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Disability Equality: In Theory and Practice

Editors

Mark Priestley and Lisa Waddington

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Article

Achieving Disability Equality: Empowering Disabled People to Take the Lead

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Abstract
Achieving disability equality calls for transformative changes to society's structures and norms. Recognizing the central role of disabled people and their organizations in this restructuring, and the call of the Convention on the Rights of Persons with Disabilities (CRPD) for their full inclusion in all legal and policy decisions relating to their rights, this article focuses on how disability groups and organizations regard their ability to effect changes in line with the CRPD. The article draws on qualitative interviews with leaders of disability organizations and activist groups in Iceland in 2016 and 2017. The findings reflect frustration among the leaders with what they perceive to be a lack of sustained progress in the decade since the country signed the CRPD. In their view, this period has been characterized by a lack of meaningful involvement of disabled people in policymaking, and a lack of political will and interest in disability affairs, which has resulted in stagnation. As a result, leaders of disabled people's organizations have begun to change their strategies and are taking steps to redefine their approaches, and reframe the issues and dialogue with authorities in a more progressive manner, demanding to have more say in the process of change.

Keywords
activist groups; CRPD; disabled people; disability equality; empowerment; policymaking; umbrella organizations

Issue
This article is part of the issue "Disability Equality: In Theory and Practice", edited by Mark Priestley (University of Leeds, UK) and Lisa Waddington (Maastricht University, The Netherlands).

1. Introduction

Achieving disability equality requires a multipronged approach that includes an accessible physical and social environment that allows disabled people to take full part in society, and where "their needs are understood as integral to the social and economic order and not identified as 'special'" (United Nations, 2010, p. 22). Furthermore, it demands full recognition of the right to autonomy and to make one's own choices (Flynn & Arstein-Kerslake, 2014; Quinn, 2010). Building on this understanding of what disability equality should at minimum encompass, this article focuses on the need to also embed within its definition an emphasis on the participation of disabled people and their representative organizations in constructing the very policies that are intended to usher in the necessary changes to structures and norms within society to ensure their enjoyment of full human rights.

The importance of the participation of marginalized groups, including disabled people, in policy making has been emphasized within the field of social sciences and human rights law (Charlton, 2000; Guldvik, Askheim, & Johansen, 2013; Minow, 1990; Oliver, 1990; Priestley et al., 2016; Young, 1990). Recognizing that society's structures and norms are a reflection of existing power relations, created and defined by dominant groups and which serve to maintain the status quo, Young (1990) maintains that ridding society of institutionalized domination and oppression is pivotal to achieving justice for marginalized groups. To do so, she argues that it is necessary for marginalized groups to be part of the political structure, setting the agenda, defining the issues and redefining the concepts that relate to their lives. A similar focus on the necessity of leveled and inclusionary participation, parity of participation, is central to Nancy Fraser's theory on justice, which maintains that all members of society should be able to interact with one another as peers (Fraser & Honneth, 2003). To this end, Fraser highlights the need to uproot both cultural and economic injustices, including norms that have been institutionalized by society and which depreciate some groups of people and undermine their standing as full and equal participants in society (Fraser & Honneth, 2003). The importance of direct citizen participation in the formulation of political issues is also highlighted in Habermas's theories on the role of the public sphere as a platform for reasoned and critical dialogue. Habermas (1991) describes the public sphere, as it emerged before the increased intertwining of the state and society in the late nineteenth and twentieth centuries, as a forum existing between civil society and the state where critical public discussion could take place among private people, free from outside pressures and where political ideology could be formulated (Habermas, 1991). As such, the public sphere allowed the citizens to develop their agenda before presenting it in the public arena, a format that could be argued as being ideal for giving marginalized groups the necessary breathing space to develop their political agenda. Regrettably, research has shown that even accessing such basic civil rights as the right to cast votes in local, national and—in the case of EU citizens—international elections often poses a challenge for disabled people, resulting in lower voter turnout among them than non-disabled people (European Union Agency for Fundamental Rights, 2010; Priestley et al., 2016; Traustadóttir & Rice, 2017; United Nations, 2011). This draws attention to the importance of empowering disabled people to participate politically at all levels, as well as to the important role that civil society organizations have in pressuring states into actualizing human rights law (Meyers, 2016).

The Convention on the Rights of Persons with Disabilities (CRPD; United Nations, 2006) embraces this perspective as it firmly recognizes the importance of the participation of disabled people in setting the policies that will affect their lives. It places a positive legal obligation on states parties to seek the input of disabled people and their representative organizations at all levels of development, monitoring, and implementation of disability rights (Sabatello, 2014). These obligations are stated in Article 4(3), which requires states to "closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations," as well as in Article 33(3), which states that persons with disabilities and their representative organizations shall be involved and participate fully in the monitoring process of their rights. Furthermore, Article 34(3)(4) addresses the participation of disabled people, their representative organizations, and experts with disabilities in the interpretation, implementation, and monitoring of the CRPD as members of the monitoring committee.

A participatory emphasis with regard to disability law and regulations has also been increasingly integrated into national legislation and institutional processes, including in Iceland where the law on disability affairs requires consultation with representatives of disability organizations (Law nr. 59/1992, adm. 152/2010) (Althing, 1992). However, as Sherlaw and Hudebine (2015) point out, having incorporated an obligatory consultation with representative organizations of disabled people still leaves unanswered the question of how these policies translate into practice and whether they, in fact, enable disabled people and their representative organizations to affect policy outcomes. To shed light on this question, this article focuses on how leaders of disability organizations and groups in Iceland perceive their effectiveness in influencing disability policy and how they have adapted their approaches in order to strengthen their ability to affect change.

2. Method

This article draws on qualitative data comprising interview transcripts. Eleven semi-structured in-depth interviews were conducted with leaders of nine disability groups and organizations in Iceland in 2016 and 2017. The aim was to obtain the leaders' views and experiences with regard to implementing change in line with the CRPD.

Purposeful sampling was used to identify and recruit participants. An effort was made to provide a balanced representation of leaders of both established disability organizations and grassroots and activist groups (hereafter referred to as activist groups). The established organizations this article refers to, including three large umbrella organizations, are comprised of both disabled people and non-disabled people. Their rules vary with regard to whether or not non-disabled members can serve in leadership positions or on their boards. Some of these organizations own and operate services for disabled people and are thus in some cases employers of staff and specialists, as well as being interest organizations. Six interviews were conducted with leaders of established organizations. Of the six leaders, three were disabled and three non-disabled.

Although there are organizational differences among the activist groups discussed in this article, they are all established and run by disabled people, and share the aim of empowering disabled people to lead the fight for achievement of all human rights. Five interviews were conducted with leaders of activist groups; in the case of a horizontally organized group, a representative was interviewed. All five were disabled.

The groups and organizations represented varied considerably in how long they had been operational, ranging from less than five years to more than fifty. Membership also varied greatly, with one of the three established umbrella organizations claiming 29 thousand members, whereas some of the activist groups had fewer than 50. This fact was not considered to be of concern as the focus of the study was predominantly on the ideology behind the methods used to advance disability equality. While the participants differed as to how long they had served as leaders of their organizations, they all had considerable experience in promoting disabled people's rights in various capacities, and all had spoken in public on the issue. Six of the 11 leaders interviewed were women and five were men. Their ages and educational backgrounds varied. All the interviews were conducted in Icelandic and direct quotations translated by the first author of this article. In addition, keeping in mind the small size of the Icelandic population, both names and identifying details have been omitted to the extent possible to ensure confidentiality. All participants gave informed consent and agreed to have the interviews recorded. In one instance, a list of topics to be discussed was provided in advance to give room for preparation.

The article's focus on the perspective of leaders of disabled people's organizations (DPOs) is derived from the belief that disabled people themselves are best positioned to judge whether policies aimed at delivering disability equality have been successful or not, a perspective adopted by Sherlaw and Hudebine (2015), as well as Disability Rights Promotion International (Samson, 2015). To this end, semi-structured interviews were chosen as a method of inquiry to gain knowledge of the subjective understanding, perspectives and meaning that participants attach to the issues. They enable the interviewees to direct the discussion to what they find to be of importance and to express the meaning they attach to concepts, while at the same time allowing the discussion to be directed toward predetermined topics in keeping with the theme of the research (Esterberg, 2002; Taylor, Bogdan, & DeVault, 2015).

The research employed the grounded theory method, which reflects the premise that theory can be developed from rigorous analysis of empirical data (Charmaz, 2014). In keeping with this approach, the collection and analysis of data was directed by the constant comparative method of grounded theory. This method calls for data gathering to be continued while data is simultaneously coded and analyzed, and analytical memos developed, with the goal of identifying central themes to help direct further data collection and theory building (Charmaz, 2014). To this end, interviews were conducted in three intervals, in December 2016, April 2017 and July 2017, until new information obtained ceased to provide further insight. At the outset, broad questions were posed to leaders of the representative organizations about their approaches to advancing the rights of disabled people. The questions were then narrowed in focus as themes began to emerge from the analysis of the interviews, which were recorded, transcribed and coded. Coding consisted of close reading of the transcripts, followed by sorting and organization of the codes, which were then collapsed into broader categories revealing patterns in the data that helped develop a deeper understanding of the issues at hand (Creswell, 2009).

3. Findings

Analysis of the data revealed that the organizations and groups interviewed could be divided into two main categories based on what they perceived to be the most effective way to advance disability equality. On one hand were those who expressed a firm commitment to working in a collaborative manner with the authorities. The cornerstone of their strategy was maintaining an open dialogue and working through negotiations within a framework established by national and local authorities, including committees and other bodies. The established interest organizations generally expressed commitment to this approach. On the other hand, activist groups run by disabled people generally did not give primary focus to collaboration with authorities. Instead, they sought to take the lead in defining the issues of priority concern to their rights and, by so doing, redefining the dialogue to incorporate and reflect their own perceptions and needs. Despite these differences, the organizations also shared some experiences and concerns as outlined below.

3.1. Collaborative Strategies

The established organizations expressed a commitment to advancing the rights of disabled people through a process of collaboration with authorities. This approach was described by one of the leaders of the established organizations in the following terms: "We perceive, or I personally, that the authorities are our collaborators, not our adversaries. I don't think we would make any progress if we played that game." Two of the established organizations, both of whom were umbrella organizations, had the right by law to be consulted on issues pertaining to policies concerning disabled people. It should be noted, however, that their appointed representatives are often non-disabled people. While expressing commitment to the collaborative approach, some of the leaders reported feeling as if decisions had at times already been made before meetings called by the authorities were convened. "Sometimes it feels to me as if it's pro forma. They have to include us. And then it's like decisions have already been made at some sort of a pre-meeting" (leader of an established organization). In addition, one leader talked about having to be vigilant to ensure that the comments and opinions expressed by the organization's representative were actually included in the minutes of the meetings. Several of the leaders of established organizations also talked about having to dedicate a lot of their time and energy to preventing roll backs of acquired rights. An example cited was a recent directive issued by the Ministry of Welfare that expanded the number of apartments permissible within apartment complexes for disabled people. The leader stated that his organization had opposed this action and pointed out that increasing the number of units was in contradiction to the CRPD. Another example where proposals by representatives of disability organizations were disregarded was the case of a proposed amendment to laws pertaining to facilitating equal access to actualize voting rights (Traustadóttir & Rice, 2017). The proposed draft legislation did not include the suggested changes by the disability organization and, as a result, did not uphold the intent of the CRPD. This is of concern as the Icelandic disability law (Althing, 1992) requires that due consideration be given in its execution to international obligations, particularly the CRPD, as stipulated by a 2010 amendment to the law.

Despite frustrations over a lack of progress and feeling that their suggestions and perspectives on issues often went unheeded or overlooked, the leaders of the established organizations expressed a firm commitment to collaboration with the authorities, stating that “we don’t see the authorities as our enemies; we see them as our collaborators.” Maintaining an open dialogue was a cornerstone of their strategy. “We don’t burn bridges,” “we don’t slam doors,” “we are not loud,” and “we don’t use foul language” were phrases they used to describe their approach to keeping the collaboration and dialogue alive.

Cultivating relationships with politicians, including parliamentarians, government ministers and elected officials at the local level, was regarded by many of the leaders as an important part of the collaborative approach. Two leaders described their approach in this regard as “lobbyism”. They talked about actively seeking the attention of individual politicians, through phone calls or personal meetings, with the intent of informing and persuading them to adopt their cause. “You just pick up the phone and call the ones you consider to be likely to speak on behalf of these issues,” is how a leader described the process.

Furthermore, a leader pointed out in this context that “we can’t use the threat of a strike as part of our negotiating tactics with authorities,” making it all the more important, in the leaders’ view, to build trust and credibility as negotiating partners. They discussed steps they had taken to strengthen their standing as collaborators and partners, including cultivating a reputation for being trustworthy, calm and professional as opposed to emotional or aggressive. “We have to be much more concerned with our credibility and be a bit careful in what we do,” a leader stated. Being able to cite facts in support of their arguments and having relevant research on hand, as well as at times conducting and sponsoring research, was stressed as important in giving their arguments more weight. Among the examples where they felt that collaboration with authorities had resulted in substantial gains for the rights of disabled people was the process that led to the ratification of the CRPD, where disability organizations reported being heavily involved behind the scenes. However, in general, progress was described as having been slow. Having to accept small steps in the right direction rather than no gain at all was often seen as an unfortunate reality. Expecting full rights to be realized in one step was considered to be unrealistic.

In keeping with their emphasis on collaboration, leaders of the established organizations rejected what they considered to be a more aggressive and confrontational approach employed by some activist groups. Nevertheless, many expressed support and even admiration for the work of these groups, particularly their effectiveness in generating public and media attention. A leader of an established organization did emphasize that rejecting the more aggressive approach did not mean that the leader’s organization shied away from bringing up uncomfortable issues in their discussions with the authorities.

While maintaining a commitment to working through a collaborative process, some leaders of the established groups had nevertheless taken deliberate steps to expand on the framework established by authorities. These initiatives, in addition to the lobbying approach, involved inviting politicians to informal discussions where issues that the organization had chosen to highlight were introduced and information material was provided. The intent was to establish personal contact with politicians and direct their focus to issues of prime importance to the organization in the hope that they would adopt them in their political agenda. In this way, the organization attempted to gain a measure of control of the dialogue while still remaining true to the focus of collaboration.

3.2. Empowering Strategies

The leaders of activist groups run by disabled people did not prioritize the collaborative approach in the same way as the leaders of the established organizations did. While the methods they employed varied, and some were horizontally organized while others had a more traditional top-down structure, they all had the same key objective: to find ways to take the lead by directing the dialogue to issues they perceived to be fundamental to their interests and to achieving disability rights.

A representative of a horizontally organized activist group identified how the group, through its meetings, provided members with a platform to voice their opinions and preferences, including with regard to which issues should be at the forefront in the fight for rights, and how these issues should be defined and presented to society at large, including the authorities. The group’s meetings had an established format with one or two members presenting on a previously agreed upon issue or theme. The presentations were then followed by general discussions where all were encouraged and given an opportunity to speak their mind. Members of the group reported feeling empowered to voice their views, first within the group and then on occasion in more public fora. This format gave the group the time and space to define issues in terms that reflected their perceptions and needs. In essence, it allowed for the redefinition of issues from a new perspective where members of the group maintained full control. A person associated with the group pointed out that "the needs of disabled people have until now traditionally been left to 'experts' to define. Now, disabled people are defining the issues themselves. This gives voice to people who are not used to having a voice." By adopting this method, members of the group were able to identify as leaders of the process and as the ones in control.

A leader of another activist group run by disabled people described a similar platform for dialogue where members took turns leading the discussion at the group's meetings and where everybody present had an opportunity to raise issues of concern to them. "This is meant to be a platform for all, that is all our members, to have a say." Through this process, the group brought issues that members wanted to focus on to the forefront. This allowed the issues to reflect the perspectives and lived experiences of the group members and then, on occasion, to be presented as such to authorities and the larger public.

The methods that these two groups employed were focused on empowering disabled people to take the lead in defining the issues and the methods used to ensure the full attainment and recognition of their rights. In both instances, the definition of the issues occurred through dialogue and peer-led discussions that took their cues from the perspectives and lived experiences of disabled people themselves.

Another strategy used by the activist groups was the initiative that one of the groups took to draft a legislative proposal to present to the authorities. By so doing, the group felt that it was both breathing life into a stalled process and taking the lead in defining the issues under discussion, with the aim of influencing the outcome. The proposed text emphasized what the group felt needed to be discussed or acted upon. The intent, as in the previous two cases, was to take charge of how the rights of disabled people were stated and defined, and, in this way, affect policy outcomes. Furthermore, the leader of the group felt that taking the lead in drafting the proposed legislation provided a measuring stick that would help evaluate the outcome document. "If other draft legislation is presented that is very much different to ours, then they [members of parliament] will at least know that it is not in line with our ideas and we can then point to that."

The methods employed by the activist groups at times reflected a sense of urgency. One leader described how members wore chains around their necks in public as a form of protest against obstacles to relocating for persons with disabilities. Another group described taking to the streets in demonstration, delivering declarations to the authorities. In one instance, a parade was organized to demonstrate the members' pride as a form of self-advocacy. Other methods included writing and publishing first person accounts of the lived realities of disabled people and the hindrances they face on a regular basis. The public demonstrations were described by the leaders as being intended to bring visibility to the fight for disability equality and to enhance public understanding of the issue. "We do this to bring attention to where there are cracks in the system and where the system needs to do better….The point is to open people's eyes to the lives of disabled people," said one leader. However, the representatives interviewed maintained that being aggressive or shocking was not in itself a deliberate strategy. Members of the activist groups described their methods as a way of opening people's eyes to the lived reality of disabled people in Iceland in the hope of sparking a wider public dialogue and gaining more control of the image presented publicly of disabled people. This approach was intended to allow disabled people to take control of the dialogue and to claim the role of experts of their own lives, and on disability in general, a role that has traditionally been occupied exclusively by others.

3.3. Shared Experiences and Concerns

Although the leaders of DPOs and activist groups in Iceland differed with regard to which approach they focused primarily on in advancing disability equality, they nevertheless shared many experiences and concerns regarding the implementation of changes in line with the CRPD.

First and foremost, they all expressed frustration over the lack of progress in achieving full recognition of the rights of disabled people, despite the fact that the government had signed the CRPD in 2007, passed an amendment to the existing disability law in 2010 requiring compliance with the CRPD, and finally ratified the Convention in 2016. The greatest hurdles to progress, in their view, included a lack of political will, particularly the will to dedicate resources to actualizing the rights of disabled people, and a lack of interest in and understanding of the lived realities of disabled people. "I just think it's laughable," one leader said. "The authorities just have to come to terms with the fact that it [securing human rights] is going to cost money." With regard to their engagement with authorities, they expressed frustration over not being heard in the sense that their comments, suggestions and opinions on matters were often not heeded and did not find their way into policies. This was also the case with the two organizations that Icelandic authorities are legally obligated to consult with in the development of policies.

The leaders also all voiced the importance of emphasizing the rights of disabled people as human rights and of referring to the CRPD in their dealings with authorities. Generating media attention to increase pressure was a strategy employed by all to some degree. All emphasized the need to adopt the CRPD into national law as an important step toward actualizing rights. Furthermore, the lack of progress led a number of leaders to express a desire to increase the use of legal avenues, that is pursuing rights through the court system to force authorities to bring about disability equality.

4. Discussion

From the perspective of disability equality as defined at the outset of this article, it is a cause for concern that the leaders of DPOs report having difficulty being heard by the authorities. Their experience was that meetings called by authorities were at times perceived to be pro forma, that sometimes it seemed as if decisions had already been made and that they even had to remain vigilant to ensure that their comments were included in the minutes of the meetings. These concerns point to a problem in actualizing the active and participatory role of disabled people called for by the CRPD. The CRPD is clear in this regard as it places a positive obligation on states parties to seek the input of disabled people and their representative organizations at all levels of development, monitoring and implementation of disability rights (Sabatello, 2014). It leaves no doubt, as Kumpuvuori and Virtanen (2017) point out, that DPOs can no longer be excluded in processes that concern them. However, in practice, the extent to which these obligations are met varies. On the one hand, there is what Kumpuvuori and Virtanen term “illusionary” participation, where there is, in fact, no real opportunity to affect the outcome of the decision-making process, either due to a lack of knowledge and skills by the DPOs or as a result of the DPOs only being brought in at the latter stages of the process. They also identify as “illusionary” participation when an opportunity to state an opinion is given but the opinion expressed is not taken into account. On the other hand, there is full participation where DPOs are a part of the decision making “in an effective manner, from the beginning to the end of the process” (Kumpuvuori & Virtanen, 2017, p. 59).

The experience of the Icelandic disability groups and organizations seems to suggest that there are still barriers to their full and effective participation in the policy-making process and with regard to their ability to effect policy outcomes and promote disability equality. The existing structure of collaboration with the authorities includes a participatory process that retains some similarities to what Kumpuvuori and Virtanen identify as “illusionary” participation rather than full participation. The result has been frustration with the pace of progress, which has led the activist groups to develop more empowering strategies that, in essence, aim at establishing disabled people as leaders of the fight for their rights. While maintaining a firm commitment to the collaborative process, the perceived lack of progress has also led the established organizations to seek ways to gain more control of the dialogue. Furthermore, leaders from both the established organizations and activist groups have expressed a desire to focus more on pursuing disability rights through the courts as a way of forcing the authorities to take action.

The findings presented in this article, particularly with regard to the activist groups, find support in Young’s (1990) theories and her conclusion that to effect fundamental change it is necessary for marginalized groups to be engaged in redefining the underlying structures and norms that maintain their marginalization. This perspective is echoed by Fraser, who argues that without the uprooting of norms that have been institutionalized by society, the full and equal participation of depreciated groups such as disabled people cannot be realized (Fraser & Honneth, 2003). It should be noted that problems in actualizing the effective participation of disabled people and their representative organizations in the policy making process without instituting structural changes have been recognized in other national contexts, including the Bulgarian (Mladenov, 2009). The approach employed by the Icelandic activist groups aligns with Young’s and Fraser’s theories. The activist groups who, unlike the established organizations that are represented exclusively by disabled people, have taken on this task by attempting to assert disabled people themselves as the leaders of the process of achieving disability equality. They do this by empowering their members to redefine, from their own perspectives and based on their lived experiences and expertise, the issues that are at the heart of the pursuit of disability equality. Only by restating the issues from their perspectives, and thus redefining the dialogue, can disabled people ensure that their interests and preferences are fully reflected in the construction of the policies that are intended to usher in the changes to the norms and structures that have served to maintain their marginalization. Furthermore, the DPOs, particularly those represented by disabled people, provide a platform that gives visibility and validity to the perspectives of disabled people, and an avenue for their integration into policies that affect the lives of disabled people.

Interestingly, there are some similarities between the methods adopted by one of the activist groups and Habermas’s theories on the public sphere as a platform for reasoned dialogue on political issues. The group has created an arena for critical dialogue among its members that is both structured in nature and, at the same time, protected from outside pressure. It brings together elements that Habermas considered ideal for developing political ideology, which could then be taken up within the public arena.

These methods have proven to be effective as they have enabled the group to develop the means of stating, and then presenting, its perspective on various disability issues.

At the outset, the article drew attention to the importance of embedding within the definition of disability equality an emphasis on the participation of disabled people and their representative organizations in constructing the very policies intended to usher in the necessary changes in society to ensure their enjoyment of full human rights. To this end, the article has drawn on writings that argue that to remove barriers to full participation it is necessary to redefine existing structures and norms and to ensure the inclusion of affected groups in the process. With these arguments in mind, and the experience of the Icelandic disability groups and organizations, the importance of States Parties embracing the CRPD's participatory requirements, by fully implementing measures to ensure the direct and active involvement of disabled people, is evident. As Sherlaw and Hudebine (2015) and Kumpuvuori and Virtanen (2017) point out, the membership of committees established by authorities to consult on new legislation and policies often does not give prominence to the voices of disabled people and their representative organizations. Sherlaw and Hudebine point to the French case where the established organizations appoint one third of the membership of consultative committees. In the Icelandic case, representatives of disabled people counted for only one sixth of the members of a working group established by the Minister of Social and Housing Affairs to review existing law on disability services (Althing, 2017). The only disabled member of the group resigned, leaving only non-disabled representatives from DPOs. In addition, one of the two organizations that appoint representatives to the committee owns and operates services for disabled people and, as such, is also an employer of staff, which complicates, at times, its ability to serve as a representative of disabled people's interests (Sherlaw & Hudebine, 2015). The issue of representation was raised by the disability community during the drafting of the CRPD, which was marked by the extensive involvement of civil society organizations (Samson, 2015; Stein & Lord, 2010). One of the suggestions put forth called for the Convention to stipulate that all members of the CRPD Monitoring Committee be disabled persons and another that the chair of the CRPD Committee be a disabled person (Stein & Lord, 2010). The intent of these suggestions was to give prominence to the lived experiences of disabled people. While these suggestions were not adopted, they nevertheless serve to direct the focus to the importance of ensuring that disabled people be in a leading position in defining the rights and policies that pertain to them. This position is embodied in the disability movement's slogan, "nothing about us without us", which makes implicit reference to the longstanding denial of disabled people's right to make decisions on matters that pertain to their lives (Samson, 2015).

5. Conclusion

The limited ability of disability groups and organizations in Iceland to effect legislation and policy that relate to their lives has led activist groups to develop new approaches that aim to empower disabled people and assert them as the leaders of the process of achieving full rights. The more recently formed activist groups have developed strategies that have enabled them to define and redefine issues that pertain to their needs and their lives, based on their own perceptions, and to present them as such in the public arena. This allows disabled people to emerge as leaders and experts in their own affairs. This article has argued that the direct involvement of disabled people in changing society's norms and structures that have served to marginalize them is necessary to effect real change and, therefore, achieve disability equality.

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Conflict of Interest

The authors declare no conflict of interests.

References

Althing. (1992). *Lög um málefni fatlaðs fólks*. (Disability Law No 59/1992.) Reykjavik: Althing.

Althing. (2017). *Frumvarp til laga um þjónustu við fatlað fólk með miklar stuðningsþarfir. (Draft legislation pertaining to services for disabled people with significant support needs*, Parliamentary document No 571-438.) Reykjavik: Althing.

Charlton, J. I. (2000). *Nothing about us without us: Disability oppression and empowerment*. Berkeley: University of California Press.

Charmaz, K. (2014). *Constructing grounded theory* (2nd ed.). Thousand Oaks: Sage.

Creswell, J. W. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches* (3rd ed.). Thousand Oaks: Sage.

Esterberg, K. G. (2002). *Qualitative methods in social research*. Boston: McGraw Hill.

European Union Agency for Fundamental Rights. (2010). *The right to political participation of persons with mental health problems and persons with intellectual disabilities*. Vienna: European Union Agency for Fundamental Rights.

Flynn, E., & Arstein-Kerslake, A. (2014). Legislating personhood: Realizing the right to support in exercising legal capacity. *International Journal of Law in Context*, *10*(1), 81–104.

Fraser, N., & Honneth, A. (2003). *Redistribution or recognition? A political-philosophical exchange*. London: Verso.

Guldvik, I., Askheim, O. P., & Johansen, V. (2013). Political citizenship and local political participation for disabled people. *Citizenship Studies*, *17*(1), 76–91.

Habermas, J. (1991). *The structural transformation of the public sphere: An inquiry into a category of bourgeois society*. Cambridge: The MIT Press.

Kumpuvuori, J., & Virtanen, R. (2017). Are we right or are we right? ‘Right approach’ in the advocacy work of organisations of persons with disabilities. In C. O’Mahony & G. Quinn (Eds.), *Disability law and policy: An analysis of the UN Convention* (pp. 55–65). Dublin: Clarus Press.

Meyers, S. (2016). NGO-Ization and human rights law: The CRPD’s civil society mandate. *Laws*, *5*, 21.

Minow, M. (1990). *Making all the difference: Inclusion, exclusion and American law*. Ithaca: Cornell University Press.

Mladenov, T. (2009). Institutional woes of participation: Bulgarian disabled people’s organisations and policy-making. *Disability & Society*, *24*, 33–45.

Oliver, M. (1990). *The politics of disablement: Critical texts in social work and the welfare state*. London: Macmillan.

Priestley, M., Stickings, M., Loja, E., Grammenos, S., Lawson, A., Waddington, L., & Fridriksdóttir, B. (2016). The political participation of disabled people in Europe: Rights, accessibility and representation. *Electoral Studies*, *42*, 1–9.

Quinn, G. (2010). *Personhood & legal capacity: Perspectives on the paradigm shift of article 12 CRPD*. Paper presented at the HPOD Conference, Harvard Law School, Boston.

Sabatello, M. (2014). A short history of the international disability rights movement. In M. Sabatello & M. Schulze (Eds.), *Human rights and disability advocacy* (pp. 13–24). Philadelphia: University of Pennsylvania Press.

Samson, R. M. (2015). Securing the full participation of persons with disabilities and their representative organizations in disability rights monitoring. In M. H. Rioux, P. C. Pinto, & G. Parekh (Eds.), *Disability, rights monitoring, and social change: Building power out of evidence*. Toronto: Canadian Scholars Press.

Sherlaw, W., & Hudebine, H. (2015). The United Nations Convention on the Rights of Persons with Disabilities: Opportunities and tensions within the social inclusion and participation of persons with disabilities. *ALTER, European Journal of Disability Research*, *9*, 9–21.

Stein, M. A., & Lord, J. E. (2010). Monitoring the Convention on the Rights of Persons with Disabilities: Innovations, lost opportunities, and future potential. *Human Rights Quarterly*, *32*(3), 689–728.

Taylor, S. J., Bogdan, R., & DeVault, M. L. (2015). *Introduction to qualitative research methods: A guidebook and resource* (4th ed.). New York: John Wiley & Sons.

Traustadóttir, R., & Rice, J. G. (2017). Kosningar, lýðræði og fatlað fólk (Elections, democracy and disabled people). *Icelandic Review of Politics & Administration*, *13*(1), 83–102.

United Nations. (2006). *The Convention on the Rights of Persons with Disabilities and Optional Protocol*. New York: United Nations.

United Nations. (2010). *Monitoring the Convention on the Rights of Persons with Disabilities: Guidance for human rights monitors* (Professional training series No. 17). New York and Geneva: United Nations.

United Nations. (2011). *Thematic study by the Office of the United Nations High Commissioner for Human Rights on Participation in Political and Public Life by Persons with Disabilities*. (A/HRC/19/36). New York: United Nations.

Young, I. M. (1990). *Justice and the politics of difference*. New Jersey: Princeton University Press.

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Article

Dis-Equality: Exploring the Juxtaposition of Disability and Equality

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Abstract

The (in)equality issues facing disabled people are extensive and long-enduring. The way(s) in which equality is conceptualised has important consequences for understandings of disability. The ambiguity of what I call *dis-equality* theory is two-fold; the apparent failure of mainstream equality theorising in, firstly, embracing disability concepts at all, and secondly, in fully incorporating the logistics of disability, particularly in relation to the social construction of such. Practices of institutional and more complex forms of discrimination are part of those deeper structures of domination and oppression which maintain disabled people in positions of disadvantage. Everyday practices, in the 'ordinary order of things' (Bourdieu, 2000), continue to be misrecognised as natural and taken for granted. This article critically explores the complexity of *dis-equality* theorising utilising a Bourdieusian lens which explicitly incorporates complex and subtle forms of discrimination, and by examining the UN Convention on the Rights of Persons with Disabilities' approach to equality. I argue that the way forward for *dis-equality* theorising in today's rights based era must be one that considers the nuances of the 'rules of the game' (Young, 1990) if it is to be effective in challenging the inequalities to which disabled people have long been subject.

Keywords

Bourdieu; disability; dis-equality; discrimination; equality; rights; UNCRPD

Issue

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1. Introduction

The (in)equality issues facing disabled people have been extensive and long-enduring. Research across the globe has echoed common refrains; that, in comparison to the non-disabled population, disabled people experience significantly higher levels of poverty, unemployment, educational underachievement, lack of access to services, inappropriate housing, and poorer health outcomes (Groce, Kett, Lang, & Trani, 2014; World Health Organisation [WHO], 2011). They are also more likely to be victims of crime, subject to abuse and excluded from political participation (Emerson & Roulstone, 2014; Schur, Kruse, & Blanck, 2013). These experiences can be exacerbated when disabled people occupy more than one disadvantaged identity category (Byrne, 2012; Crock, Ernst, & McCallum, 2014). The extent and range of inequalities experienced by disabled people has generated increasing attention in the context of austerity, neoliberal discourse, and, particularly in the UK, the 2015 investigation by the United Nations Committee on the Rights of Persons with Disabilities (CommRPD) into allegations of 'grave or systematic violations' of disabled people's human rights.

Yet disability and equality remain uneasy bedfellows. The challenges disability poses for equality theorising are the focus of this article. Whilst a range of inequalities are evident, equality theorising in the context of disability remains in its infancy. The ways in which equality has been conceptualised, both generally, and in a disability context, has been unhelpful in advancing meaningful equality for disabled people or in challenging the deeply complex forms of exclusion and discrimination that they experience. Well-meaning equality concepts can in themselves become part of the disabling framework they purport to challenge through their extensive failure to challenge taken for granted discourses.

This article argues that a more nuanced understanding of the particularities of disability and equality requires exploration of subtle forms of discrimination. The limited applicability of current equality theorising to disability is problematised and the term *dis-equality* is introduced as a means of illuminating the juxtaposition between equality and disability. Disability Studies has a rich and vibrant history of challenging the marginalisation of disability from academic debates, and of theorising the range of oppressive practices that disabled people experience (Barnes, 1991; Finkelstein, 1980; Goodley, 2010; Shakespeare, 2013). The article builds on that work by exploring the complexity of *dis-equality* theorising using a Bourdieusian lens. It also draws on the human rights framework as explicated by the UN Convention on the Rights of Persons with Disabilities (UNCRPD) to provide further insight into contemporary equality concepts and questions the extent to which these are grounded in 'safe' or conservative equality discourse. The article concludes by arguing that the way forward for *dis-equality* theorising in today's rights based era must be one that unpacks the nuances of the 'rules of the game' (Young, 1990) if it is to be effective in challenging the inequalities to which disabled people have long been subject. In other words, *dis-equality* must challenge the largely taken for granted and internalised ways of being and doing (the 'rules') of the world in which we live (the 'game').

2. In Whose Name? The Contradictions of Equality

The tenacity and cumulative nature of inequalities have generated a reinvigorated examination of the concept of equality. Yet disabled people have not been routinely included as subjects in mainstream liberal equality theorising and jurisprudence (Silvers, 1994, in disability studies see, for example, Kittay, 2005, 2007, 2011; Kristiansen, Vehman, & Shakespeare, 2009). Social inequality can be understood as a relation between a majority in whose interests the instruments and systems of a society have developed over time, and minorities who have been marginal to the design and operationalisation of these for a variety of reasons. By conceptualising the non-disabled population as the 'majority' group and the disabled population as the 'minority' group in society, the relevance of equality frameworks for disability are evident. It is this approach which underpins this discussion. The need for *dis-equality* emanates from the specific experiences and characteristics of disability. The linguistic convention of *dis-equality* is here defined and used as a means of illuminating and addressing the intricacies and complexities of equality theorising in relation to disability and vice versa; that is, the juxtaposition of disability and equality. The separation of equality and inequality into distinct concepts is not helpful and fails to consider how equality itself is often socially constructed, and ways in which equality mechanisms/tools, can in themselves become unconscious perpetrators of inequalities.

The reasons objecting to inequality are manifold. Scanlon (1997) identifies a number of reasons behind objections to inequality. Firstly, humanitarian concerns seek to eliminate inequalities to assist the alleviation of suffering or deprivation. Secondly, inequalities can reinforce stigmatisation and feelings of inferiority and domination. Thirdly, inequalities can lead to excess and unacceptable forms of power. Nagel (1977) identifies two arguments expressing the intrinsic value of equality. The communitarian view perceives equality as good for society as a whole, enabling feelings of solidarity. In contradistinction, the individualistic view perceives equality as a distributive principle and a way of meeting conflicting needs and interests in society. The relevance to disability can be easily ascertained across these dimensions despite its absence in mainstream equality theorising.

The question of why we should pursue equality is insufficient. We need to consider the question of why which equality, or more succinctly, 'equality of what?' (Sen, 1992) since "the answer we give to 'equality of what?' will not only endorse equality in that chosen space, but will have far-reaching consequences on the distributional patterns in other spaces" (Sen, 1992, p. 21). For example, to pursue equality of opportunity may lead to inequality of economic outcome. Baker, Lynch, Cantillion and Walsh (2004) have illustrated how there is no shortage of potential answers to the type of equality we should consider. Indeed, "it follows that far from being a single idea, equality refers to countless ideas, which may have very different implications and may even be incompatible" (Baker et al., 2004, p. 22). Yet disability has been conspicuously absent from these primary discussions.

While space prohibits in-depth discussion of the entire field of mainstream equality theorising, it is useful to highlight some that have been the most dominant over time. The concept of distributive justice, for example, has been outlined by Arneson (1993):

> The concern of distributive justice is to compensate individuals for misfortune. Some people are blessed with good luck, some are cursed with bad luck, and it is the responsibility of society—all of us regarded collectively—to alter the distribution of goods and evils that arises from the jumble of lotteries that constitutes human life as we know it....Distributive justice stipulates that the lucky should transfer some or all of their gains due to luck to the unlucky (cited in Anderson, 1999, pp. 289–290).

Similarly, Cohen (1989) contends that distributive justice is concerned with the distinction between 'luck' and 'choice' in relation to compensation and where any resulting inequalities reflect choices made rather than individual misfortune. The most well-known theory of distribution is Rawls' (1971) 'difference principle' which grants lexical priority to the worst off, but also allows for inequalities of office so long as these have been attained under 'fair equal opportunity'. In proposing this theory, Rawls neglects disability and subscribes to the idea of a 'normal' human being. Indicative of the time in which he was writing, this offers us an insight into the way in which the relationship between disability and equality has been fraught with tension. Rawls assumes that:

> All citizens are fully co-operating members of society over the course of a complete life. This means that everyone has sufficient intellectual powers to play a normal part in society, and no-one suffers from unusual needs that are especially difficult to fulfil, for example unusual and costly medical requirements. (Rawls, 1980, pp. 545–6)

Deviations from the 'norm' are understood as 'unusual' and 'costly', and equated with individual 'suffering'. Dworkin (1996) moves away from a Rawlsian approach to one that proposes equality of resources. An equal distribution of resources is one that is 'envy-free' where no-one 'envies' the resources others have. Dworkin incorporates compensatory mechanisms to take account of the differences in impersonal and personal resources whereby personal capacities are perceived to be the result of 'bad brute luck' (Dworkin, 1996). This approach has been subject to much criticism on the grounds that it focuses on the resources people hold rather than what they are able to do with these resources or how they are able to convert them (Anderson, 1999). Dworkin seeks only to compensate individuals for resource deficiencies and not on the basis of expensive or involuntary tastes. The problem of 'expensive' versus 'involuntary' needs is not acknowledged. This is significant since some disabled people may have *involuntary* expensive needs and require greater resources to achieve similar welfare levels or opportunities.

The conceptualisation of distributive justice in its various forms, has incorporated and reinforced medicalised understandings of disability. None have progressed the case for a positive and empowering understanding of disability, focusing instead on disability as the 'other'. The language adopted (where disability is mentioned) embed further, conceptualisations of disability that equality theorising should seek to challenge. Cohen for example has talked of 'Tiny Tim' (1989, p. 917) and 'the needy cripple' (1993, p. 16) while Dworkin (1996) has referred to the 'unfortunate'. Where equality theories that emphasise the distribution of something, also fail, is in their inherent belief that the sources of inequality result from the 'natural' order. This further individualises the 'problem' as disability is perceived to be inevitable rather than subject to majority/minority relations whereby the cultural arbitrary is presented as non-disabled and 'healthy'.

Equality of opportunity has received increasing legitimacy as evidenced in legislation such as the *Equality Act 2010* in Britain and *Section 75* of the *Northern Ireland Act* (1998). Its legitimation has been based on understandings or 'myths' of meritocracy, fair competition and 'possessive individualism' (McLaughlin, 2005). Like other forms of equality, equality of opportunity can be interpreted in various ways. Anderson (1999) contends that 'luck egalitarians' have attempted to deal with some of their critiques by moving from equality of outcome to equality of opportunity so that people only start off with equal opportunity to achieve welfare or advantage. This is evidently incompatible with equal outcome. Different groups may have different resources or capital, motivations, characteristics, or use resources in different ways. Equality of opportunity is further problematic as it ignores "the fact that cumulative disadvantage makes it difficult for members of out-groups to attain the prerequisite merit criteria" (Fredman, 2002, p. iii). Nor does it take sufficient account of the legacies of disadvantage and oppression faced by disabled people prior to entering the social field where equal opportunity is being articulated. For Fredman, the equal opportunities principle is underdeveloped and "it is crucial not just to open the gates, but also to equip people to proceed through them" (Fredman, 2002, p. 12). Thus, opportunities for disabled people do not necessarily relate to substantive outcomes or practices.

This overview and critique is intended to demonstrate that, with few exceptions, mainstream equality theorising has not been inclusive of disability. The dominant discourse has been a type of equality that is grounded in conceptions of an individual with perceived 'normal' abilities, wherein differences in ability are medicalised, and related barriers positioned as 'natural' or glossed over. As such, dominant equality theorising has in fact contributed to the inequalities that disabled people experience by positioning this group outside of equality norms, relegating disability to the margins and ultimately disconnecting disability from equality debates. It is through the concept of *dis-equality* that this article seeks to make these connections explicit.

3. Developing *Dis-Equality* through a Bourdieusian Lens

The work of Pierre Bourdieu has much to offer *dis-equality* and in helping move beyond the hitherto minimal consideration of disability in equality theorising. A Bourdieusian framework can provide the supportive architecture needed to uncover the concealed and taken for granted aspects of majority/minority relations impacting upon the lives of disabled people. Bourdieu's analysis of class enables his key concepts to be effectively applied and utilised in the exploration of disability. Aside from, for example, Riddell, Tinklin and Wilson (2005), Edwards and Imrie (2003), Holt (2010), and Holt, Bowlby and Lea (2013), application of this perspective within disability studies is noticeably sparse despite the potential for theoretical advancement.

At the core of Bourdieu's framework are the concepts of 'habitus', 'capital' and 'field'. Together these constitute

Bourdieu's theory of 'practice'. This theory of practice is central to the exploration of the dialectic between objectivity and subjectivity; the individual and society (Bourdieu, 1977) and, ultimately, in facilitating an understanding of the roots of *dis-equality*. According to Bourdieu, action, or practice is not merely a mechanical response to objective structures but is mediated by the *habitus*, the field and the availability of forms of *capital*. The Bourdieusian juxtaposition of objectivity and subjectivity can be expressed in the following way:

[(habitus)(capital)] + field = practice
(Bourdieu, 1984, p. 101)

Within the context of this article, the formula can be illustrated more specifically:

[(habitus of disability) (capital)] + field =
= the practices of disability

The emergent practices therefore become "collectively orchestrated without being the product of the orchestrating action of a conductor" (Bourdieu, 1977, p. 72). Bourdieu's 'habitus' exists in the minds of actors. The habitus of disability, as practiced by both disabled and non-disabled people, can be understood as the product of the internalization of the structures of the social world (Bourdieu, 1989, p. 18) and refers to:

> [S]ystems of durable, transposable dispositions, structured structures predisposed to function as structuring structures, that is, as principles which generate and organize practices and representations that can be objectively adapted to their outcomes without presupposing a conscious aiming at ends or an express mastery of the operations necessary in order to attain them. (Bourdieu, 1990b, p. 53)

As both structuring and structured, the habitus of disability can be transmitted by experiences, processes and institutions, but can in itself generate thoughts and action. While action may have the *appearance* of rational behaviour, this is in effect guided by a 'feel for the game'. Hence, the apparent 'rationality' of, for example, disabled people in 'choosing' between limited educational or employment options is unconsciously guided by that 'feel for the game' and the associated internalisation of social structures. The 'performative visions' or imagined possibilities (Bourdieu, 2000) that emerge are not infinite but exist within a 'structured space of possibilities' (Postone, LiPuma, & Calhoun, 1993, p. 4). These probabilities in the context of disability can be understood as being further mediated by explicit barriers and inaccessibility.

The dispositions inculcated within the habitus leads to the individual 'knowing one's place' (Bourdieu, 1990a, 1990b, 2000), and the 'others' place, that is, the place of the non-disabled majority, and which can be maintained by processes of *misrecognition*:

> The sense of one's place is a practical sense..., a practical knowledge that does not know itself, a 'learned ignorance'...which, as such, may be the victim of that particular form of misrecognition (*allodoxia*), consisting in mistakenly recognizing oneself in a particular form of representation and public enunciation of the *doxa*. The knowledge supplied by incorporation of the necessity of the social world, especially in the form of the sense of limits is quite real, like the submission which it implies and which is sometimes expressed in the imperative statements of resignation: 'That's not for us'... (Bourdieu, 2000, p. 185).

For this reason, a disabled person may, in exploring imagined possibilities of desired social roles, career prospects or citizenship, perceive those readily available to non-disabled people as 'not for the likes of us'. Such perceptions can be continually reinforced by outside agents such as teachers, parents and wider cultural assumptions as well as institutional discourses of disability and (in)equality. Understandings about ways of 'being' and 'doing' and related social divisions become naturalised and enable the familiar world or cultural arbitrary to be taken for granted. It is this naturalisation which emerges as part of those deeper structures of domination and oppression and which resound further than those physical barriers which may be initially more evident. These deep structures can become self-perpetuating and difficult to challenge given their apparent naturalised state. While acknowledging that the habitus is not 'destiny' (Bourdieu, 2000, p. 180), the dispositions constituting the habitus are durable and cannot be easily transformed. This contention appears to maintain the dominated in a position of 'doxic submission' with little opportunity of effectively challenging their location. Yet we could argue that disabled people, and the disability movement, have been actively challenging the inferior identity they have been ascribed. By the same token however, progress remains relatively slow despite ongoing challenge and it is this which Bourdieu refers to as 'durable', since it takes time for the habitus of both the disabled and non-disabled populations to be reconstituted. Even where the dominant cultural arbitrary is challenged, it will not be until the habitus of the non-disabled population is effectively transformed via the internalisation of 'new' dispositions that we will see substantive change.

The habitus of disability is mediated by the accumulation, possession and convertibility of various forms of 'capital'. The forms of 'capital' to which Bourdieu refers are resources upon which individuals and groups draw and utilise in order to maintain or enhance their (involuntarily ascribed) positions in the social order. These resources include economic, social and cultural capital. The possession and legitimation of these forms of capital, cultural capital in particular, by the dominant or non-disabled majority, dictates what is 'normal' and what is not. The spoken competences demanded by the cultural arbitrary, for example, makes it difficult for sign language users to participate across fields on an equal basis with their non-disabled peers. This is especially relevant when analysing the educational experiences of young deaf people who are sign language users and whose linguistic difference makes capital accumulation and conversion problematic. Mainstream education also assumes familiarity with the cultural arbitrary, in this context dominated by the non-disabled majority and becomes manifest in forms of teaching and assumed knowledge, being able to access classroom situations and resources without hindrance, and familiarity and usage of written and spoken English. Non-disabled people are thus able to effectively utilise those educational opportunities which are presented to them in contrast to the struggle experienced by those who are disabled by the construction of cultural norms. The legitimation of these norms is continuously reinforced by emphases on concepts such as equality of opportunity and meritocracy.

As Edwards and Imrie (2003) postulate, the 'impaired' or 'disabled' body itself becomes a 'bearer of value' or a form of physical capital, and greater value is bestowed on the 'body beautiful' of the non-disabled majority. The possession of capital then, has a symbolic dimension which facilitates the "cognition, communication and social differentiation of power relations" (Bourdieu & Passeron, 1977). This form of symbolic capital, or rather, the symbolic effects of capital, becomes an instrument of recognition, and by the same token, misrecognition, of relations between disabled and non-disabled populations (see above). Thus, the non-disabled body can become misrecognised (or mistakenly accepted as) as superior or of greater value, and perpetuated through, for example, the media. What is of significance here, is not just the potentialities of capital, but their subsequent effects. For disabled people, negative symbolic capital becomes manifest as a form of symbolic domination. As Bourdieu has argued, "there is no worse dispossession perhaps..., than that of the losers in the symbolic struggle for recognition, for access to a socially recognized social being, in a word, to humanity" (2000, p. 241).

The habitus of disability and forms of capital interact with the 'field' to produce outcomes, or *practices of disability*. The 'field' is a social microcosm constitutive of a set of objective structures and competitive positions in which the habitus of disability operates. This can refer to the field of learning, employment, independent living and so on. The largely invisible relations between individuals and groups in a particular field are contingent upon relations of power and capital (Bourdieu & Wacquant, 1992). The field becomes a site of struggle and conflict over the application of resources in a bid to maintain or enhance existing positions in the social order. Each field then, provides us with a relational frame of reference through which practices, inequalities, and ultimately, *dis-equality*, can be analysed. It is further illustrative of the ways in which complex forms of discrimination can emerge.

4. *Dis-Equality* and Complex Forms of Discrimination

Discourses of equality articulated by institutions and legal or regulatory texts can be understood as objectifications of dominant world visions. These discourses can be much less challenging than they might appear when we begin to analyse them in detail. In some cases, they can emerge as strategies of conservation or 'safe' equality. In other words, legislation and policies can be framed in a way that enables the continued legitimation of existing practices. Legislation and policies are not value free but contain implicit messages about majority/minority social group relations. In so doing, they become part of the routine regimes that enable complex forms of discrimination to persist, that is, of institutional and systemic discrimination (McLaughlin, Khaoury, & Cassin, 2006). Institutional practices routinely create inequality while systemic discrimination emanates from the taken for granted 'rules' of everyday practice(s). These 'rules' are part of the regimes of social action, or in Bourdieusian terms, part of the 'immanent structures of the game'. These routine regimes then, are part of those deeper structures of domination and oppression with which *dis-equality* should be concerned.

The language of complex forms of discrimination has much to offer *dis-equality*. Loosely defined as 'diffuse, implicit and collective rather than individual', complex forms of discrimination can be understood as those "pervading patterns in social practices which serve to exclude, devalue or disadvantage individuals sharing a minority group trait" (McLaughlin et al., 2006, p. 1). McLaughlin et al. suggest that these practices are unlikely to be intentionally discriminating given that they arise out of those 'day-to-day norms' and the taken for granted. It is precisely this which is highlighted by Bourdieu when he argues "the dominant class have only to let the system they dominate take its own course in order to exercise their domination" (Bourdieu, 1977, p. 190). Thus domination, and complex forms of discrimination, can occur below the level of individual consciousness. Achieving equality for disabled people in a system where the game has already begun, and where the rules and standards have already been set, is evidently contradictory since it implies a form of equality that enables disabled people to 'fit in' with an already constructed society and associated social systems, that is, a form of equality which fails to radically challenge the root of all inequalities. To do so implies changing a system that already works to the apparently legitimate advantage of the majority non-disabled population and on the basis of institutional 'mastery of the game' (Bourdieu, 2000, p. 230). Until there is a sense of need for the majority population to change deeper structures of domination and oppression and to instigate this change, complex forms of discrimination as experienced by disabled people in our society will prevail.

Discourses of equality in a disability context remain heavily influenced by 'regulatory texts' (Smith, 2005), that is, by textual representations of equality as legislatively expressed. Such texts are significant since they "continue to authorise and subsume local particularities resulting from the work of translation" (Smith, 2005, p. 199); they can set the scene for 'safe equality'. Legislation and policies such as the Disability Discrimination Act (1995) (DDA), Equality Act (2010), and the Special Educational Needs and Disability Act (2002) (SENDA) in the UK can be viewed as falling into this trap. For example, the medicalised definition of disability contained within these frameworks 'contradicts many of the principles of the liberal equality framework' (Woodhams & Corby, 2003, p. 159). Further, the DDA allowed failure of reasonable adjustments[1] to be justified in certain circumstances (Lawson, 2008). Indeed, what is 'reasonable' depends on a range of factors, including how practicable it is for, for example, the employer to make the adjustment, the cost of making it, the extent of any disruption to its business activities, the organisation's financial resources and how effective the adjustment would be in overcoming the individual's disadvantage To put it another way, disabled people are immediately put at a disadvantage given the construction of the 'game' (or society) by and for a non-disabled majority. Equality instruments such as those above have fitted in or around the status quo rather than attempting to seriously challenge it. This can allow for change to be encroached in 'safe' ways that are favourable to the cultural arbitrary (for example, on the grounds that change would be 'unreasonable' or disruptive to business activities). This inadequacy is archetypical of *dis-equality* instruments in today's society. The utility of a Bourdieusian framework in understanding the processes of legitimation inherent within legislative developments is central.

The UNCRPD can be understood as the most important contemporary regulatory text on *dis-equality*. It builds on the growing recognition by other treaty bodies such as the UN Committee on Economic, Social and Cultural Rights (2009), of systemic, cumulative and intersectional discrimination. The UNCRPD makes extensive references to equality and non-discrimination. A definition of discrimination is set out in Article 2 while for the first time in a human rights instrument, Article 2 defines 'reasonable accommodation' as:

> Necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.

Article 5 UNCRPD sets these terms in their context. Article 5(3) obliges States Parties to take all appropriate steps to ensure that reasonable accommodation is provided in the pursuit of equality while Article 5(4) enunciates that: 'Specific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination under the terms of the present Convention'.

All provisions of the UNCRPD must be read in light of Article 3 (General Principles). Whilst 3(b) explicitly sets out non-discrimination as a general principle alongside equality between men and women (3(g)), the remaining six principles constitute variants of the equality principle, encompassing the concepts of dignity and autonomy (3(a)), participation and inclusion (3(c)), respect for difference (3(d)), equality of opportunity (3(e)) and, in applying equality to disability; accessibility (3(f)). The remainder of the UNCRPD makes consistent references to ensuring the rights of disabled people 'on an equal basis' to non-disabled people. Substantively, the UNCRPD contains a wide range of economic, social, cultural, civil and political rights, covering areas such as education, healthcare, home and family, accessibility, mobility, information, political participation, and protection from inhuman and degrading treatment. By bringing these rights to the fore, the UNCRPD makes their applicability and relevance to the lives of disabled people clear. The fact that disabled people themselves were actively involved in the negotiation and drafting of the treaty further strengthens the inclusivity of and responsiveness of the treaty to disabled people's lived experiences.

