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Disabled People and the Intersectional Nature of Social Inclusion

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Editorial

Disabled People and the Intersectional Nature of Social Inclusion

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Abstract

This editorial introduces a thematic issue of *Social Inclusion* focusing on disabled people and the intersectional nature of social inclusion. This thematic issue includes transnational and transdisciplinary studies and expressions of lived experiences facing disabled people, their families, and allies across the globe from a social, human rights, and/or disability justice perspective. The articles comprising this issue include an explicit recognition and discussion of intertwined and socially constructed identities, labels, power, and privilege as explicated by pioneering Black feminists who introduced the concept of intersectionality. Taken together, the articles within this issue identify and articulate the powerful ideological forces and subsequent policies and practices working against transformational action. As such, we are not calling for the inclusion of disabled people into society as it is today—wrought with social, economic, and environmental crises. Rather, we seek a transformation of the status quo whereby disabled people are respected as an inherent part of human diversity with gifts and worthiness untangled from a capitalist and colonial system of exploitation, extraction, and oppression. This means that achieving social justice and inclusion requires radically reordering our economic and political systems. This thematic issue illuminates the impacts and root causes of exclusion to foment critical thinking about the possibilities for social inclusion from the perspective of those who are marginalized by the status quo.

Keywords

disability; disability justice; human rights; intersectionality; social model

Issue

This editorial is part of the issue “Disabled People and the Intersectional Nature of Social Inclusion” edited by Alexis Buettgen (McMaster University), Fernando Fontes (Universidade de Coimbra), Susan Eriksson (South-Eastern Finland University of Applied Sciences), and Colin Barnes (University of Leeds) as part of the (In)Justice International Collective.

1. Background

Disabled people comprise at least 16% of the world’s population, 80% of whom live in the Global South (World Health Organization, 2023). They are integral parts of our families, communities, and cultures. Disabled people are a part of our human diversity but continue to face discrimination and exclusion in socio-economic, political, and cultural life. They are disproportionately represented among those living in poverty, which, when analysed in depth, is usually the result of discrimination, government failure, ineptitude, immorality, criminality, or exclusive policy.

The social model of disability envisages disablement as a social construction of systemic barriers, discriminatory attitudes, and exclusion. The social model represents a shift from individual medical assumptions about disability to an analysis of how society responds to impaired individuals and disables them from full participation. The model implies that impairments would not necessarily lead to disability if society were to accommodate and include disabled people. Indeed, most people acquire their impairments (to varying degrees and in different forms) through birth, poverty, environmental hazards, violence, accident, war, and ageing. This critical approach to disability issues has become internationally influential and changed the way disabled people see themselves and organize for social change. This perspective also considers the multiple intersecting identities that people with disabilities hold, and forms of oppression related to their gender, sexuality, age, race/ethnicity, nationality, class/caste, or other characteristics.

As the social model has progressed over the past few decades, there has also been a rise in the profile of disability rights and disability justice. As a starting point, however, it is important to acknowledge that contemporary understandings and attitudes towards disability have been shaped by the onset of capitalism and its associated ideologies of individualism, liberal utilitarianism, industrialisation (specifically waged labour), and the medicalisation of social life. As a result, the injustice of disableism (in all its discriminatory forms) is endemic to most, if not all, contemporary societies.

In line with the principles of disability justice, we want to recognize and support the call to redress the historical erasure and invisiblized lives of disabled people of colour, immigrants with disabilities, disabled people who practice marginalized religions, queers with disabilities, trans and gender non-conforming disabled people, disabled people who are houseless, incarcerated, disabled people who have had their ancestral lands stolen, amongst others (Sins Invalid, 2020). In this way, the manuscripts in this issue include an explicit recognition and discussion of intertwined and socially constructed identities, labels, power, and privilege as explicated by pioneering Black feminists who introduced the concept of intersectionality. We understand intersectionality as a conceptual theory that traces its intellectual roots to the activist work of Black women, Indigenous women, and women from the Global South during the second wave of feminism (see, for example, Anzaldua, 1990; Hill-Collins, 1986; hooks, 1984; Jamieson, 1979; Lorde, 1984; Mohanty, 1984; Two-Axe Early, 1994).

From this perspective, this thematic issue is not calling for the inclusion of disabled people into society as it is today—wrought with social, economic, and environmental crises. Rather, we seek a transformation of the status quo whereby disabled people are respected as an inherent part of human diversity with gifts and worthiness that are not predicated on contributions to a capitalist and colonial system of exploitation, extraction, and oppression.

We believe this transformative change requires a collective response and collective action to address the multiple and intertwined social, economic, and environmental crises of our time. These crises include imminent ecological unraveling, gaping economic inequality, and surging white supremacy.

Transformative change requires wealthy nations of the Global North to take more responsibility for their contributions to the various crises we are experiencing and move away from individualist and nationalist ways of thinking and living—to act together as a global human community with equal respect for all other living beings. To do this, we can learn a great deal from indigenous ways of knowing and being. We can learn from the value of interdependence highlighted by disabled people. We can use the analytical tools of intersectionality as a crucial intervention because of its assertion that systemic and structural oppression can only be understood and rooted out "through an interrogation of the complex, intersecting, and overlapping ways in which power operates via the social axes of difference, namely race, class, gender, disability, age, sexuality, ethnicity, and nationality mediated by the exploitative and oppressive working of settler colonialism and transnational capitalism" (Erevelles & Morrow, 2023, p. 2). We can learn from all of those who are pushed to the margins of our societies through the inclusive design of transformative change that is anti-patriarchy, anti-capitalist, decolonial and anti-ableist.

2. About This Issue

This thematic issue includes transnational and transdisciplinary studies and expressions of lived experiences facing disabled people, their families, and allies across the globe from a social, human rights, and/or disability justice perspective. We chose these manuscripts to include a breadth of knowledge from various geographic and social locations and to advance knowledge on intersectionality in relation to disability to support the co-production of transdisciplinary knowledge, coalition building, and cross-movement organizing that transcends identity politics. Moreover, some of the manuscripts in this issue pertain to people with particular impairments (e.g., people with intellectual disabilities) and various other social identities in relation to gender, indigeneity, religion, etc., to highlight the need for recognition and inclusion of underrepresented groups in disability studies and the disability movement itself.

Accounts range from the lived experiences of climate change in Indonesia where Pirmasari and McQuaid (2023) articulate the intersections of disability with social and structural injustices that shape diverse responses to climate change and disasters. The authors highlight the challenges of cultural representations of climate disasters and disability to argue for the centring of *diffability* in disaster risk reduction decision-making.

With a focus on the inclusion of disabled women in Malawi, Huque (2023) captures the stories of grassroots women disability activists combatting their own and other's experiences of violence, abuse, and exclusion. Their stories highlight the politics and ethics of community care incorporating human rights discourse and the expression of agency, strength, and solidarity.

From an intersectional analysis of gender, disability, and religion in India, Thompson et al. (2023) show how disability remains the strongest category to determine the position of an individual in various social contexts. Their analysis of narrative interviews conducted among diverse persons with disabilities reveals that even though gender and minority religious statuses are forceful categories that independently lead to social exclusion, disability is the root cause of discrimination.

In response to this discrimination and an international push for localization of human rights, Grech et al. (2023) critically examine the barriers to implementation of the UN Convention on the Rights of Persons With Disabilities in the Global South. Their study concludes that there is a profound need for an informed, contextualized, intersectional, and geopolitical analysis where poverty is kept sharply in focus and to avoid unrealistic assumptions about disability rights frameworks.

Turning toward the scientific community, Sanmiquel-Molinero et al. (2023) draw on a pragmatic discourse analysis of Latin American scientific literature to explore the models used and dominant ideas associated with disabled parenthood. They conclude that the scientific community must transcend the leading metaphor of disability vulnerability/risk and embrace the idea of "disability as interdependency."

Shifting to the Global North, Carvalhais et al. (2023) studied the implementation of person-centred planning (PCP) for persons with intellectual disabilities in Portugal. Their study found many discrepancies in the process caused by bureaucratic practices and habits, participation of families, as well as different understandings of the general mission and vision of PCP. The results imply that a lot of work is still needed to improve PCP practice and fully support the active citizenship of persons with intellectual disabilities.

Our issue concludes with Sépulchre's (2023) explorative study of the use of intersectional praxis in the provision of disability and accessibility resources in higher education in Sweden and the United States. Based on interviews with university administrative staff, the author analyses participants' conceptions of disability as well as—based on hypothetical scenarios—the implementation of disability anti-discrimination laws in both countries. This study finds it crucial to recognise disability as "diversity" from an intersectional perspective in order to realistically advance a social justice agenda in higher education.

