It did not.
Instead she starts to look for new challenges, other ways to become active. Kari talks about
her lifestyle, as an individualist and about her competitive spirit. On her wall she has
certificates and pictures from courses, trips and excursions she has done, on the table there
are extreme sports magazines, in the hallway there is gear, even the wallpaper coming off
the wall enacts and orders her passion for sports. But how does disability fit into the
picture?

> <u>Kari</u>: "Often hard of hearing people have others do their errands to
> avoid difficult situations, but I want to manage on my own, like
> everybody else. I'm often alone; it has to do with my lifestyle. I
> prioritize myself and my things. Now that I can't talk on the phone
> anymore, my mobile has become a great friend. Last week when I
> delivered my sewing machine for repair I told them at the store that
> they can't call, but I've got no problems with SMS. Yesterday I got
> the message my machine was ready. It's so neat!"

Kari mobilizes a differential system when she talks about disability. She says that her hearing loss makes her different from people with a 'normal' hearing, those able to talk on the phone, have a job and live city life. Despite her difference Kari wants to be able to do the same things as everybody else. Looking for ways to facilitate communication she is enthused about the enabling potential of her mobile. But Kari is not only concerned with bridging differences. She also draws on difference to differentiate her own position on disability from that of 'other hard of hearing people'. Kari wants to manage on her own, she looks for ways to get people to know her and her individual abilities. In the interview, she says that most hard of hearing people rather drink coffee and complain about their problems than actually do something about it. With her reference to 'other hard of hearing', those who have others do their errands or who stay at home with their disability pensions, Kari enacts disabled people in a manner which sets them off as different from hearing people. Normally, she says, disabled people go passive, they lose their ambitions, they cannot cope, and they look for easy solutions. Kari, however, is neither normal hearing, nor normal hard of hearing. The things she does are not ordinary and she would never take the easy way out. She seeks out challenges, things that are exceptional, extreme and demanding. Kari does not, after all, want to be as everybody else, she wants to be unique.

On this, Moser has written that what is enacted through passion is a double differentiation. Kari does not merely enact a distinction between her and other hard of hearing people. The passionate subject also rests upon and reproduces the underlying distinction between disabled and non-disabled people. For Kari who seeks new challenges, trust in her own abilities and the determination to succeed is a way of becoming able, an alternative to the mainstream way of life, disabled or not. Kari is unconventional. In the way she uses technology, the activities she engages with, the lifestyle she leads she transcends hard of hearing people's restrictions by going to the extreme. Mobilizing sports as a way of life, she seeks to be more active and tougher even than normal hearing people are. Instead of living the failure of not coping in her job, unable to stay in touch with friends, passion, becomes an alternative to the more given mode of becoming disabled – that of subjecting oneself to normalization, and becoming as neutral and ordinary as possible.

The differentiation from 'normalization', from normal people and normal hard of hearing people is enacted also in Kari's use of technical aids. Recall how in chapter 8, *Designing Disability*, I argued that hearing aid producers are fixated on making technical aids 'near invisible' in order for users to avoid being stigmatized by their hearing disability. In this sense, minimization is a design strategy geared towards normalization. The idea is that if people can use technical aids unnoticed then their subjectivity will become disconnected from their disabled, shameful bodies, and they will appear as 'normal'. In contrast to normalization, Moser has argued that within an order of passion, technology is not used to

perform a Cartesian split between body and mind. Within an order of passion, technology makes possible a hybrid form of agency, which builds on intimate relationships between human and machines. Enacting passion, Kari does not wear hearing aids to hide disability, avoid stigma and normalize the hard of hearing subject. Her story is not about becoming normal. The body that goes with the passionate subject is not required to disappear into the background. The passionate body is not supposed to be neutral and invisible, but intense, present, sensual and visible. Therefore, hearing aids should not be miniature or skin coloured. On the contrary, Kari searches the internet for technical aids that are in tune with the rest of the passionate subject; creative, extreme, and dressed in orange. Enacting passion means celebrating difference, not suppressing it. As elements of passion, technical aids add to the double differentiation distinguishing Kari from the rest. Hearing aids *should* mark her off as different, different from all kinds of 'normal' people, those who want to blend in.

By using technology to exposit her difference, Kari builds relations to other passionate subjects she wants to identify with. She tells me that friends in the extreme sports community understand and respect her, not despite of, but because of her disability. When she tells them she is hard of hearing, they relate, not to stories of loss, lack and pity but to; 'the dude who went surfing in South Africa for a year and caught a 'surfer's ear',[107] or; 'that guy who lost his hearing from frost damage during a polar expedition'. Talking about her hearing loss from a position within the extreme sport community, disability is enacted as the price of living life to the max, pushing your body to the extreme, and taking part in exhilarating and noxious activities. In relation to these stories, the hearing aid becomes like the scar tissue stemming from a parachute jump gone bad, or the stitched up finger ripped off during terrain biking. In relation to these bodily injuries, Kari's technical aids are enacted as trophies, proof of the passionate subject's extremity, lack of fear, ability and willingness to let go, give into, and explore the intense experience of passion.

Then, what are the sociomaterial conditions, the artefacts, arrangements and techniques that dispose Kari for passion and allow her to challenge herself to avoid the neutral passive state of normalization? How is passion done? Kari talks about several ongoing projects, ideas to be realized; kiting on the snowy mountain, a sailing trip in the Caribbean, hitch-hiking a year in India, and so on. There is no solid plan behind these projects. Instead, ideas appear on the basis of sporadic encounters and opportunities arising, and they are realized with heterogeneous means; such as the time she went for her paragliding certificate.

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[107] A 'surfer's ear' affects people who expose their bodies to cold water next to the ear drums. When this occurs frequently, over a period of years, the ear adapts by reducing the size of the ear canal with bony growths. If left untreated the ear canal can completely and permanently close causing ear infections and/or hearing loss.

<u>Kari</u>: "So far I haven't met any hard of hearing people that are as
hooked on technology as me. At the Assistive Technology Centre they
think that I demand too much equipment, and that my use is too
unconventional. Like when I went for my paragliding certificate.
There I was, ready to fly. At first I thought I could just throw
myself into it. But there's a lot of equipment; wing, harness,
breaks, and a radio. There are several different techniques to be
mastered; descending trough B-line-stall, big ears, or spiral dive,
launching forwards, reversed, or towed… well you get the point, it's
complicated so I realized I needed verbal instructions in the air.

I figured I could use my FM equipment. I could give the sender to
the instructor on the ground and mount the receiver to my helmet.
The only problem was that I needed two senders because I had two
instructors; one helping me take-off, the other getting me safe down
again. I went to the Assistive Technology Centre to borrow an extra
set, but the consultant got really angry; 'you can't use our
equipment for that, it is for indoor use', he said. He was sure it
wasn't going to work, it was technically impossible to mount two
senders to a helmet and even if I did, the mountainous area we flew
in would block the radio signals… I mean, instead of saying; 'maybe,
we'll try figure it out', what you get when you try to do something
constructive about your life - in a not so wanted life situation -
is people who tell you what you can't do! No way, I was going to
give up that easily. I went to a friend of mine, also hard of
hearing, and borrowed her equipment. Then I visited the local HiFi
store and laid out my plan. The store manager got really excited and
helped me with the wiring. It worked! My certificate hangs right
there on the wall.

When I was back at the Assistive Technology Centre I showed the
consultant the certificate. At first he got angry again. Well, he
soon softened up and had to admit he was impressed. He wanted to
know how it worked, and I had to demonstrate and explain. Then he
said; 'no, that's not possible, the device doesn't have the
transmitting power for those conditions…' I just looked at him and
said: 'Hey, was it you or me who flew up there.'"

For Kari, independence, 'being able to do what everybody else does', and to 'manage on her
own', is important. With effort, she succeeds in re-negotiating the technological script of
her FM receiver. In the process two shifts occur. First, there is a technological
transformation. Kari has an idea of how to make technology work. She takes the FM
receivers with her from the welfare office, into the HiFi store, concludes the paragliding
course and brings it all back to the Assistive Technology Centre. Throughout this passage,
the function of her hearing equipment changes. What was first inappropriate - not to
mention technically impossible - becomes achieved and admired. From being a restricted

tool for indoors use without possibilities for individual adaptation the FM receiver is turned into an enabling device making the impossible possible. The technology becomes an enabling element in Kari's identity project. Secondly, with the reconsideration of technology the welfare consultant also takes a new perspective on Kari. By abandoning the idea that technical aids should be used to support passive, asocial and immobile use, Kari is recognized as the creative and innovative user that she wants to be; a user that can teach *him* something about technology. What is more, these shifts, one social the other technical, are entangled. The enabling capacity of the device is the outcome of the relation between technical adjustments (compatibility with other device, attachment to a helmet), and social negotiations (Kari's enacting an alternative and her resolute attempts to build alliances and surmount resistance). As a result, Kari is able to fulfil her paragliding dream while at the same time accessing the position as an innovative user in the rehabilitation system.

In Kari's story, the meaning and practices surrounding technology is characterised by the distributional system it is part of. Here use and users emerge as important elements in the shaping of technology. First Kari talks about negative experiences in a system that makes the user dependent on the goodwill of staff. When technology is put into circulation and comes into contact with alternative ordering modes technology is renegotiated and the user is transformed. On its way from the rehabilitation system and into actual contexts of use, the FM device takes on new meanings and agency is rearranged. Through the creative arrangement of people and technologies, Kari enacts the passionate subject. Gearing for flight she becomes an agent in pursuit of passion.

Moser distinguishes passionate agency from the centred, in control subject of normalization. Within an order of normalization, the non-disabled body is taken to be naturally endowed with abilities which are instrumental to the subject. The disabled body lacks this instrumental mastery but this can be compensated for by technical aids. With passion, agency is instead something acting upon the subject, like an urge or drive. Passion for nature; the crisp air, blue skies and powdered snow, and for bodily challenges; taking off, letting go, flying high, never knowing how it will end - is what makes Kari continue to seek new challenges. She enacts passion almost like an obsession; a competitive drive, a will to succeed, never accepting the impossible. However, it is not that passion opposes the active subject; instead it feeds on the duality of passive and active agency. During paragliding, Kari is at once acted upon; urged to go on, and at the same time, the active performer; throwing herself off the mountain.

The duality of passion, its dependence on active arrangement as well as passive letting go, emerges in Kari's story when she realizes that the flight she thought she could just throw herself into required a lot of preparation. Paragliding requires specific material and practical arrangements, with specific objects, techniques and routines to be learned that dispose her to passion and allows her to throw herself off the cliff. The passionate subject

position is a position between control and losing control, a position in which Kari becomes the real master, the one allowing herself to lose control, but still managing to cope. It is a de-cantered form of control. Abandonment of agency and subjectivity to passion involves elements of both passivity and active agency. There is a productive tension between the unbounded, open and passive waiting to be seized by passion and the active preparations and efforts that go into setting it up and entering into specific arrangements of objects, practices, and relations that allow such forms of agency to emerge, the set-up required to bring about passionate action.

Compared to normalization, Moser (2003:236) argues that passionate subjectivity is not enacted as a rational capacity, disconnected from its (shameful) body. Instead, the material semiotic relations within an order of passion are hybrid. It is the intimate relationship between human and machine that allows passion to emerge; 'agency is not fixed and bounded within an individualized body and actor, but emerges in relations and attachments where boundaries are blurred. It flows across attached entities, carries the actor away, acts upon it and makes it act.' Importantly, in relation to Kari's use of technical aids, passionate agency is neither dependent, nor autonomous from the material. The passionate subject emerges in heterogeneous arrangements that are open and flexible and can draw on manifold resources as long as these elements contribute to the innovative program. In setting it up, Kari is the centred control. Actively she arranges for passion, arranging for letting go and, paradoxically, becoming decentred. In contrast to normalization there are not two theories of agency at work; one for the assumed normal and another for the hard of hearing. Instead, Moser argues that there is one for all. Passionate agency emerges in relations that are hybrid, and always mediated. It is the hybrid relationship between body and machines that make possible subjectivities, emotions and intensities. Within an order of passion, body and mind is one:

> Passionate subjectivity … is not about controlling and mastering the body. Passionate subjectivities arise out of and are effects of material attachments, whether body-technology, body-body, or body-object attachments. And here the body is not singled out from, but rather folded into subjectivity as well as the technology or other forms of material arrangements (Moser 2003:228).

Through rigging for paragliding, Kari's disability is not hidden; it is an overt object of interaction. Nor does it go away by accomplishing the flight, and neither does it have to. The FM devices mounted on her helmet enacts her difference, her dependence on technical aids. But in this context, that is not necessarily a bad. The mutually reinforcing relationship between the activity Kari performs; extreme sports, and the way she does it; through special solutions, in effect works to position Kari as prodigious; far from sorry, far from

normal. The rigged communication enacts the passionate subject, willing to go far to realize a dream. Her inability to hear unaided is enacted as one more challenge to take on, another impossibility to realize, once accomplished working to increase her passionate status. In Kari's story attachment, the subject depending on a hearing aid to hear is reinvented from a bad to a good, from lack and loss to a symbol of competitive spirit, innovative thinking, extreme abilities and individual triumph. The rigged hearing takes its place among other passionate accomplishments that can be equally experienced by hard of hearing and hearing alike. And so disability does not make a difference that matters, or at least attachment is not what makes the difference.