These provisions are to be undoubtedly welcomed. They provide further recognition and insight into the metrics of substantive equality in a disability context and a much more rounded approach to *dis-equality* than has hitherto been taken. This article argues however, that in recognition of the long battle which preceded the UNCRPD's adoption, we must continue to be responsive and to push the boundaries of *dis-equality*. The UNCRPD and its typified rights is no doubt itself a challenge to and for the dominant cultural arbitrary who are obliged to make the UNCRPD rights real. However, we must also be mindful of the power of the UNCRPD as a regulatory text. To assume that a treaty, simply because it has been adopted, is value-free would be naïve. To maximise the UNCRPD's power as a tool for change for disabled people it is important to be aware of and engage with any barriers to the UNCRPD's potentialities whether implicit or explicit. The use of well-recognised equality concepts around discrimination, equality of opportunity, and 'on an equal basis with others' is arguably reflective of the cultural arbitrary on which the international human rights community is structured and into which *dis-equality* is expected to fit. In other words, these well-established equality tools have already been developed and debated by and for the non-disabled majority in the context of mainstream equality theorising as highlighted in Section 2 above. We have no guarantee that these concepts will always be interpreted at State level in a way that is meaningful for disabled people or as intended by the UNCRPD's drafters. Facilitating access to rights on 'the same basis as' non-

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[1] Equality legislation in the UK uses the phrase 'reasonable adjustment' to denote changes to practices or procedures that may be required while the CRPD uses the term 'reasonable accommodation.' See next paragraph for further details.

disabled people fails to recognise and challenge the extent to which initial rights accorded to non-disabled people now form the taken for granted rules upon which everyday practices are based. The author is not suggesting that some kind of new or different rights need to be established, rather, in order to move forward in equality and rights discourse, we need to remember where we have come from and that being explicitly granted rights 'on the same basis' as non-disabled people is further indicative of the way in which disabled people have entered the equality and rights 'game' after it has already begun and wherein the now naturalised 'rules' (practices and rights) have been based on non-disabled ideals.

International human rights law plays a critical role in legitimating new or challenging existing 'norms'. So too can they risk facilitating little more than assimilation with the dominant culture or espousing 'safe' equality if existing programmes, standards, activities, services and ways of being and doing are presented as meritorious. Similarly, as noted in Section 2, equality of opportunity assumes that fair competition can exist, that the rules of the competition are fair, and that the outcome of the competition is also fair. What the UNCRPD does not do, in relation to the latter concept, is specify precisely how the competition can be made fairer in the context of disability. Thus, assumptions of cultural familiarity risks continuing to be maintained while inequalities of condition are ignored, and the naturalisation of prescribed standards misrecognised. Whilst indicative of the importance of substantive equality, the concept of reasonable accommodation is also problematic. What is understood as 'reasonable' by one State Party may differ from another. As Mégret and Msipa (2014, p. 265) note, there 'is *a priori* something inherently contentious about what constitutes 'reasonable' accommodation'. Consideration also needs to be paid to what constitutes an 'undue burden' to the duty-bearer. Implicit within understandings of justifiable discrimination and reasonable accommodation is the idea that disabled people and their needs are both burdensome and expensive and wherein the notion of reasonableness and its subjective parameters risks becoming something of a safety net and/or an institutional conservation strategy against structural change.[2] Concepts of reasonable accommodation whilst purporting to offer a solution to exclusionary practices, can themselves become a barrier to inclusion and equality by designating some disabled people, and those with more complex needs in particular, as having needs that are 'unreasonable', 'too costly' and 'too burdensome'. Whilst viewed as a key avenue through which disabling barriers can be eradicated and of achieving substantive equality, the continuing justification for practices that are clearly discriminatory, but 'unreasonable' to remove, once again risks locating the 'problem' of disability with the individual who, but for their costly requirements perceived as resulting from individual need, would be 'able' to fully participate.

While the UNCRPD is a set of international standards, it is, to a large degree, interpreted and implemented by State parties at national levels, at least until meaning is elaborated upon by the CommRPD in its General Comments and/or Concluding Observations. In this way, the UNCRPD has the potential ability to emerge as the 'friend', not 'foe' of the cultural arbitrary if obligations can be interpreted in a way that is favourable to a State party. This resonates with Bourdieu's argument that "law does no more than symbolically consecrate…the structure of power relations among the groups and the classes that is produced and guaranteed practically by the functioning of these mechanisms" (Bourdieu, 1990b, p. 132). This is not to say that the UNCRPD does so consciously, but to highlight that it is not enough to espouse agreed aims and substantive rights, Rather, the underlying assumptions on which they can be based must be critiqued and challenged where needed and the way(s) in which they should be interpreted should be made explicit.

Some of this work is already being carried out by the CommRPD through the medium of its General Comments and Concluding Observations. Given the limited resources of CommRPD and the time it will take through to get through the initial reports of the 175 countries who have ratified to date, progress will be gradual. The CommRPD which constitutes a majority of disabled people creates a critical strategic space for the habitus of disability to be challenged among both disabled and non-disabled people, and for new imagined possibilities and performative visions to emerge. As highlighted in Section 3, it takes time for durable dispositions or mindsets to change. The UNCRPD and its Committee has a critical role to play in facilitating this change. The composition of the Committee in particular can help create direct ownership of the UNCRPD by the disability community globally and provide added legitimacy to the interpretation of UNCRPD rights. This has arguably been reaffirmed by Committee members' noted celebration of the extent of involvement by disabled people's organisations in the first UNCRPD examination of the UK in August 2017. Perhaps this is a moment in history where we see some of those durable dispositions vociferously and continuously challenged. Nonetheless, we must also be mindful of other issues that can emerge; while the CommRPD constitutes a majority of disabled people, at the time of writing, seventeen of the eighteen committee members are male.

5. Conclusion

The intricacies of 'equality' across social groups are without doubt, compelling. It is clear from research (WHO, 2011; Emerson & Roulstone, 2014; Schur et al., 2013) that inequalities abound for disabled people across a multitude of domains. The immediate barriers around accessibility, attitudes, and awareness are indicative of a

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[2] At the time of writing, a general comment on equality and non-discrimination is being drafted by the Committee on the Rights of Persons with Disabilities. A Day of General Discussion on this issue was held on 25 August 2017.

greater symptomatic cause; that of underlying complex forms of discrimination and the concealed power that underpins majority/minority relations. Yet attempts to redress these issues through equality theorising have been scant or inadequate. Questioning existing constructions of equality is important if we are to confront ideological influences and challenge their effects. So too must complex forms of discrimination be extensively identified and turned around. The aim of this article has been to illuminate the juxtaposition of disability and equality through a Bourdieusian lens. It does not claim to have addressed all the issues, but rather to create space for a more nuanced understanding of *dis-equality* and to further stimulate contemporary debate about the construction of practices of disability.

The location of complex forms of discrimination within a Bourdieusian framework facilitates exploration and challenge of those dominant cultural norms and institutional structures which have for so long categorised disabled people as innately different. The application of complex forms of discrimination to *dis-equality* theorising ultimately enables the complexity of the relationship between disability and equality to be explored by identifying the taken for granted and immanent rules on which majority/minority relations are constituted in a society designed by and for a non-disabled majority. It thus offers much potential in dissecting the nuances of social practice as experienced by disabled people.

The UNCRPD goes some way to mediating existing terms and conditions for disabled people. Such a rights based approach is an example of a more measured approach to *dis-equality* than has hitherto been the case. However, we must not be complacent. Many challenges remain, and effective implementation of these legitimised rights is an ongoing battle. The typified UNCRPD rights, by virtue of their inclusion, can be perceived as the optimum solution to the marginalisation, discrimination, and inequalities that disabled people experience, yet they risk being based on a so-called ideal cultural arbitrary that takes non-disabled roles and bodies as its prototypes. There is a need for debate on whose vision of rights a rights discourse is based upon. If no previous human rights treaties existed and the UNCRPD was the first to introduce any equality related concepts, what would this look like? Given that the UNCRPD is based on, and builds upon existing human rights treaties, there is a risk that it further naturalises the existing human rights framework, itself based initially, through the Universal Declaration of Human Rights (1948), on a conception of an able-bodied rights holder. Care must be taken to ensure that the UNCRPD does not become encroached in forms of safe equality or institutional conservation strategies by virtue of the interpretive power of States parties. Nevertheless, it is heartening that the Committee appears to be taking greater cognisance of the complex forms of discrimination that can emerge by referring to it in its work to date through, for example, General Comments and Concluding Observations. Irrespectively, open and enabling conversations need to take place about what equality really means in the context of disability, and the extent to which equality theorising can be inclusive of the needs of all disabled people. We would do well to revisit and progress the hitherto legitimised equality discourse to address contemporary gaps and challenges so that equality theorising can itself be reflective of the equality it seeks to achieve.

Conflict of Interests

The author declares no conflict of interests.

References

Anderson, E. S. (1999). What is the point of Equality? *Ethics*, *109*(2), 287–337.

Baker, J., Lynch, K., Cantillion, S., & Walsh, J. (2004). *Equality: From theory to action*. Hampshire: Palgrave Macmillan.

Barnes, C. (1991). *Disabled people in Britain and discrimination*. London: University of Calgary Press.

Bourdieu, P. (1977). *Outline of a theory of practice*. Cambridge: Cambridge University Press.

Bourdieu, P. (1984). *Distinction: A social critique of the judgement of taste*. Cambridge: Harvard University Press.

Bourdieu, P. (1989). Social space and symbolic power. *Sociological Theory*, *71*(1), 14–25.

Bourdieu, P. (1990a). *In other words*. Cambridge: Polity Press.

Bourdieu, P. (1990b). *The logic of practice*. Cambridge: Polity Press.

Bourdieu, P. (2000). *Pascalian mediations*. Cambridge: Polity Press.

Bourdieu, P., & Passeron, J. C. (1977). *Reproduction in education, society and culture*. London: Sage.

Bourdieu, P., & Wacquant, L. J. D. (1992). *An invitation to reflexive sociology*. Cambridge: Polity Press.

Byrne, B. (2012). Minding the gap? Children with disabilities and the United Nations Convention on the Rights of Persons with Disabilities. In M. Freeman (Ed.), *Law and childhood studies—Current legal issues 14*. Oxford: Oxford University Press.

Cohen, G. A. (1989). On the currency of egalitarian justice. *Ethics*, *99*(4), 906–944.

Cohen, G. A. (1993). Equality of what? On welfare, goods and capabilities. In M. Nussbaum & A. Sen (Eds.), *The quality of life*. Oxford: Clarendon Press.

Crock, M., Ernst, C., & McCallum, R. O. (2014). Where disability and displacement intersect: Asylum seekers and refugees with disabilities. *International Journal of Refugee Law*, *24*(4), 735–764.

Dworkin, R. (1996). Do liberty and equality conflict? In P. Barker (Ed.), *Living as equals*. Oxford: Oxford University Press.

Edwards, C., & Imrie, R. (2003). Disability and bodies as bearers of value. *Sociology*, *37*(2), 239–256.

Emerson, E., & Roulstone, A. (2014) Developing an evidence base for violent and disablist hate crime in Britain: Findings from the life opportunities survey. *Journal of Interpersonal Violence*, *29*(17), 3086–3104.

Finkelstein, V. (1980). *Attitudes and disabled people*. New York: World Rehabilitation Fund.

Fredman, S. (2002). *Discrimination law*. Oxford: Open University Press.

Goodley, D. (2010). *Disability studies: An interdiscplinary introduction*. London: Sage.

Groce, N. E., Kett, M., Lang, R., & Trani, J. F. (2014). Disability and Poverty: The need for a more nuanced understanding of implications for development policy and practice. In K. Soldatic & H. Meekosha (Eds.). *Disability in the Global South*. London: Routledge.

Holt, L., Bowlby, S., & Lea, J. (2013). Emotions and the habitus: Young people with socio-emotional differences (re)producing social, emotional and cultural capital in family and leisure space-times. *Emotion, Space and Society*, *9*(1), 33–41.

Holt, L. (2010). Young people's embodied social capital and performing disability. *Children's Geographies*, *8*(1), 25–37.

Kittay, E. (2005). Equality, dignity and disability. In M. A. Waldron & F. Lyons (Eds.), *Perspectives on equality: The Second Seamus Heaney Lectures* (pp., 95–122). Dublin: Liffey.

Kittay, E. (2007). A feminist care ethics, dependency and disability. *APA Newsletter for Feminism and Philosophy 6*, pp. 3–6.

Kittay, E. (2011). The ethics of care, dependency and disability. *Ratio Juris*, *24*(1), 49–58.

Kristiansen, K., Vehman, S., & Shakespeare, T. (2009). *Arguing about disability: Philosophical perspectives*. London: Routledge.

Lawson, A. (2008). *Disability and equality law in Britain: The role of reasonable adjustment*. Oxford: Hart Publishing.

McLaughlin, E. (2005). *Skeletons in the human rights cupboard: A theoretical critique of equality of opportunity and human rights* (Working Paper 6). Belfast: Equality and Social Inclusion in Ireland Project.

McLaughlin, E., Khaoury, R., & Cassin, M. (2006). *Complex forms of discrimination* (Working Paper 45). Belfast: Equality and Social Inclusion in Ireland Project.

Mégret, F., & Msipa, D. (2014). Global reasonable accommodation: How the Convention on the Rights of Persons with Disabilities changes the way we think about equality. *South African Journal on Human Rights*, *30*(2), 252–274.

Nagel, T. (1977). Equality. In M. Clayton & A. Williams (Eds.). (2002), *The ideal of equality*. Hampshire: Palgrave Macmillan.

Postone, M., LiPuma, E., & Calhoun, C. (1993). Introduction. In C. Calhoun, E. LiPuma, & M. Postone (Eds.), *Bourdieu: Critical perspectives*. Cambridge: Polity Press.

Rawls, J. (1971). *A theory of justice*. Oxford: Oxford University Press.

Rawls, J. (1980). Kantian constructivism in moral theory. *Journal of Philosophy*, *77*(9), 515–572.

Riddell, S., Tinklin, T., & Wilson, A. (2005). *Disabled students in higher education: Perspectives on widening access and changing policy*. London: Routledge.

Scanlon, T. M. (1997). The diversity of objections to inequality. In M. Clayton & A. Williams (Eds.). (2002), *The ideal of equality*. Hampshire: Palgrave Macmillan.

Schur, L., Kruse, D., & Blanck, P. (2013). *People with disabilities: Sidelined or mainstreamed?* Cambridge: Cambridge University Press.

Sen, A. (1992). *Inequality re-examined*. Oxford: Sage.

Shakespeare, T. (2013). *Disability rights and wrongs*. London: Routledge.

Silvers, A. (1994). 'Defective' agents: Equality, difference and the tyranny of the normal. The Journal of Social Philosophy's. Reprinted in R. Manning & R. Trujillo (Eds.). (1996). *Social justice in a diverse society*. London: Mayfield Publishing.

Smith, D. E. (2005). *Institutional ethnography: A sociology for people*. Toronto: AltaMira Press.

UN Committee on Economic, Social and Cultural Rights. (2009). *Non-discrimination in economic, social and cultural rights*. E/C.12/GC/20. Geneva: United Nations.

Woodhams, C., & Corby, S. (2003). Defining disability in theory and practice: A critique of the British Disability Discrimination Act 1995. *Journal of Social Policy*, *32*(2), 159–178.

World Health Organisation. (2011). *World report on disability*. Malta: WHO.

Young, I. M. (1990). Social movements and the politics of difference. In R. C. Manning & R. Trujillo (Eds.). (1996), *Social politics in a diverse society*. London: Mayfield Publishing Company.

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Article

Leveraging Employer Practices in Global Regulatory Frameworks to Improve Employment Outcomes for People with Disabilities

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Abstract
Work is an important part of life, providing both economic security and a forum to contribute one's talents and skills to society, thereby anchoring the individual in a social role. However, access to work is not equally available to people with disabilities globally. Regulatory environments that prohibit discrimination and support vocational training and educational opportunities constitute a critical first step toward economic independence. However, they have not proven sufficient in themselves. In this article, we aim to infuse deeper consideration of employer practice and demand-side policy reforms into global policy discussions of the right to work for people with disabilities. We begin by documenting the employment and economic disparities existing for people with disabilities globally, followed by a description of the international, regional, and local regulatory contexts aiming to improve labor market outcomes for people with disabilities. Next, we examine how policies can leverage employer interests to further address inequalities. We discuss employer policies and practices demonstrated in the research to facilitate recruitment, hiring, career development, retention, and meaningful workplace inclusion. The goal of the article is to synthesize existing international literature on employment rights for people with disabilities with the employer perspective.

Keywords
disability; disabled worker; employment; employment equity; employer practices; human resources; international disability policy

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1. Introduction

Work is an important part of life. It is a source of not only economic power, but also social and personal well-being. At the most basic level, work provides security by enabling the procurement of food, shelter, and other basic needs for survival and good health. Beyond that, work allows individuals to contribute to the community with their abilities and skills, and provides the means for establishing a social position from which others perceive them. Our jobs often determine how society views us, and therefore influence how we view ourselves. Equitable access to work is a basic right, and at the core of what it means to be human.

However, individuals with disabilities around the world have not been able to gain equitable access to employment. Many factors contribute to the employment disparities for individuals with disabilities. Among them are unequal preparation for the labor market, insufficient support in finding and retaining employment, and poor awareness among employers about effective recruitment and retention strategies for workers with disabilities. These barriers exist in low-, middle-, and high-income countries alike. Individuals who experience a "precarious relationship with the labor market" face additional barriers related to access to social and political participation, as well as necessities integral to quality of life (Harris, Owen, & Gould, 2012, p. 824). While many people with disabilities are able to achieve gainful employment and societal integration, as a group they face disproportionate poverty and unemployment (International Labour Organization [ILO], 2007a).

The emphasis of this article is on the role that employers—the demand-side of the disability employment continuum—play in improving outcomes for individuals with disabilities, and how government policy initiatives can drive more substantial demand-side effort (Bruyère, 2016). Traditionally, scholars have studied disability employment inequalities from the viewpoint of the individual, particularly focusing on the medical, educational, psychological, and vocational factors that affect a person's work-related functioning and job skills (Chan, Strauser, Gervey, & Lee, 2010). On the other hand, scholars describe individual rights primarily in relation to governmental action and enforcement. Both approaches tend to overlook "the fact that labor market outcomes such as employment are determined when the *supply of* individuals' labor aligns with *demand for* labor on the part of employers" (Bruyère, VanLooy, von Schrader, & Barrington, 2016, p. 5). In other words, they tend to downplay employer considerations. On the other hand, policies accounting for the demand-side aim to cultivate change at the organizational level in order to improve labor market conditions (Bruyère et al., 2016).

This article further explores the employer side of the international regulatory context, engaging in a discussion of empirically supported best practices in recruitment, hiring, advancement, retention, and full inclusion of individuals with disabilities in the workforce. We set this information in the context of the international legislative and regulatory environment that influences the behavior of employers. Policy approaches that combine supply- and demand-side reforms have not seen proper attention in the global literature, especially as applied to the responsibilities of states parties to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). In attempting to bring employer needs to the fore, we advocate policymaking efforts aimed at broadening the pool of stakeholders participating in inclusive hiring practices and increasing the accessibility of the open labor market. Employers who are open to inclusive practices, aware of both the intangible and bottom-line benefits of such practices, and equipped with the strategies to implement them, have a powerful role to play in making the labor market favorable to people with disabilities.

2. Global Situation of Work and Economic Disparities for People with Disabilities

Individuals with disabilities make up approximately 15% of the world population, or more than one billion people (World Health Organization [WHO], 2011). Projections indicate that the number and proportion of people with disabilities worldwide will continue to increase due to aging, chronic health conditions, workplace related incidents, and other factors (Harper, 2013; Houtrow, Larson, Olson, Newacheck, & Halfon, 2014; Vos et al., 2015). Low- and middle-income countries, often referred to as "developing" nations, have higher rates of disability prevalence than high-income countries: globally, nearly 80% of people with disabilities reside in low-income nations (WHO, 2011). Despite the high overall demographic representation, people with disabilities continue to be significantly under-represented in the world's labor force.

The employment rate of people with disabilities globally is 44%, compared with 75% for people without disabilities (WHO, 2011). The inactivity rate for people with disabilities is almost 2.5 times higher: 49% vs. 20% (WHO, 2011). Estimates indicate that the social exclusion of people with disabilities from the workplace results in trillions of dollars in annual loss in GDP (Metts, 2000; Ozawa & Yeo, 2006). In addition to lost labor, the marginalization of people with disabilities in employment creates "structural and social costs," including "high benefit levels and health and social inequalities" (Sainsbury & Coleman-Fountain, 2014, p. 2). Lost labor and increased social cost only further magnifies the case for demand-side focus: in many cases, employers are not even aware that they are limiting their talent pools and sacrificing productivity by forgoing inclusive recruitment and hiring practices (Kaye, Jans, & Jones, 2011). As such, employer practices research indicates that "the competition that drives business innovation could also play a part in encouraging businesses to compete with each other on issues related to diversity and inclusion" (Henry, Petkauskos, Stanislawzyk, & Vogt, 2014, p. 246).

Disparities exist in nations across economic and political conditions. In 2015, approximately 35% of working age people with disabilities in the United States attained employment in the open labor market, compared with 78% of people without disabilities (Erickson, Lee, & von Schrader, 2017). Similar trends exist in Organization for Economic Cooperation and Development (OECD) countries, where most recent figures estimate the average employment rate for people with disabilities at just over 40%, compared with approximately 75% for people without disabilities (OECD, 2009). Statistics for OECD nations show that people with disabilities are less likely to have full-time work, more likely to be un- or under-employed, have lower relative income levels, tend to earn less even when employed, and have a higher likelihood of living in poverty (OECD 2009; WHO, 2011). Income levels are much higher among groups of people with disabilities who have high educational attainment or full-time employment (OECD, 2009). Analyses of economic inactivity in the European Union (EU) shows high variation by type and severity of disability (e.g., 75% unemployment for people with mental illness in the United Kingdom) (ILO, 2007b).

Surprisingly familiar thematic barriers emerge in many disparate national contexts. These include tensions arising between employees with disabilities and employers due to legislative efforts, immoderate belief in the perceived fairness of open labor market practices, and reliance on stereotypes about people with disabilities' lack of productivity or the expense of accommodating (Harpur & Bales, 2010). Many of these themes pertain to employer perceptions and resulting practices. In many global contexts, the imposition of duties on employers meet with resistance for these reasons. However, employers who do provide accommodations report that they are typically inexpensive (Dixon, Kruse, & Van Horn, 2003), have high return-on-investment (Unger, Wehman, Yasuda, Campbell, & Green, 2002), and result in improved retention rates, organizational culture, and productivity (Kaye, Jans, & Jones, 2011).

Empirical evidence demonstrates employment disparities in a number of low- and middle-income contexts as well (see, e.g., Hoogeveen, 2005 [Uganda], Lamichhane & Okubo, 2014 [Nepal], Mitra & Sambamoorthi, 2008 [India], Mizunoya, Yamasaki, & Mitra, 2016 [Vietnam], Trani & Loeb, 2010 [Afghanistan, Zambia]). Mizunoya and Mitra (2013) assessed the employment gaps in fifteen low- and middle-income countries in Africa, Asia, and Latin America, and found statistically significant employment gaps for people with disabilities in nine out of the fifteen examples; interestingly, the six countries that had either no gap or a statistically insignificant gap were low-income nations, while all but two with a significant employment gap were middle-income.

Where poverty is widespread, persistent disability is often an additional dimension to poverty, rather than the fundamental cause (Eide & Ingstad, 2011). For this reason, Yeo and Moore (2003) describe the social, cultural, and political processes that link disability and poverty as a "vicious circle." The dimensions of the link between disability and poverty differ significantly between low- and high-income contexts, and causality can run in either direction—that is, poverty can also lead to disability. We can see this in the examples of lack of workplace safety regulations, inadequate healthcare interventions, poor nutrition and hygienic conditions, pollution, and higher prevalence of inaccessible or disabling environments. Lower income levels may also affect people with disabilities differently: additional costs for personal support, medical care, and/or assistive devices can result in greater odds of experiencing financial hardship than peers without disability at similar income levels (e.g., catastrophic health expenditure) (WHO, 2011). Government spending and activity in poverty alleviation for households that have an individual with a disability also lead to unexpected interactions. In countries where poverty is endemic, the introduction of disability grants or pensions can lead to markedly improved standards of living (Loeb, Eide, Jelsma, Ka'Toni, & Maart, 2007). However, in high-income countries, scholars cite such benefits as potential "poverty traps" that "contribute to exclusion from the labor market and result in a comparably low life income" (Eide & Ingstad, 2011, p. 5).

Issues of access to social institutions constitute one of the most intractable barriers to employment and quality of life. Access to education and training provides pathways to employment, whereas marginalization in educational opportunities only furthers employment disparities. In particular, youth with disabilities constitute a "significant proportion of the youth population in every society," and estimates indicate that approximately 80% of youth with disabilities (ages 15 to 24), or between 180 and 220 million people, live in developing countries (U.N. Division of Social Policy and Development [DSPD], 2010, p. 2). Yet youth with disabilities are less likely to start school in the first place, have lower rates of enrollment and promotion in school, and lower transition rates to post-secondary education and work than their peers without disabilities (WHO, 2011). Many countries exclude people with disabilities from mainstream schooling, and have inadequate or fragmentary school-to-work transition frameworks (Stewart, 2009).

The overall lack of services and coordination often leads to a "difficult period of upheaval and uncertainty" as youth with disabilities "transition from childhood into adulthood, primarily in the area of achieving successful employment and independent living" (DSPD, 2010, p. 4). For instance, analysis from four southern African nations found difficulties accessing rehabilitation services (between 26%–55% obtained needed services) and vocational training (between 5%–23%) (WHO, 2011). Even in high-income nations with comparatively robust rehabilitation and social service offerings, people with disabilities often report not having their everyday service needs met (between 20%–40%) (WHO, 2011). At the intersection of supply and demand, lies the availability of skilled workers equipped to meet the needs of the market. As policy concerns, the expansion of educational opportunities, demand-driven skills training, rehabilitation services, and career development opportunities for people with disabilities are of paramount importance (ILO, 2010).

2.1. International Framework for Employment and Training

The UNCRPD was the first binding international human rights treaty to codify the rights of people with disabilities on a global scale. Adopted by the General Assembly in December of 2006, the UNCRPD currently has 160 signatories and 174 ratifying parties (U.N. Enable, 2017). The Convention covers a broad array of human rights topics, including an explicit right to work and related rights pertaining to non-discrimination, awareness raising, education and training, rehabilitation, accessibility, and quality of life. The UNCRPD is a powerful international legal instrument, but as a corrective, its effectiveness is subject to national and local variation. The role of employer practices has been under-explored in scholarship on UNCRPD implementation (see, e.g., Brayley, 2012; Owen & Harris, 2012; Power, Lord, & deFranco, 2013). This is not entirely surprising, as human rights instruments generally conceptualize "rights" (often in a negative rights sense), as inhering in the individual, or alternatively seek to impose affirmative responsibilities on stakeholders without adequate attention to converging interests. However, the UNCRPD does contain certain mandates for states parties to facilitate demand-side buy-in, such as employer awareness building and incentives, and market-driven skills development practices. These elements of the CRPD warrant deeper discussion.

With any international treaty, ratification makes the terms of the agreement legally binding, although enforcement typically falls within the purview of state parties through processes of domestic incorporation (Lord & Stein, 2008). As such, "substantive rights will often get their complexion from the local cultural environment within which they have to be given concrete, practical meaning" (Ncube, 1998, pp. 14–15). Moreover, depending on the level of centralization in legal, regulatory, and enforcement mechanisms, regional variations may also shape the prospects of people with disabilities seeking to exercise their rights. For instance, in the area of employment and work, "the number, size and type of companies in the region, compliance to the law among employers, and the resources, skills and competencies of the regional employment services" may all moderate the practical effect of employment policies and laws (Sainsbury & Coleman-Fountain, 2014, p. 22).

Work and training topics play a prominent role in the UNCRPD. Article 26(1) requires that parties organize, strengthen, and/or extend comprehensive habilitation and rehabilitation programs and services in the areas of health, employment, education and social services, including effective measures "to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life." Article 27 outlines the right to work and employment "on an equal basis with others." This includes the "opportunity to gain a living by work freely chosen or accepted in a labor market and work environment that is open, inclusive and accessible." It also places a prohibition on employer discrimination (hiring, retention, and advancement), and provides rights to equal remuneration, reasonable accommodation, favorable and safe working conditions, systems for redress of grievances, union participation, and access to technical and vocational guidance and training. These are more traditional human rights edicts, primarily guaranteeing the individual a right to equal access and nondiscrimination.

However, Article 27 also calls for parties to promote advancement and return-to-work efforts, as well as alternative pathways to employment such as self-employment, entrepreneurship, cooperatives, public sector employment, and affirmative action programs/incentives. Article 27(1)(h) holds that states parties shall "promote the employment of persons with disabilities in the private sector through appropriate policies and measures, which may include affirmative action programmes, incentives and other measures." 27(1)(j) requires that participants "promote the acquisition…of work experience in the open labour market." Article 24 further contains language implicating not only a nexus between education and the right to work, but also identifying the importance of vocational training, tertiary education, and lifelong learning as human rights. Objectives like this steer the Convention into the territory of demand-side considerations—or at least into the convergence of supply and demand interests—such as employer incentives and market-driven (competitive) skills development. The UNCRPD is a modern human rights instrument, outlining rights consistent with a "substantive" notion of equality. That is, it distinguishes equal treatment from identical treatment, and extends policies beyond negative rights, towards eliminating the conditions that perpetuate discrimination (see, e.g., Committee on Economic, Social and Cultural Rights, 1994).

The balancing of supply- and demand-side policy reforms must also account for local economic factors: for instance, the concept of "productivity" in labor is contingent on which economic sectors predominate in a given region. Lower-income nations tend to feature agrarian economies where the primary sectors (e.g., agriculture, forestry, mining) account for a large share of the jobs, whereas in middle- and high-income countries, the secondary (manufacturing) and tertiary (services) sectors may be more extensive. Policy incentives, injections, and offsets must account for not only existing conditions, but also future trends. Demand-driven reforms can help enhance the agency and participation of private sector stakeholders—especially those less inclined to participate on social grounds. However, reform efforts must not merely cater to employer interests. They must utilize incentives, services, and training opportunities to "restore more choice and control to people with disabilities over the types of support they may need," and prioritize "facilitation mechanisms such as independent planning and supported decision making" (Power et al., 2013, pp. 441–442). Efforts that increase civil society's participation by fomenting employer action are good; efforts that do so while increasing agency and self-determination for people with disabilities are better.

2.2. Approaches to Implementation

The primary strategy of industrialized welfare states has been an investment in employment readiness and training programs and anti-discrimination legislation (Grover & Piggott, 2007; Humpage, 2007). However, at the time of the UNCRPD's adoption, there existed substantial heterogeneity in the types of legal protections and service systems available to people with disabilities on a country-by-country basis. The creation of new international norms must be backed by regional, national, and local implementation efforts, as the "touchstone of the CRPD's significance is whether it changes policies and practices at national level[s] and whether it makes any difference in the actual living conditions of persons with disabilities" (Waldschmidt, Sturm, Karačić, & Dins, 2017, p. 177).

Cultural attitudes remain a major threshold obstacle, particularly when it comes to implementing sweeping reforms "in a manner that responds to broad obligations while being duly consonant to domestic social and legal norms" (Lord & Stein, 2013, p. 99). For instance, analysis by Dinerstein (2017) noted that many Southeast Asian countries implicitly perpetuated medical views of disability by choosing social welfare or health agencies as the implementation "focal point," rather than justice-based agencies. Furthermore, enforcement of non-discrimination provisions can be expensive and beyond the means of countries that lack an existing mechanism. For example, one analysis found that most Pacific Island states lacked appropriately comprehensive frameworks for enforcement (Harpur & Bales, 2010). While it is outside the scope of this article to provide a comprehensive review of disability policy worldwide, in this section we provide some instructive examples of the various contextual issues at national and regional levels, particularly those that touch upon employer practices, interest convergence, and policies that encourage (rather than merely compelling) employer action.

Innovations in policies encouraging supported employment can play a role in bridging employee and employer needs. Certain EU countries (e.g., Germany, Sweden, and Norway) have developed programs to afford supported employment opportunities to people with disabilities (Waldschmidt et al., 2017). In Germany, this includes training and support in work, protecting the right to employment for people with severe disabilities, and legally defined special allowances in the workplace (tax relief, a parking badge, and protection against dismissal) (Sainsbury & Coleman-Fountain, 2014). Germany's social services subsystem offers vocational training centers for youth with disabilities, re-training centers for adults, and integration centers that help individuals with severe disabilities identify and maintain employment, move from training centers to work, and liaise with employers to moderate accommodations and special dismissal procedures. In Sweden, supported employment entails financial support for the purchase of assistive devices in the workplace by employers or individuals, as well as "special introduction and follow-up support" services (before or during the introductory period of a job and up to a year after employment commences) (Committee on the Rights of Persons with Disabilities, 2012). Norway promotes supported employment through subsidies, grants, assistive technology centers, vocational training and higher education opportunities, and incentives for the provision of accommodations (Sainsbury & Coleman-Fountain, 2014). Overall, the emphasis appears to have been effective: from 2000–2010, a 50% increase occurred in the population of Norwegians with disabilities working in supported employment (Official Norwegian Reports, 2012).

Italy instituted measures for a targeted employment framework, graduated hiring quota, and regionally implemented assessment guidelines for work capacity, job-matching candidate's skill set to employer needs, and training criteria (Agovino & Rapposelli, 2011; Law 68/1999). Penalties exist for failing to meet quotas (companies of 15–35 employees must hire one individual, 36–50 must hire two, and 50 or more have a quota of 7%), while conversely employers may receive incentives for employing people with disabilities, such as tax subsidies, wage contributions, and reimbursement for workplace adaptations (Sainsbury & Coleman-Fountain, 2014). Quota systems have been a popular policy directive in a number of contexts, with some nations opting to penalize, others to incentivize, and still others to treat quotas as explicitly or implicitly (due to lack of enforcement mechanism) aspirational. On the incentives side, Uganda, for instance, has provided tax cuts for private sector employers who employ people with disabilities at a rate of 5% of their total workforce (The Persons with Disability Act, 2006). However, 2009 amendments cut the available tax refund from 15% to 2% (Income Tax Amendment Act, 2009), a figure that commentators note is unlikely to provide the needed incentive to employers (Nyombi & Kibandama, 2014).

In some contexts, there is an element of choice. The Czech system, for instance, allows employers to employ people with disabilities "directly," or "indirectly" by commissioning goods and services from organizations that do: for 2010, direct employment accounted for 56% of the obligations met (Committee on the Rights of Persons with Disabilities, 2013; see also The Employment Act, 2004). Governments often allow employers to miss the quota in exchange for payment of a penalty or additional taxation. Serbia's quota system outlines penalties and subsidies for missing, making, or exceeding targets (see Act on Professional Rehabilitation and Employment of Persons with Disabilities, 2009; Prohibition of Discrimination Act, 2009). While many employers choose to pay the fine rather than comply, the government applies penalties to employment, education, and poverty reduction initiatives for people with disabilities (Sainsbury & Coleman-Fountain, 2014).

In many European states, Active Labour Market Policies (ALMPs) aim to improve the functioning of the labor market by directing policies towards unemployed persons, including targeted populations vulnerable to labor market exclusion (Waddington, Pedersen, & Ventegodt Liisberg, 2016). In this way, ALMPs direct policy efforts towards both the supply and demand-side of labor—equipping unemployed individuals with demand-driven skills needed to enter the labor market while simultaneously offering incentives to employers (Auer, Berg, & Cazes, 2007). The Council of Europe formalized a preference for ALMPs in its 2015 Guidelines for Member State employment policies (Council of Europe, 2015). Commentators note that these policies are not without downsides, as many national efforts have led them to adopt “work-first” measures that place pressure on individuals to leave or phase out of benefits programs. This can result in the deterioration of financial position and security for individuals who struggle to find adequate employment (Waddington et al., 2016).

Denmark has become an interesting case for ALMP reforms, both because of its high rates of general employment and “flexicurity” labor market model (Ventegodt Liisberg, 2011). The flexicurity model prioritizes both high levels of income support during unemployment and quick reentry into the labor force, especially through upgrading of skills and “activation” obligations for unemployed individuals (Danish Government, 2013). The percentage of Danish individuals with disabilities in supported employment conditions rose from less than 10% in 2002 to more than 25% in 2014 (Waddington et al., 2016). The Danish policy framework focuses on incentivizing, rather than merely compelling employers (e.g., no quota, high degree of freedom in termination/hiring decisions). Denmark’s system includes subsidies for “ice breaker” wages for recent graduates, flexjobs (subsidized wages for transitional work in special working conditions such as adapted environments or schedules), workplace alterations, mentor opportunities, job trials, and technical or personal assistance (Gupta, Larsen, & Thomsen, 2015).

Thus far we have provided background and examples of the global, regional, and local regulatory efforts to minimize employment discrimination and maximize employment outcomes, including by formulating policies which account for employer needs and interests as stakeholders (with varying levels of duty and responsibility for private sector employers). Against this backdrop, we turn now to the subject of employer practices, and adaptations to workplace culture that can support an inclusive, 21st century workforce amenable to hiring people with disabilities while also keeping the business case in focus.

3. The Importance of Employer Practices

Regulatory environments often aim not only to improve job-seeker prospects (through education, vocational training, VR services, etc.), but also to positively affect employer behavior (through incentives, nondiscrimination rules, awareness raising, etc.). Therefore, the critical next step in our examination of meaningful labor market inclusion draws us closer to the actual employment experience, and to the functioning of the enterprise itself. In this section, we discuss common organizational weaknesses and promising employer practices to help frame the strategies that governments may bake into their policy directives. Research indicates that private employers who value workforce diversity desire additional government support in adapting their recruitment and hiring practices—perhaps even beyond legally prescribed levels—and are more open to collaborating with government agencies who “understand their needs” (Henry et al., 2014).

Employers around the globe are beginning to acknowledge that people with disabilities make reliable and productive employees, and that “having a diverse workforce inclusive of those with a disability makes for a sound business case” (Kulkarni & Gopakumar, 2014, p. 446). The business case for diverse hiring practices, grounded in substantial research, operates under two notions. First, that when provided with an enabling environment, people with disabilities represent a qualified but under-tapped pool of potential workers (direct productivity). Second, that people with disabilities contribute to a diverse workforce, with attendant benefits for workplace culture, morale, and organizational reputation (indirect productivity) (ILO, 2010). Research into organizational diversity actually goes even further, indicating collateral benefits such as lower costs of discrimination and liability, greater organizational problem solving capacity, more innovation, and stronger appeal to a diverse customer base (Yap & Konrad, 2009).

Setting policy aside, the critical initial step in getting people with disabilities into the workplace lies with the employer’s recruitment, selection, and hiring processes, which may take different forms in different regions and economies. Throughout the discussion of employer practices, we encourage consideration of how government policy can reify abstract notions of equality in the workplace (turn policy into practice). Companies respond differently to public policy directives in the area of disability employment: research from Norway and Sweden, for instance, indicates certain prevalent themes in large companies’ approaches to recruitment, including the importance of support beyond mere financial incentives or offsets (e.g., advisory support or technical assistance) and the importance of “value choices” by management (Kuznetsova & Yalcin, 2017). Studies further show that employer knowledge, especially at HR and management levels, is a key threshold ingredient affecting employer commitment to disability inclusive hiring, including training of management in pertinent legal requirements and potential workplace accommodations (Chan, Strauser, Maher, et al., 2010). Government-sponsored incentives, awareness raising, and technical assistance efforts help alert management personnel of recruitment strategies, while national and local employment services can play a key role in connecting employers to job seekers with disabilities (Luecking, 2011). Research from the United Kingdom highlights the benefits of flexible, personalized approaches to job placement, which offer supported employment opportunities through careful job matching, on-the-job support, and barrier reduction (Roulstone, Harrington, & Hwang, 2014).

In a study conducted in the U.S., researchers asked 700 human resource (HR) professionals whether their organizations had put in place any of ten policies and practices that facilitate recruitment and hiring of individuals with disabilities (Erickson, von Schrader, Bruyère, Van-

Looy, & Matteson, 2014). More than half reported including disability in their diversity and inclusion statements (59%), requiring sub-contractors/suppliers to adhere to disability nondiscrimination requirements (57%), and having relationships with community organizations that promote the hiring of people with disabilities (54%). Far fewer reported having explicit organizational goals related to the recruitment and hiring of people with disabilities (25%), or participating in internships or similar programs that target people with disabilities (19%). 45% reported that their companies actively recruit individuals with disabilities, and 38% reported having senior management that demonstrates a strong commitment to hiring people with disabilities. Evidence suggests that only a small share of employers actively recruit workers with disabilities (Domzal, Houtenville, & Sharma, 2008). However, further analysis demonstrates that the more of these practices a company reports, the more likely they are to hire people with disabilities. Those organizations reporting targeted internship programs were almost six times as likely to have hired a person with a disability in the past year; those with strong senior management commitment were almost five times as likely; and those reporting relationships with a community organization were almost three times as likely (Erickson et al., 2014).

Certain multinational corporations have recently taken it upon themselves to become leaders in recruitment efforts, in part as a means to broadening their available talent pools as well as viewing “neurodiversity as a competitive advantage” (Austin & Pisano, 2017, p. 96). For example, German-based software company SAP developed a goal of 1% of its workforce to be individuals with autism by 2020 through extensive recruitment, screening, and training initiatives (Shumaker, 2015). In recent years, a number of multinational companies have reformed their HR practices as a means to accessing neurodiverse talent. These include Hewlett Packard Enterprise (now DXC Technologies), Microsoft, Willis Towers Watson, Ford, and Ernst & Young; others like Caterpillar, Dell Technologies, Deloitte, IBM, JPMorgan Chase, and UBS, have pilot or exploratory efforts in motion (Austin & Pisano, 2017). In addition to finding promising examples among large employers, public sector employment practices are often fundamental to driving reform in hiring practices. This is why advocates often push governments to conduct themselves as model employers (Brooks, Doughtery, & Price, 2015). Research suggests that private employers often look to the public sector for support in adapting their recruitment and hiring practices (Henry et al., 2014).

Getting into the workplace is only the first hurdle in employment for individuals with disabilities. Once an individual acquires a position, career development and advancement also pose challenges, and are often the site of employment discrimination against people with disabilities. People with disabilities report perceived bias in the career advancement process within organizations (von Schrader & Nazarov, 2016), are paid less and hold less-desirable jobs than their non-disabled peers (Kruse & Schur, 2003), and are far less likely to work in management, professional, and related occupations than their peers without disabilities (31.3% compared with 39.2%) (U.S. Bureau of Labor Statistics, 2016). People with disabilities also tend to experience jobs with less autonomy and decision-making compared to their peers without disabilities, as well as jobs that require less education (Colella & Bruyère, 2011). This may result from the absence of proper procedures for handling retention and advancement issues—in the US context, for instance, few employers report offering mentoring (17%) or career planning and development tools (16%), and even fewer have explicit goals or standards for retaining and advancing employees with disabilities (Erickson, von Schrader, Bruyère, & VanLooy, 2013).

More commonly, U.S. companies have formal policies for return to work or disability management (76%), and for flexible work arrangements (57%) (Erickson et al., 2013). Disability management mitigates the impact of the disability by offering comprehensive services, accommodations and workplace modifications (Doyle, Dixon, & Moore, 2003). Common practices include personalized case management, stay-at-work and transitional work assignments, creativity in making accommodations, building support systems using community resources, and training managers (Von Schrader, Bruyère, Malzer, & Erickson, 2013). Flexible work arrangements might include adapting schedules or leave to accommodate medical needs, part-time or seasonal schedules, phased retirement, flex-place arrangements, and more (von Schrader et al., 2013).

Professional development and career development practices are a critical component of inclusive employment policies at the organizational level, and can contribute to employee retention rates (Hausknecht, Rodda, & Howard, 2009), yet have received inadequate treatment in the employment-focused literature relative to other topics. In a study examining research on employment of people with disabilities research across a 20-year period (1990–2010), articles about workplace accommodation, organizational culture, recruitment and hiring were published with significantly greater frequency than research on retention and advancement (Karpur, VanLooy, & Bruyère, 2014). For most employers, there remains quite a bit of work to do in improving career advancement and retention practices. Importantly, such practices potentially benefit *all employees*, both with and without disabilities. Interestingly, personalized approaches to career development are not the norm in corporate settings, despite the fact that “flexible, supportive organizations” benefit all employees’ career development (Schur, Kruse, & Blanck, 2005).

4. Conclusion

By framing the discussion starting with broad public policy directives and challenges, then zooming in to nation-level strategies for facilitating private sector buy-in and later to actual employer practices, we hope that we have helped to apply a rudimentary taxonomy to the complicated task of converting broad international directives (policies) into real-world changes at the market and organizational levels (practice). Despite heterogeneous political and economic contexts from country-to-country, the leveling of employment opportunities is a persistent public policy challenge (from training to job procurement to advancement and beyond). This is true of low- and middle-income countries with minimal frameworks for legal enforcement or workforce development, as well as high-income countries with substantial mechanisms for both.

While the particular public policy challenges take on a national flavor defined by cultural attitudes, political and economic models, predominant market sectors, and available systems, services, and opportunities for redress, evidence from around the globe demonstrates that antidiscrimination mechanisms and workforce development offerings alone may not be enough to manifest truly inclusive conditions. Newer strains of public policy in the area of disability employment have begun to extend into the realm of employer practices, and the convergence of interests among policymakers, employers, and individual workers or jobseekers. For instance, countries have begun to adopt an array of interventions to try to address education/training inequities to facilitate skill development in an increasingly competitive labor market, as well as supports to facilitate transition to this marketplace for talent in an increasingly technology-intensive business environment.

There is a need for evaluation of these interventions, to identify effective practices that policymakers can replicate in different contexts across low-, middle-, and high-income countries. This must occur with reference to the specific context, such as how these interventions play out in the actual hiring, retention, and advancement of individuals with disabilities. The desired outcome of improved employment prospects for people with disabilities globally must be a multi-stakeholder effort, which includes government, education/training, employers, community service providers and the disability advocacy movement. Policies that attempt to widen the net by bringing new stakeholders into the effort of creating inclusive markets as collaborators and beneficiaries offer new pathways to driving effective reform.

Conflict of Interests

The authors declare no conflict of interests.

References

Act on Professional Rehabilitation and Employment of Persons with Disabilities of 2009, RS No. 53/95, 3/96, 54/96, 32/97, 64/99, 44/99 and 101/05 (2009). Retrieved from www.legislationline.org/documents/id/19333

Agovino, M., & Rapposelli, A. (2011). Inclusion of disabled people in the Italian labour market: An efficiency analysis of law 68/1999 at regional level. *Quality & Quantity*, *47*(3), 1577–1588.

Auer, P., Berg, J., & Cazes, S. (2007). Balancing flexibility and security: The role of labour market policies and institutions. *Tilburg Law Review*, *14*(1), 49–56.

Austin, R., & Pisano, G. (2017). Neurodiversity as a competitive advantage. *Harvard Business Review*, May–June, 1–9.

Brayley, J. (2012). *The future of supported and substitute decision-making*. Paper presented at the World Congress of Adult Guardianship. Melbourne, Australia.

Brooks, D., Doughtery, B., & Price, J. (2015). The federal government as a model employer and its impact on employment civil rights in America. *Employee Rights and Employment Policy Journal*, *19*(2), 151–188.

Bruyère, S. M. (Ed.). (2016). *Disability and employer practices: Research across the disciplines*. Ithaca, NY: Cornell University Press.

Bruyère, S. M., VanLooy, S. A., von Schrader, S., & Barrington, L. (2016). Disability and employment: Framing the problem and our transdisciplinary approach. In S. M. Bruyère (Ed.), *Disability and employer practices: Research across the disciplines* (pp. 1–26). Ithaca, NY: Cornell University Press.

Chan, F., Strauser, D., Gervey, R., & Lee, E. J. (2010). Introduction to demand-side factors related to employment of people with disabilities. *Journal of Occupational Rehabilitation*, *20*(4), 407–411. https://doi.org/10.1007/s10926-010-9243-7

Chan, F., Strauser, D., Maher, P., Lee, E., Jones, R., & Johnson, E. T. (2010). Demand-side factors related to employment of people with disabilities: A survey of employers in the Midwest region of the United States. *Journal of Occupational Rehabilitation*, *20*(4), 412–419.

Colella, A., & Bruyère, S. M. (2011). Disability and employment: New directions for industrial/organizational psychology. In *American Psychological Association Handbook on Industrial Organizational Psychology* (Vol. 1, pp. 473–503). Washington, DC: American Psychological Association.

Committee on Economic, Social and Cultural Rights. (1994). *General Comment No. 5*, HRI/GEN/1/Rev 8, Add.1.

Committee on the Rights of Persons with Disabilities. (2012). *Implementation of the Convention on the Rights of Persons with Disabilities. Initial reports submitted by States parties under article 35 of the Convention: Sweden*. CRPD/C/SWE/1.

Committee on the Rights of Persons with Disabilities. (2013). *Implementation of the Convention on the Rights of Persons with Disabilities: Initial reports submitted by States parties under article 35 of the Convention: Czech Republic*. CRPD/C/CZE/1.

Council of Europe. (2015). *Council Decision (EU)*

2015/1848 of 5 October 2015 on guidelines for the employment policies of the Member States for 2015 [2015] OJ L268/28.

Danish Government. (2013). *Disability policy action plan 2013: One society for all*. Retrieved from http://www.oim.dk/media/14375/disability-policy-action-plan-2013-one-society-for-all.pdf

Dinerstein, R. (2017). Norm diffusion and CRPD implementation and ASEAN. In D. L. Cogburn & T. Kempin Reuter (Eds.), *Making disability rights real in Southeast Asia: Implementing the UN Convention on the Rights of Persons with Disabilities in ASEAN*. Lanham, MD: Lexington Books.

Dixon, K. A., Kruse, D., & Van Horn, C. E. (2003). *Restricted access: A survey of employers about people with disabilities and lowering barriers to work*. New Brunswick, NJ: Rutgers University Heldrich Center for Workforce Development.

Domzal, C., Houtenville, A., & Sharma, R. (2008). *Survey of employer perspectives on the employment of people with disabilities: Technical report* (Prepared under contract to the Office of Disability and Employment Policy, U.S. Department of Labor). McLean, VA: CESSI.

Doyle, R. H., Dixon, C. G., & Moore, C. L. (2003). Expanding rehabilitation services to meet the legal needs of aging Americans. *Journal of Rehabilitation*, *69*(2), 49–54.

Eide, A. H., & Ingstad, B. (2011). *Disability and poverty: A global challenge*. Bristol, UK: Policy Press.

Erickson, W. A., Lee, C., & von Schrader, S. (2017). 2015 Disability status report: United States. Retrieved from http://www.disabilitystatistics.org

Erickson, W. A., von Schrader, S., Bruyère, S. M., & VanLooy, S. A. (2013). The employment environment: Employer perspectives, policies, and practices regarding the employment of persons with disabilities. *Rehabilitation Counseling Bulletin*, *57*(4), 195–208. https://doi.org/10.1177/0034355213509841

Erickson, W. A., von Schrader, S., Bruyère, S. M., VanLooy, S. A., & Matteson, D. S. (2014). Disability-inclusive employer practices and hiring of individuals with disabilities. *Rehabilitation Research, Policy, and Education*, *28*(4), 309–328. https://doi.org/10.1891/2168-6653.28.4.309

Grover, C., & Piggott, L. (2007). Social security, employment and incapacity benefit: Critical reflections on a new deal for welfare. *Disability & Society*, *22*(7), 733–746.

Gupta, N. D., Larsen, M., & Thomsen, L. B. (2015). Do wage subsidies for disabled workers reduce their non-employment? Evidence from the Danish Flexjob scheme. *IZA Journal of Labor Policy*, *4*(10), 1–5.

Harper, S. (2013). *Ageing societies: Myths, challenges and opportunities*. New York: Routledge.

Harpur, P., & Bales, R. (2010). The positive impact of the Convention on the Rights of Persons with Disabilities: A case study on the South Pacific and lessons from the US experience. *Northern Kentucky Law Review*, *37*(4), 363–388.

Harris, S. P., Owen, R., & Gould, R. (2012). Parity of participation in liberal welfare states: Human rights, neoliberalism, disability and employment. *Disability & Society*, *27*(6), 823–836.

Hausknecht, J. P., Rodda, J. M., & Howard, M. J. (2009). Targeted employee retention: Performance-based and job-related differences in reported reasons for staying. *Human Resource Management*, *48*(2), 269–288. https://doi.org/10.1002/hrm

Henry, A. D., Petkauskos, K., Stanislawzyk, J., & Vogt, J. (2014). Employer-recommended strategies to increase opportunities for people with disabilities. *Journal of Vocational Rehabilitation*, *41*(3), 237–248.

Hoogeveen, J. (2005). Measuring welfare for small but vulnerable groups: Poverty and disability in Uganda. *Journal of African Economies*, *14*(4), 603–631.

Houtrow, A. J., Larson, K., Olson, L. M., Newacheck, P. W., & Halfon, N. (2014). Changing trends of childhood disability, 2001–2011. *Pediatrics*, *134*(3), 530–538.

Humpage, L. (2007). Models of disability, work and welfare in Australia. *Social Policy and Administration*, *41*(3), 215–231.

Income Tax Amendment Act of 2009. Act 15. Retrieved from http://www.ulrc.go.ug/system/files_force/ulrc_resources/income-tax-amendment-act-2009.pdf

International Labour Organization. (2007a). *Facts on disability in the world of work*. Geneva: International Labour Organization.

International Labour Organization. (2007b). *The right to decent work of persons with disability*. Geneva: International Labour Organization.

International Labour Organization. (2010). *Disability in the workplace: Company practices*. Geneva: International Labour Organization.

Karpur, A., VanLooy, S. A., & Bruyère, S. M. (2014). Employer practices for employment of people with disabilities: A literature scoping review. *Rehabilitation Research, Policy, and Education*, *28*(4), 225–241.

