

Tangles in the Weave of Disability

On the structurality of disabling structures

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Thesis submitted for the
degree of Ph.D., to the
Faculty of Social
Sciences, University of
Oslo, 2011

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*Series of dissertations submitted to the
Faculty of Social Sciences, University of Oslo
No. 318*

ISSN 1504-3991

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Cover: Inger Sandved Anfinsen.
Printed in Norway: AIT Oslo AS.

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Dagmar Elisabeth Hanisch

04.12.1914 – 03.11.2008

Strø noen roser på den vei jeg vandrer,
så blir den ei så tung og hård

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Acknowledgements

First, I wish to thank my supervisors, who have guided me with support, creativity and endless patience: Ivar Frønes and Per Koren Solvang. In addition, I am especially grateful to Tom Shakespeare; without his confidence, criticism and support, my work would have been very different.

I am very grateful to my brother and sister in-arms in the research everyday. I thank Aleksandra Bartoszko, for hours of merciless reading and discussions, and for that warmth of the heart which is all too scarce in the world of academia; and Jan Grue, for a shared office space where academic (and non-academic) thoughts could change, evolve or just be shared as they came to life.

Thanks also go to those who have read or listened to parts of my work - their rigor and sincere interest have been decisive: Astrid Bergland, Eivind Engebretsen, Lars Grue, Inger Marie Lid and Willy Pedersen. I would also like to thank those who have shared of their vast knowledge: Inga Bostad, Arne Jørgen Kjosbakken, Johanne Thornes and Ingvil Øien. In particular, I am deeply grateful to my dear friends, Kjersti Horn and Mikkel Øyen, together with whom I began to think analytically about disability.

I would like to thank Oslo University College, for granting me my PhD fellowship, and Norwegian Social Research (NOVA), for access to statistical data. I would also like to thank my editors and referees.

I could never have managed without the practical support, and warm vote of confidence, from my family. I thank my father, my mother, my brother Einar and my sister Hanne. More than anything else, I am grateful to my wife Johanne, who has taken on so many responsibilities to make my work easier, and loved and comforted me through long hard nights filled with doubts and exhaustion. Finally, the last years would have been altogether different without my children Trygve and Jenny. Johanne, Trygve, Jenny: The greatest honour is due to those who have shouldered the heaviest burdens.

I dedicate this PhD thesis to the memory of my grandmother. Always deeply touched by the challenges I have met, and sincere but very hesitant when talking about them, she taught me more than anyone about the difficulties of disability.

HMH, Oslo, May 2011

Part 1: Introduction

Chapter 1: Background

The disability studies perspective

Introductions to PhD theses are sometimes referred to as “final contributions”. Some contributions clearly aim to discuss *additional* issues. Because the articles presented in this thesis present many findings and arguments, this introduction has the opposite intention. The goal of the introduction to this thesis is to explicate how the articles contribute to sociological understandings of disability and to clarify arguments where the articles did not leave space for explication.

This introduction is not the place for a review of the sociology of disability. Such reviews have been presented in depth elsewhere (Shakespeare 2006:7-67, Thomas 2007:1-80, Goodley 2010: 46-64). Within the framework of this thesis, it is sufficient to point out that it belongs to the field of disability studies rather than to what medical sociologists refer to as ‘the sociology of chronic illness and disability’. Disability studies, which, in this introduction, are restricted to Anglo-American research frontiers, define disability as a matter of social oppression. Carol Thomas sums up this ‘disciplinary divide’ as follows:

medical sociology makes sense of 'chronic illness and disability' through the *social deviance* lens, while disability studies have *social oppression* as their analytical signature. (Thomas 2007:178).

In the tradition known as the UK social model, this perspective is expressed in the analytical distinction of *impairment* and *disability*. This distinction, first developed by the

Union of the Physically Impaired Against Segregation, later became 'the dominant UK understanding of disability' (Shakespeare 2006:2). Here, disability, as opposed to impairment, is defined as a 'the disadvantage or restriction of activity caused by a contemporary social organisation that takes little or no account of people who have physical impairments' (UPIAS 1975). In the US, similar concerns have been voiced from other viewpoints, often less related to historical materialism. Lennard Davis, for instance, states the following:

the object of disability studies is not the person using the wheelchair or the Deaf person but the set of social, historical, economic and cultural processes that regulate and control the way we think about and think through the body

(Davis 1995:2)

The impairment/disability distinction and its theoretical implications have been highly contested (Shakespeare 2006:29-53, Siebers 2008:53-69). This truly unavoidable debate is nevertheless rather peripheral in the articles of this thesis. These articles and this introduction are primarily concerned with the oppressive social mechanisms affecting and oppressing people with impairments. This social process (or, if you will, *structuring*) is termed in many ways. While Mike Oliver terms it 'disablement', Carol Thomas terms it 'disablism': '*Disablism* [...] refers to the social beliefs and actions that oppress/exclude/disadvantage people with impairments' (Thomas 2007:13). Although Thomas' term is employed in article 2, and though it might be tempting to cultivate this author's perspective, the empirical findings suggest otherwise. While all three articles in this thesis present findings of disability-specific situations marked by disabling processes, they also present findings of enabling processes within those situations. Even if disabling processes are the main concern in this thesis, to name the analytical object 'disablism' would arguably conflate the complex phenomenon we call disability with disablism. Hence, this introduction employs the term disability (rather than disablement or disablism), noting that it is used in the social sense that characterizes disability studies.

Postulates in the disability studies canon: notions of structure

Disability studies is a highly diverse field, both theoretically and methodologically. Although this has reduced the number of common concerns, this theses departs from two assumptions that arguably remain commonplace: **(1)** that disability is intertwined with power relations that oppress people with impairments; and **(2)** that this intertwining implies that disability is not only a social phenomenon but also a matter of social *structure*. In sociology, it may seem completely uncontroversial, if not overtly commonsensical, to rely on these assumptions. On the one hand, ‘the nature of power’ has been one of ‘sociology’s central concerns since the classical founders’ (Giddens 2010:1). On the other hand, it is rare (if not self-contradictory) to make the sociological argument that the object of analysis is *not* a matter of social structure.

However, an important question remains: how are these postulates interpreted and conceptualized in disability studies? In a recent literature review, the Swedish sociologist Lars Grönvik examined several *readers*. From these analyses, he pinpoints five canonical works in disability studies: Mike Oliver’s *The politics of disablement*, Colin Barnes’ *Disabled people in Britain*, Gary L. Albrecht’s *Disability business*, Norah E. Groce’s *Everyone here spoke sign language* and Irving K. Zola’s *Missing pieces* (Grönvik 2007:752-753). Since Grönvik’s sampling, however, two more readers have emerged (Titchkosky & Michalko 2009, Davis 2010). When these two works are added to Grönvik’s sample (which consisted of five works), two additional works emerge as canonical: Lennard Davis’ *Enforcing of normalcy* and Rosemarie Garland-Thomson’s *Extraordinary bodies*. In Grönvik’s review, three issues are at stake: **(1)** ‘the position of the body’ (Grönvik 2007:751); **(2)** conceptualizations of the ‘processes of marginalization and exclusion’ (Grönvik 2007:758); and **(3)** the manner in which the theoretical concept of disability is operationalized and used to ‘describe empirical data’ (Grönvik 2007:754, 750).

As stated above, the concerns in this thesis are primarily limited to issue (2). This is not to say that I am subsuming these six scholars under a (strictly) social model of disability. I am only scrutinizing the canon pointed out by Grönvik and the two additional works to outline a landscape of different understandings of disabling processes. By comparing these understandings, I will have a screen with which to exhibit the contribution of this PhD thesis.

