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The CRPD and the economic model of disability: undue burdens and invisible work

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ABSTRACT

Human rights have become the dominant framework for understanding and resolving the marginalization of disabled people. Particularly since the 2007 introduction of the CRPD, many countries have formally adopted policies of ensuring equality by way of this framework. Nevertheless, socio-economic and political equality remain elusive. This article argues that part of the problem is the degree to which the human rights framework, through the principle of 'undue burdens', is compatible with an economic model of disability. In this model, full and equal participation for disabled people equates with the ability to perform socially valued roles, particularly in the field of work. This performance in turn requires a burden of invisible, i.e. unpaid and unrecognized work. The article develops the concept of invisible work in the context of disability studies, suggesting that it is an important analytical tool for identifying the shortcomings of the human rights and anti-discrimination framework.

Points of interest

- Unpaid and unacknowledged tasks that one 'has to do' in order to successfully participate in society amount to invisible work.
- The United Nations Convention on the Rights of Persons with Disabilities and most anti-discrimination laws seek to avoid an 'undue burden' for society in the inclusion of disabled people.
- The principle of 'undue burdens' means that an unreasonable amount of invisible work continues to be imposed on disabled people, even in the framework of anti-discrimination.

1. Introduction: disability and the work of inclusion

Metaphors of disability often paint an image of *passivity*. People with disabilities are routinely described as wheelchair-bound or confined to wheelchairs; deafness and blindness are routinely used to signify an absence of active interest or attention. Bruno Bettelheim's (1967) infamous 'empty fortress' metaphor for autism suggests defensiveness and isolation. Correspondingly, the word 'disabled' has among its literal meanings 'rendered inoperative' (Merriam-Webster.com 2022), 'made incapable of use or action' (en.wiktionary. org 2022), and 'incapable of functioning' (thefreedictionary.com 2022).

In terms of representing the embodied experience of disabled people, however, the semantics of passivity are profoundly inappropriate. Living as a disabled person in a disabling world, and in particular fulfilling socially valued roles, requires continual activity and effort. Another way of saying this is that life with a disability or chronic illness requires considerable amounts of *work*—work, however, that is formally unacknowledged and thus rendered invisible.

This understanding of disability has become particularly important as the framework of human rights and anti-discrimination has come to dominate representations of disability and the experience of disabled people. Envisioning the possibility of full and equal participation through the removal of barriers and the introduction of anti-discrimination measures, this framework elides the continuous effort that is required of disabled people in order to successfully perform socially valued roles.

In this article, which is part of a larger research project on the politics of disability identities in the age of human rights, I explore the relationship between the discourse of rights and anti-discrimination, and different models of disability. I then introduce and anatomize the concept of invisible work and explore its significance to the 'undue burdens' as understood in human rights and anti-discrimination discourse. I argue that in this discourse, ostensibly committed to equality of opportunity, current understandings of undue burdens mean that invisible work is inevitably imposed on disabled people, thus perpetuating disability marginalization.

2. The human rights framework, anti-discrimination, and undue burdens

The disability rights movement has been called the 'last civil rights movement' (Driedger 1989). This moniker is obviously contested, since by definition, marginalized populations are always at the risk of being overlooked and left behind in statements of such finality. Nevertheless, disability rights has manifestly, and relatively recently, become a fixture on the international political agenda. The United Nations' Convention on the Rights of Persons with

Disabilities (United Nations 2007; hereafter 'the CRPD') is the most salient and recognized expression of this shift, with its (at the time of writing) 164 signatories, 185 ratifications or accessions, and ongoing process of implementation in national legal frameworks. Alongside these national frameworks, the CRPD constitutes a paradigm of how human rights discourse understands and proposes to resolve disability marginalization in order to achieve as Article 1 puts it, 'full and equal enjoyment of all human rights and fundamental freedoms'.

Historical change is slow, and it is hard to assess the relative degree of success that has been attained by means of the human rights framework. But living standards and employment rates have stayed uncomfortably low for a considerable time, prompting the OECD to argue that a 'new policy paradigm' has yet to result in substantial changes (OECD 2022). Even in a rich, progressive country like Norway (where I am from), accession to the CRPD and an ostensibly strong commitment to its principles has not resulted in, for example, any increase in the employment rate for disabled people, which has for decades hovered around 4 in 10—as opposed to 7 in 10 for the general population (Statistics Norway 2019; 2022).

