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Shaun Grech and Karen Soldatic

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Academic Editors
Shaun Grech (The Critical Institute, Malta)
Karen Soldatic (Western Sydney University, Australia)

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Article

Shallow Inclusion (or Integration) and Deep Exclusion: En-Dis-Abling Identities through Government Webpages in Hong Kong

Alex Cockain

Department of Applied Social Sciences, The Hong Kong Polytechnic University, Kowloon, Hong Kong;
E-Mail: alex.cockain@polyu.edu.hk

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Abstract
This article is primarily concerned with how government webpages in Hong Kong claiming to embrace social inclusion and provide services and support for persons with disabilities construct issues relating to disability. These texts are not read in isolation. Instead, they are considered in conjunction with discourse produced in several United Nations documents, especially the Convention on the Rights of Persons with Disabilities, to which Hong Kong is a signatory. These documents appear to both proffer and retract social inclusion in ways that complicate, if not undermine entirely, their purportedly inclusionary intentions. This article also reflects upon commentary produced by university students at a public university in Hong Kong responding to government discourse. Such focus upon 'non-disabled' readers reveals how texts do more than merely mediate pre-existing messages. Instead, they constitute a "social location and organizer for the accomplishment of meaning", thereby counting as "a form of social action" (Titchkosky, 2007, p. 27). Through the texts they conspire to make about disability, authors and readers become complicit in the production, maintenance, and reinforcement of **non-disabled** (or **abled**)/*disabled* identities and dis/ableist ideology in ways that implicate the entire population in exclusionary processes.

Keywords
barriers; dis/ableism; exclusion; Hong Kong; integration; **non-disabled** (or **abled**)/*disabled* identities; othering; rehabilitation; social inclusion; United Nations

Issue
This article is part of the issue "Global Perspectives on Disability", edited by Shaun Grech (The Critical Institute, Malta) and Karen Soldatic (Western Sydney University, Australia).

1. Introduction

This article is primarily concerned with how government webpages in Hong Kong[1] claiming to embrace "social inclusion" (GovHK, 2016a) and provide "services and support for persons with disabilities" (GovHK, 2016b) construct issues relating to disability, although these texts are read in conjunction with other discourse. A wider corpus of discourse is relevant to this article because in 2008 the Hong Kong Special Administrative Region (hereafter, HKSAR) and the People's Republic of China (hereafter, PRC) became signatories to the United Nations Convention on the Rights of Persons with Disabilities (hereafter, UNCRPD), a human rights treaty intended to protect the "rights" and "dignity" of disabled persons.[2] First, and most prominent, is the UNCRPD itself (UN, 2006). The Convention has eight guiding principles, although most relevant to this article is the intention to realize "*[f]ull*

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[1] It is beyond the scope of this article to provide an overview of issues relating to disability in Hong Kong, both past and present. For such content, see Ngai, Wu and Chung (2018).

[2] As the UNCRPD homepage explains, the treaty and its optional protocol "was adopted on 13 December 2006 at the UN Headquarters in New York, and was opened for signature on 30 March 2007. There were 82 signatories to the Convention, 44 signatories to the Optional Protocol, and 1 ratification of the Convention. This is the highest number of signatories in history to a UN Convention on its opening day. It is the first comprehensive human rights treaty of the 21st century and is the first human rights convention to be open for signature by regional *integration* organizations. The Convention entered into force on 3 May 2008" (CRPD, n.d., emphasis added).

and *effective* participation and inclusion in society" (UN, 2006, p. 5, emphasis added). Discourse on the UNCRPD homepage constructs the Convention as immensely significant and deploys metaphorical language to celebrate the crucial role of the UN in manufacturing this. For example, the Convention is proclaimed as taking "to a new height" the "movement" from:

> Viewing persons with disabilities as 'objects' of charity, medical treatment and social protection towards viewing persons with disabilities as 'subjects' with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society. (CRPD, n.d.)

Second is the Initial Report of the HKSAR of the PRC under the UNCRPD (HKSAR, 2010). Third is the concluding observations on the initial report of China, adopted by the Committee at its eighth session (UN, 2012).

Echoing Robert McRuer's (2007, p. 5) discussion of the use of "independence" and "inclusion" within, and around, the disability rights movement, and the ways these are appropriated by the World Bank, this article reveals how "rhetorics of...inclusion mask" more exclusionary content, illustrating how texts can, as Najma Al Zidjaly (2012) also argues in an Omani context, "unintentionally harm social causes" (Al Zidjaly, 2012, p. 190). Although the texts to which this article is concerned appear to proffer social inclusion, they also contain exclusionary sub-text, or latent content that works to limit, and perhaps even retract this, thereby producing only a very shallow form of inclusion (that more closely resembles integration). However, texts do more than merely mediate pre-existing messages. Instead, they constitute a "social location and organizer for the accomplishment of meaning", thereby counting as "a form of social action" (Titchkosky, 2007, p. 27). Put differently, readers are implicated in the production of knowledge, and the exclusionary processes this is intertwined with, "because they must make the association in the act of reception" (Wodak, 2004, p. 195). In so doing, readers become complicit in the production, maintenance, and reinforcement of **non-disabled** (or **abled**)/*disabled* identities and dis/ableist ideology. More specifically, after a brief discussion relating to methodology and ethics, this article first explores inclusionary and exclusionary discourse in these texts before focusing upon students' readings of this discourse. The article concludes by contemplating how this discourse might relate to, and what it might reveal about, wider commitments to social inclusion, or the lack thereof.

2. Methodology

This article's concern with the textual enactment of disability in, and through, government webpages has been informed by my reading of Tanya Titchkosky's (2007) discussion on Canadian government texts on disability (pp. 45–78, 145–176). Titchkosky argues these not only "construct disability as a problem" but also "sponsor solutions to the problem they have constructed" (2007, p. 145). Language, like representation, is not, accordingly, incidental to the world. Instead, it is productive and words, as well as the discourse they contribute to, as Michel Foucault (1969/2002) has so evocatively claimed, have the capacity to "form the objects of which they speak" (p. 54). My recognition of the power and contingency of language and commitment to destabilize this is informed by principles associated with critical discourse analysis (hereafter, CDA), post-structural literary theory (Eagleton, 1983/2008, pp. 110–130) and, albeit to a lesser extent, the work of Jacques Lacan. As Ruth Wodak (2004) explains, CDA attempts to demystify ideologies and power "through the systematic investigation of semiotic data" (pp. 185–186). Post-structural theory, meanwhile, illuminates how ideological attempts to "draw rigid boundaries", typically through binary oppositions of one kind or another, "are sometimes betrayed into inverting or collapsing themselves" (Eagleton, 1983/2008, p. 115). Reference is made to Lacan in order to illustrate how these struggles, or 'play', are sutured by certain devices, namely a "point de capiton", or "quilting point", which anchor meanings, thereby preventing a shapeless mass of meaning from moving too freely: knotting the signified and signifier together in order to produce "the necessary illusion of a fixed meaning" (Evans, 1996, p. 151).

More specifically, I have acted in the manner of a social semiotician, collecting, documenting and cataloguing texts for the purpose of investigating them (Van Leeuwen, 2005, p. 3). Although my initial intention was to focus solely upon HKSAR discourse, it became apparent this had to be contemplated in conjunction with a wider corpus of discourse, not least because of the links that bind these documents with others in intertextuality in ways that productively problematize the taken-for-granted notion of a text as having discrete boundaries. Having limited my study to analysis of this corpus of words, I proceeded from simple coding, paying attention to the frequency (and absences and omissions) of words, to thematic coding, albeit while being methodologically attached to the notion that "there is no single set of categories waiting to be discovered" and, crucially, that there "are as many ways of 'seeing' the data as one can invent" (Dey, 1993, p. 117). This article also explores elicited written commentary produced by apparently 'non-disabled' university students at a public university in Hong Kong responding to government discourse. Such an analysis has also proceeded from the identification of absences and presences through simple 'in-vivo coding' to more speculative interpretation of the nature, and implications, of students' readings.

3. Ethical Considerations

The methodology deployed in this article raises ethical issues, of which two are especially salient. First is my us-age of students as initially uninformed research participants and, related to this, my decision not only to 'push' critical readings (which might have induced ontological anxieties for some) but also explore their commentary not for their *true* feelings—as indeed had been my intention when I initially asked them—but instead as a corpus of discursive practices. Martyn Hammersley (2014) focuses upon such ethical dilemmas when applying constructionist forms of discourse analysis to interviews, observing that attempts to remedy "deception" might be counterproductive because informants could "become self-conscious about the language they use, perhaps editing it on the basis of some notion of 'good talk', or at least trying to avoid 'bad talk'" (p. 532). I share such a view, to which I would add that boundaries between ethical and unethical research practice—like the identities to which this article is concerned—are imprecise. Even though "sticking rigidly" to codes and guidelines "cannot ensure...research is ethical" (Ali & Kelly, 2012, p. 73), I have attained students' informed consent, albeit only after the event. Students have also been given pseudonyms, thereby preserving anonymity. I have also narrated such ethical transgressions—whether 'real' or imagined, and to myself if not others—as being an unavoidable repercussion of my efforts to elaborate upon "the non-disabled psyche" and illustrate how, as Dan Goodley (2012) puts it, "non-disabled people and disablist culture...subjugate...disabled people" (p. 181).

Causing me more, and as yet unresolved, ethical anxieties is that my efforts to articulate the exclusion of disabled persons might, inadvertently, have replicated this silencing. This relates to the fact that this article explores elicited written commentary produced by purportedly 'non-disabled' university students and does not, as perhaps some readers might expect this article could (and perhaps should) have done, solicit the views of 'disabled' persons. In so doing, I am, arguably, complicit with the structures and discourses I seek to critique.[3] Although I contemplated such an absence at the outset of writing this article, telling myself this omission, or aporia, would, as it still will be, filled in a subsequent project focusing upon 'disabled' persons' readings, so conspicuous is this absence now it almost seems an "absent presence", albeit one that might implicitly inform the arguments developed in this article.[4] Despite such reservations, it is hoped the structure and content of the article, as it is now, may allow—and perhaps even force contemplation of how persons—including myself and others (perhaps even some readers) implicated in this article—are, like the wider population to which Fiona Kumari Campbell (2012) refers, implicated in "the production, operation and continuation of ableism" (p. 215). Importantly, I am willing, as Judith Butler (1997) puts it, "to be undone by the critique that he or she performs" (p. 108).[5]

4. Inclusionary and Exclusionary Discourse

The paragraphs below analyse HKSAR discourse, especially but not exclusively documents entitled *Embracing Social Inclusion* (hereafter, ESI) and *Services and Support for Persons with Disabilities* (hereafter, SSPD), and the equivalent versions of these pages in both traditional and simplified Chinese characters (GovHK, 2016a, 2016b, 2016c, 2016d, 2016e, 2016f).[6] After recognizing inclusionary content, the paragraphs explore the more voluminous sub-text, namely content that is "backgrounded, hidden, repressed, or unconscious rather than explicit" (Chandler & Munday, 2011, p. 413).

4.1. Inclusionary Discourse

ESI and SSPD contain straightforward expressions of government beneficence. These documents make inclusionary statements, such as: "The Government is committed to enhancing an inclusive society, so that all individuals can enjoy equality and respect in different areas of life" (GovHK, 2016a).

Meanwhile, the *Initial Report* not only states HK$13 million had been spent on "publicity campaigns to promote the inclusion of people with disabilities" (HKSAR, 2010, p. 31) but also that local offices of the Social Welfare department had organized activities to "promote...social inclusion and the spirit of the Convention at district level" (p. 33). Most emphatically, perhaps, is the claim that "various habilitation and rehabilitation programmes" had been implemented "to enable persons with disabilities to attain and maintain maximum independence, *full physical*, *mental* and *social* ability and *full inclusion* and *participation* in all aspects of life" (HKSAR, 2010, p. 152, emphasis added).

Such unambiguous declarations repeat, almost verbatim, the inclusionary intentions of Article 1 in the UNCRPD, namely:

> To promote, protect and ensure the *full* and equal enjoyment of *all* human rights and fundamental free-

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[3] In one regard, the absence, or lack, of 'disabled' persons in the class might highlight exclusions and/or the ways in which persons might be compelled to 'pass', thereby assimilating themselves with ableist normativity. Such tendencies to exclude—rather than include—might be even more pervasive, entrenched and institutionalized. For example, David Mitchell and Sharon Snyder (2015) claim that "even highly funded research and policy organizations devoted to the social integration of disabled people…have actively resisted the most basic form of barrier removal" (p. 64). Equally, Henri-Jacques Stiker (1997) has referred to institutional resistance to sharing the world of disability with disabled people (p. 11).

[4] Jacques Derrida (1976) writes, in ways that might be pertinent to this, that: "The presence that is thus delivered to us...is a chimera....The sign, the image, the representation, which come to supplement the absent presence are the illusions that sidetrack us" (p. 154).

[5] Butler (1997) writes that for "the 'I' to launch its critique, it must first understand that the 'I' itself is dependent upon its complicitous desire for the law to make possible its own existence" (p. 108).

[6] It is beyond the scope of this article to engage exhaustively with the entire content of these texts. Instead, this article gravitates toward 'problematic' content. The original, and complete, texts from which these words and sentences have been extracted can be found by following links included in the references at the end of this article (see, for example, CRPD, n.d.; GovHK, 2016a, 2016b, 2016c, 2016d, 2016e, 2016f; HKSAR, 2010; UN, 2006, 2012).

> doms by *all* persons with disabilities, and to promote respect for their inherent dignity. Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may *hinder* their *full* and *effective* participation in society on an *equal* basis with others. (UN, 2006, p. 4, emphasis added)

HKSAR discourse not only echoes the core ethos of the UNCRPD (cited in the introduction to this article) but also appears to accord with the numerous principles and obligations identified in CRPD (n.d.), such as awareness-raising (p. 8), accessibility (p. 9), habilitation and rehabilitation (p. 19) and participation in political and public life (p. 21). Such intertextuality between the UN and HKSAR discourse is unsurprising given the latter was a signatory to the UNCRPD. Significantly, this discourse, as Campbell (2012) explains, formulates disability in ways that transcend the “functional and medical orientation of traditional disability models” (p. 221), reflecting that “causes of disability...are external to individual bodies” (Grue, 2009, p. 306). Consequently, the acknowledgement by HKSAR and the UN of the barriers emerging because of attitudes might indicate a “spread of sociopolitical definitions” and a “shift away from medical knowledge...in disability discourse” (Grue, 2009, p. 307), although subtext complicates, and perhaps even undermines entirely, such inclusionary discourse.

4.2. Sub-Text

That latent and ostensibly “out of sight” meanings are not, as Martha Helfer (2011) claims, necessarily “deeply concealed in dark, cavernous recesses of a literary crypt...[but] hidden all too obviously...in the open” (p. xiii) is evident here. In fact, the most obvious feature of ESI is the proliferation of positive words collocated with government (Figure 1) in addition to the “Embracing” deployed in the title of this document. Such frequency is even more noticeable given the brevity of the text.

Such discourse on ESI unequivocally works to create a positive representation of their ‘own’ group, a strategy which is involved in the justification of inequality, as Van Dijk (1993) explains, especially when this works in conjunction with “the negative representation of...Others” (p. 263). Admittedly, the ‘positive’ representation of government is more obvious and is achieved through a chain of discourse which constructs an active and beneficent subject collocated with “the material process, or ‘processes of doing’ type” of verb (Flowerdew, 2012, p. 55). These signify some ‘material’ or visible tangible change in the flow of events or the environment through actions made possible through government volition. Accordingly, social inclusion, like the production of disability (in UN discourse) is registered as an ‘evolving’ concept, albeit one that, crucially, relies upon top-down, paternalistic, interventions to realize. The acting subject of these verbs is government (e.g., the “government is committed to”). However, this is often concealed through auto-passivization (e.g., to “help disabled persons plan their journeys, the Transport Department has published”). This transforms active sentences into passive ones. However, disabled people are more violently passivized as recipients of nouns (support, etc.). Such passivization makes disabled persons appear as “objects” devoid of agency, an “obfuscation” which might, as Fairclough (1989/2015) claims elsewhere, be “ideologically motivated” (p. 140), as I later explain. Through the combination of words into sentences, relatively conventional and culturally coded symbolic meanings emerge which are, as the next part of this article reveals, accessible to readers. However, this narrative, unlike that previously identified, constructs an individualized account that establishes barriers exist *inside* disabled persons and because these cannot be overcome independently the government, ipso facto, acts on disabled persons’ behalf. This discourse contravenes the processual model of disability espoused in the UNCRPD and the HKSAR *Initial Report*. However, the UN do not acknowledge such disregard, even though after 48 lexical units under the heading of “positive aspects” in the UN response to the HKSAR *Initial Report*, 1496 words are clustered under subheadings associated with “areas of concern and recommendations” (UN, 2012, pp. 8–11), a silence which further complicates, and disturbs, purportedly inclusionary intentions.

- committed
- enhancing
- enjoy (twice)
- outlines
- integrates (7)
- provided (10)
- develop
- become
- receiving
- benefit
- given
- employ
- promote
- published (3)
- help (6)
- adapt
- sponsors (2)
- facilitate
- protects
- access
- find
- operated
- choose
- attend
- enters
- covers
- admits
- encouraged
- participate
- organized
- funded

Figure 1. Positive verbs, and noun forms, in ESI.

4.2.1. Othering

Stuart Hall (1997/2013) has lucidly explained how representation works by marking differences which are constructed through language by way of binary oppositions, one of which is “dominant”: a power dimension in discourse that might be captured by writing **white**/*black*, **men**/*women*, **British**/*alien*, and so on (p. 225). As Hall (1997/2003) explains with reference to the work of Mary Douglas, stable cultures “require things to stay in their appointed place” and that what “unsettles culture is 'matter out of place'...a sign of pollution, of symbolic boundaries being transgressed" (p. 226). Such pollution is swept up or thrown out, thereby restoring order, all of which "leads us, symbolically, to close ranks, shore up culture and to stigmatize and expel anything...defined as impure, abnormal" (Hall, 1997/2013, p. 237, emphasis added). To the categories to which Hall refers, it is necessary to add **non-disabled** (or **abled**)/*disabled*. Although seemingly innocuous, the use of "their", applied to "people with disabilities" 10 times within ESI and SSPD, is instructive (GovHK, 2016a, 2016b). First, this increases psychic distance, contrasting markedly with the complete absence of 'you', or even 'we', which would, as Fairclough (1989/2015) suggests elsewhere, be more "inclusive" (p. 143). Second, 'their' covertly erases disabled persons from, or places them outside, the text which, implicitly, addresses supporters—family members and so on—who, therefore, mediate between the text, thereby protecting, or buffering, other readers (perhaps like the students whose readings are discussed during the next part of this article) from disabled persons. Third, albeit only perhaps implicitly (or through an allusion), 'their' seems to speak to and on behalf of a 'non-disabled' unity defined through a reduced, oversimplified and deficient 'disabled' other. Such processes as passivization and the absence (or erasure) of disabled persons inside the documents combine to make disabled persons, like those to whom Anita Ghai (2006) refers, appear "dis-embodied because...constructions around them...threaten to create a total invisibility of the disabled individual" (p. 147). Consequently, disabled persons likely seem even more reliant upon either supporters or the already self-constructed benevolent government. Such forms of othering combine to deny ways of thinking about the "agentive" (Mitchell & Snyder, 2015, p. 1), "leaky" (Shildrick, 1997, p. 10) and "lively materiality" of disability (Mitchell & Snyder, 2015, p. 1). Consequently, these texts might be viewed as reinforcing, rather than offering alternatives to what Robert McRuer (2006) calls "compulsory able-bodiedness", namely the notion that "able-bodied identities...[and] perspectives, are preferable and what we all, collectively, are aiming for" (p. 372, cited in Mitchell & Snyder, 2015, p. 3). However, these documents not only 'other' disabled persons. In fact, even the offer of "services which help people with disabilities, ethnic minorities, new arrivals and the underprivileged to integrate into the community" (GovHK, 2016a) conflates disparate persons, identities and groups into an undifferentiated morass of otherness, thereby constituting violently exclusionary discourse.

4.2.2. Inclusion...or Integration

In HKSAR discourse, there is slippage or parapraxis between 'inclusion' and 'integration', *gongrong* and *rongru* in the simplified Chinese version of this document (GovHK, 2016c). In fact, with the exception of the title, integration is the term used (Figure 1). In ordinary discourse, such terms are used interchangeably. In disability studies discourse, however, these terms possess different connotations. As Colin Cameron (2014) explains, inclusion involves "the creation of settings in which difference is encouraged and valued" whereas integration typically implies disabled people must "become 'more like' non-disabled people in order to get acceptance" (p. 79). Crucially, although SSPD states there are a "*wide* range of rehabilitation services...available...to help people with disabilities to develop their physical, mental and social capabilities to the *fullest possible extent*" (GovHK, 2016b, emphasis added), these only relate to training and transport. Moreover, training is restricted to "working capacity" and "employment" (GovHK, 2016b). This not only suggests a neoliberal interpretation but also an assimilationist model of inclusion. Significantly, these texts, and the 'services' they mention, resemble those practices of "neoliberal disability tolerance" that Mitchell and Snyder (2015) refer to as inclusionism, "a term specifically associated with disabled bodies operative in the policy world of neoliberalism" (p. 4). These services, nevertheless, fall short of offering what Mitchell and Snyder (2015) call "meaningful inclusion" that necessitates "*disability becomes more fully recognized as providing alternative values for living that do not simply reify reigning concepts of normalcy*" (p. 5, original emphasis). Such 'inclusion' is, therefore, closer to definitions of integration within disability studies discourses and might even exemplify what Mitchell and Snyder (2015) call disability's "grudging admission to normative social institutions through inherently neoliberal forms of redress" (p. 35).

It seems, furthermore, that inclusion comes with conditions and significantly that deviating too far from 'normal' behaviours invariably results in exclusion. On ESI, for example, it states children with "special needs enjoy equal opportunity" to receive education in public-sector ordinary schools but "those who have more complex needs or whose disabilities are so severe that *they cannot benefit* from education in mainstream schools receive education in public-sector special schools" (GovHK, 2016a, emphasis added). Such discourse locates barriers to social inclusion unambiguously *inside* disabled people rather than in the incapability of structures to include, or admit, them. This discourse functions to obscure the social mechanisms involved in social exclusion and, more generally, the ways in which "society" acts "as an oppressive disabling force" (Thomas, 2007, p. 53). A medical model of disability underpins this discourse, acting as an "anchoring point" or "point de capiton" which stops "incessant sliding of the signified under the signifier" thereby stabilizing and fixing meanings, interpretations and relationships (Chandler & Munday, 2011, p. 393).[7]

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[7] Although the UN notes "the prevalence of the medical model of disability in both the definition of disability and the enduring terminology and language of the discourse on the status of persons with disabilities" in their report addressed to the PRC (UN, 2012, p. 2), this is conspicuously absent in the section addressed to HKSAR: an absent presence.

Crucially, such a discourse not only enables "normalcy", and "'normal' social structures and artifice, to remain unquestioned" (Titchkosky, 2007, p. 165) but also displaces the onus from 'non-disabled' to 'disabled' people, implying they rather than society need to change (Cameron, 2014, p. 79) while not disturbing, and perhaps even reinforcing, the **non-disabled** (or **abled**)/*disabled* binary. Put differently, this seemingly innocuous sentence presents an assimilationist condition: either effect integration through normalization or become segregated in a *special* school. This means that the 'inclusion' of disabled people unequivocally demands a contradictory notion, namely "denying...differentness, their right to be...just the way they are" (Ravaud & Stiker, 2006, p. 925).

These documents not only produce a narrow, shallow, version of social inclusion but also a limited definition of rehabilitation.[8] These interrelate with, thereby reinforcing, each other, by virtue of both being located in a medical model of disability that functions to fix meanings. Although rehabilitation refers to a process, or processes, enabling disabled persons to "interact with their environments" (Albrecht, 2015, p. 420), in contrast to the expansive notions of barriers in UN discourse, HKSAR discourse limits these to physical and environmental barriers (e.g., the steps (not) going into a building, etc.) and does not therefore recognize socially constructed barriers, such as attitudes. Put differently, within HKSAR discourse rehabilitation focuses upon "the individual as a private entity" and therefore on the nature of a person's impairments, rather than on the "expectations and structures of the society and the community as a whole" (Albrecht, 2015, p. 421). Even the provision of transport on SSPD (called a Rehabus) while ostensibly realizing commitments to provide rehabilitation, albeit in only a bare form, can be read as perpetuating processes of segregation and, therefore, promoting exclusion rather than inclusion. This is because this conspires to remove, and erase, disability from places of quotidian life rather than, for example, working to remove attitudinal barriers, thereby enabling both 'non-disabled' and 'disabled' persons to use existing forms of transportation concurrently. The Rehabus might, therefore, be regarded as an act of dissociation. Admittedly, such discourse and the policies they become implicated in making seem not as extreme as to resemble an elimination model of exclusion (Ravaud & Stiker, 2006, p. 925). Instead, they articulate an intermingling of "segregation" (or sequestration), "assistance" and "marginalization" models (Ravaud & Stiker, 2006, p. 926).

5. Ways of Reading

The paragraphs below present an invariably partial and selective account of students' commentary reflecting upon HKSAR discourse in ESI and SSPD. The views of approximately 90 students were requested, although only 56 were submitted. A total of 14,000 words were produced.

5.1. Beneficent Government and the Robustness of the ***Non-Disabled*** *(or* ***Abled****)/Disabled Binary*

The discourse students most commonly produced not only recognized government's benevolence but also their role in facilitating a socially inclusive society. Students' commentary was, more generally, populated by relatively utopian visions (e.g., "society is full of love") of Hong Kong and one of the most prevalent words within the corpus of students' discourse was "positive", collocated with "ideas", "attitudes" and "words". One student from mainland China talked, for example, of the "kind language" which, she claimed, could "enlighten people with sympathy and comfort", even going so far as to suggest government discourse had altered her opinion of them. "As a student from mainland China, I used to think I should adapt to university life myself", she explained, "but now I feel the government cares about all minority groups". Chen's commentary might exemplify students' positive discourse:

> I think the government is trying to produce and send a very clear message that they want to do their best to take care of everyone in Hong Kong. They are trying to send the message to the public that the government will take care of everyone, and that there is no need to worry even if you are disabled. These words make me feel the government is really trying to look after people in need, and that they are willing to support those people and try to make their lives more convenient or to try to help people adapt to a new environment. I think the message the government is trying to send is clear and I feel positive about the words.

Such tendencies to read government discourse at face value was at first surprising and disappointing since students' discourse had been initially solicited for pedagogical purposes, namely to apply principles associated with CDA subsequent to a class in which they had been introduced to them. In short, students had been actively encouraged to not only search for bias but also denaturalize and deconstruct language and I was disappointed when they had not collectively done so. Such readings, nevertheless, seem to unequivocally indicate the extent to which the social conditions, or "the underlying conventions" (Fairclough, 1989/2015, p. 60), which make possible both government and students' own discourse are naturalized. For example, students' discourse like "the government is doing its best", "disabled people need help", "there is not much else which can be done", etc., reproduce, and therefore reinforce, individualized 'per-

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[8] Mitchell and Snyder (2015) observe that although rehabilitation often "refers to a productive process of recovery leading to a return to approximations of normative embodiment (and, ultimately, employability)...the term suggests something less optimum. Cultural rehabilitation refers to normalization practices at work within the neoliberal era through which nonnormative (i.e., nonproductive) bodies become culturally docile" (p. 205).

sonal tragedy' models of disability which leave social structures unquestioned. In fact, "help" was the most frequently used word in the mass of text produced by students, appearing 90 times (out of a total corpus of 14,000 words), e.g., "the government play[s] an important role to help people", "disabled people are helpless", "disabled people need the most help", etc. Alternatively, albeit perhaps related to this, students' readings might reveal how dis/ableist ideology and discourse is so "normal", "natural", and taken-for-granted it has become "invisible" (Jaworski & Thurlow, 2011, p. 21): even when students were specifically required to search for it. In fact, several students, and one male student in particular with whom I had hitherto enjoyed a good relationship, appeared frustrated and even quite irritated by my "cynical" efforts, as he put it, to incite students to re-read their readings more critically. Admittedly, students' propensities to speak government discourse might also be because of either their instrumental tendencies[9] or resistance to me, and perhaps a combination thereof rather than the power (or taken-for-grantedness) of these discourses per se. It is, nevertheless, compelling to read these processes as illustrative of recontextualization, namely "the movement of parts or elements of...texts out of their original context...into a different context" (Fairclough, 1989/2015, p. 38), in ways that reinforce them. Equally, students' readings might indicate government power: as Norman Fairclough (1989/2015) explains "the power to project one's practices as universal and 'common-sense', is a significant complement to economic and political power...exercised in discourse" (p. 64).

Although government discourse invariably shaped students' readings, they were not 'prisoners of discourse', even if they appeared to speak government discourses "*as if they were their own*", as Bronwyn Davies (2003) puts it in another context (p. 14, original emphasis). In fact, rather than reading students' tendencies to repeat government discourse as being resultant from the irresistible force of discourse, it might be more plausible to view students as being partly complicit with them, whether consciously or unconsciously. Such complicity might be because elements of already elaborated upon government discourse made firm distinctions between **non-disabled** (or **abled**)/*disabled* identities in ways which privilege the former over the latter in this binary. Because students' own identities are invested in this binary, they might be amenable, and receptive, to those previously elaborated upon allusions, located, according to my reading, in the sub-text of government discourse, albeit while being maintained, and perhaps even consolidated, by students' readings. As Wodak (2004) explains, allusions not only "suggest negative associations without being held responsible for them" but also "depend on shared knowledge": the "person who alludes to something counts on preparedness for resonance, i.e., on the preparedness of the recipients consciously to call to mind the facts that are alluded to" (p. 195). Importantly, allusions exist as a kind of repertoire of collective knowledge (Wodak, 2004, p. 195).

*5.2. Questioning the **Non-Disabled** (or **Abled**)/Disabled Binary and Aesthetic, and Ontological, Nervousness*

Nevertheless, doubts insinuated themselves into some students' discourse. In some cases this expanded in ways that evoked Michel Foucault's (1977/1995) evocative description of the "confused horror" which "spread from the scaffold" at the start of *Discipline and Punish* enveloping persons in shame (p. 9). Lam, a female student, described how when reading the Chinese terms (as opposed to the English) she found them neither "appropriate" nor "polite", as she put it. She was most concerned with the term *canji*, a generic term connoting 'disabled', 'handicapped' or 'deformed', despite being aware that the term has, as she put it, been adopted by the UN and is, as Emma Stone (1999) points out, officially endorsed and "an apparently new and neutral term" (p. 136). Her unease was even more poignant given that she could not, as she put it, "think of a more suitable term", indicating deficiencies in, and with, existing discourse.[10] Lam was, it seemed, preoccupied by language—as indeed I had wanted her and her classmates to be—and its capacity to label. She commented, for example, about how negative labels attach to persons, and groups, not only guiding attitudes and behaviour but also, as Swain, French and Cameron (2003) observe, becoming embroiled in processes of surveillance and segregation, in ways which disable persons (p. 12). She was, in short, questioning the invisibility of discourse and consequently her common-sense distinctions between **non-disabled** (or **abled**)/*disabled* were becoming challenged. This seemed to make her uneasy, perhaps because such ruminations threatened her own 'non-disabled' identity. As Lam explained:

> Words can influence how people think. If I am not wrong, I suppose this is the hidden power in discourse. It is often not clear and not apparent to people, and hard to identify in our everyday life. However, it has a big impact on our world, as words can influence and even change our thoughts without us knowing. By using certain words on the Chinese webpage, *these* people [emphasis added] sound not normal. It will make the public feel pity and sympathy for them, but also superiority at the same time.

In effect, Lam had engaged with the sub-text of government discourse. She was also witnessing the ways in

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[9] While beyond the scope of this article, students often appear to me, and themselves (if their self-assessments in both semi-structured interviews and more informal contexts can be taken as revealing their *true* feelings), as being motivated by instrumental reason. Their repetition of government discourse almost verbatim might, accordingly, be seen as tactics deployed to complete the task with the minimum amount of effort.