Barnes and Oliver, both UK sociologists, depart from the definition given by the UPIAS (Oliver 1990:11, Barnes 1991:6-7). In their refining of the UPIAS definition, as well as in the original definition itself, it seems clear that the disabling ‘contemporary organization’ is neither specific to people with impairments nor to certain sectors of contemporary society. Instead, disability is a matter of how our society, as a whole, is structured. While Oliver explicitly sets out to ‘consider the ways in which disability is “produced” within capitalist society’ (Oliver 1990:11), both sociologists share a strong and long-lasting commitment to historical materialism (Oliver 1990:25-42). Hence, the UK social model tradition employs notions of structure that have at least two distinctive traits: first, they are *totalizing* notions, wherein the disabling social structure controls or prestructures almost every element of social life; and second, the structures are primarily (re)produced by economic factors, making ‘political economy’ the ‘grand theory’ of the social model of disability (Oliver 1995:3-5).

This perspective – which was not only developed by Barnes and Oliver but also, to a large degree, by Vic Finkelstein – is furthered and refined in the oeuvre most cited in the articles of this thesis: Carol Thomas’ work. Her work on the psycho-emotional aspects of disability clearly takes the social model as its ‘point of departure’ (Thomas 1999:13). In her historical discussions of disability theory (which likely log this ‘departure’, it is exactly Finkelstein’s

analysis of disability as ‘a form of social oppression’ that ‘stands out’ (Thomas 2004:577). In her interpretation, Finkelstein’s analytical path is quite clear: ‘towards a materialist analysis of the ways in which the social oppression of disabled people is fundamentally bound up with the social relations of production in capitalist society’ (Thomas 2007:53). Although her feminist orientation sets her apart from Oliver and Barnes, her work on disablism seems equally embedded in a fundamental critique of capitalism.

Arguing that ‘people are impaired but the environment is disabling’ (Albrecht 1992:35), Gary Albrecht clearly unfolds a sociological perspective. From his perspective, the ‘environment’ is at once highly individual and highly structural. On the one hand, the focal point is ‘an individual’s immediate environment’. On the other hand, Albrecht has himself underlined that the ‘political economic analyses’ in *Disability business* ‘address the societal level’ (Albrecht 2001:655). Albrecht’s definition of disability may seem akin to Oliver’s, Barnes’ or Thomas’:

Persons with disabilities live within a political economic system that grants them a set of basic rights based on equity but at the same time allows them to be treated as less than equal citizens; to be marginalized or excluded.

(Albrecht 2003:27)

However, Albrecht does not primarily describe these systemic (or structural) features as oppression, but rather as ‘discrepancy’ or a ‘gap’. Firstly, this terminology makes it clear that Albrecht’s perspective is relational, more closely related to medical sociology than that of Barnes or Oliver. Secondly, it is clear that Albrecht’s perspective is not radically structural (social modelist) with regard to the *ontology* of disability. Unlike Oliver, for instance, who exclude impairment from discussions of disabling processes and empowerment, Albrecht insists that both theoretical developments and empowering work should ‘build on both the organic base of impairment and the social model of disability’ (Albrecht & Devlieger 1999:986). Nevertheless, he conceptualizes disabling processes (as such) in a way that is very similar to the UK social model.

Like Albrecht, neither Groce nor Zola departs from a strictly social understanding. Instead, they both arrive at the social ontology of disability as ‘one of their *conclusions*’ (Grönvik 2007:762, Grönvik’s emphasis). Groce, a medical anthropologist, emphasizes that social structures, disabling as well as enabling, are localized and contextual. It is crucial to her argument that space-specific factors, such as the prevalence of hereditary deafness or the geographical fact that islands are topographically “secluded”, are formative of the meaning and social importance of impairment on Martha’s Vineyard. The American sociologist Irving Zola, however, suggests that structures are just as formative but without sharing Groce’s emphasis on locality. Drawing on Goffman (Zola 2003:115-116, 202-203), he is primarily concerned with the social ‘baggage’ in social interactions. Both are concerned with what might be called social frames. Groce’s and Zola’s analyses both amount to fairly ‘totalizing’ perspectives that emphasize the micro or macro levels, respectively. They argue that the term handicap (which now is referred to as disability) is ‘defined by the community in which it appears’ or depends upon our ‘healthist, capitalist and hierarchical society’ (Groce 1985:4, Zola 2003:235).

Davis and Garland-Thomson give primarily historical accounts of disabling social structures. Both draw on the work of Michel Foucault (Davis 1995:51-53, Davis 2002:30-32, 80-88, Garland-Thomson 1997:16-18, 35-41). Hence, the differences between Davis’ Garland-Thomson’s perspectives can be illuminated by Foucault’s distinguishing of genealogical and archeological analysis. For Foucault, genealogical analyses map the emergence and development of discursive structures: ‘The role of genealogy is to record its history’ (Foucault 1980:162). Archeological analyses, on the other hand, are concerned with ‘homogenous fields of enunciative regularities’ that characterize ‘discursive formations’ (Foucault 2007:162). While this difference should not be overestimated (Scott 2009:351-353), it is fair to say that Davis’ perspective is these approaches are primarily diachronous and Garland-Thomson’s perspective is primarily synchronous More importantly, a genealogical analysis emphasizes how a certain discursive structure is

produced by (and formative of) a broader social structure, while an archaeological analysis emphasizes how discursive structures sustain and reveal the broader social structure.

Davis' analyses, on the one hand, are largely genealogical, aiming to investigate how disability 'is a part of a historically constructed discourse, an ideology of thinking about the body under certain historical circumstances' (Davis 1995:2). He situates disability within a fairly stable historical structure and maps this structure by studying its emergence:

As we will see, the social process of disabling arrives with industrialization and with the set of practices and discourses that are linked to eighteenth- and nineteenth-century notions of nationality, race, gender, criminality, sexual orientation, and so on

(Davis 1995:25)

Garland-Thomson's work, on the other hand, is first and foremost archaeological. Her best-known analytical concept is perhaps that of 'the normate' - 'the veiled subject position of the cultural self' (Garland-Thomson 1997:8). Investigating 'the processes and assumptions that produce both the normate and its discordant companion figures' (Garland-Thomson 1997:9), she traces the social and linguistic conditions that makes the social category 'disability' possible.

In short, these seven canonical works seem to employ four notions of structure: **(1)** socio-material structures specific to capitalism (Oliver, Barnes), **(2)** situational (localized) structures (Groce), **(3)** relational (interactional) structures that are engendered by societal "deep structures" (Zola, Albrecht) and, finally, **(4)** historical and linguistic structures (Davis, Garland-Thomson). There are, of course, numerous overlaps, which have been addressed elsewhere. Without discussing these overlaps in detail, I conclude that this introductory review has two main findings: **a)** Disability studies generally describe social structures as *strong* or almost total structures. They are seldom viewed as specific to social

arenas, individual social positions or impairment groups. Instead, the social structuring of disability is rooted in the deep structure of society. **b)** While there is considerable agreement upon the importance of structure, there is little if any agreement upon how structures are socially produced or what they “consist of”.

These two findings guide the design of this PhD thesis. On the one hand, all three articles scrutinize postulates in different notions of structure. On the other hand, the differences between the concepts discussed above suggest that they are rooted in different empirical areas. Consequently, the design encompasses different methods, different materials and different theoretical frameworks.