Taken together, the manuscripts within this issue identify and articulate the powerful ideological forces and subsequent policies and practices working against transformational action. This means that achieving social justice and inclusion requires radically reordering our economic and political systems. This thematic issue illuminates the impacts and root causes of exclusion to foment critical thinking about the possibilities for social inclusion. Disabled people experience structural vulnerability, violence, and discrimination, often as a result of neoliberal exploitation, indiscriminate impoverishment, and exclusive service provision.

3. Dedication and Conclusion

This thematic issue is the result of *Social Inclusion*'s partnership with the research network (In)Justice International (II) of which the editors of this issue are a part. II is a not-for-profit multidisciplinary global collective accessible to all. Our aim is to uncover, expose, and publicise injustices/atrocities committed against the environment, indigenous peoples, ethnic minorities, refugees, disabled people, the so-called "troublesome youth," and people from poorer class backgrounds. Injustices inflicted against gender "difference" is also an important consideration.

We dedicate this thematic issue to the founder of II, Dr. Simon Prideaux. Simon was an associate professor at the University of Leeds, UK. Over the course of his career, he wrote widely in the fields of social policy, sociology, disability studies, and crime with a particular interest in comparative access policy, welfare discourses, conditionality, and political ideologies. Before his death in 2023, Simon founded II to bring together established and emerging leaders from separate disciplines to work in complementarity with one another to explain and address the reasons why—whether it be good or bad—society and/or the economic environment has come to be in the condition that it is. Genocide, war, class, gender, social exclusion, (institutional) discrimination and racism, migration, (social) media influence, and public perception/actions are prominent aspects of our dissemination process in a dedicated opposition to (anti-)social injustice.

Simon Prideaux was hard-working, precise, and very persistent in his efforts to expand the II network and include scholars throughout the world to work for the cause, and to cover a variety of disciplines to tackle any issue of injustice. He was also a cheerful colleague and made one laugh with his wry humour. Despite of all his scholarly merits, he did not make a fuss about them. Once or twice, we heard him describe his own position as "a knower of all, master of none." Simon's contagious positive attitude was a breath of fresh air in difficult times. His generous availability, care, engagement, intellectual stimulus, and critique inspired us to continue. We miss Simon very much.

This thematic issue furthers the vision of II which is to demonstrate how theoretical knowledge helps in the understanding of why social and public policies and directions are embarked upon and their impacts on diverse disabled people. The use of factual and statistical data and other forms of research and knowledge underlines the influences and consequences of such policy-making. Indeed, with this theoretical knowledge and so-called factual reinforcement, it is then possible to devise a solution to destructive/oppressive circumstances when possible and necessary. Historical analysis and theory in conjunction with knowledge of economic socio-political conditions, influences, and outcomes also enhances understanding and, with this combination of theory and information (historical or contemporary), a more critical, wide-ranging approach can be taken toward social, environmental, and economic justice that is accessible and inclusive of all people.

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Article

Halin ai: Intersectional Experiences of Disability, Climate Change, and Disasters in Indonesia

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Abstract

Halin ai centres the lived experiences of climate change and disasters of people living with disabilities in two urban sites in Indonesia—Banjarmasin in South Kalimantan and Mataram in West Nusa Tenggara. We call for an intersectional and decolonial approach to better understand how disabilities intersect with social and structural injustices in urban settings to shape diverse responses to climate change and disasters. We highlight the economic, socio-cultural, and embodied challenges that increase vulnerability to—and ability to recover from—disasters including urban flooding and earthquakes. We draw on ethnographic and visual data from our research, including a comic illustrated by Ariel and Zaldi and sketches by Rizaldi, to centre diverse lived experiences of structural vulnerabilities and socio-cultural marginalisation, particularly concerning education and livelihoods. Foregrounding life stories in this way serves to challenge the absence of meaningful engagement of people with disabilities in disaster risk reduction and climate change actions and decision-making. Our article highlights disability as a site of both discrimination and critical embodied knowledge, simultaneously a product of structural, socio-cultural, political, and environmental injustice while also a source of innovation, resilience, and agency.

Keywords

climate change; decolonial; disability; disasters; hazards; Indonesia

Issue

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1. Disasters and Disability in Indonesia

When an earthquake struck Lombok Island in West Nusa Tenggara, Indonesia, at night in 2018, Zainal (all names in this article are pseudonyms), who is blind, was working as a massage therapist. When the building began shaking all customers began fleeing the building in panic. Zainal and his colleagues did not know where to go. Even though they were finally able to find the door and exit the building, due to limited sensory ability they had no way of knowing if they were in a safe location:

> We did not know if there were nearly falling rooves or walls around…it was near the main street as well and people were running and driving all over the place as there was a rumour about tsunami at that time.

There were no railings or guiding blocks to help them, and no one offered any help or support, so all they could do was wait and hope that it would soon be over. Meanwhile, just outside the city of Mataram, Putri—who uses crutches and a wheelchair—and is an active member of a women’s disability organisation in Lombok, explained how she and many others had been helped to flee during the same earthquake, but their mobility aids had been forgotten, reflecting a common lack of understanding by community agencies regarding the specific needs of people with disabilities during and in the aftermath of disasters (see Lindsay et al., 2022). This led to increased difficulties in the immediate aftermath of the earthquake, exacerbating their discomfort and ability to recover. Once in the shelters, she reports, women with disabilities found themselves especially vulnerable to harassment when they were asleep, and we heard many examples of women being harassed when using the toilets and washing facilities.

Indonesia is situated in the "ring of fire," prone to hazards and disasters including volcanic eruptions, landslides, earthquakes, tidal waves and abrasion, and flooding. According to Indonesia's National Disaster Mitigation Agency, in 2022 there were a reported 3,542 disasters, displacing over 5.3 million people and killing over 850 (Aditya, 2023). Within the first three months of 2023, the country recorded 564 disasters, of which more than 40% were floods, followed by extreme weather, landslides, forest fires, and earthquakes (Annur, 2023). A disaster, Rydstrom and Kinnvall (2020, p. 2) remind us, "unfolds societal dynamics at the structural level and a community's relation to its environment," which further shapes their "capability to adapt and the extent to which local knowledge can be infused to reduce vulnerability and harm." It is therefore critical we address the disproportionate and unequal impacts of disasters on people as a result of geographic, structural, and social marginalisation including poverty, gender, age, colonialism, race, ethnicity, disability, and indigeneity (see Wisner et al., 2012), and the extent to which this further excludes their experiential knowledge from decision-making. To do so here, we centre the perspectives of people with disabilities.

Evidence on the experiences of people with disabilities during Indonesia's disasters remains scant and representations of disasters by people with disabilities continues to be neglected within planning and policy at multiple scales. Following Spivak (2003) and Gaillard (2022, p. 13) we understand "representation" as a call for spaces in which diverse people with disabilities can speak, write, and ultimately define what a disaster is, what it entails, and what needs to be done to reduce risks. In the process, this can challenge the ongoing colonisation (and lack of inclusivity) of both disaster and disability discourses.

This is an urgent issue. People with disabilities are four times more likely to die when a disaster strikes than those without disabilities (UNESCAP, 2014, 2017). Disasters can worsen pre-existing disabilities and create new disabilities (Kelman & Stough, 2015; Sheppard & Landry, 2016; UNESCAP, 2014), and people with disabilities are among those least able to access support or social assistance. Critically, this vulnerability is due not to their bodies and minds, but to multiple and reinforcing systemic (and normalised) socio-cultural, economic, and political barriers in daily life (Calgaro et al., 2020, p. 370; Gaskin et al., 2017; IFRC, 2007; Sheppard & Landry, 2016; World Health Organization, 2017); as well as "the hegemony of Western knowledge in disaster studies," which supports "normative and standardised disaster risk reduction policies and actions, which in many instances fail to consider the diverse realities of very different local contexts around the world" (Gaillard, 2022, p. 2).

We thus understand disability as socially contingent and relative (Eriksen et al., 2021); as a site of discrimination and a product of structural, political, socio-cultural, and environmental injustices and violence (Belser, 2020; Lawson & Beckett, 2021; Oliver, 1996). Some bodies are more vulnerable to disabilities than others, and have different lived experiences of disability due to myriad intersecting factors, including the unequal impacts of environmental harms, social factors including gender, race and age, and the social and structural norms that standardise notions of in/ability to perform certain activities, communicate, and engage with society (Gaskin et al., 2017; Griffo, 2014). In this way, we recognise how ableism operates as a socio-political mechanism of marginalisation, systematically reinforcing the social differentiation of disability and vulnerability (S. Bell, 2019), and converging with other axes of oppression to manifest a "double invisibility" for many groups including, for example, women and children with disabilities (Jodoin et al., 2020). Increasingly popular among activists in Indonesia is the term *difabel* (*diffability*), derived by Mansour Fakih and Setiadi Purwanta, two blind people in Indonesia, from the English "differently-abled people" as a critique of the term *disabilitas* (disability), which perpetuates and re-produces the marginalisation of people with disabilities and fails to recognise (or normalise) the diversity of "ability" (Suharto et al., 2016; Thohari, 2011). Critically, we also recognise disability as a site of critical embodied and experiential knowledge and socio-political resistance (Belser, 2020). Thus, in this article, we will continue using the term "people with diffabilities." Diffabled people have the embodied knowledge, agency, and ability to strengthen decision-making processes and disaster risk reduction (DRR) strategies for the benefit of whole societies (Pertiwi et al., 2019).