ACCOUNTABILITY VS. CREATIVITY - ON THE RELATIONALITY BETWEEN NORMALIZATION AND PASSION

> Kari: "Back in 1999, I met with two technical audiologists. By then I couldn't talk on the phone no more and I was desperate to find a solution. I had read about a mobile text telephone on a NOKIA website. I thought; this is perfect, I can communicate *and* I can become mobile. I made a print out and brought it with me to the meeting, but they did not even bother to look at it. I told them that the device was already available in Sweden, and soon to be launched in Denmark. I wanted to know whether they would get it soon. No, they said, nothing like that existed and those mobile phones were not of much use in Norway because of the lack of coverage, and on and on... And these people are supposed to be the experts! Instead of discussing the possibilities with me, they treated me with suspicion, like I was being hopelessly unrealistic."

Through extreme sports Kari enacts the passionate subject. Flying high, she can take the position as one dares to go where others do not. Enacting an order of passion means escaping fate, the pitying and stigma of loss and lack, and it means escaping normalization; the neutral, ordinary life of everybody else. Passion endeavours to achieve continuous and dynamic self-realization. To realize her sporty lifestyle, Kari needs technical aids. Living on a disability pension, she cannot afford to buy gear herself. Therefore, the route towards passion goes through her ability to enact herself as an eligible client in the rehabilitation system. Through her positioning in the compensatory arrangement, Kari also enacts and belongs in a normalizing mode of ordering hearing. The information Kari finds on the internet is provided by a computer she has received from the workfare centre to use when applying for jobs, the disability pension Kari receives pays the paragliding course, her hearing aids come from the audiological clinic, and the FM device is on loan from the Assistive Technology Center. These are elements granted her by the rehabilitation system to compensate for her hearing loss and contribute to make her 'normal'. For Kari, these are

elements that go into escaping normalization and dispose her to passion. When Kari turns to the rehabilitation system for support, passion and normalization, as two modes of ordering hearing disability clash and she is met with resistance rather than support.

Borders are drawn as to what is a technical aid and how it is to be used. In Kari's story, the professional operates a service geared towards normalization. Instead of assisting her self-realizing project the professionals put restrictions on how technical aids can be used to enact a hard of hearing identity. The professionals work with rigid routines, standard solutions, and devices made for specific purposes. In their view, technical aids are designed for indoor, immobile use, certainly not for the lifestyle of a passionate subject. Passion requires spontaneity, innovative thinking, shifting roles and mouldable solutions. I suggest understanding the clash between Kari and the professionals, in terms of Moser's (2003:230-235) notions of a tension between 'creativity' and 'accountability'.

To build an order of passion relies on a creative, committed subject who can locate and connect materials to set passionate projects off. Creativity, the will to pursue change is, according to Moser, an important ingredient of the passionate subject:

> This striving is however not aiming at some pre-established destination or determination, it is open and prepared to be carried wherever passion might take one. It constitutes life as a project, a self-realization project that can and needs to be filled with and shaped by a series of different, successive or simultaneous projects (Moser 2003:238).

Kari is passionate about sports, she is interested in technology, and she negotiates her way in the rehabilitation system. She challenges prejudices to make available the position as an innovative user. She has concrete suggestions for how to solve her hearing problems and presents these to the professionals. She wants to participate in her own rehabilitation because it offers her a sense of self-worth and equability; it is about realizing her resources and finding an aspirational position on her hearing disability. Kari enacts the creative subject. As a user of rehabilitation services she wants to contribute to introduce novel concepts and potentially transform things. She is willing to challenge conventions, go beyond boundaries, and demand more. Creativity can definitely not be tamed, controlled, engineered, and strategically mobilized. In the meetings with a rehabilitation system geared towards normalization her passion becomes a problematic element of interaction.

First, compared to normalization, the passionate timeline is inverted. There are no incremental adjustments or continued and linked accommodations aiming towards a broad, long term objective of a more permanent state of functioning, be it studies, work or family life. The efforts Kari put into preparing for paragliding are done to produce a short

and intense kick. Secondly, within the normalizing order material arrangements work by way of compensation, introducing special aids and accommodated environments to enable the disabled to do what normal hearing people do. Unlike normalization, passion is not embedded in specific physical environments, technical aids or other special solutions and arrangements designed to compensate for and bridge the disability gap. Instead, Moser writes about the ordering of passion that it is not only the single elements and actors that differ from within normalization. So too does the way in which they are linked and the degree to which they are fixed in place. Within normalization, a distinction between technical aids and technology is enacted. Within an order of passion, the links are looser, more flexible, and can be reconfigured as one is moved onto new projects, needs to adopt to new conditions, and is reinventing - and so realizing – oneself and one's life. Passion implies openness to all elements and relations that can provide a solution for a given problem or challenge to be realized there and then, technical aids or mainstream gadgets alike. Such flexible arrangements are made to fit the dynamism, multiplicity and creativity of the passionate subject. Passionate ordering requires customized solutions, routines that can be surpassed as needs arise, and connections that can be made when opportunities present themselves. Passion and the arrangements it builds upon is not fixed and accountable, but fluid, in transition and flexible.

Creativity is about making new and original connections, it is the element of passion Kari enacts when she links elements within and beyond the rehabilitation system; the SMS on her mobile, a HiFi store manager, and a NOKIA web site. Her approach is problem induced. She identifies social problems – i.e. the inability to talk on the phone - then she looks for a technical solution. When she sees the text telephone on the internet, she acts on impulse; she goes to the Assistive Technology Centre to ask for it. Whether it is part of their assortment or not does not really matter. To find solutions to the problem at hand is what matters. While demands for technical aids must be accountable within an order of normalization, passion does not fulfil the same criteria of accountability. Kari's initiative is not confined to existing schemes and standards. She does not want to sit and wait for a new device to be introduced, she does not need a long term plan to take action, and she opposes rigid definition for what is and is not a technical aid. The passionate subject devotedly experiments. To be a pioneer involves sacrifice, to be willing to challenge, to dare to let go, to produce something new, unexpected, and admired. When Kari's plans are discarded in the rehabilitation system she does not give up. To be creative means breaking with application routines, technical standards, and traditional client-professional relationships and form alternative relations to arrange for passion.

However, in Kari's story there is little recognition and room for innovative thinking, shortcuts, and experiments. The rehabilitation professionals frown upon her suggestions and deem them unrealistic. The rehabilitation system works with fixed notions of technical

aids and application procedures all geared towards normalization; there the disabled subject is confined within an order of routine, plans, and standards.[108] There, actions need to be accountable. Accountability within an order of normalization requires a form of rationalization and legitimization, intended to make responsible and competent subjects. Accountability leads to effective and useful solutions, results that can be evaluated and measured according to a compensatory logic. A gap is identified, an aim singled out, a form of intervention prescribed and a procedure set in action which can later be traced back and evaluated accordingly. The openness of passion becomes problematic in a system built on accountability; how to evaluate, count and compare a paragliding course in terms of recognizable goals? The problem, Moser argues, is that passionate activities cannot be accounted for by being set up as rational processes with fixed arrangement and inserted into larger strategies and processes which imply a means-ends-logic without being made into something else.

A BALANCING ACT – THE COSTS AND RISKS OF ENACTING DIFFERENCE

Kari: "How to get through? I've always been interested in technical stuff. I guess that makes me different from most women, perhaps also men of my generation. When I visit the rehabilitation system it's to have information about technical options. The problem is that the 'specialists' know less than me. I meet women in their twenties with a bachelor degree - technical audiologists, special educators and social workers - who tell me they're not interested or clumsy with technical stuff. I'm no expert myself, but I want to learn. Nor are they able to give information that is relevant for *me*. They're really good on elderly and children, but have no experience with people my age that functions well. They should realize that hard of hearing people have different needs, because hard of hearing people are different. To treat everybody the same is not equality, that's unfair.

I think they're afraid of involving me because then they can't pull the 'clientification' card; there's no need to feel sorry for me. Some also admit it, and yet they make decisions for me... Why don't they get to know me and take use of my resources instead! Sometimes I feel like they underestimate my intellectual capacity. I hate it. My problem lies in my ears, not between them. I've gotten really angry some times. That isn't so smart because then you are someone who can't handle your disability, but there is something called justified harm… Well, it's difficult to know how to act. One the one hand, I think it's only right that I know more about my own needs than the professionals. On the other hand, it's problematic when I

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[108] According to the Norwegian National Insurance Act ('Folketrygdloven') a mainstream technology cannot be distributed as a technical aid.

do. I'm not popular because I stick my neck out and challenge them.
The problem is that I depend on these people. So how mad can I get?

Sometimes I get tired of always having to argue to defend my
position. If I still worked, I wouldn't have had the capacity for
it. Most people don't, but I tell myself; 'Kari, this is the extreme
sport of life. You never know what's going to happen.' I'm driven by
my own curiosity and I never accept the impossible. Other people
need to know for sure something is going to work to try it. I just
think that if it doesn't work, well so be it, at least I tried and
probably I learn something from that."

Kari's story began with how she left her job and city life behind. Sports became a way to escape the experiences of lack and loss when she was no longer able to lead a 'normal' life. However, turning one's back to normalization is not straightforward. For Kari, to have passion recognized and redistributed as a legitimate way of doing disability in a system geared towards normalization, entails both benefits and costs. In the clash between normalization and passion rehabilitation becomes a struggle over the ordering of disability, technology, and identity. As a political history graduate Kari knows the welfare system and her rights. But the flexible service provisions enacted in policy plans and legal documents are not readily available, they must be activated. Kari does not want to be a passive receiver of welfare and she does not want other people to tell her how to live her life. She does not want to compensate or hide her difference, she thrives on it. Kari envisions a rehabilitation system that treats people as individuals, facilitates learning and coping, and involves users in the rehabilitation process. Her aspirations are in line with the objectives in Norwegian disability policy. The current action plan on aural rehabilitation describes a new, dialogue-based rehabilitation system that recognizes individuality and mobilizes the users and their resources in the rehabilitation process (SHD 2002). Kari is familiar with this policy shift and her changing social status from patient to citizen. But, in her experience the access to service provisions is random and depends on the goodwill of the service provider. In addition, she argues that professionals tend to treat hard of hearing people as a homogenous social group. She is in opposition to a system in which the professionals are unable to adjust to her level of functioning and reluctant to recognize her unconventional lifestyle. Rather than experiencing confirmation of self-worth in encounters with the support system, Kari feels that she has to defend her right to be herself, to be different.

The Norwegian sociologist Lars Grue (2006) has problematized the gap between policy and practice. He is concerned with the effects of action plans and public discourse, not necessarily in measurable quantitative terms, but in relation to what ideals and objectives society put forward, and how this, in turn, makes visible what needs to be done to close the gap. While disability, only decades ago, was seen as a medical and individual problem,

today it is perceived as a sociopolitical issue. It is the responsibility of society to include and accommodate disabled people so that they are not hindered in participating on par with others. In this way, disability has become an integrated part of public discourse and policy development. In result, normalization is no longer exclusive, but meets competition from other modes of ordering disability. Equality and participation are chief principals of Norwegian disability policy. It means that hard of hearing people can legitimately expect and demand having their difference recognized and accommodated by society. It means that people have something to measure the service they receive against. The acknowledgment of a gap is key to the experience of something being more or less just. Kari's system critique, her description of what she experiences as unfair, is only possible because she has an underlying idea of a disparity between what *should* be and what *is*; between policy and practice. In here lies the seed for resistance and alternatives. In Foucauldian terms, Kari's right to be different - as constituted in policy documents, legal papers and commercials for technical aids - makes up the conditions of possibilities for her system critique.

Refusing to accept the practices that paternalize and pacify a resourceful user, Kari mobilizes other ordering modes when she is confronted with, and confronts what she experiences as unjust treatment. The idea that subjective hearing – different treatment for different people - should be the basis for rehabilitation programs opens a critical space from where to oppose the professional enactment of her as a passive, immobile, and asocial user of technical aids. From here, Kari draws on her multiple self to enact hearing disability differently. She finds ways to feed on resistance by mobilizing the subject position she knows from extreme sports. She enacts the passionate subject; the creative, sanguine person who never turns down a challenge and who makes the impossible possible. Kari differentiates her position on technology from that of most people her age. She differentiates her position in the rehabilitation system from those who do not stick up for themselves. She talks about making herself heard, daring to be different, and not being afraid of sticking her neck out or of failing, because unless she tries she will never get anywhere. Passion, as a mode of ordering disability, thrives on difference. For Kari, her ability to enact subject positions differently is what makes the struggle worthwhile. Within an order of passion, not knowing, taking risks and experimenting is not a bad, giving in to conformity is bad. Extreme sports is about room for unconventional lifestyles and self-realization, and about breaking boundaries and rewarding innovative thinking. Through her passion for sports, Kari enacts her hearing disability as minor or even irrelevant to other positions in the enactment of her multiple self. As a result, she can identify as a resourceful agent in the story of her life.