Design and key findings

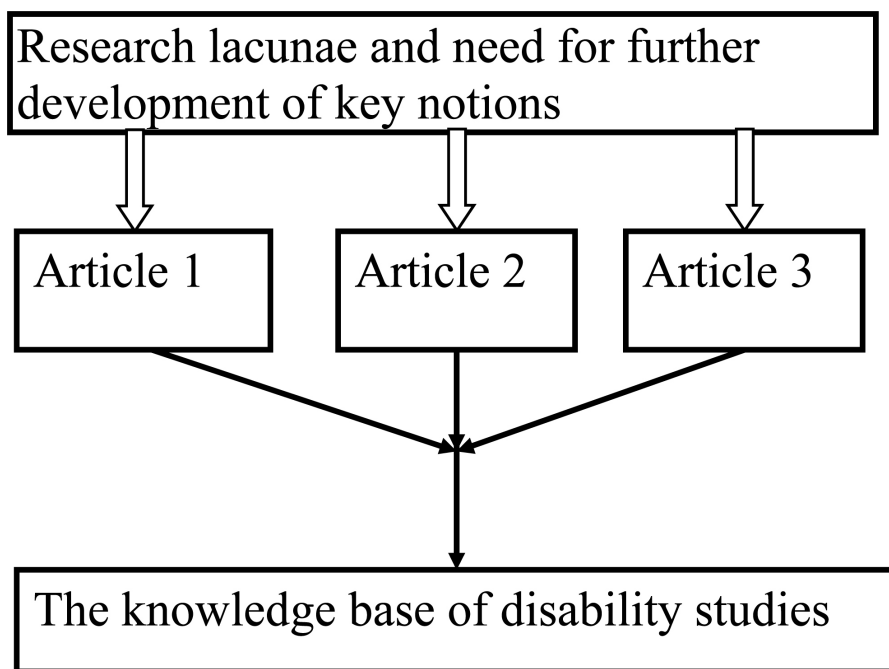
The issues discussed above are perhaps too abstract to be applied directly in empirical research. Hence, I try to approach a theoretical (general) phenomenon by combining different types of data and different methodologies. As suggested in the review above, issues of structure and convergence are crucial. Hence, I approach the three empirical phenomena at stake – spatial disabling, psycho-emotional disabling, and enabling parental narratives – with operationalized hypotheses that take this into account. The applied design can be illustrated as follows:

Hypothesis	Method	Finding
"Nina" is excluded from public space	Interview-based case study (article 1)	"Nina" is excluded from public space
The meaning of different spaces – or their <i>placeness</i> – remains the same		The placeness of both public and domestic space is reworked
Disabled adolscents exhibit lower psycho-emotional well-being than their non-disabled peers	Quantitative analyses of survey data (article 2)	Disabled adolscents exhibit lower psycho-emotional well-being than their non-disabled peers
Disabled adolscents experience less social participation than their non-disabled peers		Disabled adolscents do <i>not</i> experience less social participation than their non-disabled peers
Parental narratives rely, as most discourses on disability in contemporary society, upon the "personal tragedy theory"	Textual analyses of parental narratives (article 3)	Parental narratives are (largely) not reliant upon the "personal tragedy theory"
Parental narratives resist this tragic view on disability by way of politicized storytelling		While the tragic view is resisted by way of politicized storytelling, the most important resistance lies in narratives of appreciation

This design seems to fit many definitions of triangulation, such as Creswell and Miller's: 'triangulation is a validity procedure where researchers search for convergence among multiple and different sources of information to form themes or categories in a study'

(Creswell & Miller 2000:126). However, the notion of triangulation (at least in disability studies) tends to suggest that the design is teleological, that is, directed toward a singular finding and/or a singular argument. In Marshall and Rossman's definition, cited in the *Handbook of disability studies*, triangulation is defined as 'the act of bringing more than one source of data to bear on a single point' (Brown 2001:146).

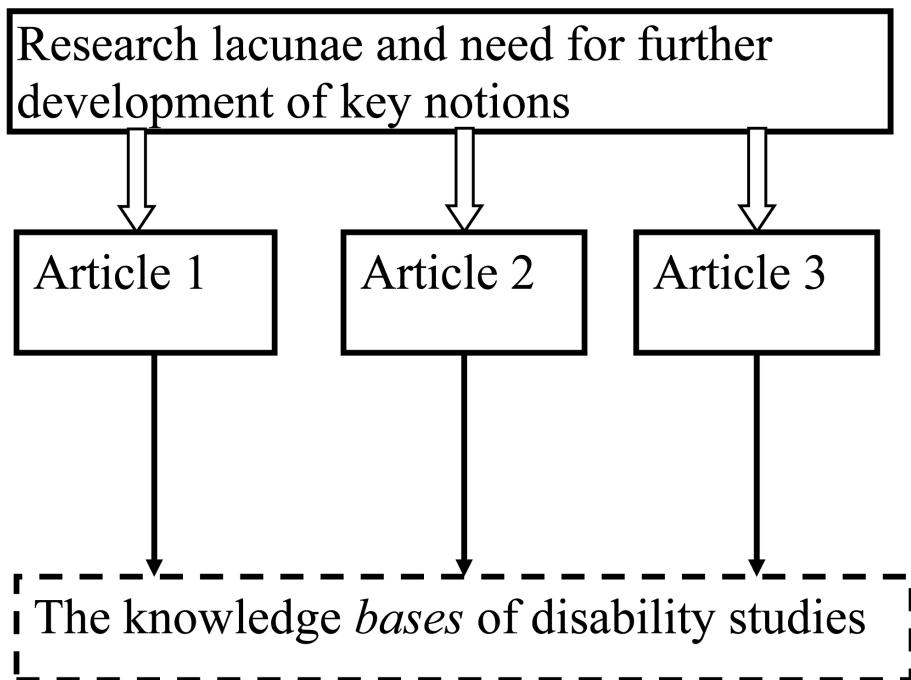
The relation between separate methods (that is, the relation between the different sub-inquiries that amount to the broader, triangulated inquiry), may seem to be a cumulative process from uncertainty toward certainty. With regard to the sub-inquiries in this thesis, this notion can be visualized as a move from lacunae and underdeveloped notions toward a strengthened knowledge basis in the research frontier:



However, the procedure entailed in this thesis is less teleological. Instead of applying established frameworks or arguing that some should replace others, the postulates of these frameworks are converted into applied (operationalized) hypotheses. The aim is not to develop any totalizable framework, but to apply these hypotheses to a few selected areas, partly to see if previously developed frameworks (which claim to be totalizable) are adequate. While all three studies present solid evidence of disabling processes, they also fail to confirm these postulates in at least three ways: **(1)** the findings are less convergent – that is, less suitable for hard-core structural analyses – than large parts of the disability studies canon seems to postulate; **(2)** aggression seems, in some contexts, to be more important than those ‘barriers to doing’ to which disability studies often give center stage; and **(3)** enabling resistance seems, as demonstrated in both articles 1 and 3, to have other

and more important focal points than social movements, identity politics or social participation.

First, these findings imply that the analytical direction is a move from (relative) certainty to (relative) uncertainty. Second, there is little overlap between the “failures”. While they do suggest theoretical developments, and many of these possible developments could be compatible with each other, they are far from composing a coherent whole. Hence, neither the sub-inquiries nor the overall argument are brought ‘to bear on a single point’. This thesis provides a *prism* rather than a *lens*.



The analytical “spreading” and the critique of overtly strong emphases on social structure are in no way “anti-structuralist”. I am not arguing that rigorous notions of social structure

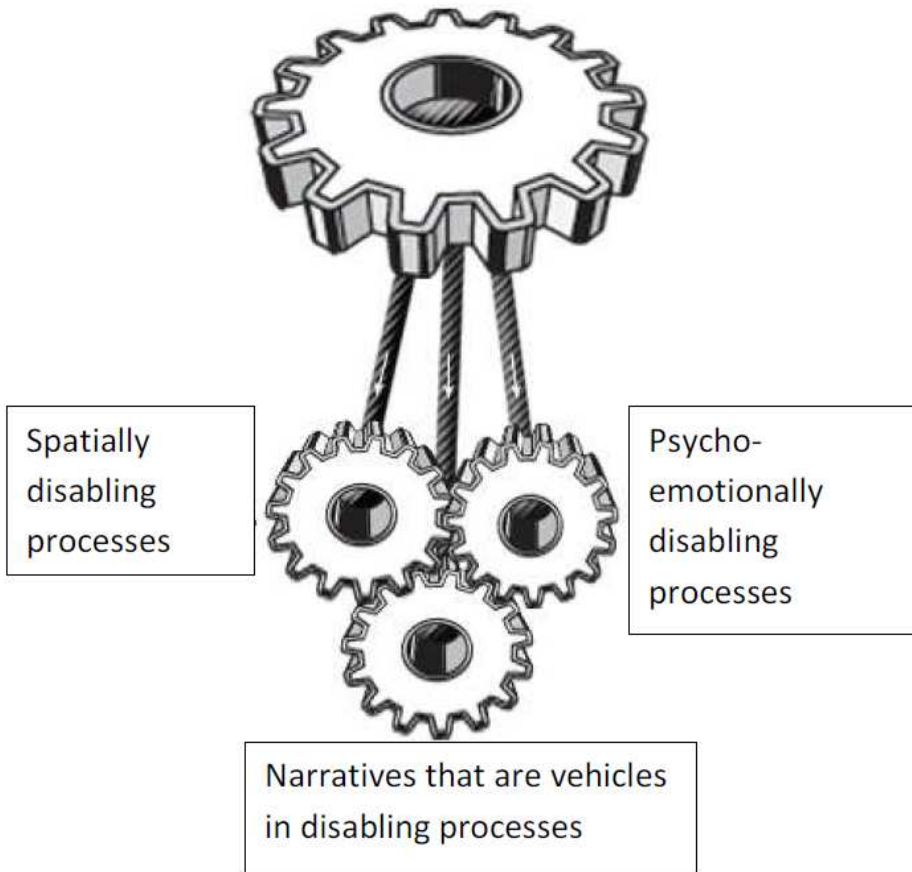
are unnecessary. Instead, it seems that the notions of structure require further explication, further interaction with general issues in social theory and, at least, some reworking to become more sensitive to the complexity of these (and other) empirical findings. The remainder of this introduction is primarily an argument as to how notions of structure could be reworked in order to achieve that sensitivity.