[10] Lam's discontent was, according to my reading, pertinent given *canji* is comprised of two characters, namely *can*, which encompasses such meanings as 'incomplete', 'deficient', 'remnant', 'ferocious', 'barbarous' and *ji*, or 'disease', 'illness' and 'suffering'.

which 'the non-disabled imaginary' appears intent upon elongating distances, both physical and psychic, between 'us' and 'them', or 'self' and 'other', through the production, maintenance and consolidation of a **non-disabled** (or **abled**)/*disabled* binary in order to reinforce what Bill Hughes (2012) poignantly terms "the emotional infrastructure of ableism" (p. 68). Her preoccupation with words reveals how despite living in dis/ableist cultures and societies, processes of internalizing these ideologies are not complete. For her, ableist words "obstinately refuse, sounding alien in the voice of the one who enacts them through speech", as Campbell (2008, p. 157) puts it elsewhere: even when it was her speaking them. Yip, meanwhile, seemed not only exasperated, and perhaps even angry, at language's lack of power to ameliorate the circumstances in which it is spoken, or written but also cynical about government discourse:

> The government acts like a giver, a provider, to help with the 'reintegration' of the disabled into society, to help them to get a 'normal' life like the rest of us. Perhaps the word 'disabled' itself already suggests a certain kind of disapproval, saying they are 'not able'. Words on these pages try to be as fair as they can but still they cannot cover the shred of empathy in them, victimizing those with disabilities by offering them 'support'. The word support implies a patronizing perspective towards disabled because help is offered by those with most power. The concessions provided to them separate the disabled from the rest of us. Just like the elderly, those labelled 'disabled' are said to need help to 'reintegrate' as if they were not in this society with us together. While the services offered aim to help disabled people cope with the challenges they find in daily life, the use of words in these paragraphs already groups the disabled and separates them from the rest of the society.

5.3. Reducing or Removing Ontological Anxieties

Readings by Lam and Yip not only register but also generate unease in ways that demonstrate how encounters between 'non-disabled' and 'disabled' persons may become a "primary scene of extreme anxiety" (Quayson, 2007, p. 17) even when these occur in mediated forms. These emerge when students confront the instability of, and imprecisions associated with, both language and self. Such readings might ostensibly indicate the fragility of power and hegemony, and the precariousness of dis/ableist ideology and the identities capable of being produced (and denied) by them. Nevertheless, given the anxieties they engender, it seems plausible students work to assuage, or expunge, these oppositional, and not only troubled but also troubling, readings of government discourse. In fact, even in short fragments of discourse, discursive knots of one kind or another were unravelled or sutured internally, in ways that re-privileged, and reinforced dis/ableist discourse and **non-disabled** (or **abled**)/*disabled* identities. Having glimpsed, albeit perhaps fleetingly, the leakiness of seemingly robust classificatory systems constructed through discourse, they needed, in effect, to be refortified. For example, Chiu had been, according to my reading, extremely disturbed by her engagement with government discourse, ruminating upon how there was "no definite taxonomy" between 'abled' and 'disabled' persons and that it is "only we who try to differentiate or, in other words, isolate people". However, her reading of government discourse still, ultimately, functioned to contain anxieties. She claimed, for example, that even though "minorities face innumerable difficulties", they are "lucky" to be born now and in a context in which there is a "government to help them, and fight for them". Chiu thereby enabled herself to conclude by articulating a positive view of government surmising their actions as being correct. Ostensibly Wong was entirely incredulous to government discourse, a scepticism which might partly be a consequence of her having attended a class in media theory that spent significant time developing tools with which to critically read media representations. Wong claimed these webpages painted an "overly exaggerated and beautified" picture, albeit one that did not deceive her. Nevertheless, only several sentences earlier she talked of feeling "comforted", "at ease" and, significantly, claimed these webpages ensured she did not need to do anything or feel guilty because "they [disabled people] are already well-protected, things are fine, they are perfectly good", although such words might, admittedly, have been spoken, or written, with the world weariness of a cynic.

6. Concluding Thoughts

This article has explored how purportedly inclusive discourse not only deflects away from the population it seems intended to address but also gives persons who engage with this discourse means through which they might reassure themselves that disabled persons are being taken care of while at the same time securing, and holding in place, **non-disabled** (or **abled**)/*disabled* identities. While this article has primarily focused upon discourse produced in Hong Kong, this exists in relation to that produced by the UN in ways that suggest international organizations are complicit in the co-production of what Campbell (2012) calls "geodisability knowledge" (p. 218). The discourse explored in this article seems to suggest, at best, only a very limited commitment to social inclusion and, perhaps, indicates far greater efforts to secure, and stabilize, **non-disabled** (or **abled**)/*disabled* binaries. In fact, these documents, despite their self-congratulatory tone, reinforce rather than weaken the ontological consistency of such categories. Related to this, while not entirely announcing social inclusion as a finished project, texts like CRPD (n.d.) not only celebrate progress but also collocate it with the government and international organizations in ways that might indicate the insidious expansion of the "practitioners of normalization rather than the inclusion” (Mitchell & Snyder, 2015, p. 71) of disabled persons. In so doing, the aspiration of social inclusion is appropriated, while being re-defined, and constructed as something that can be achieved by and through politicians and policy-makers while obscuring, and perhaps even erasing entirely, the notion that inclusion is only realizable through either “a process of struggle that has to be joined” (Oliver, 1996, p. 90) or conscientization. The effect of incorporating social inclusion into official discourse is, as John Fiske (1987/2006) argues in the context of signs of the ‘new woman’ and ‘patriarchy’, “to defuse any threat it might contain and to demonstrate” the capacity of ableism to “accommodate potentially radical movements within the existing power structure” (p. 38). Such appropriation also debilitates re-contemplation of those normalized, naturalized, taken-for-granted and ‘unthought’ categories that unequivocally act, as Scott Lash (1994) explains with reference to Pierre Bourdieu, as “preconditions of our more self-conscious...practices” (p. 154).

However, readers are also implicated in such processes or meaning making and, as much as if not more so than the documents with which they engage, hold the ideological system in place. In so doing, readers function like the Lacanian “point de capiton” which (or who) “fixes...meaning”, submitting them to some code (Žižek, 1989, p. 103) effecting or making it have a stable meaning. One corollary of such an interpretation is that ideology operates through people who “‘iron out’ contradictions...in ways which accord with the interests and projects of domination” (Fairclough & Chouliaraki, 1999, p. 26). In this regard, these ostensible “struggles” in and through discourse might necessarily be reconceptualized as figurative skirmishes in which dominant dis/ableist ideologies and discourses not only emerge unscathed but also reconsolidated, even being fortified by and through seemingly oppositional readings. Through such processes with which readers are complicit, and echoing observations on racism, **non-disabled** (or **abled**)/*disabled* identities might even be galvanized “with the intentional or unintentional support of the entire culture” (Jones, 1972, p. 172). This is because a kind of “aesthetic nervousness” (Quayson, 2007) is induced when readers like Lam confront (or are confronted by) what Judith Butler (2000) terms an “unassimilable remainder” (p. 24) as disability “escapes the confines of its negative ontology” even while discourse produces it (Titchkosky, 2007, p. 126). The discourse to which this article has referred might, therefore, be read as working to manage (or contain) such ontological anxieties and as strengthening rather than weakening what David Bolt (2012) has termed “critical avoidance” (p. 287). However, to “leave one’s thought in a state of unthought” is, as Bourdieu (1992) observes with regard to the ways in which the social world constructs its own representation, “to condemn oneself to be nothing more than the *instrument* of that which one claims to think” (p. 238, original emphasis).

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About the Author

Alex Cockain is an Assistant Professor in the Department of Applied Social Sciences at the Hong Kong Polytechnic University. He teaches courses relating to anthropology, media theory and qualitative research methods.

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Article

Power, Ideology and Structure: The Legacy of Normalization for Intellectual Disability

Murray K. Simpson

School of Education and Social Work, University of Dundee, Dundee, DD1 4HN, UK; E-Mail: m.k.simpson@dundee.ac.uk

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Abstract

Since its first formulation in English, the ‘principle of normalization’ has had a profound impact on policy and practice in the field of intellectual disability. Over the past fifty years, normalization, and Social Role Valorization, have drawn on liberal humanist philosophy, adopting varied and complex positions in relation to it. This article will consider an apparent structural correspondence between a discourse of ‘liberal equality’ with versions of normalization that emphasised conformity to social norms, and those drawing primarily on ‘liberal autonomy’, emphasising independence and self-determination of people with intellectual disabilities. Despite this seeming correspondence, the article eschews a structuralist account in favour of a discursive and rhizomatic model, in which the philosophical elements are seen as tactical forces deployed in the pursuit of wider strategic ends. The article concludes by highlighting paradoxes in contemporary thinking that can be traced to the legacy of normalization, specifically, the tensions between sameness, difference, equality and independence.

Keywords

Deleuze; disability; discourse analysis; ethics; Foucault; ideology; intellectual disability; normalization principle; power; structuralism

Issue

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1. Introduction

The principle of normalization has been identified by numerous authors as the single most significant model for policy and services in the field of intellectual disability in the past fifty years—a fact that holds true in virtually all English-speaking countries around the world, as well as many others (see, for example, Caruso & Osburn, 2011; Emerson & McGill, 1989; Keith & Keith, 2013; Kendrick, 1999; Race, 2002). Whilst not always explicitly cited in policy and legislation, it had a significant influence on the United Nations (1971) *Declaration on the Rights of Mentally Retarded Persons*; and, in the United Kingdom, both on the white paper, *Better Services for the Mentally Handicapped* (Department of Health and Social Security, 1971) and *The Report of the Committee of Enquiry into Mental Handicap Nursing and Care* (Jay, 1979), which ushered in policies of deinstitutionalization; whilst in current policy for people with intellectual disabilities[1] (Department of Health, 2001; Scottish Government, 2013), it continues to be the implicit theoretical pivot upon which services shifted to a non-institutional basis (Johnson, Walmsley, & Wolfe, 2010). As Mathews suggests:

> [It] had a major impact on social policy in the United Kingdom and the provision of care services to disabled people, and can be seen as being an influential driver in the closure of long-stay institutions and the development of more personalised, community-based alternatives. (2017, p. 1364)

Although it did set out relatively clear objectives for reformed policy and services, its principal target, at least in the early years, was the institution or hospital. In

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[1] References to ‘persons with intellectual disability’, ‘mental retardation’ and so on, refer only to conceptual categories in which some are situated and others not; they do not refer to any intrinsic characteristics of such individuals.

more recent decades, in what Altermark (2017) calls the ‘post-institutional’ era, there has been a shift towards discourses of ‘citizenship’. However, as he also notes, these have involved transformations of power, rather than its disappearance.

This leaves a key question for the present as to whether normalization continues to have any relevance or contribution to contemporary thinking in intellectual disability policies and practices. Whilst even some sympathizers (e.g. Race, 2002) have suggested that it is time to ‘move on’ from normalization debates, by critically examining the development of two broad approaches to normalization and philosophy, we can see the continued value of sociological critique in unblocking stultified thinking. Two strands, or strategies, have linked institutional critiques and putatively ‘progressive’ thinking to two different aspects of liberal humanism—equality and autonomy—with the former being more closely aligned with behavioural psychology, and its emphasis on adherence and adaptation to behavioural norms, and the latter more in evidence in thinking around community-based services and the promotion of independence. Needless to say, these are broad characterizations of approaches that in reality exhibited far less consistency or coherence. They were not entirely distinct approaches to normalization, and the elements of liberal philosophy are not mutually exclusive. The aim of this article is to highlight and account for the relative balance that was given in different texts to the two elements and to explore their connection to service frameworks in order to demonstrate the essentially tactical nature of ethical principles within service models like normalization. The hope is that, in doing so, it will open up new spaces in which ethical claims can be made and the rubric by which they can take form.

The critique will trace each of these strands in turn and show how each connects with other, wider strategies of power. It will demonstrate how these lines come together within the discourse of normalization in apparent structural correspondences. However, whilst appearing to suggest a structural correlation, the article will conclude that only a less deterministic, discursive approach can account for this association. Although the article draws on international literature, it is situated primarily in the context of the United Kingdom, where normalization and Social Role Valorization (SRV) have been less hegemonic than elsewhere.

Whilst such an analysis cannot provide a set of *solutions* to agreed upon problems, or even goals, there being no such agreement or possibility thereof, it can help to free up aspects of thinking that have become sedimented and stuck. By putting the obvious and self-evident back into play as contestable objects—’intellectual disability’ most of all—new ways of thinking are more likely to be opened up. So, although normalization tends only to be mentioned in passing in more recent general texts on intellectual disability policy (e.g. Goff & Springer, 2017; Richards, Brady, & Taylor, 2015; Sturmey & Didden, 2014), this largely reflects how its assertions and values have become implicit, producing an assumed conceptual foundation for contemporary discourse (Altermark, 2017). Gilbert, Cochrane and Greenwell (2005, p. 293), for example, suggest, that it “has been transformed into a discourse of citizenship with people with learning disabilities now managed within specialised spaces in the community which remain supervised by professionals”, whilst Corbett (2011, p. 276) credits it with the “significant politicisation of people with intellectual disabilities”. Nonetheless, there remain underlying assumptions that are particularly problematic because of the ways in which they can obscure the discursive and non-discursive effects that normalization continues to play in constituting the field of intellectual disability: its concepts, subjectivities, interventions, and so forth. As this article will demonstrate, it is at this level that a historicized critique of intellectual disability must operate, rather than dealing only with current policies, and service theories and models. Failure to do so will result in the continual replication of variants of the present.

2. Liberal Equality and Behavioural Conformity

The first strand, then, is that linking the development of the principle of normalization as a loose and sometimes contradictory discourse and operant conditioning, in particular, the way in which the former was used as an instrument of the latter—observations of mutual reinforcement and contradiction notwithstanding (e.g. Emerson & McGill, 1989). As Clarke and Clarke (1974, p. 7) suggested, behavioural techniques for the teaching of social and employment skills “were [later] termed ‘normalization’”, whilst Schalock (2004) observed that the development of adaptive behaviour was ‘integral’ to principles of normalization. Normalization also served as a tactical weapon for psychology against medically oriented institutions in favour of community facilities, which, at least in theory, had a more developmental orientation, even if the realities of deinstitutionalisation didn’t always accord with these aims (Felce, 1996; Flynn, 1980). When normalization took root in North America, the force of the human rights argument was largely rooted in a certain tradition of human rights which existed in the USA—broadly Lockean in orientation—as well as to a specific period when that tradition received particular political emphasis (see, for example, Wolfensberger, 1971). Not only was it a time when there was a general critique of institutions and institutionalisation (Goffman, 1961), but it was also one that witnessed anti-Vietnam war protests and civil rights unrest. One typical ideological strategy employed for the political advancement of normalization was to appeal to the common humanity between ‘*people* with mental retardation’—and this word was itself emphasized—and others, with a corresponding attack on the ‘de-humanizing’ institutions and practices therein. Central to arguments for normalization was the recognition of “a claim to humanity which they share with the non-handicapped" (Ryan & Thomas, 1987, p. 130), though, as Wolfensberger (1980) made clear, it would be mistaken to draw a simple equation between the two. Normalization may depend on humanization, but the latter does not necessarily lead to, or imply commitment to, the former.

The specific philosophical construction of personhood for the 'retarded' individual was not by any means unique to the issue of retardation. Nonetheless, there is ample evidence of this shifting view being tactically significant for an empiricist psychology in defining the personhood of the retarded individual. This was particularly true in the ways in which it further dichotomised soul and body, alienating consciousness from behaviour. Gold (1980, p. 19) illustrated this point with his insistence that trainers focused on tasks and behaviour as opposed to "feelings", which would constitute "manipulation". As Foucault (1979) observed, the deployment of the soul as human essence was fundamental to the coexistence of the empirical sciences of human behaviour, with humanist politics and ethics. Foucault describes its function as a 'reality reference', upon which, through the medium of the body:

> Various concepts have been constructed and domains of analysis carried out: psyche, subjectivity, personality, consciousness etc.: on it have been built scientific techniques and discourses, and the moral claims of humanism. (Foucault, 1979, pp. 29–30)

For the principle of normalization, the key function, or effect, of the soul was to establish a commonality and equality between those deemed to be and not to be 'retarded'. In addition, it depended upon a specific relationship between the retarded person, his or her body, and the observing gaze of the psychologist.

Of the various key components that make up liberal humanist philosophy, that of 'liberal equality'—equality before the law, equality of opportunity, as citizens in a democratic polity, etc.—was particularly significant in this strand of normalization. As already noted, the claims of normalization against the *dehumanizing* institution were invariably underpinned by assertions of this common humanity. The role of psychology was, perhaps, subtler, though arguably much more profound in forming the conditions of emergence for normalization (Simpson, 1998). Whilst at pains to say, unconvincingly to critics (see e.g. Brown & Smith, 1989; Perrin & Nirje, 1985), that "the goal [of normalization] is not to impose social conformity", it was, nonetheless, "to prevent or reverse involuntary or unconscious deviancy" (Wolfensberger, 1970, p. 68; see also, Wolfensberger, 1972). Behaviourism introduced another form of normalization, *viz.* the normalizing actions of disciplinary power. Thus, there were, "two…basic variables that can be manipulated for the client's benefit: his environment and, as a result of the manipulation of his environment, his behavior" (Meyerson, Kerr, & Michael, 1974, p. 377).

In this way, behaviour was reduced to the level of a 'variable', subject to expert scrutiny and control, the aim of which was to produce social integration through behaviour change—though also attitudinal and service changes. In turn, the separation and bracketing of the 'ethical' created a distinctive hierarchy of need. Thus, skills of money use or the prevention of shrieking in public were deemed to be more important on the scientific curriculum than the creation or appreciation of art. As Wolfensberger and Thomas (2007, p. 283) suggested, competence development should be directed towards the enhancement of creating and sustaining valued social roles, not with "competency for its own sake". Consequently, the 'mentally retarded' subject became an increasingly complex and managed space characterized by the containment of responsibility and self-direction, within an encompassing space of irresponsibility and alienated will.

Although often downplayed in relation to other factors, such as the putatively *sociological* basis of normalization (Wolfensberger, 1970, 1972, 1975), the impact of developments in psychology in the post-war period were highly significant for the emergence of normalization. At the same time, the picture was a complex one and Parmenter (2004) documents the ways in which behavioural psychology drove and was driven by the demands of non-institutional models of service provision. Behavioural research demonstrated what could be achieved in terms of the acquisition of social skills (Francey, 1960; Tizard, 1964) and employment skills (O'Connor & Tizard, 1956), as well as the reduction in 'maladaptive' behaviours (Beier, 1964), and a wide range of other aspects of learning and behaviour through operant conditioning (Denny, 1964). As Yates, Dyson and Hiles (2008) note, the individual tended to become obscured within normalization, which reduced its targets merely to functions of the social. This problem, they argue, is borne precisely out of irreconcilable tensions between the humanism of normalization, an essentialist view of impairment and the failure to conceive of the subject as an effect of power and knowledge. These problems are evident also in the second broad tradition of normalization, considered next.

3. Liberal Autonomy and the Self-Directed Life

Running through the dominant discourse of normalization, then, was a thread of similitude that linked together the scientific pedagogy of behaviourism and the ideology of liberal equality: a behavioural, disciplinary normality, and a shared human identity. However, although Wolfensberger's approach, or, rather, approaches, may have dominated the field, theoretically at least, they were by no means the only ones. The apparent structural correspondence between liberal humanism and strategies of governance can also be found in another strand of normalization. In this instance, the broad correlation is between an ideological base drawing principally on *liberal autonomy* and a service strategy aimed at maximizing choice and independence. Here the common thread is quite different, rather than commonality between people, it emphasizes human individuality and uniqueness via human rights and autonomy. Although normalization was not centrally about 'rights' (Wolfensberger, 2002), the discourse of 'rights' was very much in evidence from the outset of the normalization's development. Bank-Mikkelsen (1964) identified the recognition of the full and equal rights of citizenship for the people with intellectual disabilities as central to the pioneering developments in Denmark that first introduced the principle of normalization.

Several factors contributed to the fracturing of the relative theoretical homogeneity that normalization enjoyed in the 1970s. One of these was the widespread cooption of deinstitutionalisation into government policy in Western and Northern Europe, North America, and Australasia. In many of these cases, the policies, often under a general rubric of 'community care', aimed at maximizing choice and independence, most especially in countries and states where neo-liberal social policies were beginning to be pursued. Nirje (1969, 1972) had argued from the outset that the right to make or influence choices affecting one's life was fundamental to the principle of normalization at both an individual and collective level.

> They know what they are talking about, and they know that they are describing the realities of their existence….They are acting as citizens with the same right to be respected as others. (Nirje, 1972, p. 189)

The UK government policy framework of 'community care', or the service model of 'an ordinary life' (King's Fund, 1980, 1984) provide good examples of the emphasis on independence, both in the sense of self-reliance, i.e. of individuals, families and communities, and self-determination. In this formulation, 'normal' played a much more straightforward function as the creation of services that allowed for lives as ordinary, unfettered and self-determined as possible (e.g. Towell, 1988). As with Nirje (1972), the key role of service users as experts on their own circumstances and needs was central (Gathercole, 1988). From the perspective of public authorities providing and commissioning social services, the promotion of independence was also frequently linked to reduction in public support.

This conceptual approach emphasised the individual and his or her right to self-determination. Here, a typically more politicised approach both celebrated difference whilst also challenging the oppression related to it (see e.g. Szivos & Travers, 1988). Confronting the alleged emphasis on conformity to dominant social norms—white, masculine, middle class—Szivos asked: "Why should people [with intellectual disabilities] not be allowed to feel positively about what is *unique* about them?" (1991, p. 29, emphasis added)

By contrast, the normalizing pedagogy of the psychological strand exhibited a tendency to over-ride self-determination wherever it resulted in decisions and options that might not be the most 'socially valued'—most especially after Wolfensberger's (1983) conceptual reorientation towards SRV, which resulted in an even greater ambivalence towards the whole question of personal choice (see e.g. Wolfensberger, 2002). For Wolfensberger and Thomas (2007), the exercise of one's rights was firmly subordinated to cultural normativity and adaptive competence for deviant and devalued persons, rather than placing rights and choice at the centre, as Mathews (2017) suggested it did. Services were expected to implement support for rights in ways that developed "adaptive personal autonomy…[in] culturally appropriate and valued [ways, for the]…*responsible* exercise of their rights" (Wolfensberger & Thomas, 2007, p. 225, emphasis in original). The exercise of personal autonomy in ways that were 'maladaptive' was to be "governed by discipline, self-control, and a sense of responsibility" (Wolfensberger & Thomas, 2007, p. 225).

4. Normalization and Ideology: Structure and Discourse

As noted, there were sharp points of disjuncture in Wolfensberger's own work, most notably with the shift to SRV—cementing his focus on creating and maintaining valued social roles as the key to protecting devalued social groups from exclusion and harm—and times when threads came together only to part later, highlighting the need not to become concerned with authorial biographies and oeuvres (Foucault, 1972). Rather than attend to the evolution of any particular author's thinking, I have tried to present an apparent structural correspondence between certain strategies of power and ideological formations in the discourse on normalization. Specifically, one based on commonality ('human essence' as an ideology underpinning the strategy of 'behavioural competence'), and another based on individuality (with 'liberal autonomy' serving as the ideological basis for 'independence').

There is a certain attractive neatness to a structural account for these correspondences. What is lacking, however, is any apparent mechanism or structure of causation. Without recourse to the founding subject—there being no reason for supposing that authors are individually, and simultaneously, engaged in a conscious tactical appropriation of ideological elements solely in pursuance of larger power strategies—there is a hiatus in the accounting for any determination. More widely, this was, of course, one of the principal reasons for the general demise of structuralist theory (Nayar, 2014).

Post-structural approaches, with the general emphasis on 'discourse', understood as constitutive, though not determining, of subject positions (Sullivan, 2005), seem more promising analytically. In a study of the life sciences, Valle (1997) suggests three dimensions for the analysis of discourses:

> (i) the subject matter of the texts and their general rhetorical structure; (ii) the implicit or explicit 'recipient' or addressee of the text; and (iii) the presence or absence of an explicit text 'motivation', i.e. statement of purpose. (Valle, 1997, p. 79)

All three of these elements can be observed in this study of normalization and liberal philosophy. The analysis has rested on the study of the elements and structure of the discourse, and it is from here that the central problematic has arisen. In the second and third place, several implicit—and sometimes quite explicit—target audiences and objectives can be discerned, particularly relating to the general anti-medical, anti-institutional agenda. However, as the analysis has shown, the motivations and addressees are multiple, highly layered and inconsistent. In addition, the second and third components, like Kuhnian theory of scientific development (Kuhn, 1996), lead this approach to lapse into a form of collective psychology based around inter-subjective agreement on truth and meaning (Gutting, 1989). A Foucauldian approach, however, more thoroughly excludes the action of the subject from the analysis:

> The rules of discourse are not rules which individuals consciously follow….Indeed, the place, function and character of the 'knowers', authors and audiences of a discourse are also a function of these discursive rules. (Philp, 1990, p. 69)

In addition, this approach allows for the generalised account given here, whilst also accounting for the, often significant, exceptions to the correspondences suggested. Foucault (1981, p. 100) notes that elements and bodies of discourse circulate with "tactical polyvalence", pressed into service first for one, then for another strategy of power, sometimes simultaneously for two contradictory ones. Equally, two apparently exclusive elements may be held in tension within the one power-knowledge complex. For this reason, we must also avoid the approaches based merely on the play of binaries.

The principle of normalization was simultaneously: a concept, or series of concepts; a wider discursive field; and a technology of power. Little wonder then that its proponents so often felt compelled to correct the perceived errors of others in interpreting or applying it: academics, professionals, policy makers and one another (e.g. Emerson, 1990; Nirje, 1992; O'Brien, 1981; Perrin & Nirje, 1985; Wolfensberger, 1980, 2002), or, as Caruso and Osburn (2011, p. 194) put it, "safeguarding against…degradation". Deleuze and Guattari's (1988) figure of the 'rhizome' provides a useful analogy here. Like the rhizomatic tuber, normalization proliferated beyond the control of its designers, mutating and altering its growth to changing conditions. There was never a single point or strand that could be called the 'true' or 'essential' one, not even in a founding sense—perhaps most of all in a founding sense—to which we might return or aspire. Furthermore, as Shildrick and Price (2006) note, the rhizomatic proliferation of knowledge is not something to be wary of or disappointed in. At worst, there is an inevitability to its steady operations, and, in fact, it constantly opens up new inclusive opportunities for such developments, particularly at the micro-level. Goodley (2007; see also Fisher & Goodley, 2007), for example, has shown how 'rhizomatic' counter-narratives from the mothers of disabled babies have helped produce 'shelter' and resistance from dominant ones, as well as leading new forms of subjectivities.

Whilst here is not the place to develop a fully-fledged account of normalization as rhizomatic, there are a number of points to be made—following Buchanan's (2007) reading of the concept—none of which imply or require wholehearted support for the Deleuzo-Guattarian project. Firstly, the various iterations and uses of normalization that we have considered (and all the others besides) *interconnect*, though we must eschew the temptation to order them hierarchically and claim that any are more 'true', 'accurate' or possibly even 'helpful'. Secondly, and following from the first point, they are all facets of a whole that is simultaneously not a unity; "it is composed of dimensions…not units" (Buchanan, 2007). Thirdly, the proliferation of the rhizome is not 'reproductive', in the fashion of Wolfensberger's approach; instead, its growth is chaotic, unpredictable, generative of mutation and offshoots. Fourthly, it is an "infinitely modifiable map" (Buchanan, 2007), highlighting the fact that normalization, through ongoing critique, contains infinite future potentialities and directions of travel. Fifthly, the rhizome lacks any fixed centre or ruling signifier, which is why Wolfensberger's efforts at conceptual containment continually failed. Lastly, Buchanan (2007) notes that the rhizome is not "amenable to any structural or generative model"; normalization, in other words, is not a 'thing' that exists to be understood, clarified and refined. It is constantly being brought into being, and in ever new ways, with and through discourse and practice.

Some of the signs of this rhizomatic (re)generation are evident throughout this article. The institution provided a common focus and the conditions conducive to the deployment of a discourse of common humanity. In the post-institutional context, the field is fragmenting—the normative strategy has intensified, whilst new strategies have emerged, predicated on the new relations of power: choice, individual service planning, risk management. This does not, however, imply that discourse, even in its strictly ideological functions, is subservient to the actions of a sovereign power. Instead, this article highlights the way in which both liberal humanism and normalization deploy and are deployed, for reasons of tactical expediency, in "a multiple and mobile field of force relations, wherein far-reaching, but never completely stable, effects of domination are produced" (Foucault, 1981, p. 102).

The elements of philosophy explored in this article do, however, also perform an ideological *function*, in the sense that they play a legitimating role for certain practices and policies. They do not provide a foundational value base on which normalization can be said to rest, but neither are they ideological in the structuralist sense of that term; there is no structural determination in evidence, they have no intrinsic, singular or static connection to normalization, and have no fixed orientation or value. They signify a much more complex pattern of mutual induction, transformation and deployment of power and knowledge over a constantly shifting terrain.

5. Conclusion

This article has implications for common assumptions that the outcome of ethical contests is, or at least ought to be, primary and determining in shaping the life opportunities, the social and ethical position of people with intellectual disabilities, and what that might even mean (see, among others, Kittay & Carlson, 2010; Rogers, 2016). Goodey (2011, 2016), by contrast, has argued that the relationship between ethics and social practices shaping 'intellectual disability' have been far more complex and contradictory throughout history in ways that are not reducible to matters of progress. Indeed, one might be tempted to wonder whether Kittay and Carlson's (2010) eponymous debate around *Cognitive Disability and its Challenge to Moral Philosophy* might not more accurately be reversed.

The consequences of such a study for SRV, and its accompanying service assessment tool, *PASSING*, are that any further attempts to purify, define and control the concept, its dissemination and application, would be seriously misguided. One of the key features of the shift from normalization to SRV, was an increasing emphasis on the nature of the concept as empirically verifiable, objective and essentially value free; the underpinning assumption being that SRV was itself subject to 'higher order' 'supra-empirical' principles and values which give the system and its outcomes meaning (Thomas & Wolfensberger, 1999). SRV, it is suggested, should be restricted to the domain of empiricism, 'What works?', and anything else is 'religion' (Thomas & Wolfensberger, 1999); SRV itself "does not prescribe" (Wolfensberger, 2002, p. 253).

However, such a position has resulted in a certain vacillation because its proponents regard social norms and mores as both a resource for the process of valorization, as well as the primary sources of oppression (e.g. Wolfensberger, 1995). SRV reveals itself as an actively functioning system for the deployment of values, and as much more than just passively subject to the actions of ideological meta-narratives. More significantly, there can be no appeal to such 'supra-empirical' principles, since the fact-value divide on which such a supposition rests cannot be sustained. The ideological systems deployed in the various iterations of normalization have been shown to have been levelled to the same shifting terrain of power-knowledge relations as the concepts they are purported to govern. The reconceptualization of normalization as SRV did nothing to overcome this. Indeed, claims to a quasi-scientific neutrality themselves carry an ideological paradox: Critics' very attempts to raise objections on ideological grounds are dismissed as fundamentally misguided on the grounds that SRV provides no guide to what *ought* to be done (Wolfensberger, 2002), and yet, it is surely spurious to maintain that SRV is in fact neutral about what is to be done. The mere fact of determining what is and is not directly relevant to the measurement of social value is itself a matter of value, as are the mechanisms of definition and relative weighting.

Returning to Yates et al. (2008), it is important to note also that neither normalization nor SRV have resolved the paradoxical relationship between the *implied* concept of the liberal subject, and the intellectually disabled subject's actual status as produced by various lines of force (see also, Simpson, 2017). The outcome of this paradox, they contend, is the, again implicit, although necessary, silencing of the impairment, 'intellectual disability', as a concept itself, leading to further conceptual confusion. Altermark (2017) also tries to problematize this subject position by recasting the recent historiography of intellectual disability. However, he does so in a way that introduces different kinds of historical simplifications to those he attempts to critique. Following Foucault's lead, Altermark objects to analyses of power that constantly privilege the state, but he himself situates historical periods—overly monolithically—in terms of government policies. As we have seen here, the initial developments in normalization and deinstitutionalization had little to do with the state *per se*, beginning at a more micro and interstitial level with developments in operant conditioning.