However, ordering modes and the positional strategies they give rise to are more than free floating discourse and psychology. As Kari's story illustrates, they draw on and build

arrangements of social *and* material kinds. While the user-centred policy fosters expectations that difference will be accommodated, Kari meets with rehabilitation professionals that promote normalization. From the meeting, between new expectations and old prejudices emerges a subjective dilemma. For Kari, it is difficult to be positive and obedient in the meetings with professionals who act as if she has to make herself worthwhile of their services. She experiences it as humiliating when they instruct her, despite the fact that she has more formal education and life experience than them. But as gatekeepers to the technical aids that have become an integral part of her life, she still depends on their goodwill. In this situation, she finds it; 'difficult to know how to act'. Situated between two ordering modes in tension, normalization and passion, her positional strategy becomes a balancing act. On the one hand, to be passionate is to stand up for one's rights and challenge the establishment, but on the other hand, Kari cannot risk becoming too unpopular. The paradox is that in order to live out her passion for sports she depends on a normalizing arrangement that disapproves of her lifestyle. Getting through despite professional resistance is what confirms her passionate abilities. But there are costs related to enacting difference in a welfare system geared towards normalization. Kari says she is tired from always having to negotiate her way through the system. To build passion from resistance is only possible because she has deleted other elements from her life, like having a job.

A POLITICAL CHOICE

> Kari: "Hard of hearing people have to play their part in changing this. I meet a lot of people who complain in the hallways, but in the meeting with professionals they go silent. That makes me crazy, why don't they stick up for themselves! After all, it's an individual responsibility to speak up if you don't recognize the professionals' problem representation. But I guess it has to do with the collective learning disabled people have gone through in what has been an extremely paternalistic system. In that respect I don't think much have changed, I mean we keep on getting new names, clients, users, citizens, and they promise to listen to us and our demands, but I still meet the same paternalism I did 10 years ago when I started with hearing aids. Also there's still much stigma surrounding hearing disability. People don't want to talk about their disability. They don't want to be different, but it's an individual responsibility to make yourself heard. Whether society can afford to give people what they demand, well that's a political choice."

For Kari, the current gap between policy and practice is intolerable. In contrast to other hard of hearing people who choose to submit to the paternalist professional practices, Kari

takes the position as a critical impetus for change, real change, not merely nominal innovation. She objects practices that evaluate disabled people according to a constructed norm, suppress difference and reduce people and their complex lives to standard welfare categories. In her view equality is not to treat everybody the same but to give people room and resources to enact their individuality. She thinks that rehabilitation professionals should treat service users as individuals, and tailor services accordingly while utilizing their resources in the rehabilitation process. Kari calls for practices that recognize hard of hearing people not as similar entities, but as different. Enacting difference not only requires acceptance in the form of cultural recognition through policy discourse and legal rights, for Kari, positioning in an aspirational way also depends on access to the material and financial resources required to arrange for passion. On this, Kari does not deny society the right to restrict choices; 'That's a political choice', she says. Rather she is frustrated by the gap between policy and practice, the situation in which no choice is made. Where policy makers on the one hand talk about recognition and grants universal rights, but, on the other hand, operate an egalitarian system with limited resources. She demands that society lives up to the policies it passes and redistributes the materials that can enable her to live out passion.

But how far should society go in recognition of difference, as in this concrete case, should it be the responsibility of a welfare system to accommodate extreme sports? I bring this question on into the next, concluding chapter. Here, I revisit the individual stories about hearing disability, technology and politics and I ask what specifically constituted individual claims for social justice and which societal changes they perceive as necessary in order to experience societal inclusion.

INTRODUCTION

With a background from policy studies, I brought with me into the study of hearing disability an interest in political reflection. Yet, I had also often felt unease about these academic debates, on account of their theoretical level. I felt they lacked an empirical basis and, therefore, tended to lose touch with the empirical realities according to which they sought to justify their arguments. Therefore, I was keen to explore the possibility of enacting a different form of political analysis. An analysis in which the people, things and material surroundings - official documents, hearing aids and subjective accounts - that make up our heterogeneous realities could be included as important elements. The aim was to make possible a political analysis that extended the terrain of political contestation to the everyday enactment of social interactions and material practices. In combining the critical insight from Disability Studies with the analytical tools from ANT, I developed a material semiotic approach to study the ordering of hearing loss. Working with empirical material from participatory observations and interviews with hard of hearing people, I explored the conditions of possibility for hard of hearing subjectivity and the distribution of agency in policy and practice. The purpose of this final chapter is to reflect on the findings in the light of a broader debate on social justice.

In recent years, disability has emerged as an important issue in theories of justice with respect to both defining justice for disabled people and critiquing theories of justice designed to be universally based on their failure to adequately account for disability. In the light of this deficit, what policy implications can be drawn from a material semiotic approach to hearing loss? How to begin to formulate a theory of justice that can encompass the entangled experience of hearing disability? Nancy Fraser (1997, 1998, 2000) has attempted to include both a materialist and a cultural perspective in a theory of social justice. Discussing the findings from my study of hearing disability in relation to some key ideas in her theory, I hope to make an empirical contribution, however small, to the often highly abstract discussions on social justice.

Within Disability Studies there is an ongoing debate on social justice. Simplifying matters somewhat, one might argue that the dividing line goes between a social model approach and a postmodern approach. The social model on disability emphasizes that injustice stems from the political-economic structures of society and can take the form of exploitation, economic marginalization, and deprivation. A postmodern approach is focusing on cultural processes and sees injustice as stemming from social patterns of representation, interpretation and communication and can take the form of 'othering' and disrespect. While social modelists have emphasized the need for economic restructuring of the division of labour, property or income, postmodernists have emphasized the need for cultural and symbolic change, such as revaluation and preservation of difference. But are these two approaches to social justice for disabled people necessarily mutually exclusive?

One of the intentions of Nancy Fraser's project, while worthy of far more attention than can be given here, is to challenge what might be called the cultural turn in social sciences.[109] To her, it is a paradox that claims for egalitarian redistribution rooted in a materialist analysis are in decline, and that the recognition approach rooted in a culturalist perspective seems to become more central in a period when material inequalities are increasing. In her view, this downplaying of the importance of socioeconomic structures as causes of injustice is problematic since it may actually promote economic inequality. This does not imply that she denies that justice has a cultural dimension. Fraser aims to broaden the theory of social justice by developing an analytical scheme that includes both socioeconomic and cultural injustices. Although Fraser maintains that there are various differences between

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[109] The important reference here is Iris Marion Young (1998), who has taken up the exclusion from key citizenship debates of the historical and social context of individuals. Coining the concept of 'differentiated citizenship' Young argues that citizenship requires the development of a theory based not on the assumption of an undifferentiated humanity but rather on the recognition that there are group differences and some groups are actually or potentially disadvantaged. Young importantly raises the point that rights and rules which are universally formulated are blind to differences of race, culture, age or disability, and thereby perpetuate rather than undermine oppression. Young believes that the best way to realize the inclusion and participation of everyone in full citizenship is by re-articulating citizenship to become inclusive of diversity and difference. This approach to citizenship has been widely acclaimed by other feminists (see i.e. Sim 2000; Lister 2003). While Young's "differentiated citizenship" theory has much to offer oppressed groups and individuals in that it provides a substantial base for obtaining subjectivity, Fraser has been critical of Young for having an essential notion of the groups and for privileging cultural groups. On the former, the risk is that assumption of homogeneity overlooks differences within disability. On the latter, the attempt to cover both cultural and political-economic phenomena with the definition of a social group is problematic in that it may result in the loss of important conceptual distinctions.

socioeconomic injustice and cultural injustice, both are pervasive in contemporary societies and both are inherently bound in processes and practices that systematically disadvantages some groups of people. Accordingly, Fraser theorizes that a just society must include considerations both of *redistribution*; fair distribution of resources among individuals in society, and *recognition*; equal social valuation of individuals.

The dual perspective on justice enables us to combine redistribution and recognition in an integrative, not an additive way, without reducing either one to the other. However, this is not always straightforward. Fraser notes that while the redistribution approach assumes that it is classes that suffer from injustices, and that group differences must be abolished, the recognition approach insists instead that the particularities of social groups must be recognized and revalued. This means that the politics of recognition and redistribution have mutually contradictory aims as the former promotes group differentiation whereas the latter undermines it. Fraser, thus, notes how the two kinds of claims stand in tension with each other and can interfere or even work against one another.

Responding to the 'redistribution-recognition dilemma', Fraser maintains that it cannot be solved in abstract, principle terms, but needs to be resolved according to the specificity of the case in question. Exactly how justice should be re-established depends in each case on the mode and agency in which misrecognition is experienced. Critical towards identity politics, Fraser suggests that we should avoid claiming recognition of the values of various group-specific practices, traits and identities that are not, and cannot be universally shared or established as authorative in multicultural societies. Such an identity model, she argues, is theoretically deficient and politically problematic because it encourages group reification and displacement of the politics of redistribution.

Thus, Fraser (2001:24) proposes an alternative approach to recognition, based on the social status perspective: 'What requires recognition is not group-specific identity, but the status of individual group members as full partners in social interaction'. Introducing the notion of *parity of participation*, the normative core of her theory, Fraser argues that it is not compatible with justice that some individuals are denied participation in social interaction on equal terms. All individuals should have the right to participate meaningfully as peers in society. For her, this means that the distribution of material resources must secure the independence of participants. This precludes forms and levels of material inequality and economic dependence that impede parity of participation (e.g. deprivation, exploitations, large differences in income and wealth). In addition, all participants must have the same possibilities to attain cultural respect. This precludes institutionalized value patterns that deny some people the status of full partners in social interactions e.g. cultural domination, non-recognition and disrespect. Social justice requires instead that value patterns express equal respect of all participants and ensure equal opportunity for achieving social esteem.

Importantly, Fraser separates cultural respect from social esteem. She maintains that while respect should always be equal to all human beings, social esteem is dependent upon personal accomplishments and/or contributions. Here, the notion of social esteem takes on a political importance in that it assigns room for individuality. For me, this is the strongpoint of Fraser's theory of justice. Along with the redistribution and recognition remedies, Fraser (1996; 2007) has argued that we need to develop a version of anti-essentialism that permits the link between cultural politics of identity and difference with a social politics of justice and equality. With this move, she avoids conflict with the liberal principal that rights belong to individuals, not groups. Introducing the notion of participation parity, Fraser justifies group based claims as long as they relate to conditions that influence the possibility for parity of participation for the individuals that make up the group. While parity-impeding may take many different forms; legal, social, material, and so on, the source of injustice remains institutionalized patterns of cultural values that constitute some social actors as less than full members of society and prevent them from participating as peers. Accordingly, on a political level, remedying to this kind of injustice means replacing such patterns that hinder parity of participation with ones that make participation as a peer possible so that we can speak of reciprocal recognition and status equality. The nature of such remedies varies according to circumstances. Juridified forms require legal change, policy-entrenched forms require policy change, and associational forms require associational change, and so on. Apart from this, Fraser does not provide us with specific tools to study exactly how people make claims for participation parity.

Even though Fraser does not explicitly address disability, her theory has been suggested by disability scholars as a model for defining justice for individuals with disabilities (Danermark and Gellerstedt 2004; Parker 2006; 2004; Kimberlin 2009; Hugemark and Roman 2007). It is also my view that as an entangled experience, constituted by discursive patterns *and* material practices, justice for hard of hearing people demands a politics of redistribution as well as recognition. Fraser's dual model, thus, seems promising as a point of departure for a discussion of social justice for hard of hearing people.

HARD OF HEARING CLAIMS FOR SOCIAL JUSTICE

In part IV, *The Lived Experience of Being Hard of Hearing*, I have introduced five individuals and their stories about disability, technology and politics. I traced different modes of ordering hearing disability and detailed the manner in which these are enacted in everyday

life. I have showed how people draw on different ordering modes, and their multiple self when trying to position in aspirational ways. Then, I discussed costs and benefits of these positional strategies in the light of broader identity projects. Now, I mobilize the critical potential of these individual cases by reflecting on their experiences in terms of a broader debate on social justice. To set off the discussion I revisit the material from the user study. I look for exactly what constitutes peoples claims for recognition *and* redistribution. I ask how hearing loss comes to matter for recognition and redistribution, and how people balance different social justice claims. I discuss what actions they take and which societal changes they perceive as necessary in order to experience parity of participation. Finally, based on the findings, I point to some challenges for disability politics ahead.

MISSING MATERIAL LINKS

I start by revisiting Reidar and Bart's stories. They approached the aural rehabilitation systems to get hearing aids. In one sense this is straightforward, their claims were for redistribution. They wanted technical aids that could enable them to hear better so that they could participate on par in social interactions, have jobs and earn an income that makes it possible to have a house and provide for a family. Yet, their claims were not merely for redistribution. As their stories advanced, the audiological encounter also became a site for the struggle over identity. It turned out that issues of redistribution were deeply entangled with issues of recognition.