Chapter 2: The main argument

Disabling structures are diverse structures

It is one thing to question analytical postulates that have been derived from empirical or theoretical works; it is another thing to question these works as a whole. It is important neither to dismiss important findings on the basis of problematic postulates nor to reduce the analyses to those postulates. To be very clear, I am not arguing that prominent disability study traditions reduce the lives of disabled people to structural phenomena, be they material, interactional or linguistic.

With the possible exceptions of Oliver and Barnes, none of the scholars discussed above represent any 'imperialism of the social object' – I do not argue that their work amounts to 'empire-building endeavors' akin to structural functionalism (Giddens 1984:2). However, I do argue that many important scholars seem to postulate a very “well-structured” society, that is, a society ordered and maintained by stable and converging social mechanisms. This postulate can be visualized as follows.



Against this postulate, my argument throughout this thesis, is quite simple: When people's lives do belong to a social order, it is because they are socially *ordered* or constituted, not because the socially constituted result is *orderly*. Hence, empirical findings can indicate disabling processes without providing a consistent and well-ordered image of the disabling structure. It seems necessary to supplement totalizing notions – for instance, in Oliver's historical materialist perspective or Lennard Davis' Lacanian approach – with notions better suited to interpreting *disorderly* or complex results.

These notions can, as theoretical frameworks, not only be derived from the field of disability studies. Instead, there is a need to develop them as social theory, that is, with reference to debates that are not disability-specific. Relying on article 1, I find the appropriate point of departure in the work of Anthony Giddens, starting with the work in which he addresses notions of social structure in depth: *The constitution of society* (1984). Here, Giddens develops many notions to grasp diversified society.

At least two of these notions are relevant frameworks for this thesis. First, he describes a spatial diversity that he refers to as 'regionalization' or 'zoning': 'the zoning of time-space in relation to social practices' (Giddens 1984:119). Zoning encompasses the notions of 'space' versus 'place' (as applied in article 1), and the notion of place is dynamic and continuously related to the social practices taking place.

Second, he develops a notion of enervative diversity, that is, the argument that social structures facilitate, not just limit, social action. This claim that social structure 'is not to be equated with constraint' (Giddens 1984:25) and that power is 'enablement as well as constraint' (Giddens 1984:175) may seem common-sensical. Just as no disability scholar would claim that society consists of nothing but barriers, so also would few social theorists hold such a negative view of social structure. However, this is not Giddens' point. He is not arguing that all structures (and all societies) have elements that are enabling. Instead, he argues that *all* structured elements in social life (what he calls 'structural properties') are *both* constraining and facilitating, or, in the case of disability, both disabling and enabling.

While the articles in this thesis present many findings that can be related to these notions of diversity, only a few of those relations can be sketched here. With regard to spatial diversity (regionalization), there is no doubt that the whole of article 1 testifies to such processes. In particular, it seems clear that the enrichment of domestic space, whereby it becomes a different type of place than one "normally" would assume, is a form of 'zoning'

(Giddens 1984:119-130).

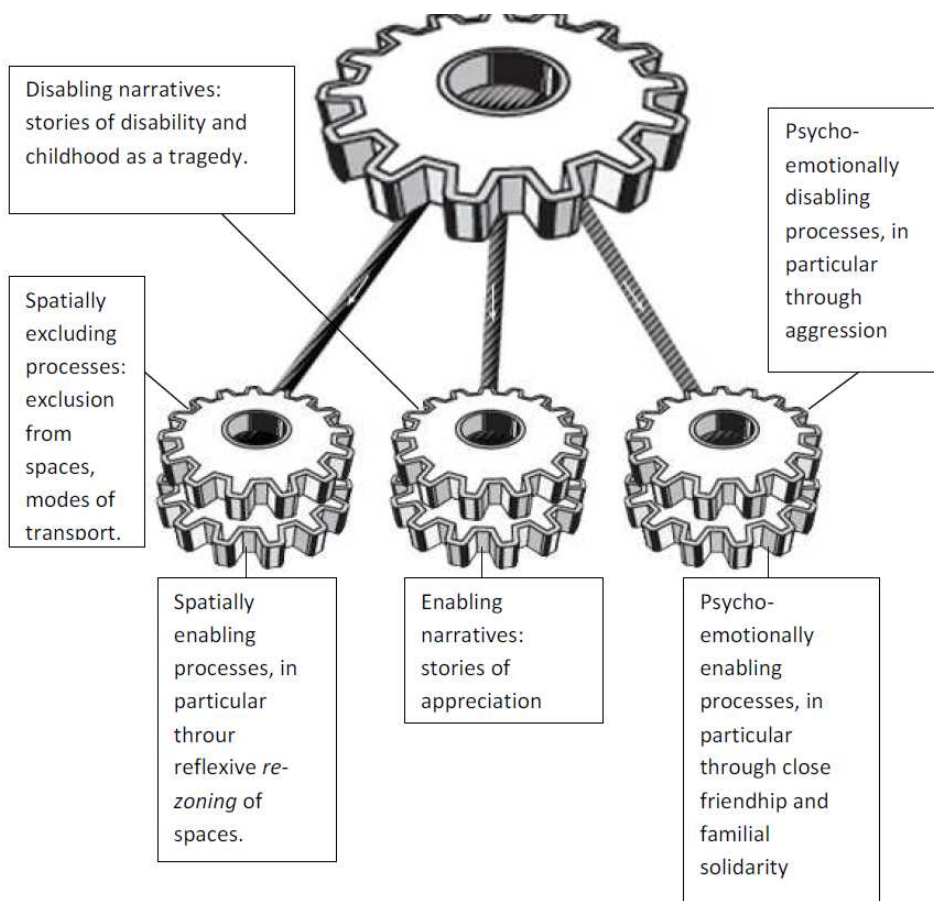
With regard to generative diversity, the best example is perhaps the discussion of Pam Fisher and Dan Goodley's work. They show that mothers 'are challenging the linear narrative'. They refer to this narrative, which they see as crucial to a medical (and, implicitly, tragic) view on disability, as 'a dominant trope within Western culture' (Fisher & Goodley 2007:66). From this outset, they move on to investigate 'active resistance against oppressive and normative values' (Fisher & Goodley 2007:73). By definition, however, this challenge is dependent upon the structure of our society. If these notions were not present in our society, it would be logically impossible to challenge them. When a challenge nevertheless takes place, with great power and a multitude of topoi (cf Article 3), we are left with two possible implications to be drawn from Fisher and Goodley's statement: **a)** the mothers are, in one way or another, *outside* the structure; or **b)** the mothers are able fighters within a social structure located within a (more or less) *enabling* social structure. Goodley would, as any other scholar in social and cultural sciences, probably dismiss implication **a)**. Hence, he clearly supports implication **b)**.