We must adopt an intersectional approach to foreground embodied diversity and highlight how poverty, structural exclusion, social disadvantage, and other categories of difference disproportionately render people with diffabilities more vulnerable to climate change and disasters (C. M. Bell, 2011; Engelman et al., 2022; Erevelles & Minear, 2010; Priestley & Hemingway, 2006). This further serves to direct attention to "gender differences in perceptions, impacts, and responses" (MacGregor, 2010, p. 137) to better understand gendered impacts, for example how women and girls with diffabilities come to be at greater risk of violence, physical abuse, and sexual exploitation after disasters due to displacement and unsafe shelters and public spaces (Calgaro et al., 2020, p. 370; Smith et al., 2012). As Green et al. (2018) argue regarding the lived experience of First Nations diffabled people in Australia, an intersectional approach is necessary if we are to address cumulative systems of social inequalities perpetuating the experience of multiple and intersecting barriers and discriminations, each of which work to amplify and compound the impact of each other (Cooms et al., 2022). Such systems shape the "set of diverse knowledge, skills and resources people can claim, access and resort to in dealing with hazards and disasters" (Gaillard, 2022, p. 31).

In Indonesia, the rights of diffabled people are protected under Law No. 8/2016 on Persons With Disabilities. This stipulates various rights for people with diffabilities from access to jobs and employment, disaster response, and support and help. On the international scale, legal frameworks and conventions (e.g., the UN Convention on the Rights of People With Disabilities, Sendai Framework for Disaster Risk Reduction 2015–2030, and the Incheon Strategy 2013–2022) recognise that inclusion in DRR processes is a human right and must be factored into DRR policy and practice to significantly reduce risk (UNESCAP, 2012; UNESCAP & UNISDR, 2012; UNISDR, 2015). People with diffabilities should therefore be afforded the same rights as any other citizen to both risk reduction and management measures and the right of equal participation in the design and implementation of DRR policies and practices. However, pathways to achieving inclusion and greater justice for diffabled people are unclear and fragmented, with very few documented cases of success (Calgaro et al., 2020, p. 369; Weibgen, 2015). In a 2013 report by the UN's Office for DRR, 85% of respondents living with diffability from 137 countries stated they were not involved in community disaster management and risk reduction processes and policies (UNISDR, 2014). As Calgaro et al. (2020, p. 373) note, diffabled people are "largely unseen, unheard and unaccounted for in all levels of disaster management due to normalised exclusionary policies and practices of communities, governments and disaster assistance organisations" (see IFRC, 2007; King et al., 2019).

People with diffabilities are routinely robbed of their agency and right to a public "voice" by normalised medical models of diffability within climate and development discourses that locate "problems" and "impairments" within individual non-conforming bodies, undermining rights-based approaches that recognise diffabled people as capable agents (Belser, 2015; Calgaro et al., 2020; Gartrell & Hoban, 2013). As the rate of disasters increases in many climate frontlines across the world, it is more important than ever that we centre the lived experiences of diffabled people. In doing so, we must situate their stories within broader postcolonial, political, socio-cultural, and geographic landscapes, and analyse "the specific historical and culture-specific meanings of disability, physical and mental differences" (Parekh, 2007, p. 150). We need to actively listen to diffabled people to better understand how interconnected systems of power work to create and reinforce systemic inequalities that increase vulnerability to—and capacities to recover from—disasters. We can then radically reconsider how we practice inclusion, representation, and engagement in climate and disaster governance. A decolonising approach is therefore as critical as an intersectional one.

Contemporary diffability studies continue to risk constituting "a form of scholarly colonialism, and needs to be re-thought taking full account of the 400 million disabled people living in the global South" (Meekosha, 2011, p. 668; see also Connell, 2011, p. 1372). As Livingston (2006, p. 125) points out, "while four-fifths of the world's disabled persons live in developing countries, there is a relative dearth of humanities and social science scholarship exploring disability in non-Western contexts." We agree with Puar (2017), who highlights the uneven risks faced by certain bodies and populations, which is further exacerbated by the intersectionality of race, age, gender, sex, cultures, poverty, and healthcare inequalities.

A postcolonial lens is necessary to understand how power structures have—and continue to—manufacture diffability. Colonialism, as Connell (2011, p. 1374) reminds us, brought "crisis to the social orders in which embodiment had been organised…creating new hierarchies of bodies," and changing "the ways in which bodily difference, impairment and ability were socially constructed." Colonial regimes disrupted socio-cultural meanings (and often acceptance) of diffability through the imposition of new gendered and patriarchal social orders. Then, as local gender orders became "subsumed in a global economy, a modernised patriarchy has become internationally hegemonic" (Connell, 2011, p. 1376). This translates into particular gendered burdens differently experienced by men, women, and sexual and gender diverse people with diffability, disproportionately so for those living in poverty. As Meekosha (2011, p. 671) points out, "disability in the global South is firmly linked to northern imperialism, centuries of colonisation and globalisation." In pre-colonial Indonesia, the perception of diffabled people was not negative, and they were often considered to have supernatural powers (Widinarsih, 2018). However, white colonialism and the introduction of "Western" medicine introduced the perception of diffability as an affliction in need of treatment (Thohari, 2011). Widinarsih (2018, p. 76) highlights how the social exclusion that led to contemporary discrimination and abuse towards diffabled people is a legacy of this colonialism, in which they came to be seen as unproductive and in need of being "normalised" through nursing homes and rehabilitation agencies. To borrow Puar's (2017) term, this perpetuated a "right to maim," in which certain bodies were—and continue to be—contained and maintained in precarious conditions.

Postcolonial diffability studies increasingly highlight how diffability and poverty go hand-in-hand. We must therefore attend to "layerings of disadvantage," which create "unexpected barriers and unique priorities for an individual and family that can be described as a "wicked problem" that is resistant to conventional approaches of redress" (Cooms et al., 2022, p. 3). In recognition of the historical, structural, and systemic manufacturing of diffabilities, we must consciously define people not by their dis—or in-ability, or their exclusion, but by diffability: adopting a "strength-based understanding of our differences" (Acker-Verney, 2016, p. 413) that directly leads from lived experience and embodied knowledge. To do so, in this article, we intentionally centre the lived experiences of diffabled people in two sites in Indonesia—Banjarmasin in South Kalimantan and Lombok in West Nusa Tenggara. Banjarmasin is situated on the third largest island in the world and located below sea level where floods regularly occur, while Lombok Island is vulnerable to coastal erosion and earthquakes. In 2018, Lombok was hit by a magnitude 7 earthquake causing over 555 fatalities. In the following section, we outline our feminist intersectional methodology before empirically exploring the experiences of those born with diffability and those who later acquire diffability. We aim to highlight the cumulative structural, socio-economic, and physical challenges that compound their vulnerability to—and ability to recover from—disasters including urban flooding and earthquakes, while simultaneously foregrounding the creativity, innovations, survival mechanisms, and activism of diffabled people.

2. Methodology

This article draws from a combination of ethnographic and applied arts methods conducted as part of a wider project adopting feminist, decolonial, and intersectional methodologies to investigate the gender-age-urban interface of climate change in Indonesia. To do so, our work explicitly focuses on marginalised urban communities including women, people with diffabilities, older and indigenous people, informal workers, and sexual- and gender-diverse communities. Conducted over nine months in 2022, our research comprised participant observation, in-depth ethnographic interviews, and 52 creative workshops that combined visual and applied arts including creative writing, drawing, digital storytelling, songwriting, and local arts.

Our creative sharing workshops involved over 15 civil society organisations led by (and serving) the communities participating in them as co-facilitators and research partners. We invited local artists to co-facilitate multiple workshops with the same group of participants to enable them to explore different perspectives on climate change and disasters in ways that embraced multiple ways of knowing including the embodied, sensory, and non-linguistic. This simultaneously served to build solidarity and raise critical consciousness of the structural injustices driving vulnerability to disasters. Artists provided training to participants in different art forms while also producing creative outputs that synthesised key experiences and perspectives.