To frame the analysis of this entanglement, I took as a starting point the emphasis on social-contextualization of expertise in disability policy and research. With this rehabilitation model, the power of the expert is sought reduced by giving priority to the perspective of the service user. I argued that this approach is problematic due to its implied perspectivism and the lack of sensitivity to the materials at work. Reidar and Bart's claims for technical aids were not merely a matter of redistribution, of gaining access to compensatory means. Because they identified as competent and capable users of technology and displayed familiarity with the welfare systems, they wanted to get to take an active part in the rehabilitation process. They expected to participate on par with the experts. Their aim was to have their experiences recognized, to confirm their social status as competent users.

Moving further into the analysis, I suggested that the integration of redistribution and recognition inherent to the audiological encounter was reflective of the social *and* material elements at work. Bart and Reidar experienced that while some identities were recognized and valued, others were misrecognized and disrespected. This rejection resulted not only from the asymmetry of the professional-lay interaction, but was enacted also by the materials in use. Material surroundings and technologies were inscribed with a medical

order that invited and inhibited specific enactments of identity. Reidar and Bart requested technologies that could recognize their agency on technological matters. They wanted devices and procedures that enabled them to take control, and that could engender specific patterns of use. However, invitation notes, bureaucratic routines, audiograms, hearing aids and assistive devices they received positioned them as passive, incompetent and irrelevant through use.

So which claims for societal change emerged from these audiological encounters? My argument was that the material semiotic approach extended the political analysis of hearing disability to include a focus on the material enactment and ordering of hearing disability in professional practice. Reading their stories as the entanglement of claims for recognition *and* for redistribution I suggested understanding them as a call for relational practice. While the social-contextual critique of the medical model has worked to heighten sensitivity for the perspective of the user in rehabilitation policy and practices, this is not in itself empowering. In a relational practice empowerment is not merely a matter of adding and shifting between perspectives, replacing the dominance of professional expertise with the more 'authentic' experience of the service user. For Reidar and Bart, parity of participation was not a matter of deciding whose pre-determined perspective should get to count. They wanted a redistributive system that recognized their agency on technological matters, and for this to have repercussion on the development and distribution of technical aids. The audiological encounter, thus, became an entanglement of cultural representation and material compositions that produced effects with regard to social status.

NORMALIZATION AT WORK

Marianne and Anouk's stories took place in the context of work. In policies aiming at equality and inclusion activation is a key instrument and the job market a key implementation area for the integration of disabled people. The aim is to facilitate disabled peoples' entry into paid work. Integration means closing the gap between individual abilities and society's expectations. To close the disability gap, universal rights are instigated to improve access to work while technical aids are provided to make up for bodily differences. For Marianne and Anouk, to have a job was not only about getting paid. To go to work meant being recognized as having the same competencies and abilities as everybody else. Work was a site for normalization. Given the tremendous efforts that are invested into realizing activation policies I wanted to investigate whether it was indeed possible to undo disability through a hard of hearing career.

At Marianne and Anouk's work, a competent colleague was someone who was not only formally qualified for the job, but also had the social ability to adapt to people and situations in highly relational, dynamic, and international work environments. Disability

was what interfered with the expectations towards being a competent colleague. Expectations that Anouk and Marianne strived to meet as they struggled to undo disability and become 'normal'. The analysis revealed how barriers to such normalization were found not only in the social interactions among colleagues, but also in the material surroundings and technologies at work. Office buildings, meeting routines, telephones and noisy canteens constructed according to an assumed bodily norm were obstacles Marianne and Anouk had to face throughout their working days when trying to close the communicative gap at work. Their normalization strategies included social, psychological and environmental adjustments. To be able to go to work as 'normal', Marianne and Anouk developed two positional strategies that by way of compensation, prioritization, and deletion sought to build and fix in place an order of the normal and turn them into competent employees. In addition, they were enrolled into a compensatory apparatus. Hearing aids were introduced, work places accommodated, and technical aids made available. The promise of technology was its ability to compensate for hearing loss and enable them to go to work as every*body* else. Thus, when Anouk started her new job, the university doctor asked her how to accommodate her hearing needs. And when Marianne 'came out', the Assistive Technology Centre gave her conference equipment to use in meetings. Technical aids were redistributive means, granted Marianne and Anouk to enable them to have jobs that provide income and social security. Yet, there were no linear, enabling effects to these technical aids. Between them technical aids produced very different results with regard to their collegial social status. Again, claims for redistribution and recognition entangled in the social and material elements at work.

Anouk was not afraid to exposit her hearing problems. Her hearing loss symbolized her cross, how despite it all, she was a competent colleague. She thrived on the possibilities and the attention technical aids gave her. Not only was she pleased with the sound they produced, the technology also affirmed her aspirational position among colleagues. She sought out a device that did not look like a technical aid, but more like a gadget that enacted her as positively different. She 'put her ear on the table' and managed to turn the technical aid from an object of dependency into an object of desire among colleagues. When these subject positions interfered - her disability, the technological user role, and her aspirational collegial status - she could take the position as the exceptional individual. Despite her hearing loss she could, seemingly, participate on par.

For Marianne, to make use of the conference equipment was a more troublesome affair. It meant having to abandon a familiar strategy. To use technical aids during meetings implied having to actively position as disabled. For her, the conference equipment worked not only to improve her listening; it also set her off as negatively different by reinforcing the competence gap between her and her colleagues. Technology enacted her dependence on collegial goodwill, a position she was reluctant to be in. With a reputation as a loner she did

not have the same social capital as Anouk to draw on. To position as disabled, for her, meant risking an already fragile social status, therefore, she rather wanted to continue the invisible work that had enabled her to, seemingly, participate on par.

The analyses accounted for the goods of normalization, in terms of enabling disabled people to go to work, but it also pointed to its limits, costs and risks in terms of Marianne and Anouk's continued hearing problems. In neither case did access to work and use of technical aids undo hearing disability. Despite the benevolent efforts to include and accommodate them at work, they continued to be different, their bodies had special needs. In the light of their continuous problems hearing, which societal changes did Marianne and Anouk call for? This is the twist to normalization; there are no calls for societal change. The problem with the gap model, as Moser (2006a) has argued, is that crucially, the misfit is attributed to individual loss or lack of function and identified as a condition in the individualized body rather than as a problem with the standards or requirements of the environment. When compensatory arrangements have been instigated society has done its part, other problems experienced by disabled people are misrecognized, and enacted as the responsibility of the individual to deal with. Experiences are not politicized. In this situation disabilities are produced all over again. Disability becomes the priorities, compensations, and concealment that Marianne and Anouk continue to strive with in order to fit into a hearing world. In here lies an implicit claim for a heightened sensitivity towards the specificities and uncertainties of social affairs.

THE RIGHT TO BE DIFFERENT

Equality and participation are chief principals of Norwegian disability policy. It means that hard of hearing people can legitimately claim to have their difference recognized and accommodated by society. Therefore, in Kari's case, I wanted to investigate what room and resources were available to position outside the mainstream, to enact difference. Kari's story began with how she left her job and city life behind. To escape experiences of lack and loss when she was no longer able to lead a 'normal' life Kari developed her own standards for the good life. She pursued her passion for sports. However, turning her back to normalization was not straightforward. It turned out that passion was in tension with, but also dependent upon normalization. In order to be able to devote herself to sports, as when completing a paragliding course, Kari needed technical aids. She needed to subject herself to normalization. Indeed it was this positioning in the normalizing order, enacting her through lack and loss, in need of redistribution. Through economic support and technical aids it is possible for her to enact difference. When entering the aural rehabilitation system, Kari's claim for recognition and redistribution led to a clash between formal rights and bureaucratic procedures, between professionals and service user. The dilemma was that in

order to live out her passion for sports she depended on a normalizing arrangement reluctant to recognize her alternative lifestyle.

The experience is illustrative for the societal struggle to realize equal citizenship for disabled people. Unable to realize the universal society, both Norway and the Netherlands assign an important role to their compensatory systems. While the ideological approach to disability has shifted from a medical model towards a social-contextual model, policies based on universal rights have been established without terminating social security policies and professional practices geared towards normalization. What results is the co-existence of policies with conflicting views of the nature of disability and the appropriate societal response. On the one hand, anti-discrimination legislations target disabled individuals as a social group, granting them full citizenship status. This bears the promise to recognize and include their differences as normal parts of the multicultural society. On the other hand, rehabilitation systems target hearing disabled individuals through large compensatory arrangements. These are designed to make up for their differences and enable them to take part in a hearing world. What prevails is a mixture of political ordering attempts which, in turn, gives rise to tensions between equality and difference in practice.

Again, claims for redistribution and recognition entangle. In Kari's case, they were enacted as a clash between the politics of normalization and the politics of difference. In the first, redistribution is geared towards normalization and recognizes a disabled subject which strives to become equal, to use technical aids to compensate for difference. In the latter, redistribution is a means to escape normality, technical aids are sought out not to compensate for, but to live out difference. Kari claimed for her alternative lifestyle to be recognized and redistributed as a legitimate way of doing disability. In the meeting with a rehabilitation system geared towards normalization, her positional strategy entailed both benefits and costs. She got access to redistribution, but not without struggle. This was Kari's quandary, situated between two ordering modes, in tension, her life became a balancing act.

So which societal changes did Kari perceive as necessary in order for her to experience social justice? Kari pointed to a disparity between what *should* be and what *is*; between disability policy recognizing difference and professional practices geared towards normalization. Her claim was for a support system that could treat people as individuals, not as a homogenous social group. She opposed the professional practice, unable to adjust to her level of functioning and reluctant to recognize her unconventional lifestyle. In her view, equality is not to treat everybody the same, but to ensure parity of participation by giving people the room and resources they need to enact their difference. For Kari, a politics of difference required more than acceptance in the form of cultural recognition through policy discourse and legal rights. To live out passion she needed access to the social and material resources that could enable her to build her passionate arrangements;

skis, paragliding courses, welfare support, a kayak, a helmet, a supportive store manager, inclusive instructors, and so on. Passion had material costs. Importantly, Kari did not deny society the right to put restrictions on redistribution: 'That's a political choice', she said. Rather she opposed the situation in which society, on the one hand, grants universal rights, while, on the other hand, operates an egalitarian system with limited resources. Her societal claim was for society to live up to the policies it passes.

TRANSCENDING THE EQUALITY- DIFFERENCE DILEMMA

Through these five in-depth case studies, I have studied different active modes of ordering hearing loss and detailed their social *and* material enactments. Then I explored *how* people draw on their multiple selves and the sociomaterial arrangements they position within when seeking social esteem. The (limited) individual freedom and the creativity people demonstrated in their attachment to people, things and material surroundings was essential for how they dealt with hearing loss in meaningful ways. Using Nancy Fraser's concept of parity of participation to reflect on the findings, I showed how hard of hearing people's claims for social justice could not be accounted for in either materialist *or* cultural terms, but had to be seen as the integrative result of claims for recognition *and* redistribution. Such entanglement, I argue, calls for new ways to think about social justice for hard of hearing people.

The variable experiences of hearing loss can not be accounted for in deterministic terms, as a group feature. Intra-group differences between hard of hearing people has to be taken into account. While the access to redistributive arrangements like welfare schemes, technical aids, and rehabilitation programs is universal, their effects are not. Whether or not social status increased or decreased, asymmetries are reinforced or made irrelevant, exceeds the recognition of disability and must include considerations of people's broader identity projects. From this it is clear that there is not *one* standard route towards justice for all hard of hearing people. The five individuals in the user study shared some experiences of lack of sound which allowed them to be categorized as allegeable for societal redistribution. However, they were also unique individuals, who experienced their hearing loss in different ways and had different aspirations for how to live their lives. Therefore, their claims for recognition and redistribution differed; people need different things to realize parity of participation.

All five case studies had in common a tension between equality and difference. On the one hand, people had to identify as members of a social group in order to justify claims for redistribution. On the other hand, they were also concerned with avoiding a group stamp. Thus, while in their meetings with the redistributive system, they identified as hard of hearing, they also claimed for their individuality and agency on rehabilitation matters to

become recognized and to have service provisions developed accordingly. Adding personal accomplishment or contribution to their position on hearing loss, they tried to surpass the recognition-redistribution dilemma by ordering their differences differently.

MAKING A WORLD OF DIFFERENCE

I started out with the ambition to open up a field hitherto dominated by professional knowledge. I wanted to look for alternative modes of enacting hearing loss. By studying hearing disability as an entangled experience it became, in analytical terms, possible to explore how the experience of hearing loss varied by reference to the multiple self, situated in and between the ongoing ordering modes activated in people's stories about disability, technology and politics. Throughout, my study of policy making, professional practices, and everyday life, hearing disability became an increasingly complex, heterogeneous, and multiple matter. Diverging from country to country, from site to site, and from person to person.