With *Modernity and self-identity* (1991), Giddens gives *The constitution of society* its counterpart. On the one hand, his analyses of the 1980s pertain to structuration, that is, to how 'forms of social conduct are reproduced chronically across time and space' (Giddens 1984:xxi). On the other hand, his work in the 1990s addresses how 'modern institutions differ from all preceding forms of social order in respect of their dynamism, the degree to which they undercut traditional habits and customs' (Giddens 1991:1). In so doing, the latter book brings two additional notions of diversification to light: 'dis-embedding' and 're-embedding'. These are somewhat Weberian terms for historical analysis, testifying to modernization rather than the state known as modernity, but they are also sociological terms that refer to patterns (of both structure and action) in our highly differentiated society.

Giddens defines spatial dis-embedding as 'the 'lifting out' of social relations from local contexts' (Giddens 1991:18). With regard to self and identity, 'dis-embedding mechanisms [...] remove prior supports on which self-identity was based' (Giddens 1991:148-149), whereby one's *being* 'has to be accomplished amid a puzzling diversity of options and possibilities' (Giddens 1991:3). Giddens' concern, however, is not dis-embedding as such, but 'the massive dynamism that modernity introduces into social human affairs' (Giddens 1991:17). Hence, the notion of dis-embedding corresponds to a notion of 're-embedding'. The "lifted out" subject is not left anomic (as in Durkheim) but is profoundly reflexive.

With regard to dis-embedding and re-embedding, article 1 explicitly relies on these concepts. On a more linguistic level, so does article 3. Traditionally, different topoi are thought to belong to specific contexts (that is, genres, stylistic conventions, and historical periods) and to *stay in their place*. While this perspective presupposes stable embedding, the findings in the articles testify to dis-embedding and re-embedding. The crux of the analysis in the article is not that these topoi, qua pervasive romantic and post-romantic 19th century topoi, have an important potential for enabling. Rather, the crux is that these topoi, qua cultural memories and traces in the 21st century disability discourse, can have a different (enabling) role that is specific to late modernity.

Giddens' perspectives arguably give three clues to further the conceptualization of disabling processes: **(1)** disabling processes are diversified, that is, they may operate in patterns that are far from convergent; **(2)** social systems, which clearly (or even primarily) are disabling, are also enabling; and **(3)** the disabling social structure must be conceptualized as a duality of structure. These conclusions suggest the following revisualization.



Disabling structuration and problematic analytical hierarchies

In line with the arguments sketched above, the sociological framework in disability studies has expanded in recent years. From a strong focus on economic marginalization in the 1980s, it has come to include a diverse and growing array of social situations. This intention of expanding is, for instance, prominent when Carol Thomas introduces the term

'psycho-emotional dimensions of disability'. She suggests 'that it is necessary to broaden the social relational focus [...] the focus should include not only a concern for 'what we *do*' and 'how we *act*' (are prevented from doing and acting) as disabled people, but also a concern for 'who we *are*' (Thomas 1999:46, original italics, my underlining).

However, this fruitful “horizontal” expansion (which is both theoretical and empirical) also engenders “vertical” problems: it becomes increasingly difficult to identify any social practices that should “stand outside”, “be prior to” or “produce” the structure. It is no longer an easy task to conceptualize disabling social processes (or, for that matter, disabling social systems) as demarcated phenomena. Following Giddens, I argue that this difficulty should not be considered an analytical failure. Instead, I suggest that the insight encapsulated in the notion of disabling processes (that is, the insight that structure and agency are interconnected) can lead to further insights. More specifically, I argue that investigations of this interconnectedness suggest that it should not be considered a one-way causal relation but rather be analyzed as a constraining (and, partly, enabling) “entity” that is continually reproduced by social agency. This is not to say that social structures are any less oppressive than the social model postulates, but only that disabling processes must be conceptualized as structuration processes.

However, the idea of structuration is incompatible with the idea of a (pre)structuring basis. Rather, use of structuration theory places analytical hierarchies under pressure. Such orders are abundant in the disability studies canon, either in the shape of methodological individualism (basis = the social subject) or in the shape of methodological collectivism (basis = the social object).

While the former hierarchy is crucial to Groce's analyses (and, partially, to Zola's), the latter is by far the most pervasive analytical hierarchy in disability studies. Mike Oliver, for instance, uses Gramsci's terms 'organic' and 'peripheral' to establish a one-way causal relationship between industrial capitalism (cause) and disabling barriers and the ideology

of disability as personal tragedy (effects). A similar postulate, if somewhat more implicit, can be found in Carol Thomas' definition of psycho-emotional disablism. She states the following:

psycho-emotional disablism involves the intended or unintended 'hurtful' words and social actions of non-disabled people (parents, professionals, complete strangers, others) in inter-personal engagements with people with impairments. [...] The effects of psycho-emotional disablism are often profound: the damage inflicted works along psychological and emotional pathways, impacting negatively on self-esteem, personal confidence and ontological security.

(Thomas 2007:73)

Here, the outcomes are large-scale phenomena. These phenomena – 'self-esteem, personal confidence and ontological security' – are presumably fairly stable. The cause, however, is not simply a heterogeneous phenomenon that consists of many different types of social actions. Many of these social actions are also inconsistent and chaotic. For instance, the hurtful words of parents can (as shown in article 3) be intertwined with love.

However, Thomas' analytical hierarchy remains. Her description of psycho-emotional disabling processes, which she calls 'socially engendered undermining', entails a past participle ('engendered'). This participle of the transitive verb *to engender* implies that Thomas' concept is in fact diachronic: while present experiences are the epistemological and thematic focus, analytical priority is given to social structures that are (in some way) prior to psycho-emotional disablism. What type of diachronic (historical) aspects are at stake here? Interestingly, Thomas explicitly traces the genus of her definition ('a form of social oppression') to Vic Finkelstein's work during the 1970s and 1980s (Thomas 2004, 577). It is interesting to draw upon her interpretation of his work, not the least because he is her most frequent point of reference (Thomas 1999, 72-81, Thomas 2004, 571-581, Thomas 2007, 51-63, 120-124). In Thomas' view, Finkelstein and Paul Hunt laid the path 'towards a materialist analysis of the ways in which the social oppression of disabled people is fundamentally bound up with the social relations of production in capitalist

society' (Thomas 2007, 53). It seems that Thomas' analysis, as with Oliver's or Barnes', is structured by a general critical analysis of capitalist or industrialist modernity. One might say that, while she demonstrates that the "driving gears" of disabling processes (the disabling social agency) are far from unified or stable, her approach presupposes some type of stable, underpinning basis.