As far as possible our research was designed and conducted in collaboration with the communities themselves to foreground local priorities and build ownership. This served to resist and subvert historical and colonial power dynamics of research by enabling the community itself to determine how this research was produced, including shaping the research questions and how they were asked, what methods and art forms were used, and how to analyse and apply the knowledge co-produced. In many cases, ethnographic interviews were conducted with participants after creative workshops to provide a safe space in which they could reflect on the workshop material and share personal experiences in more depth, as well as to reach participants who could or did not want to attend group workshops. Conversations, interviews, and workshops were conducted in either Banjarese, Sasak, or Bahasa Indonesia, and where necessary translated by our local research assistants (including those with diffabilities). All interviews and workshops were recorded and transcribed in full and data was first analysed in the original languages to maintain a connection with local contexts and centre local values. All data was collected in adherence to strict ethical and safety protocols co-designed with communities to incorporate locally situated knowledge and expertise within the ethical frameworks of the University of Leeds and the Indonesia National Research and Innovation Agency.

3. Precarious Livelihoods, Gender, and Spatial Poverty Traps

In Indonesia, poverty and diffability are often deeply intertwined, exacerbated by social exclusion and discrimination across multiple scales, from homes to public spaces, which prevents people from achieving equal opportunities. Many diffabled people are caught within spatial poverty traps, where the physical, natural, social, political, and human capital of an area is low while the poverty rates are high (Bird et al., 2010). A lack of educational and livelihood opportunities forces many into precarious low-paid work, and poor-quality housing susceptible to disasters, as we will see below.

For Pirmasari, this has personal dimensions. Her oldest brother, Ali, now 45, was known as *si bisu*, which literally translates as "mute," but in their natal village in the heart of Kalimantan Island, and Banjarmasin too, many people define it as "the deaf." He could not hear nor speak the language of everyone else in their village and slowly began to communicate using informal sign language as their family grew and villagers started to try speaking to him. When Ali was a child his neighbours and some family members often mocked him by covering their mouths and ear at him, scornful of his being unable to hear and speak. He now recounts the feeling of always being treated as if he was unable to think or help his family and everyone else. People always felt sorry or pitied him for being "different." He could not go to a *Sekolah Luar Biasa* (SLB), which literally translates as "extraordinary school" (another translation could be "unusual school"). There was (and is) no SLB in his village, and while there were SLBs on Java Island, it would have cost too much money just to travel there, let alone stay and study, so it was never viable for anyone from his village.

Ali, like many diffabled people we spoke to, has no formal education or skills training, and faces an impossible job search, with employers regularly discriminating against all diffability. He has been forced to remain dependent on family members: "I will not marry and I will never have a family of my own," he reflects. This burden of not meeting the pressure to have a family is even greater when we consider the broader context of a patriarchal society in which men are expected to be breadwinners and the heads of their own family, taking care of their own elderly parents in time. It also has ramifications for how both himself and his ageing parents will be affected by, and have the capacity to recover from, disasters. Ali's comments reflect dominant social norms in which bodies are regulated and contained as able (or not) to pursue independent livelihoods, perform agency, or fulfil masculine and feminine ideals and markers of social ageing including getting married and bearing children. Yet Ali does play a key role within his household. When floods hit his village, he actively helps, shifting electrical items out of the rising waters; when his and neighbours' houses caught fire he used the water pump engine to dowse the flames.

Hilman discusses his childhood and growing up blind in Lombok. He went to an SLB until secondary school and in 2018 applied for public school, where he was almost rejected due to his diffability. That year Lombok was hit by a huge earthquake. He was in class and did not know what to do and no one helped him. He just took cover under a table until the shaking stopped. The situation almost made him give up and return to the SLB, despite always ranking first in his class. Later, he received an offer from the university. However, the discrimination continued. On one occasion, when speaking of his ambitions, his lecturer told him that "an educator [teacher and lecturer] should not be diffabled, there is no deaf teacher right?" Hilman started to believe this was true, feeling hopeless in the face of constant discrimination. However, his ability to compete academically with the non-diffabled and his achievements to date always bring back hope.

Discrimination by employers as well as educators is widespread. In practice employers (both private and public) are hesitant to recruit people with what are known in Indonesia as "heavy diffabilities" (sensory and mobility impairments). As Misnah, a woman in Mataram explains, people often misjudge her ability to conduct work like "everyone else": "Last year I applied for culinary art training, but I was not accepted. So many businesses do not want to accept us. There are many deaf friends unemployed because no one wanted to accept them." Putri, who uses a wheelchair in Lombok, describes how a recent job requirement by a state-owned enterprise: "looked for people with handicapped diffability and the deaf, but the deaf ones should have a hearing aid so they can communicate and the handicapped ones should not use a wheelchair." In her case, diffability and age discrimination intersect: "In my case, I could not apply because of my age [47]." Many of our participants cited recent job adverts that clearly stated applicants "should not be blind, fully deaf, limp or use a wheelchair." In Banjarmasin, Fajar spoke of how, "in 2017 or 2018 during civil servants' recruitment, one of the conditions required in the applications was "not blind and not using a wheelchair." He and his wife lead a local diffability support group and filed a formal complaint to the government; the following year these conditions were removed, but a person with diffabilities has yet to be recruited. Routine exclusion and invisibility of diffabled people within workplaces act to reinforce their othering. It highlights the visibility of their diffabilities and further convinces family members that the diffabled people they care for will always remain dependent on them. This is further exacerbated by gender hierarchies, placing undue burdens on men with diffabilities to marry and act as breadwinners, and relegating women to the domestic realm.

These cases illustrate an in/visibility paradox. Due to their diffabilities, people are often rendered hypervisible and thus become a target for stigma and discrimination, including gender-based violence and harassment, while also driving their invisibility within work and public places. For women in particular this fuels their confinement to private and domestic spaces. Fears about gender-based harassment of women with sensory and mobility issues lead many parents of daughters with diffabilities to restrict their mobility and keep them at home. Community leaders from the Banjarmasin Chapter of the Indonesia Disabled People's Association reported to us increased cases of women being kept home from a young age. This had several long-term impacts including reduced educational outcomes and livelihood opportunities, social isolation from peers, and women taking on increased domestic burdens within the family including cleaning, tidying, cooking, and washing clothes. Figure 1 is an excerpt from a comic illustrated by Ariel and Zaldi to highlight some of these multiple burdens faced by young women with diffabilities as shared with us during fieldwork.

Mira and Irma, two diffabled women in Lombok, recounted how their parents often asked them to stay at home in order to protect them. As Mira wryly commented: "If I stay home I can get knowledge about washing…and if I stay home I can also look after my parents when they are old." Hilman, the blind man mentioned above, observed the contingency of this "protection":

> Usually blind women were protected more by their parents…because of the stigma in the society….Sometimes I felt really sad and cried to hear news that deaf women were raped by their closest relatives, which made me think how prone are women with disabilities…and we do not know how to protect ourselves in that situation.