It may be that the new policy paradigm simply needs more time to take effect. But it is also possible that there are central or even intrinsic features to the human rights framework that do not adequately address the ways in which disabled people continue to be marginalized. This section of the article will examine the human rights framework in terms of various models of disability, in order to identify some of its potential shortfalls.

Among the first things to note is that the human rights framework is closely intertwined with anti-discrimination, which 'as a principle and a right has a major role in [the CRPD]' (Degener 2020, 352). Article 5 'demands that State Parties prohibit all forms of disability-based discrimination' (Degener 2020, 352), and the principle of anti-discrimination recurs throughout the text. However, in lieu of fully non-discriminatory structures and institutions, achieving substantive equality is often a matter of reasonable accommodation for individuals (Lord and Brown 2010). Article 5 links the two concepts: The denial of reasonable accommodation constitutes discrimination. Crucially, however, reasonable accommodation, as defined in Article 2, cannot 'impose a disproportionate or undue burden' on other social actors. This restriction creates what appears to be an underlying contradiction in the CRPD: While the right to full and equal participation is nominally absolute, in practice it depends on a heavily qualified right to reasonable accommodation.

In so many ways, of course, this seeming contradiction is only a reframing of the foundational problem of disability justice, where high principles encounter grubby political-economic realities. But it remains important to identify the specific areas in which the problem reappears, perhaps particularly as the CRPD and human rights discourse has become, through

implementation in national laws and through adoption by disability organizations, the dominant mode for representing solutions to disability marginalization.

Degener (2017) argues that one of the chief obstacles against the successful implementation of the human rights framework is that States' Parties continue to rely on an entrenched medical model where disability is understood as an individual rather than a structural and societal problem (Pfeiffer 1998). Social analyses of disability are of course not incompatible with acknowledging the importance of individual embodiment (Shakespeare 2013a, 2013b; Thomas 1999). The problem identified by Degener is one of essentialism—and it is arguably encoded in the CRPD's preamble, where, in part (e), disability is represented relationally, as the result of an interaction between 'persons with impairments and attitudinal and environmental barriers'. A more radical, less essentialist approach might point out that the category of 'persons with impairments' is not given, but is in part *created* by structural conditions.

However, there is a problem with explaining the shortcomings of the CRPD by way of the medical model. In classical medical model essentialism, absent a cure, biophysical impairment inevitably leads to functional disability, which in turn leads to social role failure (WHO 1980). The CRPD, and by extension the States' Parties that have adopted it, envisions the successful performance of the full range of social roles by disabled people. The question is what has to happen in order for this successful performance to take place. This question focuses attention not on the obstacles to, but rather on the *costs of*, successful implementation

3. The economic model of disability

In analysing the burdens and costs of inclusion and participation, an *economic* model of disability may be invoked. This model is less well-known than either the medical or the social model, but is related more closely to the former. Building on the work of Bickenbach (1993), Smart argues that in an economic model, disability can be defined as:

> the inability to perform socially valued roles, most often work roles (sometimes referred to as 'role failure'). Similar to the medical model of disability, the economic model of disability is normative, meaning that the desired condition is the ability to work and that deviance is, therefore, the inability to work. In short, although the biomedical model reduces the definition to the single dimension of biology, the economic model reduces the definition to an economic dimension. (Smart 2004, 37–38)

Crucially, in the most reductionist version of the economic model, disability can arguably be eliminated as a social phenomenon through the successful performance of socially valued roles. Thus 'the professor in a wheelchair

does not have a disability nor does the accountant with diabetes' (Smart 2004, 38). This claim is of course problematic, because it fails to recognize that in a disabling society, disabled people's participation depends on accommodation, which is a dynamic and ongoing process, as well as a site of negotiations where the needs of disabled individuals clash with the needs of institutions. But the successful performance of socially valued roles is precisely what the CRPD envisions—with the issue of how to distribute the burdens of accommodation, and performance, to be resolved later.

The resolution of this issue, however, is central to the genealogy of the modern concept of disability. In her classical study, Deborah Stone (1984) argued that during the second industrialization, many states found it politically rational to operationalize disability as a permanent exemption for individuals from the duty to work, exempting themselves from the burdens of accommodation (and avoiding social unrest). At this historical stage, disability became reified as an individual, biophysical inability to fulfil a social role that is in fact historically and culturally contingent. In the era of human rights, however, the issue was reopened. In the United States in the 1990s, for example, the implementation of the Americans with Disabilities Act opened a vast space for the consideration of who is to bear the burden of the integration of disabled people into ableist structures (Colker 2005; Krieger 2003).