Kaye, H. S., Jans, L. H., & Jones, E. C. (2011). Why don't employers hire and retain workers with disabilities? *Journal of Occupational Rehabilitation*, *21*(4), 526–536.

Kruse, D., & Schur, L. (2003). Employment of People with Disabilities following the ADA. *Industrial Relations*, *42*(1), 31–66. https://doi.org/10.1111/1468-232X.00275

Kulkarni, M., & Gopakumar, K. V. (2014). Career management strategies for people with disabilities. *Human Resource Management*, *53*(3), 445–466.

Kuznetsova, Y., & Yalcin, B. (2017). Inclusion of persons with disabilities in mainstream employment: is it really all about the money? A case study of four large companies in Norway and Sweden. *Disability & Society*, *32*(2), 233–253.

Lamichhane, K., & Okubo, T. (2014). The nexus between disability, education, and employment: Evidence from Nepal. *Oxford Development Studies*, *42*(3), 439–453.

Loeb, M., Eide, A. H., Jelsma, J., Ka'Toni, M., & Maart, S. (2007). Poverty and disability in Eastern and Western Cape Provinces, SA. *Disability and Society*, *23*(4), 311–321.

Lord, J. E., & Stein, M. A. (2008). The domestic incorporation of human rights law and the United Nations Convention on the Rights of Persons with Disabilities. *Washington University Law Review*, *83*(4), 449–479.

Lord, J., & Stein, M. A. (2013). Prospects and practices for CRPD implementation in Africa. *African Disability Rights Yearbook*, *1*(1), 97–114.

Luecking, R. G. (2011). Connecting employers with people who have intellectual disability. *Intellectual and Developmental Disabilities*, *49*(4), 261–273.

Metts, R. L. (2000). *Disability issues, trends and recommendations for the World Bank*. Washington, DC: The World Bank.

Mitra, S., & Sambamoorthi, U. (2008). Disability and the rural labor market in India: Evidence for males in Tamil Nadu. *World Development*, *36*(5), 934–952.

Mizunoya, S., & Mitra, S. (2013). Is there a disability gap in employment rates in developing countries? *World Development*, *42*(1), 28–43.

Mizunoya, S., Yamasaki, I., & Mitra, S. (2016). The disability gap in employment rates in a developing country context: New evidence from Vietnam. *Economics Bulletin*, *36*(2), 771–777.

Ncube, W. (1998). The African cultural footprint? The changing conception of childhood. In W. Ncube (Ed.), *Law, culture, tradition and children's rights in Eastern and Southern Africa*. Farnham, UK: Ashgate Publishing.

Nyombi, C., & Kibandama, A. (2014). Access to employment for persons with disabilities in Uganda. *Labor Law Journal*, *65*(4), 248–258.

OECD. (2009). *Sickness, disability and work: Keeping on track in the economic downturn*. Paper presented at the High-Level Forum, 14-15 May 2009, Stockholm, Sweden. Retrieved from https://www.oecd.org/els/emp/42699911.pdf

Official Norwegian Reports. (2012). *Labour market measures*. Oslo: Office of the Prime Minister and Ministries.

Owen, R., & Harris, S. P. (2012). 'No rights without responsibilities': Disability rights and neoliberal reform under New Labour. *Disability Studies Quarterly*, *32*(3).

Ozawa, M. N., & Yeo, Y. H. (2006). Work status and work performance of people with disabilities: An empirical study. *Journal of Disability Policy Studies*, *17*(3), 180–190.

Power, A., Lord, J., & deFranco, A. (2013). *Active citizenship and disability: Implementing the personalisation of support*. Cambridge: Cambridge University Press.

Prohibition of Discrimination Act of 2009, Official Gazette of the Republic of Serbia No 22/2009 (2009). Retrieved from http://ravnopravnost.gov.rs/en/legislation/republic-of-serbia-legislation

Roulstone, A., Harrington, B., & Hwang, S. K. (2014). Flexible and personalised? An evaluation of a UK tailored employment support programme for jobseekers with enduring mental health problems and learning difficulties. *Scandinavian Journal of Disability Research*, *16*(1), 14–28.

Sainsbury, R., & Coleman-Fountain, E. (2014). *Diversity and change of the employment prospects of persons with disabilities: The impact of redistributive and regulatory provisions in a multilevel framework. DISCIT Deliverable 5.1*. Retrieved from https://www.researchgate.net/profile/Edmund_Coleman-Fountain/publication/310766875_Diversity_and_Change_of_the_Employment_Prospects_of_Persons_with_Disabilities_The_Impact_of_Redistributive_and_Regulatory_Provisions_in_a_Multilevel_Framework/links/5836071408aed45931c649c0/Diversity-and-Change-of-the-Employment-Prospects-of-Persons-with-Disabilities-The-Impact-of-Redistributive-and-Regulatory-Provisions-in-a-Multilevel-Framework.pdf

Schur, L., Kruse, D., & Blanck, P. (2005). Corporate culture and the employment of persons with disabilities. *Behavioral Sciences and the Law*, *23*(1), 3–20. https://doi.org/10.1002/bsl.624

Shumaker, L. (2015, April 15). Autism and employment: Early leader SAP marches forward. Retrieved from http://blog.sfgate.com/lshumaker/2015/04/12/autism-and-employment-early-leader-sap-marches-forward

Stewart, D. (2009). Transition to adult services for young people with disabilities: Current evidence to guide future research. *Developmental Medicine and Child Neurology*, *51*(4), 169–173.

The Employment Act of 2004, 435/2004 Coll. Retrieved from https://portal.mpsv.cz/sz/obecne/prav_predpisy/akt_zneni/zoz_od_1-4-2012_en.pdf

The Persons With Disabilities Act of 2006. Retrieved from http://www.ilo.org/dyn/natlex/natlex4.detail?p_lang=en&p_isn=88100&p_country=UGA&p_count=135&p_classification=08.01&p_classcount=4

Trani, J., & Loeb, M. (2010). Poverty and disability: A vicious circle? Evidence from Afghanistan and Zambia. *Journal of International Development*, *24*(51), S19–S52.

U.N. Division of Social Policy and Development. (2010). *Fact sheet: Youth with disabilities*. Retrieved from https://social.un.org/youthyear/docs/Fact%20sheet%20youth%20with%20disabilities.pdf

U.N. Enable. (2017). CRPD and Optional Protocol signatures and ratifications. Retrieved from https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

Unger, D. D., Wehman, P., Yasuda, S., Campbell, L., & Green, H. (2002). Human resource professionals and the employment of people with disabilities: a business perspective. In D. D. Unger, J. Kregel, P. Wehman, & V. Brooke (Eds.), *Employers' views of workplace supports: Virginia Commonwealth Univer-*

sity Charter Business Roundtable's national study of employers' experiences with workers with disabilities. Richmond, VA: Virginia Commonwealth University.

U.S. Bureau of Labor Statistics. (2016). *Occupational employment statistics*. Retrieved from https://www.bls.gov/oes/current/oes_nat.htm#00-0000

Ventegodt Liisberg, M. (2011). *Disability and employment: A contemporary disability human rights approach applied to Danish, Swedish and EU law and policy*. Cambridge: Intersentia.

Von Schrader, S., Bruyère, S. M., Malzer, V., & Erickson, W. A. (2013). *Absence and disability management practices for an aging workforce*. Ithaca, NY. Retrieved from http://digitalcommons.ilr.cornell.edu/edicollect/1320

Von Schrader, S., & Nazarov, Z. E. (2016). Trends and patterns in Age Discrimination in Employment Act (ADEA) charges. *Research on Aging*, *38*(5), 580–601. https://doi.org/10.1177/0164027515593989

Vos, T., Barber, R. M., Bell, B., Bertozzi-Villa, A., Biryukov, S., Bolliger, I., . . . Murray, C. J. L. (2015). Global, regional, and national incidence, prevalence, and years lived with disability for 301 acute and chronic diseases and injuries in 188 countries, 1990-2013: A systematic analysis for the Global Burden of Disease Study 2013. *The Lancet*, *386*(9995), 743–800.

Waddington, L., Pedersen, M., & Ventegodt Liisberg, M. (2016). Get a job! Active labour market policies and persons with disabilities in Danish and European Union policy. *Dublin University Law Journal*, *39*(1), 1–24.

Waldschmidt, A., Sturm, A., Karačić, A., & Dins, T. (2017). Implementing the UN CRPD in European countries: A comparative study on the involvement of organizations representing persons with disabilities. In R. Halvorsen, B. Hvinden, J. Bickenbach, D. Ferri, & A. M. Guillén Rodriguez (Eds.), *The changing disability policy system: Active citizenship and disability in Europe*. New York: Routledge.

World Health Organization. (2011). *World report on disability: Summary, 2011, WHO/NMH/VIP/11.01*. Retrieved from http://www.refworld.org/docid/50854a322.html

Yap, M., & Konrad, A. M. (2009). Gender and racial differentials in promotions: Is there a sticky floor, a mid-level bottleneck, or a glass ceiling? *Industrial Relations*, *64*(4), 593–619.

Yeo, R., & Moore, K. (2003). Including disabled people in poverty reduction work: 'Nothing about us, without us.' *World Development*, *31*(3), 571–590.

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Article

Equality of What? The Capability Approach and the Right to Education for Persons with Disabilities

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Abstract

The right to education is indispensable in unlocking other substantive human rights and in ensuring full and equal participation of persons with disabilities in mainstream society. The cornerstone of Article 24 of the United Nations Convention on the Rights of Persons with Disabilities seeks to ensure access to inclusive education for persons with disabilities on an equal basis with others as well as the full development of human potential. Since the adoption of the Convention, there has been much theorising about inclusive education; however, there has been little focus on the meaning of equality in the context of the right to education for persons with disabilities. The capability approach, developed by Amartya Sen and further refined by Martha Nussbaum, focuses on ensuring equality and developing human potential. It is often viewed as a tool that can be used to overcome the limitations of traditional equality assessments in the educational sphere, which only measure resources and outcomes. This article explores whether the capability approach can offer new insights into the vision of educational equality contained in the Convention and how that vision can be implemented at the national level.

Keywords

capability approach; CRPD; disability; education; equality; inclusive education; United Nations

Issue

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1. Introduction

The question ‘equality of what?’ is often posed during debates on political philosophy and interdisciplinary debates on distributive justice. It concerns a decision as to the elements which governmental policies and institutional structures should aim to equalise. The same question was posed by economist-philosopher Amartya Sen, who first introduced his theory of ‘basic capability equality’ in his Tanner Lectures (Sen, 1979, p. 218):

> I believe what is at issue is the interpretation of needs in the form of basic capabilities. This interpretation of needs and interests is often implicit in the demand for equality. This type of equality I shall call “basic capability equality”.

The capability approach encompasses a ‘partial theory of social justice’ (Nussbaum, 2009, p. 232) and a normative framework for the assessment of human development. In the last decade, scholars in the field of education studies have turned to the capability approach to analyse the theory and provision of education for those with special needs and/or disabilities (see, among others, Ainscow & Farrell, 2002; Florian, Dee, & Devecchi, 2008; Nind, Rix, Sheehy, & Simmons, 2005). Several scholars have written about inclusive education, with a particular focus on capabilities (see, among others, Norwich, 2014; Robeyns, 2003, 2006; Rogers, 2013; Saito, 2003; Sarojini Hart, 2012; Terzi, 2005, 2007, 2014; Toson, Burrello, & Knollman, 2013; Trani, Bakhshi, Ballanca, Biggeri, & Marchetta, 2011; Walker, 2006a; Walker & Unterhalter, 2007). Other scholars (Arnardóttir, 2011; Broderick, 2014; Broderick & Quinlivan, 2017; De Beco, 2014, 2016; Della Fina, 2017; Waddington & Toepke, 2014) have addressed the right to education in Article 24 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD or Convention). However, to date, there is scant research on the parallels between the capability approach and Article 24 CRPD (see, De Beco, 2017).

This article demonstrates that many of the underlying premises of the capability approach correlate to those contained in Article 24 CRPD. As a result, this article proposes a four-part framework, detailing insights into the vision of educational equality contained in the Convention through focussing on 'the what'; 'the why'; 'the who' and 'the how' of inclusive education. The first limb of the framework ('the what') outlines how capability equality can be invoked to shed light on the meaning of equality espoused by Article 24 CRPD. The second limb of the framework ('the why') draws on the underlying goals of inclusive education to outline the most relevant capabilities to be developed through inclusive education. The third limb of the framework ('the who') is drawn on to extract information on where to set the focus lens of inclusion. This can reveal invaluable lessons regarding pedagogical and assessment processes. The fourth limb of the framework ('the how') reveals how the inclusion of all learners can potentially be achieved through the mechanism of Universal Design for Learning (UDL). After outlining the aforementioned four-part framework, attention is paid to how that framework can be implemented at the national level.

This article is divided into seven sections. Following this first introductory section, the second section of the article outlines the key elements of the capability approach. The third section introduces Article 24 CRPD, focussing on the goals of inclusive education as well as the measures required to achieve inclusion. In section four of the article, a four-part framework is put forward, which outlines the vision of educational equality contained in Article 24 CRPD and highlights essential focal points for achieving inclusive education. Section five traces the theory of that framework into practice, while section six analyses whether the capability approach provides a complete guide to CRPD implementation. Finally, section seven presents concluding remarks.

The methodology used to highlight the salient features of the capability approach consists of descriptive desk-based research based on secondary sources. In analysing the obligations contained in Article 24 CRPD and inspiring the aforementioned four-part framework, legal doctrinal research is conducted. Recourse is had to the rules of treaty interpretation contained in the Vienna Convention on the Law of Treaties (VCLT). The interpretative tools in Articles 31 and 32 VCLT are as follows: literal interpretation according to the words contained in the text of the CRPD; systematic interpretation of the Convention's text in its overall context, including subsequent practice—namely, General Comments of the UN Committee on the Rights of Persons with Disabilities (CRPD Committee); teleological interpretation according to the object and purpose of the Convention; and supplementary means of interpretation in line with the drafting history of the Convention (Ad-Hoc CRPD Committee, 2005). A comparative normative approach is used in drawing out the aspects of convergence between Article 24 CRPD and the capability approach. It is worth noting that the selection of capabilities for the above-mentioned four-part framework is inspired by the norms and general principles underlying the CRPD as a whole and, in particular, those contained in Article 24. The case study examples that are used to illustrate the translation of inclusive education into practice are drawn from a selection of secondary sources highlighting best practice in the field.

2. The Capability Approach

In outlining his capability approach, Sen argued that neither utilitarian equality nor total utility equality nor Rawlsian equality sufficiently capture real differences amongst human beings (Sen, 1979, pp. 215–219), since the agents in such theories are generally deemed to be free, equal and independent beings. The capability approach, on the other hand, acknowledges that society is made up of individuals with unequal abilities and needs and, therefore, its basic underlying premise facilitates its application to disability studies. Sen's capability approach has been refined by philosopher Martha Nussbaum, among others. The relevant distinctions between Sen and Nussbaum's approaches are highlighted below.

The first basic conceptual distinction within the framework of the capability approach is between capabilities, on the one hand, and functionings and resources, on the other hand. Capabilities represent not the actual physical or mental ability of individuals but rather the innate potential of each individual to achieve various outcomes, defined as 'what people are actually able to do and to be' (Nussbaum, 2000, p. 5) when given real opportunities. Functionings represent various states of 'doings and beings' (Sen, 1992, p. 40), resulting in a particular outcome or achievement (reading, writing, communication, etc.), while 'resources' are the means by which to achieve the outcome. The capability approach highlights several 'conversion factors' (Sen, 1992, p. 100), such as environmental factors and social norms. These 'contribute to the determination of the individual capability set' (Trani et al., 2011, p. 152) and may affect the rate of conversion of resources into functionings. In the disability context, this mirrors the social-contextual perspective on disability, whereby disability is viewed as an *interaction* between individual impairments and the environment, attitudinal barriers, etc. (preamble, para. e CRPD).

Human diversity plays a key role in the capability approach since, according to Sen, it is 'a fundamental aspect of our interest in equality' (Sen, 1992, p. xi). Each individual forms a focal point of capability equality, according to Nussbaum (Nussbaum, 2000, p. 69). In that vein, Reindal asserts that 'it is not the group or changes of systems that are the primary subject of political justice' (Reindal, 2016, p. 8).

Central to Sen's capability approach are concepts of 'agency freedom' and 'wellbeing freedom'. The former refers to 'one's freedom to bring about achievements one values', while the latter relates to 'one's freedom to achieve those things that are constitutive of one's well being' (Sen, 1992, p. 57). According to Sen, the space within which to evaluate equality is that of capabilities, where an individual can decide what kind of life he/she values (Sen, 1992, p. 66).

Unlike Sen, who did not define universal capabilities, Nussbaum drafted a list of 'central human capabilities' as a benchmark for setting a 'social minimum' (Nussbaum, 2009, p. 232), a threshold level below which a just society seeking to guarantee the key principle of human dignity should not fall. Nussbaum's list of central human capabilities includes: life; bodily health; bodily integrity; the senses, imagination and thought; emotions; play; other species; and control (political and material) over one's environment (Nussbaum, 2000, pp. 78-80). Nussbaum points to two further capabilities, which she argues 'suffuse all the other capabilities' (Nussbaum, 2000, p. 89): i) 'practical reason', which involves 'being able to form a conception of the good and to engage in critical reflection about the planning of one's life'; and ii) affiliation, which means being able 'to engage in various forms of social interactions [and] being able to be treated as [a] dignified being whose worth is equal to that of others' (Nussbaum, 2000, pp. 79–80).

Norwich states that the fundamental distinction between Sen and Nussbaum's approaches lies in the fact that 'for Sen, agency is the key aspect of a capability', while for Nussbaum, 'the central capabilities are more an entitlement than something actively chosen' (Norwich, 2014, p. 19). Despite these differences, one can conclude that the pivotal assessment of equality under the capability approach lies not necessarily in an assessment of the means provided to an individual or the functionings achieved by that individual but in the equalisation of opportunities to develop one's innate capabilities. In the disability sphere, the equality metric is based on counteracting the impact of impairment in individualised situations and nurturing whatever capabilities each individual has in order to enable human flourishing.

Saito points to the 'potentially strong and mutually enhancing relationship' between the capability approach and education (Saito, 2003, p. 17). Several authors appear to pick up on that potential. For instance, Sarojini Hart contends that the capability approach 'offers an alternative paradigm for thinking beyond access to education and for considering the potential for individual freedoms both in and through education' (Sarojini Hart, 2012, p. 276; see also, De Beco, 2017; Rajapakse, 2016; Reindal, 2016, p. 6).

There is an absence of scholarship on the overlapping elements of the capability approach and Article 24 CRPD (see De Beco, 2017). Thus, it is an opportune time to explore whether the tenets of the capability approach align with the fundamental premises of inclusive education set out in Article 24 and whether the capability approach can be drawn on to reveal specific lessons regarding the norms contained in Article 24.

3. Article 24 CRPD: A Holistic Vision of Inclusive Education

Article 24 CRPD enshrines the first legal enunciation of inclusive education for all learners. The following subsections elaborate on the goals of inclusive education and the measures required to achieve inclusion.

3.1. The Goals of Inclusive Education

On a textual reading of the CRPD, the overarching theme of Article 24 is that education must be effective. Article 24(2)(d) provides that States Parties must ensure that 'persons with disabilities receive the support required, within the general education system, to facilitate their effective education'. This begs the question as to what effectiveness means as a metric in this context?

According to the text of Article 24(1), inclusive education systems should ensure 'the full development of human potential and sense of dignity and self-worth' and 'the strengthening of respect for…human diversity'. Furthermore, education systems must aim at the 'development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential'. These stated goals of inclusive education clearly overlap, to a significant extent, with the fundamental tenets of the capability approach.

The third goal to be achieved by inclusive education, as laid down in Article 24(1), is to enable 'persons with disabilities to participate effectively in a free society'. This defines the ultimate purpose of inclusive education and seeks to ensure that all measures adopted by States Parties to the Convention contribute to facilitating that purpose. Terzi contends that a capability perspective on educational equality can be defined 'in terms of equal effective opportunities to levels of functionings that are necessary to participate in society' (Terzi, 2007, p. 765). In a similar vein, one can deduce from the text of Article 24 that States Parties are required to create real opportunities for persons with disabilities to foster their capabilities in order to enable them to take an active role in society, where possible.

3.2. The Measures Required to Achieve Inclusion

In order to achieve the foregoing goals, Article 24 CRPD sets down an extensive list of obligations to be complied with by States Parties, the most relevant of which are outlined below. The measures required under Article 24 are based on the social-contextual model of disability, which targets disadvantages arising from the interaction between learners' impairments and external factors caused by environmental or attitudinal barriers to learning. Article 24 is also built on the human rights-based model of disability, according to which persons with disabilities are viewed as individual 'holders of rights, entitled to exercise all human rights and fundamental freedoms on an equal basis with others, entailing the provision of material support where necessary' (Broderick, 2015, p. 1).

Article 24 seeks to ensure equality of access to all levels of education (primary, secondary and tertiary education as well as vocational training, adult education and lifelong learning) and the provision of equal opportunities. Maintaining a similar focus on individualisation as the capability approach does, Article 24 CRPD seeks to address the wide diversity of needs of individual learners through requiring States Parties to take various positive measures. In that regard, Article 24(2)(c) requires States Parties to ensure that reasonable accommodation of the individual learner's requirements is provided. Reasonable accommodation, as defined in Article 2 CRPD, requires public and private parties to make 'necessary and appropriate modification and adjustments' to the environment, where requested by an individual with a disability in a particular case. An unjustified failure to provide a reasonable accommodation constitutes a form of discrimination, unless a disproportionate or undue burden can be proven by the duty-bearer.

Further individualised support measures are envisaged under Article 24(2)(e) CRPD. The latter measures are not the same as those requested in a particular, individualised case; conversely, they aim to alter the mainstream education system to ensure inclusion over a longer period of time (de Beco, 2014, p. 281). This does not mean that these measures do not have to be tailored to cater for the individual needs of each learner (de Beco, 2014, p. 281). Such individualised support measures may include personal assistance as well as the types of measures outlined in Article 24(3) CRPD, namely, facilitating the learning of Braille; providing alternative script; augmentative and alternative modes, means and formats of communication; and facilitating peer support and mentoring.

Akin to Nussbaum's list of central capabilities (endorsing practical reason and affiliation as well as emotions and play), Articles 24(2)(e) and 24(3), respectively, acknowledge the fact that education is not merely an academic tool. Rather, education should 'enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community'. To that end, States Parties must take appropriate measures to ensure that the education of persons with disabilities (and, in particular, individuals who are blind, deaf or deaf-blind) is delivered in the most appropriate languages and means of communication for the individual, and in environments which maximise academic and social development.

4. Inclusive Education Viewed through the Lens of the Capability Approach

It is evident that there are *prima facie* similarities between the capability approach and the vision of inclusive education set forth in Article 24 CRPD. This section of the article investigates whether, beyond those *prima facie* similarities, the capability approach can serve to teach States Parties to the CRPD specific lessons regarding the norms embodied in Article 24. The key observations emerging from the analysis conducted in this section are set out in a four-part framework and are aligned with 'the what', 'the why', 'the who' and 'the how' of inclusive education. These four parts of the framework relate back to the understanding of equality enshrined in Article 24 CRPD (as interpreted according to the methodological tools set out in the first section of this article).

4.1. 'The What' of Inclusion: Equality of Capabilities

The first limb of the four-part framework concerns 'the what' of inclusion. The capability approach purports that equality is measured in the realm of capabilities, such that the central factor in the search for justice relates to equalising opportunities for expanding an individual's capabilities (but not necessarily equalising outcomes). Capability equality lays down human diversity as the key equalising element in the evaluation of relative disadvantages and the fight against inequalities. Due to the fact that the capability approach is underpinned by respect for human diversity, it is equipped to deal with 'the complexity of disability' (Terzi, 2005, p. 452). This justifies invoking it to shed light on the meaning of equality espoused by Article 24 CRPD. The fact that the capability approach also adopts a social-contextual approach, much like the CRPD, means that it endorses a similar egalitarian perspective, according to which entitlement to equal opportunities arises regardless of the fact that disadvantage may accrue from impairment or external factors (Terzi, 2005, p. 452). Overall, it can be said that there is 'general agreement on the essential underlying ideas' of the capability approach and the CRPD (Harnacke, 2013, p. 777). Notwithstanding this, many questions remain unanswered as to whether the capability approach can act as a guide to CRPD implementation. These questions will be highlighted and answered in turn in the sub-sections that follow.

4.2. 'The Why' of Inclusion: The Purpose of Article 24 and Equalisation of Capabilities

One naturally wonders which capabilities should be equalised in the educational context? In order to answer that question and to build on the equality metric, it is important to take into account the underlying goals of inclusive education, highlighted above. This leads us to reflect on 'the why' of inclusion, the second limb of the four-part framework proposed in this paper.

Various authors have followed Nussbaum's example and have devised lists of 'basic capabilities' in the educational context (Mutanga & Walker, 2015, pp. 505–506; Walker, 2006b, pp. 128–129). Others have devised lists of basic capabilities which are not tailored to education but which overlap with educational capabilities (Robeyns, 2003). However, none of these lists have been tailored specifically towards inclusive education and learners with disabilities. Drawing on CRPD-specific values and informed by the principles underlying the capability approach, it is submitted that the following capabilities encapsulate the most relevant ones to be developed through inclusive education for *all* learners:

i. *Academic skills (knowledge)*: Article 24 CRPD requires that school systems foster academic development. In this context, academic skills would take into account critical thinking and problem-solving skills, promoting the knowledge required for participation in society and the economy. Depending on the severity of disability, the level of functioning following from this capability of knowledge will, inevitably, vary. However, the basic capability for knowledge should be fostered in all students. Indeed, evidence suggests that students with psychosocial and developmental disabilities can learn to problem-solve in an inclusive setting through modifications to social and communication processes (Agran, Blanchard, Wehmeyer, & Hughes, 2002, p. 279).
ii. *Life and social development skills*: The CRPD also requires the development of life and social skills. The capability approach requires that informal learning should be taken into consideration. This has been defined as a space where 'relationships and encounters' occur, 'with all the opportunities that are planned and unplanned' (European Agency for Development in Special Needs Education, 2011, p. 104).
iii. *Individual autonomy, including the freedom to make one's own choices, and independence*: Article 3(a) CRPD contains the cross-cutting general principle of individual autonomy, including the freedom to make one's own choices, and independence. Drawing on that Article, it is submitted that learner agency and autonomy should be promoted in all individuals. This autonomy capability does not find support in Nussbaum's account of capability equality. As Stein points out, Nussbaum's earlier work 'excludes certain persons with intellectual disabilities from full participation in society' (Stein, 2007, p. 102), as she 'fails to recognize those who fall below her ten central capabilities' (Stein, 2007, p. 101). According to Stein, Nussbaum's capability approach only includes persons with intellectual disabilities who are able to achieve baseline functions 'by proxy through their respective guardians' and this 'denies their individual autonomy' (Stein, 2007, pp. 109–110). In her later work, Nussbaum appears to adopt a similar perspective in the realm of cognitive disabilities (see, Nussbaum, 2009, pp. 345–350). To overcome these issues, Stein proposes a 'disability human rights paradigm', which 'emphasizes the equal dignity of all persons, and acknowledges their autonomy in directing their own development'. (Stein, 2007, p. 75). Stein's approach fits well to the autonomy capability proposed in this article. Although, when it comes to operationalising the autonomy capability in the context of young learners, this will naturally depend on support from adults. With regard to individuals with multiple disabilities or severe intellectual/learning/behavioural disabilities, promoting independence and autonomy becomes a more complex task. This point is dealt with below.
iv. *Respect for evolving capacities*: Drawing on key CRPD principles, in particular General Principle 3(h), which recognises the evolving capacities of children with disabilities, it is essential to nurture the preferences of persons with disabilities and to foster in them the capacity to make informed and reflexive choices, wherever possible. When it comes to individuals with severe or multiple disabilities, one of the main challenges lies in overcoming the perception that such individuals cannot exercise self-determination on account of the nature or extent of their impairment (Wehmeyer, 1998). The CRPD Committee urges States Parties to avoid this 'deficit approach', which focuses on the 'actual or perceived impairment' of a person with a disability and which limits opportunities 'to predefined and negative assumptions of their potential' (CRPD Committee, 2016, para. 16). Assessing the preferences of students with severe learning difficulties through alternative modes, means and formats of communication is something which Article 24(3)(a) CRPD expressly urges. Several strategies have been identified to determine the preferences of students with severe disabilities, such as, using micro-switch technology to enable students to indicate preferences; observing whether students approach an object when it is presented to them; and recording the amount of free time a student spends engaged in particular activities (Hughes, Pitkin, & Lorden, 1998).
v. *Respect for inherent dignity*: Nussbaum's later work claims that 'the touchstone' of capability equality is human dignity (Nussbaum, 2009, p. 335). Pursuant to Articles 3(a), 3(d) and 8(2)(b) CRPD, States Parties should foster in all children, from an early age, respect for the inherent dignity of all learners and the acceptance of difference.
vi. *Voice and participation in learning*: In accordance with Articles 4(3) and 7(3) CRPD, States Parties should ensure that all learners, particularly those with disabilities, are enabled to develop the capa-

bility to express their views freely on educational matters affecting them and to participate actively in knowledge acquisition.

vii. *Identity preservation*: Drawing on Articles 24(3)(b) and 24(4)(4) CRPD, inclusive education systems should prioritise the capability for learners with disabilities to preserve their individual identities and to develop them in whatever way suits their learning style. This is particularly important for students who are deaf, blind and/or deaf-blind.

viii. *Self-worth*: Nussbaum claims that capability equality guarantees the 'social bases of self-respect and non-humiliation' (Nussbaum, 2000, p. 79). In accordance with Article 24(1)(a) CRPD, inclusive education systems should foster capabilities of self-esteem in all learners in order to avoid the issue of what Nussbaum terms 'adaptive preferences' (Nussbaum, 2000, p. 139), whereby individuals adapt their preferences according to what they believe is feasible for their 'perceived' capabilities.

While the above list does not constitute an exhaustive enumeration of inclusive education capabilities, it does provide a good starting point in seeking to ensure equality of educational opportunities for all and in framing education systems which facilitate the underlying principles and goals of the CRPD.

4.3. 'The Who' of Inclusion: Individuals as an End

The capability approach also informs us about where to set the focus lens of inclusion - in other words, the third limb of the proposed framework, which centres on 'the who' of inclusion. This can reveal invaluable lessons regarding pedagogical and assessment processes.

Since capability equality targets individuals, the goal, in educational terms, is to produce capabilities for each and every learner. Nussbaum refers, in this connection, to the fact that each person is 'an end' (Nussbaum, 2011, p. 35). While capability equality focuses pivotally on human individuality, it also focuses on interdependency (Nussbaum's criterion of affiliation). This vision of inclusion matches that set forth in Article 24 CRPD, which not only focuses on system changes but mandates the adoption of reasonable accommodations and effective individualised supports for persons with disabilities.

The person-centred approach underpinning Article 24 has been remarked upon by the CRPD Committee:

> Inclusive education must aim at promoting mutual respect and value for all persons and at building educational environments in which the approach to learning, the culture of the educational institution and the curriculum itself reflect the value of diversity (CRPD Committee, 2012, para. 41).

This requires both the recognition of difference and offering general mainstream provision for all learners. The next sub-section of this article elaborates on how to achieve this delicate balance by elaborating on the fourth limb of the proposed framework—'the how' of inclusion, that is, its processes and practices.

4.4. 'The How' of Inclusion: The Dilemma of Difference Re-Visited through UDL

Several educational scholars are divided by the 'dilemma of difference' (Minow, 1990, p. 20) and tend to focus almost exclusively on either impairment (Mac Kay, 2002) or social processes (Armstrong, Armstrong, & Barton, 2000). The 'dilemma of difference' is a term used to describe the tensions inherent in focusing, on the one hand, on differential characteristics, with the attendant risks of stereotyping and labelling, and, on the other hand, ignoring differences in an attempt to provide common educational provision, bearing the risk that not all learners' needs are accommodated.

Terzi argues cogently that the capability approach manages to erase the tensions inherent in the dilemma of difference, since it allows overcoming 'the duality between individual and social models of disability and sees disability instead as inherently relational' (Terzi, 2005, p. 451). It is here that the capability approach finds particular resonance with the CRPD, which also overcomes these tensions (Broderick, 2015, p. 72).

From an equality perspective, both the capability approach and the CRPD seek to widen the 'norm' in order to reflect human diversity and individual difference, whilst also ensuring education in the mainstream. This widened norm can be given concrete formulation in the mechanism of UDL, a curriculum-based method designed to achieve maximum accessibility of educational processes for all. While implementing UDL is not without significant challenges, the ideas of differentiated instruction and 'alternative functionings' (Terzi, 2005, p. 456), or of doing the same thing in different ways, takes on increased relevance in this context. According to the CRPD Committee, this involves 'flexible curricula and teaching and learning methods adapted to different strengths, requirements and learning styles' (CRPD Committee, 2016, para. 12.c). It also entails 'maintaining high expectations for all students while allowing for multiple ways to meet expectations' (CRPD Committee, 2016, para. 26).

Since diversity in education refers not only to the diversity of needs exhibited by persons with disabilities but to the entire range of different learning abilities, needs, talents, learning styles and personalities, it is vital to link these wide-ranging considerations to key goals and outcomes to be achieved by the educational curriculum. Knowelton (1998) suggests three levels of curricular modification necessary to enhance access for all to mainstream curricula: i) curriculum adaptation (modifying the presentation and representation of content); ii) curricular augmentation (teaching students to use student-directed learning strategies); and iii) curriculum alteration (changing the curriculum to address students' specific needs). In that regard, the CRPD Committee recommends the use of individual educational plans (IEPs) to support specific learning requirements and the introduction of a pedagogy centred on students' educational objectives. (CRPD Committee, 2016, para. 71).

Authors, such as De Beco, acknowledge the fact that there are 'practical limits to differentiation in the school curriculum' and that 'education systems may never be completely adaptable to the needs of all disabled children' (De Beco, 2017, p. 10). These concerns regarding the implementation of inclusive education and universal design in learning are entirely valid, and it may be the case that a fully universal design is simply not achievable due to wide variations in impairments. Nonetheless, the ideal of inclusive education remains a worthy goal, and the capability approach certainly lends itself to teaching us valuable lessons in the quest to realise inclusion.

5. Capability Equality: From Theory to Practice in Inclusive Education

Having outlined the four-part framework above, a framework that may be used to guide pedagogical and assessment process in implementing the CRPD, it is important to reflect on the practical relevance of the above framework in the provision of public inclusive education.

In rejecting a de minimus standard for the education of persons with disabilities, the Supreme Court of the United States recently held, in *Endrew F. v. Douglas County School District*, that every child's educational program must be 'appropriately ambitious in light of his circumstances' and that children with disabilities should have the chance to 'meet challenging objectives' (*Endrew*, 2017, p. 3). One might wonder how this can be achieved in the light of the framework outlined above?

As a preliminary step, the CRPD's vision of educational equality should be enshrined in States Parties' laws and policies in order to guide educational processes. Italian law specifically includes the development of the potential of persons with disabilities 'in learning, in communication, in relationships and in socialisation' in Articles 12 and 13 of Law 104/1992[1] (Ferri, in press). Decree 378/2017, implementing Law 107/2015,[2] which is aimed at reforming the Italian educational system following ratification of the CRPD, also promotes 'educational and teaching strategies aimed at developing the potential of each individual', according to Ferri (in press).

Practical changes to school systems are also required in order to promote the key capabilities outlined above in the context of the four-part framework. Ensuring that persons with disabilities are appropriately challenged in public education and, furthermore, balancing that with the needs of children without disabilities requires a reciprocal approach. Jorgensen et al. advocate peer supports, whereby students have the opportunity to provide support and assistance to others as well as to receive support (Jorgensen, Mc Sheehan, Schuh, & Sonnenmeier, 2012, p. 7). The European Agency for Development in Special Needs Education advocates such co-operative learning or peer tutoring as an effective method in cognitive and affective (social-emotional) learning and development for all students (European Agency for Development in Special Needs Education, 2003, p. 5). As well as enhancing academic and social development skills, this type of approach can serve to enhance the capabilities of respect for diversity, evolving capacities of persons with disabilities and self-worth. Mixed-age classes (the joint education of children with heterogeneous abilities from pre-school to the fourth grade) have been advocated in certain countries, such as Austria and Finland, as a means to incorporate diverse learning rates in primary school classes. While there are certainly many challenges inherent in effectuating such an approach (Hyry-Beihammer & Hascher, 2015), it has been promoted as one that can have 'obvious' benefits at the cognitive, emotional and social levels (European Agency for Development in Special Needs Education, 2003, p. 29).

Person-centred planning aids greatly in achieving the key capabilities of self-determination, learner autonomy and participation. A Danish project, entitled 'Children's Voice', consults with parents and children to elicit their views on the well-being and experiences of each learner (UNESCO, 2017, p. 28). Involving students in the formulation of learning objectives is an effective means by which to include all students in their own learning processes. In that regard, Jorgensen et al. promote the teaching of self-advocacy skills—'how to be assertive, how to effectively communicate their perspective, how to negotiate, how to compromise, and how to deal with systems and bureaucracies' (Jorgensen et al., 2012, p. 11).

Evaluation and assessment processes should also be a key focus for States Parties. The framework outlined in section four of this article sheds light on four vital aspects of the inclusion process ('the what'; 'the why'; 'the who' and 'the how' of inclusion) and allows for the assessment of inequalities in a space other than that used for traditional equality measurements in the educational sphere, which often focus on resources and outcomes. That space is the realm of capabilities. The measurement that is used to determine whether each individual is granted equal opportunity to flourish stems from an assessment of the starting point of the individual and his/her progress towards defined and overarching goals within the mainstream curriculum, combined with the individualised goals set out in his/her IEP, designed to map personal successes. The CRPD Committee appears to agree with this perspective on how human potential can be facilitated through assessment processes. The Committee has stated that 'traditional systems of assessment, which use standardized achievement test scores as the

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[1] Law of 5 February 1992 No. 104, '*Legge-quadro per l'assistenza, l'integrazione sociale e i diritti delle persone handicappate*' in O.J. of 17 February 1992 No. 39.

[2] In O.J. No.162 of 15 July 2015.

sole indicator of success for both students and schools' (CRPD Committee, 2016, para. 74), 'must be replaced with flexible and multiple forms of assessments and the recognition of individual progress towards broad goals that provide alternative routes for learning' (CRPD Committee, 2016, para. 26). Jorgensen et al. recommend implementing an evaluation system whereby students receive grades that are reflective of 'personal best' achievements.

Connecting education systems more closely to the key capability of life development skills is also essential for ensuring real inclusion. In Spain, the project *Your Education Has No Limits: Develop Your Future* advocates awareness-raising campaigns targeted at promoting the active participation of secondary school-level individuals with disabilities in universities and in the workforce. Jorgensen et al. encourage the incorporation of annual goals in students' IEPs that not only reflect common core state standards but 'functional skills necessary for full participation in school and life in the community after high school' (Jorgensen et al., 2012, p. 3). Portuguese Decree Law 3/2008[3] goes even further than that to establish a framework for the transition process from school to employment for learners with severe intellectual disabilities (aged 15 or over). According to the European Agency for Special Needs and Inclusive Education (n.d.), the first phase of each Individual Transition Plan (ITP) is to reveal 'the wishes, interests, aspirations and competencies' of each individual. A subsequent phase of the ITP includes an assessment of the gaps in the local job market and the identification of training opportunities or internships for the individual. These are then matched to the academic, personal and social competencies of the individual, and required adjustments and special equipment are documented. Agreements are then set up with the relevant institutions, defining the competencies required for the position, the tasks to be carried out and the support needed to achieve those tasks.

Having reflected on how the capability approach inspires a four-part framework to guide educational processes and how it can teach States Parties lessons in implementing the vision of equal educational opportunities set out in Article 24 CRPD, it is apt to consider whether the capability approach can provide a complete guide to CRPD implementation?

6. The Capability Approach: A Complete Guide to CRPD Implementation?

Given that it is not possible to realise all rights at once, a complete guide to CRPD implementation should also guide States Parties on issues of prioritisation and distribution of resources. Harnacke argues that, 'due to an insufficient grounding of the capabilities which makes a hierarchy among the various capabilities impossible', the capability approach cannot fulfil this role (Harnacke, 2013, p. 777). Terzi (2007, p. 770) claims that other theories, such as Rawlsian theories on 'justice as fairness' (Rawls, 2001), need to be drawn on in order to guide this element of CRPD implementation.

Other limitations to the capability model have been identified by scholars. According to Nussbaum herself, the capability approach is a 'social-minimum approach' (Nussbaum, 2011, p. 40). Therefore, it is incomplete, since it does not make any 'commitment about how inequalities above the minimum ought to be handled' (Nussbaum, 2011, p. 40). Additionally, Norwich questions whether it is really possible to determine what counts as adequate functioning (Norwich, 2014, p. 19).

The four-part framework set out in section four of this article does not claim to solve these (arguably substantial) limitations and does not constitute a full theory of educational equality. It simply focuses on the development of capabilities as a key to guiding processes and practices in education rather than measuring functioning as the sole end goal. The effectiveness of educational systems is often measured relative to means and result. In view of the constraints associated with focusing only on resources and outcomes, this article has argued that it is pivotal to redefine the values underpinning education systems and the capability sets that are developed through education, not only for persons with disabilities but for all learners. A list of educational capabilities has, therefore, been extrapolated in this article and is set out as the second limb of the proposed framework above. It is based on key CRPD values. The proposed list of educational capabilities and the four-part framework may prove useful in answering a range of equality-related questions, including whether certain individuals are accorded more opportunities than others to convert resources into functionings. In that sense, this article demonstrates the human and social development aspect of education rather than simply the 'dominant neoliberal human capital interpretations of education as only for economic productivity and employment' (Walker, 2006a, p. 164).

The capability approach inspires a normative ethical framework and rationale for the provision of inclusive education, while the CRPD fleshes out the legal framework associated with ensuring that the goals of inclusive education are met. Reading them together provides a key to unlocking equality of opportunities for many students.

Outcomes cannot be ignored, of course, and the use of indicators for monitoring CRPD rights is an essential compliment to any approach based on capabilities. The CRPD Committee requires States Parties to develop monitoring frameworks with structural indicators (to measure barriers) and process indictors (to measure changes to the accessibility of physical environments, curriculum adaptations and teacher training), with specific benchmarks and targets attached to each indicator (CRPD Committee, 2016, para. 75). The four-part framework outlined in this article can go some way towards highlighting and solving structural and process issues in education. Nonetheless, the individualised focus of the ca-

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[3] Decreto-Lei n.º 3/2008, de 7 de Janeiro.

pability approach proves ineffective in addressing the broader issues related to CRPD implementation, as highlighted above.

During the drafting process of General Comment 4 of the CRPD Committee (on inclusive education), it was acknowledged that 'no reliable and comparable data is available' on access to education and learning outcomes for children and adult learners with intellectual disabilities, in particular (Inclusion Netherlands, 2016). In view of such deficiencies, the Committee requires States Parties to develop outcome indicators, measuring the percentage of students with disabilities in inclusive learning environments obtaining final official certification or diplomas (CRPD Committee, 2016, para. 75). Since effective participation in society is the end goal to be achieved in implementing Article 24 CRPD, and since some individuals with disabilities never manage to attain even a basic level of functioning in society, these elements of CRPD implementation certainly cannot be neglected. The capability approach does not provide much guidance in that respect. Indeed, De Beco argues that the capability approach 'does not explain whether…participation is a goal in itself or just a means to enhance capabilities' (De Beco, 2017, p. 14).

7. Conclusion

According to Sen, the question 'equality of what?' is pivotal in the search for justice. As demonstrated in this article, the capability approach inspires a four-part framework based upon justice and equality of capabilities. It advocates that social structures should respond to human diversity and allow for human flourishing.

In a similar vein to capability equality, the CRPD is based on respect for the inherent dignity of persons with disabilities, individual autonomy, including the freedom to make one's own choices; respect for difference and acceptance of persons with disabilities as part of human diversity. All of these values underpin the vision of educational equality of opportunity that Article 24 CRPD sets forth. Article 24 seeks to ensure accessible, individualised educational systems, tailored to the wide diversity of needs and innate capabilities of learners with disabilities.

In attempting to theorise equality in education, this article has drawn on the parallels between the values espoused by Article 24 CRPD and the capability approach in order to delineate a four-part framework for inclusion. In doing so, this article demonstrates how the capability approach provides a useful metric for examining inequalities. This can teach us invaluable lessons regarding the processes and practices of inclusive education. It is submitted that the vision of equality set forth in Article 24 can be strengthened if a focus is maintained in the implementation process on the 'the what', 'the why', 'the who' and 'the how' of inclusion.

These four limbs of the proposed framework shed light on learning processes, on the social value of education, on the key focal points of inclusion as well as on the role of educational structures in perpetuating or mitigating inequalities. While the capability approach has several limitations in terms of guiding inclusion and can only inspire a partial framework for CRPD implementation, this partial framework is nonetheless useful in guiding educational processes, policies and institutions towards a more holistic definition of equal opportunities.

The language of capabilities is not exclusive to disability studies, and the lessons learned from the interface between Article 24 CRPD and the capability approach can be applied to the provision of inclusive education for all individuals. This can help to ensure that each individual reaches his/her full potential and can go some way towards ensuring full and equal participation in education for persons with disabilities and as members of the community, just as Article 24 itself requires.

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Conflict of Interests

The author declares no conflict of interests.

References

Ad-Hoc CRPD Committee. (2005). Travaux préparatoires. Retrieved from www.un.org/esa/socdev/enable/rights/adhoccom.htm

Agran, M., Blanchard, C., Wehmeyer, M., & Hughes, C. (2002). Increasing the problem-solving skills of students with developmental disabilities participating in general education. *Remedial and Special Education*, *23*(5), 279–288.

Ainscow, M., & Farrell, P. (2002). *Making special education inclusive: From research to practice* (1st ed.). London: David Fulton Publishers.

Armstrong, D., Armstrong, F., & Barton, L. (2000). *Inclusive education: Policy, contexts and comparative perspectives*. London: David Fulton Publishers.

Arnardóttir, O. M. (2011). The right to inclusive education for children with disabilities—Innovations in the CRPD. In A. Eide, J. Möller, & I. Ziemele (Eds.), *Making peoples heard: Essays on human rights in honour of Gudmundur Alfredsson* (pp. 197–227). Leiden: Martinus Nijhoff Publishers.

Broderick, A. (2014). The right to inclusive education: Article 24 of the UN Convention on the Rights of Persons with Disabilities and the Irish experience. *Irish Yearbook of International Law*, *9*(1), 25–60.

Broderick, A. (2015). *The long and winding road to equality and inclusion: The United Nations Convention on the Rights of Persons with Disabilities*. Antwerp: Intersentia.

Broderick, A., & Quinlivan, S. (2017). The right to education: Article 24 of the CRPD. In C. O' Mahony, & G. Quinn (Eds.), *The UN Convention on the Rights of Persons with Disabilities: Comparative, regional and thematic perspectives* (pp. 293–208) Dublin: Clarus Press.

Committee on the Rights of Persons with Disabilities. (2012). *Concluding observations of the Committee on the Rights of Persons with Disabilities, Hungary, U.N. Doc CRPD/C/HUN/CO/1*.

Committee on the Rights of Persons with Disabilities. (2016). *General Comment 4, UN Doc. CRPD/C/GC/4*.

De Beco, G. (2014). The right to inclusive education according to Article 24 of the UN Convention on the Rights of Persons with Disabilities: Background, requirements and (remaining) questions. *Netherlands Quarterly of Human Rights*, *32*(3), 263–287.

De Beco, G. (2016). Transition to inclusive education systems according to the Convention on the Rights of Persons with Disabilities. *Nordic Journal of Human Rights*, *34*(1), 40–59.

De Beco, G. (2017). The right to inclusive education: Why is there so much opposition to its implementation? *International Journal of Law in Context*, 1–20.

Della Fina, V. (2017). Article 24 CRPD (education). In V. Della Fina, R. Cera, & G. Palmisano (Eds.), *The United Nations Convention on the Rights of Persons with Disabilities: A commentary* (pp. 439–470). Cham: Springer Publications.

Endrew F. v. Douglas County School Dist. RE–1, No. 15–827, 580 U.S. (2017).

European Agency for Development in Special Needs Education. (2011). *Participation in inclusive education: a framework for developing indicators*. Retrieved from https://www.european-agency.org/sites/default/files/participation-in-inclusive-education-a-framework-for-developing-indicators_Participation-in-Inclusive-Education.pdf

European Agency for Development in Special Needs Education. (2003). *Inclusive education and effective classroom practices*. Retrieved from https://www.european-agency.org/sites/default/files/inclusive-education-and-effective-classroom-practice_IECP-Literature-Review.pdf

European Agency for Special Needs and Inclusive Education. (n.d.). Portugal—Overview. Retrieved from https://www.european-agency.org/country-information/portugal/national-overview/complete-national-overview

Ferri, D. (in press). The past, present and future of the right to inclusive education in Italy. In S. Quinlivan, G. De Beco, & J. Lord, *The right to inclusive education in international human rights law*. Cambridge: Cambridge University Press.

Florian, L., Dee, L., & Devecchi, C. (2008). How can the capability approach contribute to understanding provision for people with learning difficulties? *Prospero*, *14*(1), 24–33.

Harnacke, C. (2013). Disability and capability: Exploring the usefulness of Martha Nussbaum's capabilities approach for the UN disability rights Convention. *Journal of Law, Medicine & Ethics*, *41*(4), 768–780.

Hughes, C., Pitkin, S., & Lorden, S. (1998). Assessing preferences and choices of persons with severe and profound mental retardation. *Education and Training in Mental Retardation and Developmental Disabilities*, *33*(4), 299–316.

Hyry-Beihammer, E. K., & Hascher, T. (2015). Multigrade teaching practices in Austrian and Finnish primary schools. *International Journal of Educational Research*, *74*(1), 104–113.

Inclusion Netherlands. (2016). Submission to draft General Comment 24 of the Committee on the Rights of Persons with Disabilities. Retrieved from http://www.ohchr.org/EN/HRBodies/CRPD/Pages/GCRightEducation.aspx

Jorgensen, C. M., Mc Sheehan, M., Schuh, M., & Sonnenmeier, R. M. (2012). *Essential best practices in inclusive education*. Durham: National Center on Inclusive Education Institute on Disability, University of New Hampshire. Retrieved from http://www.tash.org/wp-content/uploads/2011/03/Essential-Best-Practices-070312-FULL-Jorgensen.pdf

Knowelton, E. (1998). Considerations in the design of personalized curricular supports for students with developmental disabilities. *Education and Training in Mental Retardation and Developmental Disabilities*, *33*(2), 95–107.

Mac Kay, G. (2002). The disappearance of disability? Thoughts on a changing culture. *British Journal of Special Education*, *29*(4), 151–163.

Minow, M. (1990). *Making all the difference: Inclusion, exclusion and American law*. New York: Cornell University Press.

Mutanga, O., & Walker, M. (2015). Towards a disability-inclusive higher education policy through the capabilities approach. *Journal of Human Development and Capabilities*, *16*(4), 501–517.

Nind, M., Rix, J., Sheehy, K., & Simmons, K. (2005). *Curriculum and pedagogy in inclusive education: Values and practice*. London: Routledge.

Norwich, B. (2014). How does the capability approach address current issues in special educational needs, disability and inclusive education field? *Journal of Research in Special Educational Needs*, *14*(1), 16–21.

Nussbaum, M. C. (2000). *Women and human development: The capabilities approach* (1st ed.). Cambridge: Cambridge University Press.

Nussbaum, M. (2009). The capabilities of people with cognitive disabilities. *Metaphilosophy*, *40*(3/4), 331–351.

Nussbaum, M. C. (2011). *Creating capabilities: The human development approach* (1st ed.). Cambridge: Cambridge University Press.

Rajapakse, N. (2016). Amartya Sen's capability approach and education: Enhancing social justice. *Revue LISA*.

Retrieved from https://lisa.revues.org/8913

Rawls, J. (2001). *Justice as fairness: A restatement* (1st ed.). Cambridge: Harvard University Press.

Reindal, S. M. (2016). Discussing inclusive education: An inquiry into different interpretations and a search for ethical aspects of inclusion using the capabilities approach. *European Journal of Special Needs Education*, *31*(1), 1–12.

Robeyns, I. (2003). Sen's capability approach and gender inequality: Selecting relevant capabilities. *Feminist Economics*, *9*(2/3), 61–91.

Robeyns, I. (2006). Three models of education: Rights, capabilities and human capital. *Theory and Research in Education*, *4*(1), 69–84.

Rogers, C. (2013). Inclusive education and intellectual disability: A sociological engagement with Martha Nussbaum. *International Journal of Inclusive Education*, *17*(9), 988–1002.

Saito, M. (2003). Amartya Sen's capability approach to education: A critical exploration. *Journal of Philosophy of Education*, *37*(1), 17–33.

Sarojini Hart, C. (2012). The capability approach and education. *Cambridge Journal of Education*, *42*(3), 275–282.

Sen, A. (1979). *Equality of what?* Retrieved from http://tannerlectures.utah.edu/_documents/a-to-z/s/sen80.pdf

Sen, A. (1992). *Inequality re-examined* (1st ed.). Oxford: Oxford University Press.

Stein, M. A. (2007). Disability human rights. *California Law Review*, *95*(1), 75–122.

Terzi, L. (2005). Beyond the dilemma of difference: The capability approach to disability and special educational needs. *Journal of Philosophy of Education*, *39*(3), 443–459.

Terzi, L. (2007). Capability and educational equality: The just distribution of resources to students with disabilities and special educational needs. *Journal of Philosophy of Education*, *41*(4), 757–773.

Terzi, L. (2014). Reframing inclusive education: Educational equality as capability equality. *Cambridge Journal of Education*, *44*(4), 479–493.

Toson, A. L., Burrello, L. C., & Knollman, G. (2013). Educational justice for all: The capability approach and inclusive education leadership. *International Journal of Inclusive Education*, *17*(5), 490–506.

Trani, J. F., Bakhshi, P., Ballanca, N., Biggeri, M., & Marchetta, F. (2011). Disabilities through the capability approach lens: Implications for public policies. *ALTER—European Journal of Disability Research/Revue Européenne de Recherche sur le Handicap*, *5*(3), 143–157.