Other tensions and conflicts are also apparent in the maintenance of SRV, for instance, in the way in which it evinces an ongoing difficulty in adopting or aligning itself with a clear system of rights. In their book on ethics and intellectual disability, for instance, Keith and Keith (2013) conclude with a section, commending SRV as the way forward, that is devoid of reference to rights and ethical theory. Also, whilst Caruso and Osburn (2011) were insistent on the need to keep 'best practice' within the tightly regulated framework of SRV, Shevellar, Sherwin and Mackay (2012), struggle to marry the top-down enforced singular model of SRV with the principles of adult education, with its participative and experiential, bottom-up approach. Whilst wishing to ground SRV training in experiential learning and reflection, they do not anticipate and address the kind of proliferation of perspectives that Wolfensberger and those carrying on his legacy were so keen to avoid. They do, however, note the inability of SRV to halt the development of oppressive institutions now flourishing in the community.

This critique problematizes two implicit paradoxes that were evident in the two approaches to normalization and that continue to be very much in evidence today. The first derives from the professional and conceptual manoeuvring by psychology; it is the underlying assumption that *the different must be made to appear the same*. Indeed, as Simpson (2014) contends, it is the very failure of mechanisms of socialisation to inculcate disciplinary self-regulation that is constitutive of intellectual disability itself. Consequently, interventions typically involve the external imposition of what would normally be acquired and assumed. The second paradox, perhaps the more significant one, can be traced directly to the second tradition of normalization, *viz.* the unstable and logically incoherent claim of *different but equal*. The basis of any putative categorical difference here can only essentialize intellectual disability. However, doing so undermines any real basis for commensurability within liberal humanism. This paradox was captured, without irony, in the title of an earlier policy framework published by the Scottish Executive, *The Same as You?* (2000). The title, posed as a question, both implies a difference—about which the question is being asked—whilst enquiring as to whether that difference is the same.

Given these warnings, the advancement of a progressive politics for and with people with intellectual disabilities must not imply unequivocal adherence to a particular model, or even an objective. Not simply because these are never arrived at, but because the relations of power and the constitutive bodies of knowledge are constantly shifting. As Shildrick (1997) notes:

> The yearning for the certainty of absolutes has resulted historically not in justice or equality or liberty, but in the denial of moral personhood to all those categories of living beings who cannot be identified in terms of the ideal standard. But once the binary of ideal/non-ideal has been displaced, once it is acknowledged that full and final definition is always deferred, it becomes possible to seek new constructions which no longer operate on the basis of exclusion. (Shildrick, 1997, pp. 212–213)

Although, as we have seen, new constructions, whatever form they take, can shift quite easily from being instruments of liberation to ones of oppression. The never-ending attempt to fix and govern a theory, such as SRV, inevitably causes us to lose sight of how fundamentally the field has changed and, therefore, the strategic possibilities of SRV itself. Paradoxically, this change is very much due to the effects of normalization itself, albeit not always in foreseen or planned ways. That is not to say, as some have done (Race, 2002), that there is no longer any purpose to be served in studying normalization, and that only SRV and associated concepts should be considered. Indeed, rhizomatic proliferation is not the reason why normalization should be ignored, it is what presents public policy with the possibility of radically new options and directions.

Conflict of Interests

The author declares no conflict of interests.

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About the Author

Murray Simpson is a Reader at the School of Education and Social Work, University of Dundee in Scotland. He has published widely on the conceptual history of intellectual disability. His doctoral thesis outlined the emergence of intellectual disability as a discursive field linked to modernity. Current work includes the analysis of the location of intellectual disability within psychiatric discourse, disability and signification in cinema, and the application of Giorgio Agamben's work to disability.

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Article

Theorising Disability Care (Non-)Personalisation in European Countries: Comparing Personal Assistance Schemes in Switzerland, Germany, Sweden, and the United Kingdom

Christoph Tschanz

Division of Sociology, Social Policy and Social Work, University of Fribourg, 1700 Fribourg, Switzerland;
E-Mail: christoph.tschanz@unifr.ch

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Abstract

This article examines four European countries (Switzerland, Germany, Sweden, and the United Kingdom) with respect to their degree of disability care personalisation. The approach is embedded in a broader theoretical analysis, which in turn is inspired by the notion of bivalent social justice as presented by Nancy Fraser (2003). The theoretical argument is that claims for personal assistance are part of a broader movement toward emancipation. However, it is argued that the specific settings of welfare regimes provide structures that empower or mitigate the possible implementation of personal assistance schemes. The author argues that conservative-corporatist welfare regimes provide less-supportive opportunity structures for policy change pertaining to personal assistance than other welfare regimes. This heuristic argument is developed further by looking more closely at key figures of Sweden, Germany, and the United Kingdom as being ideal-typical welfare regime cases. Furthermore, the case of Switzerland is outlined in an in-depth manner as it seems to have conservative-corporatist characteristics regarding the organisation of disability care while simultaneously being difficult to theorise. It is the aim of this article to serve as a first heuristic undertaking for analysing the low level of disability care personalisation in certain continental European cases.

Keywords

comparative social policy; disability care; Nancy Fraser; personal assistance; personalisation; social movements; social services; social stratification; Switzerland; welfare state regimes

Issue

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1. Introduction

In recent years, some countries have de-institutionalised their residential disability care facilities. An emerging central idea is the organisation of disability care through personal assistance. This phenomenon has been most pronounced in the United States of America, Canada, Australasia, and—in the European context—Scandinavia and the United Kingdom (Mansell & Beadle-Brown, 2010, p. 104). Personal assistance is characterised by the direct funding of disabled people instead of the service provider and by the person’s freedom to choose the desired services (Ratzka, 2004, pp. 2–3). The policy change in disability services to personal assistance, instead of residential care (hereinafter, personalisation), is key to enable independent living. Although the term ‘personalisation’ is used ambiguously in the United Kingdom’s recent political practice (Beresford, 2014, pp. 5–6), for simplification purposes this article uses the term in its original meaning as direct payments for personal assistance (Slasberg & Beresford, 2015, p. 481). Personal assistance liberates the impaired person from the role of a passive care recipient and makes the person a “customer or boss” (Ratzka, 2004, p. 3).

In the extant literature, only a few studies (Aselmeier, 2008; Aselmeier & Weinbach, 2004; Baumgartner, 2009, 2008; Rimmerman, 2017; Rummery, 2011; Šiška, Beadle-Brown, Káňová, & Tøssebro, 2017; Waterplas & Samoy, 2005; Wemßen, 2014) compare disability care and living arrangements by including continental European countries. What is more, there are also reports (ANED, 2009; BSV, 2007; ENIL, 2017b; ESN, 2013; FRA, 2013) comparing countries of different sets of geographical origin. Nevertheless, to the best of my knowledge, there is a need for the proliferation of social-theory-grounded comparative insights regarding continental European countries.

Some continental European countries seem to show greater reluctance toward personalisation than Anglo-Saxon and Scandinavian countries. I address this issue through a comparative social-policy perspective by including the cases of Germany and Switzerland. In both cases, the policy change from residential care to personal assistance occurred to a more limited extent than within the European personalisation-pioneer countries—Sweden and the United Kingdom. The article drafts a theoretical framework in which all four countries can be compared. This analysis is embedded in a broader theoretical approach of welfare and disability theories and aims to make the first theoretical illustration for a possible framework for comparing these diverse cases by understanding the continental European cases particularly.

Following the introduction, the second part of this article lays out a possible understanding of personalisation, drawing on an overarching social theory framework. As Richardson and Powell (2011, p. 75) point out, the works of Marshall (1950) and Polanyi (1944/2001) are well-suited to provide an understanding of the underlying dynamics, which lead to similar events in countries that are otherwise quite dissimilar (for an application of Marshall, 1950, to personal assistance see: Christensen, Guldvik, & Larsson, 2014). These very well-known meta-theoretical argument classics are combined with the insights of Nancy Fraser (2013) as well as Fraser and colleagues (Fraser & Honneth, 2003). It is a central claim of this article that the bivalent understanding of social justice given by Nancy Fraser is highly fruitful for this theoretical undertaking. Within this understanding, a genuine disability theory (Drake, 1999) is included. The aim of the second part of this article is to provide a narrative for underlying dynamics that are similar in all four countries included in this comparison. The claims for personal assistance are seen as a typical claim of an emancipatory movement, given a special framework within the bivalent understanding of social justice.

The third part of this article has a slightly different aim—it attempts to provide an explanation for the more reluctant implementation of personal assistance in the two continental European countries in this comparison, and therefore tries to explain the dissimilarities in policy outcome, despite the similar claims of the emancipatory disability movement. These dissimilarities are explained with two theories—the power resource theory and corporatism theory—which are related, according to Ebbinghaus (2015), by being genuine conflict theories. Ebbinghaus (2015, p. 55) points out that one important contribution of the power resources theory applied to social policy is *The Three Worlds of Welfare Capitalism* by Gøsta Esping-Andersen (1990). This framework, which assumes different welfare regimes, is applied to explain dissimilarities regarding personalisation within the four compared countries and is combined with a somewhat bigger theoretical framework of disability rights. The insights about disability rights in the second part are combined with insights about welfare regimes in the third part in order to understand the dissimilarities.

In the fourth part, a more in-depth analysis is generated regarding the four countries. The United Kingdom, Sweden, and Germany are taken as ideal-typical cases for three different welfare regimes. Key figures about social spending and the amount of people receiving personal assistance are compared. Furthermore, Switzerland provides a challenge for regime theory because it shows key figures of the conservative-corporatist case in disability care contradicting its classification in welfare regime typology. Ciccia (2017) points out that one can overcome some limitations of regime theory by combining welfare regime macro theorising with an in-depth analysis of disaggregated concrete policies. This approach is conducted with the Swiss case in a single case study. Looking closer at Switzerland, one detects that the organisation and governance of social service in the disability sector is another key factor for theorising. So, following the insights of disability rights and the insights of welfare regimes, the insights of the organisation of social services completes the argumentative picture.

The fifth part is the conclusion. In the conclusion, the interplay of disability rights, welfare regime, and the organisation of social services are summarised again. The main aim of this article is to develop a heuristic approach to incorporate a continental European view within comparative studies about personalisation. This article attempts to make an illustrative argument that may be useful for more concrete empirical investigations in the future.

2. A Fraserian Perspective on Welfare and Disability Rights

2.1. The Bivalent Nature of Social Justice

The theory proposed by critical theorist Nancy Fraser can be very fruitful for disability policy analyses (for analyses in the Western capitalist context: Dodd, 2016; Knight, 2015; Mladenov, 2016; for analyses in the global context: Soldatic, 2013; Soldatic & Grech, 2014; for care policy: Swaton, 2017; for personal assistance: Mladenov, 2012; Mladenov, Owens, & Cribb, 2015; Owens, Mladenov, & Cribb, 2017). According to Fraser (2003), there are generally two dimensions of social justice: recognition justice and redistributive justice. The former corresponds to status-based disadvantage while the latter corresponds to socio-economic class hierarchy. In a plausible expression, the aim of redistributive justice is material egalitarianism while the aim of recognition justice is societal diversity (Fraser, 2003, p. 7). Redistributive justice is characterised by a more just distribution of income and wealth, while with recognition justice one does not have to pay the price of assimilation to gain equal respect (Fraser, 2003, p. 7). Applied to personalisation, this means:

> Fraser's two-dimensional framework implies that personalisation's potential for contributing toward social justice depends on its ability to bring together redistribution and recognition in ways that, first, guarantee the economic resources needed by service users for equal participation in social life (thus satisfying concerns about redistribution), and second, institutionalise patterns of cultural interpretation that equalise the status of service users in social interaction (thus satisfying the principle of recognition). (Owens et al., 2017, p. 8)

I mainly claim that one can achieve a fruitful link between welfare theory and disability theory by standing on the shoulders of Nancy Fraser, but this needs a constructive contention of two existing theories pertaining to the bivalent framework.

2.2. The Works of Marshall and Drake through the Bivalent Perspective

In the research field of the welfare state, the essay *Citizenship and Social Class* by T. H. Marshall (1950) is very well-known. Marshall (1950) analyses the attributions that individuals can receive in markets and compares these to the attributions that one can get as a citizen. He describes a partial withdrawal of individuals from purely market-shaped assignments toward a citizenship with social rights. The evolution of rights can be studied in different phases—the development of *civil rights* in the 18th century, *political rights* in the 19th century, and *social rights* in the 20th century (Marshall, 1950). On the other hand, Drake (1999) espouses a genuine disability theory and distinguishes between the different models of disability policies that can be observed in history. The *laissez-faire model* is characterised by the fact that the state plays a minimal role in the lives of disabled people (Drake, 1999, pp. 36–37). In this case, the burden of care falls on communities or on households and families (Budowski & Schief, 2017). The *piecemeal approach* to policy-making is characterised by the broad adoption and application of the medical model of disability; people are classified and categorised according to their impairments and the state responds to the needs of the disabled people (Drake, 1999, pp. 36–37). In the *maximal policy model*, the state starts to combat structural inequalities linked with disability and develops welfare responses to combat these disparities (Drake, 1999, pp. 36–37). The *social or rights-based model* is characterised by the fact that disability is more than a welfare issue (Drake, 1999, pp. 36–37). In this model, the state accepts disablement to be a product of society itself and accepts responsibility to serve all its citizens (Drake, 1999, p. 36). In this case, the social model of disability is fully accepted and serves as the main guide for disability policy-making.

I make the case that the difference between the theories of Marshall (1950) and Drake (1999) seems to be basically a difference in succession between the two different kinds of justice described by Nancy Fraser. This idea is inspired by a comparative educational idea of Richardson and Powell (2011, p. 76), which asserts that special education also did not follow a "benign linearity" directly from exclusion to inclusion (Richardson & Powell, 2011, p. 76). Rather, it started as a (distributive) support and service scheme for people who were totally excluded from public schooling while the new (recognition-oriented) societal norms of participation occurred later in its history (Richardson & Powell, 2011, p. 76). Long before the turning point to 'inclusive education', the school system was—and in many cases still is—characterised by supportive but non-inclusive 'special education' (Powell, 2006).

In this article, I make the fundamental claim that both theories (Drake, 1999; Marshall, 1950) lack the narrative of linearity within the framework of bivalent justice. As shown in Figure 1, both form a curve in which one kind of justice is first adopted more strongly, provoking later claims to fulfil the other part of social justice. One can understand the narrative of Marshall (1950) as that of an increase in recognition justice followed by an increase in redistributive justice: in the 18th and 19th centuries, the burgeoning class of male workers gained recognition and rights. This triggered claims for redistributive policies, which were applied as social rights in the 20th century. In contrast, Drake (1999) puts forth another narrative for the disability policy: first, the redistributive justice is increased with the implementation of welfare states. Thereafter, with a basic social security, impaired people started to claim more civil and political rights to increase recognition justice.

These thoughts are just heuristic and do not completely satisfy the complexity of these two theories. The period of these two theories was different, as were the respective study populations. While Marshall's analysis (1950) describes the development of working-class men over three centuries, Drake's examination (1999) focuses on disabled people and maps different possible cases of disability policy. But the understanding of a conversely arranged development curve can be used as a heuristic tool for approaching the current state of disability care organisation in different welfare regimes because it tells us something about the principal societal tensions.

2.3. Personal Assistance as a Form of Emancipation

Within the disability movement, there is the claim that while residential care residents are "well-fed and clean", there is a lack of "inedible" conditions like equality and

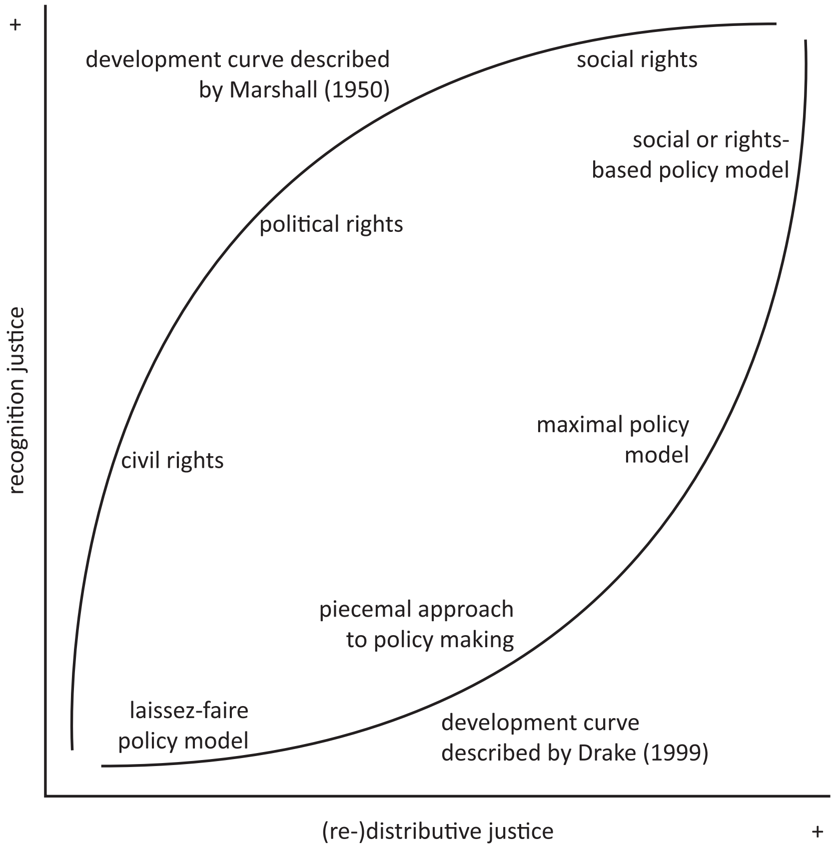

Figure 1. Synthesis of theories to explore disability rights. Source: Adaptation by author, inspired by Fraser (2003, 2013), Marshall (1950), and Drake (1999).

participation (Wehrli, 2016, p. 530). With this criticism, Peter Wehrli, one of the most influential emancipatory disability activists in Switzerland and the former leader of the Centre for Independent Living Zürich, refers to the mode of expression of the emancipatory disability movement (Krüppelbewegung) in Germany. Being "well-fed and clean [satt und sauber]" (Wehrli, 2016, p. 530) is a critical and ironic look at the condition of residential care: it points to the (over-)supply of distributive provisions like food, medical facilities, and hygienic measures, and the under-supply of recognition as an autonomous and free individual.

Drawing and expanding the work of Karl Polanyi (1944/2001), Fraser (2013) explains the current structural and ideological tensions within capitalist democracies as triple movement of marketization, social protection, and emancipation. For Fraser (2013), the new social movements established in recent decades are the main drivers of emancipation:

> Often focused more on recognition than redistribution, these movements were highly critical of the forms of social protection that were institutionalized in the welfare and development states of the post-war era. Turning a withering eye on the cultural norms encoded in social provisions, they unearthed invidious hierarchies and social exclusions. (Fraser, 2013, p. 127)

According to Dodd (2016, p. 162), the disability movement is a good example of the triple movement of emancipation because it is critical toward domination through both marketization and social protection. With the triple-movement framework, one can understand current politics in care policy (Swaton, 2017). I make the case that the claims for personal assistance (see e.g., Ratzka, 2004) are emancipatory claims for more recognition justice, pertaining to a situation in which mainly only redistribution justice is provided by the residential care institution. In other words, referring to Figure 1, the disability movement starts to act in a disability policy situation that lies in the bottom-right quadrant of the square.

3. Welfare Regime Stratification and (Non-)Personalisation

3.1. The Welfare Regime as an Opportunity Structure for Disability Movements

While the triple movement framework provides valuable insights into the politics of disability care in recent decades, it fails to explain why some countries went for a significant policy change toward personalisation while others show stability by staying stuck in the bottom-right quadrant of the square in Figure 1. I argue that the different degrees of the fulfilment of personal assistance can be explained by welfare regimes (e.g., Esping-Andersen, 1990). It is assumed that the differences of cases cannot be solely attributed to the emancipatory movement itself but rather one has to also look at the way the welfare regime was set up. Esping-Andersen (1990) provides a coherent explanation of the interwoven nature of actors, ideas, and institutions comprising a welfare regime. This work relies on the power resource theory by explaining the occurrence of a welfare regime due to class conflict (Ebbinghaus, 2015, pp. 55, 70). Ebbinghaus (2015, p. 70) points out that there are also power resource theory applications pertaining to new social movements. I follow the argument that new social movements depend on the political opportunity structures provided by the political system in which they act (see Tarrow, 2011; see for an application of this theory to disability protests: Barnartt & Scotch, 2001, chapters 6 and 7).

3.2. Welfare Regimes and (Non-)Opportunities for Claiming Personalisation Rights

One must ask whether the stratification tradition of a given welfare regime is open to the claiming of personalisation rights of the emancipatory disability movement. I argue that the class structure of a welfare regime is especially formative for the opportunity structure because both the disability movement itself and its claims for personal assistance are characterised by intersections with class. On the one hand, "people with disabilities, at least as a group, may have been the first to join the ranks of the underclass" (Charlton, 2010, p. 149) due to historical oppression. Disabled people face status-reducing effects as a group (Maschke, 2007, p. 299). On the other hand, the disability movement's claims for personal assistance resemble the middle-class claims related to self-determination and personal responsibility. Given the situation of a lack of recognition justice, the emancipatory movement claiming middle-class rights therefore strongly implies upward social status aspirations. For Esping-Andersen (1990), the regulation of social stratification is a core element of a welfare regime. According to Esping-Andersen (1990, pp. 29-30) different welfare regimes follow different patterns of how they moderate inequalities between the underclass and the middle class. Recent research shows that welfare regimes can also moderate the effects of status on subjective well-being (Samuel & Hadjar, 2016). In this line, it is assumed that they can empower or mitigate the upward social status aspirations of collective groups.

The ideal-type *social democratic regime* should provide a sufficient opportunity structure for the emancipatory disability movement. Historically, social-democratic reforms have always aimed to significantly correct the stratification produced by the market (Esping-Andersen, 1990, p. 65). The social democrats found a framework for a middle-class standardised universalism (Esping-Andersen, 1990, p. 69) aiming to provide every citizen with middle-class rights. Therefore, the idea of middle-class rights for impaired people fits well with the social-democratic ideal of common equality. Additionally, the ideal-type *liberal regime* should also provide a sufficient opportunity structure for the emancipatory disability movement. As per liberal thoughts (here, in contrast to social-democratic ideas), it is inappropriate for social policy to significantly correct stratification patterns produced by the marketplace (Esping-Andersen, 1990, p. 62). However, traditional liberal thoughts favour the provision of de jure and pre-market universalism and equality (Esping-Andersen, 1990, p. 62). Hence, the de jure provision of equal rights for disabled people should be achievable within a liberal framework (while post-market redistributive funding, in contrast to the social-democratic ideas, is ideologically under more scrutiny). Mainly in contrast to the other two regimes, the ideal-type *conservative-corporatist regime* could be an insufficient opportunity structure for the emancipatory disability movement. Stratification in conservative social policy follows the guideline of retaining traditional status relations (Esping-Andersen, 1990, p. 58). This regime is less averse to correct stratification effects caused by the market as compared to the liberal regime (Esping-Andersen, 1990). However, since the conservative-corporatist regime is guided by traditional ideas of status stability, emerging ideas of middle-class rights for impaired people are in danger of being regarded as somewhat at odds. The conservative-corporatist disability policy is characterised by "paternalism" (Waldschmidt, 2009, p. 19) and "benevolent paternalism" (Richardson & Powell, 2011, p. 184).

4. Comparing the Four Cases and a Closer Look at Switzerland

4.1. Comparing Key Figures: Switzerland as a Challenge for Regime Theory

Following Aselmeier (2008) and Aselmeier and Weinbach (2004), one can see the United Kingdom as an example of the liberal, Sweden as an example of the social democratic, and Germany as an example of the conservative-corporatist regime. Looking at recent key figures, one can detect major dissimilarities (see Table 1). The data for social spending is derived from the Organisation for Economic Cooperation and Development (OECD). Within the OECD Social Expenditure Database, there is a category called "Public Incapacity-Related Spending", with a sub-category "Benefits in Kind", which in turn has a sub-category "Residential-Care/Home-Help Services" (OECD, 2017a). This category is of great interest because personalised and residential services are measured under one umbrella. Surely, the terminology 'incapacity-related' can be criticised to follow the medical model of disability. Second, this umbrella measurement does not measure the same policies in all four countries. This umbrella category has further sub-categories, which differ in the four countries. For instance, in 2013, Switzerland spent more than two thirds of this umbrella category on

Table 1. Key figures of disability care personalisation.

Country	Welfare Regime	Social Spending on *Residential-Care/Home-Help Services*[a] as ‰ of *GDP*[b]	People with *Personal Assistance*[c] as ‰ of *Total Population*[d]
United Kingdom	liberal	2.34	3.85
Germany	conservative-corporatist	5.40	0.25
Sweden	social-democratic	16.45	2.08
Switzerland	hybrid case	4.82	0.15

Notes: Own calculations, rounded to two decimal places. Data sources: a) OECD Social Expenditure Database (OECD, 2017a); b) OECD National Accounts (OECD, 2017b); c) UK, SE & CH: ENIL Personal Assistance Tables (ENIL, 2017a), DE: Wemßen (2014, p. 8); d) Eurostat Population Database (2017). Data of a) and b) relate to the year 2013, data of c) and d) relate to a time range of 2012–2015.

"Institutions for disabled people", while in the same period, the United Kingdom spent more than three quarters for "Assistance in carrying out daily tasks: local authority personal social services" (OECD, 2017a). But the fact that personalisation is not established to the same degree in the countries included in this comparison is the main topic of this article and can be explained theoretically. Nevertheless, the umbrella category is, to the best of my knowledge, the most appropriate comparative measurement for the degree of the welfare state's redistributive social spending for disability care. The other key measurement is the proportion of people receiving personal assistance of the total population. The data comes from the Comparative Survey on Personal Assistance in Europe of ENIL for Switzerland, Sweden, and the United Kingdom, and from Wemßen (2014) for Germany.

One can see that social redistributive spending follows the welfare regime path, as expected, and follows the character of redistributive preferences described by Esping-Andersen (1990). The liberal United Kingdom has the lowest degree of redistributive spending, conservative-corporatist Germany lays in the middle, and social democratic Sweden has the highest degree of redistributive spending. In contrast, the degree of personalisation does not follow the order of having the conservative-corporatist cases between the liberal and social democratic cases. Here, the liberal United Kingdom shows the highest degree of personalisation, followed by social democratic Sweden. In contrast, the personalisation degree of conservative-corporatist Germany is much lower.

Switzerland, as such, seems to be a very interesting case because, as shown in Table 1, its degree of personalisation is even below that of Germany while the redistributive figure is somewhat below, but close to that of Germany. However, Esping-Andersen (1990) classified Switzerland as being part of the world of liberal welfare regimes. In more recent studies, Switzerland is rather classified as a hybrid case, with liberal as well as conservative characteristics (see e.g., Bonoli & Kato, 2004). Overall, Switzerland is generally hard to classify in comparative social policy (Ciccia, 2017, p. 2762). Considering its long liberal tradition of providing the male and able-bodied part of society with extended civil and political rights, the low extend of personalisation in Switzerland seems to be a challenge for the theorising of the nexus of welfare regimes and disability care personalisation. Therefore, following Ciccia (2017) the analysis of the hybrid case of Switzerland is now combined with a disaggregated in-depth policy analysis.

4.2. The Role of the Historical Institutionalization of Disability Services and Disability Organisations

Strong similarities between Switzerland and Germany are obvious by looking at the organisation of disability services. Aselmeier and Weinbach (2004) compare social services for people with intellectual disabilities in Sweden, England, and Germany. As an example of the *social democratic regime*, they see in Sweden evidence of a Universalist approach characterised by the provision of access for disabled people to common public welfare services (Aselmeier & Weinbach, 2004, p. 104). In Sweden specialised services for disabled people just played a limited role (Aselmeier & Weinbach, 2004, p. 104), thanks to access to universal welfare. Standing for the *liberal welfare regime*, in England Aselmeier and Weinbach (2004, pp. 104–105) detect Universalist community-based and rights-based policies in the hands of local social services. However, in Germany, as an example of the *conservative-corporatist model*, one can detect a historical differentiation of specialised social services for disabled people (Aselmeier & Weinbach, 2004; Rohrmann & Schädler, 2011). Charities (Wohlfahrtsverbände, private Träger) often organise these specialised social services in a corporatist tie-up with the state (Aselmeier & Weinbach, 2004, pp. 105–107). According to Aselmeier and Weinbach (2004, p. 105), the actors of these specialised disability services show a strong persistence against the implementation of more flexible services.

Münder (1998, p. 4) defines corporatism in social services as the planned and coordinated intermeshing of voluntary, as well as public, providers of social services with the aim to achieve a common goal. Corporatism within the provision of social services is linked with the welfare regime. While corporatist settings in the economy were decisive both for social democratic as for conservative-corporatist welfare regimes (Esping-

Andersen, 1990), the social democratic governance of social services follows the principle of strong public services while the Christian democratic governance follows the principle of subsidiarity (Huber & Stephens, 2000, pp. 325–326). Christian democratic governance of social services prefers the proliferation of social services by diverse stakeholders (families, clerical charities, civil society) to strong public providers with centralised governance (Huber & Stephens, 2000, pp. 325–326). In Germany, charities with historical ties to the church play an important role in the provision of social services (Münder, 1998) and especially in the provision of disability care (Rohrmann & Schädler, 2011).

Despite not being similarly influenced by Christian democratic ideas, I argue that we have major similarities in Switzerland regarding the governance of social services. We know from research about other social services that the subsidiarity-oriented governance of social services seems not to be bound to Christian democracy in Switzerland: having the Swiss Christian democrats mostly prevalent in catholic regions, Kersten (2015, chapter 6) outlines a perfect example of subsidiarity-oriented governance of victim counselling services in the protestant canton of Bern.

One can understand the corporatist setting of social services as a historically developed supplement to subsidiarity (Münder, 1998). This is especially true for disability care in Switzerland because disability care institutions were meant to supplement the caring function of the traditional family. Therefore, there are many disability organisations with a history of being established as parental organisations in Switzerland. Since Switzerland is a welfare state latecomer (Häusermann, 2010), the collective organisations of parents had to actively organize in order to convince the state to undertake some of the caring responsibility. Hence, the parents' movement was once a social movement fighting for better distributive justice for their disabled children and collectively fought for special education and residential care institutions in the 1950s, 1960s, and 1970s (see e.g., Insieme Solothurn, 2006, pp. 20–32). Therefore, both, disability organisations with a parents' movement history, as well as the specialized residential care institutions, are today important institutionalised stakeholders in Swiss disability care policy making. The existence of this kind of institutionalised stakeholders and the lack of a strong centralised governance provides a strong degree of corporatism within the field.

4.3. Limited Opportunities for Contentious Politics and Policy Change in Switzerland

The central welfare provider for disabled people in Switzerland is called Invalidenversicherung (IV). The Swiss history of the emancipatory push for personal assistance is strongly linked with the IV. After being established in 1996, the Centre for Independent Living Zürich gained momentum in 1997 with an illegal occupation of a public municipal park in Bern, right next to the BSV (the upper supervisory ministry of the IV) for several days (Wehrli, 2012). This protest provoked huge media response and support of local residents and forced the ministry to enter into dialogue with the protesters (Wehrli, 2012). In 1999, another emancipatory organisation called Fachstelle Assistenz Schweiz (FAssiS) was founded by Katharina Kanka, which organised several demonstrations and vigils (Wehrli, 2012). As result of this contentious process, the emancipatory activists were invited to a bargaining process with already institutionalised stakeholders and with policy makers, which was initiated and moderated by the BSV. On one hand, this kind of corporatist conflict moderation gave the emancipatory activist quite early access to the bargaining table. On the other hand, their abilities for further contentious actions were limited and they were forced to find coalitions with existing institutionalised stakeholders and political parties.

The likely alliance with the liberals seemed to be successful at first. Having encountered major issues in forming coalitions with the social democrats, the activists relied on the ideological support of centre-right and right-wing politicians, who openly admitted to being interested in the ability of personalisation in order to transform responsibility and reduce costs (Wehrli, 2012). This ideological support put the centre-left parties under pressure and later helped Katharina Kanka to form a multipartisan group of supporters of a personalisation reform which was also consistent with leftist and centre-left politicians. However, the then-established orthodoxy that social expenditure after the personalisation reform should be lower or at least cost-neutral was decisive for further development. In 2006, a pilot program for personal assistance was started but could not be implemented in a cost-neutral manner (Flückiger, 2011, p. 73). Mainly the non-monetized care work of relatives was, to some extent, a cost driver because this kind of work started to be monetised in the personalisation pilot (Flückiger, 2011, p. 74). The encounter with the unpaid (and mostly female) care work made it impossible for the pilot program to satisfy its orthodoxy of cost reduction. With these results, the possibility of a profound liberal reform was minimised. In addition, the simultaneous push of right-wing politicians for austerity measures within the disability pension scheme of the IV produced an additional obstacle for the activists (Wehrli, 2012). A further hindrance was the fact that within the bargaining process, the governance of disability services was further transferred to the cantonal level because of a new cantonal fiscal equalization scheme: Neuer Finanzausgleich (Flückiger, 2011, p. 45). Overall, the opportunity for a policy coalition with liberal forces for a profound policy change was restricted.