The matter of distributing the burden is a persistent problem in the disability field—with an empirical and analytical as well as a normative dimension. Medical explanations of disability tend to shift responsibility towards individuals; social explanations shift responsibility towards society. The human rights framework has not resolved the issue; to some extent it implements what Shakespeare has termed the 'predicament' framing of disability (Shakespeare 2008, 2013b). The principle of barrier removal opens for disabled people a path to socially valued roles that was barred in earlier times. But the principle of reasonable accommodation for individuals balanced against that of undue burdens imposed on institutions suggests that a gap will often remain between the accommodations that are deemed reasonable and the accommodations that are in fact necessary for 'full and equal participation'. How, in practice, is the gap closed?

4. Straddling the gap, shifting the burden: diversity inclusionism and its limits

I use the term 'gap' because it has a particular history in the disability field, deriving from the Norwegian 'gap model' of disability (Aslaksen et al. 1997), which postulates that disability can be construed as a gap between the demands made by society and the individual capabilities of disabled people. From this model derives a simple schema in which disability is a bi-causal

phenomenon and in which the burdens of accommodation can devolve both to individuals and to society.

This model was not meant to be analytically sophisticated; it is a pragmatic instrument, and has been instrumental to Norwegian disability policy for several decades. In its incipient form it predates the CRPD by decades (Sosialdepartementet 1966). It is distinct from the British social model and the largely American cultural minority model of disability (Goodley 2010; Retief and Letšosa 2018; Shakespeare 2013a; Tøssebro 2004) for many reasons, significantly in that it does not presuppose conflict between a disabled minority and a non-disabled majority or an ableist state—reflecting, perhaps the more progressive attitudes of Nordic welfare states.

Crucially, the gap model focuses, as does the economic model, on the successful performance of socially valued roles—but unlike the economic model it recognizes the burdens imposed on individuals. As applied to structural role expectations, for workers these demands can be altered through general legislation on work hours, the right to sick leave, and so on, or through disability-specific legislation on support for adapted workplaces. Individual capabilities can be enhanced through direct financial support, technical aids, or indeed through medical and therapeutic interventions. Theoretically, the disability gap can be closed if convergence is achieved between environmental demands and individual capabilities, but unless the environmental demands are radically altered, individuals must pick up the slack. What the gap model thus provides in the context of the human rights framework is a simple way of visualising what happens when environmental adaptation, barrier removal, and accommodation efforts stop short. It is still possible to straddle the gap, but the onus is put on individuals: the *undue burden* of accommodation is shifted onto disabled people themselves.

This phenomenon is of course not new; it is part of the long history in which disability is ontologically framed as a problem to be solved and the problem is located *in disabled people* (Hughes 2019). What is *new* is that the human rights framework explicitly disavows such perspectives, and that the discourse of the human rights framework has been very widely adopted. Having joined the ranks of ostensibly successful civil rights movements, disability is now regularly included among the categories that constitute *diversity,* and are to be included—at least symbolically.

Arguably, however, the ontological 'problem' frame persist by way of the economic model. Sarah Ahmed (2012) has explored the problems with the late modern ideology of diversity inclusionism in some detail, arguing that while inclusionist practices may be highly effective at eliminating *symbolically salient* barriers, they can be poorly suited to furthering real and equal participation because of the underlying concern with productivity and economic profitability. Moreover, once institutions have formally adopted a policy of diversity and inclusion and once the removal of unambiguously

discriminatory barriers has taken place, specific instances of lack of accommodation can be framed as problematic: as overreaching or as illegitimate demands for special treatment.

In the disability field, Titchkosky (2011) has provided a vivid example of the limits of diversity inclusionism. Analysing the physical space of her workplace at the University of Toronto, she identified several instances in which disability was symbolically included, but in which genuine access was not provided. A general, symbolic barrier was removed when accessible bathrooms were installed; the fact that the new bathrooms were not in fact accessible to all then became framed as an issue of individual accommodations that would impose undue burdens. In this case, inclusionist practices served as a way to forestall and end debate. Even in cases where actual access was lacking, the symbolic salience of efforts towards accommodation and inclusion allowed authorities to argue that a sufficient degree of structural change had been achieved, and that the onus was now on disabled individuals (see also Inckle 2018).