UNESCO. (2017). *A guide for ensuring inclusion and equity in education*. Retrieved from http://unesdoc.unesco.org/images/0024/002482/248254e.pdf

Waddington, L., & Toepke, C. (2014). *Moving towards inclusive education as a human right: An analysis of international legal obligations to implement inclusive education in law and policy*. Maastricht Faculty of Law Working Paper No. 2014-7. Retrieved from https://ssrn.com/abstract=2535198

Walker, M. (2006a). Towards a capability-based theory of social justice for education policy-making. *Journal of Education Policy*, *21*(2), 163–185.

Walker, M. (2006b). *Higher education pedagogies: A capabilities approach*. Maidenhead: Society for Research on Higher Education/Open University Press and McGraw-Hill.

Walker, M., & Unterhalter, E. (2007). *Sen's capability approach and social justice in education* (1st ed.). New York: Palgrave Macmillan.

Wehmeyer, M. L. (1998). Self-determination and individuals with significant disabilities: Examining meanings and misinterpretations. *Journal of the Association for Persons with Severe Handicaps*, *23*(1), 5–16.

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Article

Reasonable Accommodation as a Gateway to the Equal Enjoyment of Human Rights: From New York to Strasbourg

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Abstract

The UN Convention on the Rights of Persons with Disabilities (CRPD) explicitly embeds the concept of reasonable accommodation within the principle of non-discrimination. Article 2 of the CRPD unambiguously recognizes that reasonable accommodation is vital in enabling persons with disabilities to enjoy and exercise their rights on an equal basis with others. This article argues that in the ten years since its entry into force, the CRPD has stimulated a process of cross-fertilization. In particular, it contends that the CRPD has played a crucial role in the advancement of disability equality, and in the recognition of reasonable accommodation as a gateway to the equal enjoyment of all human rights within the European human rights system. By adopting a legal perspective and a traditional doctrinal approach, this article focuses on relevant European Court of Human Rights (ECtHR) case law. It shows the gradual adoption by the ECtHR of the concept of reasonable accommodation as an essential element to remove specific barriers or disadvantages to which a particular disabled individual would otherwise be subject. The primary emphasis of this short article is on the ECtHR case law and on the extent to which it has translated the CRPD and the work of the CRPD Committee into the European human rights system.

Keywords

disability; discrimination; equality; human rights; legislation; reasonable accommodation

Issue

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1. Introduction

The legal concept of “reasonable accommodation” (or its synonym “reasonable adjustment”)[1] first appeared in the United States. It was introduced in the US Equal Employment Opportunity Act of 1972, which amended the Civil Rights Act 1964 (Jolls, 2001; Willborn, 2016) and, shortly thereafter, in Canadian law (Banks, 2016). Originally, it defined specific solutions that the employer was obliged to adopt in order to accommodate specific needs related to religious practices. In 1973, the US Rehabilitation Act extended the concept of reasonable accommodation to the disability context. As noted by Waddington (2011, p. 187):

> The obligation to make a reasonable accommodation on the grounds of disability is based on the recognition that, on occasions, the interaction between an individual’s impairment and the physical or social environment can result in the inability to perform a particular function, job or activity in the conventional manner.

Lawson (2012, p. 846) highlights that the duty to provide reasonable accommodations entails a duty to remove barriers created by physical structures, traditional methods of communication and standard policies or practices where these would place a person with a disability at a disadvantage when compared with a non-disabled per-

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[1] The terms “reasonable accommodation” and “reasonable adjustment” are generally considered interchangeable. The term adjustement is used in some national laws, such as e.g. the UK Equality Act 2010.

son. Along the lines traced by the Rehabilitation Act, the Americans with Disabilities Act (ADA) of 1990 has introduced a provision requiring employers to adopt specific adjustments that remove the environmental and social barriers faced by persons with disabilities[2] in the workplace (Rosen, 1991). It includes a broad prohibition of discrimination on the grounds of disability and qualifies as a discriminatory behavior the denial of reasonable accommodation. In 2000, the concept of reasonable accommodation was incorporated within European Union (EU) legislation. Article 5 of Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation establishes the duty of the employer to provide disabled workers with reasonable accommodation. With the 2006 UN Convention on the Rights of Persons with Disabilities (CRPD), which entered into force in May 2008, reasonable accommodation has become an integral part of the international human rights framework. The CRPD unequivocally links the duty to accommodate to the principle of equality (Broderick, 2015a, p. 107), recognizing the role of reasonable accommodation as a gateway to the equal enjoyment of all human rights, being they civil, political or socio-economic rights (Lawson, 2008a, pp. 65–66).

The CRPD as a whole has experienced an unprecedented level of success, and, at the time of writing, it has been ratified by 175 States across the globe as well as by the EU. It has become the main legal benchmark against which the appropriateness of domestic disability laws and policies should be measured and the protection and promotion of the rights of persons with disabilities should be assessed. In Europe, the CRPD has had a significant influence on the legal discourse surrounding disability equality. The Court of Justice of the EU as well as national courts have referred to the CRPD as the key international document for the protection and promotion of the rights of persons with disabilities in their decisions. They have increasingly attempted to interpret domestic law in a manner consistent to the CRPD (Ferri, 2014; Waddington & Lawson, 2018). The CRPD itself requires States Parties to ensure full compliance with the Convention within their domestic legal order, an obligation that even extends to their national courts. However, and more broadly, the CRPD has stimulated a process of cross-fertilization and has played a crucial role in the advancement of disability equality beyond State Parties (Ferri, 2017). It has contributed to the advancement of the protection of the rights of persons with disabilities within the European human rights system of the Council of Europe, which mainly revolves around the European Convention of Human Rights (ECHR). The European Court of Human Rights ("ECtHR" or "Strasbourg Court") has referred to the CRPD in almost all of the most recent case law on disability. Lawson (2012, p. 847) suggests that "the relevance of the CRPD in questions of interpretation of the ECHR in matters relating to disability" has been fully acknowledged by the ECtHR. Favalli (2018) goes even further and argues that the ECtHR has recognized the core provisions of the CRPD as general principles of international law that must be complied with when applying and implementing the ECHR.

Against this background, this article contends that the ECtHR decisions in which the influence of the CRPD is most relevant and obvious concern the role of reasonable accommodation in ensuring equal rights for persons with disabilities. By adopting a legal perspective and a traditional doctrinal approach, this succinct article deliberately focuses on the ECtHR case law. It endeavors to discuss the extent to which it has effectively translated the CRPD and the work of the CRPD Committee into the European human rights system. In doing so, it tallies with previous research which argues that the CRPD has shed a light on the significance of reasonable accommodation as a primary tool to achieve disability equality across different jurisdictions (Brown & Lord, 2011; Ferri, 2017; Mégret & Msipa, 2014). After this Introduction, the remainder of this article is divided into five sections. Building on the broad array of literature on the topic (Broderick, 2015a, 2015b; Brown & Lord, 2011; Cera, 2017; Lawson, 2007, 2008a, 2008b, 2009, 2012, 2017), Section 2 discusses in a general fashion the role of reasonable accommodation in the CRPD, in light of the CRPD Committee's jurisprudence and general comments. Section 3 goes on to examine in a general fashion how the concept of reasonable accommodation has been incorporated into the ECHR framework by the Strasbourg court. Sections 2 and 3 provide important context for the rest of the discussion that is conducted in Section 4. The latter aims to highlight the gradual adoption by the ECtHR of the concept of reasonable accommodation. Section 5 concludes with brief remarks on the role of reasonable accommodation in ensuring disability equality.

2. Reasonable Accommodation in the CRPD

2.1. Reasonable Accommodation and Equality in the CRPD: Setting the Scene

The CRPD is underpinned by the social model of disability and embraces the view that "disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others" (UN, 2016, Preamble, lett. e). Dignity, individual autonomy, equality, accessibility and inclusion within society and the acceptance of disability as part of human diversity are some of the key principles around which the CRPD revolves and that permeate the entirety of the text. The Convention, by recasting disability as a social construction (Stein & Lord, 2009, p. 33), focuses

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[2] The terms "persons with disabilities" and "disabled people" are used interchangeably throughout this article, consistently with the idea that disability stems from the interaction between the individual impairment and social structures and systems, and in line with a social-contextual understanding of disability.

on the removal of barriers and provision of accommodations to ensure the equal enjoyment of rights by persons with disabilities, and their full participation in society. Ngwena (2013, p. 478) affirms that the emphasis placed by the CRPD on accommodating human diversity, providing individualized support, is "the Convention's greatest transformative modality".

The concept of reasonable accommodation is a core of feature of the CRPD, and is unequivocally incorporated into the non-discrimination and equality principles. Article 5(2) of the CRPD requires States Parties to prohibit discrimination on the basis of disability. The latter is defined in Article 2 of the CRPD as:

> Any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation. (UN, 2016)

Article 5(3) of the CRPD explicitly requires States Parties to take all appropriate steps to ensure that reasonable accommodation is provided. Reasonable accommodation is clearly defined in Article 2 of the CRPD as

> The necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms. (UN, 2016)

Since the Convention does place reasonable accommodation within the realm of non-discrimination and equality, according to the CRPD Committee, States Parties must immediately ensure that reasonable accommodation is provided, since the duty to accommodate is not subject to progressive realization (CRPD Committee, 2017a, para. 46).

2.2. Reasonable Accommodation as an "Incidental Right" and as a Gateway to the Equal Enjoyment of Human Rights

Aside from Articles 2 and 5 of the CRPD, reasonable accommodation is mentioned explicitly in other provisions of the Convention, for example in Article 24 on the right to education and in Article 27 on the right to work. Moreover, Article 14(2) of the CRPD explicitly recognizes that reasonable accommodations must be provided to persons with disabilities held in detention. However, as noted by Broderick (2015a, p. 155), "by virtue of the cross-cutting nature of Articles 2 and 5 of the CRPD" persons with disabilities are "holders of a fundamental right to be accommodated in a variety context and by a wide array of entities".

It is often acknowledged that the Convention does not create new rights. Rather, it "rewrites" human rights within a disability context. In doing so it does include "amplified formulations of human rights" (Kayess & French, 2008, p. 28), and creates "incidental rights" (Harpur, 2012, p. 2) which ensure those same rights can be fully enjoyed by persons with disabilities. Reasonable accommodation is one of them. Insofar as it represents a right enforceable in itself, applicable to all persons with disabilities, who, by virtue of Article 1(2) of the CRPD, 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, 2016)

Since its early decisions, the CRPD Committee has emphasized that the right to be provided with reasonable accommodation functions as a gateway to the exercise of all other rights.[3] The case of *H.M. v Sweden* (CRPD Committee, 2012) is quite exemplary in this respect. Mrs. H.M., who was suffering from a chronic disease which had led to her being unable to walk or stand, was refused planning permission to build an indoor swimming pool next to her house for her to carry out hydrotherapy which would alleviate the symptoms of her condition. The refusal of planning permission by the local authorities was due to the fact that the local urban plan did not allow new constructions in the area concerned. The Swedish administrative authority, followed by the courts, upheld the initial decision and contended that derogations from the urban plan were not permissible. Having exhausted all domestic remedies, Mrs. H.M. lodged a complaint with the CRPD Committee. The latter, in its decision, focused on the interpretation of the concepts of non-discrimination and reasonable accommodation. In particular, the CRPD Committee acknowledged that the Mrs. H.M.'s health was of paramount concern. It also held that access to a hydrotherapy pool in her home was essential, as it constituted the only effective means of protecting the right to health of the applicant. Then, the Committee recognized that a derogation from the local urban plan, to allow the construction of a hydrotherapy pool, would constitute a reasonable accommodation. In essence, it held that States Parties to the CRPD are under the obligation to consider the particular circumstances and needs of persons with disabilities and to accommodate these needs when applying domestic legislation.

The CRPD Committee has also articulated the unequivocal linkages between reasonable accommodation and the fundamental principle of human dignity. In par-

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[3] As Lawson (2009) contends, by cutting across the full spectrum of rights–civil, political, economic, social and cultural–provided for in the CRPD, reasonable accommodation plays a "peculiar bridging role".

ticular, in *X v Argentina* (CRPD Committee, 2014a) and in the "Guidelines on Article 14 of the CRPD" (CRPD Committee, 2015), the Committee explicitly referred to reasonable accommodation in places of detention as an essential gateway for the equal protection of the dignity of persons with disabilities. In a similar vein, in its most recent General Comment No. 5 on independent living, the Committee has highlighted the role of reasonable accommodation in enhancing autonomy and independence of people with disabilities (CRPD Committee, 2017a).

Reasonable accommodation could be construed as an "incidental right", using the term suggested by Harpur (2012, p. 2), in that it is essential to ensure that other existing rights are realized. It matches a corresponding duty to accommodate which is placed on a broad range of stakeholders, as well as a general obligation on State Parties to ensure the provision of reasonable accommodation. As pointed out by Brown and Lord (2011, p. 279), the duty to provide reasonable accommodation in the CRPD extends to "the State, employers, education providers, health care providers, testing and qualification bodies, providers of goods and services and private clubs". In essence, Article 5(3) of the CRPD requires States Parties to ensure that all these actors "reasonably adjust policies, practices and premises that impede the inclusion and participation of persons with disabilities" (UN, 2016). Additionally, Lawson (2008b, p. 32) suggests that Article 5(3), read in conjunction with Article 8 of the CRPD on awareness-raising, requires States Parties to encourage reflection and promote dialogue on the duty to accommodate, and on all the types of measures that can be taken.

Lawson (2012, p. 848) suggests that the individual-oriented nature of the reasonable accommodation obligation:

> Requires duty-bearers to resist making assumptions as to what might be most appropriate for a particular individual and demands that instead they engage in a dialogue with such a person about how the relevant disadvantages might most effectively be tackled.

With specific regard to the employment context, it has been observed that a "failure to consult and involve the disabled person in question would also appear to sit uncomfortably with the CRPD's general principle of respect for inherent dignity" (Ferri & Lawson, 2016, p. 49).

Even though the Convention gives a definition of reasonable accommodation in Article 2, it does not provide specific guidance on what the incidental right to be provided with an accommodation entails. Unsurprisingly, the Convention is silent on what, in practice, constitutes a reasonable accommodation and on the procedural aspects of the adoption of an accommodation. Examples of accommodations have been put forward by the CRPD Committee in its general comments relating to women with disabilities (CRPD Committee, 2016a) and with regards to the educational context (CRPD Committee, 2016b). Other examples can be found in studies or documents released by other UN bodies or agencies, such as the Office of the United Nations High Commissioner for Human Rights (OHCHR, 2010) and by the World Health Organization (WHO & World Bank, 2011). The International Labour Organization in 2016 (ILO, 2016) has also compiled a list of best practices in relation to reasonable accommodations in the employment context. The CRPD Committee has however elaborated on the concept of reasonable accommodation and its meaning. It clarified that the word "reasonable" concerns the relevance and the effectiveness of the specific accommodation in removing the individual situation of disadvantage that the person with a disability is facing, and relates to the role of the accommodation in countering discrimination. This approach is confirmed by the CRPD Committee's decision in *Jungelin v Sweden* (CRPD Committee, 2014c) and in *Michael Lockrey v Australia* (CRPD Committee, 2016c).

2.3. Reasonable accommodation v Accessibility

Although this analysis does not include a reflection on the concept of accessibility and on how (and whether) it has been translated in the ECtHR case law, it seems useful to briefly trace the boundaries of "reasonable accommodation" by comparing and contrasting it with accessibility in light of the CRPD Committee's General Comment No. 2 (CRPD Committee, 2014b).

Without delving into the theoretical question on whether accessibility is a principle, a right, or a facilitator of rights, the main difference between accessibility and reasonable accommodation is that accessibility obligations laid down in the CRPD are group related, while, as discussed above, reasonable accommodation has an individualised nature. Consequently, accessibility obligations are anticipatory in nature. The CRPD Committee affirms that the "duty to provide accessibility is an *ex ante* duty" and that States Parties therefore have "the duty to provide accessibility before receiving an individual request to enter or use a place or service" (CRPD Committee, 2014b, para. 25). The CRPD Committee has also emphasized that its most fundamental characteristic is its individualized nature. The CRPD Committee's "General Comment no. 2 on accessibility" (CRPD Committee, 2014b) and subsequent comments (CRPD Committee, 2016a, 2016b) explain that, by virtue of this individualized nature, the duty to provide reasonable accommodation arises *ex nunc*, i.e., only at the moment at which a person with a disability has need for a particular solution in a given situation. It might be argued that the duty to accommodate arises when the duty-bearer knows or ought to know (using the ordinary diligence) about the disability and of the specific needs of the person with a disability. However, the CRPD Committee has mentioned that the duty arises from the moment a person with a disability requires the accommodation in a given situation (CRPD Committee, 2016a, 2016b). Hence, there is still some ambiguity surrounding the temporal scope of the right and the corresponding duty to accommodate.

Another key difference is that reasonable accommodation obligations are subject to the limit of "undue" or "disproportionate" burden, as will be discussed in subsection 2.4. By contrast:

> The obligation to implement accessibility is unconditional, i.e. the entity obliged to provide accessibility may not excuse the omission to do so by referring to the burden of providing access for persons with disabilities. (CRPD Committee, 2014b, para. 25)

2.4. The "Disproportionate or Undue Burden" Limit

The right to be provided with a reasonable accommodation is not absolute (Waddington & Broderick, 2017, p. 12) and is subject to the "disproportionate or undue burden" limit. This means that the denial of reasonable accommodation does not constitute a discrimination when the accommodation entails a disproportionate burden on the duty bearer.

Regrettably, there is no explicit guidance in the CRPD as to what may constitute a disproportionate burden. In *Jungelin v Sweden* (CRPD Committee, 2014c) and in *Gemma Beasley v Australia* (CRPD Committee, 2016d), the CRPD Committee held that States Parties to the Convention enjoy a margin of discretion when formulating and assessing the reasonableness and proportionality of accommodation measures. *Jungelin v Sweden* is particularly relevant in this respect. The complaint made to the CRPD Committee was raised by Ms. Jungelin, a person with a visual impairment. Despite the fact that she met the required qualification for the job she had applied to, she was not hired because her potential employer's intranet system was not accessible and could not be adjusted to accommodate her sight impairment. Ms. Jungelin claimed that this amounted to a denial of reasonable accommodation, and consequently a discrimination on the grounds of disability. However, her complaints were rejected by the Swedish courts. Endorsing the defense of the employer, the domestic tribunals took the view that the cost of adjusting the computer system would have imposed a disproportionate burden on the employer. The CRPD Committee, with some dissenting opinions, concluded that the Swedish courts had carried out a thorough and well-balanced assessment of the factual circumstances at hand. The decision to deem the accommodation requested as constituting an unreasonable burden was therefore justified and the CRPD Committee held that there was no violation of Article 5 of the CRPD on equality and non-discrimination. This decision suggests that the financial cost of a requested accommodation is a relevant factor in determining whether and to what extent the duty-bearer can duly claim to be exempt from the duty to accommodate.[4] This approach is confirmed by the "General Comment No. 4 on Article 24: Right to education" which explicitly affirms that "the availability of resources and financial implications is recognized when assessing disproportionate burden" (CRPD Committee, 2016b, para. 27).

The CRPD Committee has not elaborated further on specific criteria to carry out the proportionality test, however its jurisprudence and general comments would suggest that, by its very nature, reasonable accommodation entails balancing the needs and interests of both the person with a disability and the duty-bearer.

3. Equality and Reasonable Accommodation in the ECHR: "The Feast of Stone" and the Strasbourg Judges

Within the European context, the Council of Europe, which plays a primary role in the protection of human rights, has not yet adopted any specific binding instrument on the rights of persons with disabilities. The latter are however protected by the European Social Charter (ESC) and the ECHR and through various policy initiatives (Favalli, 2018; Ferri, 2017; Seatzu, 2014). The ESC, in its revised formulation, includes an article on the right of persons with disabilities to independence, social integration and participation in the life of the community. Notably, this provision (i.e., Article 15 of the revised ESC) refers to positive measures which provide persons with disabilities with education and vocational training, and explicitly mentions that States Parties must promote measures intended "to adjust [the] working conditions to the needs of the disabled". While reasonable accommodation is not explicitly mentioned, it does seem to be encompassed within the generic reference to measures that facilitate the exercise of the freedom of movement, the right to use goods and cultural content, and the right to housing. As noted elsewhere (Ferri, 2017), the European Committee on Social Rights has, in a few occasions, highlighted the existence of the duty to accommodate as an integral element of disability equality.

By contrast to the ESC, the ECHR does not contain any express reference to disability,[5] disability rights or reasonable accommodation. However, Article 14 of the ECHR does prohibit discrimination "on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status", and, for the first time in *Glor v Switzerland* (ECtHR, 2009), the Strasbourg court established that this provision also encompasses the prohibition of discrimination on the basis of disability. The case revolved around the application of the Swiss legislation on the military-service tax, the payment of which is required for those who decide not to carry out military service. Swiss law provided a twin-track system, exempting from the payment of the

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[4] This approach is in line with that adopted at the EU level with regards to the implementation of Article 5 of Directive 2000/78.

[5] Neither disability nor persons with disabilities are mentioned in the text of the ECHR. There is only a reference to Intellectual disability in Article 5(e) ECHR on the lawful detention of "persons of unsound mind".

tax all those having a "major" disability (i.e., 40% physical or mental disability), but requiring the payment to all the others declared unfit to military service by virtue of a "minor" disability. The applicant, Mr. Glor, who suffered from diabetes was declared unsuited for military service. Since his condition did not meet the threshold of 40% physical or mental disability required by Swiss law, he was required to pay the military-service exemption tax, for not carrying his military service. Mr. Glor argued that the disability threshold provided by Swiss law (40% physical or mental disability) was discriminatory and violated Article 14 of the ECHR. The Strasbourg Court considered that the Swiss authorities failed to strike a balance between the protection of the interests of the community and respect for the rights of Mr. Glor as a person with a disability. The ECtHR recognized that the list of grounds of discrimination of Article 14 is not exhaustive and that discrimination based on disability is included under the "other status" grounds. It held that the distinction made by the Swiss authorities between persons who were unfit for service and not liable to the tax in question and persons who were unsuited but still obliged to pay it was not justified and constituted discrimination. Favalli (2018) highlights that, in *Glor v Switzerland*, the ECtHR has also adopted a broad conceptualization of what constitutes a disability in line with the CRPD. This author suggests that such a broad conceptualization has been upheld in subsequent decisions in which the Court has extended the application of the non-discrimination protection under Article 14 of the ECHR to persons affected by HIV, as a form of disability. In *Kiyutin v Russia* (ECtHR, 2011) the Strasbourg judges considered that the refusal of a residence permit to Mr. Kiyutin because he was HIV-positive constituted a discrimination prohibited by Article 14. The ECtHR went on to affirm that a distinction made on the grounds of an individual's health status, including conditions such as an HIV infection, should be covered—either as a disability or a form thereof—by the term "other status" listed in Article 14 of the ECHR. The same approach has been taken in *I.B. v. Greece* (ECtHR, 2013), which concerned HIV-based discrimination in the employment context. Timmer (2013) affirms that the latter case is also particularly notable in that it embraces the social model of disability, and the role of social barriers and stigma in creating discrimination and preventing equal treatment.

As it will be further discussed in Section 4, the explicit recognition that any discrimination based on disability is prohibited under the ECHR goes hand in hand with the acknowledgement of the right of persons with disabilities to be provided with reasonable accommodation. First, in *Glor*, the Court incidentally observed that the Swiss authorities had not taken sufficient account of Mr. Glor's individual circumstances, imposed on Mr. Glor the payment of the military-service tax and did not propose to him any alternative services compatible with his disability. Although the ECHR has not explicitly recognized a right to obtain reasonable accommodations, the judgment can be interpreted as an implicit recognition that some form of obligation to provide reasonable accommodation is included in the principle of non-discrimination laid down in Article 14 of the ECHR (Broderick, 2015b). The ECtHR adopted a more explicit approach in *Ḉam v Turkey* (ECtHR, 2016a). This case concerned the refusal to enroll the applicant, a girl with a visual impairment, as a student at the Turkish National Music Academy. Even though Ms. Çam had demonstrated adequate ability in playing the Turkish lute (*bağlama*), she was refused admission because the music courses were not accessible to blind people. The applicant alleged that she had been discriminated against on account of her blindness and complained of a violation of Article 14 of the ECHR read in conjunction with Article 2 Protocol 1 on the right to education. It its decision, the ECtHR held that discrimination on the grounds of disability under Article 14 ECHR encompasses the denial of reasonable accommodations as defined by Article 2 of the CRPD. The Strasbourg judges stated that, by refusing to register the applicant without accommodating her needs, the Turkish authorities had prevented her, without any objective justification, from exercising her right to education.

A month after *Ḉam v Turkey*, in *Guberina v Croatia* (ECtHR, 2016b), the ECtHR elaborated further on the concept of reasonable accommodation. The case arose from the complaint of the father of a severely disabled child and concerned a tax exemption on the purchase of a home. Mr. Guberina lived in a flat located on the third floor of an inaccessible building in Zagreb. Since his child had found it increasingly difficult to live in the flat, the applicant and his family decided to move to a different and more accessible accommodation and purchase a new flat. Mr. Guberina requested a tax exemption on the purchase of the new property. According to Croatian legislation, this exemption was in fact available to buyers who moved in order to solve their "housing needs", when their previous property did not possess "basic infrastructures" (i.e., did not satisfy basic hygiene and technical requirements). The applicant argued that accessibility was a feature of "basic infrastructure", and his previous flat did not satisfy his family's housing needs. By contracts the Croatian authorities decided that the applicant's old flat possessed all basic infrastructures features and dismissed his request, without taking into consideration his son's particular circumstances. After having exhausted all domestic remedies, Mr. Guberina alleged the violation of Articles 8 and 14 of the ECHR in conjunction with Protocol 1 on the right to property. The ECtHR reaffirmed the need to give an extensive interpretation to the concept of non-discrimination on the basis of disability, including discrimination by association. In addition, and most notably for the purpose of this analysis, the Court recalled the concept of reasonable accommodation as defined in Article 2 of the CRPD and held that the Croatian authorities failed to consider the specific needs of the applicant's disabled son. The ECtHR considered that that the manner in which the Croatian legislation had been applied in practice had failed to accommodate the specific needs of the applicant, in breach of the CRPD.

4. Synergies between the CRPD and the ECHR

4.1. Reasonable Accommodation and Equality

The seeds of the acknowledgment of reasonable accommodation as a tool to ensure disability equality are long standing in the European human rights system. They predate *Glor v Switzerland* and can be found in cases dating back to the late 1990s and early 2000s (De Schutter, 2005), such as *Botta v Italy* (ECtHR, 1998) and *Price v United Kingdom* (ECtHR, 2001).[6] However, only in *Glor v Switzerland*, and more palpably in *Ḉam v Turkey* and *Guberina v Croatia*, has the ECtHR interpreted the concept of discrimination on the grounds of disability as encompassing the denial of reasonable accommodation. It is not a coincidence that the importance of reasonable accommodation in the context of the application of Article 14 of the ECHR has emerged after the entry into force of the CRPD, and that, in each of these cases, the ECtHR refers several times and explicitly to the definition of reasonable accommodation laid down in Article 2 of the CRPD. In Ḉam the Court read Article 14 of the ECHR in the light of the CRPD and held that persons with disabilities are entitled to reasonable accommodation, which is essential:

> To ensure 'the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms' (Article 2 of the Convention on the Rights of Persons with Disabilities…). Such reasonable accommodation helps to correct factual inequalities which are unjustified and therefore amount to discrimination. (ECtHR, 2016a, para. 65)

The Strasbourg court embraced a concept of substantive equality that fully encompasses the duty to take account of the needs of people with disabilities and to accommodate those needs accordingly. In *Glor v Switzerland*, *Ḉam v Turkey* and *Guberina v Croatia*, it places a great emphasis on the necessity to consider the specific and individual circumstances of persons with disabilities and to accommodate these when applying domestic legislation. In this respect, the reasoning of the ECtHR in *Guberina v Croatia* presents interesting similarities to the CRPD's Committee decision in *H.M. v Sweden*. In *H.M.*, Swedish authorities failed to consider the specific health situation of the applicant when denying the planning permission, and, in *Guberina*, Croatian authorities did not recognize:

> The factual specificity of the applicant's situation with regard to the question of basic infrastructure and technical accommodation requirements to meet the special housing needs of his family. The domestic authorities adopted an overly restrictive position on the applicant's particular case, by failing to take into account the specific needs of the applicant and his family when applying the condition relating to "basic infrastructure requirements" to their particular case, as opposed to other cases where elements such as the surface area of a flat, or access to electricity, water and other public utilities, might have suggested adequate and sufficient basic infrastructure requirements. (ECtHR, 2016b, para. 86)

In both cases, national authorities should have gone beyond a strict interpretation of national law and acted in a manner consistent with the CRPD.

4.2. Reasonable Accommodation as an "Incidental Right" and as a Gateway to the Equal Enjoyment of Human Rights

The Strasbourg judges have clearly embraced a view of reasonable accommodation as entailing the removal of the specific disadvantage faced by the person with a disability in order to ensure substantive equality. While *Glor v Switzerland* is merely suggestive of a right of persons with disabilities to be provided with reasonable accommodation (Broderick, 2015b, p. 15; Brown & Lord, 2011, p. 291), *Ḉam v Turkey* and *Guberina v Croatia* are indeed more explicit. It can be inferred from these cases that persons with disabilities have a right to reasonable accommodation, which is enforceable as an individual standalone right within the framework of non-discrimination and equality, even though it is contingent on the enforcement of another substantive right (e.g., in *Ḉam*, the right to education).

The elaboration by the ECtHR of the right to be provided with a reasonable accommodation is still in its infancy. However, both the CRPD Committee and the ECtHR conceptualize reasonable accommodation as "quintessentially individualized".[7] This is well exemplified by the ECtHR's statement in *Glor* that recognizes "special forms of civilian service *tailored* (emphasis added) to the needs of people in the applicant's situation are perfectly envisageable" (ECtHR, 2009, para. 95). This approach is

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[6] In the latter case, as suggested by Lord & Brown (2011) and by Lawson (2012), the ECtHR acknowledged that reasonable accommodation is an essential element to protect human dignity and prevent inhuman treatment, even though it did not place it in the realm of the equality norm. Ms Price, who had a serious kidney condition, was sentenced to three nights in custody. During her stay in prison she was kept in inadequate cell, and she had serious difficulties in using toilets facilities which substantially aggravated her physical condition. The ECtHR stated that the conditions in which Ms Price was held amounted to degrading treatment, and addressed the failure to accommodate the needs of MS Price as woman with disability in a prison setting. A similar approach has been taken in subsequent cases, such as *Jasinskis v. Latvia* (ECtHR, 2010) and *Grimailovs v. Latvia* (ECtHR, 2013b), which also cite the CRPD. In all these cases, reasonable accommodation is considered an element inherent to the application of Article 3 of the ECHR which prohibits torture and inhuman and degrading treatment or punishment. This approach is similar to the one adopted by the CRPD Committee in *X v Argentina* and sits well with the interpretation given to Article 14(2) CRPD.

[7] This expression is used by Gerard Quinn (Quinn, 2007).

confirmed by the recent case of *Kacper Nowakowski v Poland* (ECtHR, 2017), in which the Court considered (to a very limited extent and somewhat implicitly) the role of reasonable accommodation and referred to the specific needs of persons with disabilities. The case concerned the rights of a Deaf father to contact his son, who also had a hearing impairment. Mr. Nowakowski, the applicant, complained that the dismissal of his request to extend contact with his son had been solely on the ground of his disability and had been discriminatory. He alleged the violation of Article 8 (right to respect for private and family life) and Article 14 (prohibition of discrimination) of the ECHR. The ECtHR decision focused on Article 8, rather than on Article 14. When deciding the case, the ECtHR examined the reasons that led national courts to dismiss Mr. Nowakowski's request. The Strasbourg court highlighted that Polish courts involved the child's mother in the contact arrangements, since she was able to communicate both orally and in sign language. However, this solution ignored the existing animosity between the parents and the frequent complaints by the applicant that the mother had attempted to obstruct contact and to marginalise his role. The Court, considering the specific factual situation, held that the applicant and his child would have required more time than would be the case in a normal situation. It stated that the dismissal of Mr. Nowakowski's application for extension of contact meant that the applicant kept his right to two hours of contact per week in the presence of the child's mother. The ECtHR went on to affirm that:

> The domestic courts should have envisaged additional measures, more adapted to the *specific* circumstances of the case….(emphasis added) Having regard to the specifics of the applicant's situation and the nature of his disability, the authorities were required to implement *particular* measures that took due account of the applicant's situation. The Court refers here to the second sentence of Article 23 § 2 of the CRPD, which provides that State Parties shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities. (ECtHR, 2017, para. 93)

However, similar to the CRPD's Committee, the Strasbourg court has so far refrained from giving specific guidance on what might constitute a reasonable accommodation. In *Çam*, the Strasbourg court affirmed:

> The Court is not unaware that every child has his or her specific educational needs, and this applies particularly to children with disabilities. In the educational sphere, the Court acknowledges that reasonable accommodation may take a variety of forms, whether physical or non-physical, educational or organisational, in terms of the architectural accessibility of school buildings, teacher training, curricular adaptation or appropriate facilities. That being the case, the Court emphasises that it is not its task to define the resources to be implemented in order to meet the educational needs of children with disabilities. The national authorities, by reason of their direct and continuous contact with the vital forces of their countries, are in principle better placed than an international court to evaluate local needs and conditions in this respect. (ECtHR, 2016a, para. 66)

Similarly, in *Kacper Nowakowski v Poland* the ECtHR held that it was up to the national court to identify suitable accommodations:

> The domestic courts' duty, in cases like the present one, is to address the issue of what steps can be taken to remove existing barriers and to facilitate contact between the child and the non-custodial parent. However, in the instant case they failed to consider any means that would have assisted the applicant in overcoming the barriers arising from his disability. (ECtHR, 2017, para. 95)

Both the CRPD Committee and the ECtHR leave States Parties (and national authorities) with a wide margin of appreciation in determining what kind of accommodations might be reasonable (i.e., effective in the particular situation). Some additional indication of what might constitute a reasonable accommodation within the scope of the European human rights system could have been provided in *Bayrakcı v Turkey* (ECtHR, 2016c). The case concerned a disabled employee who alleged the lack of suitable toilet facilities installed at his workplace. The Court, however, declared the applicant's complaint inadmissible for failure to exhaust domestic remedies. In *I.B. v Greece*, the Court also missed an opportunity to elaborate on reasonable accommodation. As noted by Timmer (2013), the Strasbourg Court, in line with domestic courts, emphasized that the applicant's health status had not diminished his work capacity, but carefully avoided considering whether reasonable accommodations might be necessary for persons with HIV-related illness to carry out their work.

Finally, the ECtHR has not yet been directly confronted with procedural aspects, and has, thus far, been unable to elaborate on the "disproportionate or undue burden" limit. The CRPD Committee still offers limited guidance in this respect, but, arguably, the forthcoming General Comment No. 6 on the right of persons with disabilities to equality and non-discrimination has the potential to stimulate cross-fertilization between the ECHR and the CRPD. The CRPD's Committee has identified implementation gaps with regard to Article 5 of the CRPD and intends to clarify, among others the concept of substantive equality and the limits, processes and duties relating to the provision of reasonable accommodation (CRPD Committee, 2017b). It is expected that additional synergies might occur between the CRPD Committee's work and the ECtHR case law.

5. Conclusion

In 2011, Brown and Lord argued that the CRPD and its complaint mechanism should rouse and stimulate "the somewhat sluggish development" of the concept of reasonable accommodation in the ECtHR and other regional systems (Brown & Lord, 2011, p. 273). Seven years after the release of their paper, it seems that indeed the CRPD and the jurisprudence of the CRPD Committee have prompted an evolution in the understanding of the concept of equality and non-discrimination in the European human rights system. As this short article has attempted to show, the Strasbourg court case law gradually adopted the concept of reasonable accommodation as set out in the CRPD. As well explained by Waddington and Broderick (2017, p. 12), reasonable accommodation "is *an individualised* response to the particular needs of *an individual with disabilities* to ensure equal opportunities" (emphasis added), and the ECtHR has clearly and unequivocally embraced this view. The Strasbourg judges, by referring to the CRPD, have recognized that reasonable accommodation is an essential element in removing specific barriers or disadvantages to which a particular disabled individual would otherwise be subject. Campos Velho notes that in the CRPD the role of reasonable accommodation is conceptually linked to the prevention and elimination of segregation, humiliation and stigma (Campos Velho Martel, 2011, p. 103). This approach seems to have been at least partially adopted by the ECtHR, especially in *Ćam* and *Guberina*.

There is still a long way to go before the cross-cutting application of reasonable accommodation can be assured in practice. There are also several procedural aspects to be unveiled and explored, especially when it comes to the adoption and choice of a specific accommodation and to the disproportionate burden limit. However, the ECtHR and the CRPD Committee will most certainly have the possibility to elaborate further on these aspects, stimulating new synergies and convergences.

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Conflict of Interests

The author declares no conflict of interests.

References

Banks, K. (2016). Reasonable accommodation as equal opportunity in Canadian employment law. In R. Blanpain & F. Hendrickx (Eds.), *Reasonable accommodation in the modern workplace. Potential and limits of the integrative logics of labour law* (pp. 27–25). Alphen aan den Rijn, The Netherlands: Kluwer Law International.

Broderick, A. (2015a). *The long and winding road to equality and inclusions for persons with disabilities*. Antwerp, The Netherlands: Intersentia.

Broderick, A. (2015b). A reflection on substantive equality jurisprudence: The standard of scrutiny at the ECtHR for differential treatment of Roma and persons with disabilities. *International Journal of discrimination and the Law*, *15*(1/2), 101–122.

Brown, R., & Lord, J. (2011). The role of reasonable accommodation in securing substantive equality for persons with disabilities: The UN Convention on the Rights of Persons with Disabilities. In M. H. Rioux, L. Basser, & M. Jones (Eds.), *Critical perspectives on human rights and disability law* (pp. 273–307) Leiden and Boston: Martinus Nijhoff/Brill Academic. Campos Velho Martel, L. de (2011). Reasonable accommodation: The new concept from an inclusive constitutional perspective. *International Journal on Human Rights*, *8*(14), 84–110.

Cera, R. (2017). Article2: Definitions. In V. Della Fina, R. Cera, & G. Palmisano (Eds.), *The United Nations Convention on Human Rights: A commentary* (pp. 107–118). Cham: Springer.

Committee on the Rights of Persons with Disabilities. (2012). *H.M. v Sweden* (Communication No. 3/2011).

Committee on the Rights of Persons with Disabilities. (2014a). *X v Argentina* (Communication No. 8/2012).

Committee on the Rights of Persons with Disabilities. (2014b). *General Comment No. 2 on Accessibility* (UN Doc. CRPD/C/GC/2).

Committee on the Rights of Persons with Disabilities. (2014c). *Marie-Louise Jungelin v Sweden* (Communication No. 5/2011).

Committee on the Rights of Persons with Disabilities. (2015). Guidelines on Article 14 of the Convention on the Rights of Persons with Disabilities. Retrieved from http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx

Committee on the Rights of Persons with Disabilities. (2016a). *General Comment No. 3 Article 6: Women and girls with disabilities* (UN Doc. CRPD/C/GC/3).

Committee on the Rights of Persons with Disabilities. (2016b). *General Comment No. 4 on Article 24: Right to inclusive education* (UN Doc. CRPD/C/GC/4).

Committee on the Rights of Persons with Disabilities. (2016c). *Michael Lockrey v Australia* (Communication No. /2011).

Committee on the Rights of Persons with Disabilities. (2016d). *Gemma Beasley v Australia* (Communication No. 11/2013).

Committee on the Rights of Persons with Disabilities. (2017a). *General Comment No. 5 Article 19: Living independently and being included in the community* (UN Doc. CRPD/C/18/1).

Committee on the Rights of Persons with Disabilities. (2017b). Call for submissions: Draft General Comment on the right of persons with disabilities to equality and non-discrimination (article 5). Retrieved from http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CallPersonsDisabilitiesEqualityResponsability.aspx

De Schutter, O. (2005). Reasonable accommodations and positive obligations under the European Convention on Human Rights. In A. Lawson & C. Gooding (Eds.), *Disability rights in Europe: From theory to practice* (pp. 35–63). London: Hart Publishing.

European Court of Human Rights. (1998). *Botta v Italy* (153/1996/772/973).

European Court of Human Rights. (2001). *Price v UK*, Application No. 33394/96.

European Court of Human Rights. (2009). *Glor v Switzerland*, Application No. 13444/04.

European Court of Human Rights. (2011). *Kiyutin v Russia*, Application No. 2700/10.

European Court of Human Rights. (2013). *I.B. v Greece*, Application No. 552/10.

European Court of Human Rights. (2016a). *Cam v Turkey*, Application No. 51500/08.

European Court of Human Rights. (2016b). *Guberina v Croatia*, Application No. 23682/13.

European Court of Human Rights. (2016c). *Bayrakcı v Turkey*, Application No. 2643/09.

European Court of Human Rights. (2017). *Kacper Nowakowski v. Poland*, Application No. 32407/13.

Favalli, S. (2018). The United Nations Convention on the Rights of Persons with Disabilities in the case law of the European Court of Human Rights and in the Council of Europe Disability Strategy 2017–2023: 'From zero to hero'. *Human Rights Law Review*.

Ferri, D. (2014). Legal scholarship and disability in Italy. Recent developments and new perspectives. In L. Waddington, G. Quinn, & E. Flynn (Eds.), *European yearbook of disability law* (pp. 129–151). Antwerp: Intersentia.

Ferri, D. (2017). L'accomodamento ragionevole per le persone con disabilità in Europa: Da Transatlantic Borrowing alla Cross-Fertilization. *Diritto Pubblico Comparato ed Europeo*, *2*, 381–420.

Ferri, D., & Lawson, A. (2016). *Reasonable accommodation for disabled people in employment contexts*. Luxembourg: Publications Office of the European Union.

Harpur, P. (2012). Embracing the new disability rights paradigm: The importance of the Convention on the Rights of Persons with Disabilities. *Disability & Society*, *27*(1), 1–14.

International Labour Office. (2016). *Promoting diversity and inclusion through workplace adjustments: A practical guide*. Geneva: ILO.

Jolls, C. (2001). Antidiscrimination and accommodation. *Yale Law School*. Retrieved from http://digitalcommons.law.yale.edu/cgi/viewcontent.cgi?article=2413&context=fss_papers

Kayess, R., & French, P. (2008). Out of darkness into light? Introducing the Convention on the Rights of Persons with Disabilities. *Human Rights Law Review*, *8*(1), 1–34.

Lawson, A. (2007). The United Nations Convention on the Rights of Persons with Disabilities: New era or false dawn? *Syracuse Journal of International Law and Commerce*, *34*, 563–620.

Lawson, A. (2008a). People with psychosocial impairments or conditions, reasonable accommodation and the convention on the rights of persons with disabilities. *International Trends in Mental Health Laws*, *26*(2), 62–84.

Lawson, A. (2008b). *Disability and equality law in Britain: The role of reasonable adjustment*. Portland, USA: Hart Publishing.

Lawson, A. (2009). The UN convention on the rights of persons with disabilities and European disability law: A catalyst for cohesion? In O. Arnardottir & G. Quinn (Eds.), *The United Nations Convention on the Rights of Persons with Disabilities: European and Scandinavian perspectives* (pp. 81–110). Leiden, The Netherlands: Martinus Nijhoff.

Lawson, A. (2012). Disability equality, reasonable accommodation and the avoidance of ill-treatment in places of detention: The role of supranational monitoring and inspection bodies. *The International Journal of Human Rights*, *16*(6), 845–864.

Lawson, A. (2017). Reasonable accommodation in the Convention on the Rights of Persons with Disabilities and non-discrimination in employment: Rising to the challenges? In C. O'Mahony & G. Quinn (Eds.), *Disability law and policy: An analysis of the UN Convention*. London: Clarus Press.

Mégret, F., & Msipa, D. (2014). Global reasonable accommodation: How the convention on the rights of persons with disabilities changes the way we think about equality. *South African Journal on Human Rights*, *30*(2), 252–274.

Ngwena, C. G. (2013). The human right to inclusive education: Exploring a double discourse of inclusive education using South Africa as a case study. *Netherlands Quarterly of Human Rights*, *31*, 473–504.

Office of the United Nations High Commissioner for Human Rights. (2010). *Equality and non-discrimination under article 5 of the Convention on the Rights of Persons with Disabilities* (UN Doc. A/HRC/34/26).

Quinn, G. (2007). Disability discrimination law in the European Union. In H. Meenan (Ed.), *Equality law in an enlarged European Union. Understanding the Article 13 Directives*. Cambridge: Cambridge University Press.

Rosen, S. (1991). Disability accommodation and the labor market. In C. Weaver (Ed.), *Disability and work* (pp. 18–30). Washington, DC: American Enterprise Institute.

Seatzu, F. (2014). Does the European Convention on Human Rights protect the disabled? In *Annuaire International des Droits de l'Homme* (pp. 397–420). Strasbourg: Sakkoulas.

Stein, M. A., & Lord, J. E. (2009). Future prospects for the United Nations Convention on disability. In G. Quinn & O. M. Arnardottir (Eds.), *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (pp. 17–64). Leiden, The Netherlands: Brill.

Timmer, A. (2013), HIV-based employment discrimination: The ECtHR takes a strong stance in *I.B. v. Greece*. Retrieved from https://strasbourgobservers.com/2013/10/21/hiv-based-employment-discrimination-the-ecthr-takes-a-strong-stance-in-i-b-v-greece/#more-2160

UN. (2016). *Convention on the Rights of Persons with Disabilities*. Retrieved from www.un.org/disabilities/documents/convention/convoptprot-e.pdf

Waddington, L. (2011). Reasonable accommodation. Time to extend the duty to accommodate beyond disability? *NTM|NJCM-Bulletin*, *36*(2), 186–198.

Waddington, L., & Broderick, A. (2017). *Promoting equality and non-discrimination for persons with disabilities*. Strasbourg: Council of Europe Publishing.

Waddington, L., & Lawson, A. (2018). *The United Nations Convention on the Rights of Persons with Disabilities in practice: A comparative analysis of the role of courts*. Oxford: Oxford University Press.

Willborn, S. L. (2016). Reasonable accommodation in the United States. In R. Blanpain & F. Hendrickx (Eds.), *Reasonable accommodation in the modern workplace. Potential and limits of the integrative logics of labour law* (pp. 9–26). Alphen aan den Rijn, The Netherlands: Kluwer Law International.

WHO, & World Bank. (2011). *World report on disability*. Retrieved from http://www.who.int/disabilities/world_report/2011/report.pdf

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Article

Disability, Access to Food and the UN CRPD: Navigating Discourses of Human Rights in the Netherlands

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Abstract
In 2016, the Netherlands ratified the UN Convention on the Rights of Persons with Disabilities (UN CRPD), one of the last developed nations to do so. In this article, we explore how equal access to food provides a lens through which barriers to implementing a rights-based approach to disability equality can be examined in countries that are historically resistant to such discourses. Through a literature review, policy research, and interviews with disabled people, representatives of disabled people's organisations, Dutch legal scholars, food researchers, and foodbanks, we have explored barriers to equal food access in the Netherlands, and current approaches to overcoming social, economic and physical barriers. Our analysis indicates that implementation of the UN CRPD and other relevant international and EU policies continues to be limited in the Netherlands due to narrow interpretations, leading to policies and practices that do not foster equal access to resources and environments. Dutch understandings of disability equality are evolving, but encounter opposition from an entrenched system of separation and resistance to mandating change, including a reluctance to even collect data about inequality. From this basis, we identify knowledge gaps and make recommendations for steps the Netherlands could take to ensure equal access to food.

Keywords
accessibility; disability; economic rights; food; human rights; social rights

Issue
This article is part of the issue "Disability Equality: In Theory and Practice", edited by Mark Priestley (University of Leeds, UK) and Lisa Waddington (Maastricht University, The Netherlands).

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1. Introduction

In 2016, the authors evaluated an annual campaign to improve disability access in the Netherlands, the *Week van de Toegankelijkheid* ('Accessibility Week'). The campaign was sponsored by Ieder(in), a network of Dutch disability groups. Every year the week has a theme, and in 2016 it was access to dining out and eating together. Our evaluation began with a literature review. We found ample literature related to the primary issue of access to cafés and restaurants, ranging from reports written by Disabled Peoples' Organisations (DPOs, for example, GehandicaptenPlatform Venray, 2014) to the Dutch building code's accessibility rules for restaurants and other public spaces (Koninkrijk der Nederlanden, 2012). We conducted 16 semi-structured interviews with leaders and members of disability groups and disabled people, who helped us identify issues to explore further.

While Ieder(in)'s 2016 campaign concentrated on dining out, we had concerns that for many disabled people in the Netherlands, there were problems with access to food that went beyond physical access to restaurants. We therefore decided to look at access to food more broadly and at a deeper level. Our methodology included an additional 25 semi-structured interviews with disabled people, members and leaders of DPOs, and policymakers; additional brief informal interviews; and observations, including visits to eating establishments with DPOs.

We began by interviewing people who were part of groups involved in the Ieder(in) network and its original accessibility project, deliberately choosing to speak to people with a broad cross-section of physical and intellectual/developmental disabilities, from rural, suburban and urban areas. To this base we added contacts suggested by initial interviewees, and then sought out people with disabilities and members of DPOs who were not part of the Ieder(in) network but could offer perspectives from disabled people who had not previously been represented in the first or second sample, such as people with autism and young disabled activists. We also sought interviews with Dutch academics who were actively researching the right to food and food banks, and national and regional policymakers, to gain a systemic view. Finally, we conducted interviews with food-related service providers to learn more about their practices regarding food provision and people with disabilities.

We did face some limitations based on the sample available. Because we began the research as part of a project run by a network of DPOs and disability service organisations, the people with disabilities interviewed tended to be those who were members of DPOs. These ranged from small local groups to large national advocacy organisations, but the views and experiences of these individuals may not be representative of all Dutch people with disabilities. In particular, very few of our respondents resided in supported living or institutional care.

2. Literature Review

Access to adequate food is necessary for human survival. It has therefore been enshrined in international policies as a human rights issue, particularly in Article 25 of the Universal Declaration of Human Rights and Article 11 of the International Covenant on Economic, Social and Cultural Rights (ICESCR; Hospes & van der Meulen, 2009). The right to adequate food is also recognised in the food security guidelines of the UN Food and Agriculture Organisation (FAO Council, 2004); Article 28 of the UN Convention on the Rights of Persons with Disabilities (UN CRPD); Articles 11 and 12 of the UN Convention on the Elimination of All Forms of Discrimination Against Women, and Article 24 of the Convention on the Rights of the Child (Golay & Özden, 2012); and as an "indispensable right" in the Declaration of the Rights of Indigenous Peoples (Knuth, 2009).

The constitutions of a few EU countries recognise the right to a "decent'' or ''adequate'' standard of living, which implicitly includes access to adequate food, as a basic human right. This list currently includes the Czech Republic, Romania, Germany and the Netherlands. The right to the means to live a "dignified" life, also implicitly including access to adequate food, is recognised in Belgium, Finland and Malta (Knuth & Vidar, 2011). Access to food and food security issues are increasingly on the European Union's agenda as well, although pronouncements are typically geared towards the EU's role in alleviating famine and malnutrition outside Europe (for example, European Commission, 2013). The right to food is indirectly supported by Article 4(1) and other sections of the European Social Charter (Just Fair, 2014). Most recently, the "right to adequate minimum income benefits ensuring a life in dignity at all stages of life, and effective access to enabling goods and services," implicitly including adequate food, has been included in the European Pillar of Social Rights (European Parliament, Council of the European Union, & European Commission, 2017, p. 20), which further states that "people with disabilities have the right to income support that ensures living in dignity" (p. 21).

Worldwide, people with disabilities are more likely than people without disabilities to encounter barriers to adequate food (Conference of States Parties to the Convention on the Rights of Persons with Disabilities, 2015). The quantity and quality of food that disabled people can access may be limited by these barriers, even in developed Western countries (Webber, Sobal, & Dollahite, 2007). Inadequate access to food can also produce disability through the long-term effects of malnutrition, or exacerbate existing disability (Groce et al., 2014). Access barriers include physical barriers, attitudinal barriers, differential treatment, and inadequate information (de Jong et al., 2013). Impaired capacity, lack of support to prepare food or eat, lack of adequate income, lack of transportation or other help to obtain food, being unable to enter and use public eating establishments, or feeling unwelcome in public situations involving food (cafés, restaurants, public celebrations and events) can impact access (Webber et al., 2007).

Traditionally, the food needs of people with disabilities in the Netherlands have been addressed through state income-transfer programmes or charities. However, in July 2016 the Netherlands ratified the UN CRPD, marking a first step towards a rights-based approach to disability equality, which is predicated on seeing people with disabilities as active members of society who are empowered to claim the same rights as others rather than a socially protected class dependent on medical or charity support (Kayess & French, 2008).

2.1. Access to Food for Disabled People in Developed Countries

It is clear that having a disability often impacts access to food, including in developed countries. However, we found almost no research on whether the Netherlands is an exception to this rule, despite court rulings that have claimed this is the case (Hospes & van der Meulen, 2009).

The experiences of disabled people in other developed countries, such as the United Kingdom and Canada, indicate that *food poverty* is a significant issue for disabled people (e.g., Vozoris & Tarasuk, 2003). For example, in the UK, people with long-term illnesses or disabilities form the largest group of individuals who require help from foodbanks to survive (New Economic Models in the Digital Economy Group, University of Hull, & The Trussell Trust, 2016). Malnutrition is believed to affect at least three million people in the UK: residents of care homes and people with an intellectual disability are high-risk groups (Andalo, 2014). There have even been cases of British disabled people dying in circumstances where malnutrition was a factor or perhaps even the cause (for example, Gentleman, 2014), due to benefit sanctions.

People with disabilities are often reliant on state income assistance programmes. The Netherlands, like most other developed countries, has cut disability benefits in recent years and introduced increased conditionality. While concern has been raised about how this may impact disabled peoples' access to food (Hospes & van der Meulen, 2009), we did not find any research on this topic. However, Riches and Silvasti (2014) note that food budgets are usually the only part of poor people's spending that is "elastic": housing, utilities, and healthcare costs cannot be cut by the consumer, who is then faced with dilemmas such as "heating or eating."