In the bargaining process, it was as much decisive that the other likely allies, the Swiss social democrats, were very sceptical about the claims of the emancipatory activists (Wehrli, 2012). The position of the social democrats in the early 2000s can be understood by looking at the corporatist settings of disability service providers and disability organisations with which they were aligned. First, the syndicates of the disability care institutions, mainly INSOS (syndicate of disability care institutions) and Curaviva (syndicate of all care institutions, including those for the elderly), are important players within the field of disability care. These syndicates have traditionally strong ties with social democratic politicians. Second, the social democrats have traditionally strong ties with institutionalised disability organisations. For the emancipatory activists, however, the influence of the historically grown parents' organisations proved to be very challenging. The parents' organisations opposed major claims of the emancipatory movement and particularly argued for the continuance and protection of institutional care in the field of intellectual disability (Wehrli, 2012). Third, a social democratic policy maker earns praise by joining the board of trustees (Stiftungsrat) of a disability care institution as an unpaid member. Being part of such a board provides the politician with an inside overview of the challenges the institutional provider faces but does not provide the politician with a critical look from the outside at the parameters being set up by institutionalisation. Fourth, the orthodoxy of cost-neutrality prevented a possible coalition with the trade unions of care workers and therefore the formation of a progressive left-leaning coalition for personal assistance. For the trade syndicate, the underlying ideas of cost reduction were deplorable and the proposed wages for personal assistants unsatisfactory (VPOD, 2009). In closing, the Swiss social democrats were, on this issue, more strongly influenced by their ties with certain actors and institutions rather than by their ideas of universalism and equality. Overall, the opportunity for policy coalitions with social democratic forces for profound policy change was restricted.

Since January 1, 2012, the IV has provided an official contribution called Assistenzbeitrag, which allows people to employ personal assistants (Egloff, 2017). In practical terms, this personal assistance system mostly includes people older than 18, with a strong focus on people with physical disabilities (Büro BASS, 2017, pp. 22, 73). This system is means-tested and has a strict and long assessment procedure one has to actively initiate. The Swiss government projects the dropouts of residential care institutions to not be greater than 10% in the long run (Egloff, 2017, pp. 133–142, see the full book for a substantive qualitative in-depth analysis regarding this phenomenon).

4.4. Stability through Institutionalised Status Inequalities: Or Bringing Regime Theory Back In

I now return to regime theory. The possibility to analyse the effects of a bundle of policies rather than single policies represents a major advance of regime theory (Ciccia, 2017, pp. 2763–2764). I argue that the emergent effect produced by the Swiss disability care policy bundle is the best explanation for the current state of art in Swiss disability care policy.

Overall, the Swiss welfare state is a historically matured multilayer system, being predominantly Bismarckian while simultaneously relying on other diversely structured social policy systems (Häusermann, 2010, pp. 211–212). The IV, which was established in 1960 has Bismarckian characteristics. The Bismarckian social legislation had a significant impact on the ideas of the Swiss political elites at the beginning of the 20th century (Lengwiler, 2007, p. 50). However, the high degree of federalism in Switzerland and social-legislation hindering referenda made the coherent implementation of the Bismarckian social legislation unachievable (Lengwiler, 2007, pp. 55–60). On the other hand, the Beveridge approach, which provided an alternative to Bismarckian social insurance, was heavily debated in 1943 in Switzerland but was rejected by important interest groups (Degen, 2006, p. 33). This led to the establishment of a mixed, but overall Bismarckian system in the golden years of welfare state expansion after the Second World War. Regarding the eligible population, the IV is not genuinely Bismarckian, although its procedures for benefit-assessments are highly influenced by Bismarckian ideas.

Bismarckian social policy was never intended to support societal change; rather, its purpose is to conserve societal class and status structures. It is aimed to protect societal groups from the market, but does not aim to significantly change the relations between societal groups. This conservative stratification tradition seems to be a stabiliser for residential care in Switzerland: the personal assistance system is mainly designed for disabled people, who already have middle-class skills and a middle-class consciousness. The assessment procedure is particularly designed for these people and does not empower other people to gain a middle-class right and middle-class skills. Therefore, the stability of the existing residential care path is maintained by institutionalised status inequalities. It provides access to personal assistance only to those people who are successful in the assessment procedure thanks to their skills of rights claiming, and simultaneously hampers the energy of the disability activists with the most potential to conduct contentious actions. Overall, the Swiss personal assistance system allows the stability of residential care facilities and simultaneously provides pacification of possible emancipatory protests.

5. Conclusion

Within this heuristic undertaking, we have seen that the analysis of bivalent social justice is helpful for theorising personalisation. The evolvement of disability rights following a path of nonlinear distribution of both kinds of justice led to the claim for more recognition justice through emancipatory movements (Fraser, 2013). According to Fraser (2013), emancipatory movements are aiming to overcome oppressive social protection and they can possibly ally with marketization forces or with (new) forces of social protection. However, this article analysed a case in which none of these possible alliances occurred profoundly. I argued that conservative-corporatist disability care cases have a strong institutionalisation of oppressive social protection and benevolent paternalism. We verified that in the case of Switzerland, this setting could not (yet) be profoundly transformed by forces of emancipation. In this respect, the case of Switzerland did prove to be illuminating. Switzerland seems to resemble conservative-corporatist cases in the field of disability care. Therefore, the Swiss case provides some insights on the process of limited personalisation of disability care in continental European countries. Furthermore, the analysis of the characteristics of Switzerland in this policy field is a contribution to welfare regime research.

Nonetheless, some limitations have to be mentioned as well. First, this analysis lacks the potential to provide general evidence for all continental European countries. Instead, it only provides evidence that the developments in Switzerland have been shaped by continental European conservative-corporatist specificities. Second, the influence of the welfare regime as an opportunity structure may decrease in the future because of transnationalisation (Sturm, Waldschmidt, Karačić, & Dins, 2017). Article 19 of the UN Convention on the Rights of Persons with Disabilities will particularly provide an important tool for political actors who aim to increase independent living. Third, this analysis is only a heuristic approach. Further theoretical and empirical insights of personalisation in continental European countries would be highly desirable.

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Conflict of Interest

The author declares no conflict of interest.

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About the Author

Christoph Tschanz is a PhD candidate at the University of Fribourg, Switzerland, where he works at the Division of Sociology, Social Policy, and Social Work funded by a Doc.CH grant provided by the SNSF. Part of this analysis was conducted during a stay as visiting PhD candidate at the Institute of Education & Society (InES), at the University of Luxembourg. He is specialising in comparative perspectives on European disability policies. Christoph holds a Master's degree in Sociology and a Bachelor's degree in Remedial Education and Social Pedagogy, both from the University of Fribourg. He previously worked as a social pedagogue in a supported employment program for people with an autism-spectrum condition.

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Workplace Adaptations Promoting the Inclusion of Persons with Disabilities in Mainstream Employment: A Case-Study on Employers' Responses in Norway

Yuliya Kuznetsova [1,]* and João Paulo Cerdeira Bento [2]

[1] NOVA Norwegian Social Research, Oslo Metropolitan University, 0130 Oslo, Norway; E-Mail: ykuznets2011@gmail.com
[2] Department of Economics, Management, Industrial Engineering and Tourism, University of Aveiro, 3810–193 Aveiro, Portugal; E-Mail: jpbento@ua.pt

* Corresponding author

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Abstract
This case-study conducted in Norway investigates employers' responses to policy measures implemented throughout 2006–2015 and aimed at promoting the inclusion of persons with disabilities (PwDs) into mainstream employment by providing workplace adaptations. For this purpose, we apply a multi-method approach by combining in-depth qualitative interviews conducted with the managers at two large private companies in Norway and quantitative shift-share analysis performed on the Norwegian Disabled People LFS data. While the shift-share analysis has demonstrated positive effects in the employment of PwDs at the national level and in providing adaptations at work during 2011–2015 for 'changes of working time', 'need for one or more adaptations' and 'changes of work tasks', 'physical adaptations' remain negative. The qualitative interviews report that 'flexibility' or 'changes of working time' is the main workplace adaptation the managers at both companies provide to own employees who return to work after acquiring a disability or having a long-term illness. Both companies demonstrate high conformity to accessibility standards, however, the provision of workplace adaptations to PwDs without prior work experience remains limited or absent despite the disability policy measures in Norway in that period and the companies' commitment to inclusion.

Keywords
accessibility; anti-discrimination; company; disability; employment; legislation; workplace adaptations

Issue
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1. Introduction

Persons with disabilities (PwDs) have long been excluded from mainstream employment due to multiple discriminatory barriers (Hogan, Kyaw-Myint, Harris, & Denronden, 2012; Vornholt, Uitdewilligen, & Nijhuis, 2013). The 'social model' of disability since its adoption in the 1970s has framed a new disability policy paradigm aimed at removing disabling societal barriers by promoting non-discrimination, equal treatment, and accessible environments (Lawson & Priestley, 2017). The EU Employment Equality Framework Directive (Council Directive 2000/78/EC, 2000) and the UN Convention on the Rights of Persons with Disabilities (UN CRPD) impose on employers the duty to provide 'reasonable accommodation' or 'appropriate modification, adaptations and/or adjustments' to enable PwDs 'to have access to, participate in, or advance in employment…and in work environment that is open, inclusive and accessible'. This duty is required to be transposed into national law and is considered a 'substantive equality measure having the potential to result in fundamental structural transformations' (Kayess & French, 2008, p. 9).

First adopted in the US and the UK, the anti-discrimination legislation has gradually evolved in the majority of European countries (Waddington, 2013). Nevertheless, alongside the anti-discrimination legislation, many EU countries continue to operate the quota system that puts employers of a certain size and in both the private and public sectors, under a strict obligation to employ a fixed percentage of PwDs. Compliance, however, remains relatively low (Fuchs, 2014; Moody et al., 2016; OECD, 2003). Instead, the 'reasonable accommodation duty' introduced by anti-discrimination legislation does not specify or limit the range of accommodations (Balser, 2007) and is believed to ensure PwDs equal access to mainstream employment (Hvinden, 2013; Schur et al., 2014). Furthermore, employers are expected to take action only if 'accommodation' does not lead to excessive costs or turns into 'a disproportionate burden' (Waddington, 2008).

Nevertheless, employers often express concerns about adaptation costs preventing them from hiring and/or retaining PwDs (Erickson, Schrader, Bruyère, VanLooy, & Matteson, 2014; Henry, Petkauskos, Stanislawzyk, & Vogt, 2014; Hernandez et al., 2009; Vornholt et al., 2013). Indeed, provision of workplace adaptations depends on PwDs' needs, and may vary from alterations/adaptations of buildings and facilities to purchase of necessary assistive technology/equipment and/or require modifications of work tasks/schedules (Balser, 2007; Hernandez et al., 2009; Nevala, Pehkonen, Koskela, Ruusuvuori, & Anttila, 2015). In practice, workplace adaptations may involve limited costs and are beneficial both to employers and PwDs (Hartnett, Stuart, Thurman, Loy, & Batiste, 2011; Nevala et al., 2015; Schartz, Hendricks, & Blanck, 2006; Schur et al., 2014). In particular, providing workplace flexibility by modifying job tasks, work scheduling and/or location appears not to be costly, though it does require on-going effort (Padkapayeva et al., 2016). Public financial support is available to cover a part of adaptation costs for employers (Hvinden, 2013). Still, employers may demonstrate prejudices and stereotypes against persons with certain types of disabilities, in particular, psychiatric disabilities, learning disabilities and/or mental illnesses, who would require greater supervision and attention (Ju, Roberts, & Zhang, 2013; McDowell & Fossey, 2015; Zissi, Rontos, Papageorgiou, Pierrakou, & Chtouris, 2007).

Prior research has argued that concerns about costs are mainly expressed by small and medium-sized companies, whereas large companies have sufficient financial and human resources and policies in place, as well as an inclusive organisational culture, that allow them to provide the necessary workplace adaptations (Erickson et al., 2014; Hernandez et al., 2009; Ju et al., 2013; Morgan & Melina, 2005; Schartz et al., 2006). Other researchers, on the contrary, have argued that large companies' public commitments to non-discrimination, equality and accessibility standards, positive attitudes and explicit global inclusive strategies may not always translate into positive hiring decisions for PwDs (Ball, Monaco, Schmeling, Helen, & Blanck, 2005; Ju et al., 2013). Still, despite their size, large companies may also express concerns about costs and state their need for additional support to include PwDs (Henry et al., 2014; Hernandez et al., 2009; Kaye, Jans, & Jones, 2011). Despite best practices of disability inclusion (e.g., ILO, 2010), and limited case-studies on accessibility (e.g., Sandler & Blanck, 2005), how large companies respond to disability policy measures and ensure the inclusion and adaptations for PwDs, remains under researched.

Unlike the rest of Europe, the Nordic countries have traditionally been portrayed as generous welfare states, where high employment rates, equality standards, and employers' corporate social responsibility and contribution to social inclusion are well-established (Halvorsen, Hvinden, & Schøyen, 2015; Mandal & Ose, 2015; OECD, 2017). In Nordic countries, a 'relational model of disability' that views disability as 'relative to the environment' has been prevalent in public policy since the 1970s (Tøssebro, 2004, p. 4). This understanding has been less radical in removing existing societal barriers than a 'social model' of disability (Halvorsen & Hvinden, 2009; Tøssebro, 2016). Nordic countries have not implemented quotas in mainstream employment, but have prioritised rehabilitation, vocational training, job placement services (e.g. work training in regular workplaces) and, in some cases, publicly subsidised and sheltered jobs at private companies, and provided considerable public support to employers and to PwDs (Duell, Singh, & Tergeist, 2009; Halvorsen & Hvinden, 2009). However, despite visible similarities, practical responses and newly adopted social regulatory policy measures to achieve the highest employment rates and make employers responsible differ at the national levels (Halvorsen et al., 2015). Therefore, Tøssebro (2016) appoints to the need for more research on the effects that current disability social regulation policies in Nordic countries, particularly in Norway, have on the workplace adaptations provided to PwDs.

Given this background, the present case-study has been conducted in Norway to explore how policy measures implemented over the period 2006–2015 have impacted employers' responses to ensuring the inclusion of PwDs in mainstream employment by providing adaptations at work.

2. Policy Measures Promoting Employers' Responsibility to PwDs in Norway

In Norway, the employers' obligation to ensure proper working conditions for employees has been primarily regulated by The Work Environment Act (*Arbeidsmiljøloven*) since 1977 (WEA, last amended in 2015). However, the WEA did not provide any protection for PwDs against discrimination until 2004, when, following the EU Directive (2000/78/EC), it incorporated stricter measures to oblige employers to adapt the workplace for PwDs. These were mainly aimed at their own employees (Hvinden, 2004; Vedeler, 2014). The most recent WEA amendments of 2015 concerned temporary employment and working hours that were argued to ensure more flexibility and increase the chances for PwDs to enter working life (Dahl & Lorentzen, 2017).

Furthermore, based on its corporative tradition, Norway has given high priority to promoting employers' voluntary commitment. *A More Inclusive Working Life Agreement* (hereafter, 'IA Agreement'), in effect since 2001, aims to increase employers' responsibility (both in the public and private sectors) for own employees and for the unemployed vulnerable groups (Dahl & Lorentzen, 2017; Mandal & Ose, 2015). This is a voluntary tripartite agreement signed between the three social partners: the government (Norwegian Welfare Directorate—NAV), the employers' organisations and the social partners (trade/labour unions). The IA Agreement commits employers to implementing three goals: 1) reducing sickness absence and facilitate working conditions for [own] employees with special needs, 2) promoting employment of people with reduced functional abilities recommended by NAV, and 3) retaining ageing workers. The regional NAV Working Life Centres provide various types of support including financial assistance that covers workplace adaptation costs, advisory support, follow up, etc. (Mandal & Ose, 2015). The IA Agreement has been renewed several times, the latest for the period of 2014–2018, with the majority of medium and large private companies having signed it (Olsen, Svendal, & Amundsen, 2005; Ose, Brattlid, & Slettebak, 2013). While the number of PwDs reported by the IA enterprises has increased, slightly more in the public sector than in the private, challenges have been reported with regard to facilitating the workplace for PwDs with chronic illnesses, musculoskeletal disorders and mental disorders (Hansen & Haualand, 2012; Svalund & Hansen, 2013). Additionally, the Jobs Strategy for PwDs (2011–13) accompanies the IA Agreement and aims to promote work-experience programmes specifically for young PwDs, mainly in the public sector.

Influenced by the international and European anti-discrimination and equality laws, Norway also adopted The Anti-Discrimination and Accessibility Act (ADAA) in 2009 (amended in 2013) (Halvorsen & Hvinden, 2009; Tøssebro, 2016). The aim of the ADAA is to intensify the duty on public employers and private-sector employers with more than 50 employees to ensure non-discrimination and to provide reasonable accommodation for PwDs outside the workplace, and to introduce 'the universal design' standards. Small enterprises remain exempt from this obligation (Svalund & Hansen, 2013). The ADAA prepared the ground for Norway's ratification of the UNCRPD in 2013 (Strand, 2014). However, simple and inexpensive workplace adaptations prevail (Tøssebro, 2016), and some scholars argue that enforcement of the 'accommodation' duty in Norway remains relatively weak (Halvorsen & Hvinden, 2014).

3. Methods

The case-study method allows to study 'events within their real-life context' (Yin, 2009). However, to understand the full complexities of national policies on workplace adaptations, Vedeler and Schreuer (2011) recommend applying a multi-method approach. This case-study adopts an inductive qualitative approach (Morse, 2003, p. 199) and uses two different data sources gathered separately: in-depth qualitative interviews and a quantitative analysis performed on national statistical data. The qualitative component allowed us to collect in-depth information on companies' practices regarding the inclusion of PwDs. A quantitative component was sequentially added to support the core qualitative approach, and to compare the results obtained from the analysis of the companies.

For collecting qualitative data, the objective was to select 'successful or positive cases' where the outcome of interest occurs (Mahoney & Goertz, 2006). The main selection criteria, therefore, concerned large private companies (with 250+ employees) that operate in Norway and have a commitment to include PwDs among their workforce. To simplify access to potential companies, the first author asked for an 'endorsement from a higher authority' (Flick, 2006, p. 116)—recommendations from the employers' association and a trade union in Norway. In total, out of the 11 large companies recommended, eight corresponding to the selection criteria were selected for further contact. Only two, however, agreed to participate: one multinational consulting company represented in Norway and headquartered in the US (C1), and one Norwegian multinational engineering company represented in approximately 20 countries worldwide (C2). The other companies declined for different reasons, such as already taking part in similar research, insufficient time to participate in an in-depth study or having no PwDs among their employees.

The open-ended and semi-structured interviews (with an average duration of 60 minutes) were conducted in English by the first author between August and November 2012 with the senior and middle-level managers at the premises of the two companies. The HR managers became the 'key contacts' who provided information and access to other interviewees. Each interviewee signed the individual consent form which stipulated that the names of the companies and personal data of the interviewees would not be disclosed. For this study, 12 interviews are presented:

- Country manager, HR leader, HR/diversity manager, HR senior analyst, supervisor, Consultant/Project leader at C1; and
- Diversity manager, HR/inclusion manager, HR manager, HR administrative manager, HSE manager, Department manager/Supervisor at C2.

The interviews were analysed using the inductive thematic analysis with the help of the qualitative software Nvivo (Bazeley & Jackson, 2013). The main goal was to study the 'phenomenon' through the personal experiences of 'insiders' and not to collect data based on a predefined hypothesis (Yin, 2009).

The data for the quantitative analysis were collected and analysed by the second author in 2016 from the Norwegian Disabled People Labour Force Survey (LFS) for the period 2006–2015. These data cover PwDs aged 15–66, their labour force status, and work adaptations before and after job start (SSB, 2016). LFS defines 'disability' in terms of 'a difficulty to perform any daily activity, due to a longstanding health problem', and is based on whether survey respondents perceive themselves as having a disability (or a 'functional impairment' in Norwegian translation). To perform the shift-share analysis, the data set was divided into 5-year intervals taking into account policy measures that promote the inclusion of PwDs in each period: 1) 2006–2010 covering the IA Agreement and the WEA provisions; and 2) 2011–2015 including the ADAA together with other ongoing policy measures. The results were verified and discussed between the authors, and then compared to the results of the qualitative interviews.

4. Results

4.1. Results of the Interview Analysis

The results of the qualitative interviews demonstrate the experiences of the responsible managers at two large companies in Norway with ensuring the inclusion of PwDs in mainstream employment, providing adaptations at work, as well as their awareness of the evolving disability policy measures. The thematic analysis of the interviews revealed 'workplace adaptations' to be one of the main overarching theme consisting of four sub-themes: 'providing adaptations in response to policy measures'; 'changes of work tasks'; 'changes of working time'; and 'physical adaptations'.

4.1.1. Providing Adaptations in Response to Policy Measures

The interviewees at both companies demonstrated general awareness about non-discrimination, equality and accessibility standards. However, they associated it with neither the UN CRPD nor with the anti-discrimination law. Neither company had a corporate policy to specifically address non-discrimination, equal treatment and/or accommodation of PwDs since their global corporate policies already included these principles. The Country manager at C1 mentioned "The Global Corporate Guide on inclusive and accessible workplace", but the HR managers in the Norwegian office did not consider it applicable in their local practices. The interviewees from C2 mentioned corporate HSE policy as the main policy regulating workplace adaptations for employees.

The interviewees at both companies expressed high awareness of accessibility norms in relation to buildings/facilities, though they did not relate these explicitly to anti-discrimination legislation:

> Every building [constructed] after 2010 should have an entrance adapted for wheelchair users. (HR senior analyst, C1)

> There are requirements from the government for new buildings. (HR/diversity manager, C1)

> We meet all necessary building accessibility [requirements] and have no problem in having PwDs. (HR manager, C2)

Instead, the interviewees at C1 expressed concerns about the accessibility of their clients' premises, especially if employees with disabilities were supposed to work on projects:

> There will be no problem in our building if you are on a wheelchair, though it might be heavy to work at a client's site. (Consultant/Project leader)

> In that [client's] place it may not be possible to come in a wheelchair. (HR leader)

At the local office of C2, the interviewees reported problems connected with local transportation. However, the corporate office provided a "free bus to take employees to work and back home" (Diversity manager).

The interviewees at both companies, however, had not experienced recruiting PwDs who would require substantial workplace adaptations. The HR managers at both companies reported that they "never had job applicants in wheelchairs" and did not specifically set out to recruit PwDs. Consequently, they mentioned that no adaptations were provided during recruitment, however, assured to provide it, whenever required, in accordance with non-discrimination and equality standards. The interviewees at C2 considered it would be impossible to hire PwDs for offshore posts, contrary to office-related positions, because of their strict health requirements.

Furthermore, both companies joined the IA Agreement in 2001 (with the exception of the C2's corporate office). The interviewees, however, did not report providing PwDs with work training opportunities at their companies. Instead, they favoured mainly older employees and those returning after long-term sicknesses/illnesses, who did not require workplace adaptations. Mandal and Ose (2015), Vedeler and Schreuer (2011) and Ose, Brattlid and Slettebak (2013) argued that the public sector in Norway made higher commitments to adapting working conditions and recruiting PwDs than the private sector, therefore PwDs mainly applied for positions in the public sector. The interviewees themselves mentioned that other companies (also in the public sector) “are doing better than them” in including PwDs.

4.1.2. Changes of Work Tasks

According to Nevala et al. (2015) and Vedeler and Schreuer (2011), modifying duties for employees who cannot perform former job functions because of disability is important. The interviewees at both companies, however, did not report making significant changes in work tasks for PwDs. At C1, the supervisor told of one employee who they retained after acquiring a disability (not work-related) and who performed the same work tasks because he “was a really good specialist”. At C2, the HR managers reported that they could facilitate “different kinds of things for PwDs—even substitute some work tasks”, however, all work adaptations needed to be discussed with managers/supervisors responsible. The interviewees also mentioned that PwDs might have “hidden or invisible” impairments they could not disclose, as well as their needs for adaptations, when applying for jobs. Prior research confirmed that PwDs did not disclose their disabilities and concealed invisible impairments because of existing prejudices and fear of discrimination (Foster & Wass, 2012).

The managers at both companies reported higher chances of changing work tasks for their own employees after sicknesses or long-term illnesses/disabilities, as required by the WEA and corporate HSE policy. For instance, at C2, offshore employees who got injured and could not continue working offshore were relocated, requalified and given other office-related duties. However, the interviewees considered to adapt the work tasks for “new PwDs”, especially those with intellectual impairments, very challenging:

> We select candidates for work training based on their prior experience to perform certain work tasks. (HR/diversity manager; HR leader, C1)
>
> It is difficult to arrange work tasks for persons with mental illnesses, that goes beyond just providing a new chair or hoping a person gets better. (HR/inclusion manager, C2)
>
> It is easier if a person is disabled in some physical way, like having an arm that does not work, because we work in teams and it would be a problem if somebody cannot interact with others. (HR administrative manager, C2)
>
> Our company is not a kindergarten [that has] to arrange the work tasks specifically for these people. (Department manager/Supervisor, C2)

These findings show the importance of the managers and supervisors’ attitudes towards PwDs and how this affects their handling of accommodation requests, which is in line with the findings of Hogan et al. (2012), and and Schur et al. (2014). Still, at both companies, the main responsibility for the inclusion of PwDs was principally on the HR managers, with the supervisors showing reluctance to engage.

4.1.3. Changes of Working Time

Prior research has found that changes in work schedules is the most common workplace adaptation measure provided by employers (Padkapayeva et al., 2016; Schur et al., 2014). Likewise, the interviewees in this study confirmed that the most frequently provided workplace adaptation was changes of working time—flexible or reduced working hours, working from home and part-time positions. “I was given flexibility to work from anywhere….If I had to work full-time, I would never make it”, reported HR/diversity manager at C1 who experienced coming back to work after long-term sick leave. The supervisor at C1 who likewise came back after a long-term sick leave also initially worked only a 50% schedule. He also mentioned that an employee with acquired disability after retention “worked on reduced time schedule, did not work overtime, and did not perform demanding work”. The Consultant/Project lead remembered working on a project with a person with a hearing difficulty, who “was given flexibility and could have longer breaks and/or did not work in the afternoons”. The HR interviewees from C2 mentioned that they “were extremely flexible, especially, if somebody got injured”. The HR managers mentioned that employees on sick leave could have remote access to work from home. The Department manager added that employees were generally allowed to stay at home if they had children or for some other valid reason, because he considered important “taking care of own employees and providing them with flexibility”.

All these measures, however, were targeting own employees, who got sick or returned to work after sick leave. Nothing was mentioned regarding newly hired PwDs and especially those with congenital disabilities. The interviewees at C1 mentioned that it might be more difficult to “sell consultants on a reduced work schedule less than 80%” or “substitute a person for a long time”. These findings confirm prior research (Halvorsen & Hvinden, 2009, 2014) that considered employers in Norway more likely to arrange the necessary provision for their own employees than for PwDs without any employment experience. Despite McDowell and Fossey (2015) showing that flexible scheduling/reduced hours could also be an important type of workplace adjustment for employees with mental illnesses, the interviewees did not report any accommodations provided for them, instead showing prejudices against their being hired or accepted for work training.

4.1.4. Physical Adaptations of Workplace

Padkapayeva et al. (2016) argued that modifying workstations to meet the needs of PwDs is also an important workplace adaptation measure besides arranging accessibility of the building/facilities. Regarding accessibility of buildings/facilities, the interviewees considered their companies having all necessary conditions for disabled employees:

> If we had an applicant in a wheelchair, it would not be a problem as this building is accessible. (HR leader, C1)
>
> We have all necessary accessible facilities, especially for employees in wheelchairs and/or with audio-visual disabilities. (HR manager, C2)
>
> Easily accessible premises. (Diversity manager, C2)
>
> Adapted elevators and toilets. (HSE manager, C2)
>
> Renovated building and accessible parking spaces. (HR/inclusion manager, C2)

However, the interviewees at both companies regarded the corporate building/office as more suitable for PwDs due to its more accessible working conditions and the prevalence of office-related positions.

Regarding workplace modifications, the interviewees at both companies mentioned changing computer desks, providing special chairs or changing the workplace location for own employees. At C1, the HR interviewees provided "special phones for an employee with a hearing disability" and "reading glasses for an employee who had acquired disability". The Consultant/Project leader also reported accommodating an employee with a hearing difficulty by changing her table position. The supervisor mentioned providing "a predictable working environment with less noise" for an employee with acquired disability "to work without disturbances". However, these adaptations neither involved high costs to the companies nor financial support from NAV. Only one employee with acquired disability received a subsidy from NAV that partially covered his travel costs to and from work, which he had requested himself.

The interviewees at C2 did not experience providing as many workplace adaptations as at C1. Both corporate and local offices of C2 had occupational physiotherapists, who regularly evaluated employees' adaptation needs, and HSE managers, who supervised employees' working conditions, as required by the HSE and WEA regulations. However, the interviewees at C2 stressed that it would still be easier for them to accommodate "a person who is disabled in some physical way than a person with social or intellectual problems". The interviewees from C2 did not request any financial support from NAV for providing physical adaptations at the workplace since they considered it "a time-consuming and bureaucratic process". These findings are in accordance with Vedeler and Schreuer (2011) who confirmed that the process of getting public support and funding was complicated, and argued that providing workplace adaptations instead greatly depended on managers' willingness and initiatives.

4.2. Results of Shift-Share Analysis

The quantitative analysis has targeted to explore the national employment growth of PwDs and adaptations provided in Norway between 2006–2010 and 2011–2015. For this purpose, an enhanced version of the shift-share method (Artige & van Neuss, 2014; Gialis & Tsampra, 2015) was applied that allowed to decompose data into 'subsets' and 'subgroups' to assess changes in employment of PwDs and workplace adaptation measures. The 'subsets' cover PwDs 'whose jobs have not been adapted' and those 'whose jobs have been adapted'. The 'subgroups' contain the types of adaptations defined by Statistics Norway (see Table 1). This method computes a combination of three shift-share effects. The first comprises the '*national growth effect*' (NE) that explains how much of the adaptations subgroup's growth in employment of PwDs may be attributed to the overall growth of employment of PwDs at the national level. The second is the '*subset growth effect*' (SE) that represents the adaptations subgroup's growth in employment of PwDs that is due to the employment growth in one of the two subsets at the national level. The third is the '*subgroup growth effect*' in a subset, which is also known as the '*competitive effect*' (CE). This indicates how much change in a subset may be explained by particular advantages that the subgroup possesses. A positive CE for an adaptation subgroup in a subset indicates that the subgroup is outperforming national trends. A negative CE effect indicates that a subgroup in a subset is underperforming compared to national trends. This method requires that the sum of all the shift-share components for any given subgroup must equal the total growth rate of PwDs employment for the same subgroup in each period.

Positive changes are reported by NE in both periods. The total growth rate of PwDs was higher in 2011–2015 than in 2006–2010, 18.8% and 4.3% respectively (see Table 1). The growth rate of SE in the subgroup 'need for one or more adaptations' switched from a negative value to a positive one between the two periods, arguably demonstrating the increase of employed PwD and of provided adaptations. Positive growth rates of CE were observed in the second period for 'need for one or more adaptations', 'changes of work tasks' and 'changes of working time'. The CE effect for subgroup 'physical adaptations of workplace' remains with a negative growth rate, although it was smaller in magnitude compared to the first period. The remaining two subgroups, 'no need for adaptation' and 'changes of work tasks', show decreasing growth rates of CE from the first period to the second. The subgroup 'changes of working time' shows

Table 1. Results of shift-share analysis.