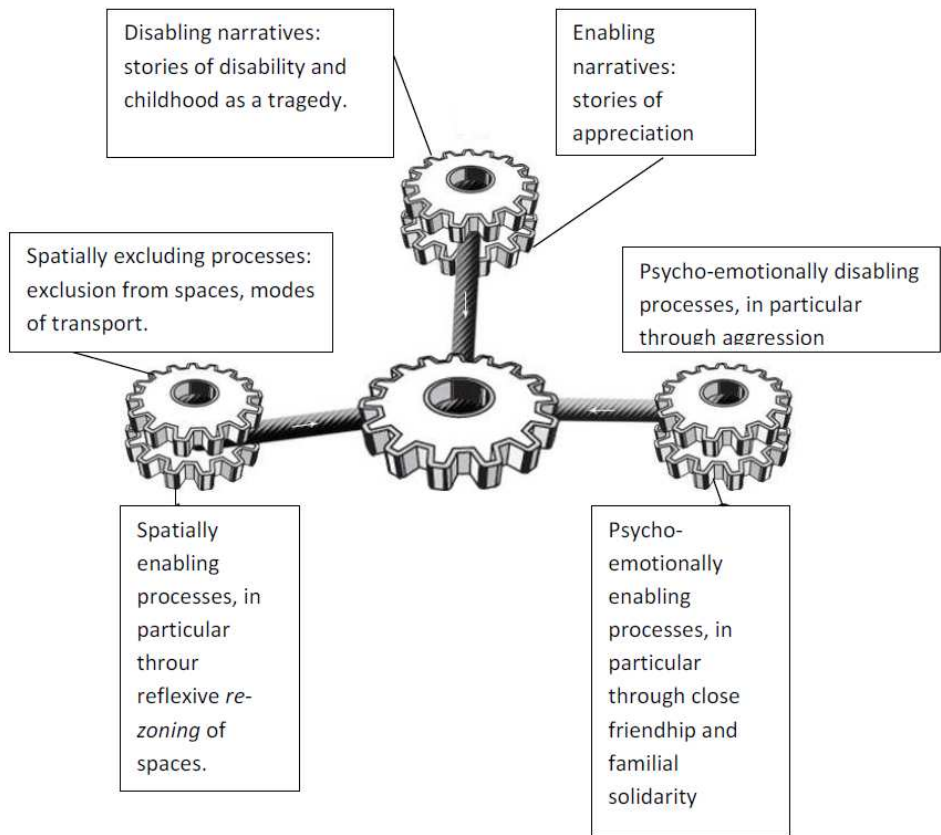
However it remains unclear if it is supported by the theoretical developments that Thomas herself has taken part in: as more and more phenomena, even such generic categories as 'intended or unintended [...] social actions', have been relocated at level 2, as aspects of *disability*, so it becomes increasingly difficult to describe or exemplify this basis of *disabling processes*.

In Giddens' terms, I argue that this is a case of 'the implacable causal forms which structural sociologists have in mind' (Giddens 1984:181). The problem is not that one emphasizes social structure or investigates the oppression that these structures amount to – both are fully justified – but that one carries simplistic misconceptions of what social structures really are:

It is not accurate to see the structural properties of social systems as 'social products' because this tends to imply that pre-constituted actors somehow come together to create them. In reproducing structural features, to repeat a phrase used earlier, agents also reproduce the conditions that make such action possible. Structure has no existence independent of the knowledge that agents have about what they do in their day-to-day activity. [...] The duality of structure is always the main grounding of continuities in social reproduction across time-space.

(Giddens 1984:26-27)

It has already been argued **(1)** that disabling structures are not detached from social agency but are inseparable from ongoing structuration. It has also been argued **(2)** that no particular form of agency can be placed in a privileged (analytically prior) position. Finally, it has been argued **(3)** that 'structural properties' are far from fully stable. Hence, all actions facilitate the social structure – and some more than others (dependent upon the particular social and historical situation). Therefore, structural properties are certainly the driving wheels in disabling processes, but they are not necessarily overarching structures. Hence, the diagram should be re-visualized, for instance, with socialization and parental narratives in a (situation-specific) primary position.



By implication, the arguments above not only indicate that disabling processes have diverse effects and are diversely (re)produced. They also indicate that these processes may be very different from each other. In my view, the lack of convergence raises the question of whether disability can be demarcated as a singular phenomenon. From the findings in article 2, for instance, the lacking convergence between ‘barriers to being’ and ‘barriers to doing’ can be given a moderate and a radical interpretation. The moderate approach suggests that **(1)** disabling processes primarily amount to a unified latent phenomenon,

which has dispersed manifestations in a diversified society. The radical approach, however, suggests that **(2)** such processes should be considered as a group of manifestations of different (and perhaps not all disability-related) latent phenomena that affect people with impairments. The tension between these interpretations contributes to a possible “blurring” or “destabilizing” of sociological understanding.

While this point may seem to be a minor and rather common-sensical extension of the previous argument, it has important methodological and disciplinary implications. In large areas of disability studies such as areas that are included in all three articles in this thesis, there is a tendency to place empirical areas, theories or scientific disciplines outside the analytical center of gravitation. *Expansions* are, by definition, processes wherein slightly peripheral phenomena are included in the field of some already justified phenomenon. If the expansion breaks loose from such hierarchies, as illustrated in the figure above, it may lose its unified direction.

The above has important ramifications, not least for the relations between different empirical areas and different theoretical approaches. If, for example, Oliver or Barnes' notions of social structure are taken for granted, then some aspects of life (such as intimate experiences or cultural representations) and certain approaches (such as narrative analysis or psychoanalytic theory) would certainly be outside the center of gravitation. Alternatively, to quote the philosopher Martin Davies (cf. article 2), Barnes and Oliver suggest that, for instance, socio-economic barriers and historical materialism are 'analytical prior' to intimate experiences or narrative analysis (Davies 1998). That is to say, Barnes and Oliver's frameworks imply that the former should inform the latter and that the latter could (or should) be described in terms of the former, without this relation being truly mutual.

However, if such hierarchies (or orders of analytical priority) are destabilized, it becomes less clear which areas or methodologies might engender developments in others. It is possible, and even likely, that arguments questioning ontological hierarchies will question epistemological, methodological or disciplinary hierarchies as well.

From the disability studies canon to Giddens to Kristeva

The arguments described above have gradually expanded, multiplied and combined 'radical structuralist' theories on disability (Goodley 2010:60-62). After suggesting horizontal expansions, in Liz Crow's famous dictum *including all of our lives* (Crow 1996), a vertical argument has questioned the internal consistency of structuralist argument such as Carol Thomas'. By and large, my arguments nevertheless follow Thomas' argument that disability studies entail (and should entail) 'a multiplicity of sociological ideas and approaches'; they may also be subscriptions to her arguments for 'the prospects for, and desirability of, a singular *sociology of disability*' (Thomas 2007:178, Thomas' emphasis).

While such a subscription may be reasonable, it may also be problematic. In empirical terms, the findings presented in these thesis can be summed up as non-convergent and profoundly *complex* patterns, both sector-dependent and consisting simultaneously of disabling and enabling processes, which are not easily understood within structuralist frameworks.

While the combination of different frameworks makes it easier to interpret these complexities, it is by no means clear that the frameworks themselves (per se, as separate

theoretical constructs) are sensitive to complexity. To the contrary, most of the frameworks discussed above seem to provide “disorderly” phenomena such as uncertainty, aggression or love the secondary status of analytical derivatives. If so, they remain somewhat inadequate vis-à-vis the findings, and also incompatible with the arguments presented in this thesis, which precisely questions this kind of analytical hierarchy in disability studies. If the understanding of structure is problematic, the problem will not be remedied by combining frameworks with equally problematic understandings of structure. How, then, can these disorderly phenomena become primary in the analysis without the analysis lapsing into methodological individualism?

Facing this challenge, Giddens' work – which, most of all, is about explaining ‘the recursive ordering of social practices’ (Giddens 1984:3) – is of little help. Instead, disorderly phenomena are highlighted (in articles 2 and 3) in ways that draw on the work of Julia Kristeva. On the one hand, psychoanalytic theory may seem alien to, say, Giddens. On the other hand, he explicitly presents his three-level model of the social agent ‘in place of the traditional psychoanalytic triad of ego, super-ego and id’ (Giddens 1984:7). Furthermore, he refers extensively to psychoanalytic theory, that is, to Freud (Giddens 1984:52-60, Giddens 1991:64-69) and Lacan (Giddens 1979:38-40) alike.

In *Central problems in social theory* (1979), the book that predominantly set the stage for *The constitution of society*, Giddens even discusses Kristeva’s theories on the subject at length (Giddens 1979:32-44). He views Kristeva's theories as valuable in their attempt 'to develop a novel theory of structuration', but he argues that they lack the exact thing that he himself set out to develop: 'an adequate analysis of human agency' (Giddens 1979:10, 39). Although it is very tempting to discuss the possible psychoanalytic foundations of Giddens, this thesis is not the place to trace the genealogy of the theory of structuration. Instead, it is my intention to pave the way for an extension of the Giddensian argument. Just as Giddens

let Kristeva's work set the stage for his own reconceptualizations, so I believe that his work on the duality of constraint and enablement sets the stage for interesting interchanges between disability studies and Kristeva's work.