This then, is the intervention of material semiotics. To bring out different ways of being hard of hearing. To detail, and so attend to, the specificities and uncertainties of specific experiences. To describe difference is not innocent. Research, is performative material semiotic scholars argue (Haraway 1991). As a researcher one does not neutrally report on a given object, one takes part in enacting that object in specific ways. To do research is to be involved in ontological politics (Mol 2003; Law 2004). Through descriptions, research makes a (limited) difference:

> In this way of thinking, politics is about intervening to make a difference and about being sufficiently modest to resist the idea that there is a single or explicit mode of ordering the world. It is about accepting, in other words, that ordering is partial, incomplete, always more or less local, more or less implicit, and therefore more or less disconcerting. And then again, it is about being sensitive to practice, recognizing that it is a matter of being flexible enough to make differences in different ways in different circumstances (Law Forthcoming:11).

Adopting this sensitivity to difference, the five case studies can be read as a reflection of the gradual expansion of the disability issue in disability studies and disability policy. In the writings of disability scholars (my own work included), disability has gone from being conceptualized as a medical condition, enacted primarily as a struggle for autonomy and

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agency in the clinical encounter, to becoming situated throughout the entire range of public spaces, schools, work places, theatres, even the venues of extreme sports.

A first shift, moving the study of hearing disability out of the audiological domain was prompted by the critique of professional reductionism and lack of contextualization of experiences of disability. Reidar and Bart's stories revealed how the problem with realizing 'empowering' practices hinged on the difficulties with recognizing the multiple self as a source for rehabilitation. But should professionals deal with social problems. When the entire complexity of the service user is brought into the narrow realm of technical audiology, the risk is that professionals will medicalize a wide range of psychological, social, economic, and political problems. The critical question is this, should the audiological encounter continue to be promoted as a main site for the realization of equality policies?

In order to open up for disability as a more holistic, lived experience, analyses of how disability is taken up and made relevant in other public institutions have been added. This opened up the disability issue further, and allowed disabled people to be presented with more complexity in academic writing. Enacting this shift, I analysed two hard of hearing careers. When disabled people are included at work, they are no longer merely service users, they are enacted as multiple selves, and expected to do, or be enabled to do, their jobs as everybody else. However, there were not only benefits to being included. To do a normal job, as 'normal' people, entailed costs and risks too. Despite the tremendous efforts put into activation policies and programmes, in practice, it was not possible to undo disability and turn Marianne and Anouk into 'normal' colleagues. Instead, they had to continue the prioritisations, compensations, and deletions that enabled them to position as competent at work. While their efforts to become included were extreme, it is not to be expected that this is a viable option for everybody. In the situation where employment continues to be promoted as the main site for realization of disabled identity and social participation, the social exclusion and the lack of self-worth associated with unemployment is reinforced. The critical question is this, should paid work continue to be promoted as the main site for the realization of disabled identity?

Scholars within Disability Studies have called attention to the individual work on closing the gap and the costs of striving to, or failing to live up to the expectations at work. This new line of research questions the claim for full inclusion. Instead of finding ways to close the gap between expectations and realizations, a better option, they argue, is to challenge the norm itself, the idea that people should be made able to participate on par (Moser 2003; 2007; Winance 2008; Barnes and Mercer 2005).[110] Here then, a new shift occurs, as

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[110] According to Wynance (2007:634) to work on the norm means; 'coming to terms with how 'normality' or 'difference' are no longer objective characteristics that depend on whether or not one has a given

these disability scholars argue that we need to become more open towards alternative ways of living and valuing disability. Rather than merely finding ways to include disabled people in the job market what is needed is a fundamental re-evaluation of the value put on different forms of human activity. Consequently, disability is enacted in yet new domains, opening up for new experiences, outside normalization. In my work, Kari, with her passionate ordering of disability through extreme sports, came to represent this opening up to difference. Here it is no longer the multiple self which is sought integrated into the inclusive society, into work. Instead, Kari's story is about choosing to position outside the mainstream, and for that choice to be recognized and redistributed by society as a legitimate way of doing disability.

Current policy making on disability aims to recognize this diversity. Disabled people have been granted with universal rights for inclusion and participation. Rehabilitation is no longer just a medical condition, it is a sociopolitical issue. The hard of hearing is no longer a patient or client, but an individual and a full citizen. Society is called upon to take responsibility to include and accommodate disabled people so that they are not hindered in participating on par with the non-disabled. But how to deal with all this diversity in practice? How to realize participation parity for hard of hearing people? While inherently hesitant towards prescription, the material semiotic analyst is not precluded from posing critical questions. Therefore, I want to end this book by reflecting on the costs of opening up to difference.

DEALING WITH DISABILITY DILEMMAS - STRONG OR MODEST POLITICS

To conceptualize hearing loss as an entangled experience, has meant to consider disability as a varied experience, emerging from the multiple self and enacted throughout the entire spectre of social and material relations that people are (dis-)abled by throughout their everyday lives. But if the experience of disability inherently relates to the broader identity projects of the individual, then what justifies and restricts disabled people's claims for social justice? When audiological practices are to become empowering affairs, should every new consultation and every hearing device be custom-made? When disabled people are to be included at work, can all work places and public spaces be universally designed to meet

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attribute, but are relative qualities, built through interaction.' The need is for strategies that will accommodate differences instead of seeking to compensate and do away with it.

the (sometimes contradicting) needs of all employees? When sports becomes a way of life, should all the new challenges passion might stir up be accommodated with ever more advanced gear? The critical question is this; how to distinguish between identity and self-realization when disability is moved out of welfare systems and labour markets and into the entirety of societal life? What is *just* participation in a modern, multicultural, and affluent welfare society?

In international disability policy, the aim is a society for everyone, characterised by equality and participation. Granted universal rights, disabled people can legitimately expect to be included as equals in varied activities. However, parity of participation requires more than recognition of difference. Redistribution of economic resources and material changes is needed to enable people to participate on par. A core problem with Fraser's theorizing is that she does not specify what exactly it is that everybody legitimately should be able to participate in. Here, material semiotics is useful in that it details the processes in which people make claims for social justice. The findings highlight how difficult it is to translate visions of an inclusive society from texts in policy document into empowering audiological procedures, enabling technologies, and inclusive everyday practices. As such, the material semiotic analysis makes visible gaps between policy and practice. But how to deal with normativity in relation to the analysis; does pointing to elements needed to realize the inclusive society, implicitly criticizing policy makers for their failure to fulfil ideals, also mean that this is what *should* be done?

STRONG CLAIMS

The findings of the study *could* be used to substantiate stronger redistributive claims. This would imply detailing people's claim for recognition and pointing out the social and material resources needed to ensure participation parity; more technical aids better tailored to meet individual preferences, universally designed public spaces, and stronger legislative frameworks. While surely possible, this response is not without risks, neither for society nor for the individual.

One of the main findings from this study was that it is not possible to do away with disability. Rather than to compensate for hearing loss or make hard of hearing people 'normal', redistributive arrangements opened for new ways of ordering hearing loss, and new opportunities for the enactment of hard of hearing subjectivity. Given that it is not possible to eliminate disability by compensatory means, the critical question is whether the formulation of yet stronger policy claims will work to increase the gap and the dissatisfaction for those unable to meet the new expectations for participation.

Where does this idea that people should be in control in all sites and situations come from anyway? Does sensitivity towards the multiplicity of modes of ordering disability also mean that all claims for recognition and redistribution always and necessarily legitimate just because they come from a member of a marginalized group? Empowerment and the redistributive claims that follow the rhetoric - setting up aural rehabilitation systems, labour markets, and lifestyle as a matter of options and choices – is not an innocent, neutral, or a more authentic mode of ordering hearing disability. As Moser (2003) and Mol (2008) have argued before me, individualization already implies a specific kind of ordering. Making choices, one is already enacted and enacting a specific discretionary subjectivity, within a particular mode of ordering. It is not outside or prior to ordering, but already ordered. To have or be given choice is not a neutral thing. It is an enactment, and one that tends to naturalize and de-politicize itself. Claims for individuality and agency also have their origin from somewhere outside and in relation to the person. Claims for holistic care, custom-made technologies, alternative lifestyles, these are elements that can be mobilized to enrol disability into marketing strategies promoting consumption as self-realization, professional turf wars challenging established medical hierarchies, or health care managers embracing automation to prompt cost efficiency.

My point is not that option and choice cannot produce empowering experiences. Rather I want to argue that instead of enacting the aspirations of the hard of hearing as non-debatable, we should scrutinize all claims for justice. The critical question is what increasingly stronger claims will mean for solidarity and social responsibility? Redistributive systems are based on collective payments grounded in principles of solidarity. Solidarity is an ideological rationale and commitment to fair distribution of resources that reflects a mixture of various philosophical, religious, and cultural traditions. Solidarity entails a strong responsibility of society for the needs of the individual in relation to health and welfare. It is a system in which individuals by way of compulsory payments to insurance schemes or national taxation take part in guaranteeing equal access to a certain level of welfare and health care. In order to remain legitimate, such systems depend on publicly supported criteria for redistribution, mechanisms for sorting out allegeable candidates, and gatekeepers that are trusted to distinguish between legitimate and unwarranted claims. The problem, in this context, with the introduction of universal rights is that they tend to undermine political responsibility by stalling priority making. As ever more advanced technical aids are developed and paid for by systems of collective solidarity, already under political pressure, a potentially expensive increase in costs could threaten the legitimacy of claims from the group as a whole. As an effect of the critique of professional paternalism and particularism, the individual service user has become more independent, autonomous, and empowered. At the same time the acceptance of politics in the shape of collective, non-flexible arrangements has diminished. What does this mean for collective solidarity? How to do responsible politics from here?

MODEST POLITICS

An alternative response to the gap between policy and practice is a modest politics. A modest politics takes into account that policy making, as much as being involved in the elimination of disabilities, is also involved in the production of gaps. A modest politic hesitates making universal promises. By instigating universal rights, expectations are created that disabled people should be fully included, just as everyone else, whatever the societal and individual costs. This, in turn, may produce feelings of lack and loss for those unable to live up to the ideals of the good life. A modest politics shifts the focus from policy making to the processes of realizing the political. The focus goes from the coherent strategies enacted in policy documents and debates, on to the messy, multiple and uncertain processes that unfolds in practice. Rather than to reiterate and reinforce claims

or universal rights, a modest politics is trying to become specific about the ways hard of hearing people should be included and how to go about achieving this goal. This, in turn, invites careful thinking not only about the goods, but also the limits, costs and risks of politics.

While universal rights are represented as essentially abstract, I still believe that it is possible to incorporate notions of diversity and difference into the conceptualisations without sacrificing the principle of common and equal rights which in itself is necessary for accommodating difference. If, however, society should continue the line with a politics of recognition (universal rights) and redistribution (welfare system) these must be handled as integrative, not as functions of separate institutions. Thus, while a modest politics demands recognition of social groups, it reserves a space for individuality, and maintains the right to limit claims, which again evokes issues of priority and responsibility. Traditionally, conceptualizations of disability have hinged on notions of people being in a position to take care of themselves or in need of care from others. In my view, the challenge for disability policy cannot be solved by falling back on either one of the two. Instead, what is needed is a form of shared, reciprocal responsibility. It entails that those influencing and being influenced by disability policy and practice are involved both in formulating, and limiting claims for social justice.

From the analysis of the lived experience of hard of hearing, three claims for just welfare systems were singled out. Service users demanded that their competencies are recognized, they reserved a right to be different, and they urged for sensitivity towards the specificities and uncertainties of human affairs. But does that mean that society should provide any solution disabled people demand? The question is how to regulate redistribution of collective resources. On what grounds should claims be made and assessed according to what standard? Should it be through a bureaucratic system, a market, or a self-regulating

principle of some kind? Following the troublesome history of professional-lay relationships, professionals are no longer seen as fit to voice concerns and make decisions on behalf of their clients. This, however, highlights the important societal responsibility in defining standards and assigning expertise that can work as gatekeepers for collective resources.

Service users, on their side, are not passive subjects merely acted upon by policy makers and professionals. They are active individuals with their own ideas of the good life, and projects to realize this. They use elements of disability discourse actively in the enactment of their multiple selves. Opening up for difference, means coming to terms with how people are more than hard of hearing. That also means that their claims for participation parity cannot always be justified with reference to disability. To distinguish between recognition and self-realization calls for prioritisation. Here, the responsibility of the hard of hearing community is important. Claims for recognition of individuality should take into account that systems of collective solidarity operate with limited resources. Thus, in my view, the task ahead is not to make even stronger claims. Instead, in order to justify the continuation of systems of collective solidarity, the challenge is to find legitimate ways to prioritise between, and limit claims. The challenge for the hard of hearing community is not only to define oneself as a social group, but also to take part in the perpetual inter-, and intra-group processes to define acceptable identities and make priorities for redistribution. This perspective demands that hard of hearing people become active participants in political and welfare institutions rather than passive beholders of rights. Such a geography of responsibility delegates not only rights, but also the responsibility to choose among and justify ones rights claims. Reciprocal responsibility enacts disabled people as equal and accountable partners in social affairs.

LIST OF REFERENCES

Abberley, P. (2002). Work, disability and european social theory. In C. Barnes, M. Oliver and L. Barton (Eds.), *Disability Studies today* (pp. 121-138). Cambridge: Polity Press.

---------- . (1987). The concept of oppression and the development of a social theory of disability. Disability, Handicap and Society, 2(1), 5—19.