Crucially, these moves do not formally preclude or bar the performance of socially valued roles for disabled people, as did earlier, more explicitly discriminatory regimes. But in order for the 'gap to be closed', considerable effort is required on the part of the people who are to be included. The next section will consider this effort in economic terms, as *invisible work*.

5. Invisible work: what one 'has to do'

From an economic perspective, inclusionism must have limits. Some barriers affect a very large number of people, while others affect only a few. Some barriers can be removed relatively cheaply, while others are very expensive. Full and equal access must be weighed against the costs imposed upon institutions, employers, and service providers, etc.

A key limitation to the CRPD lies in its conceptual apparatus, wherein shortfalls of accommodation are framed in terms of *violations*. The system of official reports and shadow reports on the implementation of the CRPD lay out the ways in which such violations can be documented. The Monitoring Guidelines for Human Rights Monitors, referring to the principle that 'barriers to the full exercise of rights' (Office of the High Commisioner for Human Rights 2010, 8) should be removed, exhorts monitors to identify breaches of rights and violations of the convention, as well as closely examining the level of resources that are actually directed towards accommodation.

This work is crucial, yet it relies in part on a binary notion of fulfilled versus breached human rights, and draws on the lived experience of disabled people primarily as a means of documenting such breaches. The limitations of this approach become salient when we consider that a life lived with breached human rights does not pause or stop. For disabled people excluded

from education or work, there is still the problem of subsistence; for disabled people living in a stigmatizing culture, there is the problem of building and maintaining their identities and sense of self-worth. The inclusionist paradigm frames disabled people primarily as *objects of inclusion*. While it in fact shifts agency onto them, it does not sufficiently recognize the main implication, which is that socially valued roles can be performed more successfully than before, but not without a cost.

I propose here a shift in analytical optics by way of the concept of *invisible work*. Invisible work, here, is the work that is imposed upon disabled people through lack of access and accommodation; the work that results from the breach of rights. It is constituted by the tasks that are necessary in order to operate in an inaccessible world, but also, crucially, by the tasks that must be carried out in order to secure the kind of access and accommodation that is *contingently* available. Through the recognition of undue burdens, the human rights framework presupposes invisible work. I suggest here that the unpacking of this prerequisite is a major task for disability research.

The concept of invisible work derives primarily from feminist sociology and activism, through analytical and political efforts to achieve recognition of a number of tasks that women were (and are) disproportionately expected to carry out without monetary or even social compensation—in order to be perceived as fulfilling a social role. It is first and foremost associated with a seminal article by Arlene Kaplan Daniels (1987). In her article, Daniels takes as a starting point the folk understanding of 'work' as activities that one 'has to do'—and gets paid for doing. Pointing out that women, in particular, are obliged to do many things without getting paid, Daniels discusses the limitations of the classical notion of *paid* work. For her, 'work' is more comprehensively understood as the set of tasks that need to be carried out for the successful performance of social roles. Some are paid, some are unpaid, and the unpaid tasks are often rendered invisible in a social sense too, i.e. they are neither formally nor socially acknowledged.

Daniels argues that the mechanisms that render some forms of work invisible have a mystifying as well as a moral function. Women's unpaid work in the home becomes framed both as a moral and a natural duty; something has to appear to be done spontaneously and willingly. Referencing Hochschild's (1983) work on emotional labour, Daniels draws attention to the way that invisible work is closely connected to the performative management of emotion, i.e. taking responsibility for and attending to the reactions and needs of others. As pointed out by Reeve (2002, 2004, 2006), in an ableist society disability identity is shaped, to an extreme degree, and by comparable mechanisms.

For Daniels, women who are obliged through social conventions to carry out different kinds of unacknowledged work are put in a double bind, which itself serves to keep the work invisible. In order to avoid the stigma of failing

to perform the social role expected of them, they must not only carry out the tasks, but also conceal the effort that is actually involved. This double bind, in particular indicates the significance of invisible work to the field of disability and chronic illness. The paradigm of human rights and the attendant ideal of full and equal participation ambitiously sets out a range of valorised social roles for people with disabilities and illnesses—the roles of student, employee, citizen, and so on. Fulfilling these roles is nevertheless predicated on considerable effort, and it is in the interest of many people to conceal this effort in order to escape stigma.