		Subsets						Growth rates (%)							
		Employees with disability whose jobs have not been adapted (%)		Employees with disability whose jobs have been adapted (%)		Employees with disabilities, total (%)		2006–2010				2011–2015			
	Types of adaptation	2006–2010	2011–2015	2006–2010	2011–2015	2006–2010	2011–2015	NE	SE	CE	Total	NE	SE	CE	Total
Subgroups	No need for adaptation	17.7	21.4	12.5	13.5	14,8	17.0	4.3	−0.3	10.8	14.8	18.8	−0.7	−1.1	17.0
	Need for one or more adaptations	−16.7	13.3	−8.7	31.6	−12.8	23.5	4.3	−0.2	−16.9	−12.8	18.8	0.9	3.8	23.5
	Changes of work tasks	0.1	0.0	37.5	42.9	12.0	16.7	4.3	−6.8	14.5	12.0	18.8	−4.9	2.8	16.7
	Changes of working time	−8.3	33.3	−22.2	66.7	−14.3	50.0	4.3	1.1	−19.7	−14.3	18.8	−0.2	31.4	50.0
	Physical adaptations of workplace	−8.3	−12.5	−27.3	22.2	−17.4	5.9	4.3	0.4	−22.1	−17.4	18.8	0.8	−13.7	5.9
	Total	3.9	16.4	4.6	20.8	4.3	18.8								

Note: Calculations performed on Statistics Norway data (SSB, 2016).

the highest positive growth rate of CE between 2006–2010 and 2011–2015, while ‘physical adaptations of workplace’ presents the highest negative value. The above-mentioned growth effects are presented graphically in Figure 1. In conclusion, the shift-share analysis reveals that CE demonstrates stronger effects than the other effects (NE and SE). This is particularly visible in the second period showing that ‘changes of working time’, ‘need for one or more adaptations’ and ‘changes of work tasks’ have been given more importance by the Norwegian employers. The CE of ‘no need for adaptation’ decreased from the first to the second period, compared to ‘need for one of more adaptations’, suggesting employers’ greater responsiveness towards PwDs who need adaptations.

5. Concluding Discussion

This case-study has applied a multi-method approach based on qualitative interviews at two large companies and quantitative shift-share analysis on the LFS data on Norway to explore employers’ responses to policy measures in ensuring the inclusion of PwDs in mainstream employment by providing adaptations at work.

The shift-share results demonstrated considerable growth in employment of PwDs and in provision of adaptations at work at the national level from the first period (2006–2010) to the second (2011–2015). From these findings, we may infer that during the last period, when all policy measures—the anti-discrimination legislation, the IA Agreement and the labour law (WEA), are in place, employers have become more responsive to including PwDs in mainstream employment and providing workplace adaptations. In contrast, from the interviewees’ responses at two large companies, there was no indication that workplace adaptations were made for PwDs without prior work experience, because there were no such job applicants or trainees. Despite the high accessibility standards of the companies’ buildings and facili-

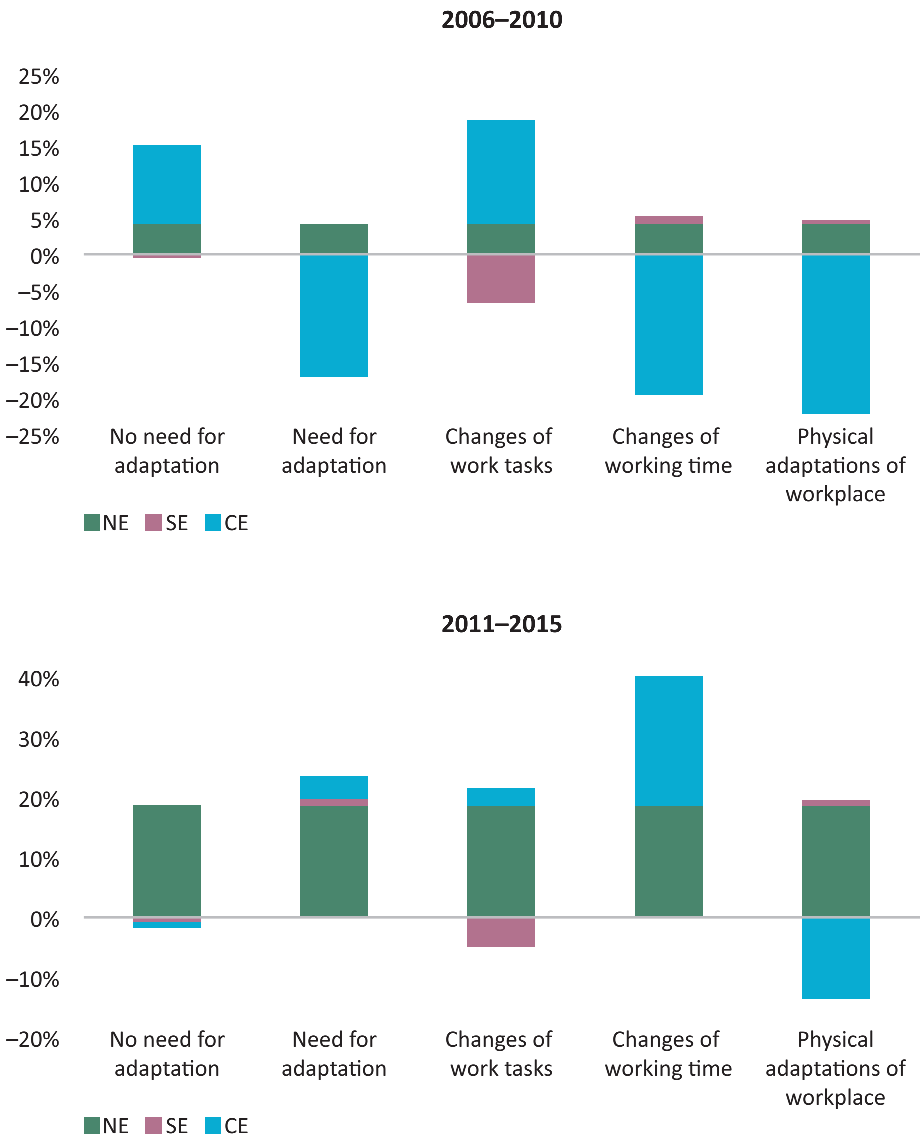

Figure 1. Graph of shift-share analysis.

ties, the corporate policies only broadly addressed non-discrimination and equality obligations; they did not refer specifically to anti-discrimination legislation, and accessibility standards were not applied during the recruitment process. Likewise, Halvorsen and Hvinden (2014), argued that Norwegian employers were often willing to accommodate the needs of employees yet claimed that they did not receive applications from persons who explicitly state that they are disabled.

Regarding specific types of provided adaptations, the shift-share analysis highlighted important changes for 'changes of working time', 'need for one or more adaptations' and 'changes of work tasks'. The qualitative interviews, likewise, demonstrated that workplace adaptations such as changes of work tasks and working time were those most often provided, though mainly to own employees who acquired disabilities or returned to work after long-term illnesses. These responses also referred to the companies' conformity to the national labour legislation—WEA, to the IA Agreement, and to the corporate HSE policy—all requiring employers to improve working conditions for own employees. This finding, however, is not new, as prior research has indicated the prevalence of retaining current employees and reducing their sick leave rather than increasing the employment prospects of PwDs outside the labour market (Dahl & Lorentzen, 2017; Halvorsen & Hvinden, 2014).

The result of the shift-share analysis for 'changes of working time' in 2011–2015 may indicate the increased importance of 'flexibility'. This may be associated with temporary employment, where many PwDs are employed, according to Ekberg et al. (2016). This finding may likewise reflect the prevalence of part-time work among PwDs in Norway, which might have also increased due to recent changes in WEA, as reported by Dahl and Lorentzen (2017). However, the interviewees did not report any PwDs employed part-time or on a reduced work schedule and, in fact, rejected the possibility of their being employed for part-time positions. The flexible arrangements provided, mainly concerned own employees, though this did not bring more PwDs into mainstream employment, especially those with mental (or more severe) impairments, who would require flexible scheduling and support (McDowell & Fossey, 2015). With regard to 'physical adaptations', the shift-share result shows this to be lagging behind. Both companies reported ensuring accessible buildings and/or facilities but did not provide more substantial workplace adaptations because there were no PwDs who would require these adaptations. As argued by Erickson et al. (2014), job applicants may be unaware that they can request accommodations. However, the prevalence of workplace adaptations provided mainly for persons with physical disabilities arguably indicates a lack of prior experience in providing adaptations for employees with other types of impairments and reveals the prejudices the managers might have against PwDs with more severe disabilities.

While we could not draw any conclusions from the shift-share analysis regarding costs involved in workplace adaptations, the qualitative interviews revealed that the responsible managers did not request financial support from NAV. This was because many of provided adaptations were not costly and the interviewees did not report having PwDs among their trainees (or employees) who would require substantial workplace adaptations that might result in excessive costs. This finding is in line with Ose et al. (2013) and Dahl and Lorentzen (2017) who argued that even though employers were eligible for financial support for reasonable accommodation, recruiting PwDs had been given lower priority than reducing sick-leave absence and early retirement from working life of own employees in Norway. Halvorsen and Hvinden (2014) confirmed that the burdens for co-workers appeared to be of larger concern than the costs to accommodate PwDs in the workplace. In line with prior research (Ose et al., 2013; Svalund & Hansen, 2013), the major funding was therefore provided to public companies in Norway that demonstrated greater awareness and involvement in including PwDs.

In conclusion, it can be stated that despite the anti-discrimination legislation obligations and the 'reasonable accommodation duty' aimed at promoting the inclusion of PwDs in mainstream employment, provided adaptations may, in practice, depend more on the HR managers' or supervisors' attitudes and decisions, and on the companies' policies than on associated costs. While the managers do not disregard the importance of the non-discrimination, equal treatment and accessibility standards mentioned in the corporate policies, this has so far not resulted in their active inclusion of PwDs among the workforce. And, whereas the responsible managers may associate providing workplace adaptations mainly with employees with mobility or sensory disabilities, the provision of more substantial adaptations to persons with other types of impairments is still limited, as also demonstrated by the two companies in this case-study. The results obtained, therefore, reveal a discrepancy between the employment changes in the shift-share data of PwDs and the responses from the interviews that show the companies' practices in this respect.

This case-study has significant limitations. From these findings, it is not possible to make generalised conclusions regarding type of industry and/or disability, and the practices of other large companies in Norway or any other countries. The interviews were conducted predominantly with managers responsible for policy implementation, which could potentially result in them controlling the obtained data and reflect their own perspectives. Moreover, given the data limitations, the shift-share analysis, applied here to provide additional insights into the research question, does not claim any causal relationship between the adaptations provided and employment of PwDs. With this in mind, future research may consider examining in more detail such causal relationships by conducting a large-scale survey that involves a random sample of a larger number of companies in different business sectors (both public and private). Additionally, the first-hand experience of PwDs, who are either already employed at the companies and have received adaptations at work or are job applicants who need adaptations, could be considered. Furthermore, issues that may require greater attention in future research would be flexible working arrangements and part-time employment, which emerged as important workplace adaptations from this study.

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Conflict of Interests

The authors declare no conflict of interests.

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About the Authors

Yuliya Kuznetsova is a PhD student at NTNU, Department of Social Work, Trondheim, Norway. Since 2015, she has been working as a research assistant for Disability and Human Rights Observatory (ODDH) at the University of Lisbon, ISCSP, Portugal. Throughout 2011–2014 she had been employed as an Early Stage Researcher at NOVA (Norwegian Social Research Institute, Oslo, Norway) under the project Disability Rights Expanding Accessible Markets (DREAM), ID: 265057, stemming from the EU Marie Curie Initial Training Network Funding Programme.

João Paulo Cerdeira Bento is a Lecturer in Economics and a member of the Research Unit on Governance, Competitiveness and Public Policy (GOVCOPP) at the University of Aveiro, Portugal. He received his PhD in Economics from the University of Reading, United Kingdom. His research interests include economics and international business. He is an invited Lecturer at Green Energy Management School (GEM), Department of Statistics and Quantitative Methods, University of Milano-Bicocca, Italy.

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Article

Deaf Learners' Experiences in Malaysian Schools: Access, Equality and Communication

Khairul Farhah Khairuddin [1,2,*], Susie Miles [1] and Wendy McCracken [1]

[1] School of Environment, Education and Development, University of Manchester, Manchester, M13 9PL, UK; E-Mails: khairulfarhah.khairuddin@manchester.ac.uk (K.F.K.), susie.miles@manchester.ac.uk (S.M.), wendy.mccracken@manchester.ac.uk (W.M.)
[2] Faculty of Education, National University of Malaysia, 43600 Bangi, Malaysia

* Corresponding author

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Abstract
The Government of Malaysia has embraced international policy guidelines relating to disability equality, including the United Nations Convention on the Rights of Persons with Disabilities. Its aim is to ensure that 75% of children with disabilities are included in mainstream classrooms by 2025 as part of a wider agenda to eliminate discrimination against people with disabilities. Including deaf children on an equal basis in the linguistically diverse, exam-oriented Malaysian school system is an ambitious and complex task given the difficulties they face in developing effective language and communication skills. The data presented here are taken from a larger study which explored teachers', head teachers', parents', and children's experiences of inclusion through in-depth interviews in three Malaysian schools. The study design was informed by a framework developed in the UK to guide best practice of educating deaf children in mainstream schools and focused specifically on the learning environment. This article presents contrasting educational experiences of two deaf adults, and then considers the experiences of four deaf children in their government-funded primary schools. A series of inter-related dimensions of inclusion were identified—these include curricular, organisational, social, acoustic and linguistic dimensions, which impact upon children's ability to communicate and learn on an equal basis. Poor maintenance of assistive technology, insufficient teacher training and awareness, inflexibility of the education system, and limited home-school communication are some of the factors constraining efforts to promote equal participation in learning. There are promising signs, however, of teacher collaboration and the creation of more equitable and child-centred educational opportunities for deaf children.

Keywords
cochlear implants; communication; deaf equality; deaf learners; deafness; hearing aids; inclusion; Malaysia; schools; sign language

Issue
This article is part of the issue "Global Perspectives on Disability", edited by Shaun Grech (The Critical Institute, Malta) and Karen Soldatic (Western Sydney University, Australia).

1. Introduction

The purpose of this article is to examine the educational experiences of two deaf adults and four primary age deaf learners in the light of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). We begin by introducing the linguistically diverse Malaysian context, and by examining the influence of the CRPD and other national and international policy guidelines on the development of more inclusive and equitable quality education for deaf children.

The contrasting experiences of the 'successful' deaf adults, who were educated prior to the introduction of the national policy on inclusive education and the ratification of the CRPD, highlight a series of complex and inter-related dimensions of inclusion. They also illustrate the ‘deaf inclusion dilemma’ and some of the assumptions made about disability equality in education. Although the four deaf children are being educated post-CRPD, they are experiencing barriers to their participation and learning similar to those experienced by the deaf adults. In scrutinising the education of both the adults and the children, we identify ways in which barriers to equal recognition and treatment of deaf children in mainstream settings can be overcome.

Similar to other low and middle-income countries, literature focusing on the numbers of deaf children attending different types of educational provision, and the management of technological and sign language support for deaf students in mainstream settings, is scarce in Malaysia, and, if it does exist, it is not easy to locate. The first author has played a critical role in researching policy and practice in the inclusion of deaf learners in mainstream schools, much of which is not available in the public domain or in published documents.

2. The Malaysian Context

Malaysia has an ethnically and linguistically diverse population of 31 million, which includes Malay (55%), Chinese (24%), Bumiputera (12%), Indians (8%), with other minorities constituting just 1% (Department of Statistics Malaysia, 2017). High levels of investment have been sustained in education since independence in 1957, with “6.1% of GDP” being spent on education (United Nations Development Programme, 2016, p. 231). The primary school enrolment rate is 94%, and the primary school dropout rate has been reduced to just 0.2% (Ministry of Education, 2014a).

A distinction is made in Malaysia between ‘national schools’ (government-funded) and ‘vernacular schools’ (partially government-funded). Malay is the language of instruction in mainstream government-funded schools, which are attended by 77% of children, 20% of whom speak Malay as an additional language. Vernacular schools cater to 22% of the school age population where the medium of instruction is either Mandarin or Tamil in addition to Malay and English (Ministry of Education, 2014b), and the remainder of pupils are privately educated. The study reported here focuses on three Malay-medium, government-funded ‘national’ primary schools.

There are approximately 3000 deaf learners in three officially recognised types of educational settings within the formal special education system in Malaysia (Special Education Division, 2013):

- Special schools (26 altogether) are mostly residential and attended by approximately 40% of deaf children. There are also twelve (12) privately owned special schools catering to 600 pupils with a range of disabilities (Ministry of Education, 2014b);
- The Special Education Integrated Programme (SEIP) (*Program Pendidikan Khas Integrasi*) was first introduced in 1963. It is now catering to approximately 60% of deaf children in ‘units’ attached to 23% of government-funded primary schools (N = 1345);
- The Inclusive Education Programme (IEP) (*Program Pendidikan Inklusif*) officially registers children who are included in mainstream classrooms.

The IEP was established following the Salamanca Statement (UNESCO, 1994), and through the Education Act (1996). It caters to 6% of learners with disabilities and approximately 1% of deaf children. The term ‘inklusif’ has been adapted from English, as there is no Malay word for ‘inclusion’, and is used to mean the official placement of pupils with disabilities in mainstream classrooms. The inclusion of children with disabilities in their local schools has been described as being “unconscious” (Lee & Low, 2013, p. 2) as they are not attached to either the SEIP or IEP. In this sense, the term ‘inclusion’ has its own particular meaning in the Malaysian school system; children are considered to be included if they attend a mainstream school without any specialist support; and ‘partially included’ if they spend some of their time in a mainstream classroom and the rest of the time in the SEIP (Ministry of Education, 2013a). Children with disabilities are required to pass school-based assessments before they can be accepted into the IEP (Ministry of Education, 2013a). The highly pressured and competitive examination-oriented mainstream education system is considered unsuitable for children regarded as having ‘low academic ability’ (Jelas & Ali, 2012).

The Persons with Disabilities Act (2008) states that, “[p]ersons with disabilities shall not be excluded from the general education system on the basis of disabilities” (Article 28, p. 24). In 2010, the Government signed and ratified the CRPD which specifies that children with disabilities have the right to access “inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live” (United Nations, 2006, Article 24). Inclusive education is defined in the national policy as the “concept of placing Special Educational Needs (SEN) students into mainstream classes to be educated alongside their peers, *either with or without additional support* and within the present school system” (Ministry of Education, 2004, p. 28, emphasis added). Interestingly, the Government recognises the limitations of its commitment by acknowledging that:

> This concept of inclusive education might not be in line with the ideal concept based on ‘acceptance, belonging and about providing school settings in which all disadvantaged children can be valued equally and be provided with equal educational opportunities’. (Ministry of Education, 2004, p. 28–29)

The General Comment 4 on Article 24 (Committee on the Rights of Persons with Disabilities, 2016)—henceforth referred to as the General Comment—asserts that deaf children have the right to access the language of instruction that is "most appropriate":

> Students who are blind, deaf or deafblind must be provided with education delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize personal, academic and social development both within and outside formal school settings. (para. 35, p. 10)

The interpretation of the term "most appropriate" is critical, and suggests that the language needs of deaf children should be met on an individual basis. The General Comment also highlights the importance of being able to communicate in all aspects of life, not just in school.

The Government has set the ambitious target of ensuring that 75% of students with disabilities, including deaf students, will be educated in mainstream classrooms by 2025 (Ministry of Education, 2013b). This is part of a wider agenda to eliminate discrimination against people with disabilities. Although this demonstrates the Government's commitment to international rights-based educational agendas, it is an ambitious target in the case of deaf children given the need to attend to individual language learning needs, including sign language, in the context of considerable linguistic and cultural diversity.

Malaysian Sign Language (MSL) is recognised by the Government as the official language of Deaf people in the Malaysian Persons with Disabilities Act (2008). The use of upper case, or capital, 'D' is used to denote membership of the social, cultural, and linguistic minority group of Deaf people who use their own native Sign language, in line with the World Federation of the Deaf (WFD) policy guidelines. It also distinguishes Deaf people from other individuals who experience hearing loss, but do not use sign language.

The language of instruction for deaf children is referred to as Total Communication, which is a combination of communication strategies, including the Hand Code of Malay, speech, finger spelling, writing and lip reading (Tee, 1990). Teachers of the deaf are trained to teach using 'Hand Code of Malay' (*Bahasa Melayu Kod Tangan*) alongside speech. This is an approach designed to support spoken Malay, and is not a language in its own right. MSL is not taught in schools in Malaysia (Yasin, Tahar, Bari, & Manaf, 2017), neither is Sign Bilingualism used.

Support for learning MSL is only provided by non-governmental organizations, such as the Malaysian Federation of the Deaf, and training for interpreters is also limited (Yusoff, 2014). Teaching instruction using other modes of communication, such as cued speech, is only provided in a private school administered by the National Deaf Association of Malaysia with little evidence of success (Yasin, Bari, & Hassan, 2013). The communication practices in Malaysian schools are therefore not in line with the WFD recommendation that:

> Quality education in the national sign language(s) and the national written language(s) is one of [the] key factors for fulfilling the education and broader human rights of deaf children and adult deaf learners (World Federation of the Deaf, 2016, p. 3).

Due to advances in the use of audiological technology in Malaysia, parents are more likely to have contact with medical professionals than with educationalists before their children start school (UNICEF Malaysia, 2014). Therefore, doctors and audiologists have the most direct influence on deaf children's mode of communication as they are involved in the initial diagnosis and the fitting of hearing aids. Cochlear implants have been provided to more than 600 severely and profoundly deaf children by the Ministry of Health since hospitals began offering this service in 1995 (Goh, Fadzilah, Abdullah, Othman, & Umat, 2018; Yusoff, Umat, & Mukari, 2017). The introduction of the Newborn Hearing Screening in 2001 has further strengthened this service (Ministry of Health, 2015).

While advanced medical services are available, guidance for parents on how to make decisions about educational provision for their deaf children is not provided (UNICEF Malaysia, 2014). Those children who receive cochlear implants and digital hearing aids are likely to be advised by medical professionals to attend their local school. In this sense, parents are not able to make informed choices about their children's education and mode of communication. Currently there are no specialist teachers available to support deaf children outside of the established special education services. Since there is no sign language support provided in mainstream schools, being able to speak is an essential prerequisite for being able to participate on an equal basis in the examination-oriented mainstream schools of Malaysia. At the same time, the high cost of hearing aids and cochlear implants limits the number of children who can benefit from this technology since not all parents can afford this. Although subsidies are available from the Government, approval of these subsidies can take up to two years and so parents often have to cover the cost of the technology and its maintenance. The availability of technology alone is not sufficient. Daily maintenance is required if it is to be used reliably and appropriately (Archbold & O'Donoghue, 2007).

3. Deaf Learners' Experiences

This study is the first of its kind in Malaysia. It took place in three government funded primary schools in Selangor, the most developed state in which the capital, Kuala Lumpur is situated. Individual semi-structured interviews (Kvale & Brinkmann, 2009) were conducted in 2016 with thirty-seven (37) participants, including two (2) deaf adults, three (3) head teachers, two (2) SEIP coordinators, three (3) SEIP teachers, five (5) mainstream teachers, two (2) teachers of the deaf, three (3) teaching assistants, seven (7) parents of deaf children, seven (7) deaf children (4 boys and 3 girls aged 9 to 13) and three (3) of their hearing classmates. The aim of this larger study was to gain a better understanding of the experience of inclusion from the perspective of all the 'key actors' involved in this complex process, and especially deaf learners whose views have not been researched in the Malaysian context. In addition, individual interviews were conducted opportunistically during the main data collection period with two deaf adults who had experience of primary, secondary and tertiary education in Malaysia. The question that guides this article is: what are deaf learners' experiences of being included in education?

It proved impossible to identify a pre-existing framework in the literature that was relevant to the exploration of education stakeholders' experience of the inclusion of deaf children in low or middle-income countries. The UK's 'National Quality Standards: Resource provisions for deaf children and young people in mainstream schools' (National Deaf Children's Society & National Sensory Impairment Partnership, 2011) was adapted for use in this study, and the themes used to develop the individual semi-structured interview schedules included: positive attitudes; making reasonable adjustments; respect; friendship; communication; achievement; embedded specialist provision; training for staff; and developing acoustic settings. This study was conducted with approval from the University of Manchester's Research Ethics Committee and from the Malaysian government. The schools were identified through a shortlist of deaf children attending mainstream schools drawn up with support from two sources: the Ministry of Education and the Cochlear Implant Centre, Institute-HEARS.

The first author, a qualified teacher of the deaf from Malaysia, conducted interviews entirely in the Malay language, both spoken and signed. The children were asked to give their assent to participate and parents were contacted to give their informed consent for their child's participation. The children were free to choose their preferred mode of communication during the interview. Prior to data collection, the children were assured that their decision to participate was voluntary, that the interviews were confidential, and that participation in the study would not affect their grades. All recorded data were transcribed and analysed with computer assisted qualitative data analysis software (CAQDAS) Nvivo 10 (Gibbs, 2005). A thematic analysis approach was applied to identify patterns through a rigorous process of data familiarisation, data coding, and the development and revision of key themes (Braun & Clarke, 2006).

4. Reflecting on Contrasting Experiences of Education and Communication

Zack and Yuyu are profoundly deaf and their parents were able to afford speech therapy and early amplification. They were both educated in government-funded schools in Selangor State, but have had different experiences of the education system, largely due to the modes of communication used in the schools they attended, as illustrated by the following vignettes:

> Zack is in his early 20s, and has worn hearing aids since he was four years old, when his mother became concerned about his difficulty in speaking their home language, Malay. Zack's mother helped him to learn to speak. He attended the local school with his siblings following a speech therapist's recommendation. Zack says that it was difficult to make friends, and, "School was challenging". The teachers spoke too quickly which made it difficult for him to hear, and so he learned to focus on the teachers' lips. His parents went over his schoolwork with him in the evenings, and his secondary school teachers gave him extra tuition on a voluntary basis in break times. He passed the Malaysian Certificate of Education, completed a diploma and is currently an undergraduate student of Animal Science at a prestigious university in Malaysia. "Now", he says, "I have made a lot of friends".

The relative wealth and dedicated support of Zack's parents and his teachers' extra tuition helped Zack to maintain his hearing aids, learn to speak, and achieve academically in the exam-focused education system. Although Zack reported that he was socially isolated in school, the opportunity to interact with people from diverse backgrounds at the university has developed his confidence.

By contrast, Yuyu was educated almost entirely within the separate educational setting of the SEIP at primary and secondary level, from the 1990s onwards:

> Yuyu is in her mid-30s, and was fitted with hearing aids at the age of three, around the same time that her older brother's deafness was identified. Yuyu had regular speech therapy, but stopped wearing the hearing aids when she was ten because she "didn't find them helpful". Yuyu's parents speak Mandarin, Malay and English. Yuyu says that her first language is Malay, as she uses written Malay to communicate with those who don't know MSL. She communicates in MSL with Deaf people, although she uses some speech when communicating with her mother who has learnt to use Hand Code of Malay, and her father uses home Malay signs for individual words such as "bath, study, sleep, and eat". After completing the Malaysian Certificate of Education, Yuyu studied for her High School certificate in a mainstream school for two years before undertaking an undergraduate degree in Special Education, and has been teaching deaf children in an SEIP for about 8 years.

Having supportive parents and a deaf older brother, and being able to complete the majority of her education with other deaf children, have helped Yuyu to become an accomplished user of MSL, and prepared her well for her current profession. Being able to hear spoken language at an early age probably helped her to establish proficient sign language skills and fully participate in the education system (Leigh & Johnston, 2004). However, Yuyu relies on written communication with people who do not know sign language. During the four-year undergraduate course, she only had occasional support from a sign language interpreter due to the university's budget restrictions and the interpreter's limited knowledge of her subjects. After graduating, Yuyu became a volunteer at a Deaf Association centre in the capital, Kuala Lumpur, where she socialises with other Deaf people. Yuyu's experience highlights the importance of gaining literacy skills as they have profound and lasting repercussions for the lives of deaf individuals (Mayer & Akamatsu, 2003).

5. Dimensions of Inclusion and Exclusion

Zack and Yuyu's educational and career trajectories highlight some of the disputes and contradictions in the practice, policy and discourse of inclusive education as they relate to the education of deaf children in Malaysia and internationally. Educational choices are usually made by parents, are often fraught with uncertainty, and have major repercussions for adult life. In low and middle-income countries information about communication modes and educational settings is not always available to parents (Leigh, Newall, & Newall, 2010).

Yuyu's deafness is a central part of her identity, and she considers herself to be a member of a linguistic minority which has its own culture and mode of communication (McIlroy & Storbeck, 2011). Indeed, Article 21 of the Salamanca Statement (UNESCO, 1994) recognises that the particular communication needs of deaf learners can sometimes justify separate educational provision. Although Yuyu was not educated in a special school, the SEIP programme has effectively created small special schools within mainstream schools, where a maximum of 8 to 10 children have full-time support, although not all teachers are specialists in deaf education. These are spaces where Deaf culture can thrive and where equal participation is possible (Jarvis, 2002).

However, the organisation of deaf children into small special 'units' means that schools are rarely able to provide the more advanced curricular access required for secondary and tertiary educational success (Angelides & Aravi, 2015). It is unlikely that Zack would have been able to study at university if he had only been exposed to the restricted curriculum available in specialist settings, yet the consequence of being the only deaf learner at school appears to have led to considerable social isolation and having to study much harder than his peers (Jarvis, 2007). At the same time, having the opportunity to learn in mainstream settings opened up career possibilities for Zack which would otherwise have remained closed. It also enabled him to have a wider friendship group (Antia, 2015), although this did not include deaf peers.

We now turn, in the next section, to the experiences of Aisyah, Akwan, Ben and Caliph, four (4) of the seven (7) children in the main study who have been selected because of the severe nature of their deafness. They have been given pseudonyms which match the first letter of their school pseudonyms: Aman, Bijak and Cherdik. Each school has over 1,500 pupils, aged 6 to 12, and has a staff of 70 to 90 teachers. Although the first author participated in school activities for two to three weeks to build rapport prior to conducting the interviews, the children were sometimes shy, and only spoke (or signed) in very short phrases. Questions were repeated several times and long pauses allowed for the children to formulate their answers. Through the children's experiences, we explore the organisational and curricular limitations of the SEIP, the social isolation of the mainstream, and the linguistic separation between these two types of educational setting.

6. Experiences in the Special Education Integrated Programme (SEIP)

Aisyah, Akwan and Ben are aged 9 to 13, and are from Malay-speaking families. They attend the SEIP in Aman and Bijak schools, respectively. Each SEIP caters to approximately 60 to 80 pupils with learning disabilities, with just seven deaf children in Aman, and eight deaf children in Bijak. The deaf children are educated in a separate classroom within the SEIP, which has its own administrative structures, separate from the mainstream school. The deaf children and teachers spend most of their time in this 'gated community'. They occasionally participate in the weekly formal school assembly and other activities in the main school, but the SEIP also organises its own separate activities, such as Sports Day. It is common for deaf children to be placed in an SEIP without a trained teacher of the deaf, and this is the case in Aman. Although the teachers in Aman have had no formal training on how to teach deaf children, they have had more than ten years' experience of teaching deaf pupils, and have studied sign vocabulary from books in their own time, and learned to sign 'on the job'.

Akwan is nine and has been wearing digital hearing aids since the age of three. His mother chose to send him to the SEIP in Aman school because she considers him too young to attend school far away from home, even though his 17-year-old brother attends a residential secondary school for deaf children. She also thinks that the SEIP provides him with more individual attention from teachers. Akwan says that he likes his hearing aids because they help him to communicate with his two classmates and his teachers. Although the SEIP is a specialist facility designed to accommodate deaf children, the walls between the classrooms are not soundproofed, and Akwan finds the background noise distracting. This is a common complaint from deaf children, especially in mainstream classrooms where there is little awareness or understanding of the importance of good acoustics, and noise reduction and management (Iantaffi, Jarvis, & Sinka, 2003). However, Akwan reports that he likes to go to school because he has friends, and when he cannot hear clearly because of the background noise, he is able to watch the teacher signing (Jarvis, 2007).

Aisyah began to learn to sign at the age of seven when she started school. She is now thirteen and is repeating the Year 6 class. She has no hearing aids, does not speak and has a limited knowledge of the Hand Code of Malay. Her older sister has recently started to learn to sign, but Aisyah's mother refuses to believe that Aisyah is deaf, and is convinced that her difficulty in speaking is the result of a supernatural force. Aisyah is socially isolated and reported that Aman school is "boring and difficult". She has difficulty understanding lessons because of her limited language skills, the teachers find it difficult to teach abstract concepts, and Aisyah struggles to understand their explanations. As the curriculum becomes more demanding, Aisyah is falling behind.