With regard to *constraint*, Giddens' refusal of 'implacable causal forms' places the action of social agents in the heart of the social driving gear. Furthermore, it is worth noting that Giddens' notion of structuration emphasizes social meaning and the knowledge of individual social agents. As previously quoted: 'Structure has no existence independent of the knowledge that agents have' (Giddens 1984:26). Applying this insight to, say, Garland-Thomson's notion of the normate, we must acknowledge **(1)** that the study of this 'cultural self' must be a study of how it is continuously (re)produced and **(2)** that this reproduction must be considered as *competent* acts performed by social agents.

With regard to *enablement*, both the canon of disability studies and Giddens' work seem to define enablement as the power of independent social agents. Although this definition is no surprise because constraints are conceptualized as barriers to the actions of individuals, it tells us something about what Giddens and many disability studies canon have in common: while constraining agency is viewed as stable and recurrent, enabling agency is viewed as a matter of independence.

Both of these assumptions are somewhat inadequate for the findings presented in this PhD thesis. On the one hand, disabling agency is not "passive" or indifferent vis-à-vis people with impairments. Disabling processes (or other forms of constraining) are not only about what some agents *cannot do* but are also about what other social agents *do* to them. This theme is explicitly demonstrated in article 2, which shows that aggression and violence seem more decisive regarding low degrees of psycho-emotional well-being than barriers to social participation.

On the other hand, the findings suggest that enablement may be just as connected to interpersonal bonds as to independence. While article 1 shows how spatial enablement in adolescence is connected to intimate family relations rather than independence and “normal” ideas of the transition to adulthood, article 2 shows that close friendship is the area of self-perception least marked by disabling processes. Finally, article 3 shows that *love* (rather than empowerment and the political fight for individual rights) is the crux of the enabling narrative.

As argued in articles 2 and 3, Kristeva's work is a better fit for these two phenomena than many strands of disability theory. On the one hand, aggression and the disgust and contempt that are so crucial to the cultural (re)imagination of the normate are profoundly narcissistic. On the other hand, much of the enabling agency, both in everyday practices and in language, is the agency of love. The search is not for symmetry but for intimacy. This pair of antitheses is different than those suggested in, say, Zola or Groce. Narcissism, as expressed by the aggressive pushing-away, harming or humiliating of those who are different from oneself, does not find its utopical counterpart in total independence. Oppressive, abusive self-love is not overcome if only everyone could be equally self-absorbed. Instead, it is overcome by love for others. That is to say, within the framework of this thesis, this type of narcissism is overcome by loving relational intimacy within the family or among close friends.

Theory of science: An ontological argument

In this PhD thesis, closely related theoretical arguments are developed from methodologically very different investigations. As the notion of structure is under scrutiny,

and the scrutiny draws upon such theorists as Julia Kristeva and Jacques Lacan, it is tempting to locate the thesis within a certain research frontier: the field of so-called poststructuralist disability studies. Without raising a full-scale discussion of what poststructuralism is or is not, it is important to stress that none of the articles should be viewed as poststructuralist.

In her overview (Thomas 2007:63-69), Carol Thomas argues that poststructuralist perspectives are **(1)** characterized by an ‘almost entire’ concentration on ‘culture, language and discourse’ (Thomas 2007:63), **(2)** take on the analytical ‘task’ of deconstructing ‘dominant social discourses and cultural representations’ (Thomas 2007:64) and ‘draw attention to the underpinning binary thinking that informs and constructs’ disability and/or disablism (Thomas 2007:65). Furthermore, she adds that **(3)** such perspectives ‘owe as much to Foucault as to Derrida’, given their special commitment to the historical development of both disability and disablism (Thomas 2007:68). Even more recently, Dan Goodley has added two additional characteristics. In his account, poststructuralist disability studies entail **(4)** ‘a particular focus on the institutional creation of impairment’ (Goodley 2010:103). Finally, Thomas and Goodley share the common view that **(5)** poststructuralist disability studies ‘are characterized by the use of *constructionist* epistemologies’ (Thomas 2007:35, Thomas’ emphasis).

With regard to criteria 1-4, it seems clear that my articles (or at least the overall contribution they amount to) are not “poststructuralist”. First, cultural and linguistic data are of limited importance to article 1 and are not addressed in article 2; they are, frankly, only important to article 3. To the extent that language is important, no Derridean deconstruction is performed to scrutinize binaries. Similarly, the historical aspects addressed in article 3, and (indirectly) in article 1, are neither analyzed “genealogically” nor “archeologically”. Instead, the emphasis is placed on love and enabling resistance in people’s struggle with language.

Second, neither issues of historicity (in line with Foucault) nor issues of ambiguity and strictly semiotic problems (in line with Derrida) are addressed in the articles. All of the material is synchronous (that is, contemporary), and the interpretative position (both in article 1 and article 3) differs explicitly from any *hermeneutics of suspicion*. Third, the social binaries (and/or the creation of impairment) are (almost) taken for granted. While article 1 is based on informants recruited on the basis of impairment, article 2 constructs a dichotomous variable (disabled vs. non-disabled) without scrutinizing this distinction in any way. In article 3, a study interpreting books that explicitly distinguish disabled children from “ordinary” children, the social ‘marking’ of children is left unexplored.

With regard to the fifth criterion, however, the image is a bit more blurred, depending on how we define ‘constructionist’. In Thomas’ case, she warns that constructionism implies, or at least *threatens* to imply, the ‘collapse’ of ‘the ontological into the epistemological’. In my view, the articles do not suggest such implications. Not only does article 2 employ quantitative data in a way that is alien to any hard-core *cultural turn*, but the refusal of the hermeneutics of suspicion is clearly aimed at avoiding the ‘collapse’ of ontology.

This thesis is perhaps 'constructionist' but no more so than large parts of the canon sketched above. Unlike the “poststructuralist” research field, which is often framed in opposition to this canon (Shakespeare & Watson 2002, Thomas 2007:63-69), this thesis scrutinizes the social model tradition rather than dismisses it, and this scrutiny is ontological, not epistemological, in nature.

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Part 2: Article Summaries

Article 1: Hanisch, H. (2011). "Disabled adolescence – spaces, places and plans for the future." *ALTER European Journal of Disability Research*, 5(2), p. 93-103

Abstract: Recent theories of modernity, in particular the work of Anthony Giddens, have had a significant impact on youth research. However, Giddens has rarely taken the insights of disability research into account. Similarly, many disability scholars have criticized or even rejected his theoretical framework. Thus, research on disabled adolescents has remained estranged from the mainstream of youth research. This paper aims to show that these two perspectives can be fruitfully combined. This proposition is developed through a case study, which is based on interviews of a disabled 15-year-old girl and her mother. Aspects of spatiality and mobility of the young adolescent are explored in her everyday practices as well as in her dreams and plans for the future. These interviews evidence that the informant's everyday life is marked by disabling barriers in spaces and places; but they also put forward that her practices and plans reveal competence, reflexiveness and complexity. On the one hand, the substance of the interviews suggests that Giddens' "ideal-typical" descriptions of late modernity may be inadequate, at least to the extent that they presuppose an able body in an almost barrier-free environment. On the other hand, the reported spatial practices can be enlightened by Giddens' analyses of "dis-embedding" and "re-embedding". To conclude, we recommend that disability studies integrate, adapt and develop "Giddensian" strands of modernisation theory, rather than dismiss them.

This article based on two in-depth interviews, or rather a pair of interviews, conducted separately with a fourteen year old girl and her mother. As domestic space was an important subject in the interviews, they took place at home. More specifically, the mother was interviewed in the "common ground" of the familial space (the living room), while "Nina" was interviewed behind closed doors in her bedroom.