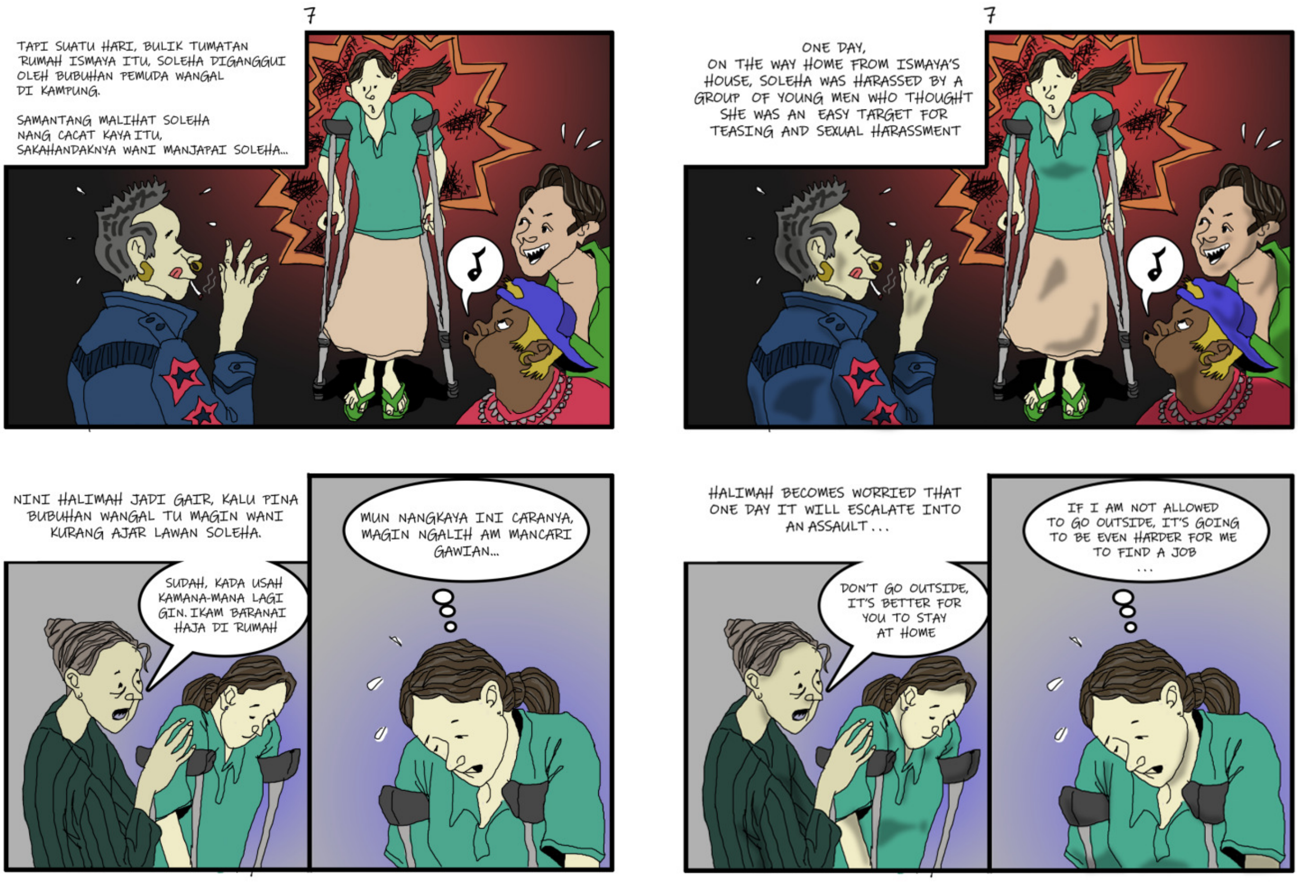

Figure 1. Excerpt from a Banjarese comic (with English translation) illustrated by Ariel and Zaldi about the experiences of women with diffabilities facing harassment on the street.

The intersecting forces of poverty, gender, age, and stigma not only shape the lives of people born with diffabilities, but also increase the risks of people acquiring diffabilities. Informal work and accompanying precarious incomes often restrict people's access to quality healthcare and routine medication, intersecting with ageing to exacerbate medical conditions, often leading to permanent diffabilities. During the writing of this article alone, we heard the distressing news that one of our participants had become blind due to ongoing complex health issues and persistent stress, while another had lost his legs due to a traffic accident. When we met Ahmad, a fisherman in his late 50s in Lombok. He had been recently paralysed from a diving accident. He used to work as a compressor diver: a fishing technique where he dived down to 30 meters using a dive regulator with a hose connected to an air compressor machine on a boat. Ahmad, along with many other compressor divers across Indonesia, did not wear proper scuba equipment and had limited access to diving health and safety standards, making them prone to decompression sickness. At the same time, as fishing communities in Lombok explained to us, economic pressures placed on men as the heads of their households translated into burdens to provide more money to the family, often forcing fishermen to push their bodies to the limit and jeopardise their own health (Rakhman, 2018). In March 2022 after a long dive in Bali Strait, Ahmad was taken to hospital and put in a hyperbaric chamber. He could only afford to pay for 2.5 hours, not enough time to treat his decompression sickness, and thus led to his permanent paralysis. He has since been forced to sell his boat and engines due to economic difficulty. His economic precarity continues to rob him of his dignity as well as his health. He is unable to afford catheters or ongoing medical treatment, and spends his days confined to bed, placing a plastic cup inside his shorts to capture his urine.

Ahmad's case is not uncommon in Lombok. Fishermen have long faced injury, paralysis, or even death at sea in the pursuit of their precarious livelihoods. Their bodies are thus maintained in a precarious condition by the layering of economic, social, and environmental burdens. Fishing is becoming ever riskier as fishermen are forced to go further out to sea to fish, with limited equipment and a lack of communication devices (see Stoltz et al., 2021). As the fishing communities in Mataram say: "*aiq sere rapet, empaq sere jaoq*" (the water is getting closer, the fish is getting further). Coastal abrasion is bringing the sea closer to their houses, with high seas and rising levels of sand shrinking the height of their houses, all serving to increase anxiety among the fishing communities who live by the beach, increasingly trapping them in cycles of poverty, diffability, and disaster.

The disproportionate environmental burdens faced by diffabled people was most obviously reflected in their residence in poor neighbourhoods vulnerable to disasters. In Banjarmasin, for example, many of our participants were forced by precarious livelihoods to live in poor quality, semi-permanent wooden housing on the riverside, which are increasingly vulnerable to flooding. In some cases, their flooring was literally rotting away from repeated soaking from rising water levels. Nila, who had become blind due to old age, said all she can do when it floods is to close her door so that her plates, cups, and other precious belongings do not float away. She simply sits on the bridge in front of her house to wait for the waters to recede. Environmental burdens facing these neighbourhoods—poor water and sanitation, bad roads, informal housing, water, and air pollution—intersect with the impacts of poverty—poor education, precarious livelihoods, and inadequate healthcare—to exacerbate the impacts of disasters, especially fires and floods, reducing residents' capacities to plan for or sustainably recover. Such layers of disadvantage disproportionately affect those with diffabilities, as well as the family members who care for them.

Figure 2 was drawn by Rahimah, a woman who uses crutches to move around, during a creative workshop in Banjarmasin.

When flood waters suddenly enter their house, she and her daughter have to seek immediate refuge on the bed, as this is the driest place in their house. Fajar, her husband, who is blind, has tried to adapt all of their rental houses to cope with the floods by making stands—known in Banjarese as *bakatil*—to protect their bed, fridge, and other equipment from flood damage. The floods make the floor slippery and too dangerous for her to move safely around, so her husband must do everything during flood events and clean up the house when the water recedes. She describes the indignity of flooding disasters as she is forced to urinate next to the bed as she cannot reach their toilet. When the water levels are really high, the polluted water is just three centimetres shy of reaching the mattress, so when a boat passes their riverside house, the wake can push the water up to soak their mattress. Sometimes the flood waters enter the house for a few hours every day, so it becomes a routine for the family. Through time, they slowly learnt the flood patterns: When it comes and when it will dry. However, they report worsening and more unpredictable floods over the past five years, reflecting statements from the River Agency ("Banjarmasin semakin sering," 2023), with the worst floods hitting in 2021.

Rahimah and Fajar have always lived in rental houses that were designed by and for non-diffabled people. It is rare in Banjarmasin to find rental houses that can aptly accommodate diffability. In 2022, Rahimah and Fajar were forcibly evicted from their previous rented accommodation (pictured in Figure 2) due to late rent payments. The prolonged Covid-19 lockdown and the floods that regularly hit their house had directly affected their livelihoods. Fajar, who works as a masseur—a common occupation for blind men in Indonesia, lost nearly all customers during the lockdowns, forcing the family to rely upon Rahimah, whose only income at that time was sewing and selling face masks. On a day-to-day basis, they survived on people's generosity, both during the pandemic and in the aftermath of floods.

This community social support system plays a central role in enabling many people in their neighbourhoods to survive and "recover" from shocks and ongoing crises. Fajar and Rahimah lead a social support network for

Figure 2. Rahimah draws her situation during flooding in Banjarmasin: She and her daughter sit on the bed while her husband makes tea.

diffabled people in Banjarmasin, playing an active role in helping those excluded from formal and informal support in their neighbourhoods. As Rahimah recounts:

> There was a paralysed couple in Kampung Melayu. They did not receive any help or support. They were missed out when people did surveys to receive support. They contacted us. We did not know how to help as we were in the same situation [flooded], so we contacted the fire brigade we knew, who were then willing to check on them, and only after that, people and local authorities there were aware that there were people who had been missed out in the neighbourhood. Even though the communal kitchen was situated close to their house…they said they were always being missed out. They said they saw people distributing support and help [in the neighbourhood] but they do not open the door of their house during floods, worried that rubbish [in the water] will enter their house.

Rahimah and Fajar are also active in collecting data about diffabled people living in the city. There is no formal data available on the population with diffabilities, so they work voluntarily at the grassroots to identify people across the city, then leverage their networks in the private sector or government to try and source necessary support. During the worst floods, they help mobilise and distribute food donations. Rahimah rides a three-wheeled motorcycle (see Figure 3) that she and her husband personally modified so she can drive it with just one leg and her husband can ride in the purpose-built sidecar. It cost them IDR 5 million (US$ 340) in 2012, representing more than four times the monthly minimum wage in South Kalimantan that year. They have had to adapt the motorcycle at their own cost to accommodate their needs, and they spoke of recently having to draw on precious savings to fix the motorcycle after it was submerged by prolonged flood waters.

Figure 3. Rahimah and her a three-wheeled motorcycle, drawn by Rizaldi.