Ben is twelve and has worn hearing aids since he was two, when he became deaf as a result of severe jaundice. His mother wanted him to speak, so she sent him to a mainstream school where he had no support from a qualified teacher of the deaf. After four years he was advised by the mainstream teachers to move to the SEIP classroom at Bijak School because he could not keep up with the fast pace of the lessons. In the SEIP he receives specialist support from two trained teachers of the deaf, the curriculum is less challenging, and the class has just three deaf children. Ben has been taught to sign and can now communicate with his two deaf classmates and participate in lessons. He now has both sign language and speech, although sign language is dominant. He enjoys school and seems happy with the pace of learning. Although Ben has access to a narrow curriculum, he has gained communication skills.

Regular exposure to an accessible language, and meaningful interactions with others who are capable users, is essential for deaf children to become literate enough to benefit from formal education (Mayer, 2007). Late identification and limited access to amplification, and the fact that more than 90% of parents of deaf children are not deaf and have no sign language skills (Mitchell & Karchmer, 2004), represent considerable barriers to equal participation in education.

7. Attending a Mainstream School without Specialist Support

Caliph is ten years old and has a profound hearing loss which was only identified at the age of eighteen months when his mother noticed his lack of response to loud noises. At the age of two, he had a cochlear implant fitted to his right ear and a hearing aid in his left ear. Caliph attends speech therapy and his mother practises with him at home. Active in an NGO for parents of deaf children, Caliph's mother is clearly both determined and committed to his overall welfare and educational development. Similar to Zack's mother, she wanted Caliph to speak the home language, Malay.

Caliph attends Cherdik School with his older brother. Caliph is the only deaf child known to be attending this school and there are no specialist teachers. The Ministry of Education does not keep records of deaf children educated in mainstream schools as they are outside the formal special education system, and so Caliph was identified for this study through the cochlear implant team.

Caliph is in a class with twenty-five students whose academic attainment is considered to be 'low', and where the curriculum has been simplified. Yet Caliph commented: "The teachers teach, but sometimes I don't understand the lesson". Caliph sits at the front with his friend, Chad. He enjoys school and plays with his friends at home after school. Caliph's difficulty in understanding may have been because his cochlear implant had not been working reliably for eight months and he was managing with one hearing aid, however, his mother was committed to solving this problem. Caliph talked about his love of sport, and about practising for Sports Day. Attending mainstream school has enabled Caliph to participate in a wide range of school activities and he has lots of friends, both at home and school.

Although it is not possible to generalise from Caliph's experience, as he is the only child in this study with a cochlear implant, having spoken language has helped him to be socially included. Reliable maintenance is, however, critical in being able to continue to develop and practise spoken language (Archbold & O'Donoghue, 2007). Even though Caliph is in a small class, he struggles to access the limited curriculum without reliable assistive technology and specialist support. The extent to which his low achievement is due to a failure of technology and appropriate communication support is difficult to establish.

8. Addressing the Deaf Inclusion Dilemma

We have argued here that it is a combination of increased political will as a result of the CRPD, as well as advances in audiological technology and related specialist knowledge, which have provided deaf learners with more equal opportunities to use their hearing more effectively and develop greater spoken language abilities (Goh et al., 2018). This, in turn, has had an impact on the choices available to deaf children and their parents. As the data have illustrated, support for children and their families in the early years is critical (Moeller, Carr, Seaver, Stredler-Brown, & Holzinger, 2013). At the same time, teacher training is not keeping pace with sign language development and technological opportunities, or with the need to promote greater deaf awareness in the education system, as recommended by the CRPD.

Cochlear implants and digital hearing aids are only effective when teachers and parents have the necessary expertise to check and maintain them. However, teachers in Malaysia have limited audiological training and so children do not gain the full benefit from this technology. In addition, the lack of coordination between the ministries of health and education means that deaf children are not provided with equitable educational opportunities and services.

Most of the available literature on the experiences of deaf children in mainstream education focuses on high-income countries and makes assumptions about the availability of sufficient resources, including the latest technology (Bakhshi, Kett, & Oliver, 2013). A review of inclusive education in low-and-middle income countries focusing specifically on deaf children found only one paper on education in mainstream schools, as most studies focus on education in special school settings (Wapling, 2016). Limited research on the education of deaf children in low and middle-income countries means that policy makers have insufficient knowledge and understanding of how to develop, secure and sustain appropriate educational services. The General Comment provides much needed guidance for practitioners and policy makers on how to interpret and implement Article 24 for deaf learners.

The findings of our study suggest that flexibility is key to the development of more equal opportunities for deaf children. Three of the children spend most of their time in separate classrooms with only two to three classmates, within a gated community, mostly excluded from the wider school community. This separate provision can be seen as being beneficial to deaf pupils by providing them with equal opportunities to participate in learning and access the curriculum with support from specialist teachers (Lynas, 2002), but the very small number of children in these separate classrooms means that they have limited opportunity to develop communication skills and to socialise. The rigid examination-oriented curriculum within the mainstream education system makes it difficult for deaf children to follow the fast-paced lessons. In our larger study three out of five mainstream teachers interviewed were committed to supporting deaf children to remain in their classrooms. In situations where the assistive technology was not working or the child did not pass the school exams, all five of the school leaders interviewed suggested that the parents move their children to specialist settings, either the SEIP or a school for the deaf.

Increasingly, audiological technology and professional knowledge are being made available, and sometimes affordable, in developing countries (McPherson, 2008). However, regular and reliable maintenance of cochlear implants and hearing aids, and school policies which promote effective communication, such as noise reduction, lip reading, lip speaking (Archbold & O'Donoghue, 2007) and sign language (World Federation of the Deaf, 2016) are essential if deaf children are to have equal educational opportunities. Determining 'the most appropriate' language of instruction is an ongoing policy and practice challenge, especially in countries with diverse languages and ethnicities (Rhoades, Price, & Perigoe, 2004).

Equal access to spoken, written and signed communication is a pre-requisite for equal participation. In many contexts in the global South, deaf children do not have equal access to assistive technology, such as hearing aids and cochlear implants. In this case sign language is, arguably, the most appropriate language of education (McIlroy & Storbeck, 2011), as made clear in the General Comment. Although the Hand Code of Malay provides access to language in school, it does not necessarily enable communication with family members, and can lead to restricted curricular access, as our data have illustrated.

Sign bilingualism is one possible way forward, but in the context of limited resources and expertise, as in Malaysia, it is unlikely to be implemented effectively in the immediate future, and Leigh and Johnston (2004) have argued that there is a lack of evidence to support the effectiveness of this approach. Deaf children's ability to learn language and literacy skills is reduced by late identification and intervention (Lederberg, Schick, & Spencer, 2013). Indeed, children who enter school with little or no language are likely to have to spend time 'catching up', rather than having equal access to the curriculum. Parents' difficulties in accepting their children's deafness can also result in children having no mother tongue or sign language skills before they start school (Wilson, Miles, & Kaplan, 2008). Yet opportunities for parents and other family members to learn sign language are rarely available, even in highly resourced contexts (Johnston, Leigh, & Foreman, 2002). Zack, Yuyu and Caliph have all benefitted from the efforts of their dedicated parents and early exposure to spoken language, yet their parents have had limited access to sign language.

This article has not attempted to make any comparisons between the education of deaf children in special schools and those attending more mainstream provision. It is important to acknowledge that 40% of deaf children continue to be educated in special schools in Malaysia, and that this option seems likely to continue to be available as part of the continuum of provision. In contrast to the dominant view of inclusion being about 'mainstream' education, Olsson, Dag and Kullberg (2017) have argued for:

> The importance of special schools for deaf and hard-of-hearing persons when it comes to both academic and social inclusion. Social inclusion during adolescence is ultimately of great importance for becoming well integrated in society. (Olsson et l., 2017, p. 13)

They go on to argue that:

> [P]ersons with disabilities should have the possibility to live their lives under conditions that are as similar as possible to those of the rest of the population. In this case, for the studied groups, normalisation seems to be promoted by attending special school. (Olsson et al., 2017, p. 13)

9. Conclusion

This study demonstrates that the availability of advanced audiological technology has enabled an increasing number of deaf children to develop spoken language and participate in mainstream schools in Malaysia. The significance of this study is in highlighting the specific barriers faced by deaf children in achieving their educational potential. In exploring deaf children's experiences of mainstream schools, this article raises more questions than it is able to answer, such as: what is the purpose of schooling and education for deaf children; what would an equal education system look like; and how can there be more flexibility in relation to communication methods and approaches in the education of deaf children?

Meaningful communication, whether spoken, written and/or signed, is central to the equal participation of deaf learners in any type of educational setting. Our findings highlight the fact that there is little understanding of the importance of a good quality acoustic environment in Malaysian schools, including in specialist settings, and that educationalists do not have relevant training in, or responsibility for, the maintenance of assistive technology. The study also illustrates the varied communication practices taking place in schools, and the dominance of Hand Code of Malay as part of a total communication approach, rather than the structured use of MSL. The fact that professionals are beginning to collaborate with each other to promote more equal participation for deaf children shows some potential for the development of inclusive practices.

In summary, this study represents the beginning of a longer term and more complex evaluation of educational environments in Malaysia. One possible way forward is for schools to monitor the many different dimensions of inclusion (social, curricular, organisational, linguistic and acoustic) and so evaluate the effectiveness of educational provision for deaf learners. An appreciation of the importance of developing a broad range of flexible support structures in accommodating individual differences between deaf children would also be helpful in developing more equal education practices (Archbold, 2015). Deaf learners' and their families' perspectives are, arguably, an essential part of developing more comprehensive and responsive approaches to deaf equality in educational settings, and this study represents an important step in this direction.

School stakeholders, including policy makers, will need help in understanding that it is not enough to simply 'include' deaf children in a classroom environment. To include deaf learners on an equal basis in all the dimensions of inclusion identified in this article will require inter-ministerial collaboration, as well as a step change in the awareness of professionals about disability and deaf equality in education in line with the CRPD.

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Conflict of Interests

The authors declare no conflict of interests.

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About the Authors

Khairul Farhah Khairuddin is a Postgraduate Researcher at the University of Manchester, UK. She was trained as a teacher of the deaf in Malaysia and taught deaf children in secondary schools in Selangor. She holds an MA in Special Education from the University of Newcastle, Australia. Her research focuses on inclusive education for deaf children in Malaysian primary schools.

Susie Miles began her career as a teacher of deaf children in the UK before moving to Swaziland, where she taught in a residential school for deaf children. She later set up Speech and Hearing clinics in Swaziland and became Save the Children's Regional Disability Advisor for Southern Africa. As the founding coordinator of the Enabling Education Network (EENET), she worked closely with, and did consultancies for, a wide range of international agencies, including UNICEF and UNESCO. She is currently a Senior Lecturer in Inclusive Education at the University of Manchester.

Wendy McCracken is a Professor of Deaf Education at the University of Manchester and is the Programme Director of the MSc Deaf Education. She is recognised nationally and internationally, and has received the TS Littler Award for Services to Audiology and Deaf Education 2017—the most prestigious award given by the British Society of Audiology. She is also a recipient of the National Teaching Fellowship for her work in setting high academic and practice standards through maintaining strong links with service providers.

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Article

A Refamilialized System? An Analysis of Recent Developments of Personal Assistance in Sweden

Dietmar Rauch *, Elisabeth Olin and Anna Dunér

Department of Social Work, University of Gothenburg, 40530 Gothenburg, Sweden; E-Mails: dietmar.rauch@socwork.gu.se (D.R.), elisabeth.olin@socwork.gu.se (E.O.), anna.duner@socwork.gu.se (A.D.)

* Corresponding author

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Abstract
The Swedish system of disability support is often praised for its comparably well-developed Personal Assistance (PA) scheme. PA is formally prescribed as a social right for disabled people with comprehensive support needs in the *Act Concerning Support and Services to Persons with Certain Functional Impairments* (LSS). In the decade following the introduction of LSS in 1994, the PA-scheme expanded steadily to accommodate the support needs of more and more disabled people. It is commonly believed that the expansion of PA has substantially boosted the agency of both disabled people and their relatives. This article critically discusses in what direction the Swedish system of disability support has moved in the past decade. Is the common image of a system moving towards an ever increasing *defamilialization* of disability support still accurate? Or are there signs of stagnation, or even reversal towards refamilialization? What are the possible consequences of the more recent developments for disabled people and their relatives in terms of agency and equality? These questions will be discussed with the help of an analysis of the regulatory framework of disability support, statistical data and findings from public reports.

Keywords
agency; assistance allowance; defamilialization; disability support; equality; familialism; personal assistance; Sweden

Issue
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1. Introduction

Traditionally, the support of disabled people was almost exclusively a family matter with very little involvement of other agents. Only since the rise of modern welfare states from the late 19th century, certain states started to accept a limited public responsibility for the support needs of disabled people and, consequently, residential service facilities for this group started to emerge. From the second half of the 20th century, in many countries, the public support responsibility was widened to cover a larger proportion of disabled people and, in part as a reaction to the claims of the Independent Living Movement (Askheim, Bengtsson, & Bjelke, 2014), the major form of support changed from residential facilities to home-based support services.

This partial transfer of support responsibility from the family to the state has by some been coined as *defamilialization* (e.g., Lister, 1994; McLaughlin & Glendinning, 1994). In comparative studies about social service regimes, the Scandinavian countries are usually characterized as outstanding pioneer cases concerning their capacity to defamilialize support (e.g., Esping-Andersen, 1999; Lewis, 2001), mainly due to their comparably well-developed public childcare and eldercare systems (e.g., Sipilä, 1997; Anttonen, 2003). Less has been written about disability support regimes from a comparative perspective. Yet, the available studies suggest that the Scandinavian countries have achieved a comparatively high degree of defamilialization also when it comes to disability support. In these studies (e.g., Askheim et al., 2014; Szebehely & Trydegård, 2007), the role of the Swedish Personal Assistance (PA) system in particular, introduced in the *Act Concerning Support and Services to Persons with Certain Functional Impairments* (LSS) has been emphasized. The intention with the reform was to advance self-determination and participation in society for people with comprehensive support needs.

The main aim of this article is to critically discuss in what direction Swedish disability support in the form of PA has been heading in the past decade when it comes to the balance of support responsibility between the public sector and the family. Is the common image of a system that is moving towards more and more defamilialization of support still accurate? Or are there signs of stagnation or even reversal towards refamilialization? What are the possible consequences of the recent developments in the Swedish PA-system for both disabled people and their relatives in terms of agency and equality?

In the following section the theoretical framework of this article will be sketched out. In particular, the concept of defamilialization will be discussed here. Thereafter the data and methodology of the study are described. Subsequently, the main formal traits of the Swedish disability support system since the introduction of the LSS in the mid-1990s will be illustrated, followed by an analysis of the development of PA in the past 10 years, based on public statistics and public reports. Finally, the possible consequences of these developments in terms of equality and agency for support givers and recipients are discussed before the main findings will be wrapped up in the conclusion.

2. Theoretical Concepts

2.1. Defamilialization

One of the main tasks of modern welfare states is to provide services to those needing practical and/or personal support. The main target groups of these services are children, older and disabled people. Probably the two most important functions of these services are: (1) to make sure that the needs of support are properly met, and (2) to lessen the dependency of (potential) familial support givers and support recipients from each other (Rauch, 2007).

In theoretical terms, the second function can be approached with the concept of defamilialization, initially developed by Ruther Lister (1994) and defined as "the degree to which individual adults can uphold a socially accepted standard of living, independently of family relationships" (Lister, 1994, p. 37). While Lister originally mainly focused on *economic* aspects of defamilialization (i.e., financial/economic autonomy), the focus in this article will shift to the question of *social* dependency between (potential) familial support-givers and support-recipients. One basic assumption here is that a familial support relation increases the dependency of both parties (Dunér & Olin, 2018; McLaughlin & Glendinning, 1994). If support-giving is at least partially transferred to other actors outside the family—in other words, if it becomes defamilialized—the personal autonomy and agency of both support-givers and support-recipients will be elevated (Leitner & Lessenich, 2007; O'Connor, 1993; Ulmanen, 2015). Here, familialized support is in no way regarded, in itself, as an inferior or undesirable form of support. Of course, familial support is essential for many disabled people. Some do prefer familial support and emphasize its intrinsic value. Others have a more ambiguous stance towards it. And yet others do prefer public or other types of support (e.g., Dunér & Olin, 2018). The very point is rather that real agency of support-givers and support-recipients presupposes that disabled people and their relatives have a real chance to choose the support form they desire.

Many articles on social services calculate or relate to overall defamilialization scores for certain care schemes in order to analyze the impact of these on agency and equality (e.g., Esping-Andersen, 1999; Lohmann & Zagel, 2015; Rauch, 2007). However, it is often overlooked that defamilialization can be distributed unequally across different social groups in society. Depending on the institutional structure of the support solution in question, some segments in society might gain more defamilialization of support than others. In this article we will explicitly address this question by introducing the concept of *segmented defamilialization*, understood as defamilialization which is only granted to some groups in society (e.g., social classes, citizens of certain regions, etc.) but not, to the same degree, to others.

2.2. Agency and Equality

In this article, the concept of defamilialization will be tightly linked to concepts of agency and equality. Equality presupposes according to Amartya Sen (1992) not only equal access to material resources but also *equality of agency*. Agency will be defined here as the ability of individuals to make their own choices. Defamilialized disability support can be argued to raise the agency of both disabled people and their relatives. The availability of extra-familial support options grants close relatives greater agency to choose to what extent they would like to dedicate their time to the support of their disabled relative or rather to alternative activities, such as labor, leisure, and so on. Likewise, defamilialized support options give disabled people the agency to choose between different support forms. They might want to choose extra familial support if they deem that this support form increases their independency in society more than familial support. To sum up, defamilialized disability support has the capacity to enhance the *richness* in terms of agency among both groups and thus improves their social position in relation to other groups in society. In other words, it can contribute to increase the equality between those who are disabled and those who are not.

3. Data, Operational Assumptions and Analytical Framework

The discussions in this article will be based on analyses of legal regulations concerning PA, public statistics and findings from public reports. In the first step of analysis, the legal framework of PA and the related Assistance Allowance (AA) will be discussed. In the second and main step of analysis, public statistics from, among others, the Swedish Social Insurance Agency (SSIA) and the Swedish National Board for Health and Welfare (NBHW) will be used to study the development of PA since the introduction of LSS in the mid-1990s. Here, focus will be on the development of the number of PA-recipients per capita, approval rates and withdrawn PA-admissions, as well as on the average amount of assistance hours granted per recipient. A combined analysis of these indicators will be used to discuss developmental trends concerning the degree of defamilialization of disability support in general and among different social groups. The main underlying operational assumptions are:

1. Relative number of recipients: the higher the relative number (share per 100.000 residents) of PA-recipients, the higher is ceteris paribus the overall share of people with disability receiving at least partially defamilialized assistance;
2. Approval and withdrawal rate: the higher the share of declined PA-applications and the higher the share of withdrawn PA-admissions, the higher is ceteris paribus the share of people wishing to receive but being excluded from getting defamilialized assistance;
3. Service intensity: the higher the number of PA-hours per PA-recipient, the deeper is the degree of support defamilialization among those receiving PA.

The quantitative data will be interpreted with the help of SSIA's own enquiries about the development of AA. This allows us to better understand alterations over time concerning admission assessments.

Taken together, the first two steps of analysis will help us to identify defamilialization or refamilialization trends in Swedish disability support. The third step of analysis, which will mainly be based on a report from the NBHW, can give us tentative findings about possible consequences of these developments for the agency of both familial support-givers and support-recipients as well as the social position of these two groups in relation to other groups in society.

4. The Legal Framework: LSS and the System of PA

A major legal cornerstone of the Swedish system of disability support is the LSS introduced in 1994. LSS defines three target groups for disability support measures (SFS, 1993): persons with learning difficulties, autism or a condition similar to autism (group 1), persons with significant pervasive cognitive impairment related to brain damage acquired in adult life due to external violence or physical sickness (group 2), and people with other permanent physical or mental impairments not due to normal aging causing significant difficulties with daily life activities and therefore a substantial need of support and service (group 3) (LSS, 1§).

All persons in these three groups are to be granted certain social rights if they need support for their living and their needs are not met in other ways (LSS, 7§). Probably the most important social right (and the one I will focus on in the following) specified in LSS is the right to PA. PA is according to LSS (9a§) to be granted to individuals from the three categories mentioned above, provided the conditions of LSS 7§ are fulfilled, if they are because of large and consistent impairment need help with either: (1) their personal hygiene, (2) meals, (3) getting dressed and undressed, (4) communication with others or (5) other assistance requiring detailed knowledge of the person.

The right to PA is intimately linked to the so-called AA, administered by the SSIA and jointly financed by the state and local municipalities. AA is to be granted to individuals qualifying for PA according to the regulations above, if they are regarded to need assistance in accordance with LSS 9a§ more than 20 hours per week. Other personal needs may be counted in as well (SSIA, 2017b). If granted, AA is to be used by the beneficiaries to finance their PA. AA-admission is to be re-evaluated and, consequently, can be withdrawn, reduced, remain unchanged or expanded each second year. People who are regarded to need less than 20 hours of PA, can still be entitled to PA fully administered and financed by local authorities (in short, *municipal PA*). About 75% to 80% of all current PA-recipients are covered by AA (SSIA, 2017a).

There is no doubt that the introduction of LSS has sparked a tremendous rise of PA in the period 1995–2010 (see Figure 1). However, in recent years several administrative court rulings and governmental appropriation directives may have influenced the development of PA in a reverse direction (NBHW, 2017b; SSIA, 2017b). To assess the impact of these recent de facto changes of the regulatory framework of PA we will discuss statistical data concerning PA-coverage, approval rates, withdrawal decisions and service intensity.

5. Analysis of the Development of PA-Coverage, Approval Rates, Admission Criteria and Service Intensity

Figures for the development of PA are available since 1994. They indicate that the total number of PA-recipients (comprising both AA-recipients and recipients of municipal PA) has increased steadily from the introduction of LSS in 1994 up until about 2010–2011. Also, the

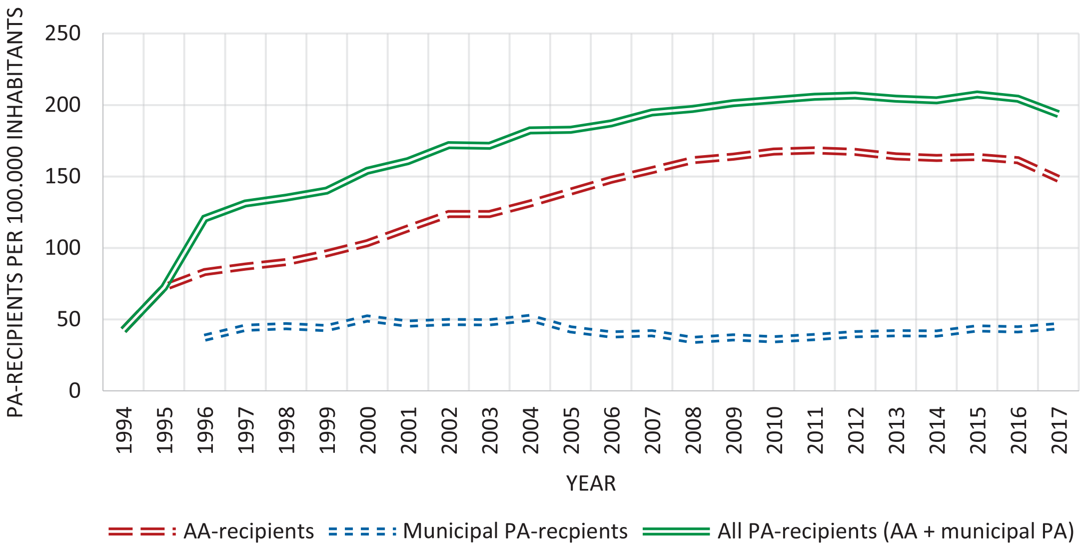

Figure 1. Relative number of PA-recipients, 1994–2017. Sources: own calculations based on Statistics Sweden (2018), SSIA (2017a) and NBHW (2017a); data from SSIA retrieved from Independent Living Institute (2018).

overall amount of admitted PA-hours has risen throughout this period, as well as the number of hours allocated per PA-recipient. Altogether, this early period of PA-development, can be described as a period of constant growth (SSIA, 2016). The main question to address below is what happened since then.

5.1. The Relative Number of Recipients: A Proxy for PA-Coverage

It is virtually impossible to exactly calculate coverage levels for disability support schemes, since there are no reliable figures about the number of disabled people and their support needs. However, assuming that there are no major short-term fluctuations in this group, the development of the relative number of recipients of PA (number of recipients per 100,000 inhabitants) can serve as a proxy to grasp trends in coverage development.

The relative number of PA-recipients has risen steadily up until about 2010–2011 (see Figure 1). From this point of time we can see a stagnant trend until about 2015 and a decline for the most recent period until 2017. This decline is due to a shrinking number of AA-recipients, which is only partially compensated by a slightly rising number of municipal PA-recipients.

Can these figures be regarded as a sign of a trend reversal, as regards the process of defamilialization of disability support? The answer depends on whether the declining number of people included in the PA-system is regarded as an indication of declining support needs or rather as an expression of stronger admission restrictions.

5.2. Approval Rate, Withdrawal Decisions and Assessment Criteria

Figures on the approval rate for first-time AA-applications strongly suggest that rather the latter is the case (see figure 2, below). In 2005 about 70% of all AA-applications were approved. Around 2010 the approval rate hovered around 50%. According to the most recent figures from January to June 2017, now only 17% of all people seeking AA are admitted. The shrinking approval rate is not due to a rising number of applicants. By contrary, the absolute number of AA-applicants per year has been relatively stable since 2005, hovering around 2,500 applications per year (SSIA, 2017b, p. 39).

It has not only become much harder to get access to AA for first-time applicants. Also, those who are already covered by AA run a heightened risk to lose their AA at the two-year follow-up checkpoints. The proportion of follow-ups leading to AA-withdrawal has remained stable at around 8% in the period 2009–2016, yet it has doubled from 2016 to 2017 according to provisional figures from the SSIA (2017b, p. 52–53).

According to the SSIA's own analyses (2017a, 2017b) the development concerning approval and withdrawal rates is mostly due to sharpened assessment criteria. These have in turn partly been prompted by two Supreme Administrative Court (SAC) rulings from 2012 and 2015. The SAC-ruling from 2012 (HFD, 2012) prescribes that the need of assistance for medical self-care, such as assistance with ostomy, catheter and enteral nutrition cannot be regarded as a basic need in the sense of LSS (NBHW, 2017b, p. 19). Another SAC-decision from 2015 stipulates that only mental health problems can constitute other assistance needs, "requiring detailed knowledge of the person" (HFD, 2015). Therefore, for example, the need of assistance with breathing, handling of epileptic seizures, etc., would not constitute a PA need according to LSS (NBHW, 2017b, p. 19). Yet another SAC-decision from July 2017 (HFD, 2017) was expected to drastically reduce the chances of applicants to receive AA in the future, prescribing that waiting hours and preparedness of PA-staff in between active assistance activ-

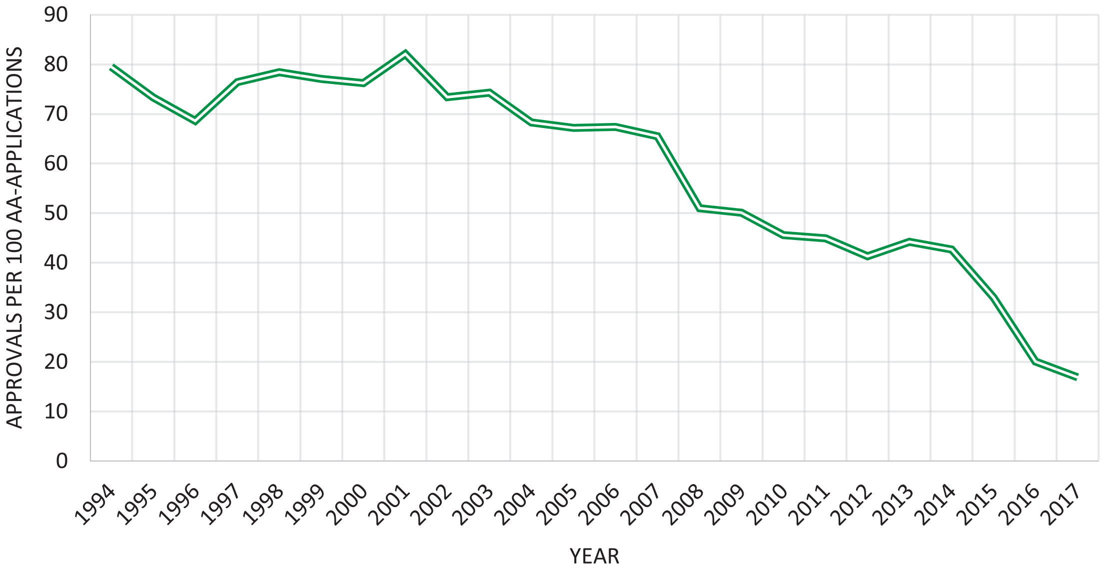

Figure 2. Approval rate for first-time AA-applications, 1994–2017. Sources: SSIA (2017a); data from SSIA retrieved from Independent Living Institute (2018).

ities shall not be counted when PA needs are calculated. The government has pledged to attempt to halt the potential impact of this recent court decision (Government of Sweden, 2018).

More recently, also governmental appropriation directives calling for cost containment have implicitly encouraged SSIA to sharpen admission criteria. The appropriation directive from 2015 explicitly instructed SSIA to "contribute to reduce the development of admitted hours in the Assistance Allowance" (Government of Sweden, 2015). SSIA has also on its own become active to tighten admission criteria for AA. Already in 2007 SSIA specified that in the future only "very personal" needs are to be regarded as basic needs in the sense of LSS (Näsman, 2016). SSIA now regards, for instance, certain forms of *motivational assistance* no longer as a basic need in the sense of LSS. When it comes to children applying for AA, it is often argued that motivational assistance as well as other types of assistance such as constant supervision can instead be expected to be a part of parents' "ordinary responsibility" for their children (SSIA, 2017a, p. 29). Therefore, particularly children with autism or similar conditions now run a much higher risk of non-approval in admission or re-evaluation assessments. Yet, the chances of approval have shrunken for all categories covered by LSS (see SSIA, 2017a, pp. 19f).

Altogether, it can be concluded that the admission threshold for AA has substantially been raised. Only to a small extent the declining approval rate for AA has been compensated by a slightly rising influx of PA-applicants into municipal PA (see figures on municipal PA above).

5.3. Service Intensity

As we have seen above, the coverage of PA and, in particular, the admission chances for first-time PA-applicants have been reduced in the past recent years. Looking at intensity figures another trend can be observed (see Figure 3). The number of assistance hours granted per average AA-recipient has risen steadily since 1995, except for the last year. Looking at overall data covering both AA and municipal PA a slight decrease of the average service intensity per recipient can be observed, though, since an increasing proportion of those who get PA now must rely on municipal PA, which per definition has a lower service intensity.

How can we understand this trend? As said above, in the past decade it has become harder and harder to get admitted to AA, meaning that to an increasing extent only those with very extensive support needs are granted access to the PA-system. Hence, the observed trend simply mirrors the fact that PA has become more and more focused on people who need comprehensive assistance, whereas others are barred from access.

Altogether, the figures presented here suggest that the current Swedish PA-system is in a critical situation. Looking solely at long time series about coverage figures, no dramatic changes can be seen yet. However, digging deeper and focusing on the development of approval rates for first-time AA-applicants and analysing recent Administrative Court decisions another picture emerges, suggesting that we might be witnessing the very beginning of a dismantling of the universal and defamilializing character of Swedish PA. Access to AA now seems to be reserved for those with very extensive needs of assistance, whereas others who also may have substantial support needs mostly are declined access. When it comes to disabled children, PA is often declined with the explicit motivation that their parents can be expected to take care of their needs due to their legally stipulated parental responsibility (Fridström Montoya, 2017; SSIA, 2017b).