Hansen B.H. (2007, November 2). Byrden av omstilling ("The burden of reorganization", not available in English). Aftenposten.

Akrich, M. (1992). The description of technical objects. In W. Bijker, and J. Law (Eds.), *Shaping technology/building society: Studies in sociotechnical change* (pp. 205–244). Cambridge, MA: MIT Press.

Akrich, M. and B. Latour. B. (1992). A Summary of a convenient vocabulary for the semiotics of human and nonhuman assemblies. In W. Bijker and J. Law (Eds.), In Shaping technology, building society: Studies in sociotechnical change (pp. 259-264). Cambridge, MA: MIT Press.

Andersen, S. (2006). Aktiv informantintervjuing ("Active informant interviewing", not available in English). Norsk Statsvitenskapelig Tidsskrift. 22 (3) 278-296.

Andersen, M.L. and Collins, P.H. (1995). *Race, Class, and Gender. An anthology*. Second edition. Belmont, CA: Wadsworth Publishing Company.

Alm Andreassen, Tone (2003). *Brukermedvirkning, politikk og velferdsstat*. ("User involvement, politics and welfare state", not available in English) (Doctoral dissertation) Oslo: Arbeidsforskningsinstituttets skriftserie.

---------- . (2008). Når pasienter blir brukere. En utfordring for ekspertisens.posisjon i helsepolitikken In K. Asdal and I. B. Moser (Eds.), *Ekspertise og brukermakt* ("Expertise and User involvement", not available in English) (pp. 93-117), Oslo: Unipub forlag.

Appiah, A.K. (1994). Identity, authenticity, survival: Multicultural societies and social reproduction. In C. Taylor and A. Gutmann (Eds.), *Multiculturalism* (pp 149-165). Princeton: Princeton University Press.

Asdal, K. (2003). The problematic nature of nature: the post-constructivist challenge to environmental history. History and Theory. 42 (4) 60-74.

Asdal, K., Brenna, B. and Moser, I. B. (Eds.) (2007). *Technoscience. The politics of interventions*. Oslo: Unipub AS.

AZOS (2006). PACT projecten AZOS Eindrapportage. Amsterdam: Stichting Platform for Audiological Clinical Work. Retrieved on March 15, 2007, from http://pact.cc/public/projects/

Bacchi, C. (1991). What's the Problem? In E. Meehan and S. Sevenhuijsen (Eds.), Equality, politics and gender (pp. 71–87). London: Sage.

---------- . (1999). *Women, policy and politics. The construction of policy problems.* London, California, New Dehli: Sage.

---------- . (2000). Policy as discourse: what does it mean? Where does it get us? Discourse: Studies in the Cultural Politics of Education 21(1) 45–57.

Barad, K. (2007). *Meeting the universe halfway: Quantum physics and the entanglement of matter and eaning*. Durham: Duke University Press.

Barnes, B. (1974). *Scientific knowledge and sociological theory*, London: Routledge and Kegan Paul.

Barnes, C. (1991). *Disabled people in Britain and discrimination*. London: Hurst and Co.

---------- . (1998). The social model of disability: A sociological phenomenon ignored by sociologists?. In T. Shakespeare (Ed.) *The Disability reader: Social science perspectives* (pp. 65–78). London: Cassell Academic.

Barnes, C. and Mercer, G. (2005). Disability, work and welfare: challenging the social exclusion of disabled people. Work, Employment and Society. 19(3), 527- 545.

Barnes P, and Ward A. B. (2000). *Textbook of rehabilitation medicine.* Oxford: Oxford University Press.

Barron, K. (Ed.) (2004). *Genus och funktionshinder* ("Gender and disability", not available in English). Lund: Studentlitteratur.

Bloor, D. (1976). *Knowledge and social Imagery*. London: Routledge and Kegan Paul.

Beleen, J. (2008). In *Weg met onze schuchterheid - Nederlandse Vereniging voor Slechthorenden 1908-2008* ("Overcoming our minority complex – the Ducth organization for hard of hearing people 1908-2008", not available in English). Houten: Colofon and Nederlandse Vereniging voor Slechthorenden.

Blume, S. (1999). Histories of Cochlear Implants.Social Science and Medicine. 49, 1257-1268.

Bourdieu, P. (1977). *Outline of a theory of practice*. Cambridge and New York: Cambridge University Press.

Bowker, G.C. and Star, S.L. (1999). Sorting *things out: Classification and its consequences*. Cambridge, MA: MIT Press.

Brown, N. and Webster, A. (2004). *New medical technologies and society: Reordering life*. Cambridge: Polity Press.

Butler, J. (1990). *Gender trouble: Feminism and the subversion of identity*. London:. Routledge.

Callon, M. (1980). Struggles and negotiations to define what is problematic and what is not: The sociology of translation. In K. D. Knorr, R. Krohn and R. D. Whitley (Eds.), *The social process of*

scientific investigation: Sociology of the sciences yearbook (pp. 197-219)*.* Dordrecht and Boston, MA: Reidel.

---------- . (1986). Some elements of a sociology of translation: domestication of the scallops and the fishermen of Saint Brieuc bay. In J. Law (Ed.) *Power, action and belief: A new sociology of knowledge?* (196-233). Sociological Review Monograph. London: Routledge and Kegan Paul.

---------- . (1998). An essay on framing and overflowing: Economic externalities revisited by sociology. In M. Callon (Ed.) *The laws of the markets.* (244-269) Sociological review monograph series*.* Oxford: Wiley-Blackwell.

Callon, M. and Latour, B. (1981). Unscrewing the Big Leviathan: How actors macrostructure reality and how sociologists help them to do so. In, K. D. Knorr-Cetina and A. V. Cicourel (Eds.), *Advances in Social Theory and Methodology: Toward an Integration of Micro- and Macro-Sociologies* (277-303). Boston, MA: Routledge and Kegan Paul.

Cerny, P. (1990). *The changing architecture of politics: Structure, agency, and the future.* Londo: Sage Publications.

Chappell, A.L. (1998). Still out in the cold: People with learning difficulties and the social model of disability In T. Shakespeare (Ed.), The disability reader: Social science perspectives (pp. 211–220). London: Cassell.

Christensen, T. (2005). The Norwegian state transformed? West European Politics. 28, 721 – 739.

Collins, H.M. (1991). Captives and victims: comment on Scott, Richards and Martin. Science, Technology, and Human Values. 16, (4), 249-250.

Connolly, W.E. (1991). *Identity/Difference: Democratic negotiations of political paradox.* New York: Cornell University Press.

---------- . (2005). *Pluralism.* Durham and London: Duke University Press. Corker, M. (2000). Disability politics, language planning and inclusive social policy. Disability and Society. 15(3), 445–461.

---------- . (1998) *Deaf and disabled or deafness disabled.* Buckingham: Open University Press.

---------- . (2002). Deafness/Disability problematising notions of identity, culture and structure. In Ridell, S. and Watson, N. (Eds), *Disability, culture and identity*. London: Pearson.

Corker, M. and Shakespeare, T. (2002). *Disability/postmodernity: embodying disability theory.* London: Continuum.

Couser, T.G. (2005). Paradigm's Cost: Representing Vulnerable Subjects. Literature and Medicine. 24 (1), 19-30.

Cox, R.H. (1993). *The development of the Dutch welfare state. From workers' insurance to universal entitlement.* Pittsburgh, PA: Pittsburgh University Press.

Crow, L. (1996). Including all of our lives: Renewing the social model of disability. In Barnes, C. and Mercer G (Eds.), *Exploring the Divide: Illness and Disability,* (55-73)*.* Leeds: Disability Press.

Danermark, B., Coniavitis Gellerstedt, L. (2004). Social justice: Redistribution and recognition - a non-reductionist perspective on disability. Disability and Society. 19 (4), 339-353.

Danforth, S. (2001). A pragmatic evaluation of three models of disability in special education*.* Journal of Developmental and Physical Disabilities. 13 (4), 343-359.

Davis, L.J. (1995). *Enforcing normalcy: Disability, deafness, and the body*. London, New York: Verso.

---------- . (2000). Disability Studies as ethnographic research and text: Research strategies and roles for promoting social change. Disability and Society. 15 (2),191 – 206.

---------- . (2003). *Bending over backwards: Disability, dismodernism, and other difficult positions*. New York: New York University Press

De Nora, T. (2000). *Music in everyday life*. Cambridge: Cambridge University Press.

Diedrich, L, (2005). Introduction: genealogies of disability, Cultural Studies. 19 (6), 649–666.

Escobar, A. (1996). Constructing nature: Elements for a poststructuralist political ecology. In Peet, R. and Watts, M. (Eds) Liberation ecologies: Environment, development, and social movements. (pp. 46-68). London.: Routledge.

EUROSTAT (2001). Disability and Social participation in Europe. Policy report retrived from: http://epp.eurostat.cec.eu.int/cache/ITY_OFFPUB/KS-AW-01-001/EN/KS-AW-01-001-EN.PDF

Falkenberg, E-S. (2007). Holistic aural rehabilitation: A challenge. Scandinavian Journal of Disability Research. 9 (2), 78-90.

Finkelstein, V. (1996). The disability movement has run out of steam. Disability Now, 11.

---------- . (1980). Attitudes and disabled people: Issues for discussion. Working paper retrieved from: http://www.leeds.ac.uk/disability-studies/archiveuk/finkelstein/attitudes.pdf

Finlayson, A. and Valentine, J. (2002). *Politics and poststructuralism: An introduction.* Edinburgh: Edinburgh University Press.

Flyvbjerg, B. (2004). Five misunderstandings about case-study research. In C. Seale et al. (Eds). *Qualitative research practice* (pp. 420-434)*.* London: Sage.

Fraser, N. (1997). *Justice interrupts. Critical reflections on the "Postsocialist" Condition*. New York: Routledge.

---------- . (1998). From Redistribution to recognition? Dilemmas of justice in a 'Post-Socialist' age. In A. Phillips (Ed.) *Feminism and politics* (pp 430-460)*.* Oxford: Oxford University Press.

---------- . (2000). Rethinking Recognition. New Left Review. 3, 107-120.

---------- . (2001). Recognition without ethics? Theory, Culture and Society. 18, 21–42.

Froestad, J. and Ravneberg B. (1991). *Fra veldedighet til rettighet* ("From chairty to justice", not available in English)*.* Oslo: Norges Handikappforbund.

Froestad, J. Solvang, P. and Söder, M. (2000). *Funksjonshemming, politikk og samfunn* ("Disability, politics and society", not available in English)*.* Oslo: Gyldendal Akademisk.

Forester, J. (1993). Learning from practice stories: the priority of practical judgement. In Fischer, F. and Forester, J. (Eds.), The argumentative turn in policy analysis and planning (pp. 186 – 209). Durham: Duke University Press.

Foucault, M. (1972). *The archaeology of knowledge*. London: Tavistock.

---------- . (1980). In C. Gordon (Ed.), *Power/Knowledge*: *Selected interviews and other writings 1972-1977*, London: Harvester.

---------- . (1984). Nietzsche, genealogy, history. In Rabinow, P (Ed.). *The Foucault Reader* New York: Pantheon Books.

---------- . (1988). The ethic of the care for the self as a practice of freedom. In J. Bernauer and D. Rasmussen (Eds.), *The final Foucault*, Cambridge MA: MIT Press.

---------- . (2003). *Society must be defended*: Lectures at the Collège de France, 1975–76, London: Allen Lane an imprint of Penguin Books.

Galis, V. (2006). From shrieks to technical reports: technology, disability and political processes in building Athens Metro. (Doctoral dissertation, LiU-Tryck, Linkoping University, 2006).

Garfinkel, H. (1967). *Studies in ethnomethodology*. Englewood Cliffs: Prentice Hall.

Garland-Thompson, R. (1997). *Extraordinary bodies*, New York: Columbia University Press.

Gavey, N. (1989). Feminist poststructuralism and discourse analysis: Contributions to feminist psychology. Psychology of Women Quarterly. 13, 459-475.

Gier de, E., Henke R., and Vijgen, J. (2001). *The Dutch Disability Insurance Act (WAO) and the role of research in Policy Change.* Working paper. Amsterdam: Amsterdam School of Social sciences.

Gleeson, B. (1999). *Geographies of disability*. London: Routledge.

GN ReSound (2005). '*ReSoundAir*' plus - Mer forsterking. Flere tilfredse brukere ('ReSoundAir plus – More enhancement. More satisfied users). Commercial brochure. Oslo: GN Resound.

Goffman, E. (1959). *The Presentation of self in everyday life*. New York: Anchor.

Goggin, G. and Newell, C. (2003). *Digital disability: The social construction of disability in new media.* Lanham, MD: Rowman & Littlefield.

---------- . (2005). Editorial. Disability Studies Quartley. 25 (2).

Gorz, A. (1999). *Reclaiming work: Beyond the wage-based society*. Cambridge: Polity Press.

Gottweis, H. (1998). *Governing molecules. The discursive politics of genetic engineering in europe and in the United States.* Cambridge, MA: MIT Press.