The EU defines food poverty as being unable to afford a meal with meat, chicken, fish or vegetarian equivalent, every second day. Across the EU, the average for food poverty among disabled people was 16.1%, compared with 7.5% of non-disabled people of similar age. Amongst people aged 65+, the average EU food poverty rate was lower: 6.8% amongst disabled seniors, though still double when compared with 3.3% of non-disabled seniors (Eurostat, 2016). However, Eurostat's statistics do not include people living in collective households or institutions. Adults living in congregate supported housing or institutional settings, and adults who cannot afford their own apartment in a country like the Netherlands, where rents are very high, will include a large number of disabled people.

For disabled people in institutional settings, food choice may be limited when group meals are served to save money, when group provision is preferred due to government or corporate policy, when food choices are limited or unhealthy, or when inadequate help is provided for residents who need assistance to eat. For example, in one study, Dutch government policy was found to push small, parent-initiated residences for adults with intellectual or developmental disabilities to serve group meals rather than to support individuals to cook for themselves (Reindl, Waltz, & Schippers, 2016). In another, access to kitchen facilities in a large rehabilitation center for young disabled adults was curtailed in favour of residents taking meals in a café setting (Waltz, Speelmans, & Cardol, 2016). In the latter case, the main choices available were often fried or processed foods.

Other researchers have described so-called *food deserts* where access to food may be primarily via small convenience shops or fast-food outlets, with higher food costs and less healthy, nutritious food available. Webber, Sobal and Dollahite (2007) show how disability, income, and location combine to limit access to adequate food in the United States. Access to grocery shopping may also be affected by sensory or physical disabilities or sensory-perceptual issues experienced by people with autism.

Getting practical support from family and friends can be more problematic for people who are isolated from social networks. Lack of accessible transport, not being able to travel alone, and being denied access to settings were experiences that resonated with some disabled people we spoke with. For example, one young man from a small Dutch town described trying to enter a bar with friends, but being refused entry by the doorman because of his walking frame, even though a friend in a wheelchair was allowed to enter (personal communication, October 2016). Unequal treatment and discrimination can be significant barriers to access.

2.2. Disability and Poverty

Palmer (2011) outlines different ways of conceptualising poverty and disability and shows how the two intersect, "each a cause for and a consequence of the other" (p. 210). Palmer found no single factor responsible for poverty, but rather an interconnected web of factors, such as disability, socioeconomic status and geographical location. In high-income countries, the employment rate of people with disabilities is usually much lower than the rest of the working-age population, and for households including a person with a disability, informal caregiving becomes an additional financial cost for the household (Palmer, 2011).

Wolbring and Mackay (2014) point out that disabled people are rarely mentioned in food security news coverage in North America or the UK. They found no existing studies on media coverage of disability and food security. They also found that in Canada, most reports contained no data on disabled people experiencing food insecurity, even though some other social groups were included (Wolbring & Mackay, 2014). Similarly, other minority groups, such as immigrants and indigenous people, were also often missing from media coverage of food security. The authors concluded: "From a disability studies perspective, increasing the visibility of the food security problems disabled people face is needed but for them to be actively involved in the discussion around food security many barriers have to be removed" (Wolbring & Mackay, 2014, p. 22).

There is a similar knowledge gap within data collection in the Netherlands. Foodbanks collect information on age, gender, marital status, single parents, and length of foodbank use, but not disability. In 2016 Voedselbanken Nederland noted that there was increased "diversity" in its client base, lumping "people with chronic illness" in with self-employed people, people with debts, and small business owners (Voedselbanken Nederland, 2016).

2.3. Benefits and Access to Food

Changes to benefits levels and eligibility have had a major impact on how much money disabled people in the Netherlands have to spend on food; in addition, food prices have risen at more than twice the rate of inflation: as of June 2017, 2.7% versus 1.1% (OECD, 2017). Foodbanks in the Amsterdam area reported in 2015 that, following a policy cutting benefits by 30% when two or more people share an address (for example, flatmates or partners), they saw a huge increase in new clients. Up to 7000 residents were said to be unable to cover their food costs anymore because of this change (AT5, 2015).

In the past two years, increases have been under 1% per year: in other words, the income of benefit recipients has decreased relative to inflation (Rijksoverheid, 2015, 2016a). This means that benefits have not kept up with increased costs, including both higher food prices and extra costs borne by people who have a disability, in areas like transportation, equipment and healthcare. In addition, eligibility for benefits has been increasingly tightened and made more conditional in the past two decades, especially for claimants under age 50 (Droepping, Hvinden, & van Oorschot, 2000; OECD, 2007, 2014).

2.4. Food Poverty in the Netherlands

We found very little literature about food poverty in the Netherlands. A notable exception was van der Horst, Pascucci and Bol's (2014) work on the experiences of foodbank users. These authors found that the emotional impact of foodbanks is under-investigated. They argued that receivers are forced to dismiss personal food preferences and norms about how to obtain food. In addition, when the interactions are framed as charitable giving, this can cause negative emotions such as shame: "Shame is not just considered an effect of poverty, it is even being seen as one of the causes for the persistence of poverty, even across generations" (van der Horst et al., 2014, p. 1509). They suggest further study of these human interactions in order to understand charitable giving and the emotional impact of unequal relations between giver and recipient, in order to change the relationship.

MUG, an Amsterdam-based free magazine for benefit claimants and low-wage workers, has consistently highlighted issues regarding foodbanks, including unfamiliar foods such as goose meat, vegetables removed from supermarkets due to boycotts, and expired food being given away in food packets (*MUG Magazine*, n.d.). Additional critical literature on the foodbank approach to food poverty includes Riches (2002), Riches and Silvasti (2014), Tarasuk and Eakin (2005) and Bol (2010).

2.5. Legal and Policy Environment Regarding the Right to Food in the Netherlands

Hospes and van der Meulen (2009), Wernaart (2013) and Wernaart and van der Meulen (2016) provide information about UN, EU and Dutch policy and legal frameworks regarding the right to food. These authors note that although the Netherlands has ratified many UN treaties that include access to food as a basic human right, and is also subject to similar EU laws and policies, there is no legal remedy for people whose right to food has been limited, such as asylum seekers with no right to state support and no right to work. There is an assumption, these authors say, that no one in in the Netherlands goes hungry, and that any exceptions can be diverted towards charities.

2.6. Other Access to Food Issues in the Netherlands

The Netherlands has a high percentage of disabled people living in various forms of institutional care compared to most other EU countries. There is a good understanding of disability-related dietary needs in many facilities (Beukers, 2013), but as noted earlier, institutions usually offer residents little or no choice about what, when or where they eat.

Research has also found a clear correlation between nutritional status and education level, with those who have no or primary education, a category that would include more disabled people than other levels, eating significantly less fruit, vegetables, and fish than those with higher levels of education (Geurts, Beukers, & van Rossum, 2013). Although the Dutch government collects statistics on nutritional differences between ethnic groups and age groups, it does not collect statistics about the nutritional status of disabled people (Volksgezondheidenzorg, 2017).

We are aware that individual patients/clients and self-advocacy groups have lodged complaints about food-related issues in recent years (Stichting Geschillencommissies voor Consumentenzaken, 2017). However, we did not find research that specifically examined food choice, quality or access in Dutch institutions for disabled people.

2.7. Accessibility of Food Information

There is little research about people with intellectual disabilities, access to nutrition information, and support for healthy eating in the Netherlands. For people with an intellectual impairment, it can be difficult to understand and discuss health and nutrition issues (de Winter, Jansen, & Evenhuis, 2011). Technology could be helpful, such as the online application 'MeMaatje,' which can be used to schedule exercise and healthy meals, and helps users reflect on their choices. Researchers found that 75% of users with a disability were satisfied with the app and found it user-friendly or somewhat user-friendly (Oostland-Sikkema & Smit, 2014). However, in this study, caretakers noted that many users were unable to tell time and/or read texts and were therefore unable to use the application's diary feature. Caretakers also commented that confusion had arisen from images used in the application: if the foods shown were not to the taste of the users, they might resist eating the meals (Oostland-Sikkema & Smit, 2014).

People with visual or hearing impairments can also face information barriers.

3. Results

3.1. Barriers and Facilitators

During the evaluation project, we observed many activities focused on access to eating out throughout the Netherlands. We also spoke to many individuals who dealt with the question of accessibility every day regarding their experience with local cafes and restaurants. Our respondents differentiated between physical accessibility and social accessibility. Usually, the first barriers mentioned were physical: is it possible for everyone to enter the facility? Am I able to move around freely? Is there an accessible toilet? Next, respondents typically commented on the atmosphere, including lighting and sound, and the attitude of staff towards disabled patrons. Respondents then highlighted the social experience of going out for a meal. The majority of people spoke about the quality of their company, the meal itself, the feeling of togetherness. People described positive experiences they had whilst eating out: someone offered to help them use a ramp, a waiter offered to cut their meat for them. Positive experiences were noticeably connected to social or emotional impacts. We also observed ways that establishments sought to minimise barriers to access whilst accompanying disabled people who were visiting or performing access audits on local eating establishments, including assisting people with buffets, reading menus to blind patrons, and using portable ramps to permit access to historic buildings used as restaurants.

Negative experiences, on the other hand, were mostly connected to physical barriers. Respondents offered two examples of a wheelchair-accessible toilet being promised, but not available. One turned out to be used as a storage facility, the other 'accessible' toilet was downstairs in a basement. We also observed physical barriers to access when accompanying disabled people who were performing access audits on local eating establishments. These included inaccessible toilets, buffets and bars that were too high for small people or wheelchair users to access, crowded layouts, and lack of entrance ramps.

When asked what a 'perfect' accessible restaurant would be like, almost every respondent described the same restaurants they already enjoy, but with an emphasis on the attitude of the staff. If the staff is friendly and helpful, respondents noted, barriers to access can often be overlooked or overcome.

Our interviews indicated that, while absolute food poverty was not an issue for those we spoke with, there were a number of access issues. These included access to grocery stores, cafes and restaurants, menus, and restaurant websites.

3.2. Foodbanks and Disability in the Netherlands

Voedselbank Nederland is a national association that sets guidelines on how foodbanks throughout the Netherlands should be run. Individual foodbanks are able to adjust these guidelines when managing their programmes. Voedselbank Nederland recommends that branches provide food parcels to an individual for up to three years; this is related to the length of the Dutch debt-relief programme. Once accepted, a recipient has the right to food parcels for six months, after which another meeting takes place to reassess their situation (personal communication, September 2016).

Voedselbank Nederland publishes data on recipients, including gender, marital status, and whether or not they have children. However, they do not keep track of how many recipients have a disability. Several local foodbanks were asked for data regarding the number of clients with a disability. All that responded explained that they also do not keep track of these figures. Four foodbanks said they were aware of distributing to several clients with a disability, whereas two responded that they were unaware of any clients with a disability (personal communications, local foodbanks and Voedselbanken Nederland, September 2016).

One foodbank responded that they know of some clients who are "mentally challenged" (personal communication, September 2016), but they were unsure of whether to describe them as disabled. An expert who has carried out research on the use of foodbanks in the Netherlands (van der Horst et al., 2014) offered possible reasons for the lack of data on disability in the Netherlands, particularly when it comes to foodbanks:

> I wonder whether they may have a clear concept of what a disability would be. In my time [observing in foodbanks] I have not seen people with wheelchairs or (visibly) blind or deaf people. But one of the higher-up people I spoke to divided the population [of foodbank users] into a few bigger chunks. One of these was people who don't have the mental capacity to manage in modern society. Maybe people who don't understand the concept of credit. One example was somebody who took an advertisement for a phone literally—"zero euros"—and ended up in debt….Things such as depression or substance abuse, and how they might affect your ability to earn or manage your finances. (van der Horst, personal communication, January 2017)

Recipients with disabilities were further discussed during an in-depth interview with the intake coordinator of one

Dutch foodbank that has been in operation since 2014. Currently, it provides parcels for around 60 recipients per month. The coordinator said they do not collect information about recipients' disability status because "we don't believe it matters" (personal communication, September 2016). They estimated that between one-fourth and one-third have a visible physical or intellectual disability. Additionally, the coordinator explained that clients are often sent to them from mental health or addiction services and other organisations; the foodbank also refers recipients to support providers as needed.

Clients with mobility impairments may struggle to travel to the distribution point or carry their parcel home. Workers at two food-parcel distribution points said they were accessible for wheelchairs and mobility scooters, and added that several clients use adapted vehicles (personal communication, September 2016). One foodbank representative said they arrange deliveries for clients who are unable to pick up their parcels due to a disability or illness (personal communication, September 2016).

An expert further noted that clients with certain disabilities might be categorised as "unworthy receivers" due to their behaviour or attendance:

> The foodbank mimics the state welfare system in many ways, even though it is a private charity—it sets up rules, criteria and forms, and you need to be referred. I think there is also a concern that if receivers do not come to pick up their food, they may not actually be in need. But there are plenty of reasons why people would not pick up their parcels. One of these might be that the food provided is not good, and not worth it. Another reason might be because the receiver is suffering from depression. (van der Horst, personal communication, January 2017)

One foodbank decided not to offer a delivery service for those clients unable to come to the distribution point. Its coordinator said that some clients would be likely to rely too much on the deliveries and come to abuse the service: "you are helping people, not pampering them," she commented. She noted that many recipients were able to find creative solutions amongst themselves. Clients with a car might offer to deliver a package to someone who was temporarily unable to come to the distribution point. However, she added, "public transport here is not well connected, so people do need to cross large distances by foot or bicycle." The coordinator also noted that sometimes recipients are banned from the facility due to bad behaviour, which may or may not be due to a mental condition. In these situations, the foodbank considers the issue to be beyond its scope (personal communication, September 2016).

In discussing the contents of a typical food parcel, it became clear that the food available is often dependent on what local retailers or producers donate. Sometimes this means that products are unusual, unfamiliar or difficult to cook. The foodbank coordinator explained that a local farm occasionally provides vegetables, some of which recipients complain about. This can create additional difficulties for someone with a disability, they admitted:

> I can imagine if you have a rheumatic condition, and we offer you celeriac, which I happened to be preparing the other day because we had a lot of them left over, and I was thinking to myself, 'what a lot of effort goes into preparing this.' In that case, there is nothing we can do, we're not able to prepare food in this space. (personal communication, September 2016)

Food parcels often include products past or close to their expiration dates. Typical consumer behaviour contains embodied taboos around eating expired food due to potential risks; however, foodbanks require their receivers to overcome these inhibitions (van der Horst et al., 2014). In addition, the inclusion of many fatty and sugary products can have an infantilizing effect, making receivers feel they are not perceived as adults who require healthy meals (van der Horst et al., 2014).

An expert explained that the expectation of gratitude from a foodbank receiver could be especially traumatic for people with disabilities. Receivers do not want to feel that they are personally responsible for circumstances out of their control. "*When it comes to a receiver with a disability, it may be that a caring approach is required, rather than a standardised approach. A young person who cannot cook can be taught to cook, but for other people, not being able to cook meals for themselves might be a static problem*" (van der Horst, personal communication, January 2017).

While Voedselbank Nederland's policy states that a client should be offered a regular parcel for no more than three years, one foodbank coordinator agreed that a client might need long-term assistance, and for this reason their organisation deviates from the national guideline. They explained that several clients, some with physical or intellectual disabilities, are recognised as needing food assistance for a longer period of time, perhaps indefinitely (personal communication, September 2016). Some of these clients might not receive the extended government support they have requested, and are therefore heavily dependent on the parcel they receive from the foodbank, she noted.

3.3. Other Food-Related Initiatives and Disability

When disabled people face functional limitations or external barriers, cooking meals or getting to a supermarket can be problematic, restricting access to healthy food. This might be addressed by daily food delivery services. However, these services do not allow much choice, limit social interaction, and can be costly. Some community-based projects in the Netherlands aim to improve access to food through other means. The online application 'Thuis Afgehaald' set out to connect people with amateur cooks in their neighbourhood so that they could buy and pick up home-cooked meals for an affordable price. As a branch of this service, the company set up 'Bijzonder Thuis Afgehaald' specifically for people who are not able to cook for themselves. This branch has currently connected 667 'vulnerable recipients' with home cooks (personal communication, February 2016).

The project manager of 'Bijzonder Thuis Afgehaald' explained that their service has made a difference in the eating habits of recipients. Many customers used to rely on microwave meals, sandwiches or fast food. "Research has shown that meals from our home cooks contain more fresh vegetables, pure products and little salt," she said (personal communication, February 2016). She provided the example of a home cook who prepares meals for a woman who has dementia:

> This cook prepares food five days a week for this woman and passes on updates to her daughter and granddaughter who live elsewhere. In the weekend, the relatives visit this woman, and during the week she receives professional care. The relatives are very happy to count on the home cook, who enjoys being able to help. (personal communication, February 2016)

The need for this service may reflect changes in the Dutch welfare system. The project manager noted that her team often receives requests from caregivers who are looking for meals and support for their parents. Many caregivers have discovered 'Bijzonder Thuis Afgehaald' through search engines or newspapers, rather than through professional referrals. She said this was "another nice example of the shift towards informal care" (personal communication, February 2016), but one can question whether such a shift is necessarily positive, as it produces inequalities based on access to information and social contacts.

Other initiatives include 'social restaurants' (volkskeukens or 'vokos') run by community groups.

3.4. Enforcing the Right to Food

We found that many disabled people hoped that the Netherlands' recent ratification of the UN CRPD would bring an end to differential and problematic treatment. However, we learned from an expert on the right to food and other social and economic rights that the Netherlands has not always implemented social-economic rights embedded in other UN treaties that it has ratified (Wernaart, personal communication, 2016). In 2013, a National Action Plan on Human Rights was presented by the Dutch government, which acknowledged the need for a more systematic approach (Rijksoverheid, 2016b). Interestingly, this report mentioned the right to food, but only in regards to prisoners and residents of Aruba (*op cit.*) Legal scholars are divided on whether the Netherlands should be considered a moderately or fully monistic country. While some hold that it is moderately monistic, and therefore that constitutional implementation of international law requires parliamentary approval and official publication (for example, Alkema, 2011), the majority view is that national courts can give direct effect to international law (Vlemminx & Meuwese, 2013). However, there is some reluctance to do so. For example, in the context of asylum seekers with neither a right to public support nor the right to work, the right to food has not been upheld in Dutch court cases. The only citation of the Netherlands' obligations regarding the right to food under UN treaties has so far been in cases regarding migrant children, with judicial rulings mentioning—but not relying on—the UN Convention on the Rights of the Child (Hospes & van der Meulen, 2009; Wernaart & van der Meulen, 2016). At this time, "the Dutch Courts unanimously reject direct effect of Article 11 ICESCR" as it is not seen as "binding on all persons" (Wernaart & van der Meulen, 2016, p. 87). Dutch courts also generally do not refer to EU laws unless these have specifically been incorporated into the Dutch legal code by Parliament.

Much will therefore depend on whether the Dutch state acts to fully incorporate the provisions of the UN CRPD into national legislation and policy, thereby creating a new area of enforceable, human-rights-based law. There has been a gradual, albeit slow, move in this direction over the past 20 years. Since 2011, human rights claims can be adjudicated by the College van de Rechten van de Mens (Netherlands Institute for Human Rights). Its decisions are non-binding, but contribute to jurisprudence.

4. Conclusion

Our research respondents highlighted the fact that experiences involving food, such as eating out and attending community events, are crucial locations for exclusion or inclusion. Access to adequate food is an even more critical issue, due to its impact on health and wellbeing. However, interviews with disabled people, experts, policymakers and foodbank personnel substantiated that many disabled people in the Netherlands face physical, social, attitudinal and/or economic barriers when accessing food and dining experiences. The scale of the problem is unknown, however, because the state and relevant institutions involved with food policy and provision do not collect data about disabled people and access to adequate food. It is clearly problematic for the state, foodbanks and other institutions to rely on assumptions and estimates.

While we found insufficient research on disabled peoples' access to food in the Netherlands, we uncovered evidence of barriers that affected the entire spectrum of access-to-food issues across all forms of disability. As noted, many disabled people in the Netherlands hope that ratification of the UN CRPD will lead to local and national policies that establish and enforce standards on accessibility and inclusion, including social and economic rights. In an era of austerity budgets across Europe, this may be an uphill battle.

5. Recommendations

Understanding the scope of barriers to adequate food for disabled people in the Netherlands will require research that investigates current nutritional intake differences between disabled and non-disabled people, accessibility and use of information about healthy eating, choice and control over meals (especially for those in institutional care), whether disability benefits are too low to permit access to adequate food, use of emergency food provision programmes and other charitable or non-state help services by disabled people, and physical, transport and support barriers that may affect the ability of disabled people to prepare and eat meals independently and access grocery stores and eating establishments. Research should also consider the impact of intersectionality, such as differential impacts on ethnic minorities or women who have disabilities. As Neihof (2013) has noted, care and care needs are gendered, and these often determine the ability of households to manage on the budget available in order to avoid food poverty.

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Conflicts of Interest

The authors declare no conflicts of interest.

References

Alkema, E. A. (2011). Netherlands. In D. Shelton (Ed.), *International law and domestic legal systems: Incorporation, transformation and persuasion*. Oxford: Oxford University Press.

Andalo, D. (2014, March 17). Malnutrition: It's time the UK public recognised it as a problem we face. *The Guardian*. Retrieved from https://www.theguardian.com/healthcare-network/2014/mar/17/malnutrition-uk-problem

AT5. (2015, July 30). Voedselbank vreest enorme toestroom nieuwe klanten. *AT5*. Retrieved from: http://www.at5.nl/artikelen/144759/voedselbank_vreest_enorme_toestroom_nieuwe_klanten

Beukers, D. (2013). Voeding en gehandicaptenzorg. *Nutrinews*, 2, 12–16. Retrieved from http://www.dietistvg.nl/downloads/literatuur/2013_NN_juni_gehandicaptenzorg.pdf

Bol, W. (2010). *Een voedselpakket: Mooi meegenomen?* (Masters thesis). Wageningen University, Wageningen, Netherlands.

Conference of States Parties to the Convention on the Rights of Persons with Disabilities. (2015). *Report of the Eighth Session*. New York: United Nations. Retrieved from: http://www.un.org/disabilities/documents/COP/cosp8_report_e.pdf

de Jong, J. M., den Exeter, A. P., & Hulst, E. H. (2013). *Economische gevolgen van ratificatie van het VN Verdrag Handicap*. Rotterdam: SEOR, Universiteit van Rotterdam. Retrieved from http://www.mensenrechten.nl/sites/default/files/Eindrapportage%20economische%20gevolgen%20VN%20verdrag%20Handicap%5B2%5D.pdf

de Winter, C. F., Jansen, A. A. C., & Evenhuis, H. M. (2011). Physical conditions and challenging behavior in people with intellectual disability: A systematic review. *Journal of Intellectual Disability Research*, *55*(7), 675–698.

Droepping, J. A., Hvinden, B., & van Oorschot, W.J.H. (2000). Reconstruction and reorientation: Changing disability policies in the Netherlands and Norway. *European Journal of Social Security*, *2*(1), 35–68.

European Commission. (2013). *Communication from the Commission to the European Parliament and the Council: Enhancing maternal and child nutrition in external assistance: An EU policy framework*. Brussels: European Commission. Retrieved from http://ec.europa.eu/europeaid/documents/enhancing_maternal-child_nutrition_ in_external_assistance_en.pdf

European Parliament, Council of the European Union, & European Commission (2017). *European Pillar of Social Rights*. Luxembourg: Publications Office of the European Union. Retrieved from https://ec.europa.eu/commission/sites/beta-political/files/social-summit-european-pillar-social-rights-booklet_en.pdf

Eurostat. (2016). *Statistics explained: People at risk of poverty or social exclusion*. Retrieved from http://ec.europa.eu/eurostat/statistics-explained/index.php/People_at_risk_of_poverty_or_social_exclusion

FAO Council. (2004). *Voluntary guidelines to support the progressive realization of the right to adequate food in the context of national food security*. Rome: FAO Council. Retrieved from http://www.fao.org/docrep/meeting/009/y9825e/y9825e00.htm

GehandicaptenPlatform Venray. (2014). *Bereikbaarheid, toegankleijkheid, bruikbaarheid van een aantal Venrayse horeca gelegenheden*. Venray: GehandicaptenPlatform Venray.

Gentleman, A. (2014, August 3). 'No one should die penniless and alone': The victims of Britain's harsh welfare sanctions. *The Guardian*. Retrieved from https://www.theguardian.com/society/2014/aug/03/victims-britains-harsh-welfare-sanctions

Geurts, M., Beukers, M., & van Rossum, C. T. M. (2013). *Memo: Consumptie groenten, fruit, vis en een aantal nutriënten opgedeeld naar opleidingsniveau en verstedelijking*. Bilthoven: RIVM.

Golay, C., & Özden, M. (2012). *The right to food*. Geneva: Human Rights Programme of the Europe-Third World Centre (CETIM).

Groce, N., Challenger, E., Berman-Bieler, R., Farkas, A., Yilmaz, N., Schultink, W., . . . & Kerac, M. (2014). Malnutrition and disability: Unexplored opportunities for collaboration. *Paediatrics and International Child Health*, *34*(4), 308–314.

Hospes, O., & van der Meulen, B. (Eds.). (2009). *Fed up with the right to food? The Netherlands' policies and practices regarding the human right to adequate food*. Wageningen: Wageningen Academic Publishers.

Just Fair. (2014). *Going hungry? The human right to food in the UK*. London: Just Fair Consortium. Retrieved from https://www.barrowcadbury.org.uk/wp-content/uploads/2014/04/Going-Hungry-Human-Right-to-Food-REPORT-FINAL-1.pdf

Kayess, R., & French, P. (2008). Out of darkness into light? Introducing the Convention on the Rights of Persons with Disabilities. *Human Rights Law Review*, *8*(1), 1–34.

Knuth, L. (2009). *The right to adequate food and indigenous peoples*. Rome: FAO. Retrieved from http://www.fao.org/docrep/016/ap552e/ap552e.pdf

Knuth, L., & Vidar, M. (2011). *Constitutional and legal protection of the right to food around the world*. Rome: Food and Agriculture Organisation of the United Nations. Retrieved from http://www.fao.org/docrep/016/ap554e/ap554e.pdf

Koninkrijk der Nederlanden. (2012). *Bouwbesluit 2012*. Delft: BRIS. Retrieved from http://www.bouwbesluitonline.nl

MUG Magazine. (n.d.). 'Voedsel' series. Amsterdam: Stichting ter Bevordering van de Belangen van Uitkeringsgerechtigden. Retrieved from http://www.mugweb.nl/page/4/?s=voedsel

Neihof, A. (2013). *The 'facticity' of households and its significance*. Wageningen: Wageningen University. Retrieved from http://edepot.wur.nl/264761

New Economic Models in the Digital Economy Group, University of Hull, & The Trussell Trust. (2016). *Mapping hunger: New technology to help tackle UK poverty*. Retrieved from https://www.trusselltrust.org/wp-content/uploads/sites/2/2016/04/Mapping-Hunger-Report.pdf

OECD. (2007). *Sickness and disability schemes in the Netherlands*. Paris: Organisation for Economic Co-Operation and Development. Retrieved from http://www.oecd.org/social/soc/41429917.pdf

OECD. (2014). *Ageing and employment policies: Netherlands 2014: Working better with age*. Paris: OECD Publishing. Retrieved from http://www.oecd-ilibrary.org/social-issues-migration-health/ageing-and-employment-policies-netherlands-2014_9789264208155-en

OECD. (2017). *Inflation (CPI): Netherlands*. Paris: Organisation for Economic Co-Operation and Development. Retrieved from https://data.oecd.org/price/inflation-cpi.htm

Oostland-Sikkema, A., & Smit, K. (2014). Bruikbaarheid en effect van MeMaatje op lichaamssamenstelling en eet- en beweegpatroon bij mensen met een verstandelijke beperking (Bachelors thesis). Hanzehogeschool Groningen, Groningen, Netherlands.

Palmer, M. (2011). Disability and poverty: A conceptual review. *Journal of Disability Policy Studies*, *21*(4), 210–218.

Reindl, M. S., Waltz, M., & Schippers, A. (2016). Personalization, self-advocacy and inclusion: An evaluation of parent-initiated supported living schemes for people with intellectual and developmental disabilities in the Netherlands. *Journal of Intellectual Disabilities*, *20*(2), 121–136.

Riches, G. (Ed.). (2002). *First world hunger*. Basingstoke: Palgrave Macmillan.

Riches, G., & Silvasti, T. (Eds.). (2014). *First world hunger revisited*. Basingstoke: Palgrave Macmillan.

Rijksoverheid (2015). *Uitkeringsbedragen per 1 juli 2015*. Retrieved from https://www.rijksoverheid.nl/binaries/rijksoverheid/documenten/brochures/2015/06/29/sociale-verzekeringen-en-bijstandsuitkeringen-per-1-juli-2015/uitkeringsbedragen-per-1-juli-2015-rectificatie.pdf

Rijksoverheid. (2016a). Uitkeringsbedragen per 1 juli 2016. Retrieved from https://www.rijksoverheid.nl/documenten/publicaties/2016/06/28/uitkeringsbedragen-per-1-juli-2016

Rijksoverheid. (2016b). *Sixth periodic report: Kingdom of the Netherlands: International covenant on economic, social and cultural rights*. The Hague: Rijksoverheid. Retrieved from https://www.rijksoverheid.nl/binaries/rijksoverheid/documenten/rapporten/2016/02/01/international-covenant-on-economic-social-and-cultural-rights/international-covenant-on-economic-social-and-cultural-rights.pdf

Stichting Geschillencommissies voor Consumentenzaken. (2017). Geestelijk Gezondheidszorg (Klachten). Retrieved from https://www.degeschillencommissiezorg.nl/clienten/zorgcommissies/geestelijke-gezondheidszorg

Tarasuk, V. S., & Eakin, J. M. (2005). Food assistance through 'surplus' food: Insights from an ethnographic study of food bank work. *Agriculture and Human Values*, *22*(2), 177–186.

Van der Horst, H., Pascucci, S., & Bol, W. (2014). The 'dark side' of food banks? Exploring emotional responses of food bank receivers in the Netherlands. *British Food Journal*, *116*(9), 1506–1520.

Vlemminx, F. M. C., & Meuwese, A. C. M. (2013). Commentaar op Artikel 93 van de Grondwet. In E. M. H. Hirsch Ballen G. & Leenknegt (Eds.), *Artikelsgewijs Commentaar op de Grondwet*. Retrieved from https://www.nederlandrechtsstaat.nl/module/nlrs/script/viewer.asp?soort=commentaar&artikel=93

Voedselbanken Nederland. (2016). *Feiten en cijfers Voedselbanken Nederland*. Houten: Voedselbanken Nederland.

Volksgezondheidenzorg. (2017). *Voeding: Cijfers &*

context—Bevolkingsgroepen. Retrieved from https://www.volksgezondheidenzorg.info/onderwerp/voeding/cijfers-context/bevolkingsgroepen#node-groente-en-fruitconsumptie-naar-opleidingsniveau-volwassenen

Vozoris, N. T., & Tarasuk, V. S. (2003). Household food insufficiency is associated with poorer health. *Journal of Nutrition*, *133*(1), 120–126.

Waltz, M., Speelmans, G., & Cardol, M. (2016). Supporting young adults on the autism spectrum towards independence: Lessons from the Netherlands. *Good Autism Practice*, *17*(2), 5–15.

Webber, C. B., Sobal, J., & Dollahite, J. S. (2007). Physical disabilities and food access among limited resource households. *Disability Studies Quarterly*, *27*(3).

Wernaart, B. (2013). *The enforceability of the human right to adequate food: A comparative study*. Wageningen: Wageningen Academic Publishers.

Wernaart, B., & van der Meulen, B. (2016). The right to food in international law with case studies from the Netherlands and Belgium. In G. Steier & K. K. Patel (Eds.), *International food law and policy* (pp. 67–100). Cham, Switzerland: Springer.

Wolbring, G., & Mackay, R. (2014). Analysis of newspaper coverage of food security through a disability studies lens. *Journal of Sustainable Development*, *7*(4), 1–27.

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Article

Rehabilitation as a Disability Equality Issue: A Conceptual Shift for Disability Studies?

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Abstract
Rehabilitation is a controversial subject in disability studies, often discussed in terms of oppression, normalisation, and unwanted intrusion. While there may be good reasons for positioning rehabilitation in this way, this has also meant that, as a lived experience, it is under-researched and neglected in disabilities literature, as we show by surveying leading disability studies journals. With some notable exceptions, rehabilitation research has remained the preserve of the rehabilitation sciences, and such studies have rarely included the voices of disabled people themselves, as we also demonstrate by surveying a cross-section of rehabilitation science literature. Next, drawing on new research, we argue for reframing access to rehabilitation as a disability equality issue. Through in-depth discussion of two case studies, we demonstrate that rehabilitation can be a tool for inclusion and for supporting an equal life. Indeed, we contend that rehabilitation merits disability researchers' sustained engagement, precisely to ensure that a 'right-based rehabilitation' policy and practice can be developed, which is *not* oppressive, but reflects the views and experiences of the disabled people who rehabilitation should serve.

Keywords
concept; disability; equality; rehabilitation; rights

Issue
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1. Introduction

Definitions of rehabilitation are contested. For example, outside clinical care, the term has been used in social contexts, which include vocational rehabilitation helping people access employment, and in rehabilitating ex-offenders. The focus of this article is health-related rehabilitation. The World Health Organisation (WHO) defines rehabilitation based on the *International Classification of Functioning, Disability and Health*:

> As set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments. (WHO, 2011, p. 96)

In this approach, disability is defined as a decrement in functioning, which rehabilitation can help reduce. In the WHO approach, as expressed in the *World Report on Disability* (2011), rehabilitation comprises rehabilitation medicine; physical, occupational and other therapies; and assistive devices. However, in the Convention on the Rights of Persons with Disabilities (CRPD; UN, 2006), rehabilitation is conceptualised as a broader process of social transformation which may not have been explicitly realised in rehabilitative practices to date.

Tensions in both definitions of, and attitudes to, rehabilitation run through this article. Two of the authors have an insider status (Corbin Dwyer & Buckle, 2009), one having experienced childhood habilitation for hemiplegia, the other having experienced in-patient rehabilitation after spinal cord injury as an adult. The former experienced physiotherapy as a profoundly intrusive experience, impinging much more on her life than the direct effects of her relatively mild impairment. It was partly through reflecting on her experience of habilitation that she came to disability studies, finding it to be an emancipatory academic (and activist) space. Conversely, the latter experienced physiotherapy as empowering, enabling him to regain functioning and thus maximise his social participation. These divergent attitudes to rehabilitation reflect a wider ambivalence within the disability rights community.

Authors within the materialist disability studies tradition have re-defined disability in terms of social barriers and oppression, rather than deficits in personal functioning (Oliver, 1990), otherwise known as the 'social model'. The goal of this disability rights approach is to remove environmental barriers and discrimination, whereas rehabilitation may be considered suspect because it attempts to fix the origins of limitations within individuals (Finkelstein, 1980). Disability studies academics have written of their personal experience of rehabilitation as oppressive, because they see it as emphasising "normalisation" (Abberley, 1995; Finkelstein, 2004; Oliver, 1990, 1993). For example, in his professorial inaugural lecture, Michael Oliver (1993) posed the question 'what's so wonderful about walking?', and thereby querying the very desirability of 'optimal functioning'. Later, Michael Oliver and Colin Barnes asserted that:

> Clearly the concept of rehabilitation is laden with normative assumptions clustered around an able-bodied/mind ideal. And, despite its limitations in terms of returning people with acquired impairments such as spinal cord injury, for example, to their former status, it has little or no relevance or meaning for people born with congenital conditions such as blindness or deafness other than to enforce their sense of inadequacy and difference. (Oliver & Barnes, 2012, p. 42)

That some disabled people hold ambivalent views about rehabilitation may be understandable, especially when seeing the development of rehabilitation within a historical context where the statistical norm became an increasingly influential referent for medical practice (Davis, 1995; Gibson, 2016). Furthermore, within this branch of disability studies, rehabilitation is understood as a practice that is 'done to' rather than 'done with' the collaboration of the patient. Within this context, rehabilitation professionals may understandably be experienced as suspect, because representing a mode of acting towards disabled people that privileges the professional's voice over that of the patient (Finkelstein, 1980).

While there may be good reasons for positioning rehabilitation in this way, this has also meant that, as a lived experience, it is under-researched and neglected (Shakespeare, 2014). With some notable exceptions (e.g., Bevan, 2014; Bezmez, 2016; Crisp, 2000; Hammell, 2006; Swart & Horton, 2015), rehabilitation research has therefore, by default remained the preserve of the rehabilitation sciences. This is reflected in our analysis of recent papers (January 2011 to December 2015) published in the four leading disability studies journals (*Disability and Society, Alter, Scandinavian Journal of Disability Research, Disability Studies Quarterly*). Of 954 articles published, only 41 (∼4%), focused on rehabilitation. This might indicate relatively low research interest, especially given the relevance of rehabilitation in many disabled people's lives. Some research does prioritise the lived experience of disability in rehabilitation, with research studies focusing on participatory, inclusive and patient-centred rehabilitation (e.g., Byrnes et al., 2012; Lund, Tamm, & Bränholm, 2001) and in health settings (Cook & Inglis, 2012). Additionally, there is other research based on first-person perspectives of individuals going through rehabilitation (e.g., Arntzen, Hamran, & Borg, 2015; Chun & Lee, 2013).

Nonetheless the critique remains that, firstly, most of this work comes from rehabilitation sciences scholarship which remains separated from disability studies and, secondly, that both fields of study would benefit from mutual contributions. For instance, Chun and Lee (2013) identify feelings of gratitude when comparing levels of injury with individuals whose impairments are more severe, following traumatic spinal cord injury. Disability scholars might be critical of this comparison. On the other hand, if disability scholars engaged with rehabilitation sciences this might facilitate more nuanced approaches to rehabilitation.

From the rehabilitation sciences perspective, the scope of the materialist disability research critique of rehabilitation, as highlighted in Oliver's previous quotation, could itself be criticised. For example, spinal cord injury rehabilitation measures for muscles, bowels, bladder, skin are all about living healthily in the new, paralysed, status, not regaining the former status of being "a walker" (WHO, 2014). Second, there is a danger in traducing the whole field of rehabilitation when challenging the cure obsession of some charity campaigns. Finally, contradicting Oliver and Barnes (2012), people who are born with or who acquire sight or hearing loss, do experience habilitation and rehabilitation interventions and assistive technologies, such as magnifiers, white canes, cochlear implants and other corrective surgery. Some papers by 'founding fathers' in materialist disability studies are more nuanced, such as Finkelstein (1984), who concludes that, where patients are actively involved, medicine and rehabilitation can and should prevent and mitigate impairment.

To balance the emphasis on disability studies, three multi-disciplinary rehabilitation journals were also selected for review: *The International Journal of Therapy and Rehabilitation*; *Disability and Rehabilitation* and; *Clinical Rehabilitation* for the same search dates, but this time studies were included where the voices of patients were heard in rehabilitation processes, particularly focusing on two conditions: one congenital (cerebral palsy) and one acquired (spinal cord injury). The 164 rehabilitation science articles reviewed produced no substantial evidence of public and patient involvement—in contrast to the more developed practices of participatory and emancipatory research in the disability studies literature (Oliver & Hasler, 1987). Fewer than 10% of articles indicated that research participants were involved in some way, such as data analysis, interview piloting or checking transcripts (Bourke, Hay-Smith, Snell, & Dejong, 2015; Byrnes et al., 2012; Chun & Lee, 2013; Dew, Llewellyn, & Balandin, 2014; Guilcher et al., 2013; Huang, Wang, & Chan, 2013; Kim & Shin, 2012; Moll & Cott, 2013; Papadimitriou & Stone, 2011; Shikako-Thomas, Bogossian, Lach, Shevell, & Majnemer, 2013; Smith, Papathomas, Martin Ginis, & Latimer-Cheung, 2013; Goodridge et al., 2015; Van de Velde et al., 2012).

Moll and Cott (2013) present insights yielded by qualitative research with adults with cerebral palsy, who reported on the problems of a 'rehabilitation' wholly conceived as 'normalisation'. Such an approach to interventions did not offer people with cerebral palsy what they needed to be able to manage their bodies as they age (Moll & Cott, 2013). However, this article appears unique within the cerebral palsy literature in questioning received ideas about rehabilitation. Other important insights in this literature include: an emphasis on agency rather than autonomy, which might help rehabilitation patients to adjust to their new situation and to be more comfortable with themselves (Van de Velde et al., 2012; see also Bezmez, 2016; Papadimitriou, 2008). The experience of psychological loss associated with acquired impairment should not be underestimated (Clifton, 2014). For congenital and lifelong impairments, an emphasis on nourishing bodily self-awareness and on learning how to manage the ageing body may be more appropriate than an emphasis on normalisation (Brunton & Bartlett, 2013; Moll & Cott, 2013). Despite these positive insights, our reviews of literature suggest that rehabilitation is marginal within disability studies, and the voices of disabled people are marginal within rehabilitation sciences. The lack of emphasis on the voices of disabled people might in part reflect the professional focus of the rehabilitation science journals searched, and their preference for methodologies with measurable outcomes over qualitative methodologies which privilege the opinions and experiences of participants.

Health-related rehabilitation comprises a very broad and diverse set of interventions, and rehabilitation professionals vary in their outlook and behaviour. Not all rehabilitation interventions are experienced as appropriate, let alone effective; some professionals act in oppressive ways (Oliver, 1993). The disability community itself has a range of views and experiences regarding rehabilitation. Many disabled people derive considerable benefit from habilitation and rehabilitation: some regain the ability to walk (as with 10% of people with spinal cord injury including one of the current authors); others regain functional speech; many manage to use artificial limbs successfully. The danger surely lies in a blanket dismissal of a whole area of healthcare and human experience. A more nuanced approach is required.

Shakespeare (2014) has argued that the materialist disability studies commitment to a 'strong' social model has hampered the development of disciplinary alliances (for example, with medical sociology) that could lead to research promoting the human rights of all disabled people. He and others reject the dualist social model understanding of disability as over-simplified and reductionist. Rather than reducing disability to either impairment, or barriers or oppression, they call for a relational approach to disability, which conceptualises disability as the outcome of the interactions between the person with the impairment, and the wider context. Critical realists set out a "laminated" approach (Danermark & Gellerstedt, 2004), referring to different levels of reality. From this perspective, the range of appropriate responses to disability could include: healthcare to prevent or treat the health condition; rehabilitation to maximise functioning; psychological interventions; removal of barriers in environments; social provision of independent living supports; legal protections to combat discrimination.

The ambiguous position of rehabilitation within progressive responses to disability is also evidenced in human rights law. Within the CRPD, rehabilitation is covered under Article 25, Health, and Article 26, Rehabilitation. Article 25 explicitly states 'States parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation'. This suggests that there is a right to health-related rehabilitation, within an overall right to health. Article 26 calls on all States to:

> Take effective and appropriate measures…to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes.

Yet, significantly, Article 26 does not conceptualise any distinct right to rehabilitation. This appears to be because Convention was negotiated under a somewhat contradictory UN General Assembly mandate to draft a treaty that paralleled existing human rights instruments, rather than one which created new rights (Kayess & French, 2008, p. 20). Because there had been no explicit right to rehabilitation in the existing human rights architecture, it was not expressed as a stand-alone right in the CRPD. Equality in the CRPD is often phrased in terms of disabled people achieving access to, for example, services, "on an equal basis to others". Yet when it comes to a specific service such as rehabilitation, which may be particularly relevant to people with long-term conditions, it is not then a matter of equality with non-disabled people. It is a matter of meeting needs associated with impairments. Without appropriate rehabilitation, people cannot enjoy equality of opportunity in education and employment. Drawing on new research taking place at the University of East Anglia, we argue in this article that rehabilitation and access to rehabilitation is therefore a disability equality issue. We call for a dialogue between disability studies/disability rights and rehabilitation sciences (see also Bevan, 2014; Hammell, 2006; Gibson, 2015).

Through an in-depth discussion of two case studies, which examine in detail the meaning of rehabilitation as a social experience in the lives of disabled people, we demonstrate that rehabilitation can be a tool for inclusion and for an equal life. Indeed, we contend that rehabilitation merits a sustained engagement from disability researchers precisely to help ensure a 'right-based rehabilitation' policy and practice can be developed which is *not* oppressive, but which instead reflects the views and experiences of the disabled people it should serve.

2. Methods

Our qualitative research explores the importance and meaning of health-related rehabilitation seen as a social process in disabled people's lives. This article draws on primarily two research studies. The first explored disabled people's experiences of, and views about, rehabilitation in England: this study included people with differing congenital and acquired impairments and was based on semi-structured interviews, focus groups and a creative writing group (Case study 1). The second study looked at disabled people who had experienced acquired brain injury or who had undergone amputations, on two wards of a rehabilitation hospital in England, and entailed in-depth interviews, focus group discussions and participant observations (Case study 2). Although the main findings of this research are drawn from these two research studies, at times the article draws on comparable findings from an ethnographic research project conducted previously in Turkey by one of the authors. For the purposes of this article, the various forms of data have been used to generate rich case studies, which reflect the wider data, but specific experiences with analytic resonance and relevance are presented for discussion here (Crowe et al., 2011).

The first case study is drawn from Harriet Cooper's ongoing research project, 'Rights-based Rehabilitation: A qualitative research project co-produced with disabled people'. This project is being supported by an advisory group of disabled individuals which meets to discuss aspects of research design, implementation, analysis and dissemination. While the data has now largely been collected, a comprehensive phenomenological analysis of themes in the data is yet to be completed. The emergent themes to be discussed here are indicative rather than comprehensive or definitively situated within the broader data set. This particular case study was therefore selected for inclusion in this article as it offers a wide-ranging critical illustration of ways in which rehabilitation can be understood as a disability equality issue. The richness of the case study was facilitated by the rapport developed between Mary (not her real name) and Harriet during the course of the interview, and through their shared interest in disability rights.

The second case study is drawn from fieldwork undertaken from October 2016 to February 2017, including interviews with 10 patients and 8 family members and focus group discussions with doctors (4), nurses (5), physiotherapists and occupational therapists (6). Additionally, participant observation was undertaken with 5 families as they were visiting the patients; finally, 5 in-depth interviews were conducted with academic experts in rehabilitation. All the interviewees staying in the neurological services were patients with mental capacity, who could consent and talk. Our first contact with interested participants was initiated by a member of the staff and we were then invited to meet with the patients and their families. The particular case study was selected because it introduces an important social aspect of physical rehabilitation, in providing room for socialisation and peer support. This theme was not examined in the first case study. The study has several limitations: first, the original focus of the second research study lies in examining the role of the family in in-patient rehabilitation in the UK. Thus, interview questions primarily focused on family roles with information on rights-based rehabilitation to promote disability equality being derived from the responses to these questions, to set the framework for the case study. In consequence, some data on rehabilitation services and dynamics specific to rehabilitation such as rehabilitation techniques were not available. However, the emphasis on the importance of having a communal rehabilitation experience remained essential. Second and relatedly, the focus on family roles made it necessary to draw on the fieldwork conducted in the amputee service to ensure the depth and soundness of the analysis in Case study 2.

The studies received ethical permission from the UEA Faculty of Medicine and Health Sciences Research Ethics Committee and the South East Coast Brighton & Sussex NHS Research Ethics Committee, respectively. All the names in the case studies have been changed.

3. Results and Discussion

The two case studies analysed in this section emphasise different aspects of rights-based rehabilitation. Thus, even though they have themes that overlap, they are in fact more complementary in terms of initiating a discussion on rights-based rehabilitation, which can promote disability equality. The first case foregrounds the issues of maintaining access to services, i.e. the question of whether rehabilitation is withheld or restricted, and the appropriateness of the treatments on offer. This raises the central question of whether rehabilitation offered is relevant to the patient's needs. The second case discusses an issue often neglected in health-related rehabilitation, namely the importance of making room for socialisation and peer support while receiving health-related treatment. This case provides information which broadens existing conceptions of rehabilitation. The first-person accounts in both case studies demonstrate how all three issues have significance for developing rights-based rehabilitation to promote disability equality.

3.1. Case Study 1: Mary

3.1.1. Mary's 'Battle' for Access

Mary is a woman in late middle age, who has been living with multiple sclerosis for thirty-five years. In her interview, she described her different struggles as she sought to access rehabilitation services. Mary deployed a battle metaphor (including the 'big battle' and the 'constant battle') when she identified where rehabilitation was withheld, or restricted, and when she believed it was not relevant to her needs:

> Later on, to me rehabilitation wasn't actually responding to me, it was, um, it had put me in a category, a person with MS, er…who therefore would have…set treatments….Um, and everything turned into a battle because, it wasn't actually what I was wanting…or what I needed.

The concept of the battle was used frequently by Mary to characterise her experience; as a result it appears several times in the case study, even when the data is being discussed in terms of another theme. It is a relevant detail because it highlights the amount of energy that was expended by Mary to obtain and maintain access to the rehabilitation services she needed.

3.1.2. Obtaining Appropriate Treatment: The Importance of User Involvement

Mary described her struggle to obtain the immune-suppressing treatment beta-interferon, and her experience of being categorised as someone who would not benefit from it. She appealed to the Health Secretary, and eventually won the right to receive the treatment, which she found had a profoundly positive effect on her relapsing-remitting MS.

Mary also described her efforts to receive the right treatment for continence control as 'a struggle' and as something which 'again turned into a battle':

> People wanted to catheterise me. Again, er, because it was easier and cheaper than getting people in to help me get to the toilet. So that again was a struggle because I found a catheter very uncomfortable; my bladder reacts to it and pushes it out.

For Mary, being helped to use the toilet via a toileting sling allowed her to maintain muscle strength and lung capacity; she regarded it as part of her rehabilitation. Moreover, using a catheter had caused her to suffer severe bladder infections. Yet the care providers restricted the number of continence pads she could have and the frequency of the care-workers' visits to assist her with toileting, which again began a battle of proving need for pads and care-worker visits. These experiences are perceived to have 'turned into' battles, due to 'shrinking availability' of services. When something 'turns into' a battle, there is the implication that energy and resources could have been saved—on all sides—if the 'battle' simply were not necessary.

3.1.3. Resource-Scarcity Creates Access and Equality Issues

Several times, Mary made a connection between a failure to have her needs met and the rationing of state resources. She talked about how she lost her access to assistance with her arm splints, when the relevant healthcare professional moved away and was not replaced, meaning that Mary's arm splints have gradually deteriorated. In Mary's experience, decisions have been made on the basis of cost-effectiveness rather than being taken in accordance with need.

At one stage there had been an attempt to remove her continuous physiotherapy and to offer Mary only a limited number of sessions, after which she would have had to return to her GP and request a new referral. According to Mary, this was not because her own need had decreased, but because others were not able to access the physiotherapy they needed. Again, Mary had to appeal to the health authority, and won her case.

3.1.4. Rights-Based Rehabilitation Makes Space for the Voices of Disabled People

As well as depicting her struggle against rationing of scarce NHS resources, Mary's story also illustrates the specific relevance of the concept of 'expert by experience'. Mary found that she needed to contest received ideas about what would be right for her. Her knowledge and understanding were sometimes overlooked, and the views of medical professionals dominated. Sometimes this seemed to be because the NHS had a fixed notion of the needs of a person with MS, rather than a flexible notion relevant to her own experience of disability. Sometimes it seemed to be because of discriminatory assumptions about disabled people. For example, she reported that it was suggested to her that one way to avoid the need for a more expensive wheelchair would be to go to bed during the day, but she felt this would dramatically reduce her quality of life:

> I have a different view on what I want to do, and I want to, I want to live, until I die, and that's the way I want to do it, and so again it's a battle of how I want to do it.

Mary's commitment to self-determination, and to 'follow[ing] her instinct' have contributed to her success in obtaining access to rehabilitation services. A less empowered or supported individual might have conformed and lost control and functioning.

3.1.5. Uncertainty about Access Can Erode One's Sense of Personhood

One of the long-term effects of the uncertainty Mary has experienced in relation to service provision has been to erode her sense of entitlement, and even her sense of personhood. Mary explained that she felt as though she was a 'burden':

> It's like…you've had—you've had your character deconstructed….You lose your right to be the person you were because you're taking resources, and therefore you will do as you're told.

When her physiotherapy was withdrawn, Mary's condition went downhill, and she also experienced considerable distress at the uncertainty of not knowing whether her treatment would continue, affecting her ability to plan or to maintain her health:

> The distress…when you don't know that people are going to agree with you…is quite profound, and stress, is the thing that triggers MS, which makes it worse, so it was actually damaging me.

Mary located the problem in the 'systems' and not in the individuals who were involved in her rehabilitation, whom she held in high regard. With one significant exception, the rehabilitation professionals Mary had encountered were, in her words, 'wonderful'.

In summary, huge amounts of emotional, physical and administrative labour were involved in the process of fighting for what Mary needs to maintain her quality of life. She has had some very positive experiences of rehabilitation but reports that she has had to struggle to obtain the right services for herself on an ongoing basis. Mary joked that while her husband could enjoy retirement, she still had the full time job of arranging her access to care and treatment.

3.2. Case Study 2: Robert

The main themes discussed in Mary's case related to maintaining access to rehabilitation and the appropriateness of treatments on offer. This second case study highlights a different theme, in order to argue that rehabilitation is also a disability equality issue because it can affect opportunities for disabled people to be part of relevant social networks and to take part in social interactions, when going through the rehabilitation process itself. Limited opportunities for socialisation during rehabilitation can lead to feelings of loneliness and despair at a time which can already bring many challenges. We argue that although traditionally and practically it has not always been the case, in-patient rehabilitation is distinctive when compared to other treatment experiences, because it is supposed to facilitate a transition to a new life with a new bodily status. Often this process takes months or even years, which precludes a quick cure for the patient. Rehabilitation is a process for managing liminality (Hammell, 2006), which necessitates the creation of spaces that contain some of the characteristics of the everyday life beyond the hospital walls. Socialisation is one of those characteristic processes. Another is the way that families personalise routines and environments to make them familiar and welcoming to their loved ones. We argue that rehabilitation can promote disability equality if it develops a holistic approach to the complex needs of individuals who experience it. The discussion below illustrates this claim in the light of the experiences in two different hospital wards, neurological and amputee services, in a specialist rehabilitation hospital in England. We identify how the way that rehabilitation is organised may lead to a sense of isolation and loneliness in people. Similar to the case of Mary, we show that this state of affairs is not perceived as a failure of the individual professionals by the patient, for staff are described as doing everything they can. Again, this case demonstrates that when an individual's complex needs are not met, this can erode that individual's sense of personhood, and stir up feelings of being a "burden". At a more general level, both case studies draw attention to the importance of including disabled people within rehabilitation processes through practices which can integrate their complex needs. Both case studies also highlight how people are disabled by society as well as by their bodies. Mary's case demonstrated this in critically discussing fixed ideas about disability which are based on NHS assumptions rather than on patients' needs; the second case study illustrates this by drawing attention to the lack of attention paid to the patients' need to socialise as they go through rehabilitation.