There is a critical lack of data about diffabled people in both Banjarmasin and Lombok, often driven by social invisibility within the communities that surround them. This invisibility often actively excludes people from social assistance, support, and help (Lindsay et al., 2022). Nila, an older blind woman who lives on her own, has never received social assistance from the government. She lives in a leaning house by the river in Banjarmasin, prone to regular flooding, and has no access to clean water in her kitchen or toilet. She relies on her neighbour for immediate assistance to escape flooding and lock her house. During disasters, people reported that their social support networks of families and neighbours were the most active. The government was always considered late in responding, too mired in bureaucracy, and the help they gave was much less than private or personal support from neighbours and other citizens. In some cases, people said it felt “like begging” to get some assistance from the government, even when they needed “help to eat.”

In the absence of the state, people come together to help each other in the face of disasters. For Fajar and Rahimah, as well as Dina—their friend, another woman living in Banjarmasin—it is their embodied knowledge of what it feels like to endure difficulty in the face of disaster that drives their own motivation to build solidarity with—and mobilise support for—diffabled people. The most active social support networks are led from within the community but encompass a growing network of government and civil society actors.

Yet despite the active roles played by Rahimah and Fajar and their networks, and the data they have gathered, they speak with frustration of being judged for their diffabilities and thus routinely excluded from policy- and decision-making about their experiences and needs. Their embodied knowledge is routinely neglected in urban and disaster planning. Even when it comes to the implementation of accessibility measures across the city, non-diffabled authorities tend to decide and enact their own visions of what is needed by diffabled people, and in both sites we have struggled to identify any disaster planning measures responding to the needs or barriers of diffabled people. In one of the only examples, Zainal, in Mataram, described how during a training on what to do during an earthquake, a small-magnitude quake hit and the non-diffabled trainer fled the room, leaving the diffabled participants to find their own way out of the building. This state of disaster planning represents an ongoing form of colonisation over diffabled bodies, with non-diffabled authorities creating knowledge about and actions on the needs of diffabled people, echoing Spivak's (2003) key work "Can the Subaltern Speak?" When it comes to disaster planning in Indonesia, people with diffabilities are repeatedly rendered a subaltern voice, unheard and silenced (Cameron, 2022). This reflects the global scale, where diffabled people are routinely excluded from DRR processes (Gartrell et al., 2020). Their needs are defined by persistent framings of diffability as inability. The ongoing biopolitics of disaster planning and diffability define diffabled people as both subaltern and other, justifying their exclusion and representation by non-diffabled actors who speak on their behalf.

4. *Halin ai*: Conclusion and Recommendations

Halin ai in Banjarese translates to "well, what can I do?" This term is frequently evoked by diffabled people and is used to describe the feeling of "what else can I do?" when everything is happening out of your control. Banjar and Lombok societies are in Muslim-majority regions, as Indonesia is in general. Disaster is frequently understood as something that happens to one's life and is often seen as destiny from God, as with one's fortune and luck (Samuels, 2016). Thus, instead of fighting it or holding a grudge about it, people respond by creating a space to negotiate with or adapt to disasters. Fajar and Rahimah do not fight the floods that come regularly; instead, they learn to understand the patterns so they are prepared for the waters when they come. Their creativity and resolve to adapt to disasters and to help others build on lifetimes of adapting to a world that favours the non-diffabled and continues to speak on their behalf. When disaster strikes they mobilise and lead community responses within a vibrant support network of people with diverse diffabilities, regularly advocating for inclusive change and stronger political representation. Fajar and Rahimah's experiences highlight the key roles diffabled people are playing as they perform agency, resist marginalisation, lead social change, and practice ongoing adaptation to precarious and rapidly evolving conditions.

However, they do so in a hostile landscape and in the face of unpredictable disasters. As we have demonstrated, the vulnerability of diffabled people to disasters is a socio-political product of systemic exclusion and continuous (re)production of prejudice and discrimination (Nario-Redmond, 2019; Priestley & Hemingway, 2006). Their perspectives and experiences should be at the forefront of DRR processes and knowledge production about disasters. A decolonial, intersectional, and critical diffability lens is therefore paramount if we are to meaningfully include the knowledge, rights, and equal opportunities of diffabled people within global climate and disaster discourses. This would foster DRR and climate strategies that promote dignity, respect embodied diversity, more fully recognise people's capacities and skills, and open safe constructive spaces for contesting prevailing perspectives and systemic exclusion (S. Bell et al., 2020; Barclay et al., 2019).

The able-bodied dis-ability to hear and/or understand the experiences of diffabled people has often led to a homogenisation of diffability experiences within one single category that is equated with inability and dependence. This neglects abilities in favour of dis-abilities and negates the diversity of individual experiences, or the multiple ways in which ableism intersects with gender, age, race, class, poverty, and so on. It serves to depoliticise and take the focus off structural problems exacerbating vulnerability; and is at risk of "inclusive marginalisation," partially accommodating diffabilities at an individual rather than socio-structural level (Grue, 2019). This distances communities from holding those accountable for climate change and disasters to account. Furthermore, why must diffabled people be forced to find the resources within themselves to challenge these structural problems and inequities?

So, *halin ai?* What can we do? Diffability must be normalised and put at the heart of climate and DRR decision-making. Our public spaces, workplaces, homes, research teams, and decision-making tables as well as our policies and actions to prepare for climate change and disasters, must be transformed through the inclusion of the embodied and experiential knowledge of diffabled people as part of a new status quo. We must identify and directly tackle structural barriers, increase visibility, and actively work to make prejudice and discrimination towards disabilities unacceptable. Our climate actions must demand social, environmental, and disaster justice for diffabled people, directly challenge systemic and intersecting inequalities, and be designed from the ground up by those who live, embody, and resist these injustices every day. In Banjarmasin, for example, we are beginning such work with our Kayuh Baimbai Project, translating the research we describe here into creative interventions led by diffabled people to shape new inclusive disaster preparedness processes and knowledge production at multiple scales, from engaging with the City Government and disaster practitioners and firefighters, to working collaboratively in communities amongst leaders, neighbours, and extended and immediate families. *Kawa baucap*, *kawa manggawi*, *kawa manyandang*: If we can say it, we can do it, and we can handle it. Words without action mean nothing.

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Conflict of Interests

The authors declare no conflict of interests.

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Article

Women and the Federation of Disability Organizations in Malawi: Experiences of Struggle and Solidarity

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Abstract

Women with disabilities are among the most marginalised members of the Federation of Disability Organizations in Malawi (FEDOMA), facing particular challenges related to sexual and gender-based violence and family/home life; women with disabilities are both abused because of their embodied womanhood *and* denied many socially-valued "traditional women's roles." However, women within Malawi's disability rights movement transgress the boundaries of these social restraints. In this article, I share stories of women disability activists, drawn from an interview and participant observation-based project, co-designed with FEDOMA to explore the experiences of grassroots activists. In telling their stories, the women of FEDOMA detailed processes of empowerment and change, combatting their own and others' experiences of violence, abuse, and exclusion. I discuss the ways in which women activists embodied roles that altered their communities and built activist networks, supporting one another in expressing agency, strength, and solidarity. Their work highlights a politics of care that emphasises the "traditional" *and* the "modern," incorporating individualised human rights discourse into an ethics of community caring and expanding this collective inclusion to the oppressed and marginalised. In focusing on the experiences of Malawi's women disability activists, we gain a more complex understanding of mechanisms of marginalisation, resistance, and empowerment.

Keywords

activism; advocacy; Afro-centric disability studies; disability; feminine politics of care; hybridity; Malawi; women's resistance

Issue

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1. Introduction

The Federation of Disability Organizations in Malawi (FEDOMA) was founded in 1999 (Chauluka & Chiumya, n.d.) by disability rights activists/advocates to unite Malawi's Disabled Persons' Organisations (DPOs) and form a stronger disability rights movement (DRM) in the country. The organisation foregrounds intersectionality and local relevance in their practices, particularly emphasising women's and youth's issues (FEDOMA, n.d.). FEDOMA engages in extensive grassroots advocacy work, as national legislation is usually implemented at the district level in Malawi. FEDOMA's grassroots work is conducted across Malawi's 28 districts by district disability forums (DDFs) and smaller area disability forums (ADFs), locally based groups consisting of volunteers drawn from constituent DPOs to monitor and advocate for rights implementation at the local level (for more information about FEDOMA's structure and advocacy work see Huque, 2023; Huque & Amos, 2018). Chataika (2017) suggests that most DRMs consider the issues of women with disabilities (the preferred terminology of FEDOMA activists) to be women's movement issues, and women's movements consider these issues for the disability movement. However, FEDOMA leadership and grassroots members maintain that the organisation is committed to addressing the challenges faced by women with disabilities, intentionally integrating "women's issues" into "general" movement spaces and encouraging the development of women-specific spaces within the organisation. These spaces are a result of the work of women activists, engaging within the organisation across a multitude of scales and spaces, from headquarters to remote grassroots outposts. Their work is specific to the Malawian context and incorporates a hybridisation of cultural understandings and the globalised rhetoric of (individual) human rights.