On the conceptual level, invisible work can also be deployed in order to solve the key issue with the economic model of disability, as discussed by Smart. The wheelchair-user professor and the accountant with diabetes may now be considered *disabled* after all, because of their accrued burden of invisible work, e.g. in navigating semi-accessible environments and inhospitable circumstance. Furthermore, the concept recognizes and acknowledges that disabled people who do not perform paid, formally recognized work, may nevertheless carry out considerable invisible work in order to fulfil other socially valued roles, such as partner, parent, or carer.

6. Anatomizing invisible work

Over the last few decades, invisible work has been extensively theorized as well as investigated in empirical settings (Crain, Poster, and Cherry 2016; DeVault 2014; Hatton 2017). Work rendered invisible by social structures has been distinguished from *hidden* work, which is to a greater degree willingly concealed by those who carry it out, and from invisible *labour*, which is (poorly) paid work that is conducted out of the public view. Furthermore, Daniels' view of the distinctly gendered history of invisible work has been supplemented with analyses of other power relations that contribute to its dynamics, not least racism and racialization (Clair, Beatty, and Maclean 2005).

The concept of invisible work offers a novel perspective on the inclusionist dilemma by providing analytical insight into the gap between the lofty ideals of anti-discrimination and the lived experience of disability. In practice, of course, the gap has never been perfectly closed and very likely never will be, for political and economic reasons. That nearly every disabled person experiences a shortfall of accommodations, and that this is true even in putatively generous welfare states such as Norway, that budget considerations and a strong gatekeeping apparatus remains as relevant as when they where identified by Deborah Stone—these are not issues that need to be belaboured. Rather, it seems important to understand *how* the shortfall is made up—by hook, crook, and invisible work. Here, at least two productive directions of inquiry can be discerned. The first, which lies perhaps closer to Daniels' original investigations, but also beyond the scope of this article, concern the care

work performed for disabled people and people with chronic illnesses by others, particularly family members.

Care work is its own field of study; here, the concept of invisible work is intended to build on previous investigations into the issues of self-care, self-management, accessibility management, and 'disability admin' (Branham and Kane 2015; Emens 2020; Katzman & Kinsella 2018; Unruh & Pratt 2008) in order to query the distinction between formally recognized care work and the informal, unpaid work in its most direct relevance for disabled people themselves. A focus on invisible work may show that it is, for disabled individuals, necessary not only for daily living, but as an underpinning of and safety net below the formally recognized work. Such work is carried out in a great number of situations and settings, united, as in Daniel's original article, by the way in which they relate to role expectations and social norms. Tentatively, we can define invisible work in this context as *all of the unpaid and/or unrecognized tasks that disabled people are obliged to carry out in order to participate in different areas of society whenever accessibility is absent or insufficient*. With the caveat that many tasks have aspects of all three categories to them, Daniels' original distinction between *physical* work, *logistical* work, and *emotion* work still seems valid and useful. Each dimension of a task is particularly useful in exploring the consequences of a task not done, but also in making visible the lack of provisions that make the task necessary.

Crucially, the invisible work carried out by disabled people contributes to them being able to function as students, employees, customers, recipients of health care—and to fulfilling the role expectations associated with being a romantic partner or spouse, a parent, a caregiver, and so on. It serves to bolster the low rate of employment from even lower levels, and so—much like the gendered invisible work previously identified—serves as an informal underpinning to the formal economy.

One example of this dynamic is bathroom access. This is a perennial issue for people with mobility impairments and many chronic illnesses, in settings both public and semi-public, as in the case of universities (cf. Titchkosky 2011), and workplaces. The *physical* aspect of a lack of accessible bathrooms is viscerally relevant; when facilities are inaccessible or only partly accessible, this involves extra physical effort as well as extra time. Since accessible bathrooms are in many cases few and far between, the *logistical* work of locating them may be considerable. Oftentimes access is contingent and may require interactions with staff or other gatekeepers; in such cases *emotion* work is required.

Detailing invisible work serves two main purposes. First, it allows for close analysis in terms of what visible work it facilitates. Second, it highlights what the consequences are if it is *not* done. The consequences of work not done, for individuals, may of course be hugely variable. Some people with mobility impairments or chronic illnesses will avoid certain venues, locations or areas

for lack of bathroom access, with corresponding impact on their ability to participate in various social contexts. Correspondingly, the work that is done by individuals in order to accommodate the lack of accommodation will simply serve to conceal the problem. An absence of disabled people in a particular context will rarely be construed as problematic until it is actively identified as such.