Robert (not his real name) is a 72-year-old man, who in the previous eight months had had one hip replacement operation, two strokes, and two brain operations, eventually leading to him living with the condition of epilepsy. At the time of the interview, he had been an in-patient in the neurological rehabilitation service for about a month. Robert was estranged from most of his family members and the only person who occasionally visited him was his partner, with whom he had been having an on-and-off relationship over recent years. He was staying in a single room, which he associated with feelings of "being stuck in", because he had not been out of his room on his own since he had been in the hospital. Asked about what he disliked about rehabilitation, he responded: "The things I don't like is being stuck to that bed; being stuck in this room".

Throughout the interview, Robert emphasised themes related to feelings of isolation, loneliness, despair and despondence. Asked about his plans for the time after discharge Robert replied:

> I don't know if things are going to get any worse. My eyesight has diminished ever so much since the stroke. I get very despondent. Loneliness I've never felt, I've been lonely before many times in my life but I've never felt lonely, do you understand?….Now I feel it as loneliness, it's despair sometimes. I don't think there is anything else I can tell you. Nobody told me anything about what a stroke entails when I had it….What to expect and that is frightening when you get these things thrown at you umm…..I've lost an awful lot because of the stroke. I've no confidence now, whereas before I was self-confident in everything I did. That's what worries me about getting discharged and going back to the flat. How will I cope?

Robert's feeling of living now with loneliness not only relates to his complicated past, as someone who is estranged from the family, or the dramatic change he had to go through in his life situation, but also to how the rehabilitation process itself is organised. His emphasis on how he had never felt being lonely as "loneliness", before having had the stroke, and "being stuck" in the room, is telling in that respect. Similarly, the experiences of some patients in the amputee service, as explained in subsequent paragraphs, demonstrate that if complementary services such as peer support and provision of space for socialisation were to be integrated into existing rehabilitation schemes, patients' experience of rehabilitation might change significantly. This sense of isolation demonstrates the complex needs of individuals as they go through in-patient rehabilitation, and the importance of being part of relevant social networks as a feature of rights-based rehabilitation that promotes disability equality. In this context Robert seemed to value highly any interaction with staff. Asked about what he liked about rehabilitation, he answered:

> The things I do like are the nurses; they do everything they can for you…they are really nice.

Thus, as seen in the case for Mary, Robert also did not perceive the sources of his distress as deriving from the individual staff members. At the same time, it was hard for Robert to call for the nurses every time he needed them:

> They say all the nurses here are good they get you what you need in the night. You don't realise how much you do need when you can't walk because I get out of bed and walk over to that container with the wipe sheets or the light switch I've got to get someone to come and do it…which I don't like. I think it's wasting their time.

Similarly to Mary's reported experiences of uncertainty about her sense of personhood, when encountering problems in accessing services, Robert's experiences of such feelings of loneliness and despair led him to question his own enacted personality and the relationships he did or did not form over the years:

> In my previous life I wasn't very nice person to anybody…I was a nasty person. I'd hurt people.

Robert's experience of in-patient rehabilitation is telling, in illustrating how, in an already-challenging life episode entailing increased fragility and need for support, experiences of being additionally secluded by the conditions of rehabilitation, engendering feelings of being "stuck" to a bed in a room with few social interactions, can add unhelpful feelings of loneliness and despair. We contend that a rights-based rehabilitation practice promoting disability equality needs to engage with the psychological impact of acquiring impairment as well, and foreground the importance here of forming meaningful social networks.

Within the framework of the same field study, interviews and participant observation were also conducted in the amputee rehabilitation service of the same hospital. The amputee rehabilitation service differed from the neurological service, in that most patients were not individually isolated, but stayed in rooms for three or four people. Furthermore, most patients in the amputee ward did not experience the cognitive difficulties specific to the experience of many patients within the neurological services, such as loss of memory or confusion. As a result, the amputee service emerges as offering a space that may be more conducive than some other rehabilitation services to generating feelings of community and camaraderie.

This specificity in organising and experiencing the amputee service was highlighted in our various casual chats with the staff members, even from setting up arrangements for interviews. At the initial stage of reaching out to interested participants, NHS staff acted as mediators. The first time we were informed about interested patients, a staff member flagged up three people, all of whom wanted to be interviewed. These were all patients staying in the same room, who had been informed about the study at the same time and collectively decided to participate. In addition, when we first went into the ward to make appointments with the respective patients, they were sitting in their wheelchairs in a semi-circle, and socialising. Our initial meeting to arrange the interview dates was also a collective gathering, where patients were having a social welcoming chat with us. Our subsequent meetings in the amputee ward involved similar, more socially-interactive encounters, which felt quite different from our recruitment experience in the neurological service settings. Sometimes, patients spontaneously referred to other patients' experiences with whom they shared their room. For instance, Kate was explaining some problems she was having in her interactions with the staff and suggested that Lisa had similar issues:

> In fact that upset me and that upset Lisa. I may be speaking out of turn, but she probably won't even tell you because she is very, very quiet.

Thus, for Kate this was a collectively-experienced problem, described almost as a "patients versus the staff" polarising discourse, which could be perceived as illustrating the collective character of rehabilitation for amputee patients and the shared sense of community and camaraderie in the amputee ward.

The interviews conducted with the patients in the amputee service did not bring up themes of loneliness. This was not because patients were not stressed about making a transition to a life with an amputated leg. This transition is experienced as stressful; and needs to be planned, especially when it comes to issues of accessibility at home after discharge. Yet, the loneliness and despair mentioned by Robert and several other participants in the neurological services were not mentioned by the participants in the amputee ward. To a certain extent, this might have to do with the particularities of the different impairments. Yet, we contend that a rehabilitation process which enabled patients to share collectively the rehabilitation process in time and space, also plays a significant factor. This is corroborated by findings from a previous study conducted in a Turkish rehabilitation hospital, demonstrating how opportunities for socialisation as patients went through the rehabilitation process, constituted one of the most important aspects of the whole experience:

> The thing we liked most were our meetings in the evening after dinner time…We would get together about 10–12 people….We would not talk about our illness but have general chat (about the government, the economy)….Everyone would be telling their stories about parts of their lives. (Mehmet—not real name)

These more specific insights link contexts with experiences of rehabilitation, showing that rehabilitation can promote disability equality if it makes space for forming social networks within the process, rather than engendering isolation or other life-disruptions or patients, where they are not essential or intrinsic to the treatment process, as, for instance, experiences of pain and nausea within life chemotherapy. We realise the complexities of accomplishing this goal, especially since it requires service providers to develop a patient-focused, comprehensive, holistic understanding of rehabilitation. Yet, if rehabilitation practices are indeed about facilitating a transition into a new life with a new bodily status, this complexity needs to be acknowledged. As such, disability equality can be promoted by facilitating access to rehabilitation services that are based on an adequate assessment of patients' complex needs. The importance of comprehensive rehabilitation programmes has been highlighted by both the aforementioned Article 26 of the CRPD, and a considerable amount of literature (e.g., Byrnes et al., 2012; Dewar & Nolan, 2013; Falkenberg, 2007). Some literature also discussed the specific significance of socialisation and peer support in reducing psychological stress and promoting wellbeing during in-patient and community-based rehabilitation (Jain, McLean, Adler, & Rosen, 2016; Parker et al. 2016; Szalai et al., 2017). One additional factor to highlight here relates to the potential value of developing appropriate inner architectural design to allow more room for socialisation. In this respect, our earlier experience in the Turkish rehabilitation hospital demonstrated the importance of having communal spaces, like inner courtyards, while undergoing rehabilitation. Although sociological studies have often neglected the role of the built environment in medical practice (Martin, Nettleton, Buse, Prior, & Twigg, 2015), we argue for its significance in rehabilitation, and particularly in a rights-based approach.

4. Limitations of This Research

The authors are working towards a conception of rights-based rehabilitation, which undoubtedly requires more evidence, analysis and debate, also drawing on the contributions of others (Siegert & Ward, 2010; Skempes & Bickenbach, 2015). Key features of this approach are that it should:

- Be based on partnership with disabled people, for example through peer support;
- Make space for the voices of disabled people;
- Refer to a comprehensive, holistic understanding of rehabilitation where the complex needs of patients are taken into consideration;
- Be open to diverse ways of functioning, rather than imposing rigid normalisation of impaired bodies;
- See assistive technology as a valid alternative strategy for functioning, rather than a tool for normalisation;
- Understand that people are disabled by society as well as by their bodies, requiring a wider response that challenges social and economic disempowerment;
- Understand that health-related rehabilitation is relevant and important to many but not all people with impairment.

More consultation with wider communities of disabled people is needed before these elements can be validated.

We note that others have stressed freedom, well-being, and dignity as key features of a human rights perspective on rehabilitation, and we would not contest this. However, we would argue for the importance of taking a political as well as a philosophical perspective.

Our literature review was limited by our choice of journals for review and selected time-frame. For example, *Disability and Rehabilitation* published articles on disability rights in the year before our review started (Siegert & Ward, 2010); moreover, there are other journals in the health-related rehabilitation field, some of which are more ready to publish rights-based papers (Skempes & Bickenbach, 2015). The lack of emphasis on the voices of disabled people might in part reflect the professional focus of the rehabilitation science journals searched, and their preference for methodologies with measurable outcomes over qualitative methodologies which privilege the opinions and experiences of participants. A future literature search might include occupational therapy journals, for example, to examine whether voices remain as marginal in this field. It should also be noted that the a small but burgeoning field of critical rehabilitation studies, exemplified by groups such as the Critical Physiotherapy Network (https://criticalphysio.net) is also beginning to challenge prevailing discourses.

Our empirical research was qualitative, and based in one English county, and a few rehabilitation settings, and a few disability organisations, with less than 50 respondents in total. Our interpretations are inevitably interpretative and can be accused of being subjective, like all qualitative research. Using this data, it is impossible to draw broad conclusions about the wider rehabilitation sector, or the total population of individuals experiencing rehabilitation. The original focus of the second research study lies in finding out the role of the family in in-patient rehabilitation in the UK. Thus, interview questions primarily focused on family role and information on rights-based rehabilitation to promote disability equality was derived from the responses to these questions, which set the framework of the case study. As such, some data on rehabilitation services and dynamics specific to rehabilitation like for instance techniques of rehabilitation were not available. Still the emphasis on the importance of having a communal rehabilitation experience is essential. Second and related to the first point, the focus on family role made it necessary to draw upon the fieldwork conducted in the amputee service. Data collected in the amputee service enriched the depth and soundness of the analysis in case study.

5. Concluding Remarks

The premise of this article is that disability is *both* a decrement in functioning, *and* the experience of barriers and discrimination. The disability rights and rehabilitation sciences approaches offer different and equally valid ways of dealing with the loss that often comes with impairment, one which celebrates the resilience of individuals and their capacity to adapt, and the other which calls for society to adapt. We contend that rehabilitation merits sustained engagement from disability researchers as well as rehabilitation scientists, in order to develop rights-based rehabilitation schemes that promote disability equality. For this purpose, based on the first-person accounts and experiences of primarily two disabled people, who go through health-related rehabilitation, Mary and Robert, this article sought to find out the main contours of rights-based rehabilitation. Mary and Robert's experiences foregrounded three important components of rights-based rehabilitation.

First, if rehabilitation is one of the diverse needs faced by many disabled people, then access to rehabilitation is an equality issue. Mary's interview reveals that accessing rehabilitation can be a real 'battle'. Resilience, determination and expertise about one's needs can sometimes be a prerequisite to obtaining access to the right services, and these strengths are not available to all disabled people. Mary struggled to obtain rehabilitation services such as ongoing physiotherapy to keep her muscles in use, and she had to fight for this when she was being encouraged to opt for treatments such as muscle relaxants, which, in her lived experience, reduced her physical capacities and were likely to make her more dependent in the long-term.

Second, beyond the issue of accessing services, there appears to be an equality issue around perceptions of what was right for Mary, which seemed at times to be shaped by others' views about the kind of quality of life she can expect as a disabled person, rather than drawing on Mary's own knowledge of how she can best be supported, via rehabilitation, to determine her own life. Therefore, rights-based rehabilitation must genuinely acknowledge the importance of disabled people's own views and choices regarding their lives and expectations, not as a matter of lip service, through dialogue between professional and patient to form the basis of the service.

Finally, the ways that rehabilitation services are delivered have to be sensitive to the other needs that disabled people also have, beyond the physical (Shakespeare, 2014), to be healed emotionally, to connect with others, to participate, to make sense of their lives. In other words, rights-based rehabilitation would be holistic, rather than reductionist. Robert's sense of isolation and loneliness demonstrated the significance of services that provide room for social networks and peer support, and that they need to be understood as essential aspects of rehabilitation. This point is emphasised also by Skempes and Bickenbach (2015), who argue for an extension of rehabilitation services to ensure that people's needs are properly covered. They call for a rights-based approach to rehabilitation, which considers holistic models of care provision that move beyond a curative approach and "promote alternative means of optimizing functioning such as self-management and peer support". Similarly, Siegert and Ward (2010) refer to a study by Slettebø, Caspari, Lohne, Aasgaard and Nåden (2009), whose qualitative interviews in an in-patient setting for people with traumatic head injuries suggested that support enhanced dignity.

In-patient rehabilitation is not like any other treatment process. It takes often longer and is supposed to aim at facilitating a transition to a new life with a new bodily status. Hence, room should be allowed for some aspects of everyday life that are conventionally associated with life beyond the hospital walls.

The case studies demonstrate that resource constraints in the UK health system appeared to restrict choices, possibly making it harder to achieve rights-based rehabilitation services. This could erode the individual's sense of personhood/entitlement and reinforce feelings of being a "burden". It is exactly for this reason that closer collaboration between disability and rehabilitation scholars and research on rehabilitation as a lived experience is needed.

The UK has better rehabilitation services than most of the world, and a stronger emphasis on patient autonomy than many cultures. In many developing countries, the full implementation of rehabilitation policies has 'lagged' due to a number of 'systemic barriers' (WHO, 2011, p. 104). Among these barriers, the WHO cites 'absence of engagement with people with disabilities' in relation to the design, delivery and evaluation of rehabilitation services (2011, p. 105). So it is not simply a matter of funding services, but also developing and managing services in ways which are empowering and which help people enjoy their rights as disabled people. There is an urgent need to improve understanding and dialogue between the rehabilitation profession and the disability community (Hammel, 2006), in all parts of the world. Rehabilitation sciences need to take on the human rights-based approach which now dominates global and national policy on disability (UN, 2006; WHO 2011). Just as importantly, disability studies and disability policy need to make space for the contribution of health-related rehabilitation, as one element in a multi-disciplinary approach to improving the lives of disabled people (Shakespeare, 2014).

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Conflict of Interests

The authors declare no conflict of interests.

References

Abberley, P. (1995). Disabling ideology in health and welfare—The case of occupational therapy. *Disability and Society*, *10*(2), 221–232.

Arntzen, C., Hamran, T., & Borg, T. (2015). Body, participation and self-transformations during and after in-patient stroke rehabilitation. *Scandinavian Journal of Disability Research*, *17*(4), 300–320.

Bevan, J. (2014). Disabled occupational therapists: Asset, liability…or 'watering down' the profession? *Disability and Society*, *29*(4), 583–596.

Bezmez, D. (2016). Looking for a 'cure': Negotiating 'walking' in a Turkish rehabilitation hospital. Disability and Society, 31(3), 389-405.

Bourke, J. A., Hay-Smith, E. J. C., Snell, D. L., & Dejong, G. (2015). Attending to biographical disruption: The experience of rehabilitation following tetraplegia due to spinal cord injury. *Disability & Rehabilitation*, *37*(4), 296–303.

Brunton, L. K., & Bartlett, D. J. (2013). The bodily experience of cerebral palsy: A journey to self-awareness. *Disability & Rehabilitation*, *35*(23), 1981–1990.

Byrnes, M., Beilby, J., Ray, P., Mclennan, R., Ker, J., & Schug, S. (2012). Patient-focused goal planning process and outcome after spinal cord injury rehabilitation: Quantitative and qualitative audit. *Clinical Rehabilitation*, *26*(12), 1141–1149.

Chun, S., & Lee, Y. (2013). 'I am just thankful': The experience of gratitude following traumatic spinal cord injury. *Disability & Rehabilitation*, *35*(1), 11–19.

Clifton, S. (2014). Grieving my broken body: An autoethnographic account of spinal cord injury as an experience of grief. *Disability & Rehabilitation*, *36*(21), 1823–1829.

Cook, T., & Inglis, P. (2012). Participatory research with men with learning disability: Informed consent. *Tizard Learning Disability Review*, *17*(2), 92–101.

Corbin Dwyer, S., & Buckle, J. L. (2009). The space between: On being an insider-outsider in qualitative research. *International Journal of Qualitative Methods*, *8*(1), 54–63.

Crisp, R. (2000). A qualitative study of the perceptions of individuals with disabilities concerning health and rehabilitation professionals. *Disability and Society*, *15*(2), 355–367.

Crowe, S., Cresswell, K., Robertson A., Huby, G., Avery, A., & Sheikh, A. (2011). The case study approach. *BMC Medical Research Methodology*, *11*(1), 100–108.

Danermark, B., & Gellerstedt, L. C. (2004). Social justice: Redistribution and recognition. A non-reductionist perspective on disability. *Disability and Society*, *19*(4), 339–353.

Davis, L. (1995). *Enforcing normalcy: Disability, deafness, and the body*. London and New York: Verso.

Dew, A., Llewellyn, G., & Balandin, S. (2014). Exploring the later life relationship between adults with cerebral palsy and their non-disabled siblings. *Disability*

& Rehabilitation, *36*(9), 756–764.

Dewar, B., & Nolan, M. (2013). Caring about caring: Developing a model to implement compassionate relationship centred care in an older people care setting. *International Journal of Nursing Studies*, *50*, 1247–1258.

Falkenberg, E. (2007). Holistic aural rehabilitation: A challenge. *Scandinavian Journal of Disability Research*, *9*(2), 78–90.

Finkelstein, V. (1980). *Attitudes and disabled people*. New York: World Rehabilitation Fund.

Finkelstein, V. (1984). Rehabilitation services. In T. Lobstein & Namibia Support Committee Health Collective (Eds.), *Namibia: Reclaiming the peoples' health*. AON Publications.

Finkelstein, V. (2004). Representing disability. In J. Swain, S. French, C. Barnes, & C. Thomas (Eds.), *Disabling barriers, enabling environments*. London: Sage.

Gibson, B. (2016). *Rehabilitation: A post-critical approach*. Florida: Taylor and Francis.

Goodridge, D., Rogers, M., Klassen, L., Jeffery, B., Knox, K., Rohatinsky, N., & Linassi, G. (2015). Access to health and support services: Perspectives of people living with a long-term traumatic spinal cord injury in rural and urban areas. *Disability & Rehabilitation*, *37*(16), 1401–1410.

Guilcher, S. J. T., Craven, B. C., Mccoll, M. A., Lemieux-Charles, L., Casciaro, T., & Jaglal, S. B. (2012). Application of the Andersen's health care utilization framework to secondary complications of spinal cord injury: A scoping review. *Disability & Rehabilitation*, *34*(7), 531–541.

Hammell, K. W. (2006). *Perspectives on disability & rehabilitation: Contesting assumptions; Challenging practice*. London: Churchill Livingstone.

Huang, I.-C., Wang, Y.-T., & Chan, F. (2013). Employment outcomes of adults with cerebral palsy in Taiwan. *Disability & Rehabilitation*, *35*(3), 228–235.

Jain, S., McLean, C., Adler, E., & Rosen, C. (2016). Peer support and outcome for veterans with posttraumatic stress disorder (PTSD) in a residential rehabilitation program. *Community Mental Health Journal*, *52*(8), 1089–1092.

Kayess, R., & French, P. (2008). Out of darkness into light? Introducing the Convention on the Rights of Persons with Disabilities. *Human Rights Law Review*, *8*(1), 1–34.

Kim, H.-R., & Shin, H. I. (2012). When is it appropriate to deliver a prognosis to Korean persons with acute spinal cord injury? *Disability & Rehabilitation*, *34*(16), 1396–1403.

Lund, M. L., Tamm, M., & Bränholm, I. (2001) Patients' perceptions of their participation in rehabilitation planning and professionals' view of their strategies to encourage it. *Occupational Therapy International*, *8*(33), 151–167.

Martin, D., Nettleton, S., Buse, C., Prior, L., & Twigg, J. (2015). Architecture, embodiment and health care: A place for sociology. *Sociology of Health & Illness*, *37*, 1007–1022.

Moll, L. R., & Cott, C. A. (2013). The paradox of normalization through rehabilitation: Growing up and growing older with cerebral palsy. *Disability & Rehabilitation*, *35*(15), 1276–1283.

Oliver, M. (1990). *The politics of disablement*. Basingstoke: Macmillan.

Oliver, M. (1993). *What's so wonderful about walking?* Inaugural Professorial Lecture, University of Greenwich, February. Retrieved from http://disability-studies.leeds.ac.uk/files/library/Oliver-PROFLEC.pdf

Oliver, M., & Barnes, C. (2012). *The new politics of disablement*. Basingstoke: Palgrave Macmillan.

Oliver, M., & Hasler, F. (1987). Disability and self-help: A case study of the Spinal Injuries Association. *Disability, Handicap and Society*, *2*(2), 113–125.

Papadimitriou, C. (2008). Becoming en-wheeled: The situated accomplishment of re-embodiment as a wheelchair user after spinal cord injury. *Disability & Society*, *23*(7), 691–704.

Papadimitriou, C., & Stone, D. (2011). Addressing existential disruption in traumatic spinal cord injury: A new approach to human temporality in inpatient rehabilitation. *Disability & Rehabilitation*, *33*(21/22), 2121–2133.

Parker, S., Dark, F., Newman, E., Korman, N., Meurk, C., Siskind, D., & Harris, M. (2016). Longitudinal comparative evaluation of the equivalence of an integrated peer-support and clinical staffing model for residential mental health rehabilitation: A mixed methods protocol incorporating multiple stakeholder perspectives. *BMC Psychiatry*, *16*, 1–21.

Shakespeare, T. (2014). *Disability rights and wrongs revisited*. Abingdon: Routledge.

Shikako-Thomas, K., Bogossian, A., Lach, L. M., Shevell, M., & Majnemer, A. (2013). Parents' perspectives on the quality of life of adolescents with cerebral palsy: Trajectory, choices and hope. *Disability & Rehabilitation*, *35*(25), 2113–2122.

Siegert, R. J., & Ward, T. (2010). Dignity, rights and capabilities in clinical rehabilitation. *Disability and Rehabilitation*, *32*, 2138–2146.

Skempes, D., & Bickenbach, J. (2015). Strengthening rehabilitation for people with disabilities: A human rights approach as the essential next step to accelerating global progress. *American Journal of Physical Medicine and Rehabilitation*, *94*, 823–828.

Slettebø, A., Caspari, S., Lohne, V., Aasgaard, T., & Nåden, D. (2009). Dignity in the life of people with head injuries. *Journal of Advanced Nursing*, *65*, 2426–2433.

Smith, B., Papathomas, A., Martin Ginis, K. A., & Latimer-Cheung, A. E. (2013). Understanding physical activity in spinal cord injury rehabilitation: Translating and communicating research through stories. *Disability & Rehabilitation*, *35*(24), 2046–2055.

Swart, J., & Horton, S. (2015). From patients to teachers: The perspectives of trainers with aphasia in a UK

Conversation Partner Scheme. *Aphasiology*, *29*(2), 195–213.

Szalai, M., Szirmai, A., Füge, K., Makai, A., Erdélyi, G., Prémusz, V., & Bódis, J. (2017). Special aspects of social support: Qualitative analysis of oncologic rehabilitation through a belly dancing peer support group. *European Journal of Cancer Care*, *26*(6).

UN. (2006). *Convention on the rights of persons with disabilities*. New York: United Nations.

Van De Velde, D., Bracke, P., Van Hove, G., Josephsson, S., Devisch, I., & Vanderstraeten, G. (2012). The illusion and the paradox of being autonomous, experiences from persons with spinal cord injury in their transition period from hospital to home. *Disability & Rehabilitation*, *34*(6), 491–502.

World Health Organisation. (2001). *International classification of functioning, disability and health*. Geneva: WHO.

World Health Organisation, & World Bank. (2011). *World report on disability*. Geneva: WHO.

World Health Organization, & ISCOS. (2014). *International perspectives on spinal cord injury*. Geneva: WHO.

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Article

Inclusions and Exclusions in Rural Tanzanian Primary Schools: Material Barriers, Teacher Agency and Disability Equality

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Abstract
This article begins with the assumption that the argument for the inclusion of children with disabilities in mainstream schools, championed by Sustainable Development Goal 4 and Article 24 of the UN Convention on the Rights of Persons with Disabilities, has largely been accepted nationally and internationally by policy makers, and is increasingly being accepted by teachers. In interrogating the complex craft of developing inclusive and equal learning environments for children with disabilities, this article draws upon Kershner's 'core aspects of teachers' knowledge and knowing', and in particular, 'the school as a site for the development of teaching expertise and the creation of knowledge'. Data is presented from in-depth interviews following videoed lesson observations with experienced teachers in 15 rural, urban and coastal primary schools in four districts in Tanzania. Findings indicate that the teachers' practice is moving unevenly towards disability equality, and involves processes of inclusions and exclusions. This involves teacher autonomy, agency and reflective practice in the context of material, attitudinal, structural, pedagogic and curricular barriers. The teachers' expertise has potential to inform national and international policy developments, and so reduce the evident rhetoric-reality gap. In conclusion, it is argued that inclusive education needs to grapple with disability as a social construct, and lessons are drawn for the further fulfilment of the rights of children with disabilities to equal participation in education.

Keywords
disability; inclusive education; pedagogy; primary school; rights; Sustainable Development Goals; Tanzania

Issue
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1. Introduction

This article critically explores the current international policy context in relation to disability equality in education and its implementation by ordinary primary school teachers in mainstream schools in Tanzania. The research question framing the article is: how can rural primary school teachers' experience inform the development of more disability equal educational policy and practices? This article is timely because it highlights the disconnect between the grand global debates which support disability equality in education, and the limited availability of relevant pre- and in-service teacher education. This article also contributes to the limited and scattered literature on effective and equitable classroom practice in the global South from a disability equality and inclusive education perspective.

We begin by identifying the guiding global debates on education for all, inclusive education and disability equality that demonstrate increasing evidence of 'equal recognition' at an international and national policy level. We then consider some of the key legal obligations outlined in the General Comment 4 (Committee on the Rights of Persons with Disabilities, 2016), which builds on Article 24 to provide a framework for a human rights approach to inclusive education. In order to avoid confusion with the Convention on the Rights of Persons with Disabilities (UN, 2006), henceforth we refer to the Committee's General Comment on Article 24 simply as the 'General Comment'.

The scarcity of research and training on inclusive pedagogy in the global South means that teachers who are at the frontline of realising disability rights in education receive little guidance on best practice. Seeking to address this gap in the literature, we present interview data from 15 Tanzanian primary schools that reflect teachers' constructions of disability in their day-to-day teaching of early reading and mathematics. The socialist history of Tanzania, the long-term commitment to inclusion of disabled children and the Africanist policies of its first President, Julius Nyerere, are likely to have had a powerful influence on some of these teachers' generally positive practices.

Inclusive education, we argue, needs to grapple with disability as a social construct given the structural inequalities in post-colonial contexts, and global imbalances of power. Singal and Muthukrishna (2014) have rightly expressed their concern that the models which frame international discussions are 'exclusively anchored in the industrialised, liberalised, individualistic scripting of the North' (p. 294). Indeed, Grech (2014, p. 130) argues that:

> Disability discourse including that on inclusive education continues to be fabricated in the global North and transferred to the global South, with little or no alertness to context or culture, or how this discourse is framed, applied (or otherwise) or even resisted in practice.

While we concur with these sentiments, in our understanding inclusive education 'also goes beyond the inclusion of disabled learners…to an examination of the threats to equity which may exist in a particular context' for all learners (Miles, 2009a, p. 22).

As educationalists, we consider the concept of inclusive education to be about removing physical, attitudinal and structural barriers and enabling the social and academic participation of all learners, while recognizing the specific barriers some children with disabilities can face in mainstream settings. However, we also recognise that education cannot be seen in isolation from the competing priorities of poor, rural families who often have to 'choose between education and more basic needs, in particular feeding and medicating the disabled person' (Grech, 2014, p. 141). Barriers to equal participation are not only within the primary classroom, but relate to nutrition, transport to and from school, family and community attitudes and relevance and accessibility of the language of education and of the curriculum. International discussions have tended to overlook local understandings of inclusion and the fact that education for 'all' does not always mean 'all', so efforts to do need to be made to prevent the exclusion of children with disabilities from education (Miles & Singal, 2010).

The theoretical stance of this article has been influenced by the notion of 'inclusions' and 'exclusions' co-existing in practice and being part of an ongoing process of development (Dyson, 1999). We are aware that the 'different theoretical notions of inclusion are constructed [and] arise from different discourses' (Dyson, 1999, p. 36), and that the Tanzanian teachers' discourse is almost certainly influenced, though not dominated by, medical constructs of disability. Our analysis has been further informed by Kershner's (2014, p. 854) core aspects of teachers' knowledge and knowing about disability, as we recognise that "schools can be sites for the development of teaching expertise and the creation of knowledge" alongside the development of 'specialist' expertise on disability equality and inclusive pedagogy emerging from teachers' practice.

2. Increasing Recognition of Disability Equality in Education

The Education 2030 Framework for Action has been created to guide global efforts to *reach* the most vulnerable and marginalised children. It stresses that 'every learner matters and matters equally' (UNESCO, 2017, p. 13). Sustainable Development Goal 4 commits governments to 'addressing all forms of exclusion and marginalization, disparities and inequalities in access, participation and learning outcomes' at all levels of education from early childhood through to tertiary and lifelong learning. In pushing for transformation rather than steady linear progression, it also claims that:

> Inclusion and equity in and through education is the cornerstone of a transformative education agenda, and we therefore commit to addressing all forms of exclusion and marginalization, disparities and inequalities in access, participation and learning outcomes.

Children with disabilities have the dual protection of the Convention on the Rights of the Child (UN, 1989)—which guarantees protection from 'discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status' (Article 2)—and the Convention on the Rights of Persons with Disabilities (Article 24) which specifies the right to access 'inclusive, quality and free primary and secondary education on an equal basis with others in the communities in which they live'.

Educationalists do not always recognise the critical role played by the disability rights movement in advocating and lobbying for mainstreaming and inclusion in education over many decades, and in the Convention on the Rights of Persons with Disabilities (CRPD) process (Malinga & Gumbo, 2016). The United Nations (UN) Standard Rules on the Equalization of Opportunities for Persons with Disabilities (UN, 1993) deployed the disability equality concept explicitly, for example:

> Inclusion and participation are essential to human dignity and to the enjoyment and exercise of human rights. Within the field of education, this is reflected in the development of strategies that seek to bring about a genuine equalization of opportunity. (para. 6)

The Salamanca Statement (UNESCO, 1994) built on the Standard Rules and referred to equality of access, equality of opportunity and gender equality. There was much less emphasis on disability equality in the Dakar Framework for Action (UNESCO, 2000), which instead referred to the need for 'special treatment' for children with disabilities. Critically, however, Article 24 is wide open to interpretation, enabling schools to determine whether 'reasonable adjustments' can or cannot be made for some children with disabilities, and therefore equal access and treatment are often denied. The General Comment now provides governments, international agencies, ministries of education, teacher education colleges and schools with detailed, practical guidelines on making inclusive education a reality. For example, Paragraph 35 of the General Comment specifies that all teachers should be trained in the human rights model of disability which we discuss later.

So, while political will and international rhetoric have never been so strong in supporting governments to provide equal access to education for the most vulnerable children:

> Frameworks of accountability and performativity are defended by governments on the basis of inclusion, entitlement and equity when evidence points to the injustices produced by such frameworks for both professionals and those for whom they are responsible. (Allan, 2010, p. 607)

Indeed, SDG4 targets, particularly on literacy and numeracy, mean that stakes are high, and countries in the global South experience unreasonably high levels of surveillance in their continued subaltern positioning as they strive towards the development of western style services and aspirational ideals:

> European nations developed formal disability services slowly from the early nineteenth century onwards, within the means of their economies, without the censorious gaze of wealthy foreign monitors, and with decades of ongoing debate about methods and strategies. Whatever 'mistakes' they now, with the hindsight of history, may appear to have made seldom looked or felt like mistakes but seemed the best compromise at the time between idealism, realism, resources and knowledge. By contrast, economically weaker countries…have a plethora of modern knowledge, techniques and conflicting advice offered them, but lack the space, time and freedom to experiment for themselves. (Miles & Hossain, 1999, p. 82)

Rather than being seen as another global policy of surveillance, the CRPD is 'projected as a development tool critical in eliminating poverty' (Winzer & Mazurek, 2017, p. 3). Education continues to be recognised as a key factor in lifting people out of poverty, and not just as a mechanism for realising human capital, but central to social justice and basic freedom (Terzi, 2008). The recognition that all children have a right to education as a matter of justice challenges those education systems which still consider some children with disabilities to be *ineducable* and so continue to be denied their rights to equal access. The additional danger of the preoccupation with access, or 'getting children into school', however, is that dialogue about the many and various 'inclusions' does not take place, and inclusion is reduced to a basic concern with 'place' (Dyson, 1999, p. 49).

The notion of what it means to be included in a particular cultural context tends to be neglected in the inclusive education literature. Concerns have rightly been expressed that inclusive education, as conceived in Northern contexts, places a disproportionate emphasis on the rights of individuals and that this can, in turn, pose risks to long-established social systems, and collectivist ways of being on which family and community stability and solidarity rely in contexts of chronic poverty (Grech, 2014). Having had personal experience of growing up with a disability in a rural area of Tanzania, Kisanji (1998) has written a great deal about the inherent inclusivity of traditional African communities. He has questioned the appropriateness of importing concepts of inclusion developed in Northern contexts and argues that Tanzania's 'customary education principles of universality, relevance, functionality and community localization are central to the success of an inclusive education system' (Kisanji, 1998, p. 54).

At the level of national government, the General Comment reinforces this 'responsibility for the education of persons with disabilities at all levels, together with the education of others, must rest with the education ministry' (para. 58). At the same time, it emphasises the importance of inter-sectoral collaboration and commitment to inclusive education, acknowledging that inclusive education, 'cannot be realized by education ministries in isolation' (para. 59), and clarity about ministerial responsibility and financing for disability in education is essential for disability equality (WHO, 2011). A prime example of the need for ministerial collaboration relates to material concerns for water, sanitation, textbooks, hearing and vision tests, eyeglasses, crutches, wheelchairs, hearing aids, and magnifiers, all of which underpin inclusive education, yet are the primary responsibility of Health or Social Care. 'Medical' concerns, such as the lack of availability and affordability of eyeglasses (Glewwe, Park, & Zhao, 2016), are often neglected in research and development programmes, yet they are one of the reasons why so many children drop out of school. The importance of assistive technology to inclusion is addressed by Articles 26 and 32 of the CRPD, and the General Comment acknowledges that the absence of assistive technologies represents a fundamental material barrier to inclusive education—an issue recognized by the World Health Organisation (WHO, 2014).

The General Comment suggests that teachers should take courses focused on the human rights model of disability, inclusive pedagogy, and on 'how to identify students' functional abilities—strengths, abilities and learning styles—to ensure their participation in inclusive educational environments' (para. 69). This would help to balance the current emphasis on 'special education', and would need to be managed carefully to ensure that teachers understand the intersectionality between disability and gender, poverty, ethnicity and sexuality, for example, so that their practice becomes more inclusive of all learners. Currently, however, these finer points of classroom practice are left to ordinary classroom teachers, despite global advocacy for disability equality and UN commitment to inclusion.

Literature on inclusive classroom practice and learning processes in Southern countries remains scarce. There is a disproportionate focus on teacher attitudes as well as on 'access and attendance, with less attention paid to what happens within classrooms' (Wapling, 2016, p. 2). This supports the findings of a rigorous literature review of effective pedagogies in developing countries which found only two papers on inclusive pedagogies of sufficient quality to be included (Westbrook, Durrani, Brown, Orr, & Pryor, 2014). We argue in this article that enquiries into processes and causes of 'inclusions and exclusions' will have a greater impact on disability equality in education than the measurement of academic outcomes and increased surveillance.

3. Introducing the Tanzanian Context

Tanzania has 29 special schools and 239 units attached to mainstream schools serving its population of 54 million, and it is estimated that approximately 3% of the school age population has a disability. Disability is cited by 2.8% of children aged 7–16 years as the reason for dropping out of school, and 'more than half of children with disabilities aged 7–16 years who were not attending school said that this was due to disability or illness' (Riggall & Croft, 2016, p. 82).

Tanzania led the way in East Africa in explicitly including children with disabilities through its Education Act in 1969. The Constitution prohibited discrimination against people with disabilities in 1977, and the Law of the Child, enacted in 2009, has effectively adopted the Convention on the Rights of the Child and the CRPD was ratified in 2009. The Persons with Disabilities Act of 2010 is supportive of a rights-based view of disability with an overt focus on equal participation. This Act includes a duty to report parents and caregivers in the case of any infringements of the right to education of their children with disabilities. It also states that: 'every child with disability shall attend an ordinary public or private school except where a need for special communication is required' (The United Republic of Tanzania, 2010, p. 24), and Tanzania is one of the few African countries to have legislated for the right to assistive devices (Riggall & Croft, 2016).

The data we are presenting in this article formed part of a much larger study, *The Teacher Preparation in Africa*, 2010–11, funded by the William and Flora Hewlett Foundation, which compared primary school trainees' knowledge and ability to teach early reading and mathematics with Newly Qualified Teachers (NQTs) and experienced teachers in Ghana, Kenya, Mali, Senegal, Tanzania and Uganda (Akyeampong, Pryor, Lussier, & Westbook, 2013; Pryor, Akyeampong, Westbrook, & Lussier, 2012). The second author was the Principal Investigator of the research in Tanzania and Uganda. Teachers gave informed written consent knowing that they could withdraw at any time, and full ethical approval was granted by the institutions involved in each context. As is the case with most educational research, there was no overt focus on inclusion or disability equality.

One of the unexpected early findings during the field work was the richness of the data emerging in Tanzania. The experienced (mostly female) teachers in Tanzania were remarkably aware and imaginative in their teaching of children with disabilities, yet disability was not mentioned by any of the teachers in the other five countries. Opportunistically, the research team made a decision to focus specifically on teachers' views and practices of disability equality in the classroom in the subsequent interviews. The full data set comprised questionnaires from trainees, NQTs and experienced teachers from four locations (one rural, two metropolitan and one coastal), as well as interviews and focus group discussions with teacher educators and trainees at four representative teacher training colleges, videoed observations of teaching and interviews with 39 NQTs from 24 schools and with 15 experienced teachers who had participated in Continuing Professional Development (CPD) programmes for reading and mathematics. The focus of this article is on the latter group of 15 teachers.

All interviews took place in Kiswahili and were translated by a Kenyan teacher of the deaf with doctoral experience. Transcripts were analysed thematically by the authors from the perspective of how and why all learners were included, and teachers' constructions of inclusions and exclusions in day-to-day classroom practices. Teachers talked confidently about, and readily identified, children with disabilities who were attending school 'as normal' (Dyson, 1999, p. 39). They spoke about children who were blind, visually impaired, had albinism, hearing impairments, or who were 'short' and stunted through malnutrition, had physical impairments, and cognitive impairments, who they referred to as 'slow learners'. Some children had to sit on the floor because there were not enough chairs and desks, nor were there sufficient textbooks. The first few years of formal learning are particularly critical for children from economically poor backgrounds, given that approximately 250 million children, many of whom have disabilities, fail to attain minimum standards of literacy and numeracy even after attending four years of primary school (UNESCO, 2012).

We have selected data which is representative of the 15 experienced teachers (13 women, 2 men) from 15 different primary schools, who have had between five and 37 years of experience, and teach classes of 60–80 children in the first three years of primary school. Pseudonyms have been used to protect their identities, and are presented here with the number of years they have been teaching: Sophia (5 years); Justina (14 years); Joyce (15 years); Rose (22 years); and Catharine (37 years). We consider the processes through which these teachers have developed inclusive pedagogies and highlight how their practices can inform policies on disability equality in education. In addition to Dyson's (1999) concept of inclusions and exclusions, we have drawn upon Kershner's (2014) core aspects of teachers' knowledge and knowing through dialogue within and beyond the teaching profession. Although this framework is based on research in England, it provides a useful structure for monitoring the development of 'specialist' expertise as it emerges from practice:

1. The importance of understanding child development and learning in context;
2. Reflection and imagination: the value of knowing that you do not know everything and believing that change is possible;
3. The need to communicate understanding and resolve differences between the people who have useful knowledge: a relational process;
4. The need to recognise the school as a site for the development of teaching expertise and the creation of knowledge (Kershner, 2014, pp. 852–854).

The General Comment also encourages all stakeholders to collaborate and problem-solve in line with Kershner's (2014) core aspects, therefore acknowledging the relational process involved in developing 'specialist' expertise. Of the 88 experienced Tanzanian teachers surveyed in this study, only one had attended a course about inclusion, and only 53 (63.3%) reported having received training on reading, mathematics and 'participatory' child-centred methods, mostly through upgrading qualifications rather than bespoke CPD. These teachers have, therefore, developed their knowledge and expertise unevenly, over time and without being connected to national or international debates about disability equality and inclusion.

4. Rural Primary Schools as Sites for the Development of Disability-Focused Expertise

The experienced teachers' knowledge and expertise needs to be seen in relation to the younger, less experienced NQTs, who demonstrated positive attitudes towards children with disabilities, but did not teach equitably. Indeed, the NQTs reported their difficulties in identifying and adequately responding to the large group of 'slow learners' in their classes, and that they used generic, rather than individualised, strategies, such as repetition. However, their socio-cultural view of learners led them to blame the shortage of resources and the narrow curriculum for the difficulties they faced, rather than locating the 'problem' within the learners (Westbrook & Croft, 2015).

What is striking about the more experienced teachers is that they demonstrated considerable skills in their attempts to include all children, and acute awareness of how they exclude children with disabilities in various ways. Sophia reports a big shift in her attitudes following a short training course on inclusion:

> At first I considered these kids [with disabilities] as a disturbance to my class because you may be teaching then a kid come and ask you to take him/her to the toilet. Then you have to stop teaching and attend him/her. But after attending that seminar we were told to love them, so now I feel normal…..The environment of the child may affect his/her learning. So, the training helped me a lot!

This instruction to 'love' the children with disabilities constituted the removal of an exclusionary barrier in Sophia's attitude towards the child who needed personal assistance. By enacting this newly acquired knowledge and 'learning in context' (Kershner, 2014, p. 852), Sophia developed a sociocultural construction of disability. Similarly, Arbeiter and Hartley (2002) found that daily exposure to children with disabilities enabled teachers in Uganda to create the conditions conducive to teaching inclusively.

However, the large class sizes meant that teachers were unable to attend to, or physically reach, all the children. Catharine points out that when movement is restricted in overcrowded classrooms selecting 3–4 pupils who answer correctly is an indication that 'the lesson went on well'. Faced with these physical barriers, checking on learning at all in this context could be viewed as an achievement (Westbrook & Croft, 2015). It was noticeable that some teachers tended to focus on children with their hands up, those who were mobile and so able to walk to the chalkboard, or who were simply seated at the front. Yet teachers reported moving learners with visual and physical disabilities, and those who were 'short', to the front of the classroom so that they could see and hear the teacher. This enabled children who needed the most help to be situated in the heart of the classroom. Although apparently a simple intervention, the act of 'insisting' that the children were seated at the front so that they could see well demonstrates teachers' agency. In an earlier study in a Tanzanian primary school, Mmbaga (2002) observed children with visual impairments being seated on the front row by teachers, and then being mostly overlooked—similarly, the least academically able were seated at the back and were rarely paid any attention.

The movement of the subject specialist teachers every 30 minutes to another class, or the change of focus to another subject in the same class, meant that pedagogical practice and appropriate seating were not always consistent, or possible. Justina accepted that many children were marginalised from, and not engaged in learning. Teachers resorted to writing words and calculations on the chalkboard, which was not visible from the back of the class. Textbook shortages meant that all children experience daily inequities, and teachers have become accustomed to teaching inequitably. Justina acknowledged that she often selected 'the few trusted ones' who can read well to hold the textbook 'to represent the others', and sometimes resorted to punishment:

> Sometimes, to be frank, I give them some punishments so that I am able to control the class so that they do not make noise but instead listen to what is being read.

In contrast to the NQTs' classrooms, the experienced teachers had homemade charts and teaching materials on display, and several teachers had adapted these specifically for children with disabilities, as Rose reports:

> My manila [paper] had large font size and it was also a little bit bold. Also, all other items had white colour. The aim was to enable albino students to see well because they have partial visual impairment. That is why I was asking them…'can you see well'?

Writing in large font on the chalkboard, and using manila sheets to enable students with albinism to learn, are specific pedagogical adaptations, and indicate that inclusion for Rose is not only physical, social or medical, but determined by the level to which children with disabilities are enabled to grasp academic content. Rose explained that she refers to circular objects, such as dinner plates, to link the concept of a circle in mathematics lessons to children's existing knowledge. She also instructed children with visual impairments to feel the shape of their desk as an example of a rectangle. Here is imagination and reflection in action (Kershner, 2014). Rose and Justina used Braille texts routinely in their teaching practice. In response to the question, 'If you had a class without students with special educational needs, would you have used different methods?' Rose replied:

> No! I would have used the same methods because it's not that the methods I use are for helping only the students with special needs, but also the rest. Maybe if there were the blind then we would have to have their reading tools. Even the ones who can see can use them. So the teaching aid and the methods that I used here I could also use then.

Rose's epistemological construction of disability and her teaching practice benefit all learners, rather than privileging only a few. Another of the 'varieties' of inclusions identified involved Sophia's use of singing and patient repetition:

> I go slowly, step by step, teaching them basic things, not like the way I do for others. For example, for these children I can just say give me two things, then I write him number two and ask him to spell it by singing. But tomorrow he may forget and you start again.

Sophia added, 'So they don't go far'. While this could indicate a deterministic, medical construction, Sophia assumes capability by differentiating learning through spelling and persisting with this, even while recognizing that progress can be slow. Sophia also recognizes the importance of establishing friendship for children with disabilities, who she says are:

> 'Not seriously [in school] for learning'. They have just come to school so that they enjoy their peers' company, and to develop the sense of love and self-identity.

The importance Sophia puts on social inclusion has to be read in the context of the central importance of community in Tanzania (Kisanji, 1998). She also says, 'They can stay in one class for two years before they proceed to the next class', indicating that the school is flexible and allows some children to repeat grades in order to meet prescribed learning outcomes, rather than assuming that they would simply drop out. Similarly Rose and Justina reported that they had not learned sufficient sign language, and so had '*failed*' those students with hearing impairments, despite having seated them at the front, ensured that their faces could be seen, and spoken 'loudly'. Being aware of what they do not know signals their desire to act on this (Kershner, 2014).

5. Discussion

Slee (2001, p. 172) has argued that inclusive education is an oxymoron since 'schools were never really meant for everyone. The more they have been called upon to include the masses, the more they have developed the technologies of exclusion and containment'. Indeed, there is plenty of evidence of such practices globally, including in materially rich environments (Alves, Andreasson, Karlsson, & Miles, 2016). One of the reasons why we chose to focus on the Tanzanian teachers' 'knowledge and knowing' as a focus for this thematic issue, was precisely because very few of the experienced teachers were practising 'exclusion and containment'. Instead they are responding to learners with disabilities as successfully as their training, the rigid curriculum and poor material conditions allow. They do not use the language of equality or inclusion, but are conscious that inclusion and exclusion co-exist in practice (Dyson, 1999). Furthermore, children with disabilities are not seen by most teachers as 'problems to be fixed'. They also show that disability can be seen within inclusive education as an opportunity for 'democratising and enriching learning' (UNESCO, 2017, p. 13).

The Tanzanian teachers adapt seating, their speech, posture and explanations, and create teaching and learning materials to enable greater participation and learning, including making use of assistive devices, as stipulated in the CRPD. In contrast to the NQTs, these experienced teachers go beyond generic strategies to adapt their pedagogy to specific individual impairments, are confident in using assistive devices, and strive to overcome material barriers of inadequate seating and large classes. Most importantly, they are aware that they 'do not know everything' and believe that change is possible (Kershner, 2014). They also demonstrate this by being willing to take risks and try things out in practice. We argue here that these teachers have developed some basic disability equality expertise as part of their everyday practice, without professing to be teaching inclusively, and without having had any specialist training. This sort of experiential learning is not unusual (see for example, Miles, 2009b), but tends to be unrecognised.

The General Comment has made some helpful recommendations about the possible focus of teacher training for inclusive education as a mainstream activity, which would require teacher educators to grapple with disability as a social construct. Despite the apparently strong inclusive policy focus in East and Southern Africa, there is no evidence of 'teacher training for inclusive education as a mainstream activity' (Riggall & Croft, 2016, p. 12). Training courses are mainly offered to teachers of children with disabilities and emphasise special education approaches rather than disability equality. For some of the Tanzanian teachers, medical, socio-cultural and interactionist models of disability remain influential and are visible in their practice. Justina's account of her failure to create equal conditions, and her lack of sign language knowledge are representative of some of the other teachers' practice. This shows how disability inequality can be reproduced through a narrow conceptualisation of 'learning', for example, and through the use of punishment to control learners. By contrast, Rose's construction of disability is a transformative one, which sees her develop a more imaginative practice of ensuring that learners with disabilities grasp mathematical concepts and have direct sight of texts on an equal basis to their peers—a construction that benefits all learners, and provides a glimpse of the transformational education agenda envisaged by the SDGs.

Even so, it could be argued that the human rights debate, as enshrined in international policy, is out of step with the material inequalities of insufficient desks and books, and overcrowded curricula and classrooms in which many learners are routinely excluded, and in particular those with disabilities. An equal right to education is largely contingent on the material context (Vavrus & Bartlett, 2012), and teachers' resistance to teaching equitably can undermine disability equality policies in any context. Exclusions here are structural, and rooted in material, physical, curricular and knowledge deficits.

6. Conclusions

We have argued that the experienced teachers' practices in Tanzania are moving unevenly, but discernibly towards disability equality. This is enabled by processes of inclusions in classrooms created by teacher autonomy, agency and reflective and imaginative practice, alongside material, attitudinal, structural, pedagogic and curricular barriers. This unevenness illustrates the limits of inclusive education as a construct and the considerable challenges that exist for full disability equality to take place. It also highlights the need for inclusive education to grapple with disability as a social construct. There is a need for academics and policy makers to consider the material as well as curricular and policy basis of inclusion. We suggest that a commitment to measuring the development of inclusive processes should be prioritized over narrow academic outcomes, and this would enable teachers to develop knowledge and expertise through collaborative learning.

Disability equality measures are more likely to develop in meaningful ways once inclusive classroom practices have become better established. Similarly, government commitment is needed to address the fragility, inconsistency and unaffordability of specialized knowledge and services. Children with disabilities will have a limited experience of inclusive education, if even the most basic assistive devices are not made available. Finally, it is important to emphasise that ongoing efforts to educate policy makers about the complexity of creating equitable education systems are just as vital to the meaningful achievement of the General Comment as preparing and supporting teachers to respond to diversity.

In summary, we have argued that the achievement of equality for learners with disabilities currently relies largely upon the ingenuity of ordinary classroom teachers. Disability equality should not, however, have to rely on this. Communication and dissemination of existing expertise developed within classroom and school contexts by experienced teachers (Kershner, 2104) would go a long way towards ensuring that adaptive pedagogy, clearly written texts, imaginative explanations, good use of assistive devices and classroom re-organization become commonplace in the physical 'place' of the classroom. In this sense, the teachers' inclusive practices can be seen as effective pedagogies which could inform teacher education colleges and policy makers. The reconstruction of disability in order to 'reimagine education' (Winzer & Mazurek, 2017, p. 18) thus becomes probable, rather than locked into policy or theory, and merely aspirational.

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Conflict of Interests

The authors declare no conflict of interests.

References

Akyeampong, K., Pryor, J., Lussier, K., & Westbook, J. (2013). Improving teaching and learning of basic maths and reading in Africa: does teacher preparation count? *International Journal of Educational Development*, *33*(3), 272–282.

Allan, J. (2010). The sociology of disability and the struggle for inclusive education. *British Journal of Sociology in Education*, *31*(5), 603–619.

Alves, I., Andreasson, I., Karlsson, Y., & Miles, S. (2016). Constructions of student identity in talk and text: A focus on special educational needs in Sweden and England. In D. Beach & A. Dyson (Eds.), *Equity in education in cold climates, in Sweden and England*. London: The Tufnell Press.

Arbeiter, S., & Hartley, S. (2002). Teachers' and pupils' experiences of integrated education in Uganda. *International Journal of Disability, Development and Education*, *49*(1), 61–78.

Committee on the Rights of Persons with Disabilities. (2016). *General comment No. 4 (2016) on the right to inclusive education*. New York: United Nations.

Dyson, A. (1999). Inclusion and inclusions: Theories and discourses in inclusive education. In H. Daniels & P. Garner (Eds.), *World yearbook of education 1999: Inclusive education* (pp. 36–53). London: Kogan Page.

Glewwe, P., Park, A., & Zhao, M. (2016). A better vision for development: Eyeglasses and academic performance in rural primary schools in China. *Journal of Development Economics*, *122*, 170–182.