Grace, V.M. (1991). The marketing of empowerment and the construction of the health consumer: A critique of health promotion. International Journal of Health Services. 21, 329-343.

Grit, K. & Wilfred, D. (2002). The dynamics of the Dutch Health Care System: A discourse analysis. Review of Social Economy. 60 (3) 377-401.

Grint, K. and Woolgar, S. (1997). *The machine at work: Technology, work, and organization*. Cambridge, MA: Polity Press.

Grinten V.d, T. E.D. (2002). *Policymaking and research characteristics, models, relations. Course on evidence-based health policy*. Rotterdam: NIHES.

Groce, N.E. (1985). *Everyone here spoke sign language: Hereditary deafness on Marthas* Vineyard. Cambridge: Harvard University Press.

Grue, L. (2006). *Funksjonshemning, retorikk og forståelse* (Disability, rethorics and understanding). Dokumentasjonssenterets skriftserie 01/06. Oslo: Nasjonalt dokumentasjonssenter for personer med nedsatt funksjonsevne.

Haug, F. (1992). *Beyond female masochism*. Bristol: Verso.

Haraway, D.J. (1991). Situated knowledges: The science question in feminism and the privilege of partial perspective. In D.J. Haraway (Ed.), Simians, cyborgs and women: The reinvention of nature (pp. 183-201). London: Free Association Books.

Harbers, H. (Ed.) (2005). *Inside the Politics of Technology*. Amsterdam: Amsterdam University Press.

Harbers, H., Mol, A., and Stollmeijer, A. (2002). Food matters: Arguments for an ethnography of daily care. Theory, Culture and Society. 19 (5/6) 207-226.

Hawkesworth, M. E. (1988). *Theoretical issues in policy analysis*. Albany: SUNY Press.

Hemerijck, A. (1993). *The historical contingencies of Dutch corporatism*. (Doctoral dissertation). Balliol College, Oxford.

Van der Hoek, P. (2000). *Does the Dutch model really exist?* Working paper retrived from http://mpra.ub.uni-muenchen.de/5905/1/MPRA_paper_5905.pdf

van Houten, D. and Bellemakers, C. (2002). Equal citizenship for all. Disability policies in the Netherlands: Empowerment of marginals. Disability and Society. 17 (2) 171-185.

van Houten, D. and G.C. Jacobs (2005). Empowerment of Marginals: Strategic Paradoxes. Disability & Society. 20 (6) 641-654.

Hughes, T.P. (1983). *Networks of Power. Electrification in Western Society*, *1880-1930*. London: The John Hopkins Press.

Hugemark, A. and Roman, C. (2007). Diversity and divisions in the Swedish disability movement: Disability, gender, and social justice. Scandinavian Journal of Disability Research. 1, 26-45.

Hvinden, B and Oorschot, W.v. (Eds.) (2001). *Disability policies in European countries*. den Haag: Kluwer Law International.

Hyde, M. (1996). Fifty years of failure: Employment services for disabled Ppople in the UK. Work, Employment and Society. 12(4) 683-700.

Ingstad, B, and Reynolds, S. Whyte, (Eds.) (1995). *Disability and Culture*. Berkeley, Los Angeles, London: University of California Press.

Jasanoff, S. (Ed.) (1995). *Handbook of science and technology studies.* London: Sage.

Justis- og politidepartementet (2005). *NOU 2005:8 Likeverd og tilgjengelighet. Rettslig vern mot diskriminering på grunnlag av nedsatt funksjonsevne. Bedret tilgjengelighet for alle*. Oslo: Statens forvaltningstjeneste.

Katz, J. (1984). *The Silent World of Doctor and Patient*. New York: Free Press.

Kerz, J., Werner, M. and Wesser, E. (1995). *Vad vet vi om rehabilitering*? Svensk rehabiliteringsforskning 1980-1993 ("What do we know about rehabilitation? Swedish rehabilitation research 1980-1993", not available in English). Studier i välfärdssamhälle, socialförsäkring och arbetsliv, Vol. 6, Lund Bokbox: förlag.

Kildal, N. (1998). Velferd og arbeidsplikt - Om arbeidslinjensbegrunnelser ("Welfare and work ethics: on activation policy rationales", not available in English.). Tidskrift for Velferdsforskning. 1 (1) 18-34.

Kimberlin, S.E. (2009). Political science theory and disability. Journal of Human Behavior in the Social Environment. 1, 26 – 43.

Kool, J. Jansen, J. Veen v.d.E. and Nagtegaal, J. (2006). Startnotitie Disability Studies in Nederland ("Founding document Disability Studies in the Netherlands", not available in English). Retrived from: http://www.zonmw.nl/fileadmin/cm/vraagsturing/documenten/startnotitie_DS.pdf

Kramer, R. (1981). Voluntary *Agencies in the Welfare State.* Berkley: University of California Press.

Kroes, M. (2006, August 26). Applaus. posted to http://cgraad.web-log.nl/

Kruks, S. (2001). Retrieving *experience: Subjectivity and recognition in feminist politics.* Ithaca: Cornell University Press.

Laclau, E. (1996). Emancipation(s). London: Verso .

Laclau, E. and Mouffe, C. (1985). *Hegemony and socialist strategy*. London: Verso.

Lakoff, G. (1987). *Women, fire, and dangerous things: What categories reveal about the mind.* Chicago: University of Chicago.

Latour, B. (1986). Visualization and cognition: Thinking with eyes and hands. Knowledge and Society. 6, 1-40.

---------- . (1987*). Science in action*. Cambridge, MA: Harvard University Press.

---------- . (1990). Drawing things together. In (Eds.) Lynch M. and S. Woolgar, *Representation in scientific practice* (pp. 19-68). Cambridge, MA: MIT Press.

---------- . (1993). *We have never been Modern.* Cambridge: Harvard University Press.

---------- . (1999). *On Recalling ANT*. In J. Law and J. Hassard (Eds.) Actor Network and After. Oxford., Blackwell.

Latour, B. and Woolgar, S. (1979). *Laboratory life. The social construction of scientific facts*. Sage Library of Social Research, Volume 80. London: Sage.

Law, J. (Forthcoming). Constitutions and Interferences: Politics in STS*.

---------- . (2007). Actor-network theory and material semiotics*. Working paper retrived from: http://www.heterogeneities.net/publications/Law-ANTandMaterialSemiotics.pdf.

---------- . (2004). After method: Mess in social science research. London: Routledge.

---------- . (1999). After ANT: Topology, naming and Complexity. In J. Law and J. Hassard (Eds.) *Actor Network Theory and After*. Oxford and Keele: Blackwell and the Sociological Review.

---------- . (1997). *Traduction/Trahison: Notes on ANT*. Working paper retrived from: http://www.comp.lancs.ac.uk/sociology/stslaw2.html

---------- . (1994). *Organizing modernity*. Oxford: Blackwell.

---------- . (1987). Technology and heterogeneous engineering: The case of the Portugese expansion. In W. E. Bijker, T. P. Hughes and T. J. Pinch (Eds.), *The social construction of technological systems.* London: The MIT Press.

Law, J. and Mol, A. (2002). *Complexities: Social studies of knowledge practices.* Durham and London: Duke University press.

Leibfried, S. (1993). Towards a European welfare state? in C. Jones (Ed.) *New perspectives on the welfare state in Europe* (pp 133-56). London: Routledge.

Lie, M. (1998). *Computer Dialogues. Technology, Gender and Change*. Trondheim: NTNU Senter for kvinneforskning, skriftserie 2/98.

Lie, M. and Sørensen, K.H (Eds.) (1996) *Making technology our own? Domesticating technology into everyday life.* Oslo: Scandinavian University Press.

Lister, R. (2003). *Citizenship: Feminist Perspectives* (2nd ed). London: Palgrave Macmillan.

Livingston, S. (2005). *Redesigning the sound barrier.* In Thompson, H. and Thomas, N. (Eds.), *A supersonic future in Blueprint Broadsides An occasional series of essays to encourage debate about design* (pp. 19-20).

Lieth, L.v.d. (2002). *Audiology in a Scandinavian Concept*. In: Plant, Geoff (ed.): Proceedings. First International Adult Aural Rehabilitation Conference. Portland, Maine, USA, May 2001.

Lieverdink, H. (2001). The marginal success of regulated competition policy in the Netherlands. Social Science and Medicine. 52, 1183–1194.

Lynch, M. (1990). The externalized retina: Selection and mathematization in the visual documentation of objects in the life sciences. In M. Lynch and S. Woolgar (Eds), *Representation in Scientific Practice* Cambridge(pp. 153–86). Cambrigde, MA: MIT Press.

---------- . (1985). *Art and Artifact in Laboratory Science: A Study of Shop Work and Shop Talk in a Research Laboratory*). London: Routledge and Kegan Paul.

Lynch, M., and Woolgar, S. (Eds.) (1990). *Representation in scientific practice*. Cambridge, MA: MIT Press.

Lødemel, I. and Tricky, H. (2001). *An offer you can't refuse. Workfare in international perspective*. Bristol: The Policy Press.

Marcus, G.E. (1995). Ethnography in/of the world system: The emergence of multi-Sited ethnography. Annual Review of Anthropology. 24, 95-117.

Markussen, T. (2005). Practicing performativity: Transformative moments in research. European Journal of Women's Studies 12(3) 329-344.

Martin, B., Richards, E. and Scott, P. (1991). Who's a captive? Who's a victim? Response to Collins' method talk. Science, Technology and Human Values. 16 (2) 249-250.

Marin, B., Prinz, C. and Queisser, M. (Eds.) (2004). *Transforming disability welfare policies.* Aldershot: Ashgate, and the European Centre Vienna.

May, C. (2007). The clinical encounter and the problem of context. Sociology. 41, 29.

McLean, A. (1995). Empowerment and the psychiatric consumer/ex-patient movement in the United States: contradictions, crisis and change. Social Science and Medicine. 40 (8) 1053–1071.

McNay, L. (1992). *Foucault and feminism.* Cambridge, MA: Polity Press .

Meulen t.R. and Jotterand, F. (2008). Individual responsibility and solidarity in european health Care. The Journal of Medicine and Philosophy. 33, 191-197.

Ministerie van Volksgezondheid, Welzijn and Sport (2006). *The new care system in the Netherlands durability, solidarity, choice, quality, efficiency.* Retrived from: http://www.minvws.nl/en/folders/z/2006/the-new-health-insurance-system-in-three-languages.asp

---------- . (2005). *Equal treatment in practice vision and measures for people with disabilities, make it happen!* Retrieved from: http://www.minvws.nl/images/equal-treatment-in-practice_tcm20-108008.pdf.

---------- . (2005). *New foundations for health care with a solid future*. Retrieved from: http://www.nvzziekenhuizen.nl/dsc?c=getobject&s=obj&!sessionid=1WdpDcXH5WfcxG1jmb5WBNDecGa19fs1WDcV!js7tW8nhb9oWMdxXGwqyxTagM31&objectid=15142&!dsname=nvz

---------- . (2004). *Health care in an aging society – a challenge for all European countries.* Retrieved from: http://www.minvws.nl/en/folders/iz/health-care-in-an-ageing-society-a-challenge-for-all-european-countries.asp

Mol, A. (1999) Ontological politics. A word and some questions. In Law J. og Hassard J. (Eds.) *Actor network theory and after* (pp. 74-90)*.* Oxford: Blackwell, and The sociological review.

---------- . (2003). *The body multiple: Ontology in medical practice.* Durham and London: Duke University Press.

---------- . (2006). Proving or improving: On health care research as a form of self-reflection. Qualitative Health Research 16 (3) 405-414.

---------- . (2008). The *Logic of care: Health and the problem of patient choice.* London: Routledge.

Mol, A. and Berg, M. (Eds.) (1998). *Differences in medicine: Unravelling practices, techniques, and bodies* Durham and London: Duke University Press.

Morris. J. (1991) *Pride against prejudice: Transforming attitudes to disability*. London: The Women's Press.

---------- . (Ed.) (1996). *Encounters with strangers*. London: The Women's Press.

Mort, M., Finch, T. and May, C. (2008). Making and unmaking telepatients: Identity and governance in new health technologies. Science Technology and Human Values. 34, 9.

Moser, I. (2003). Road traffic accidents: The ordering of subjects, bodies and disability. (Doctoral dissertation) Oslo: Unipub forlag.

---------- . (2005). On becoming disabled and articulating alternatives. Cultural Studies. 19 (6) 667-700.

---------- . (2006a). Disability and the promises of technology: Technology, subjectivity and embodiment with an order of the normal. Information, Communication and Society. 9 (3) 373-395.

---------- . (2006b). Sociotechnical practices and difference: On the interferences between disability, gender and class. Science, Technology and Human Values. 31 (5) 537-565.

Moser, I, and Law, J. (1998). What makes a person? Ethics, politics and methods. Paper for the EASST-conferences in Lisbon, 30.9.-3.10.1998.

---------- . (1999) *Good passages, bad passages.* In J. Law and John Hassard (Eds.) Actor Network Theory and After (pp. 196-219). Oxford and Keele: Blackwell.