The interplay between dimensions of invisible work is likely pervasive. Emotional tasks often amount to concealing, minimizing or downplaying the physical strain and difficulty associated with limited accommodation. From the formal contexts of securing employment to informal contexts of social interaction, disabled people are charged with combating stigma and counteracting negative stereotypes. Such stereotypes often amount to disabled people being difficult, hostile, or helpless, and are largely at odds with the social roles of diligent student, effective employee, or attractive romantic partner. The category of logistical tasks, too, is interlinked with the other categories. Even in cases where disability accommodation is available, it is often available *on request*. Not only may successful interactions with service providers depend on advance planning; they may also, unpredictably, involve extra physical effort and emotion management. In each case, invisible work serves partly to support the status quo; it is work that one 'has to do' in order to be an *includable* person with a disability or chronic illness. In other words: the *appearance* that the gap of disability has been bridged may well be achieved, but at considerable individual cost.

7. The disability paradox: visible rights and invisible work

In practical terms, mapping and describing the invisible work actually carried out by disabled people is an important task for the social sciences, and one that the social sciences have conducted for some time, without necessarily using the concept actively. Mike Oliver's (1990) canonical rephrasing of the wording used in survey forms, from phrases that suggested that problems of access were intrinsic to people's embodiment, to phrases that located the problems in lack of accommodation, have shown the power of a conceptual and perspectival shift in the field of disability. Making the invisible visible means, perhaps, carving a path to recognition. But it is also important to understand the degree to which invisible work is in fact (1) an *unrecognized barrier* to equality and full societal participation, (2) a *passive force* counteracting these goals, and (3) a *structurally embedded* feature of the 'undue burdens' clauses in national and international rights-based frameworks. Inclusionism would very likely not have succeeded as an institutionally supported ideology without the underpinning of such work, but with it, 'inclusion' oftentimes remains a symbolic gesture without real impact.

Logistical work, in particular, is embedded and implied in contemporary regimes of disability rights. This is not an accidental by-product of or a bug in the inclusionist paradigm, but a feature. Since the scope and extent of disability accommodation is usually constrained by the principle of 'undue burdens' (or variations thereof). Since institutions may argue that accommodation is too costly in terms of money or effort, accommodation is a site of negotiation, which in turn requires effort for those who seek it. In some cases (such as the highly litigious United States), the work of seeking accommodation may be compensated, but in many if not most cases it is not. It is simply the effort needed to achieve an absolute minimum of participation, far from the ideal of 'free and equal'.

Crucially, disability rights tend to be publicly symbolically salient, while the work needed to enforce them takes place privately and out of sight. The world is now, as it was not previously, suffused with the blue-and-white wheelchair icon, signifying that parking spaces have been set aside, bathrooms made accessible, and ramps built. Other icons indicate the presence of guiding lines, closed captioning, and teleloops, while restaurant menus and grocery packaging increasingly warn of allergens in food.

However, these symbols and their attendant accessibility features and accommodation are not universally present. Neither are they universally accurate or dependable. A person with a severe nut allergy will be wise to call the restaurant ahead of time in order to be (relatively) confident of the mechanics of the venue's food preparation, while a wheelchair user planning to stay in a hotel will be equally wise to request pictures of the accessible rooms, and to be provided with the precise interior dimensions of the promised elevator. A person planning to apply for a job with a company or an organization which professes respect for diversity and an equal-opportunity hiring process must nevertheless take time to decide whether and at which point they will disclose their disability, knowing that the resulting social interaction may be emotionally fraught and in many cases extremely brief.

8. The hidden cost of invisible work: intersectionality and the significance of socio-economic resources

The efforts required of disabled people in order for them to fulfil social role expectations amount to an expenditure of resources. Physical and emotional efforts take a toll on the body, while logistical efforts require competence and knowledge of both formal and informal structures.

The resources in question are unevenly distributed. As pointed out by Kimberlé Crenshaw (2018, 2017), in every case of social marginalization intersectionality plays a significant role. While disabled people, as a group, tend to have less resources available than the general population—lower levels of education and employment, less money, and smaller social networks—they

also constitute the world's largest minority, and likely its most heterogeneous.

The onus to carry out invisible work therefore likely works as a driver of inequality *within* the group of disabled people. The inclusionist paradigm and its attendant regime of accommodation-upon-request requires untold amounts of paperwork and social interactions that presuppose skills that are closely linked to education levels and class background. Individual arrangements in service provision become progressively more common as the price of those services increases. Put simply, a five star hotel is much more likely to arrange for accessible accommodation than a one-star hotel.