Grech, S. (2014). Disability, poverty and education: Perceived barriers and (dis)connections in rural Guatemala. *Disability in the Global South*, *1*(1), 128–152.

Kershner, R. (2014). What do classroom teachers need to know about meeting special educational needs? In L. Florian (Ed.), *The Sage handbook of special education* (2nd ed., Vol. 2, pp. 841–867). London: Sage.

Kisanji, J. (1998). The march towards inclusive education in non-Western countries: Retracing the steps. *International Journal of Inclusive Education*, *2*(1), 55–72.

Malinga, J., & Gumbo, T. (2016). Advocacy and lobbying: The road map from charity to human rights. In E. G. Iriate, R. McConkey, & R. Gilligan (Eds.), *Disability and human rights. Global perspectives*. London: Palgrave Macmillan.

Miles, M., & Hossain, F. (1999). Rights and disabilities in educational provision in Pakistan and Bangladesh: Roots, rhetoric, reality. In L. Barton & F. Armstrong (Eds.), *Disability and human rights in education: Cross cultural perspectives*. Buckingham, UK: Open University Press.

Miles, S. (2009a). *Creating conversations: An inclusive approach to the networking of knowledge about education in southern contexts*. PhD Thesis, Manchester: University of Manchester.

Miles, S. (2009b). Engaging with teachers' knowledge: Promoting inclusion in Zambia. *Disability and Society*, *24*(5), 611–624.

Miles, S., & Singal, N. (2010). The education for all and inclusive education debate: Conflict, contradiction or opportunity? *International Journal of Inclusive Education*, *14*(1), 1–15.

Mmbaga, D. R. (2002). *The inclusive classroom in Tanzania. Dream or reality?* Stockholm: Institute of International Education, Stockholm University.

Pryor, J., Akyeampong, K., Westbrook, J., & Lussier, K. (2012). Rethinking teacher preparation and professional development in Africa: An analysis of the curriculum of teacher education in the teaching of early reading and mathematics. *Curriculum Journal*, *23*(4), 409–502.

Riggall, A., & Croft, A. (2016). *Eastern and Southern Africa regional study on the fulfilment of the right to education of children with disabilities*. Reading, UK: Education Development Trust.

Singal, N., & Muthukrishna, N. (2014). Education, childhood and disability in countries of the South—Repositioning the debates. *Childhood*, *21*(3), 293–307.

Slee, R. (2001). Social justice and the changing directions in educational research: The case of inclusive education. *International Journal of Inclusive Education*, *5*(2/3), 167–177.

Terzi, L. (2008). *Justice and equality in education. A capability perspective on disability and special educational needs*. London: Continuum.

The United Republic of Tanzania. (2010). *People with Disabilities Act, No 9*. Dar-es-Salaam: The United Republic of Tanzania. Retrieved from http://www.usicd.org/doc/wcms_151288.pdf

United Nations. (1989). *Convention on the rights of the child*. New York: UN.

United Nations. (1993). *The standard rules on the equal-*

ization of opportunities for persons with disabilities. New York: UN.

United Nations. (2006). *Convention on the rights of persons with disabilities and optional protocol*. New York: UN.

UNESCO. (1994). *The Salamanca statement and framework for action on special needs education*. Paris: UNESCO.

UNESCO. (2000). *Education for all: Meeting our collective commitments. Notes on the Dakar framework for action*. Paris: UNESCO.

UNESCO. (2012). *Youth and skills: Putting education to work. Global monitoring report—Education for all*. Paris: UNESCO.

UNESCO. (2017). *A guide for ensuring inclusion and equity in education*. Paris: UNESCO.

Vavrus, F., & Bartlett, L. (2012). Comparative pedagogies and epistemological diversity: Social and material contexts of teaching in Tanzania. *Comparative Education Review*, *56*(4), 634–658.

Wapling, L. (2016). *Inclusive education and children with disabilities: Quality education for all in low and middle income countries*. Bensheim: CBM. Retrieved from http://www.cbm.org/article/downloads/54741/Quality_Education_for_All_LMIC_Evidence_Review_CBM_2016_Full_Report.pdf

Westbrook, J., Durrani, N., Brown, R., Orr, D., & Pryor, J. (2014). *Pedagogy, curriculum, teaching practice & teacher education in developing countries. A rigorous literature review*. London: Department for International Development.

Westbrook, J., & Croft, A. (2015). Beginning to teach inclusively: An analysis of newly-qualified teacher pedagogy in lower primary classes in Tanzania. *Teaching and Teacher Education*, *51*, 38–56.

Winzer, M., & Mazurek, K. (2017). The Convention on the Rights of Persons with Disabilities. Reconstructing disability to reimagine education. In M. Tejero-Hughes & E. Talbott (Eds.), *The Wiley handbook of diversity in special education*. Chichester: Wiley Blackwell.

World Health Organisation. (2011). *World report on disability*. Geneva, Switzerland: WHO.

World Health Organisation. (2014). *Global cooperation on assistive technology*. Geneva: WHO. Retrieved from http://www.who.int/phi/implementation/assistive_technology/phi_gate/en

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Review

Education, Work, and Motherhood in Low and Middle Income Countries: A Review of Equality Challenges and Opportunities for Women with Disabilities

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Abstract

This study looks at the equality challenges and opportunities for women with disabilities in low and middle income countries (LMICs) to participate and succeed in education, employment and motherhood. It is based on a systematic review of the literature from academic and non-governmental organization databases. The search of these databases yielded 24 articles, which were subsequently passed through open, axial, and selective coding. The resulting review found that women with disabilities in LMICs have severe difficulty participating and succeeding in education, employment and motherhood due to a number of interrelated factors: (i) hampered access to education, employment, intimacy and marriage, (ii) stigma and cultural practices resulting in discrimination and prejudice, and (iii) lack of support from family, teachers and institutions—all of which are exacerbated by poverty. Support from families, communities, the government, and non-governmental organizations improves women's ability to fulfil their social roles (as students, employees and mothers), resulting in a better quality of life. Strategies that create awareness, minimize poverty and facilitate justice may improve the opportunities for women with disabilities in LMICs to participate in education, employment and motherhood, as well as their ability to succeed in these domains.

Keywords

capability; disability; education; employment; low and middle income countries; motherhood; social roles; women with disabilities

Issue

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1. Introduction

Participation in social roles that are valued by society can lead to many benefits for those who have the opportunity to take on these roles (Osburn, 2006). Among other things, these benefits may include: a sense of belonging, an education, the development and exercise of one's capabilities, opportunities to participate in society, a decent material standard of living, and opportunities for work and self-support (Osburn, 2006; Wolfensberger, Thomas, & Caruso, 1996). The purpose of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities (Article 1), and it sets out a number of rights of persons with disabilities, including the right to education and employment on an equal basis to others, as well as certain rights related to family and reproduction (United Nations, 2006). The Convention recognises that "disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others" (Preamble, para. e, United Nations, 2006). It requires states parties to be aware that persons with disabilities enjoy legal capacity on an equal basis with others and should be supported to exercise their legal capacity (Article 12, United Nations, 2006). The Convention makes the participation of persons with disabilities one of its principles and enshrines the right of disabled persons to participate fully and equally in the community, in education, and in all aspects of life. According to the World Disability Report (WHO & World Bank, 2011), participation in social roles by people with disabilities is much more limited than participation by the general population; this is particularly true for women with disabilities, who suffer double discrimination on account of disability and gender. The 2030 Sustainable Development Agenda (6), which is captured in the Sustainable Development Goals (SDGs; United Nations, n.d.) (7), states that addressing the needs of, and barriers faced by, people in disadvantaged groups is a prerequisite for an inclusive and equitable society. This is reflected in the pledge 'leave no one behind'.

Understanding the opportunities and challenges that women with disabilities in low and middle income countries (LMICs) face in participating meaningfully in education, employment and family life (Tefera & Van Engen, 2016; Tefera, Van Engen, Van der Klink, & Schippers, 2017) is critical, not only to the articulation of inclusive development theories, but also to the design of appropriate (family) interventions to improve quality of life. While there has been increased interest in disability issues in developing countries, there is limited data available in this field (Loeb & Eide, 2008). The existing data is often fragmented and anecdotal (Groce, Kett, Lang, & Trani, 2011). The small, but growing, literature base indicates that the substantial links between education, employment and family life are more multifaceted and interrelated than previously assumed. The intersectionality of high levels of poverty with gender and disability in LMICs makes disability equality substantially different in these countries than in high income countries, which are also typically better researched. Our review, therefore, focused specifically on disability equality in LMICs.

To critically analyse all present and published knowledge, we systematically reviewed the literature on LMICs that looks at the relationship between education, employment and motherhood as providing access to the major social roles of student, employee and mother in order to answer the following research question:

> What are the important challenges and opportunities for women with disabilities in low and middle income countries to participate in education, employment and motherhood, and what factors determine their participation in the important social roles emerging from these (of student, employee and mother), as well as their achievement of valuable goals in life?

In the following paragraphs we introduce the concept of 'social role valorization' (SRV; Osburn, 2006; Wolfensberger, 1983; Wolfensberger & Thomas, 2005) and the capability approach (Nussbaum, 2006; Robeyns, 2005; Sen, 1983, 2009), which will be used as a guiding framework to understand disability inequality in participation in social roles and the achievement of valuable goals in life. Subsequently, we present the literature review, with a focus on the roles that women with disabilities have as students, employees and mothers. In the discussion of this review, we will argue that these roles are interrelated, as achievements in one impact on opportunities in the others.

2. Theoretical Framework

The social roles that individuals identify with and that others in society attribute to them vary. The concept of shaping social roles by means of enhancement of competencies and image is referred to as SRV, a term coined by Wolfensberger (1983). Women with disabilities can identify as students, employees, mothers and so forth. These roles are valued in society—but not all people are valued by society. People with disabilities are often societally devalued, or at high risk of becoming devalued (Osburn, 2006). For example, society does not identify women with disabilities as capable of playing a valuable role as students, employees or mothers. Adopting valued social roles allows women with disabilities to engage in meaningful activities, which promotes self-esteem and confidence, which, in turn, helps them to improve their quality of life (Osburn, 2006; Flynn & Aubury, 1999; Gardner & Carran, 2005; Lemay, 2006). Ultimately, participation in valued social roles can lead to the adoption of other valued social roles. For example, a woman with a disability who is educated and employed may be confident enough to strive for additional socially-valued roles, such as marriage and motherhood.

As stigma is imposed on women with disabilities, and cannot be 'disposed' of, women often tend to internalize and accept society's negative evaluation. Being stigmatized results in rejection, exclusion and discrimination, thus limiting the opportunities for women with disabilities to achieve their potential and increasing the likelihood of poor treatment by others in society. Wolfensberger and Thomas (1994) emphasize that if people are devalued by society, or are at risk of being devalued, their acquisition of valued social roles may decrease the stigma and discrimination they experience.

Another framework that can help us to understand the disability inequality of women in LMICs is the capability approach. This approach, introduced by Sen (1980, 1993, 2009), is a normative approach that states that individuals should have the capabilities to conceive, pursue, and revise their life plans (Alkire, 2002, 2005; Nussbaum, 2006; Robeyns, 2005; Sen, 1999; Venkatapuram, 2011). Society or societal institutions should enable people to achieve these capabilities. There are three important elements in the capability approach, namely: *capabilities*, *functionings* and *freedom*. In the most basic sense, functionings represent the states and activities that constitute a person's being: "beings and doings people have reason to value" (Sen, 1992, p. 40). The capabilities of an individual reflect the different combinations of functionings that a person is able to achieve, depending on his or her particular circumstances—in other words, the various combinations of what s/he can do or be. According to Sen, an individual's well-being should be assessed in terms of capabilities (potentials to achieve), as functionings (achievements) may be the result of constrained choices or reflect a limitation in choices.

So, it is important to evaluate what an individual can do, or is able (and enabled) to do, and not just what they actually do. Capabilities represent a person's opportunity and ability to achieve valuable outcomes, taking into account relevant personal characteristics and external factors: being able and enabled.

In the capability approach it is recognized that all people are different in terms of their resources and characteristics. Because people differ in terms of these 'inputs', people also need different means or 'conversion factors' to achieve equity in opportunities and outcomes. Therefore, in the capability approach, justice is not considered to be *equality in means* (everybody has the right to the same means), but *equality in outcomes* (everybody should have the same opportunity to achieve valuable outcomes). Hence, equality for women with disabilities is about having the opportunity and ability to shape one's life in terms of one's valued goals in relation to education, employment and motherhood, which might require extra means for this group. This emphasis on equality in outcomes is in accordance with the above mentioned requirement of the CRPD (Article 12, United Nations, 2006).

3. Method

The review methodology by Hannula, Kaunoen and Tarkka (2007, p. 105) was followed for the literature review. By exploring and evaluating findings of previous published research, a review constitutes an essential aspect of all research related to the themes, enabling the work to be set in the context of what is known and what is not known (Saunders & Rojon, 2011). Grounded theory, as a method of rigorously reviewing literature, was used during the analysis stage (Wolfswinkel, Furtmueller, & Wilderom, 2013). This method involves five steps: define, search, select, analyse, and present. Several databases were used to identify suitable articles: Web of Science, PsychINFO, Google Scholar, and MEDLINE. The keywords and combination of keywords used to search all databases included: "(disabled women or women with disabilities) OR (low or middle income countries or Global South), OR education OR employment OR (motherhood or intimacy or marriage) OR family life". The criteria for the inclusion of articles were: (i) published in English, (ii) full article accessible, and (iii) peer reviewed and published during the period 2006–2015. Articles were excluded when: (i) there was no reference to women with disabilities, (ii) developing or low or middle income countries were not addressed, and (iii) there was no reference to either of the three themes (education, employment, or motherhood) and no reference to the terms disabled, disabling, disability or disabilities. A total of 25,566 articles were initially identified and included in the search.

The selection process is outlined indicated in Chart 1, which shows the coding process from the database selection up to the final coding round and the final selection of articles to analyse.

4. Coding

The analysis stage passed through open, axial and selective coding. In the open coding, all statements about education, employment and motherhood were selected. During the axial coding, concepts were categorized based on the three themes (education, employment, motherhood). Repeated ideas (different authors using similar terms to explain the same idea of discrimination in relation to the themes) were included if they were expressed in different ways. Two coders (first and fourth author) independently selected key fragments from the articles on the themes of education, employment and motherhood, producing a table that also included some of the study characteristics of the articles (e.g., sample information, methodology). The two tables were compared by the second and third author and a final table created, which was subsequently used for the analyses (available from the authors upon request).

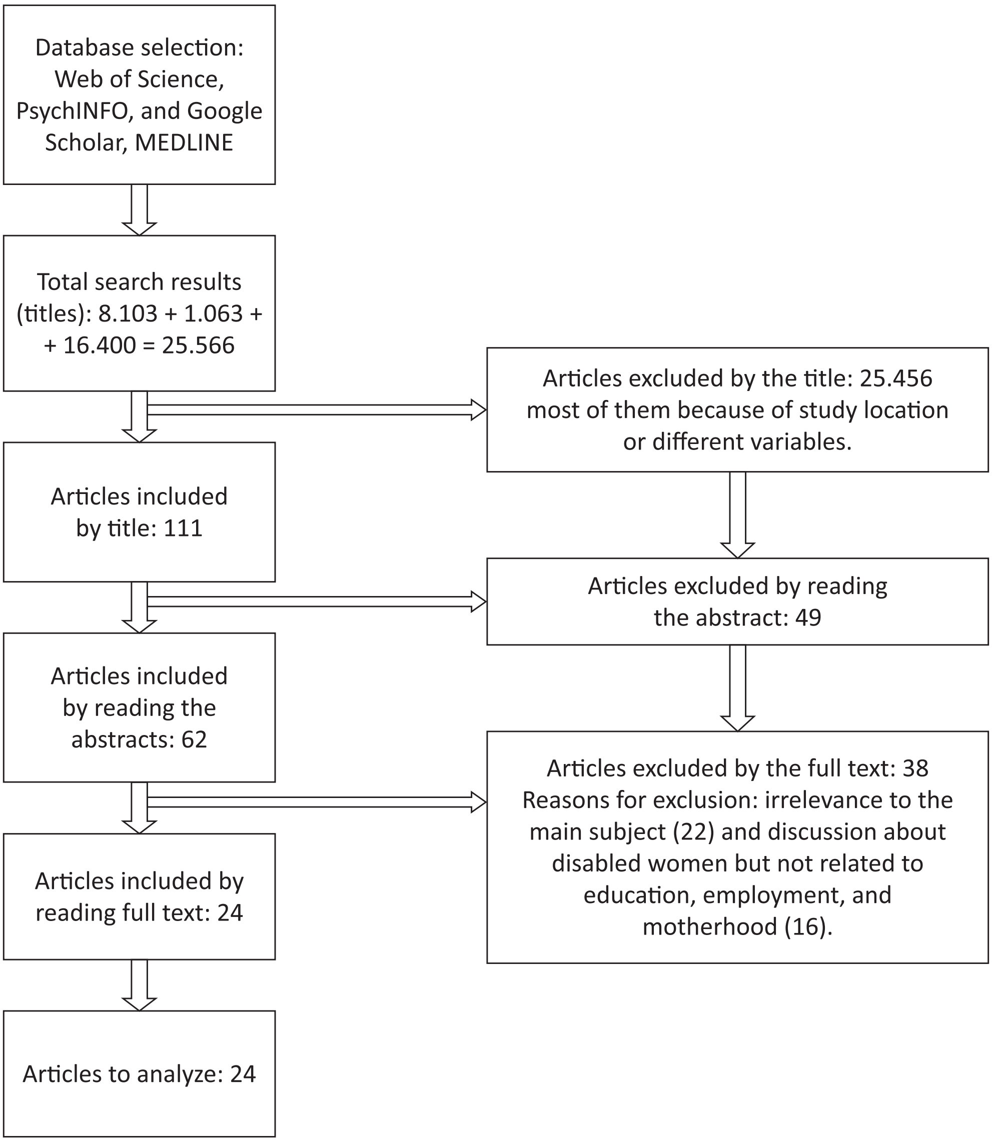

Chart 1. Study selection process.

5. Description of Sample

The 24 articles follow different methodologies. There were: 11 qualitative studies (Braathen & Kvam, 2008; Dark and Light Blind Care, 2008; Dhungana, 2007; Kassah, Kassah, & Agbota, 2013; Kiani, 2009; Kvam & Braathen, 2008; Lamichhane, 2012a; Mitra, Posarac, & Vick, 2011; Morrison et al., 2014; Naami, Hayashi, & Liese, 2012; Simkhada et al., 2013; Tuomi, Lehtomäki, & Matonya, 2015), 7 reviews (Emmett & Alant, 2006; Groce et al., 2011; Moodley & Graham, 2015; Opini, 2010; Ortoleva, 2010; Parnes et al., 2009), 1 quantitative study (Naami, 2015), 2 mixed studies (qualitative and quantitative) (Lamichhane, 2012b; Salome, Mbugua, & Ong'eta, 2013), 1 examination of UN disability convention proceedings (UN & UNC, 2012), 1 examination of domestic legislation (Gupta, 2013), and 1 conference paper (which is on the right to autonomy and self-determination) (Frohmader & Ortoleva, 2013).

6. Results

This section presents the results of the literature review in terms of how access to education, employment, intimacy and marriage; stigma related to cultural values and cultural practices; and support (or the lack thereof) influences the participation of disabled women in education, employment, and motherhood and family life.

6.1. Education

In the literature reviewed, there are 16 articles that mention the education issues of women with disabilities in LMICs. In a study using the World Health Survey data, Mitra et al. (2011) compared 15 developing countries in Sub-Saharan Africa, Asia and Latin America in terms of the prevalence of disability and differences between individuals with and without disabilities for several indicators of poverty, including the proportion of primary school completion. In all countries, except Burkina Faso (where lack of primary school education is low in general, less than 89%), the proportion of primary school completion rates is lower among persons with disabilities. In Mauritius and Zimbabwe, primary school completion for persons with disabilities is about the same as for persons without disabilities. In other countries, such as Ghana, Kenya, Malawi, Zambia, Bangladesh, Lao PDR, Pakistan, Philippines, Brazil, Dominican Republic, Mexico and Paraguay, the difference in primary school completion rates between persons with and without disabilities is somewhat smaller. Mitra et al. (2011) conclude that, in terms of poverty (using a multidimensional indicator of poverty including education), women generally fare worse than men. Unfortunately, there are no analyses comparing poverty among men and women with and without disabilities.

In a study using different sources of panel data, Moodley and Graham (2015) compared the education level of men and women with and without disabilities in South Africa. They found that the higher you go in terms of education level, the lower the completion rate of women and men with disabilities. Although primary school completion among men and women with disabilities is higher (26.1% and 28.6%, respectively) than among men and women without disabilities (21.4% and 20.0%, respectively), the reverse pattern is found with higher levels of education: 32.7% of men and 30.8% of women with disabilities have 'some secondary education', compared to 50.6% of men and 48.4% of women without disabilities. The proportion of individuals with completed secondary level education is smallest for women with disabilities (9.2%), compared to disabled men (12.8%), non-disabled women (16.6%), and non-disabled men (16.5%). Tertiary education attainment is low: 1.6% for non-disabled men and women, compared to 0.7% for men and women with disabilities. In a large survey among men and women with disabilities (in which 42.1% of the respondents were women with disabilities) conducted in the Kathmandu valley of Nepal, Lamichhane (2012a, 2012b) found the average years of schooling for persons with disabilities to be 8.8 years, compared to the country average of 9.4 years. However, those with hearing impairments (6.9 years) had much less schooling than those with visual (9 years) or physical impairments (10.9 years).

6.1.1. Accessibility

Reports that review different databases (Mitra et al., 2011; Opini, 2010; Parnes et al., 2009; UN General Assembly, 2012) conclude that women with disabilities face more difficulties than men with disabilities, or people without disabilities, in gaining access to education. For many of those who do access education, the continuation of education is also an issue. A study by Kassah et al. (2013), which interviewed five women with physical disabilities in Ghana who had faced physical abuse, found that the women did not complete school because of inability to pay school fees. Braathen and Kvam (2008) also found lack of money to be a main reason for quitting school early, while Kiani (2009), in explaining the perceived inability of women with disabilities in Cameroon, noted that some families prioritize their non-disabled daughters when paying school fees, as they believe educating women with disabilities is a waste of money. Other reasons for discontinuing education mentioned in the articles were: physical inaccessibility of schools (Braathen & Kvam, 2008, Kiani, 2009), inadequate training of school teachers (Simkhada et al., 2013), and lack of encouragement from teachers (Tuomi et al., 2015).

6.1.2. Stigma Related to Cultural Values and Practices

A number of articles cite societal expectations that women with disabilities are either unable or unworthy of education as a major reason for lack of education opportunities. Kvam and Braathen in their study of the daily lives of 23 women with disabilities in Malawi (2008a) and follow-up study by Braathen and Kvam, using focus groups and interviews (2008b), as well as Lamichhane (2012a), who studied the employment situation of 402 persons with disabilities in Nepal, describe how the societal expectation that women with disabilities do not need education or special schools hinders women with disabilities from participating in education. Simkhada et al. (2013), in their qualitative exploratory study of knowledge and attitudes towards women with disabilities in rural Nepal, found that women with disabilities in LIMCs suffer from limited availability of resources for education (e.g., Braille facilities), because resources are channelled to non-disabled students, as women with disabilities are considered incapable of participating in education. Salome et al. (2013) report that low expectations by teachers and peers undermine female students' self-esteem. Female students are also teased and taunted by their peers and teachers and reported told that they are incapable of achieving high grades. Moreover, they also report that many women with disabilities experience gender based violence while undergoing education (Salome et al., 2013).

6.1.3. Support and Lack of Support

Four of the articles reviewed indicate family resistance to the education of women with disabilities (Dhungana, 2007; Kiani, 2009; Lamichhane, 2012a; Kassah et al., 2013). Some families not only deny girls with disabilities access to school, but hide them away due to fear of stigma (Gupta, 2013; Lamichhane, 2012a). Kassah et al. (2013) explain the lack of support from parents and other family members as reluctance to support their daughters with disabilities. Respondents in that study indicated that families prioritize the education needs of their non-disabled children, because they believe that educating children with disabilities is a waste of resources.

Yet, paradoxically, some articles mention that educating women with disabilities promotes their acceptance by their family and society. For example, Tuomi et al. (2015) note that educated women with disabilities gain value and respect within their family and are allowed to take part in family discussions and decision-making. Braathen and Kvam (2008a) found that educating women with disabilities makes them more confident.

Several articles also stress the importance of support within the education system. Emmett and Alant (2006), for instance, conclude this from a pilot study that interviewed Tanzanian women with disabilities in higher education. Tuomi et al. (2015) found clear indications that services, such as guidance and counselling, contribute to the success of women with disabilities who have started education. The authors acknowledge that the extra help received by disabled women contributes significantly to their success; for example, some teachers give women with disabilities preferential seating, which enables these students to become known to their teachers.

6.2. Employment

There are 14 articles that discuss the participation of women with disabilities in LMICs in employment. In some articles the participation of women with disabilities is compared to the participation of either men with disabilities or women without disabilities. On a global scale, the employment rate of men without disabilities is 85%, compared to 75% for women without disabilities; for men with disabilities, the employment rate is 52%, compared to 48% for women with disabilities (Salome et al., 2013). In LMICs, much larger differences are reported between men and women with disabilities: almost 60% of women with disabilities in Ghana are unemployed, compared to 40% of men with disabilities (Naami, 2015).

Employment has three important aspects: obtaining employment, job retention, and employment conditions. For all three aspects, more problems are experienced by women with disabilities in LMICs as discussed in the following sub-sections.

6.2.1. Obtaining and Retaining Employment

Nine studies mention obtaining employment (Dark and Light Blind Care, 2008; Gupta, 2013; Kiani, 2009; Lamichhane, 2012b; Moodley & Graham, 2015; Naami, 2015; OHCHR, 2012; Ortoleva, 2010; Opini, 2010) and one study mentions retaining a job as problems for women with disabilities (OHCHR, 2012). Furthermore, even when women with disabilities in LMICs have obtained and retained a job, they have difficulties with employment conditions. Lower than average wages are reported for employed women with disabilities in three studies (OHCHR, 2012; Naami, 2015; Ortoleva, 2010). Little career progression for women with disabilities is reported in two studies (Naami, 2015; OHCHR, 2012) and less interesting jobs for women with disabilities is mentioned in two studies (Naami, 2015; Ortoleva, 2010). Underemployment, related to lower wages, but also to less challenging jobs, for women with disabilities is referred to in one study (Groce et al., 2011).

6.2.2. Employment Conditions

Several studies mention the relationship between employment conditions and other aspects of the lives of women with disabilities in LMICs. Although in most studies the design did not allow for conclusions to be drawn on causal relationships, eight studies make suggestions about the causes of the poor employment status of these women. Cultural stigma—referred to 'stereotyping', 'discrimination' or 'traditional attitudes'—is mentioned in five studies (Dark and Light Blind Care, 2008; Gupta, 2013; Kiani, 2009; Lamichhane, 2012b; Naami, 2015). Related to this, Moodley and Graham (2015) report that, in South Africa, black women with disabilities experience discrimination based on the intersection between disability, gender, race and poverty. Moodley and Graham (2015) further explain that women with disabilities experience stigma simultaneously because of disability and (related) unemployment.

Lack of education and vocational skills of women with disabilities is named in three studies (Dhungana, 2007; Naami, 2015; Opini, 2010). Opini states that there is a mismatch between the vocational skills that women with disabilities are trained in and the needs of the job market. In a review on the participation of persons with disabilities in the labour force, Opini (2010) reported that women with disabilities are further disadvantaged because of their gender. In two studies, the consequences of being unemployed are identified. Naami (2015) states that the limited participation of women with disabilities in the labour force results in their limited power and influence in decision-making, both at home and in the community. Moodley and Graham (2015, p. 31) describe the constraints women with disabilities face in terms of their gender, particularly with regard to labour market participation and income.

6.3. Motherhood and Family Life

There are 12 articles that discuss the experiences with motherhood and family life among women with disabilities in LMICs. Braathen and Kvam (2008) underline the needs of women with disabilities in terms of having children and establishing a family. However, women with disabilities are not expected to have relationships and are generally perceived as 'asexual'. Due to such perceptions, they have been denied the roles associated with womanhood, including the role of being a mother (Gupta, 2013). Furthermore, men prefer not to marry women with disabilities, because they are considered incapable of looking after their family. Additionally, there are myths that the presence of women with disabilities can bring bad luck to the family (Dhungana, 2007).

Married life is more difficult to obtain for women with disabilities in LMICs such as Malawi and Ghana, as such women are perceived to be unable to perform the duties of a good wife and mother, according to societal expectations, and, therefore, may not be seen as suitable wives (Braathen & Kvam, 2008; Price, 2011). Kassah et al. (2013) also confirm that women with disabilities are not considered to be capable of living up to female role expectations in terms of housekeeping, parenting, and motherhood. The practice of excluding women with disabilities from intimacy and married life results from the perception that they are either passive receivers of help or patients, or unable to fulfil the duties of marriage or give birth, as mentioned by Morrison et al. (2014) in a qualitative study about women's with disabilities in rural Nepal.

Other authors also report that women with disabilities in LMICs have a low likelihood of becoming intimate and married (Emmet & Alant, 2006; Braathen & Kvam, 2008; Parnes et al., 2009; Morrison et al., 2014; Kassah et al., 2013). According to Kiani (2009), one of the main challenges that all participants in two focus group discussions held in Cameroon shared was finding a suitable marital relationship. One woman stated that many men were afraid of women with disabilities due to the false belief that disability is contagious. Other women felt that African cultural norms expect women to perform household chores while bringing in an income. This places difficult expectations on women with disabilities, who are seen by men as 'unfit' partners (Kiani, 2009).

Besides obtaining a relationship, retaining a relationship it is also a problem for women with disabilities. The reviewed articles indicate a high divorce rate among women with disabilities who were married. If they manage to get married and become pregnant, their pregnancy may become a source of embarrassment. Many women with disabilities become embarrassed and this often prevents them from telling their in-laws about their pregnancy (Morrison et al., 2014). If they do not get married, women with disabilities are afraid of bringing shame on their family if their pregnancy is visible (Morrison et al., 2014). Emmet and Alant (2007) report in their study that women with disabilities are twice as prone to divorce or separation than women without disabilities. Both Braathen and Kvam (2008) and Kassah et al. (2013) found that the majority of women with disabilities in their study were divorced, widowed, or had never been married.

Braathen and Kvam (2008) mention pregnancy as one of the reasons for divorce among women with disabilities, as many men approach women with disabilities with the intention of exploiting them and using them as sex tools, rather than marrying them and having children. This is in accordance with the findings of Parnes et al. (2009), who studied the issues and implications of disability in low-income countries. A survey that they performed in Orissa, India, found that 100% of women and girls with disabilities were physically abused at home, 25% of women with intellectual disabilities had been raped, and 6% of women with disabilities had been forcibly sterilized.

If they succeeded in obtaining and retaining intimacy and married life, become pregnant and experienced motherhood, women with disabilities also experience many other problems. Regarding motherhood, women with disabilities, especially those with cognitive disabilities, have been stereotyped as incapable mothers (Gupta, 2013). Women with disabilities are discriminated against in relation to motherhood because of societal denial of maternity, parenting, and parental rights (Frohmader & Ortoleva, 2013; Gupta, 2013). Accordingly, systemic prejudice and discrimination against them continues to result in multiple and extreme violations of their sexual and reproductive rights, through practices such as forced contraception and/or limited or no contraceptive choices, poorly-managed pregnancy and birth, forced or coerced abortion, the termination of parental rights, and denial of, or forced, marriage (Frohmader & Ortoleva, 2013). The same authors state that the denial of the parental rights of women with disabilities can lead to the removal of their children as:

> Recent data demonstrates that a parent with a disability (usually a mother) is up to ten times more likely than other parents to have a child removed from their care, with the child being removed by authorities on the basis of the parents' disability, rather than any evidence of child neglect. (Frohmader & Ortoleva, 2013, p. 6)

The inaccessibility of health care services also limits pregnant women with disabilities from giving birth by increasing the likelihood of miscarriage and even death. Some sources suggest that women with disabilities also experience denial of maternal health services (Smith, Murray, Yousafzai, & Kasonka, 2004).

7. Discussion

From this review, we can conclude that women with disabilities in LMICs experience huge difficulties with respect to education, employment and motherhood. This concerns both obtaining and retaining the roles (of student, employee, mother), as well performing them. On a personal level, this means that many women with disabilities experience inequality as they are excluded from living the life they would like. Even if not all women with disabilities long for education, employment or motherhood, those who do are deprived of "the right to autonomy and self-determination, i.e., the right of everyone to make free and informed decisions and have full control over their body such as being married and have children—without any form of discrimination, stigma, coercion or violence" (Frohmader & Ortoleva, 2013, p. 2). This right also includes the roles of being a student or employee (Brown, Emerson, Falk, & Freedman, 1971).

The three social roles of student, employee and mother are interrelated. For example, providing disabled women with better education opportunities potentially has a great impact on increasing their employability; some of the reviewed articles found lack of education to be a factor in the low employment level of women with disabilities in LMICs. Consequently, the potential that women with disabilities demonstrate in their education and employment can be proof of their capability to fulfil other social responsibilities, such as married life and motherhood. For example, societies in LMICs generally exclude women with disabilities from motherhood responsibilities, which is one of the most socially valued roles in LMICs, as it is believed that they cannot take care of their children. Meanwhile, showing society that women with disabilities can be educated and employed implies that they can also handle other social roles and responsibilities, such as married life and motherhood. Their limited participation in the labour force results in reduced power and influence in decision-making, both at home and in the community (Kiani, 2009). Moreover, the financial power that women with disabilities acquire from their employment can contribute to the safe growth of their children, especially in LMICs where women with disabilities do not receive any financial support from the government. This, in turn, may minimize the fears men have about marrying women with disabilities with regard to the cost of married life and raising children (Tefera & Van Engen, 2016).

As expressed in most of the reviewed articles, lack of means is an important cause of the low participation of women with disabilities in social roles. Poverty alleviation is stated as an important strategy for minimizing discrimination (Eide & Ingstad, 2011). The link between inequality and poverty can be explained by considering the fact that poor people in LMICs generally lack essential means (such as adequate food, shelter, education, and health care) and access to employment in LMICs is limited. When it comes to women with disabilities, in addition to the poverty that they face alongside other citizens, their gender and disability make it harder for them to compete for the available resources with members of society without disabilities. In other words, the government and society prefer to invest the scarce resources for the betterment of those without disabilities. In some of the reviewed articles, parents were reported to be hesitant to invest in the education of children with disabilities, seeing it as a bad investment, as they believe that children with disabilities do not have the ability to succeed at school and will remain dependent on them whether they send them to school or not. So, there is a lack of awareness among the relevant stakeholders (governments, educators, employers, and families) in relation to the potential of people with disabilities.

Both social role theory and capability approach can be framed as helpful in identifying and analysing the important roles (capabilities) of disabled women. Moreover, the capability approach, in stating that people with less resources are entitled to more means to achieve equal outcomes, can serve as an intervention paradigm. The approach provides the theoretical base for a policy of 'positive discrimination'. This can also play a role in raising awareness of the issues faced by women with disabilities among stakeholders.

Lack of awareness can also give space to cultural beliefs that spark discrimination. For instance, in some communities, disability is considered to be a curse and families of children with disabilities are blamed for the presence of a disabled member, inferring that someone must have sinned and offended God. This moral model of disability takes disability as a defect caused by moral lapse, sin, or failure of faith (Olkin, 2002). Such beliefs may force families to hide their daughters with disabilities. Hence, the need for awareness creation arises (WHO & World Bank, 2011). Economic empowerment and poverty alleviation alone cannot create a conducive environment for women with disabilities, without also convincing society that women with disabilities have the potential to learn, work and marry. These findings resonate with the concept of intersectionality, which conceives inequality as simultaneously caused by multiple and interactive factors such as gender, class, ethnicity and disability (Björnsdottir, 2010; Meekosha, 2011; Weber, 2001).

The valued roles of student, employee and mother lose some of their significance when it comes to the situation of women with disabilities. For example, giving birth without being married is not socially acceptable and, therefore, being an unmarried mother is a devalued role in most LMICs. But, when it comes to women with disabilities, being an unmarried mother becomes a valued social role, as women with disabilities are not expected to get married.

In general, the studies conclude that participation in important social roles and the achievement of valuable life goals is hampered for women with disabilities due to limited accessibility, stigma and lack of support. Poverty exacerbates this situation, as does discrimination, which hinders women with disabilities from participating and succeeding in these major life domains.

8. Limitations

In this review, the focus on education, employment and motherhood in LMICs does not allow consideration of all the challenges and opportunities faced by women with disabilities. The review may have been more critical and comprehensive if it had involved other important themes, such as health (the availability and accessibility of health centres). Similarly, focusing on LMICs in the search procedure limited the number of articles reviewed, as most of the literature available on these themes is written about developed countries. However, our focus did allow us to unfold issues on accessibility, stigma and support, which are important and intertwined moderators for individuals in achieving their capabilities in education, employment and family life.

9. Recommendation for Future Research

Although the capability approach is a very useful framework guiding our review of the literature, the capability approach in principle suggests that what are essential and valued goals in life can only be articulated by people themselves (i.e., women with disabilities) and cannot be defined by policy makers, politicians or academics. We, therefore, call for research that uses approaches that give room for women with disabilities to articulate their valued goals in life and the opportunities and challenges that affect the accomplishment of these valued goals.

10. Conclusion

The review examined the important challenges and opportunities of women with disabilities in LMICs in relation to their participation in education, employment and motherhood, and the elements that regulate their participation in these important social roles. The theoretical frameworks, SRV and capability approach, helped us to systematically identify and precisely defined relationships among the three social roles of student, employee and mother.

The review found that there is a need to increase awareness and understanding among governments, educators, employers, and families about the life experiences of disabled women in LMICS. If different parts of society are aware and understand the need to fulfil the valued social roles and capabilities of disabled women in relation to education, employment, and motherhood, society will increase the inclusion of women with disabilities by sharing the available resources for the betterment of all citizens. Hence, it is important to develop a better understanding of the lives of disabled women in LMICs in order to minimize the obstacles to equality that they face in participating and succeeding in all valued social roles.

Moreover, governments, educators, employers and families need to understand that denying women with disabilities access to valued social roles deprives them of their basic human rights. CRPD states the need to respect differences and accept disabilities as part of human diversity and humanity, and emphasizes the need for equality and equality of opportunity between persons with disabilities and those without (United Nations, 2006). Furthermore, CRPD clearly requires state parties to ensure that persons with disabilities enjoy legal capacity on an equal basis with others (Frohmader & Ortoleva, 2013).

Our final conclusion from the findings of the review is that there is a need to build a disability component into all aspects of national and international development efforts (Morrison et al., 2014). As presented by Groce et al. (2011) and Frohmader and Ortoleva (2013), the inclusion of persons with disabilities should be a routine part of all programmes that address chronic poverty, because the inclusion of disability in addressing poverty leads to the equal distribution of available resources, which minimizes discrimination against women with disabilities in LMICs in terms of participating and succeeding social roles in education, employment, and motherhood. Moreover, as some of the reviewed articles state, the authorities in LMICs should ensure justice by updating (and implementing) policies designed to minimize and prevent discrimination against disabled women. Furthermore, equal distribution of resources would allow disabled women to develop to their full potential in such a way that they can participate in all domains of life and contribute to their communities and society as a whole.

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Conflict of Interests

The authors declare no conflict of interests.

References

Alkire, S. (2002). Dimensions of human development. *World development*, *30*(2), 181–205.

Alkire, S. (2005). Why the capability approach? *Journal of Human Development*, *6*, 115–133.

Björnsdottir, K. (2010). Resisting the reflection: Identity in inclusive life history research. *Disability Studies Quarterly*, *30*(3/4).

Braathen, S. H., & Kvam, M. H. (2008). Can anything good come out of this mouth? Female experiences of disability in Malawi. *Disability and Society*, *23*(5), 461–474.

Brown, B. A., Emerson, T. I., Falk, G., & Freedman, A. E. (1971). The equal rights amendment: A constitutional basis for equal rights for women. *The Yale Law Journal*, *80*(5), 871–985.

Dark and Light Blind Care. (2008). Inclusion of disabled people in vocational training and income. An overview of international experiences and approaches. *Light for the World*, 1–37.

Dhungana, B. M. (2007). The lives of disabled women in Nepal: Vulnerability without support. *Disability and Society*, *21*(2), 133–146.

Eide, A. H., & Ingstad B. (2011). *Disability and poverty: A global challenge*. Bristol: Policy Press.

Emmett, T., & Alant, E. (2006). Women and disability: Exploring the interface of multiple disadvantage. *Development Southern Africa*, *23*(4), 445–460.

Flynn, R., & Aubury, T. (1999). Integration of persons with developmental or psychiatric disabilities: Conceptualization and measurement. In R. Flynn & R. Lemay (Eds.), *A quarter-century of normalization and social role valorization: Evolution and impact* (pp. 271–304). Ottawa: University of Ottawa Press.

Frohmader, C., & Ortoleva, S. (2013). *The sexual and reproductive rights of women and girls with disabilities*. Paper presented at the ICPD BEYOND 2014. International Conference on Human Rights, Australia.

Gardner, J., & Carran, D. (2005). Attainment of personal outcomes by people with developmental disabilities. *Mental Retardation*, *43*(3), 157–174. Groce, N., Kett, M., Lang, R., & Trani, J.-F. (2011). Disability and poverty: The need for a more nuanced understanding of implications for development policy and practice. *Third World Quarterly*, *32*(8), 1493–1513.

Gupta, R. (2013). Twin tracking for women with disabilities in disability legislation. *Centre for Disability Studies*, 1–21.

Hannula, L., Kaunoen, M., & Tarkka, M.-T. (2007). A systematic review of professional support interventions for breastfeeding. *Journal of Clinical Nursing*, *17*, 1132–1143.

Kassah, B. L. L., Kassah, A. K., & Agbota, T. K. (2013). Abuse of physically disabled women in Ghana: Its emotional consequences and coping strategies. *Disability and Rehabilitation*, *36*(8), 665–671.

Kiani, S. (2009). Women with disabilities in the North West Province of Cameroon: Resilient and deserving of greater attention. *Disability and Society*, *24*(4), 517–531.

Kvam, M. H., & Braathen, S. H. (2008). "I thought…maybe this is my chance". Sexual abuse against girls and women with disabilities in Malawi. *Sexual Abuse*, *20*(1), 5–24.

Lamichhane, K. (2012a). Disability and barriers to education: Evidence from Nepal. *Scandinavian Journal of Disability Research*, *15*(4), 311–324.

Lamichhane, K. (2012b). Employment situation and life changes for people with disabilities: Evidence from Nepal. *Disability and Society*, *27*(4), 471–485.

Lemay, R. (2006). Social role valorization insights into the social integration conundrum. *Mental Retardation*, *44*(1), 1–12.

Loeb, M., & Eide, A. H. (2008). Poverty and disability in Eastern and Western Cape Provinces, South Africa. *Disability and Society*, *23*(4), 311–321.

Meekosha, H. (2011). Decolonising disability: Thinking and acting globally. *Disability & Society*, *26*(6), 667–682.

Mitra, S., Posarac, A., & Vick, B. (2011). *Disability and poverty in developing countries: A snapshot from the World Health Survey* (World Bank, SP Discussion Paper No. 1109).

Moodley, J., & Graham, L. (2015). The importance of intersectionality in disability and gender studies. *Agenda*, *29*(2), 24–33.

Morrison, J., Basnet, M., Budhathoki, B., Adhikari, D., Tumbahangphe, K., Manandhar, D., . . . Groce, N. (2014). Disabled women's maternal and newborn health care in rural Nepal: A qualitative study. *Midwifery*, *30*, 1132–1139.

Naami, A. (2015). Disability, gender, and employment relationship in Africa: The case of Ghana. *African Journal of Disability*, *4*(1), 95–105.

Naami, A., Hayashi, R., & Liese, H. (2012). The unemployment of women with physical disabilities in Ghana: Issues and recommendations. *Disability and Society*, *27*(2), 191–204.

Nussbaum, M. (2006). Frontiers of justice: Disability, nationality, species membership. London: The Belknap Press of Harvard University Press.

OHCHR. (2012). *Thematic study on the issue of violence against women and girls and disability*. Geneva: OHCHR.

Olkin, R. (2002). Could you hold the door for me? Including disability in diversity. *Cultural Diversity and Ethnic Minority Psychology*, *8*(2), 130.

Opini, B. M. (2010). A review of the participation of disabled persons in the labour force: The Kenyan context. *Disability and Society*, *25*(3), 271–287.

Ortoleva, S. (2010). Women with disabilities: The forgotten peace builders. *Blue Law International*, *33*(83), 83–141.

Osburn, J. (2006). An overview of social role valorization theory. *The SRV Journal*, *1*(1), 4–13.

Parnes, P., Cameron, D., Christie, N., Cockburn, L., Hashemi, G., & Yoshida, K. (2009). Disability in low-income countries: Issues and implications. *Disability and Rehabilitation*, *31*(14), 1170–1180.

Price, J. (2011). *The seeds of a movement-disabled women and their struggle to organize*. Toronto: Association For Women's Rights in Development.

Robeyns, I. (2005). The capability approach: A theoretical survey. *Journal of Human Development*, 93–114.

Salome, N., Mbugua, P., & Ong'eta, W. (2013). Gender and disability: Voices of female students with disabilities on gender based violence in higher education, Kenya. *International Journal of Education and Research*, *1*(4), 1–12.

Saunders, M. N., & Rojon, C. (2011). On the attributes of a critical literature review. *Coaching: An International Journal of Theory, Research and Practice*, *4*(2), 156–162.

Sen, A. (1980). Description as choice. *Oxford Economic Papers*, *32*(3), 353–369.

Sen, A. K. (1983). Poor, relatively speaking. *Oxford Economic Papers*, *35*(2), 153–169.

Sen, A. K. (1992). *Inequality reexamined*. New York: Russell Sage Foundation.

Sen, A. K. (1993). Capability and well-being. In *The quality of life*.

Sen, A. K. (1999). *Development as freedom*. New York: Knopf.

Sen, A. K. (2009). *The idea of justice*. Allen Lane: London.

Simkhada, P. P., Shyangdan, D., Van Teljlingen, E. R., Kadel, S., Stephen, J., & Gurung, T. (2013). Women's knowledge of and attitude towards disability in rural Nepal. *Disability and Rehabilitation*, *35*(7), 603–613.

Smith, E., Murray, S. F., Yousafzai, A. K., & Kasonka, L. (2004). Barriers to accessing safe motherhood and reproductive health services: The situation of women with disabilities in Lusaka, Zambia. *Disability and Rehabilitation*, *26*(2), 121–127.

Tefera, B., & Van Engen, M. (2016). The disability paradox: Better opportunities versus the hardships of high-achieving disabled women of Ethiopia. *Canadian Journal of Disability Studies*, *5*(1), 107–132.

Tefera, B., Van Engen, M., Van der Klink, J., & Schippers, A. (2017). The grace of motherhood: Disabled women contending with societal denial of intimacy, pregnancy, and motherhood in Ethiopia. *Disability & Society*, 1–24.

Tuomi, M. T., Lehtomäki, E., & Matonya, M. (2015). As capable as other students: Tanzanian women with disabilities in higher education. *International Journal of Disability, Development and Education*, *62*(2), 202–214.

UN General Assembly. (2012). *Human Rights Council resolution on the rights of persons with disabilities: participation in political and public life* (A/HRC/19/L.9/Rev.1). New York: United Nations.

UN, & UNC. (2012). *Discussion paper for the informal session. Conference of states parties to the convention on the rights of persons with disabilities*. New York: United Nations.

United Nations. (2006). *United Nations convention on the rights of persons with disabilities*. United Nations.

United Nations (n.d). Sustainable Development Goals. 17 goals to transform our world. http://www.un.org/sustainabledevelopment/sustainable-development-goals

Venkatapuram, S. (2011). *Health justice: An argument from the capabilities approach*. Cambridge: Polity Press.

Weber, L. (2001). *Understanding race, class, gender, and sexuality: A conceptual framework*. Boston: McGrawHill.

WHO, & World Bank (2011). *World report on disability*. Geneva: World Health Organization.

Wolfensberger, W. (1983). Social role valorization: A proposed new term for the principle of normalization. *Mental Retardation*, *21*(6), 234.

Wolfensberger, W., & Thomas, S. (2005). *Introductory social role valorization workshop training package*. Syracuse, NY: Training Institute for Human Service Planning, Leadership and Change Agency, Syracuse University.

Wolfensberger, W., Thomas, S., & Caruso, G. (1996). Some of the universal "good things of life" which the implementation of Social Role Valorization can be expected to make more accessible to devalued people. *International Social Role Valorization Journal*, *2*(2), 12–14.

Wolfswinkel, J. F., Furtmueller, E., & Wilderom, C. P. (2013). Using grounded theory as a method for rigorously reviewing literature. *European Journal of Information Systems*, *22*(1), 45–55.

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Article

Social Inclusion through Community Living: Current Situation, Advances and Gaps in Policy, Practice and Research

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Abstract
This article draws on the findings of the EU Framework 7 project DISCIT to explore the living situation of people with disabilities a decade after the adoption of the UN Convention on the Rights of Persons with Disabilities in nine European countries representing different welfare state models and different stages in the process of deinstitutionalisation. A review of the research literature, policy and available statistics was combined with interviews with key informants in each country to explore the current living situation, changes over time and the barriers to, and facilitators for change. The article focuses in particular on whether people are experiencing opportunities for social inclusion on an equal basis with others. Although a lack of available data hampered conclusions on living situation, it was clear that there had been some change in terms of policy and funding streams available to support community living. Some countries had moved slightly towards community living, while others reported more people in institutions or the development of bigger services in the community. There was evidence of continued inequality in the living situation and full inclusion of people with disabilities, with those with intellectual disability and psychosocial disabilities being the most affected. In terms of barriers (and consequently facilitators) there were three sources: 1) policy, 2) social care and support systems, and 3) awareness, attitudes and advocacy. The need to involve people with disabilities in policymaking and the need for a co-ordinated approach between all actors in the disability sector was seen as critical for achieving further change.

Keywords
community living; disability; inclusion; policy

Issue
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1. Introduction

Social inclusion has long been considered a key element of quality of life (see, for example, Schalock et al., 2002) and is intrinsically related to many other key concepts such as (active) citizenship (DISCIT, 2013). In order to have full and meaningful inclusion in your local community and in society more generally, you need to have presence in that community, feel part of that community and to be actively participating in, and contributing to, that community (O’Brien, 1987; Mansell & Beadle-Brown, 2012; Miller & Katz, 2002). The latter is sometimes referred to as having “a valued role” (Wolfensberger, 2000).

The importance of both presence in the community and active participation is echoed in the UN Convention on the Rights of Persons with Disabilities (UN CRPD; United Nations, 2006), in particular in Articles 19, 29 and

30. Article 19 gives people with disabilities the right to a home in the community like everyone else, choice over their living situation and support for full inclusion and participation in the community. Article 29 affords people the right to participation in political and public life while Article 30 outlines the right to participation in cultural life, recreation, leisure and sports. However, living situation, participation in all aspects of community life, having choice and autonomy, is not just to be made available but to be done so on an equal basis with others. In addition, having support as needed to exercise these rights is also a critical concept throughout the Convention, thus emphasising the importance of equality (as opposed to equity). For example, Article 19 uses "with choices equal to others", "opportunity to choose their place of residence and where and with whom they live on an equal basis with others" and "Community services and facilities for the general population are available on an equal basis to persons with disabilities".

The 2017 general comment on Article 19 (Committee on the Rights of Persons with Disabilities, 2017, para. 13) reminds us that the principles of equality and non-discrimination are core to all human rights instruments and that even in 1994 the Committee on Economic, Social and Cultural Rights highlighted that "segregation and isolation through the imposition of social barriers" counts as discrimination". As argued prior to the UN CPRD (e.g., by Rosenthal & Kanter, 2002), institutionalisation deprives people of their right to live as equal citizens in the community by imposing both physical and social barriers. This article will focus on community living as the first step to full inclusion and participation in the community and to achieving true equality.

The early definitions of "community care" such as those put forward by the King's Fund and the Ordinary Life programme in the UK (King's Fund, 1980) were very similar to the concepts now enscribed in the UN CRPD. The vision of community care was set out as:

- Using accommodation located among the rest of the population, which is adequate, appropriate and accessible to the individual;
- Using the range of accommodation options ordinarily available to the wider population;
- Enabling people, to the greatest extent possible, to choose where, with whom and how they live;
- Providing whatever help is required to enable people to participate successfully in the community.

It is important to note that even here, the idea of equality was implicit in the definition of community living—it is about making the same range of accommodation options available to people with disabilities as to everyone else.

More recently, the vision of community-based services has come to refer to a model where there is separation of support from the provision of accommodation (sometimes called "Supported Living", (Allard, 1996; Kinsella, 1993; Stevens, 2004). Support is provided to people within their own home (rented or owned). In this model, people are also usually involved in planning their support, such as where they live, who supports them and how support is provided. Overall, these services are intended to support people to live as full citizens rather than expecting people to fit into standardised models or structures. For the most part, this model of community-based support is achieved through the availability of personal budgets and personal assistance.

The current article draws on findings from a European Commission Framework 7 project on active citizenship for people with disabilities (DISCIT)[1] across nine countries. The nine countries represent different areas of Europe, different welfare state models (Esping-Andersen, 1990; Deacon, 1993) and are at different stages in the process of developing community-based services for people with disabilities: Norway and Sweden (Socio-democratic welfare state model); Germany and Italy (conservative/corporatist welfare state model); UK and Ireland (Anglo-Saxon/Liberal welfare state model; and Czech Republic and Serbia (post-communist and developing welfare state models). This article is the first in a series looking at the living situation and community participation of people with a disability one decade after the adoption of the UN CRPD and a decade on from the publication of the report from the European Commission funded project on the outcomes and costs of Deinstitutionalisation and Community Living (DECLOC). The latter report identified that at least one million people with disabilities were living in institutions in Europe, with this being a substantial underestimate (Mansell, Knapp, Beadle-Brown, & Beecham, 2007). This article aims to 1) map what is already known about the living situation and inclusion of people with disabilities (and whether they have choice in particular over their living situation) through existing research, official statistics and from those working in the field in each country, and 2) identify barriers and facilitators to achieving widespread community living.