Malawian women with disabilities face particular challenges related to sexual and gender-based violence and family/home life; women with disabilities are both abused because of their embodied womanhood and denied many socially-valued, ”traditional” women's roles. In a review of statistics around the "intersection of gender and disability," Chataika (2017, p. 185) highlights worse outcomes for African girls and women with disabilities when compared to women without disabilities and men with disabilities in school attendance, literacy, job markets, experiences of violence and sexual assault, access to justice, and mortality. Violent acts committed against women with disabilities in Malawi also take the form of sexual exploitation and abandonment after they become pregnant (Barrett & Marshall, 2017).

Schriempf (2001) notes that women with disabilities are often denied access to the socially expected roles of women, such as marriage and childbearing, but "paradoxically, they are viewed as 'woman enough' to be sexually objectified" (p. 60). Frederick (2017) argues that women without disabilities "confront a moral imperative to become mothers" (p. 131) while the opposite is true of women with disabilities. The perception of women with disabilities as "incapable" caregivers extends to the economic aspects of caregiving, including limited access to work (both waged and subsistence/agricultural, in the case of Malawi). However, women with disabilities' practical circumstances often mean that they *do* have experiences of caregiving and supporting themselves and their families. Engagement in caregiving is an important component of the resistance of women with disabilities, and this extends into Malawi's DRM. While the experiences of the Malawian disability activists who participated in this study reflect these forms of social exclusion and violence, these women also transgress the boundaries of social restraints on their perceived ”womanhood," or lack thereof.

Societal norms around gendered divisions in Malawian society today reflect a hybridisation of pre-colonial, colonial, and modern-day (neo-colonial) structures. In pre-colonial times, the area now known as "Malawi" contained a variety of different types of societies, including matrilineal societies whose social structures do not fit into a binaristic view of gender roles and power. In many societies, women held prominent roles, engaged in trade and agricultural production, and participated in village politics (Mandala, 1984). Some matrilineal tribes had complex power relationships in which most men would marry into a woman's family, move to her village, and work her family's land, rather than wives moving to their husbands' natal villages (Peters, 2010). Men were heads of households, but through kinship ties with women—fathers, uncles, and brothers, as opposed to husbands (Kachapila, 2006; Segal, 2008).

Christian missionaries and British colonialism introduced Western conceptualisations of patriarchy and gendered divisions to Malawi as a mechanism of social control (Barry & Grady, 2019). Colonisers' focus on economic exploitation and commoditisation attempted to enforce such divisions; labour such as tobacco crop production was open only to men, though they were often in practice aided by their wives. Towards the end of the colonial period, some women engaged in waged labour independently of their husbands (Kachapila, 2006). In addition to aiding their husbands in cash crop production, women worked brewing beer, processing food, and producing maize and groundnuts as ways to move toward economic security (Kachapila, 2006). These activities can be seen as forms of resistance through which women continued to engage in their roles as providers and stewards of kinship groups. These examples disrupt tidy Western paradigms of traditional cultures as oppressive and of capitalism as liberating.

Following the end of colonial rule, Dr. Hastings Banda's authoritarian government blurred the lines between an imagined united "Malawian" traditionalism and colonial institutions, drawing on the power of men in matrilineal societies to cement his rule while paying lip service to the role of women in these traditions (Segal, 2008). This included establishing women as keepers of the home and supporters of men—things women had always engaged in, but to which they were now (meant to be) limited (Segal, 2008). This limited women's inclusion in waged formal work in Malawi's evolving capitalist system, enforcing women as solely "domestic providers, doing what they were *said* to have always done" (Segal, 2008, p. 16, emphasis added). However, women did continue to resist within these patriarchal ideals, often becoming de facto heads of households while men sought work away from the family home (Segal, 2008; Sturges, 1998). Today, neo-colonial global capitalism has brought a goal of "economic empowerment" to Malawian women through NGO-led programmes intended to develop women's waged labour skills. If viewed ahistorically, a focus on this more recent turn toward "empowerment" misses that women often already have these skills, but lack the capital to invest in them; it also conceals the resistance of women through their acts of care and provision for kinship groups. Within low-resource settings, resistance operates as a key means of survival. Mkandawire-Valhmu et al. (2013) reflect that representing African women as victims of their countries' cultural structures without agency reflects "Eurocentric and hegemonic discourse" (p. 333). They highlight that this viewpoint ignores African women's history of organising and responding to "severe hardships…often while occupying spaces on the margins of society" (Mkandawire-Valhmu et al., 2013, p. 334). Mkandawire-Valhmu et al.'s (2013) own study findings "hardly suggest that [Malawian] women consider themselves victims…women [were] actively involved in shaping and determining their own destiny" (p. 346). This focus on Malawian women's perspectives on their own identities and positions is of particular importance for understanding their participation in social movements.

The post/neo-colonial work of NGOs promoting economic empowerment of women as a means to reduce minority-world perceptions of oppression in colonially exploited countries such as Malawi has also contributed to a renewed and more visible resistance to prescribed gender roles. "Women speak of *gender* as something we can be made aware of and understand. They point out how 'doing *gender*' makes them less vulnerable and more independent" (Adolfsson & Madsen, 2020, p. 64). Adolfsson and Madsen (2020) found that in Malawi, gender was a new concept, something one "does," altering the division of labour from more recent history: "Daily practices that used to be only for women/only for men have, with the onset of *gender*, become shared work that both men and women can do" (p. 63). Thus, while there remains a gendered division in Malawi, the "practice" of gender can be one that reduces gendered thinking about the practicalities of daily life. At the same time, the concept of gender highlights a men/women binary that does not consider non-binary and gender non-conforming individuals in its theoretical approaches. It remains to be seen what the practical implications of gender as an inclusive practice might bring about for non-binary and gender non-conforming people in Malawi.

Day (2008) argues that, historically, "female autonomy" has been an important concept in African communities, which Western feminist movements overlook, and that African women possessed a "consciousness of their rights and responsibilities as women long before the influence of the Western feminist movement" (p. 497). This consciousness and assumption of rights reflects Kandiyoti's (1988) "bargaining with patriarchy" (p. 274), which focuses on the subtle engagement of women in activities within the constraints of a patriarchal society that can constitute resistance to oppression. This means that even in "traditional" spaces and roles, women can exercise agency and engage in resistance against their subjugation. Asaki and Hayes (2011) argue that women's grassroots groups have the same aims as more "formal" social protection agencies, but their community structures and principles are the foundation of sustainable social change. They provide the example of a "collective kitchen," which addressed both survival needs and "offered women a space for political activism" (Asaki & Hayes, 2011, p. 248), opening up new spaces for resistance that transgressed private home–public boundaries.

Reflecting and drawing on feminist studies calls for more contextually-based, majority-world-focused work. UK-and-USA-led social models of disability, widely held to be the standard for disability movements and studies, have recently been challenged as limited. Place-specific (Haang'andu, 2020; Hamel & Falola, 2021) and new materialist (Feely, 2016) approaches to disability studies have emerged, challenging the universal application of minority-world disability paradigms (though calls for this are not new within majority-world social movements). Price and Goyal (2016) highlight the "pressure to generalize, universalize, and exclude" (p. 304) in disability studies. Haang'andu (2020) suggests "Afro-centric" disability studies as a way to move beyond Euro-and-USA-centric approaches to disability. Araneda-Urrutia and Infante's (2020) work goes a step further and suggests we need a "de-modelling" in disability studies, focusing on local specificity in activism, drawing instead on assemblage theories to connect aspects of divergent DRMs. A de-modelling approach enables considerations of space, place, time, and intersectionality within a particular context. This can help us to engage more deeply with and learn from the specifics of individual DRMs, highlighting ways of working within differently resourced and situated contexts. These calls echo feminist scholars' work on diversifying feminist approaches to research. Day (2008) connects the problem with Western feminist interpretations of African spaces not just to a disregard for intersectionality but also to a misunderstanding of culture and society through the imposition of a Western perspective, similar to recent critiques of mainstream disability studies. Piedalue (2016) calls for a "reframing [which] acknowledges that historically and place-specific cultural practices intertwine with regional patriarchies and structural violence, but refuses the conflation of culture with gendered oppression among non-white, non-Western people and places" (p. 4). Using an Afro-, Malawi-, and individual organisation-centric approach that resists the draw to generalise enables focus on specificity, alternative forms of resistance, and the intersectional forces individual groups work with/against. In calling for "Africanizing disability," Hamel and Falola (2021) note that "an African approach…combines the insights of disability studies with the actual contexts of African experiences and acknowledges both how Africa creates problems for traditional disability studies approaches, even as it offers exciting new potentialities" (pp. 1–2). In this article, I draw on these calls for place-specific models of disability and contextually aware feminist work, focusing specifically on the women of Malawi's DRM and the circumstances they experience and use to build their movement. At the same time, it is necessary to keep in mind the complex history of colonialism, racism, exploitation, and poverty discussed in this introduction, as well as the shifting and nuanced view of "gender" as an introduced concept in Malawi. To do this, I integrate a critical feminist approach to exploring the work of FEDOMA's women activists in a few key ways: (a) through a focus on the agency of women with disabilities, rather than treating the latter as merely oppressed "subjects," and (b) through use of a situated approach, focusing on activists' life experiences. This approach uses a de-modelling disability studies lens to imagine resistance as specific and situated, within particular spaces and places—in this case, focusing on the ways of working of Malawian DRM activists, within their contexts.