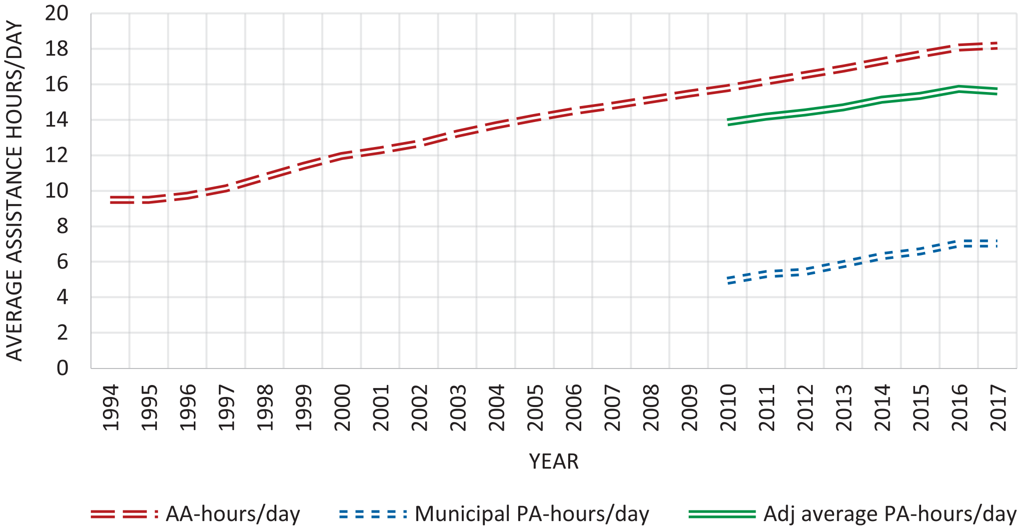

Figure 3. PA-intensity, 1994–2017. Source: own calculations based on data from SSIA, retrieved from Independent Living Institute (2018).

6. Discussion: Possible Consequences for Agency and Equality

The figures above reveal that a large proportion of AA-applications are declined. In this section, we will discuss the possible consequences of AA-decline for the agency and the equality of the affected disabled people and their families.

6.1. Agency

In a recent enquiry, the Swedish NBHW has analyzed the fate of 460 disabled persons who have either been declined access to AA or have experienced withdrawn AA in the first half of 2017 (NBHW, 2017b). In this group, 40% are children. According to NBHW's analyses many in this group have considerable support needs. Nevertheless, 20% are now without any support services whatsoever. Two thirds receive municipal PA, which, however, normally does not exceed 20 hours per week. Some receive other municipal services, such as *relief care service in the home* and *short-term residential care*. For most affected persons, all these alternative services have proven to be non-sufficient in relation to their needs of assistance. NBHW's report also reveals that close relatives of disabled people with declined AA very often have to take over a high support responsibility, which often is conceived as too high to be manageable. Because of that, an increasing number of disabled people end up in LSS-homes. Statistical data confirm that this form of residential disability support is on the rise again (NBHW, 2017a, p. 31).

From the enquiry of NBHW and also from another study carried out by Näsman (2016) yielding similar results, it can be concluded that AA-decline has huge consequences for the agency and the life chances of many disabled people and their relatives. The affected disabled people often become very strongly dependent on familial support or, alternatively, they will be bound to a residential support facility, which arguably hits their agency even more drastically. AA-decline also vastly deteriorates the agency of many relatives of disabled people with comprehensive support needs, who often are forced to abstain themselves from active participation in social life—including labor market participation—and to live with the social and material consequences thereof.

6.2. Equality

What then are the consequences for equality? Here we will distinguish between functionality related, gender related, class related and local equality.

6.2.1. Functionality Related Equality

One of the main ambitions of LSS is to further "equality in living conditions" and thus to allow disabled people with comprehensive support needs to "live as others" (SFS, 1993, 5§). This goal has probably never been fully met (von Granitz, Reine, Sonnander, & Winblad, 2017), yet the rather unique universal and generous character of Swedish PA, allowed huge strides in the right direction in the period of PA-expansion. However, in the most recent years PA has become much weaker in terms of universalism and defamilialization of support responsibilities and, in consequence, also its agency boosting function has started to crumble. As argued above, the agency of many disabled people and their relatives has been reduced because of the tightened AA-assessment criteria. Following the argument of Sen (1992) that agency is a major dimension of equality, this implies that *functionality related inequality* is on the rise again.

6.2.2. Gender Equality

Given the fact that informal support is predominantly carried out by women, it is often argued that defamilialization primarily boosts the agency of women and, therefore, that it is an important precondition of gender equality (e.g., McLaughlin & Glendinning, 1994; Ulmanen, 2015). Yet, in the current Swedish PA-system we are rather witnessing a refamilialization trend. Arguably, this trend most probably implies a deepening of *gender inequality*.

6.2.3. Class Equality

In the last decade, we have seen a rise of commercial household services in Sweden, prompted by the introduction of an earmarked tax deduction for the purchase of these services in 2006 (Erlandsson, Storm, Stranz, Szebehely, & Trydegård, 2013). We know that a significant portion of older persons resorts to these kind of services as an alternative to home help services (Erlandsson et. al, 2013; Ulmanen & Szebehely, 2015) and there have been rumors in the press that disabled people with declined PA are starting to do the same. Can these commercial services to some extent compensate for the decreased public PA-provision?

Some social policy researchers do conceive commercial personal services as a possible alternative route towards defamilialization (Esping-Andersen, 1999; Saraceno, 2010). However, the problem with this second route of defamilialization is that it is only accessible for the economically privileged. Only publicly regulated services are granted universally, based on citizenship and/or needs. Commercial services are instead allocated after purchasing power. Figures about the consumption of commercial services among older people reveal that these services are indeed foremost consumed by high income groups (Erlandsson et al., 2013; Ulmanen & Szebehely, 2015). Most probably we would see the same situation in the field of disability support: in case of declined or insufficient PA, only the affluent can afford to purchase commercial support alternatives, but not the less affluent, who only can resort to familial support. Hence, we can conclude that we will end up with a *segmented defamilialization* of support, if commercial services replace publicly administered PA to a significant extent. In other words, the current development of PA might in the longer run also imply a deepened *class related inequality* among disabled people who are excluded from AA. People with lower education already are underprivileged when it comes to PA-access, since they are less likely to have the capacity to effectively claim their social rights, in particular if they are required to take up a legal fight against authorities.

6.2.4. Local Equality

One of the main reasons behind the introduction of AA and the related transfer of the main admission approval responsibility to the SSIA, was to establish a uniform admission standard across the country (Näsman, 2016). Ironically, the recent development of AA forces many PA applicants to apply for municipal PA. Yet, Swedish municipalities employ very different admission criteria and therefore the chances of PA applicants to be at least admitted municipal PA differ substantially between municipalities (NBHW, 2017b). Moreover, the possibility to purchase commercial service alternatives varies greatly across the country. These services tend to be available only in densely populated areas (Erlandsson et al., 2013). Altogether, this means that the recent sharpening of admission criteria for AA most probably also engenders an increasing *local inequality* among disabled in need of support.

7. Conclusion

The Swedish disability support system is often praised by international observers. PA is conceived as the crown jewel of this system. It is assumed to be universally accessible for all disabled people with comprehensive needs of assistance. Due to this assumed character, Swedish PA is believed to effectively enable disabled people and their relatives to lessen their mutual dependency, to boost their agency and to enhance their social position in society. This image of Swedish PA has been underpinned by statistical data witnessing a constantly rising relative number of PA-recipients from the introduction of LSS in 1994 up until about 2010–2011.

Yet, data from the past decade about approval rates for AA-seekers as well as analyses of changed admission criteria suggest, that we might be in the wake of a reversed development. Potential newcomers to the PA-system meet drastically decreased chances to pass the admission tests. Those already covered by PA run a heightened risk to lose their PA, when their assistance needs are scrutinized in their next re-assessment. Not only disabled people with minor support needs are affected, but also certain groups who according to a common-sense definition of comprehensive disability should qualify for AA, such as persons with physical impairments in need of breathing assistance or children with autism in need of motivational assistance. If this recent trend continues, we might very well be witnessing the very beginning of the dismantling of PA as a universal support system for disabled people with substantial support needs.

There will definitely be consequences both on the individual and the societal level if this trend is allowed to continue. On the individual level, we will see that an ever-larger number of disabled people will have to turn to municipal service alternatives, which do not have the capacity or quality to fully satisfy their support needs (Näsman, 2016). As a result, a large group of disabled people and their relatives will be exposed to increased familial dependency, a low level of agency and consequently reduced life chances both in economic and other terms (Näsman, 2016; NBHW, 2017b).

In the long run, there will also be consequences on the societal level, both in terms of inequality and economic sustainability. A dwindling state sponsored disability support means more inequality (both in terms of economic resources and agency) between disabled and their relatives on one hand, and those unaffected by disability on the other. Female relatives will be particularly hit by diminished agency and therefore also gender equality will be influenced negatively. A rising proportion of disabled people, will need to find alternative support solutions. Yet, commercial service alternatives that potentially can replace familial support are only accessible for the economically privileged and thus also class differentials will rise within the group of disabled and their families. Interestingly, the recent trend of PA-austerity can also be questioned from a strict economic standpoint. As Knutsson (2017) and Näsman (2016) have argued, the economic savings from reducing access to PA are most probably much lower than the alternative costs in terms of shrinking employment activity and heightened dependency on welfare benefits among disabled and their relatives. Altogether, it can be argued that a continued austerity in the PA-sector most probably will be detrimental for both the social and the economic sustainability of the Swedish society.

The recent trend in the PA-sector can only be reverted if we understand its main causes. The governmental appropriation directive from 2015 suggests that cost containment motives might be one important cause behind the most recent sharpening of admission criteria. Most certainly, vagueness in the stipulations of LSS about what needs constitute *basic needs* is another important cause. This vagueness has made possible the recent SAC rulings (Näsman, 2016). Political decision-makers will have to re-evaluate both the recent cost containment strategy as well as the legal design of LSS if they want to save the Swedish PA-system from collapse. But they will have to act swiftly to get the actual development of the system back into line with the universal and emancipatory ambition of LSS. If decision makers rather choose to take a passive stance, the universal, empowering and equalizing PA-system that we have come to know will disappear and will be replaced by a more old-fashioned system, characterized by familial dependency, poor agency and much less equality—a system that not only would be disadvantageous for the affected disabled people and their families, but also for society as a whole.

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Conflict of Interests

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About the Authors

Dietmar Rauch is Senior Lecturer in social work. His research areas are social policy, social care services and old age policy.

Elisabeth Olin is Professor in social work. Her research concerns the life situation of disabled people, primarily related to various aspects of their daily living, social relationships and participation in society.

Anna Dunér is Professor in social work. Her research areas are formal and informal support networks, and social work with older and disabled people.

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Article

'Evidence' of Neglect as a Form of Structural Violence: Parents with Intellectual Disabilities and Custody Deprivation

Hanna Björg Sigurjónsdóttir * and James G. Rice

Faculty of Social and Human Sciences, University of Iceland, 105 Reykjavík, Iceland; E-Mails: hbs@hi.is (H.B.S.), james@hi.is (J.G.R.)

* Corresponding author

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Abstract

This contribution draws upon the findings from a multi-year project in Iceland entitled *Family Life and Disability*. One goal of the project was to analyse whether or not parents with intellectual disabilities (ID) experienced differential treatment in custody deprivation proceedings. The dataset consisted of the analysis of publicly available court documents concerning custody deprivation cases from 2012 to 2017. The project later expanded its dataset to include supplementary information provided by parents. The initial findings mirrored that of the international literature, that parents with ID faced disproportionate levels of permanent custody deprivation and prejudicial attitudes from the child protection system. This contribution critically explores the evidence of parenting neglect that forms of basis for custody deprivation in our dataset. Both authors noted a preponderance of evidence in our dataset that appeared strange and at times absurd, and generally did not appear in cases were ID was not a factor. We contend that this evidence played a prejudicial role in the outcome of these cases. In conclusion we argue that the patterned reliance upon this kind of 'evidence' is a form of structural violence which serves to unjustly exclude marginalised groups from the parenting role.

Keywords

child protection; custody deprivation; disability; Iceland; intellectual disability; structural violence

Issue

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1. Introduction

This contribution focuses on one particular problematic that emerged during the course of the project *Family Life and Disability* which was conducted in Iceland from 2014 until 2017. This problem concerned how to analyse some of the odd, strange or at times even absurd evidence of parental neglect that routinely appeared in the analysis of our data. The dataset for this project was a national sample of publicly accessible court documents concerning permanent custody deprivation cases over the years 2002 through to 2012. This was later extended up until the time of writing and also included further supplementary information provided to us by some parents. Our primary, but not exclusive, focus was on cases concerning parents with intellectual disabilities (ID) who had lost custody of their children as the result of actions undertaken by the child protection system. We contend that a careful analysis of the documents pertaining to child protection cases can help to reveal some of the systemic problems underlying how child protection is practiced. The international literature is clear that parents with disabilities, particularly ID, face disproportionate rates of custody deprivation as the result of the entrenched stigmas and negative perceptions held against parents with disabilities and which excludes them from the parenting role. We contend that disability discrimination or prejudice against people with ID can shape crucial decisions in the child protection process and this is influential at every stage of the child protection process, from notifications, to parenting assessments, to the implementation and evaluation of support measures and in the final decisions of the cases. In this article, our goal is to demonstrate some of the effects of these biases through a close examination of how some evidence of parental neglect or incompetence is produced in these cases. The analytical framework that follows is intended as an exploration of how we may interpret these findings, as well as to invite debate.

In the data collection and assessment stages of our project we remained perplexed as to why we found such strange evidence of parenting neglect or incompetence predominantly in cases concerning parents with ID, and significantly less so in cases that concerned parents in other situations, such as parents with substance abuse issues. We noted an almost total absence of this kind of evidence in cases that concerned the direct and severe abuse or neglect of children for which there was clear and uncontested evidence that children were in immediate danger or risk in terms of their health, safety or development. It was not until the later stages of the project that we started to realise the possible significance of this finding. We will present some examples of this kind of evidence which exemplifies the patterns that we have noted before turning to a brief case study. The first author has been involved in research pertaining to parents with ID in Iceland for many years. During the course of our more recent project it became apparent, during a reanalysis of some older data, that this kind of 'absurd' evidence about the parenting capabilities of parents with disabilities has been a feature of Icelandic child protection for many years. This contribution will conclude with an analysis of a previously unpublished case study which details the struggles by two parents with ID to retain custody of their newborn child. The details are presented through data collected through interviews with all relevant parties: the parents, some extended family of the parents, the parents' lawyer, the municipal social worker assigned to the case, the prenatal care and maternity ward professionals involved, child protection workers, the disabled persons' ombudsman tasked to safeguard the parents' rights, and the psychologist assigned to evaluate the parents. Informed by the insights drawn from our *Family Life and Disability* project and the scholarly literature, we will argue that biases, prejudiced assumptions and even fears about the parenting capabilities of people with ID play a significant role in influencing the child protection process, the nature of the evidence collected and the results of unjust outcomes and unnecessary custody deprivation.

2. Parenting and ID

The international literature (e.g., Alexius & Hollander, 2014; Aunos, Goupil, & Feldman, 2003; Gould & Dodd, 2014; Lightfoot, Hill, & LaLiberte, 2010; Lightfoot, Laliberte, & Cho, 2017; McConnell & Llewellyn, 2000; McConnell, Llewellyn, & Ferronato, 2006; Reinders, 2008), as well as research in Iceland (Sigurjónsdóttir & Rice, 2016; Traustadóttir & Sigurjónsdóttir, 2008), has shown that parents with disabilities, particularly parents with ID, face disproportionate rates of interference from child protection authorities and significant risks of custody deprivation. The literature suggests that fear, prejudice, negative attitudes and discrimination play a significant role in explaining the additional scrutiny from child protection services faced by parents with disabilities. Some scholars (e.g. Alexius & Hollander, 2014) argue that evidence of direct discrimination in child protection matters is difficult to prove, though they contend that certain practices could indeed be understood as discriminatory. One example, arguably, of direct discrimination in the Icelandic context can be found within the guidelines produced by the national child protection agency. These guidelines define what is meant by neglect and which includes leaving children in the care of a person who is "mentally retarded" (*þroskaheftur*) (Freysteinsdóttir, 2012, p. 8). However, the politics of disability have been changing in Iceland and child protection practices need to reflect these changes, particularly as disability matters are increasingly framed as human rights issues. Iceland ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2016. Article 23 concerning respect for home and the family states that all forms of discrimination against persons with disabilities, "in all matters relating to marriage, family, parenthood and relationships", need to be eliminated. (UNCRPD, 2006). Not all parents with ID or related impairments lose custody of their children in Iceland. But for those who do, disability status is sometimes cited by the child protection authorities as the primary reason for custody deprivation (e.g. unable to benefit from treatment or training). However, in our experience of cases in which low IQ is referred to, much of the evidence as to the role that IQ plays in parenting is unclear, ambiguous and often indirect and inferred from a compilation from many, often quite dubious, sources that comprise the kind of evidence under discussion here. The accuracy of the instruments used to predict the risks of child abuse or neglect in general have been questioned in the literature and often fail to provide critical information on what kinds of support are effective in specific circumstances (see e.g. Taylor, Baldwin, & Spencer, 2008). Our contention is that much of the evidence that revolves around the disability status of the parent in various ways speaks more to the ignorance or fears held by the professionals in the system than it does to any real danger faced by their children. We contend that these fears colour the entire process, exaggerating the weaknesses of these parents, minimizing their strengths, and casting doubt upon the effectiveness of support measures. As such it is very difficult for these parents to be treated fairly by the system and to receive the tailored and meaningful support they need to be effective parents. The child protection system need only demonstrate a reasonable level of 'risk' of neglect—not even evidence of direct abuse or neglect—to terminate custody. It is here where this kind of evidence plays an important role.

3. Evidence and Absurdities

At one point in our research we began to discuss what to do with the 'absurdities'. Early in the process we noticed time and time again statements in our dataset from child protection workers, psychologists conducting parenting assessments, and those hired to supervise and monitor parents under investigation (known as *tilsjón* in Iceland) examples of what we considered to be 'odd' or 'absurd' evidence. This included such things as the observation there was a cat on the bed in a parent's home, with no explanation as to its significance or relevance for an investigation of parenting neglect. Or that there were fingerprint smudges on a window pane, which one would normally expect in a household with children. Or a comment from an anonymous source that a child's teeth were broken and in poor shape, yet a report from a healthcare worker from the same time period made no such observation. Or a comment that there was a dresser in a child's bedroom full of small toys that the child had been rooting through, with no further explanation of its import and leaving the reader adrift as to why this was problematic and what it had to do with the matter at hand. Or the observation that there was a 'Russian lightbulb' in the parent's living room, which in Iceland refers to a naked lightbulb without a cover; we later discovered that this 'Russian lightbulb' was merely part of a lighting system in place when the parent moved in and never used. We could easily fill an entire article with these kinds of mundane, seemingly unimportant, sometimes contradictory and most certainly odd observations that we routinely encountered in our project data. We initially left this kind of 'evidence' of parenting neglect unanalysed, reserving it for humorous anecdotes to be used in classrooms and conference presentations about the difficulties that parents with ID in Iceland faced during their encounters with the child protection system. However, as we continued to find more examples of this kind of material we began to ponder its significance.

We consulted a legal professional, concerned that there were matters at play that were beyond our professional knowledge base. We raised this with a professor of law who dismissed this line of questioning because, from her point of view, it is not relevant. A comment made in an assessment of a home by a child protection worker that there was a cat on the bed might be strange, but it would never be a justification for custody deprivation and in her view not worthy of our attention. This is indeed true, as none of this kind of evidence, as individual statements of fact, could ever constitute child abuse or neglect, or be grounds for custody deprivation. Social work in general is concerned with evidence in the form of patterns, not isolated examples (Munro, 2008). There is, for example, nothing in the guidelines issued by the national child protection agency in Iceland concerning neglect pertaining to cats on beds or smudges on windows, and these kinds of observations would most likely never prompt a notification to the system of parenting neglect, let alone form the basis for an investigation. In our estimation, child protection workers and case managers would not see this as evidence either, but rather as merely objective descriptions of the parents' homes and behaviours. Yet the extent to which we encountered this kind of material on a regular basis continued to trouble us, considering as well how often it appeared in cases of parents with ID compared with other parents. Questions remained as to why these kinds of statements were made in the first place and deemed important enough to be entered into a logbook or parenting assessment. Our tentative conclusion is that it was the disability status of the parents that somehow allowed for this evidence to exist and to be given the weight of significance within parenting assessments and reports and which served to present an overall image of parental neglect and incompetence.

When we encountered examples of this 'absurd evidence' in the research process, to call it absurd would admittedly be charitable. During our research sessions we would shake our heads and exclaim something to the effect that this was 'so stupid'. Yet 'stupid' is hardly an appropriate academic framework for analysis and we remained stymied as to what to do with this kind of data. In the absence of clear or direct evidence of neglect these cases were, in our analysis, at their core about the system's response to parents with ID who were rendered ineligible for the parenting role on the basis of disability. Lacking direct or convincing evidence of neglect, the narrative produced in order to justify and legitimate the decision to terminate custody was a composite of different sources of information collected during the investigation and assessment process. This composite collection of seemingly trivial things in isolation served to become, in tandem, the much sought after pattern of neglect or incompetence.

4. Structural Violence and System Abuse

One possible analytical framework in order to understand this kind of evidence and how it came to be can be found in the work of the anthropologist David Graeber (2012). Graeber, in his analysis of bureaucracy, does not resist invoking the term 'stupid' and 'stupidity' in order to understand the everyday forms of disempowerment produced by the workings of bureaucracy, but he uses the term in a very specific way and in conjunction with a theory of violence. The child protection system in Iceland, comprised of a national level agency and a series of local, municipal level committees, is most certainly a bureaucratically organised system and can be argued to exhibit many of the traits and practices that Graeber defines as 'stupid'. However, far from a simplistic analysis or childish name-calling, Graeber develops a sophisticated analysis predicated on the notion of 'structural violence' that we feel aptly describes the power relations that these parents are subjected to. Graeber's work challenges our early assumption that the absurd evidence we encountered was primarily the result of a lack of training, a lack of appropriate education or, simply put, a form of incompetence or 'stupidity'. Graeber, considering the classic work on power and bureaucracy from Weber to Foucault, notes that despite their differences these scholars shared the assumption that this form of power was rational, ordered, purposeful and very effective. Our error was interpreting this evidence as irrational rather than as a different form of rationality.

Violence, like stupidity, is a common, everyday term that in the context of the analysis that Graeber puts forth could be easily misconstrued. Graeber is clear that violence takes many forms. It is generally accepted that bureaucratic agencies routinely apply 'force'; they make us do things on a regular basis that we may not want to, such as pay taxes, trim our hedges, and observe a myriad of seemingly nonsensical by-laws. Repeated infractions may result in warnings, fines and possibly custodial arrangements for a continued lack of compliance. These are all forms of force and Graeber contends that force is "just a euphemistic way to refer to violence" (Graeber, 2012, p. 112). While warnings or fines from a municipal agency about a hedge not being trimmed properly or putting out garbage too early or mixing paper with plastic in a recycling bin may not appear to be a form of violence, in this sense they can be construed as such. A court order to permanently remove custody of child from a birth parent is a clearer form of violence. In the context of parenting with intellectual disability, Booth and Booth (1998) have referred to this as 'system abuse', as they contend that a system intended to protect and support vulnerable families has instead wrought harm and destruction. This often occurs in the form of low-level daily injustices which is not reducible to a single act or actor, but which can result in dramatic outcomes such as permanent child custody deprivation. Following Booth and Booth, we contend that the outcome of custody deprivation is only the more observable and apparent form of this systemic violence, but the underlying process itself is comprised of a series of more mundane forms of ongoing practices that are not often held up for inspection. To avoid the confusion with the common association of violence with physical violence conducted by a human agent, social scientists have preferred to frame this as 'structural violence', especially in the context of marginalized populations. Graeber summarizes structural violence, drawing upon the earlier work of Johann Galtung (1969), as "any institutional arrangement that, by its very operation, regularly causes physical or psychological harm to a certain portion of the population, or imposes limits on their freedom" (Graeber, 2012, p. 112).

We are fully aware that the official mission statement of the child protection authorities in Iceland, as elsewhere, tasks such agencies with harm reduction concerning children. If we can consider the family to be a social-cultural institutional arrangement, the child protection system can be seen as an agent that acts against structural violence applied toward children and this is an endeavour that we strongly support. However, we also need to consider the forms of structural violence that are routinely applied toward persons with disabilities, and parents with ID in particular, by this system that is supposed to support them. What we observe in our research are not just actions against individuals, or occurrences within specific cases, but patterns of structural violence against marginalized parents that share commonalities, such as the factor of disability. We observe this occurring on a routine basis and not just in the context of the 'absurdities' under consideration here. There is a high degree of collusion among various institutions and it must be remembered that many of the allies of the parents, such as lawyers and even family, often defer to the opinions of professionals whose voices are generally treated as representing the official interpretation of events. There is perhaps no greater form of violence permitted under civil law than permanently removing children from birth parents. It is a violent act, and one which has far reaching consequences for the parents, their extended families, and the children who in many cases are placed into foster care. Placed into this framework this provides strong argumentation that permanent custody deprivation must only occur under the most serious of situations in which the health, security and development of children is in immediate danger or with strong evidence of serious risks of such. The analysis of structural violence also demands a rigorous and critical approach to analysing child protection practices, such as how investigations are conducted, evidence is collected and analysed, and support is implemented and monitored, especially so pertaining to marginalized parents. It is the context of structural violence that helps to explain the existence of this 'absurd' or 'stupid' evidence of neglect and its significance, without which we merely have a body of strange observations made by those who collect information about parents on behalf of the child protection system. It is also not helpful to dismiss the descriptions of child protection staff and allied professionals about cats on beds or Russian lightbulbs as nonsensical, stupid or trivial comments, or to dismiss the individuals who make and note these observations as less than intelligent, as they are not. Graeber contends that it is structural violence which allows this 'stupidity' to exist and thrive in the first place. In our context, it is the culturally patterned hostility toward parents with ID which informs child protection work and which in turns allows this information to be perceived as significant and meaningful evidence of neglectful parenting. The observations that support these views, no matter it seems how absurd, are accepted as part of the narrative of these parents. As Graeber argues:

> It is not so much that bureaucratic procedures are inherently stupid, or even that they tend to pro-

> duce behavior that they themselves define as stupid, but rather, that they are invariably ways of managing social situations that are already stupid because they are founded on structural violence. (Graeber 2012, p. 112)

5. A Case Study Example

In order to illustrate some of these processes at work, we have decided to present in some detail a case study that was originally collected by the first author and subsequently re-analysed in light of our current findings placed into Graeber's analytical framework. This particular case study affords a level of detail about a specific case that would not be apparent from court records alone as it also draws upon interview material with all relevant parties. It also is an excellent example of the matter under discussion and it illustrates that little has changed in Iceland as it exhibits the same patterns found within our more recent dataset. Graeber argues that he does not intend to characterise bureaucracies and their staff and actions as 'stupid' in the simple sense, but that the social situations can themselves be said to be stupid in the first place because they are "founded on structural violence" (Graeber, 2012, p. 112). Our case study appears to fit well with Graeber's analysis. The case involved a couple in their twenties who became a 'case' when the woman's mother contacted the local social services seeking advice on behalf of her daughter, as the couple were having their first child and they both had mild ID and would need some support. Before the due date, however, the mother became ill and had to have a caesarean which resulted in her having to stay in the hospital for 10 days to recover. The case concluded with the newborn being removed from the parents 11 days after birth and being placed into a temporary shelter, followed by an expedited process which led to permanent custody deprivation; the parents' attempts to contest the process were not successful. Over the course of these events it is clear that numerous factors of 'stupidity' led to this outcome. Many of the professionals in their reflections upon the case cited the lack of inter-agency cooperation as a primary factor in the outcome. For example, the original social worker from the municipal social services began planning a support system to implement before the child was born. Once the case moved from being governed by the local social services to that of children's protection, this form of support was no longer available under this other system and the parents were not able to get the kind of long-term, specialised support they needed. In another context, the lack of inter-agency cooperation and the lack of continuity in how a case is worked when it moves from one agency to another could be analysed as an outcome based upon poor planning and service management. However, what makes this case 'stupid' in Graeber's sense is that the parents not only had to contend with poorly organised services, but a deeper form of structural violence that allowed this 'stupidity' to thrive and ultimately determine the outcome of custody deprivation as the result of the fears and prejudices that revolved around the category of intellectual disability.

The lack of inter-agency cooperation certainly did not help the situation, but in analysing the interview material it is apparent that the prejudices, fears, misconceptions, and lack of knowledge or training in this area concerning ID and parenting was the significant factor which produced a good deal of absurd evidence and all but ensured this kind of outcome. Where cooperation did occur, such between the parents' lawyer and the disabled persons' ombudsman, this harmonious relationship (as it was described by the lawyer) seemed to be driven by the tacit acceptance the child would probably be better off with foster parents due to their perception of the parents' disabilities and lack of capability. The fact that the parents' own lawyer and the ombudsman felt this way, when it is their job to advocate on behalf of the parents, illustrates the structural violence inherent in the system that the parents had to negotiate from the outset. Both the father and the mother's mother commented upon this. The latter, after describing a very formal and solemn meeting hosted by children's protective services, noted: "It was so strange; it was as if our lawyer was representing the child protection service and not my daughter and her partner. No one appeared to be supporting us". This is a consistent pattern in our larger experience that the fears are so great among support professionals about the dangers that parents with ID pose to their children that many will favour the view of the system, tacitly or explicitly. The parents' lawyer argued that he felt he had no choice when confronted with reports from healthcare workers and child protection staff but to accept their results: "As a lawyer I had to draw a line somewhere, put away my legal power and trust professionals". Here is an outcome produced as the result of structural violence, 'stupidity' in Graeber's specialised sense. It is of course rational to trust professionals in one sense, but with a close examination of the case data it is clear that this trust is misplaced.

The analysis of the data reveals quite clearly that there were vast differences in professional knowledge concerning intellectual disability in general and ID and parenting in specific. The gross injustice is that it is the voices of those who appeared to be the least knowledgeable that were given prominence. The professionals involved, ranging from social workers to midwives, prenatal care nurses, to maternity unit workers, child protection staff and legal professionals all held their own specialised disciplinary knowledge, but most either displayed good knowledge of the issues, or admitted their own lack of knowledge in this area was a problem. Children's protective services was the only agency that consistently maintained their 'professionalism' in this area and did not appear to be self-critical, even when it became clear that the case manager had little contact with the parents and the staff of the shelter, tasked to surveil and evaluate the parents, had little knowledge in this area as well. The initial social worker was adamant that support measures at the least had to be between 3 to 6 months in duration to be effective, including basic support such as housing and finance, along with specialised support for parent training and education for parents with ID, which the couple appeared happy to receive. With the unexpected emergency caesarean, the lack of liaison with the maternity unit and with the social worker out of the country at the time, a panic seemed to ensue within the hospital. The staff were uncertain what to do when the parents were about to be discharged without any apparent support measures up and running and in place. Under pressure to move the process forward, and under advice from the social worker, the matter was transferred to child protection where the only support available under that system was a supervised flat for training parents (which was booked at the time) or else temporary shelter with limited contact with the parents. Both options fell far short of what social services envisioned. Both the social worker, and an infant nurse with experience with parents with ID, scoffed at these measures as a recipe for failure. The infant nurse commented:

> I consider a three-month period in the training home the minimum time required for these parents….All parents with their first child need a lot of support to learn to care for their child. Parents with learning difficulties are no different, they just need more time and support.

What is striking is the lack of knowledge on the part of other agencies that generally went unrecognised when the decision was made to terminate custody. A member of the hospital's maternity unit, whose reports were given significant prominence, simply did not know what was available or even needed for parents with this kind of impairment: "What other help and assistance could they get outside the hospital? We didn't know and it was extremely frustrating when social services abdicated their responsibility". This person continued: "Trying to assess the case without the information and knowledge in the field of learning disability makes the whole task enormous". Even within the child protection system it is clear that there was little appreciation for the needs of parents with ID. The child protection case manager described the two workers at the temporary shelter and training facility as 'experienced' yet appeared satisfied that the parents were given only four weeks to demonstrate their capability as parents. The staff at the shelter concurred: "We believe the training period was long enough….We don't believe longer time would have changed anything".