---------- . (2003). Making voices: New media technologies, disabilities, and articulation. In Rasmussen, T. et al. (Eds.) *Innovation: Media, Methods, and Theories* (pp. 491-521). Cambridge, MA: MIT-Press.

Neumann, I. (2001). *Mening, materialitet, makt. En innføring i diskursanalyse* ("Meaning, materiality and power: An introduction to discourse analysis", not available in English). Bergen: Fagbokforlaget.

Nielssen, A.R. (1997). Hørselshemmedes Landsforbund i medgang og motvind 1947-1997. In Flakne, O. (Ed.), *Men bakom synger skog*en…. ("In the background the forest sings", not available in English), Oslo:Hørselshemmedes Landsforbund.

Normann, T., Sandvin, J.T. and Thommesen, H. (2004). *A Holistic Approach to Rehabilitation* Oslo: Kommuneforlaget.

Olaussen, I. (2008). Fra aktiv stat til aktiv forbruker-borger: om den norske politikken for funksjonshemmede. In K. Asdal and I. B. Moser (Eds.), *Ekspertise og brukermakt* ("Expertise and User involvement", not available in English) (pp. 117-145). Oslo: Unipub.

OECD (2003). *Transforming Disability into Ability.*Retrieved from:
http://www.oecd.org/document/14/0,3343,en_2649_34747_35290126_1_1_1_1,00.html

Oliver, M.J. (1990). *The politics of disablement*. Basingstoke: Macmillan.

---------- . (Ed.) (1991). *Social work, disabled people and disabling environments*. London: Jessica Kingsley.

---------- . (1996). *Understanding disability*: *From theory to practice.* Basingstoke: Macmillan.

---------- . (1999). Capitalism, disability and ideology: A materialist critique of the Normalization principle. Working paper retrieved from: http://www.independentliving.org/docs3/oliver99.pdf .

Oorschot, W.v. (2004). Balancing work and welfare: activation and flexicurity policies in The Netherlands, 1980-2000. International Journal of Social Welfare..1, 15-27.

Oorschot, W.v. and Boos C. (2000). The battle against numbers: disability policies in the Netherlands. European Journal of Social Security. 2 (4) 343-362.

Oudshoorn, N. and Pinch, T. (Eds.) (2003). *How users Matter. The co-construction of users and technologies*. Cambridge MA: MIT Press.

Oudshoorn, N., Rudinow A.S. and Lie, M. (2002). On gender and Things: Reflections on an Exhibition on Gendered Artifacts. Women's Studies International Forum. 25 (4) 471-483.

Parker, S. (2006). International Justice: the United Nations, Human Rights and disability. Journal of Comparative Social Welfare. 22 (1) 63 — 78.

Parsons, W. (1995). *Public policy: An Introduction to the theory and practice of policy analysis*, Edward Elgar: Aldershot.

Petersen, A,. Barns, I., Dudley, J. and Harris, P. (1999). *Poststrunturalism, citizenship and social policy*. New York: Routledge.

Pinch T. & K., Bijsterveld (2004). Sound studies: New technologies and music. Social Studies of Science. 34 (5) 635-648.

Pickering, A. (1995). *The Mangle of practice: Time, agency and science*. Chicago and London: University of Chicago Press.

Thomas, P. (2004). Speaking of sound: Language and the professionalization of sound-recording engineers. Social Studies of Science 34(5) 733–58.

Power, M. (2004). Counting, control and calculation: Reflections on measuring and management. Human Relations. 57 (6) 765-83.

Priestley, M. (2003). *Disability: a life course approach*. Cambridge: Polity Press.

Rapley, T. (2004). Interviews. In C. Seale, et al. (eds.) *Qualitative research practice*. London: Sage.

Rabinow, P. (1986). *The Foucault reader*. London: Penguin.

Rabinow, P. and Rose, N. (Eds.) (1994). *The essential Foucault*. New York: The New Press.

Ring, L. (1994). Sexual harassment and the production of gender. Differences: A Journal of Feminist Cultural Studies. 6(1) 129–166.

Roe, E. (1994). *Narrative policy analysis: Theory and practice*. Durham: Duke University Press.

Rohracher H. (Ed.) (2005). *User involvement in innovation processes*. Strategies and limitations from a socio-technical perspective. Munchen: Profil-Verlag.

Roulstone, A. (2000). Disability, the New Deal and disabled people: Unpacking the latest dependency discourse. Disability and Society. 15 (2) 427–443.

Sarup, M. (1996). *Identity, culture and postmodern world*. Edinburgh: Edinburgh University Press.

Schram, S. F. (1993). Postmodern policy Analysis: Discourse and identity in welfare policy. Policy Sciences 26 (3) 249-270.

Schwandt, T. A. (2004). *Evaluating Holistic Rehabilitation Praxis*. Oslo: Kommuneforlaget.

Schön, D. and Rein, M. (1994). *Frame reflection: toward the resolution of intractable policy controversies*. New York: Basic Books.

Scott, Joan W. (1992). Experience. In J. Butler and J. Scott (Eds.), *Feminists theorize the political* (pp. 22-40). New York: Routledge.

Scott, J.W. (1988). Gender and the politics of *history*. New York: Columbia University Press.

Schwartz-Cowan, R., (1987). *The consumption junction: a proposal for research strategies in the sociology of technology*. In Bijker, W., Hughes, T., Pinch, T. (Eds.), *The social Construction of technological systems. New directions in the sociology and history of technology* (pp. 261–280). Cambridge, MA: MIT Press.

Seip, A-L. (1984). *Sosialhjelpstaten blir til* ("The beginning of the welfare state", not available in English). Oslo: Gyldendal Norsk Forlag.

Shapiro, M. (1992). *Reading the postmodern polity: Political theory as textual practice.* Minneapolis: University of Minnesota Press.

Shakespeare, T. (1996). Disability, identity and difference. In C. Barnes and G. Mercer (Eds.), *Exploring the divide* (pp. 94 – 113). Leeds: The Disability Press.

---------- . (2000). *Help*. London: Venture Press, British Association of Social Workers.

---------- . (2002). The Social model of disability: an outdated ideology? Research in Social sciences and Disability. 2, 9-28.

---------- . (2006). *Disability rights and wrongs*. London: Routledge.

Silbermann, A. (1963). *The sociology of music*. London: Routledge and Kegan Paul.

Siim, B. (2000). *Gender and citizenship. Politics and agency in France, Britain and Demark*. Cambridge, MA: Cambridge University Press.

Sirnes, T. (2001). Three discourses. Three countries. One sector. A comparison of theatre policy in Norway, Sweden and Finland from a discourse-perspective. Nordisk kulturpolitisk tidsskrift. 1, 46-84.

Sismondo, S. (2004). *An introduction to science and technology studies*. Malden, MA: Blackwell.

Smith, B.R. (1999). *The acoustic world of early modern England*: *Attending to the O-factor.* Chicago: University of Chicago Press.

Solvang, P. (2007). Developing and ambivalence perspective on medical labelling in education: case dyslexia. International Studies in Sociology of Education. (17) 1-2, 79-74.

Sosial- og helsedepartementet (2001). *NOU 2001:22 Fra bruker til borger. En strategi for nedbygging av funksjonshemmende barrierer*. Oslo: Statens forvaltningstjeneste.

---------- . (2002). Handlingsplan. *Et helhetlig rehabiliteringstilbud til hørselshemmede. Plan for utvikling og organisering av tjenestetilbudet.* Oslo: Statens forvaltningstjeneste.

Spelman, E. V. (1988). *Inessential woman: Problems of exclusion in feminist thought.* Boston: Beacon.

Star, S. L. (1991). Power, technologies and the phenomenology of conventions: on being allergic to onions. In J. Law (Ed.) *A sociology of monsters? Essays on power, technology and domination* (pp. 26-56)*.* Sociological Review Monograph. London: Routled.

Star, S. L. and Strauss, A. (1999). Layers of silence, arenas of voice: The ecology of visible and invisible work. Computer Supported Cooperative Work. 1, 9-30.

Stjernø, S. (2005). *Solidarity in Europe: The history of an idea.* Cambridge: Cambridge University Press.

Stenvoll, D. (2003). *Politisk argumentasjon. En analyse av norske stortingsdebatter om seksualitet og reproduksjon* 1945-2001 ("Political argumentation. An analysis of Norwegian Parlamentary debates on sexuality and reproduction 1945-2001", not available in English). Bergen: Stein Rokkan senter for flerfaglige samfunnsstudier.

Stewart, J. and Williams, R. (2005). The wrong trousers? Beyond the design fallacy: Social learning and the user. In H. Rohracher (Ed.), *User involvement in innovation processes. Strategies and limitations from a socio-technical perspective* (pp. 39-73). , Munchen: Profil-Verlag.

Stone, D.A. (1988). *Policy paradox and political reasoning.* Illinois: Glenview.

Struhkamp, R. (2004). Dealing with disability: inquiries into a clinical craft. (Doctoral dissertation, University of Twente, 2004).

Suchman, L.A. (1987). *Plans and situated actions: The problem of human-machine communications*. Cambridge, UK: Cambridge University Press.

Taylor, R.F. (2004). Extending conceptual boundaries: Work, voluntary work and employment. Work, Employment and Society. 1, 29–49.

Thomas, C. (1999). *Female forms: Experiencing and understanding disability*. Buckingham: Open University Press.

Carol, T. and Corker, M. (2002). A journey around the social model. In M. Corker and T. Shakespeare,(Eds.), *Disability/Postmodernism: Embodying disability* theory (pp. 18-31).   London: Continuum.

Thompson, C. (earlier Cussin) (1998). Ontological choreography: Agency for women patients in an infertility clinic. In M. Berg and A. Mol (Eds.), Differences in medicine: Unraveling practices, techniques and bodies. Durham: Duke University Press.

Thompson, H. and Thomas, N. (2005) A supersonic future. Blueprint Broadsides: An occasional series of essays to encourage debate about design. 11, 3-19.

Torfing, J. (1999). *New theories of discourse*: *Laclau, Mouffe, and Zizek*. Oxford and Malden: Blackwell Publishers Inc.

Torfing, J. (2004). Discourse theory: Achievements, arguments and challenges. In Howarth, D. & J. Torfing (Eds.), *Discourse theory in European politics: Identity, policy and governance*. Basingstoke: Palgrave.

Traweek, S. (1988). *Beamtimes and Lifetimes: The World of High-energy Physicists.* Cambridge MA: Harvard University Press.

Traustdottir, R. (1991). Mothers who care: gender, disability, and family life. Journal of Family Issues. 12 (2) 211-228.

Tremain, S.L. (2005). *Foucault, governmentality and critical disability theory.* In S.L. Tremain (Ed.) *Foucault and the government of disability* (pp. 1-27). Michigan: University of Michigan Press.

Union of the Physically Impaired Against Segregation (1976). *The fundamental principles of disability*. London: UPIAS.

Valentine, G. and Skelton, T. (2008). Changing spaces: the role of the internet in shaping Deaf geographies. Social and Cultural Geography. 9 (5) 469 — 485.

Vink, D. (Ed.) (2003). *Everyday engineering: An ethnography of design and innovation*. Cambridge, MA: MIT Press.

Wajcman, J. (1991). *Feminism Confronts Technology.* Proceedings from 'In Action for Equity: The Second Decade': The Sixth international GASAT conference. Sydney: Allen and Unwin.

Wendell, Susan. (1996). *The rejected body: Feminist philosophical reflections on disability* New York: Routledge.

West, C. og Zimmerman D.H.: (1987). Doing gender. Gender and Society. 1 (2) 125 – 151.

---------- . (1995). Doing difference. Gender and Society. 9, 8-3.

Wetherell, M., Taylor, S., Yates, S., (2001). *Discourse theory and practice: A reader*. London: Sage.

White, S. (1991). *Political theory and postmodernism*. Cambridge: Cambridge University Press.

Winther Jørgensen, M. and Phillips, L. (2002). *Discourse analysis as theory and method*. London: Sage.

WHO (1986). *Ottawa Charter for Health Promotion*. Geneva: World Health Organization.

Williams, S. J. (1999). Is anybody there? Critical realism, chronic illness and the disability debate. Sociology of Health & Illness. 21 (6) 797–819.

Williams S.J. (2002). Corporeal reflections on the biological: Reductionism, constructionsm and beyond. In Bendelow et al. (Eds.), *Gender, health and healing: the public/private divide* (pp. 13–33). London: Routledge.

Winance, M. (2006). Trying Out the Wheelchair. Science, Technology and Human Values. 31(1) 52-72.

---------- . (2008). Being normally different? Changes to normalisation processes: From alignment to work on the norm. Disability and Society. 22 (6) 625-638.

Yanow, D. (2000). *Conducting interpretive policy analysis*. Newbury Park, CA: Sage.

Young, I.M. (1998). Polity and group difference: A critique of the ideal of universal citizenship. In, G. Shafir (Ed.), *The citizenship debates: A Reader* (pp. 263-289). Minneapolis: University of Minnesota Press.

Østerud, Ø. (2005). Introduction: The peculiarities of Norway. *West European Politics.* 28 (4) 705-720.