The difference between the feminist conception of invisible work and the disability conception may at first appear significant. The feminist concept of invisible work was first used to explain how women's unpaid work supported the ability of men to carry out paid work. On the part of disabled people, invisible work may simply appear as the cost of doing business—the business of being in the world. But this amounts to a false dichotomy. First, the concept of intersectionality serves as a reminder that disabled people are neither *only* disabled nor necessarily have disability as their primary identity; disability intersects with gender as well as with age, ethnicity, sexuality, and social class. Disabled people may of course carry the responsibilities of maintaining a household and providing care for family members, as well as being obliged to carry out gendered invisible work.

Second, while the invisible work required of disabled people is a precondition for their fulfilment of roles that allow for participation in society, a failure to fulfil these roles does not mean that disabled people suddenly cease to exist. Failing to fulfil role expectations can under some circumstances mean leaving the educational system or becoming unemployed—or never entering these fields in the first place.

However, because the invisible work in question centres more clearly on the individual and individual embodiment, along with the consequences of work not done, the task of making the work visible is that much harder. The consequences of invisible work not have done will, for disabled people, manifest as further marginalization, greater exclusion, and poorer life outcomes. It is therefore particularly important to recognize the degree to which it is presumed by and built into contemporary disability rights regimes, including in the human rights framework. I have argued elsewhere [REFERENCE OMITTED] that the CRPD provides, in practice, for a minimal degree of accommodation, rather than the equality of opportunity that it ostensibly promotes. The concept of invisible work allows for a more precise description of the way in which the human rights framework falls short of its aims.

9. Coda: inclusionism and universal achievement values

The human rights framework and its inclusionist agenda is largely a force for good. Inclusionist practices are often carried out by people with good intentions, and may provide much more positive results than most other alternatives. But there is insufficient recognition of how the human rights framework, and indeed inclusionist discourse, is compatible with norms of individual productivity.

While much top-level political discourse about and public norms concerning disability are currently pro-inclusion, historically, the systematic *exclusion* of disabled people from various parts of society has been both ubiquitous, empirically, and normatively unproblematized. This exclusion has been justified in many ways; the inclusion of disabled people has sometimes been presented as a direct threat to societal well-being, as in eugenic rhetoric, sometimes as a 'problem' that must be bracketed for the time being, as in the political philosophy of John Rawls (Malhotra 2006; Nussbaum 2007; Rawls 1999).

Generally, disabled people have been normatively framed as *too costly* or *insufficiently valuable* to be included. The inclusion of disabled people in educational systems, for instance, would impose intolerable ('undue') burdens on their non-disabled peers, and so it is legitimate to deny them access to education—or, at best, provide access to a separate educational system.

The story about the great societal shift towards inclusionism, which involved the work of activists, academics, organizations, politicians, and many others, has been told many times—including as the story of an axiological shift. Crucially, from the 1970s onwards, national laws and international declarations about disability have increasingly framed it as a quality of human beings that does not, in itself, make anyone *worth less*. Section (h) of the CRPD's preamble states that '[…] discrimination against any person on the basis of disability is a violation of the inherent dignity and worth of the human person'.

It is somewhat paradoxical; therefore, that the shift towards inclusionism has been accompanied by a strengthening of what Varul (2010) has called 'universal achievement values' in the field of illness and disability. Varul points out that in political as well as cultural terms, most instances of positive framing of disability conform to ideals of productivity and societal utility. Disabled people become valorised by proving themselves to be economically productive or societally useful.

Perhaps the most visible figure of positive disability representation in contemporary public discourse, the one that is most amenable to the 'universal achievement values', is the *supercrip* (M. Hardin and B. Hardin 2004; Howe 2011; Kama 2004), whether manifesting as a motivational speaker, a model employee, or a Paralympic athlete. A supercrip is a disabled person who is seen to transcend their disability—that is, someone who, in terms of the gap model, closes the gap entirely through individual effort, thus obviating the need for further structural reform.

The historian Paul Longmore famously termed the history of disability a 'hidden history' (Longmore et al. 1987); in the case of disability, bringing the hidden into view has long been a crucially important act of resistance. Going forward, then, it seems imperative not only to make visible the invisible work of disability, but also those axiological mechanisms that render invisible work a natural duty rather than an externally imposed burden.

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