Not only did the ignorance about what constitutes meaningful and individually tailored support play a critical role in producing the outcomes, there was a surprising level of candidness among some of those involved about the prejudice about ID as a factor. The parents of course saw this for what it was and noted the paternalism with the support system as problematic, let alone the open hostility they later encountered in the child protection system. The father, for example, balked at the social worker's insistence that they needed support with things such as shopping, when he was eager to learn about parenting. He commented: "We always did these things by ourselves. They [social services] were making us much more disabled than we are". He argued, as probably all first-time parents do, what he needed help with was taking care of an infant: "I didn't know anything about babies but the way we were treated I feel like they expected us to be born into the parental role". The lack of knowledge about intellectual disability ensured the production of absurd statements. For example, in the view of the staff of the maternity ward, the parents were essentially perceived as children. As one worker put it: "We soon recognised how they were like small children themselves who could not assess their child's needs accurately….There were many things in their behaviour that made us feel like they were children looking after a child". Others, such as workers in the child protection system, perceived the mother as barely able to articulate her thoughts. This is a markedly different assessment from those with experience with persons with ID, such as a pre-natal health specialist who described the mother as having "slight learning difficulties". The child protection workers at the shelter, whose negative assessment played a pivotal role in the custody deprivation process, acknowledged preconceptions and misconceptions of the parents as playing a role in their work, citing the information they received from the maternity unit in specific:

> The picture painted from the hospital was painted in very dark colours, darker colours than it actually was. It caused difficulties because we didn't know them [the parents] and we were told that their ability was very little and that they couldn't learn. That wasn't right.

Given the dominance of these views of the parents it is unlikely that any report could possibly present an objective and unbiased view of their capabilities and support needs. Those with more informed and progressive views complained that they were rarely, if ever, consulted once the case became a child protection matter.

An additional absurdity is that the disability status of the parents was also selectively invoked or acknowledged. The same workers who received the 'dark picture' of the parents at times insisted that they treat them like any other parent, forgetting that these parents may require specialised educational or training methods ("We always had to tell her exactly what she had to do. It was not enough, like it is with most parents, just to say you just do this or that"). This also appeared to be the case when the parents' legitimate frustrations were dismissed or misinterpreted. Throughout the case there was constant evidence that the parents were getting mixed messages about breast-feeding, or not; when to hold the child and how, or not. This would be confusing for any new parents, let alone for parents of an infant they only had limited access to and during which time they were under intense scrutiny ("We were watching them all the time, especially her, we just sat the whole day watching her", said a shelter worker). Not only was the factor of ID at times selectively forgotten, and the artificial scenario under which they were supposed to demonstrate parenting skills, so was the basic context itself. Two weeks after giving birth to her first child under difficult circumstances, the mother was struggling with numerous and powerful bureaucratic entities that threatened to permanently remove her child, all the while she was still recovering from a major operation and fatigued. Only the driving narrative that she was ineligible for the parenting role as the result of her impairment itself could explain this lacuna within the child protection system concerning her situation. The continued complaints that the mother was withdrawn, listless, passive, and lacked energy played a significant role in the final outcome (said a shelter worker: "We would not have trusted her to be alone with the child, in the beginning she couldn't carry it up the stairs") and there was little attention paid to the context under which these observations were produced.

6. Concluding Remarks

The end result of this case, like many others we have analysed over the course of our larger project, arose as the result of numerous factors, but the link which bound these factors together is the negative and fearful perception of intellectual disability and parenting. We are not suggesting that the system should not respond to parents with support needs; quite the contrary. The system also needs to respond to international human rights treaties that Iceland is a party to, such as the UNCRPD, which calls for the elimination of discrimination against person with disabilities "in all matters relating to marriage, family, parenthood and relationships" (UNCRPD, 2006). But it is clear that inter-agency cooperation and human rights treaties are not enough if key actors within the system lack knowledge and experience in this area, and the lack of knowledge is filled with shared prejudices and misconceptions. A 'stupid' outcome, in Graeber's (2012) sense, is inevitable without the willingness to be critical and to interrogate preconceptions and prejudice. Above all, there needs to be a recognition that the process can be a form of system abuse and a product of structural violence. This was well put by the parents' lawyer from the case study who commented: "I believe the parents needed trauma counselling at the hospital when the child was taken temporarily and then again at the final custodial removal stage." Trauma is, by definition, a sudden physical or psychological shock as the result of a form of violence and trauma is what these parents experienced. Without an honest interrogation of how the child protection system, broadly speaking, responds to parents with ID, as well as other marginalised groups, child protection will remain to be a deeply flawed and problematic process.

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Conflict of Interests

The authors declare no conflict of interests.

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About the Authors

Hanna Björg Sigurjónsdóttir graduated from the University of Sheffield, UK, in 2005. She is currently a Professor in Disability Studies at the University of Iceland and a member of the Centre for Disability Studies at the University of Iceland. Much of her research has focused on families headed by parents with intellectual disabilities and their children. She collaborates with Dr. James Rice in the project Family Life and Disability, which is supported by the University of Iceland's Research Fund from 2014 to 2017.

James G. Rice is a Canadian anthropologist who graduated from the Memorial University of Newfoundland, Canada, in 2007. He is currently an Assistant Professor of Anthropology, as well as member of the Centre for Disability Studies at the University of Iceland. He is a collaborator with Dr. Hanna Björg Sigurjónsdóttir in the Family Life and Disability project, which is supported by the University of Iceland's Research Fund from 2014 to 2017.

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Article

Being a Disabled Patient: Negotiating the Social Practices of Hospitals in England

Stuart Read *, Val Williams, Pauline Heslop, Victoria Mason-Angelow and Caroline Miles

Norah Fry Centre for Disability Studies, University of Bristol, Bristol, BS8 1TZ, UK; E-Mails: stuart.read@bristol.ac.uk (S.R.), val.williams@bristol.ac.uk (V.W.), pauline.heslop@bristol.ac.uk (P.H.), victoria.mason-angelow@ndti.org.uk (V.M.-A.), caroline.miles@bristol.ac.uk (C.M.)

* Corresponding author

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Abstract

Accessing hospital care and being a patient is a highly individualised process, but it is also dependent on the culture and practices of the hospital and the staff who run it. Each hospital usually has a standard way of ‘doing things’, and a lack of flexibility in this may mean that there are challenges in effectively responding to the needs of disabled people who require ‘reasonably adjusted’ care. Based on qualitative stories told by disabled people accessing hospital services in England, this article describes how hospital practices have the potential to shape a person’s health care experiences. This article uses insights from social practice theories to argue that in order to address the potential problems of ‘misfitting’ that disabled people can experience, we first need to understand and challenge the embedded hospital practices that can continue to disadvantage disabled people.

Keywords

disability identification; disabled people; hospital; patient care; social practices

Issue

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1. Introduction

We start with a seemingly simple problem, that of ensuring that disabled people who need hospital care in the UK receive fair and equal treatment. In the UK, the Equality Act 2010 imposes duties on organisations and service providers to ensure that disabled people are not discriminated against or treated less favourably than non-disabled people (Equality Act, 2010). For example, within the context of health care, the Equality Act 2010 provides disabled people with protections against being denied access to services, or receiving poor care, because of their disability. One protection is that health care providers must make changes or ‘reasonable adjustments’ to their existing practices to ensure that disabled people do not experience ‘substantial’ disadvantage. The Act provides an ‘anticipatory’ duty, for example by ensuring that the general environment is accessible to the range of people likely to need hospital care, with wheelchair accessible buildings and clear signage. In addition, there is a requirement to respond to the needs of individual disabled people, by, for example, changing the timing or length of an appointment, or ensuring that a family member can be involved in a disabled patient’s care (Equality & Human Rights Commission, 2015; MacArthur et al., 2015). Despite the legal framework of the Equality Act 2010, however, it is known that there remain significant inequities for disabled people throughout the UK health care system, including issues with transport, waiting lists, and additional health care cost implications (Sakellariou & Rotarou, 2017; Tuffrey-Wijne et al., 2014), and delays in diagnosis and treatment, such as for people with intellectual disabilities (Heslop et al., 2013).

In this article we are interested in how hospital practices, and adjustments to those practices, are experienced by disabled people, at the embodied level of their physical and emotional experience. As became evident from our research, disability-related needs were often invisible or, notwithstanding the legal protections in place, ignored within the hospital system, and thus a major issue for disabled patients was the need to repeatedly advocate for themselves and explain their needs to staff. It is not always easy to know who counts as disabled, and the act of declaring or disclosing a disability is tightly bound up with the experience of being a patient in a hospital. We shall therefore provide next a brief overview of how the definition and meaning of disability can be shaped by cultural and systemic factors, before turning to an explanation of the social practice theories on which this article is based.

Although disability theorists are widely united in opposing a deficit model of disability (Oliver, 2013; Thomas, 2004), the turn towards a social model of disability is not always sufficient, given that disability is a fluid, context-related concept. Disability 'identification' is often problematic, and fraught with conflicting narratives, including those of disabled people themselves. Despite positive affirmations of disability pride (Swain & Cameron, 1999), the identity of 'being disabled' is far from straightforward. Rejection of the disability identity is common, with many people with specific impairments refusing to see themselves as disabled (Watson, 2002). We explore identity in this article as an ongoing 'becoming' rather than as a one-off event. Disabled people themselves have foregrounded the interrelations between impairment effects and disability, which result in limitations, pain or difficulties, irrespective of the outer social world (Crow, 1996; Shakespeare, 2006). Further, the identity of 'being disabled' is closely dependent on social class, circumstance and on legal protections (see Williams, Swift, & Mason, 2015). Those protections afforded by the Equality Act 2010 raise particularly problematic issues for identification, since an individual is only protected against 'discrimination arising from a disability' (section 15) if the organisation knew or could reasonably have been expected to know that they had a disability (section 15, subsection 2).

In this article, our aim is to apply social practice theoretical approaches, in order to better understand the disabling situations created by hospitals. The turn towards social practices (Reckwitz, 2002; Shove, Pantzar, & Watson, 2012) directs the attention of social scientists towards the material, interconnected and 'ordered' ways in which things get done in everyday life, including within hospitals (Blue & Spurling, 2017). Practices in this sense are not just the activities of practitioners or health care workers, but are simply the human activities in which we all may engage, and a social practice approach helps us to appreciate in more detail how practices are constituted, and how they could evolve or be changed to become more enabling. Shove et al. (2012) argue that social practices are influenced by three interconnected sets of elements: materials, competence and meaning. Materials are the tangible components that are implicated within a social practice. Competence refers to people's capability or knowledge to engage in a social practice. Meaning is the understanding and value people have of a social practice (e.g., an awareness about what is acceptable in this context). All these features that come together to make up a particular social practice will have an influence on how people feel about themselves, how they give meaning to their experience, and ultimately on how they identify or include themselves within particular practices. For instance, Lamont-Robinson, Williams and Thompson (2018) have shown in a different context how objects may be significant in shaping people's decisions and actions within individual practices, which in turn are then 'continually shifting and re-developing' (Lamont-Robinson et al., 2018, p. 2). When someone enters an environment where things are done in ways that do not include their own needs or perspectives, then the material elements of that practice (in this case, maybe waiting rooms, complex written information, or medical equipment) combine with the human interactions in that environment, to create what is often a negative, disempowering and 'misfitting' experience. Robillard (1999) observes in detail the disabling effect of encounters in an intensive care unit for someone who cannot communicate because of paralysis, and using an ethnomethodological lens (Garfinkel, 1967), he shows how such encounters impact on his own emotions and identity as an academic.

These ideas have started to resonate for disability theorists interested in how disabled people interact with an environment that may not be suited to their bodies or needs (e.g., Abrams, 2016; Garland-Thomson, 2011; Titchkosky, 2008, 2011). Even when the environment is 'adapted' to be made more accessible (Lamont-Robinson et al., 2018), individual disabled people can experience their own impairments in both positive and negative ways. Thus, a social practice argument would suggest that the experiences of disabled people in hospital can be influenced by a myriad of factors, both internal and contextual.

Our focus in this article is therefore both on the practices themselves, but also on the emotional impact of those practices, revealed through the lens of individual disabled people's narratives. As Goodley, Liddiard and Runswick-Cole (2018) note, in their exploration of theories of affect, '[t]he turn to affect is not simply about addressing a missing psycho-emotional dimension in social theory. Affect theory responds to the ways in which affects are mobilised by economic and cultural forces' (Goodley et al., 2018, p. 199). The meaning associated with one's own condition or disability is tightly bound up with the social experiences and material arrangements of a particular context (Titchkosky, 2011), such as a hospital where a disabled person may be a patient. Being disabled in hospital may therefore be a complicated process for many reasons, as it may shape, and be shaped by, disabled people's overall experience as a patient and how staff respond to them. For example, the very notion of a 'reasonable adjustment' in hospital care can be problematic if it singles out a disabled patient as non-normative or as a 'misfit' (Garland-Thomson, 2011).

This article was written in 2017–2018 at a time of huge pressure in the UK health care system, particularly within hospitals in England, with frequent media reports about the difficulties experienced by patients and hospital staff. That is why it is important to reflect here on the ways in which the ideas about social practices may help to identify low-cost solutions which are based on creative changes to existing practices. Social practices do not exist in a vacuum, but in general they are tightly interconnected (Blue & Spurling, 2017), and understanding those connections can be a key to better practice for all. Disabled patients' needs may be specific and individual, but their solutions may well be of universal benefit.

Moving back specifically to the relationship between disability and hospital care, we start from the position that disabled people, like others in the population, have needs for health care services (Burns, 2017); however, they may have additional health care needs associated with their impairments. For instance, when compared to individuals without an impairment, disabled people are more likely to experience chronic pain and arthritis (Havercamp, Scandlin, & Roth, 2004), and require more use of health care services (Allerton & Emerson, 2012). People with intellectual disabilities are also more likely to have health comorbidities than others in the population, such as epilepsy (Cooper et al., 2015; Marriott & Robertson, 2014). Therefore, it is necessary not just to know and record the health service needs of disabled people, but to also understand how social practices interconnect with, and shape their experience of accessing adjusted health care. In this article we will seek to explore further disabled people's accounts of accessing hospital care in England, and highlight how their experiences and feelings are affected, both by existing standard hospital practices and also by the personalised adjustments made for them.

2. Overview of Study

The study data on which this article draws comes from a wide programme of research which is co-produced with disabled people's organisations (Williams et al., 2018), seeking to understand and challenge disabling social situations from several different domains of life. For this study, we have been analysing provisions of reasonable adjustments within the National Health Service (NHS) in England. We have taken a mixed-methodology approach, incorporating data from a variety of sources, such as an audit, online surveys and interviews. In our study we are interested in looking at systems of care from a social practice perspective (Blue & Spurling, 2017; Williams et al., 2018). We suggest that any hospital has a standard way of 'doing things', which can shape not just how hospital staff and patients interact with the service, but also disabled people's experience as patients. Therefore, this study sought to understand disabled people's experiences of how they interact with, and are affected by, existing hospital practices.

This article focuses solely on twenty-one qualitative interviews with disabled adults who volunteered to share their story of a recent hospital experience. All participants who took part did so on the basis that they already self-identified as disabled. We did not require our participants to discuss their impairments in the interviews, however, the experiences they shared indicated that they had personal experience of a range of impairments (e.g., sensory impairments, physical impairments, mental health conditions, and intellectual disabilities). The sample consisted of twelve women, and eight men, with the remaining interview completed by a husband and wife collaboratively who both identified as disabled. People were recruited from a broad range of locations across England. The semi-structured interviews from which data were gathered asked participants to describe the stages of their hospital visit in the style of a 'journey', starting from before they arrived, and finishing at when they left hospital. Each interview was completed with the disabled person at their own home ($n = 14$), or by telephone ($n = 7$), and lasted approximately one hour. Interviews were recorded and transcribed, anonymising all names and details. The study received ethical approval from the Faculty of Social Sciences and Law Committee for Research Ethics, University of Bristol.

2.1. Analysis

We first read all our interview transcripts multiple times, and coded our data using 'process coding' (Saldaña, 2015), which aims to highlight the actions and practices on which experiential accounts are based, such as the social practices that disabled people and health care staff 'do' within a hospital setting. The interviews were then analysed using thematic analysis (Braun & Clarke, 2006), which involved collating recorded process codes of similar meanings, and relating these to each other. This in turn, led to the construction and shaping of larger cross-cutting themes describing broad hospital practices. Process codes and themes were modified as new ideas emerged from the interviews. The lead author self-identifies as disabled, and has significant personal experience of accessing UK health services. His lived experience was used to help understand and interpret the findings. Collaborative discussions with others in the team also took place to refine and confirm the reported themes.

In the forthcoming section we will organise our findings under four types of social practice which emerged from the data: 1) being alerted to disabled people and their needs; 2) getting to and from hospital; 3) accessing 'good' information; and 4) getting what disabled people came for (i.e., the purpose of their hospital visit). Substantial quotations are included, so that we can reflect on the detail of emotion, reaction and embodied experience expressed by disabled people who have been hospital patients.

3. Findings

3.1. Being Alerted to Disabled People and Their Needs

In order to explore the experiences of disabled people, we first need to understand the terminology used by hospitals about their systems to become aware of disabled people and their needs. The first is what we call here 'identification', which is where hospital staff recognise that a patient is disabled. To achieve this, disabled people could describe the issue they face, naming it as a particular impairment, and subsequently ask for support, or this could also be accomplished on their behalf by a health professional or a family member or carer (Tuffrey-Wijne et al., 2013). The second is 'flagging', which involves formally marking patient records in order to alert hospital staff to a patient's disability, such as by adding a 'flag' or some other form of notification to patient records or notes; or having the patient carry a specific document describing their personalised information (Tuffrey-Wijne et al., 2013). While identification can take place without flagging, flagging cannot take place without prior identification that the person is disabled. Collectively then, the many ways of being alerted to the needs of disabled people expose a number of hospital social practices that shape how an individual patient engages with the service, and participants in this study did not necessarily experience these processes in the same way as the professional logic, nor the hospital's duties under the Equality Act 2010, would imply.

When considering the reasonable adjustments needed by an individual patient, that person must first be identified as disabled, which may be a daunting process in and of itself. One woman explained that while she welcomed her personal needs being identified, she felt that other disabled people might have reservations in identifying as disabled within the health care environment.

> (9) Well, it's pretty obvious I am disabled, you know….But…it does need some flagging up. Certainly unseen disabilities….But I suppose, yeah, there are some that have got things wrong that they don't want people to know.

This individual's example also highlights that hospital staff may be more able to recognise people with visible impairments, who self-identify, when compared to people with less visible impairments. Therefore, the typical identification procedures of hospitals may also influence disabled people's decisions to identify, since deciding to tell someone about a disability is made far more straightforward if that knowledge is shared from the outset.

Regardless of how a disabled person's needs are identified, in order for an individual's care needs to be met effectively, practices have to incorporate and respond to these needs. If hospitals do not have appropriate practices in place, this makes the process of identifying for disabled people potentially meaningless. Participants discussed how at times, hospitals may not be effective at accommodating disabled people's needs, even following identification. For example, one man described:

> (16) So, my biggest complaint is that the fact that I'm disabled has no significance whatsoever in the system. Whatsoever. They are not really bothered about you being disabled. You're just another patient, aren't you?

A similar story was reported for methods of formal flagging systems, where participants discussed how their disability and needs for adjusted care may not be routinely recorded, or that hospital staff may not adapt their practice to accommodate this flag. For example, one woman described:

> (11) Some people seem to have a record of it when I go in, and other people don't. Yeah, so it seems as if sometimes…people don't notice that it's there, either, when it's written.

3.2. Getting to and from Hospital

Hospital practices go beyond simply identifying the reasonable adjustment needs of disabled people—they shape whether and how these reasonable adjustments are enacted. Take for example, getting to or from the hospital doorway. This of course involves a journey for everyone, generally using some form of motorised transport, such as an ambulance or a relative with a car. The act of getting to hospital involves numerous connected social practices, such as planning the journey, using a particular method of transport, and parking. Each of these social practices, and the people that are involved within them (e.g., disabled people and staff), are connected, and must work together effectively to ensure a positive experience. A common experience for our participants was that accessing hospital transport was problematic for several reasons, such as the service not being wheelchair accessible, or that journeys often ran to tight schedules, or took a long route in order to pick up multiple passengers. One woman commented:

> (8) If you go with a friend, you can say, 'Can we go really early, to have time to prepare myself when I'm actually there…not running in at the last minute?' But with the hospital cars provided, they do cut it quite fine. And that was a problem to me.

Thus, if participants decided to use hospital transport, in order to ensure that their individual needs were met, they relied heavily on the sensitivity and knowledge of staff involved, which was not always evident. One woman described:

> (6) I know now, but I didn't know at the time, when I started first getting transport, I just thought, *Oh, I'm safe. I've got an ambulance driver*. And I'm sure these people that have had heart transplants and lung transplants felt the same. But they [ambulance driver] are not. All they are is they've had first aid.

The practices involved in getting to hospital are a key example of how the interconnections between different players are vital to a patient's experience of fitting or misfitting into the hospital system. This was also true for disabled people making their own journeys to hospital independently, with one participant noting the expectation that she would have to announce her arrival, while inconveniencing other drivers:

> (3) One of the things that happens then is…there's a barrier to actually get into the car parks….I have a car which I load from the back with a ramp that goes down, and it fixes, because I drive from a power chair. So, I'm fixed in, and I'm not terribly tall. So, I can't actually reach to press the button to release the barrier. We've had a conversation about that with the [Trust]…[their] idea is that they should put a note on the barrier with a phone number, so that I would phone to let them know that I'm outside. That doesn't work really, because you're out of pocket anyway, for the phone call, and you cause a blockage for everybody behind.

3.3. Accessing Good Information

The point at which people accessing hospital care 'become' patients is potentially problematic as this can result in some conflicted feelings about a person's own identity and how they will be treated (Sokol, 2004). This is especially true for disabled people, and study participants expressed concerns about hospital processes for receiving and sharing information about their care. People wanted clear and understandable information and at times, reported that this was not forthcoming. They spoke of their need for adjusted information, and their struggles in obtaining this, with one participant highlighting that hospital staff may not necessarily understand how to provide accessible information for disabled patients: (4) "When you do get there…they don't know that they can do it in large print". This, in turn, may create feelings of disempowerment: (2) "I'm not the boss any more. I am kind of like a—I'm a nobody. Because I'm sat down here, and all this conversation's going over my head."

However, there was also a fear that one's disability could result in patronising treatment. One participant with a visual impairment pointed out that information she received from hospital staff may be unnecessarily over-simplified, explaining that: (5) "I've got a degree, and a postgraduate qualification, and a whole working life at senior level behind me. And it's offensive to be spoken down to." Another participant expressed concern at being seen as a difficult patient, because of a need for a specific format of information:

> (12) The endocrinology departments…they send letters like so small print….I don't even ask large print anymore, because they, they already are not really helpful medically….I don't want to risk them not liking me….I don't want to be the difficult patient.

Entering a hospital for any patient is often associated with some anxiety, especially if one is being tested for a particular condition, or when the outcome of treatment is risky or unknown. However, this anxiety can be exacerbated for disabled patients who may need reasonable adjustments to how information is provided about their treatment. There were many examples from participants about how they felt they were not kept informed of their treatment, which at times caused anxiety. A common practice which our participants reflected on was that of sitting in a reception area, and waiting for their name to be called, or for their professional to come along. One man described feeling forgotten while waiting for a specialist, as his visual impairment meant that he experienced difficulty in seeing what was going on or how the appointment process was working:

> (20) These appointments take two, three, even sometimes four, five hours, you know….So that's a shame, because while you're waiting…you're…thinking, did, did they [forget] you…so…from then it's like a big, big stress.

Such negative experiences can contribute to a sense of isolation reported by many of our participants. For example, another participant described:

> (11) I mean there are lots of different kinds of situations where that could be the case for any disability, where, because of the adjustments you need, and they're not in place, you suddenly feel very isolated from what's going on. And on the day of an operation, or in any health situation, I think the last thing you want is to feel alone and isolated.

In this sense, effective communication was highly valued by participants. Adjusting practices to include time for personal communication may seem difficult to achieve, but much of this is about paying attention to the person. For example, one woman described: (7) "They [hospital staff] treated me alright. When I was an in-patient, and also before, the consultant was good. He was saying all the things that [were] going to happen."

3.4. Getting What You Came for

The notion of making a 'reasonable adjustment' can imply a rather straightforward arrangement, whereby a practice that was previously inaccessible or difficult to access, is simply made accessible. However, our participants described some complex interactions between their own experiences of pain or fear, their disability-related needs, and the actual procedure for which they had entered hospital. Some disabled people described how they felt they became 'objects', and thus their reasonable adjustment needs were ignored by health professionals. One participant with a physical impairment described how he was required by a medical professional to manually move himself on a hospital bed, and given the nature of his impairment, this was not something he was able to do independently. He described how his specific needs were therefore disregarded:

> (15) She [health professional] said, 'Well he can walk. He can walk. He can walk there, can't he?' And I said, 'Well yeah, I can walk'. She said, 'Start getting undressed'…there was no sort of realising that I actually needed somebody in there.

The result of problematic hospital practices was, on occasions, that disabled people were made to feel embarrassed at being the cause of chaos or confusion, and this concern was exacerbated by the verbal comments of staff. For example, one participant who required use of a wheelchair to attend his hospital appointment, discussed the following experience:

> (18) Once they'd got me onto the bed, then they had to move the wheelchair themselves, and with powered wheelchairs, you can disengage the motors and it acts like a manual wheelchair. But to try and tell someone how to disengage...plus I had a respiratory mask on. So, they can't understand you, and then they try to operate it by…the power stick. And of course, the wheelchair goes in opposite direction, it's banging against very expensive equipment, running over people's toes, they're making comments about, 'Oh, this wheelchair', you know, and you feel very much that it's your fault. That you've brought your wheelchair in, that you need.

Other participants spoke about how they had to go through hospital procedures that were not suited to their individual needs. For instance, one participant with a physical impairment described having to complete a lengthy assessment, and she became extremely distressed because of the discomfort this caused.

> (6) I was expected to climb on this bike. As far as they were concerned, they had a job to do, and they had to get me on the bike first, and then inject me, and then tell me to be doing all this cycling. And it was too high; I thought I was going to fall off all the time.

In addition, screens, monitors and other equipment and artefacts represent in some respects the mystique as well as expertise of the medical profession, and could result in the patient becoming side-lined by the practitioner. While this may be so for any patient, this aspect of hospital practices can be particularly problematic for a disabled patient. The above participant added the following example in relation to her hospital procedure:

> (6) But the whole experience that particular day was, the chap that was doing the diagnostic test was so [enthralled] with what he was doing, looking at the heart and all this on the telly, it was almost as if he'd just blotted me out. Because I was crying on the table for ages, and he was just carrying on. And he was teaching another student. So, he was really teaching her, so he wasn't really able to deal with me.

Because of her evident distress, she was told she did not have to undergo the next level of tests, even though she was aware that others were having the full procedure, and so she left hospital not knowing whether the tests had been fully completed and whether accurate results would be recorded. Fear and panic associated with disability needs can thus exacerbate, and be exacerbated by, the feelings of anxiety about the procedure itself and its results.

Nevertheless, episodes of care were not always problematic. Some participants reported how they valued being viewed and treated by their health provider in a more 'human' way. For example, one woman noted how her health care provider understood that being a disabled patient was one aspect of her multiple identity roles, which in turn, allowed her health care to be individualised to meet her specific needs:

> (10) Now the doctor in charge there was a fantastic lady…she spontaneously said, 'Would you like your daughter to come in and meet with me? Would you like her to have a tour?' And I was like, 'No, she's fine, we've dealt with it all'. But I thought that was really intuitive, and that was really meeting the needs. Because…if I had…been worried about my daughter….I wouldn't have been able to cope....I wouldn't have been able to make the most of my treatment…so I think you're not just a patient, you're also a mother, a father, an employee, a neighbour. You know, you have other aspects to your life, apart from the fact that you've got that disability....And I thought that was really good, that she met that need by responding to that human need, or that need as a mother.

4. Discussion

The findings reported in this article represent potentially difficult experiences for disabled patients who need to request adjustments to meet their individual needs, but misfit within a relatively intractable system not designed to fit individual circumstances. These experiences appear to breach both the letter and the spirit of the Equality Act 2010. The extent to which knowledge and implementation of Equality Act duties are embedded within social practices in health care settings requires further research.

The image of the disabled woman at a car park barrier, unable to move forward, is a symbol maybe for how several participants felt about their hospital experience. It is important to note, however, that our account in this article cannot be generalised to all disabled people, but should be read as a qualitative enquiry into the connections between a set of practices and the personal experiences of being a patient in hospital. What we have outlined in our analysis is how each stage of the hospital journey includes practices which can be disabling—or can become more enabling. Problems arise when things are designed in such a way that disabled people are forced to confront their difference, and to make that difference visible to others. As we have seen, this can become a problem in itself, resulting in disabled patients feeling guilty, anxious or just frustrated. Further, the interaction between being a patient and being a disabled person can be problematic, when people feel they are perceived as difficult. Being a ‘good patient’ (Sokol, 2004) is associated with passivity and acceptance of the expertise of the medical profession. It seems then, that disabled people may have to navigate a difficult balance between maintaining the positive integrity of their role as a disabled patient, while also responding to disabling social practices that may challenge that integrity, in order to obtain good support. All this requires considerable emotional work, at a point when arguably one’s focus should be on one’s own health. The Equality Act 2010 legislation, intended to mitigate or remove disabling practices seems, on the face of these personal accounts, to have had little impact on day-to-day experiences.

How then can social practice theories allow us to analyse and shift the practices in hospital care? Blue and Spurling (2017) take a historical approach to the analysis of change in the interconnected practices within hospitals, arguing that there is a ‘connective tissue’ which includes time management and materiality, binding practices together in a hospital. For instance, a patient’s records and indeed their disability-related needs, may be one form of materiality which is shared between different departments and professionals in a system. While that interconnection of material elements in a practice may be important, this article has also shown how values and meanings are contained in the interactions with disabled people in hospital. In a negative sense, that value system can become apparent when a patient is made to feel that their individual needs are secondary to the needs of the technology or the medical procedure. Robillard (1999), like some of our own participants, was often made to feel that he constituted the problem, and that he was positioned as powerless by the failures of communication which went on around him. Unfortunately, the very notion of a ‘reasonable adjustment’ can also have this effect, as we have seen in this article, since the disabled patient is made to feel different and problematic. Thus, a social practice approach might be relevant not just to the provision of reasonable adjustments themselves, but to an understanding of how such adjustments might be made routinely within a more fluid or patient-centred system while ensuring compliance with specific legal duties. In practical terms, what we are suggesting is that any institutionalised or professional practice can be open to change, that human rights legislation can and should make a difference to those practices, and that a positive way forward is to focus on understanding the experiences of disabled patients themselves.

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Conflicts of interest

The authors report no conflicts of interest.

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About the Authors

Stuart Read is a Senior Research Associate at the Norah Fry Centre for Disability Studies, University of Bristol, working on the strand of ‘Getting Things Changed’ relating to hospital services. He completed his PhD in Psychology in 2015. Stuart has particular interests in disability identity and identity presentation, as well as understanding how disabled people experience and navigate disabling social barriers in a number of different contexts. Stuart identifies as a disabled person.

Val Williams is a Professor at Norah Fry Centre for Disability Studies, and has a background in Further Education and inclusion. She is chiefly interested in working with disabled people in 'inclusive research' designs, and also has an active engagement with methods to analyse social interaction. She leads the team conducting the research programme known as 'Getting Things Changed'.

Pauline Heslop led the Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) from 2010–2013 which identified potentially modifiable factors associated with premature deaths in people with learning disabilities. She is now the Programme Lead for the national Learning Disabilities Mortality Review (LeDeR) Programme, and leads the research on hospital services in 'Getting Things Changed'.

Victoria Mason-Angelow is a Research and Evaluation Consultant at NDTi, having recently joined the organisation from the Norah Fry Centre for Disability Studies (NFCDS) where she was a Research Associate. In her role at NFCDS, Victoria worked on a variety of studies relating to the lives of people with intellectual disabilities and those who identify as disabled within a UK Higher Education context. During her time at NFCDS Victoria also completed her PhD in Disability Studies, and conducted interviews in the 'Getting Things Changed' project.

Caroline Miles is a Research Associate at the Norah Fry Centre for Disability Studies (NFCDS), and is also completing a School for Social Care Research (SSCR) Fellowship, 'The Legal Context of Social Care'. Caroline is a qualified solicitor with 13 years' experience in legal aid social welfare and community care law. Caroline initially joined NFCDS in 2015 as Research Associate for an adult care assessment research project, 'Values of Assessment', before moving to the 'Getting Things Changed' project. Caroline identifies as disabled and is a wheelchair user.

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