In empirical terms, the article made seven key findings: **(1)** While “Nina” was not excluded from school space, and experienced school as a place marked by growth and friendship, she was very little present in public space. **(2)** There was very little intertwining, or flow, between domestic and public space. **(3)** Instead, domestic space was clearly enriched: it was not only a place for family life, but also for Nina's rich friendship with her best friend. **(4)** Furthermore, the familial “placeness” is also mobilized and drawn into public space. **(5)** Both Nina and her mother envision the future in a similar way. Imagining Nina's adulthood, they envision that she may live in a separate apartment in an extension to the family home. **(6)** The familial enriching of spaces, which some would see as compensatory response to disabling processes, cannot be reduced to “indirect effects” of disabling processes. **(7)** Several of the familial spatial practices – such as the enriching opening-up of domestic space, or the reimagination of transition to adulthood – should be considered acts of reembedding where “normal” expectations are left behind to the benefit of a richer daily life.

With regard to possible limitations, it would have been very interesting to observe spatial practices. That would perhaps have provided richer insights, especially with regard to Nina's interaction with her best friend. This being said, the interviews (which essentially are narrative data) also provided an interesting interface between two of the forms of disabling processes that are investigated in this thesis. These interviews, where both Nina and her mother were asked to describe everyday life and envision the future provided parallel insights into enabling practices *and* enabling narrating.

Article 2: Hanisch, H. (2011). "Psycho-emotional disablism and normate narcissism." Submitted to *Disability & Society*

Abstract: A recent interest in psycho-emotional aspects within disability studies, sparked off in part by Carol Thomas' *Female forms* (1999), presupposes a convergence between this kind of disablism and barriers to social participation. Based on survey data from Norway, this study presents strong evidence of psychoemotional disablism among adolescents. However, the data do not demonstrate reduced social participation. Instead of confirming the convergence between 'barriers to being' and 'barriers to doing' that Thomas and others postulate, the analyses show that disabled adolescents are disproportionately exposed to aggression, violence and bullying. In line with recent research, the study argues that the findings are better elucidated if insights from Thomas are combined with insights from Jacques Lacan. However, this expansion retains the postulate of coherent and converging social structures. To let the findings from this study inform our perspective on psycho-emotional disablism, Thomas' feminist materialist framework should be supplemented by the work of Julia Kristeva.

This article investigates a specific set of survey data: *Young in Norway 2002*. This belongs to an ongoing series of surveys, which deal with adolescents' living conditions in a broad sense. Firstly, a few postulates is derived from Carol Thomas' very influential sociological work on disabling processes (Thomas 1999, Thomas 2007), but they are only partly confirmed by the empirical findings.

Secondly, a related perspective (from Dan Goodley and Katherine Runswick-Cole) is drawn upon. However, the empirical findings demand a framework that is sensitive to the complexities of the findings, as well as to the complexities of the interaction with non-disabled peers. Instead, three empirical findings – the discrepancy between different forms of barriers, the strong findings on violence, and the fact that the disabled respondents reported that their non-disabled students were disturbed or felt uneasy around them – suggests a different framework. Drawing extensively on Julia Kristeva's work on narcissism and abjection, but also on Rosemarie Garland-Thomson's work on 'the normate', it is suggested that the *structurality* of the disabling processes is possible to conceptualize in several ways. On the one hand, many well-known findings (such as Thomas') suggest that we should describe disabling processes with analytical building blocks derived from barriers to doing (restriction of activity). On the other hand, the findings in this study, suggest that quarries for such building blocks also can be found in the psychoanalytic theories of Julia Kristeva.

The article presents six major findings: **(1)** Disabled adolescents have clearly lower psycho-emotional well-being than their non-disabled peers, both with regard to self-perception and otherwise. **(2)** The negative association between disability and social participation, which a vast amount

of disability studies research suggest, was not found in these particular data. (3) Hence, 'barriers to doing' do not seem to shed much light on 'barriers to being'. (4) Associations between disability and different forms of aggression – such as bullying and violence – seem much more illuminating. (5) The increased aggression towards disabled adolescents seem to cut across many variables that otherwise are important in regard to both violence and psycho-emotional well-being (such as gender). (6) To the extent that certain aspects of life provided resilience to psychoemotional disability, or at least seemed unaffected by disabling processes, close friendship stood out. It is suggested that this kind of relations, in a daily life which is marked by disabling process, remain a site of enabling. With regard to limitations, the theoretical framing may be seen as problematic. The framework, developed to address the pattern of specific disabling processes and aggression, rather than the pattern of general processes and “silent” (stable) barriers often addressed by disability scholars, draws extensively on Julia Kristeva’s work on narcissism. In other words: Data from the disabled adolescents, reporting of violence and aggression, are framed within a framework which ultimately addresses the subjectivity of the non-disabled aggressors. While this may leave the argument with limited explanatory power, the argument does not claim to be an explanation in this sense. It is only claimed that these theories are a better *fit* (for the empirical findings), and therefore a better point of departure for further attempts at explanation.

**Article 3: Hanisch, H. (2011). "Narrating dignity: stories, intertexts and loving narrating in the narratives of parents with disabled children."
Submitted to *Sociology of Health & Illness***

Abstract: A recent interest in enabling parental narratives has highlighted how parental 'facilitating of dignity' (Rappana-Olsen 2001) also takes place in language and particularly in personal narratives. Parental narratives have also, increasingly, been seen as integral to the resistance against disabling processes. However, scholars have often scrutinized *which* stories of disabled childhood are conveyed in the narratives, rather than *how* those stories are conveyed. In this article, stories published by Scandinavian Disability Rights organizations are examined closely, focusing on narratological structure and intertextual relations. With regard to narrative structure, the study shows that the narratives are hyperbolic: Rather than opposing disabling and prejudice discourses with narratives that claim to be (objectively) *true*, parents oppose those discourses by demonstrating another, appreciating language with which to describe disabled children (and life in their families). With regard to intertextual relations, the so-called disability culture (or disability community) seems less important than the notion of resistance may suggest. Instead, romantic and post-romantic intertexts prove to be surprisingly important.

This article investigates a relatively small corpus of published narratives, published in books that are connected with Disability Rights organizations. The analyses are strictly narratological, without investigating the social context directly. Primarily employing the theories of Gerard Genette, the main contribution is perhaps that it distinguishes clearly between what the parents tell their readers about (the stories), the tales as such (the narratives), and the narrative act (the narrating).

Arguably, many studies on cultural representations of childhood and disability reduce the question *how is childhood disability represented?* to *what imagination (or story) is “contained” or “conveyed” in representations of childhood disability?*. While the latter question is very important, Genette’s framework covers all three aspects. Emphasizing *how* the stories are told, it is suggested that many of the narratives should be interpreted as hyperboles.

The study presents six key findings: **(1)** The threefold typology suggested by Fisher and Goodley – distinguishing between stories of *normality*, stories of *resistance* and stories of *appreciation* – is confirmed. **(2)** The (more or less politicized) theme of resistance seems less pervasive than suggested by Fisher, Goodley and others, both in its own right and as a gateway to appreciating narrating. **(3)** This fact, that the appreciation is only partly related to social themes, calls for a less dualistic approach. **(4)** Although the social roots of oppressive narratives may be found in the political or economic orders of society, the roots of this narrative appreciation is not found in the contexts which actively fight the oppressive social order. **(5)** The theoretical framework benefits from including the work of Julia Kristeva alongside sociological theories on disability, as it foregrounds the love that clearly characterizes the narrating. **(6)** The intertextual connections for enabling narratives, which many scholars find in notions of politics or pride, is also (and, in some cases, mainly) to be found in romantic and post-romantic representations of childhood disability.

With regard to limitations, some would perhaps argue that the choice of corpus obstructs the relation between this work and that of, say, Pamela Fisher and Dan Goodley. Their work is rooted in the British research project *Parents, Professionals and Disabled Babies: Identifying Enabling Care*. In that project, the data was collected mainly through interviews, but also through ethnographic observation methods. Hence, these researchers approached the broad field of families with disabled children, whereas this study only investigates the narratives of those parents who themselves made the initial action (by publishing their narratives). While this may lead to misrepresentation, omitting parents

who feel less empowered, it also aids a more efficient highlighting of the duplicity of this narrating: The parental counter-narrating are at once very personal and very political.