2. Methodology

2.1. Part 1: Review of Existing Information, Policy and Research

Existing sources of data in each country were collated and reviewed in 2014–2015 by the research team from each country to identify and collate relevant material using a template to ensure consistency in the data collated. Sources included government statistics and publications, legislation and other policy, publications by NGOs and DPOs and academic research. The type of data collated included (where available): prevalence of disability in the countries; policies and systems supporting the develop-

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ment of community-based support; the nature of accommodation and support services that exist in each country and the number of people in a range of different living situations; progress towards the closure of institutional services; information on choice of living situation and support; any information on how people with disabilities participate in their local community, access community facilities and events and whether they receive support to do so; and recognised barriers and threats to community living. In terms of type of accommodation services available, researchers were asked to describe the services in terms of size, form and organisation, staffing, location, and population served. Based on this information, accommodation services were coded by the authors into the following categories:

- Small groups homes (<10 places)—usually 24-hour support;
- Apartment with support provided by/funded by state, etc.—usually less than 24-hour support;
- Own home (rented/owned) with assistance (up to 24 hours);
- Larger residential home (10 or more but less than 30 places);
- Institution (30 places or more).

Sources of all the data included in the template were also provided for each country and data were examined to assess, as far as possible, its internal consistency and any inconsistencies between different sources.

2.2. Informant Interviews

A series of semi-structured interviews were conducted with informants who were judged to have some expertise or knowledge around disabilities issues. Eighty-four informants were interviewed across the nine countries. Those interviewed included: representatives of innovative community-based services and organisations, including disabled people organisations (DPOs); representatives from official or government positions at national, federal/regional and local level; academics; and disabled people themselves.

Reports from each interview were prepared in English and 36 of these informants (four from each of the nine countries) who could comment on community living aspects specifically were selected for detailed analysis. Of those for whom data on characteristics were available: 50% were male; 61% were from DPO or NGOs (25% from NGOs and the remainder were from DPOs, including those who themselves had a disability); three people classified themselves as disability activists; 65% worked at a national level.

The reports from the interviews were thematically analysed and initially coded for the following topics, paying attention to variation by disability group or geographic location:

- Current situation of people with disabilities and the support received;
- Changes in situation over time;
- Barriers to the development of community living;
- Facilitators of the development of community living;
- What is needed for successful development of community living in this country?

Under each of these topics, overarching themes and subthemes were identified. Three members of the lead research team for the DISCIT work package focusing on community living read and coded the reports and all the themes and sub themes were then collated in one document (preserving the identification by country). Any additional points that did not fit into one of the initial themes were also recorded along with quotations that might be useful for illustrating key points. The second author then collated all the subthemes for final synthesis. For the topics where most information was available (i.e., barriers and facilitators) the themes and subthemes were summarised diagrammatically. These diagrams also give an indication of which themes were identified in each country. It is important to note that if an issue was mentioned by even one informant within a country it was included. However, different informants in the same countries often raised the similar themes. We have not identified which interviewers made which points but rather we have collated the main findings from across the interviews. Interestingly, contradictory reports between informants within each country were not found, although of course opinions and perspectives on the situation did vary. Any quotations provided are for illustrative purposes only.

3. Findings

3.1. What Do We Know About Living Situation of People with Disabilities and How Has It Changed in the Past 10 Years?

As in previous research (Mansell et al., 2007) the completeness and quality of the data available was a substantial issue. Even when information was available on the number of people receiving a service, information on the size and/or nature of those services were not always available. In other cases, the data is only on the number of places in a setting, not how many people are actually living there. In some countries, the name of a service could potentially be misleading—for example, in the Czech Republic large residential provisions were officially named ‘institutions’ up to 2006. Due to legislative changes, the same settings are now named ‘homes for people with disabilities’, but with no indication of whether those living there had experienced any change. This is similar to what had been observed in Denmark and Finland (Tøssebro et al., 2012).

The figures reported in Table 1 below are therefore presented with caution and as illustrative rather than definitive.

The available statistical data indicated that services for more than 30 people still existed in all nine countries but with differences between the countries and across disability groups. For example, Sweden only has larger establishments in the form of acute services for people with mental health problems and in Norway and Sweden only a small number of people with severe or multiple physical disabilities live in larger establishments, although in both countries, a recent trend towards bigger or more clustered settings had been reported (Tøssebro et al., 2012). In the UK, although current policy seeks to change this, there is still a tendency for some people with intellectual disability (ID) and/or autism (in particular those who have displayed challenging behaviour) to be placed in hospital style settings and many larger residential establishments still exist.

In Serbia, Czech Republic, Italy and Germany, institutional provision is still the main form of provision with little change since previous research (Mansell et al., 2007); in fact, in Italy, numbers of people in larger residential provisions reported now were higher than in 2006/2007 (Mansell et al., 2007). Overall, in all countries larger residential provisions were currently more commonly used for people with ID or mental health problems and less for people with physical or sensory disabilities. The exception to this was Italy where institutional provision for people with ID and mental health problems was challenged earlier than in other countries and where community support was more developed.

Table 1 below also summarises the nature of community-based support available and, where available, the number of people accessing each different type of community-based support. For the most part, this information was only available for people with ID and there was substantial variation between the countries in terms of the numbers or proportions in different settings.

In some countries such as Norway, Sweden, Switzerland, Germany, and the UK, some people with disabilities are supported to live in their own home (on their own or shared with other people), rather than living in a group home or other residential setting in the community. This trend was also emerging as an option in the Czech Republic. However, apart from in the UK, this option is primarily accessed only by those with less severe disabilities. For those with more severe and complex needs, the only option if people are not able to live with their families, is institutional or at least residential care settings. In some countries such as Italy, Germany, Switzerland and Serbia these can be larger hospital-like settings or larger group homes (e.g., for 24 people). In Ireland, options range from small group homes through to larger residential settings and campuses. In others, such as Norway, these are likely to be group homes (identified as small flats co-located with other flats with staff support available up to 24 hours a day).

It is important to note that having a higher proportion of adults living with their families may not denote good community-based support. Variation in the number of people living with their families often reflects religious beliefs and family traditions but it may also reflect a lack of community-based support—in at least some countries the only options were living with family or in an institution. The lower proportion of people living with their family in Norway reflects to some extent the policy to support people with disabilities to be able to move out of the family home and live independently in the community as well as the policy to support parents to have "a life after children".

3.2. What Choice Do People Have in Relation to Their Living Situation and Other Elements of Their Life?

Official statistics or research about the number of people who have choice over their living situation was only available for the UK and Ireland and only for people with ID. In Ireland, a survey found that more than half of people with ID had no choice about with whom they lived or where they lived (Inclusive Research Network, 2010). In the UK, similar figures have been reported—almost 50% of people report no choice in where they live and 1/3 of people reported no choice about with whom they live (Hatton & Waters, 2013).

In the other countries, it was generally reported that, apart from where people were receiving personal budgets or had a service in the form of personal assistance, choice over where and with whom to live was limited, especially for those with more severe levels of ID. In Norway and Sweden, choice about living situation and support depended very much on the level of service required. In Norway 22% reported that they had taken part in decisions on where they live, and 15% on with whom they live (Söderström & Tøssebro, 2011). Those who needed more intense support were often unable to access a range of choices—being steered towards a group home with only one group home available locally. In the Czech Republic, although in principle people have choice over where they live, in reality this is still currently difficult to achieve (Šiška, 2011).

3.3. Barriers and Facilitators to Community Living

For the most part, this section draws on the findings from the interviews with informants. Some of the data used comes from the research teams in each country via the templates mentioned above. Seven clusters of themes related to barriers were identified and for the purpose of this article have been organised into three core areas. These were:

1. Policy and politics;
2. Social care and support systems:
    - Funding availability and systems;

Table 1. Where people with disabilities live in each country and numbers/proportions where available.

	Living with family	Small groups homes (<10 places)—usually 24Hr support	Apartment with support provided by/funded by state, etc.—usually less than 24 hour support	Own home (rented/owned) with assistance (up to 24 hours)	Larger residential home (10 or more but less than 30 places)	Institution (30 places or more)
Norway	98% of children live with family. No exact figures available for adults provided. In 1999 21% of people with ID over 21 lived with their families.	Yes—primarily for people with ID—average size 7 places.	Yes both for people with ID and some for people with MH	Yes—15% of people with ID are in this type of setting	Lately some group homes for more than 10 people are set up but very few above 30. In the 1990s few group homes were for more than 5.	150-200 people with severe physical or multiple disabilities live in Health and Welfare Centres.
Sweden	Not available.	Yes—for all client groups	Not clear from the data.	Yes	A small number of people with mental health needs still live in groups homes of up to 20 people but mostly these have closed now	None reported in 2006/2007 DECLOC report. No updates in 2016.
UK	No official figures but various reports have found that around 60% of adults with ID live with family. 2004 Learning Disability Survey found 67% in family home.	Yes—this still remains the most common form of accommodation and support service in the UK	Yes—exists usually for people with challenging behaviour	Yes—this is increasing. In 2010/2011 42,625 people with ID were using self-directed support or direct payments—81% more than 2009/2010. However, the biggest increase was for council services only—i.e., where the individual allocation is still used to pay for social care services that are traditional and not really new models	Yes—there are some larger residential services based in the community that provide for between 10 and 30 people (usually less than 20). Primarily for people with ID but also with physical and sensory disabilities.	66,342 was the estimate given in 2006/2007 DECLOC report. No updated official statistics in 2016 but likely to be less due to the closure of remaining long stay hospitals, NHS campuses and the ongoing closure of assessment and treatment units, and private hospitals for people with IDD. Approximately 2500 people with IDD are still in inpatient services which range in size.

Table 1. Where people with disabilities live in each country and numbers/proportions where available. (Cont.)

	Living with family	Small groups homes (<10 places)—usually 24Hr support	Apartment with support provided by/funded by state, etc.—usually less than 24 hour support	Own home (rented/owned) with assistance (up to 24 hours)	Larger residential home (10 or more but less than 30 places)	Institution (30 places or more)
Czech Republic	Numbers not available	Yes—usually 6 to 10 places—all disability groups but not mixed.	Yes—some institutions rent flats for those who don't need so much support to live in—usually as a group though.	Is possible with social assistance funding. Tendency growing but no exact numbers available.		30987 were recorded in the 2006/2007 DECLOC report. No updated data in 2016.
Serbia	563000 live with families—98% of those with a disability.	441 adults and 661 children (size not indicated)		196 adults		Very little information but approximately 8000 people thought to be in institution, primarily accounted for by people with psychosocial disabilities (47%) and people with ID (32%).
Ireland	85.5% of people with physical and sensory disabilities and 66.4% of people with ID live with family members	4226 people with ID. Also used by a small number of people with physical disabilities			2561 people with ID. 343 people with physical and sensory disabilities. 52 people with psychosocial disabilities.	5123 had been reported in 2006/2007 DECLOC report. Approximately 4000 people reported for 2016. Mainly ID but also some psychosocial disabilities and sensory disabilities.

Table 1. Where people with disabilities live in each country and numbers/proportions where available. (Cont.)

	Living with family	**Small groups homes (<10 places)—usually 24Hr support**	**Apartment with support provided by/funded by state, etc.—usually less than 24 hour support**	**Own home (rented/owned) with assistance (up to 24 hours)**	**Larger residential home (10 or more but less than 30 places)**	**Institution (30 places or more)**
Germany	No recent figures available—in 1990s had been estimated at approximately half of people with disabilities.	No recent figures but DECLOC report identified that this type of service exists, although in the minority.	No recent figures but DECLOC report identified that this type of service exists, although in the minority.	No recent figures but DECLOC report identified that this type of service exists, although in the minority.	No recent figures but DECLOC report identified that this type of service exists—most common type of community-based support.	190,146 estimated in 2006/2007 DECLOC report. Updated to 202,359 in 2016. 64% are people with ID; 26% psychosocial disabilities.
Switzerland	No data available for living with family—only private households which are not necessarily family homes—could be person in their own home.	1,134,000 persons with disabilities (94%) lived in private households in 2010: physical disability—76.4%, ID 6.8% both 15.8%, neither physical nor intellectual 1.0% Personal assistance payments: persons with disabilities who are unable to take care of themselves are entitled to receive extra disability benefits to pay for the extra costs that arise due to these limitations. The percentage of persons who receive such benefits and who live at home has risen from 50% in 2004 to 59% in 2011. There were more than 25000 people living in some form of service provision (referred to as institutions but no information available on size): physical disability 11.0%, psychosocial disability 20.1% ID 55.4%, sensory disability 2.7%, others (addiction, etc.) 10.7%				No data available o size of setting. 25000 people living in some type of service. 55% were people with ID, 20% psychosocial and 11% physical disabilities.
Italy	Majority live with their family—main support for 83% of people with disabilities is their family.	Smaller family houses from 7 to 9 places	Supported apartments—from 1 to 4 people who have chosen to live with other people. Only for people with physical and sensory disabilities with low support needs.		Smaller Sanatorium Residences—RSA—from 12 to 120 people. 2 or more people frequently share a room. Larger family Houses—from 10 disability groups were	153,798 had been estimated in 2006/2007 DECLOC report. In 2016 this was 190,134. People from all—20 places in institutions.

- Co-ordination and organisation across levels of government and other agencies;
- Availability and flexibility of services and support in the community;
- Perverse incentives for the maintenance of institutional provision, contractions in the system and issues of definition and conceptualisation.

3. Attitudes, awareness and advocacy:

- Attitudes and awareness;
- Influence of people with disabilities and their representatives.

3.3.1. Policy and Politics

Although all countries studied were reported to have at least some national policies and/or legislation in support of the social inclusion, self-determination and deinstitutionalisation of people with disabilities, expert informants reported substantial variation in the extent and usefulness of existing policy (see Figure 1). In some countries, policy was very limited or the policy that existed was perceived to have the wrong focus or was not helpful in promoting community living. For example, informant identified weak policy on accessibility in Sweden; policy in Norway being open to interpretation and medical model still prevalent in Ireland. In addition, guardianships laws were seen to impact on whether people have real choice and control. Even where good policy existed, it was reported that there were issues of full implementation in Serbia, Czech Republic, Italy and Ireland.

A lack of government focus or priority on disability issues was also identified as a barrier in the Czech Republic, Norway, Italy and Germany. In addition, in Norway, the almost exclusive focus on promoting personal budgets to the exclusion of all other options for services was viewed as problematic especially for those with more complex needs.

Other political factors included the lack of political stability in Italy, the controlling nature of government in Italy and Serbia, the way the government responded to crises in the UK and factors related to government focus on costs, expenditure and rationing of services in Germany, Ireland, UK and Sweden.

3.3.2. Social Care and Support Systems

In all countries except Norway and Sweden, interviewees identified the issue of a lack of spending on disability as a key barrier. In some cases, this was due to a general reduction in spending over time. In others, it was due to austerity measures as a result of the financial crisis (see Figure 2). The lack of funding applied both directly in terms of funding for support and housing and also in terms of funding for schemes that would help people be more independent and therefore reduce reliance on formal services. Examples included lack of funding for families to prevent institutionalisation or lack of eligibil-

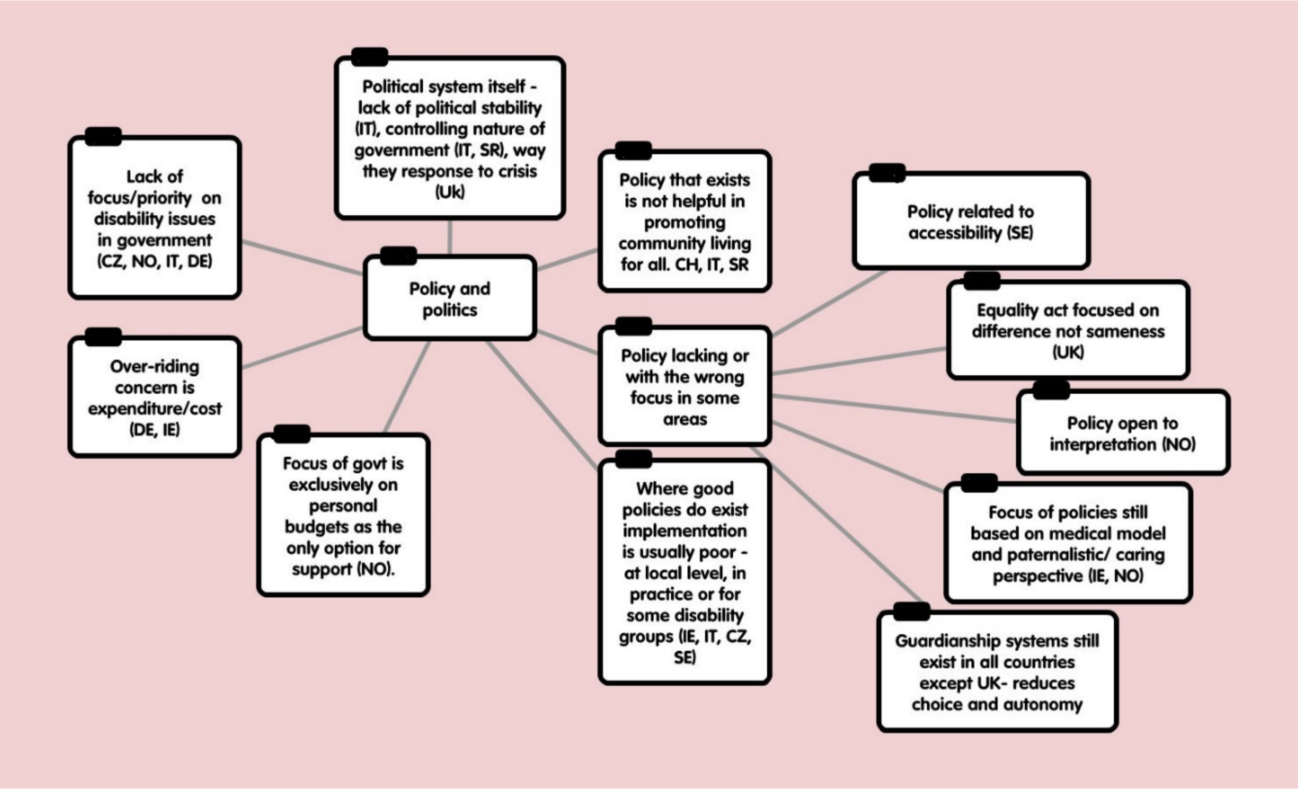

Figure 1. Themes identified in the cluster related to policy and politics.

ity for funding for services such as self-help groups for those with psychosocial disabilities. Inefficiency in spending, spending on the wrong types of support, misuse of structural funds and lack of leadership related to spending were also identified as issues, especially in Italy.

There were three core barriers identified that affected co-ordination and consistency within the system (see Figure 3). Geographical fragmentation was a factor in most countries, for example, regional variation was reported between Länder in Germany, cantons in Switzerland and local authorities in the UK. In six of the nine countries, interviewees identified a lack of co-ordination between different levels of government as a barrier to widespread change happening more consistently and sometimes this was identified as a way of cost shunting from one department or level of government to another. Finally, interviewees in Sweden, Ireland and Germany identified compartmentalisation of the system as a barrier along with lack of co-ordination and co-operation between service providers, agencies and across sectors (e.g., health, social care, education, transport, etc.).

3.3.3. Availability and Flexibility of Services and Support in the Community

This was one of the bigger clusters, with nine themes (see Figure 1). The only country not represented within this cluster was Serbia where this was not raised as an issue—possibly because services in the community were relatively rare as this quote from one of the informants from Serbia illustrates: ‘Everything is still a matter of who knows who, and of individual efforts. There is no systemic support or conditions’.

Firstly, in Switzerland, Germany and Italy, the issue of the bureaucracy involved in obtaining and then managing a personal budget or personal assistance made it difficult and off-putting for many people with disabilities. The fact that people had to be employers for personal assistants was a particular issue raised. There was also discrimination against people with ID and psychosocial disabilities. In Italy, assistance was only given for personal and health care and not for social assistance which made it less useful for those with more severe disabilities:

> Another problem is the discrimination of people with psychosocial problems and with cognitive impairments since the eligibility for the assistance budget depends on the eligibility for the so-called Hilflosenentschädigung (“compensation for the helpless”), for which restrictions exist for people with psychosocial problems and cognitive impairments….Only few people are able to overcome the barriers on the way to receiving the assistance budget. (CH)

Secondly, in Switzerland, Czech Republic, Italy and Germany, institutional services were still being built or at the very least still being used for new people entering the service system. In the Czech Republic, the continued use

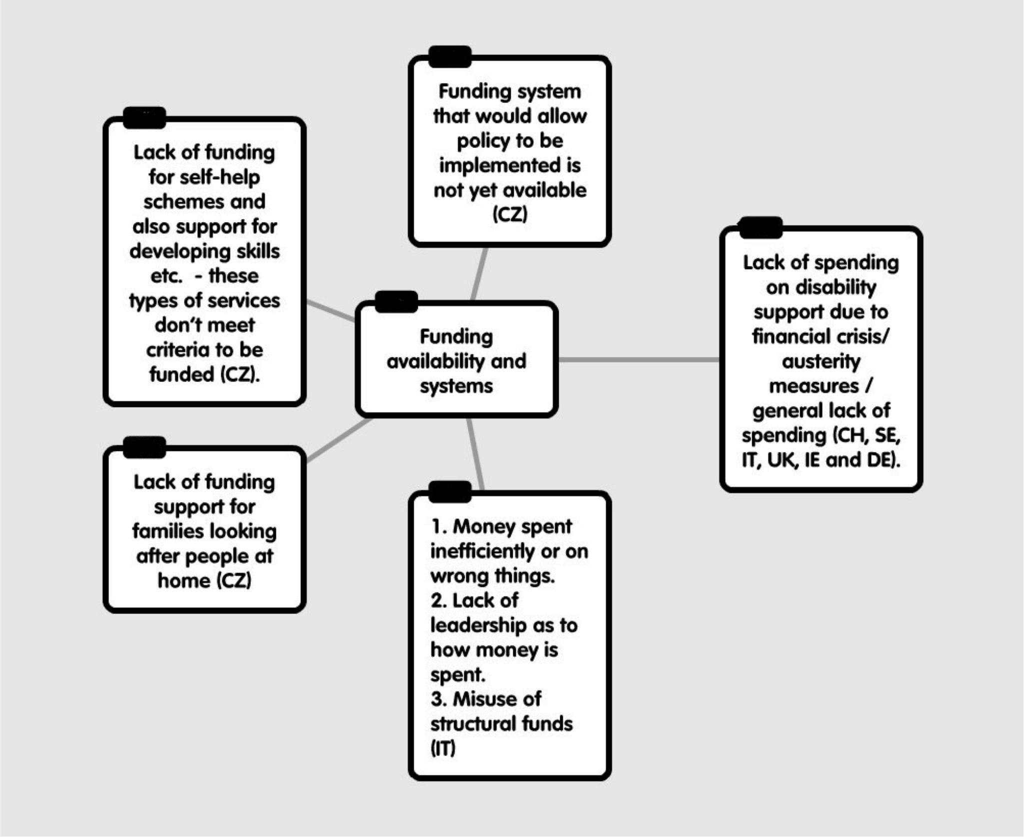

Figure 2. Themes related to the cluster of funding availability and funding systems.

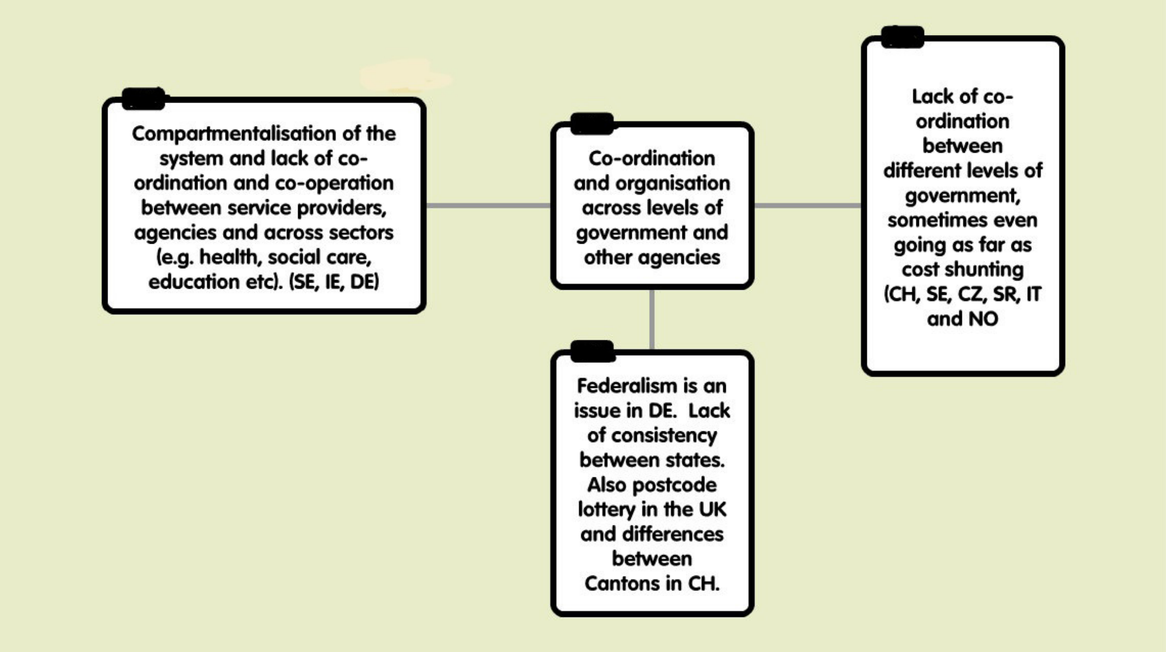

Figure 3. Themes identified within the cluster of co-ordination and organisation across levels of government and other agencies.

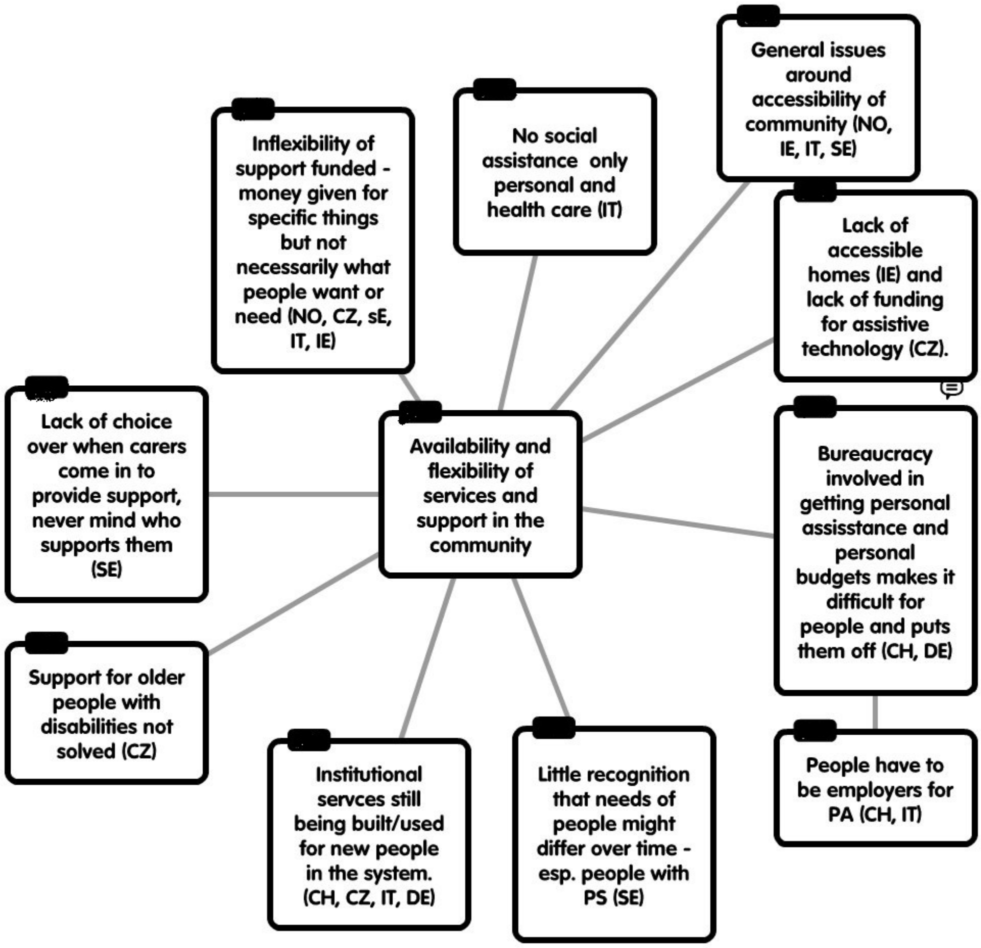

Figure 4. Themes identified within the cluster of availability and flexibility of services and support in the community (PA = personal assistant, PS = psychosocial disabilities).

of institution was compounded by uncertainly in how to support older people with disabilities and gave rise to the belief that institutions were still needed.

Inflexibility of funded support was raised as an issue in six of the nine countries (NO, CZ, SE, IT and IE) with money sometimes given but not necessarily for the support desired or needed. For those with mental health conditions, this inflexibility was reflected in the lack of recognition that the needs of people might differ over time and as such support might need to vary over time. Inflexibility was also reflected in the lack of choice over *who* provides support and *when* support is provided.

Finally, there were barriers identified around the accessibility of community in general (Norway, Ireland, Italy and Sweden), accessible homes (Ireland) and the availability of assistive technology in the Czech Republic.

3.3.4. Perverse Incentives for the Maintenance of Institutional Provision, Contradictions in the System and Issues of Definition and Conceptualisation

Figure 5 illustrates that there were still financial incentives for institutional services in some countries. For example, in Germany and Switzerland it was identified that local levels of government were motivated to keep institutions open as this is cheaper for them than community-based services. The per capita basis for funding psychiatric care in Ireland meant that so there was no incentive to close the institutions.

In Germany, one informant reported that First Civil Society Report on UN CRPD 2013 highlighted that the word the word integration is purposely rather than the word inclusion (Alliance of German Non-Governmental Organizations regarding the UN Convention on the Rights of Persons with Disabilities, 2013).

Finally, there was an issue about inherent attitudes or ways of working within the systems, for example in many countries, the systems still fostered dependency rather than independence. This is related to the deep-rooted attitude in society that disability = charity required, which was felt to be related to the increase (Italy) or at least maintenance (Germany) of special/segregated educational provision. Individual resources and contact and being able to speak up for yourself were felt to determine the services received.

3.3.5. Awareness, Attitudes and Advocacy

Figure 6 illustrates the themes focused on awareness of issues faced and attitudes towards people with disabilities, with many emerging themes interlinked. It was noted that society was more individualistic and less

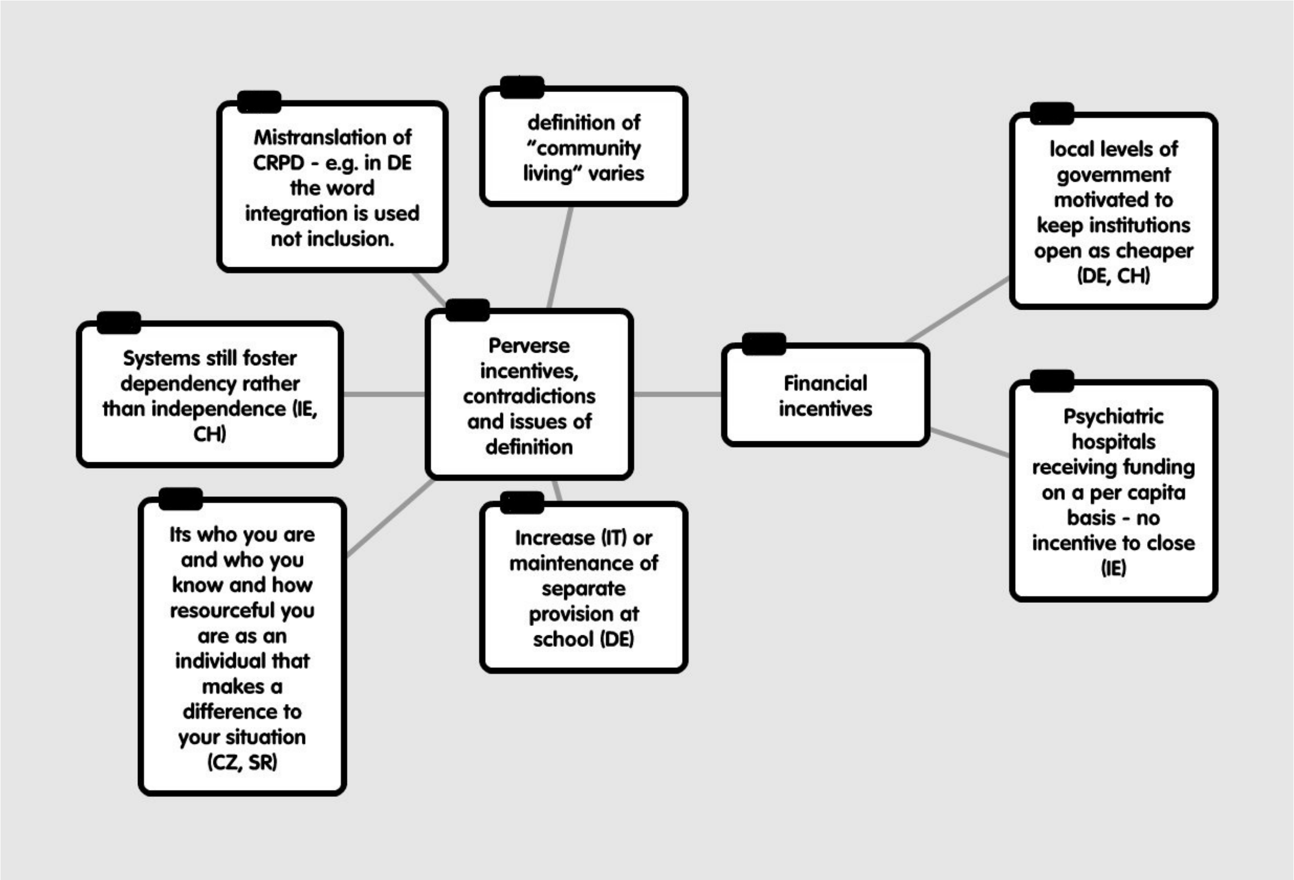

Figure 5. Themes within the cluster on perverse incentives for the maintenance of institutional provision, contradictions in the system and issues of definition and conceptualisation.

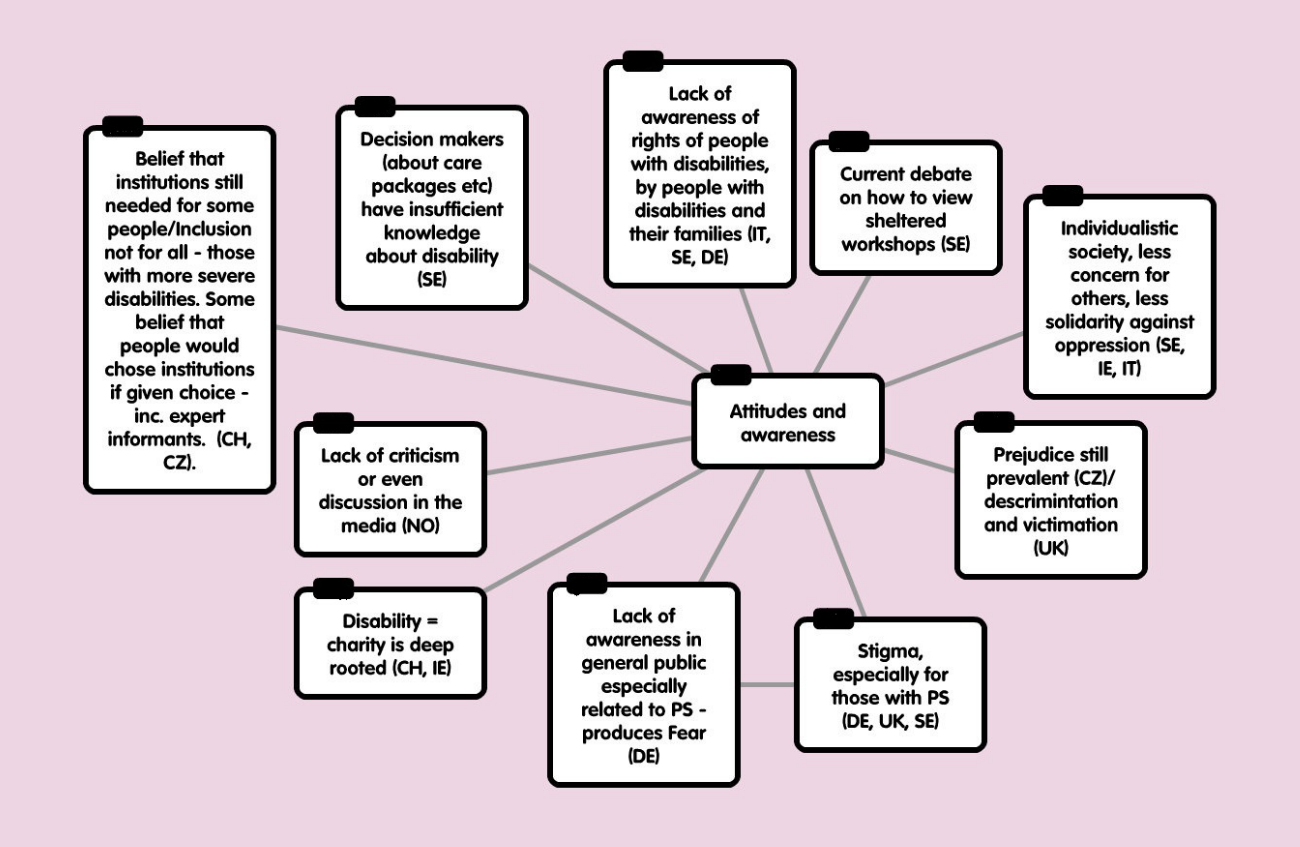

Figure 6. Themes identified within the cluster on attitudes and awareness (PS = psychosocial disability).

concerned about others or at least with less solidarity against oppression than in the past. Prejudice, discrimination, victimisation and stigma were raised as issue, in particular in the Czech Republic, Germany and Sweden, especially with regard to people with mental health conditions, with a lack of awareness around mental health conditions being identified in Germany.

Lack of knowledge and awareness on the part of decision makers (i.e., those deciding on care packages) was raised as a barrier in Sweden, as was a lack of awareness of the rights of people with disabilities by people with disabilities themselves and their families. The latter was also seen as a barrier to change in Italy and Germany.

As mentioned above, there was still a belief that institutions were needed, in particular in Czech Republic and Switzerland, although this was at times somewhat confused by differing definitions of an institution. This belief extended to the fact that people would choose to live in institutions and that having institutions was necessary to give people a full range of choices. These attitudes also applied to some of the interviewees, which was concerning given their leading role in advocating for or delivering community living. Another barrier related to the deep-rooted belief—in Ireland and Switzerland in particular—that disability equated to charity and that the primary aim of services and support mechanisms, was to care for, rather than empower and enable, people.

The lack of criticism or even discussion related to disability issues in the media was raised as an issue in Norway. Unlike in other countries such as the UK, where scandals were common and much debated, in Norway there appeared little discussion about the situation of people with disabilities.

The final cluster of themes revolved around the influence of people with disabilities. For all countries, the lack of involvement of people with disabilities (both directly and through disabled people's organisations) in the political arena emerged as an issue. In the UK, Serbia and Ireland, it was identified that influence was limited to the "elite"—i.e., powerful, well-resourced and well-known individuals. In Switzerland, it was noted that politicians do not acknowledge the need to involved people with disabilities—they do not necessarily subscribe to the "nothing about us without us" maxim. Finally, in Norway, Italy and Sweden, the fragmentation of disabled people's organisations was identified as an issue—they were not working together to put forward a united front and as such were not strong enough to influence government and local decision makers.

3.4. Facilitators of Community Living

As one might imagine, the facilitators identified by informants in each country were in general the opposite of the barriers already outlined above. Figure 7 below presents the key facilitators that were identified by the informants as having been important in bringing about change in favour of community living.

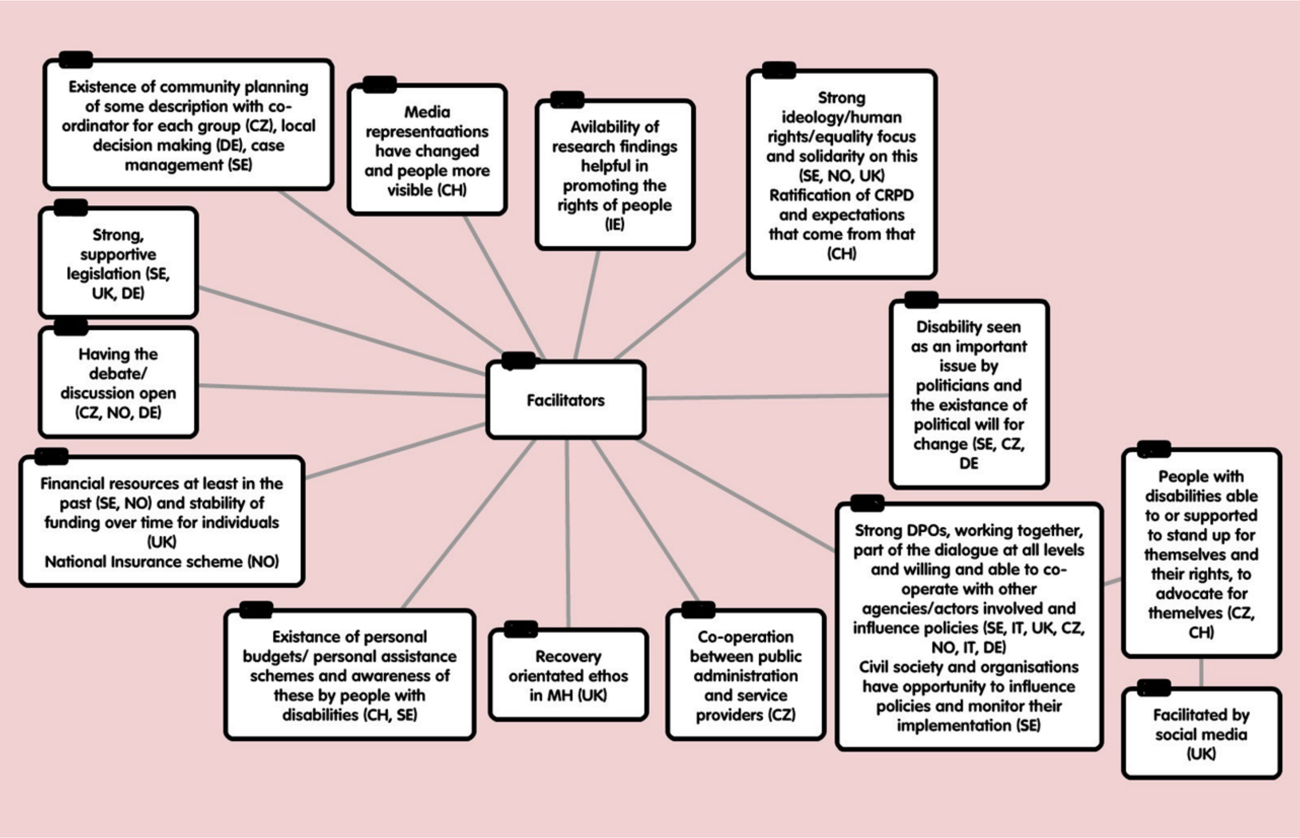

Figure 7. Themes arising under the topic of facilitating factors for community living.

The facilitators that were seen as most important for future success included good co-ordination between different levels of government and between different agencies and services—allowing a more holistic and comprehensive approach to ensure people's needs are met. Also, important for future changes was the involvement of people with disabilities in decision- and policy-making and collaboration of disabled people's organisations for a stronger, united voice.

4. Conclusions

This article aimed to provide an overview of the current situation for people with disabilities, in terms of community living as defined in the UN CRPD Article 19. Living and actively participating in your local community, with equal opportunities and choices to those experienced by those without disabilities, is a critical first step to full social inclusion and active citizenship. Although there appeared to have been some advances in the development of policy and funding systems in some countries to allow, for example, personal budgets and personal assistance, there has been little change in the numbers of people with disabilities living in larger congregate settings and little evidence of strong development of community-based services to prevent institutionalisation. In some countries, families are still the primary or indeed only form of community living but with little to no support. Only in the Nordic countries was there a policy and associated practices to ensure that adults with disabilities could live independently from their parents.

However, as for previous studies, getting an accurate and detailed picture of the living situation of people with disabilities was hampered by a lack of reliable data in almost all countries. Mansell et al. (2007) concluded that none of the 28 countries in the DECLOC study were yet in compliance with Article 31—ten years on, this appears to still be the case. For some of the countries in this study, the data collected in 2006/2007 as part of the DECLOC study was the most recent data available on the living situation of people with disabilities. Only in Ireland was there any type of register that provided data on living situation and support—although this was only for people with ID and those with physical and sensory disabilities who were known to services and did not include those that were living at home on their own or with family without support. Even when information was available on the number of people receiving a service, the size and/or nature of those services were not always available. In other cases, the data is only on the number of places in a setting, not how many people are actually living there. The lack of complete, or at least reliable and accurate, data is in itself a barrier to the developing of a strong system of community-based support as it makes it difficult to check whether nations are "progressively realising" even Article 19 of the UN CRPD and thus limits accountability for the process.

Secondly, a true understanding of whether people with disabilities are really experiencing community living on an equal basis with others is hampered by variations in definitions used—e.g., what is an institution in one country may not be classed as an institution in another country. The only type of service/support about which there was more certainty was personal budgets and personal assistance, where in general, people receiving this type of support were living in their own home in the community. However, no official data, and almost no research, existed on the quality of those supports, on whether people had choice about their living situation and support, or whether the support they received supported their inclusion in the community more generally. There was also no research found that allowed comment on whether those with disabilities had access to the same range of housing options as the rest of the population and whether they had access to community-based facilities on an equal basis with others.

Compiling statistical data from many different sources and of varying quality can result in methodological weakness and limit the conclusions that can be drawn. Whilst having reliable and consistent data to compare across countries would be methodologically preferable, in reality such comparable data does not currently exist. As such, it was considered essential to use the data that were available, recognising the limitations.

With regards to issues related to drawing on the views of a relatively small number of informants in each country, it is recognised that the views and experiences reported may not be either universal or representative. However, there is still validity in gathering these experiences—if those responsible or active in helping people live and participate in the community have experienced such issues in their work, it is highly likely that other people will also have experienced them.

Despite these limitations, it was clear that people were still living in institutional settings in almost every country. In some countries, this was still the main form of provision, whilst in others small improvements had been observed. Although there were important differences between different regions, it was the variation between different groups of people with disabilities that was most striking. Evidence of inequality between different disability groups was apparent in the findings. Community living was more thoroughly developed for those with mobility difficulties and those with visual impairments and was least developed for those with ID, especially those with the most severe or complex needs. For this group of people, the only option in most cases where people are not able to live with their families remains institutional or residential care settings. Only in the UK were those with severe ID reported to regularly access personal budgets and personal assistance. Apart from in Italy, where mental health services were reformed first, people with psychosocial disabilities were considered to receive the poorest support, with the lack of flexibility in support raised as a key issue.

In terms of barriers to and facilitators of community living, cuts in public spending and changes in public governance were amongst the explanatory factors identified. Supportive policy and funding systems were both seen as important but sometimes either didn’t go far enough, were still based on a medical model, still included incentives for institutions, and were easily misinterpreted or simply not flexible enough to meet the needs of individuals. The need to involve people with disabilities in policymaking and the need for a co-ordinated approach between all actors in the disability sector was seen as critical for achieving further change. A more holistic approach to services and support was identified as needed for success.

Awareness and attitudes in general were also identified as a barrier with some indication that the views and actions of other members of the community can also be a barrier to active participation although research on this is limited.

The availability of personal budgets, direct payments or other individualised funding systems were reported as a core facilitator of community living. However, where personal budgets existed they were often made very complex to access, only available to some people, limited by a lack of available services for people to purchase and were sometimes seen by governments as a way of saving money. Where people did get involved in their community, this was often seen as down to personal will and the level and quality of support someone gets, which was not always formal support.

This article drew on official information, previous research in each country and the views of those who were seen to have some expertise on the situation for people with disabilities in their countries. Although some of these were people with disabilities themselves, many were not. However, findings from interviews with over 200 people with disabilities, across the nine countries and born between 1945 and 1995, identified many of the same issues, barriers and facilitators. The difference between the people with disabilities and the informants was that those with disabilities focused more on the barriers to how they could exercise their active citizenship personally rather than at a systems level (Šiška, Beadle-Brown, Káňová, & Kittelsaa, 2017). Negative attitudes, low awareness and low expectations were also see as a key barrier by those with disabilities as well as the availability and flexibility of support services. People reported that sometimes the support they received was just what was available not what they needed and often they had little choice over who supported them and when support was provided. Those who had a personal budget fared slightly better but even then, receiving the support they needed to be active in the local community was not guaranteed. Lack of training for staff was also identified as an issue and discrimination and issues of accessibility were key barriers to gaining employment and taking part in leisure and cultural activities.

When it came to facilitators of community living and active citizenship, those with disabilities did talk about some more systemic issues such as greater accessibility and investment in services. One participant finished his interview with a call for politics to "engage more, care more and do more" (Šiška et al., 2017, p. 59).

In conclusion, there continues to be a lack of data available that allows definitive comment on whether the countries involved in this study are really moving towards successful implementation of the UN CRPD. However, from what information is available, it appears that not only do people with disabilities still face inequality in comparison to people without disabilities but there is still a lack of equality between disability groups with more advancements towards community living and participation, on an equal basis with others, for those with mobility and sensory disabilities than those with intellectual or psychosocial disabilities.

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Conflict of Interests

The authors declare no conflict of interests.

References

Alliance of German Non-Governmental Organizations regarding the UN Convention on the Rights of Persons with Disabilities. (2013). *First civil society report on the implementation of the UN convention on the rights of persons with disabilities in Germany*.

Allard, M. A. (1996). Supported living policies and programmes in the USA. In J. Mansell & K. Ericsson (Eds.), *Deinstitutionalization and community living: Intellectual disability services in Britain, Scandinavia and the USA* (pp. 97–116). London: Chapman and Hall.

Committee on the Rights of Persons with Disabilities. (2017). *General comment No. 5 (2017) on living independently and being included in the community (CRPD/C/GC/5)*. Retrieved from http://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx

Deacon, B. (1993). Developments in East European social policy. In C. Jones (Ed.), *New perspectives on the welfare state in Europe*. London: Routledge.

DISCIT. (2013). WP2: *Active citizenship for Europeans with disabilities—Current knowledge and analytical framework*. Retrieved from https://blogg.hioa.no/discit/files/2016/02/DISCIT-D2_1-Active-Citizenship-for-persons-with-disabilities_October-2013.pdf

Esping-Andersen, G. (1990). *The three worlds of welfare capitalism*. Cambridge: Polity Press.

Hatton, C., & Waters, J. (2013). *National personal budgets survey 2013: Summary of main findings and next steps*. Lancaster: Lancaster University and In Control.

Inclusive Research Network. (2010). *Where we live: A national study done by members of the Inclusive Research Network through surveys*. Inclusive Research Network.

King's Fund. (1980). *An ordinary life: Comprehensive locally-based residential services for mentally handicapped people*. London: King's Fund.

Kinsella, P. (1993). *Supported living: A new paradigm*. Manchester: National Development Team.

Mansell, J., & Beadle-Brown, J. (2012). *Active support: Enabling and empowering people with intellectual disabilities*. London: Jessica Kingsley Publishers.

Mansell, J., Knapp, M., Beadle-Brown, J., & Beecham, J. (2007). *Deinstitutionalisation and community living—Outcomes and costs (Report of a European study, Volume 2: Main report)*. Canterbury: Tizard Centre, University of Kent.

Miller, F. A., & Katz, J. H. (2002). *The inclusion breakthrough: Unleashing the real power of diversity*. San Francisco, CA: Berrett-Koehler.

O'Brien, J. (1987). A guide to life-style planning. In G. T. Bellamy & B. Wilcox (Eds.), *A comprehensive guide to the activities catalog: An alternative curriculum for youths and adults with severe disabilities* (pp. 175–189). Baltimore: Paul H. Brookes.

Rosenthal, E., & Kanter, A. (2002). The right to community integration for people with disabilities under United States and international law. In *Principles to practice; Disability rights law and policy international and national perspectives* (pp. 309–368). Ardsley, NY: Transnational Publishers.

Schalock, R. L., Brown, I., Brown, R., Cummins, R. A., Felce, D., Matikka, L., & Parmenter, T. (2002). Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities: Report of an International Panel of Experts. *Mental Retardation*, *40*(6), 457–470.

Šiška, J. (2011). *ANED, country report on the implementation of policies supporting independent living for disabled people, Czech Republic*. Retrieved from http://www.disability-europe.net/downloads/333-cz-8-request-07-aned-2009-task-5-request-template-to-publish-to-ec

Šiška, J., Beadle-Brown, J., Káňová, S., & Kittelsaa, A. M. (2017). Change and diversity in community living in Europe—The experiences of persons with disabilities. In R. Halvorsen, B. Hvindem, J. Beadle Brown, M. Biggeri, J. Tøssebro, & A. Waldschmidt (Eds.), *Understanding the lived experiences of persons with disabilities in nine countries. Active citizenship and disability in Europe* (Vol. 2, pp. 49–65). London: Routledge.

Söderström, S., & Tøssebro, J. (2011). *Innfridde mål elelr brudte visjoner [Fulfilled ideals or broken promises]*. Trondheim, NTNU Social Research.

Stevens, A. (2004). Closer to home: A critique of British government policy towards accommodating learning disabled people in their own homes. *Critical Social Policy*, *24*(2), 233–254.

Tøssebro, J., Bonfils, I. S., Teittinen, A., Tideman, M., Traustadóttir, R., & Vesala, H. T. (2012). Normalization fifty years beyond—Current trends in the Nordic Countries. *Journal of Policy and Practice in Intellectual Disabilities*, *9*, 134–146.

United Nations. (2006). *Convention on the rights of persons with disabilities*. New York: United Nations.

Wolfensberger, W. (2000). A brief overview of social role valorization. *Mental Retardation*, *38*(2), 105–123.

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