2. Methods

The stories of women disability activists in this article are drawn from a larger interview and participant observation-based project, co-designed with FEDOMA, to explore the experiences of grassroots advocates. FEDOMA staff, managers, and grassroots members helped conceptualise, plan, and implement the study, which received ethical approval from both the University of St Andrews and the Malawi government's National Committee on Research in the Social Sciences and Humanities.

Powers (2017) highlights the growth in various forms of action research in disability studies as demonstrative of growth in respect for the voices of community members in research development. The establishment of communities as partners in research can disrupt traditional power differentials in research relationships, contribute to participant well-being, and reduce the risk of researchers taking advantage of participants and offering nothing in return.

"Full" participatory co-researching in this case proved to be beyond time, funding, and other legal and resource constraints. Van der Meulen (2011) highlights that the "ideology" of participatory research is more often a focal point of discussions on its use than actual methodology. A participatory design process is a practical endeavour, which acknowledges that we cannot always achieve "full" participation. Designing a project collaboratively can help incorporate a participatory ethos into different aspects of "doing" research and help translate the ideal into the practical. In this case, the participatory design period enabled me to learn about the movement and its structures, and collaboratively develop research questions and methods in line with the stated needs and wants of FEDOMA's membership.

I conducted fieldwork from November 2018 to January 2019, after the participatory project design period (September–November 2017). During the project design, FEDOMA representatives and I worked together to determine which grassroots groups I would visit during data collection; we chose one district from each of Malawi's three regions plus a fourth from an urban centre (identified in this article as D1, D2, D3, D4). Due to challenges in communication infrastructure, I arranged to meet grassroots activists in each district after my arrival, and recruited participants from within FEDOMA's grassroots membership in that district, aided by key contacts, especially DDF/ADF board members. I undertook participant observation within FEDOMA's headquarters and grassroots outposts. I interviewed 22 FEDOMA grassroots members: 20 people with disabilities, two mothers of children with disabilities, and eight FEDOMA headquarters staff/managers, three of whom also had disabilities. Sixteen interviewees were women, 14 men. Gender identity was self-reported by participants during the interviews using their own words; none of the participants identified as gender non-conforming, non-binary, or transgender. Additionally, all of the romantic relationships/partnerships discussed were heterosexual-passing. This may be because LGBTQ+ identities and gender non-conformity are in many ways stigmatised in Malawi, and I was a relative stranger to the people I interviewed, despite spending time with the participants during the ethnographic portions of the project (for an in-depth discussion of the forms of repression experienced by LGBTQ+ and gender non-conforming people in Malawi, its connection to colonialism and Christian missionaries, as well as the dangers of focusing only on repression without considering the work being done in favour of LGBTQ+ rights in Malawi see Currier, 2019). Interviewees chose whether a pseudonym or their real name would be used in outputs; in this article, names with an asterisk (*) after their initial use are pseudonyms. Furthermore, person-first language (e.g., persons with disabilities), is the preferred terminology of the Malawian activists who helped develop and participated in the project reported in this article; as such, this is the terminology I use in works based on this project, unless directly quoting from another source.

Interviews were semi-structured and in-depth, focusing on the life stories of each participant, including their life, advocacy work, key issues of focus, hopes for the future, and their experiences and voices within FEDOMA and the DRM. Participants were asked to introduce themselves however they saw fit at the start of the interviews, then were asked some broad additional background questions at the end of the interview, including information about their families, hobbies, religions, disabilities, and other groups and activities they participate in. The interview guide did not contain specific questions about gender and activism, but gender, and particularly the experiences of women, emerged as a key theme from the interview analysis as part of the interviewees' stories about their advocacy work.

Ethical concerns for this study included the usefulness of the research to the disability activists who contributed their time and knowledge, and accessibility. The participatory research design process was an attempt to ensure that the study reflected FEDOMA and its members' priorities. Interviews were conducted in English, Chichewa, and/or sign language, depending on the needs of the participant. I travelled to conduct interviews with J. E., who acted as a local guide and English–Chichewa translator; we contracted a sign language interpreter of the interviewee's choice for interviews as required. Interviews were conducted in a variety of places based on the convenience of the interviewee—including group meeting spaces, work sites, and private homes. Interviews were recorded, and I transcribed the

English language version of the interviews (which were translated in situ). We were able to provide transport (or funds for transport) in many cases. We adjusted our approach throughout data collection to ensure accessibility and safety as far as possible. Not only did engaging with each individual personally regarding their accessibility needs contribute to conducting the research as ethically as possible, but it also provided us opportunities to gain rich insight into participants' daily lives and engage with them in their work, family, and activist activities.

Two rounds of initial coding in NVivo were conducted on the interview transcripts and participant observation fieldnotes, resulting in a set of 50 codes covering a range of thematic material discussed in interviews. An extensive third round of coding was conducted by hand diagrammatically, connecting and identifying synergies and conflicts between the themes. I completed data collection prior to the Covid-19 pandemic, with the intention that I would return to validate the study results with the participants. However, lockdowns forced the cancellation of the return visit to Malawi, which limited the participatory nature of the study (the first output from this study was a report written for FEDOMA to use in developing their five-year plan and share amongst grassroots groups; I had not received feedback on the contents of this report at the time of writing this article).

I applied an inductive, grounded-theory approach to data coding (Basit, 2003). I chose this approach to draw key areas for analysis from participants' stories, in an attempt to ensure the analysis was "grounded in the views of the participants" (Hartley & Muhit, 2003, p. 105). Part of my approach to mitigating my researcher's voice overshadowing that of participants (to the extent that this is even possible within a research setting) was to engage with the data without a preconceived set of codes. This also enabled me to focus on and be led by individual activists' (and the movement's) stories and language.

One of the key themes that emerged from the data was that of the role of women's advocacy work, the complexities of which I explore (in part) in this article. As mentioned above, specific questions about gender roles in advocacy were not initially asked during interviews, but if participants raised this topic themselves, they were encouraged to discuss them and elaborate. Of critical importance was the tension between women's performance of valued social roles in conjunction with their advocacy roles, and the stigma and expectations of society that they should not be "able" to successfully perform these roles. Key thematic intersections included the particular challenges faced by women with disabilities, women as agents of empowerment processes, familial roles—particularly mothering in grassroots activism—and intergenerational solidarity.

3. Results

Many of the experiences of women disability activists within FEDOMA focused on both the struggles and solidarity of women. Both men and women highlighted similar challenges faced by women with disabilities to those discussed in the previously highlighted research, including sexual violence, exclusion, and abandonment by partners. The perception of women with disabilities as having lower status was particularly emphasised in issues around relationships. Several women told stories of abandonment by lovers, boyfriends, or husbands, especially after becoming pregnant:

> Being a woman with disability, most of the men, they just come and…give them pregnant. They deny them. Because they just say: "I will marry." But they will not. So being given a pregnant is also painful. (Lyness, D2)

Men will engage in sexual relationships with women with disabilities but refuse to "legitimise" relationships through marriage—leaving women with disabilities to care for their children on their own—despite the perception that they are not "capable" of family care-work.

Emma* (D2) was abandoned by two men by the time of her interview. She had hope, though, of forming a nuclear family, saying she would like to form a relationship with a man with a disability:

> I got married in those days, and my…husband denied me because of my nature….Some people, they were saying: "No—she will bring a big problem on your life. Maybe she can fall on the fire, or in water, so you better leave her." So, he left me….It was so hard. Being denied by someone whom I trusted…it was painful for me. Now, I am not married, but I got this baby from someone else….I live alone….I hope to get married to someone who is also a disabled person. It would be a great joy for me.

Emma's story highlights the trauma of abandonment by her partners. Her ex-husband divorced her as a result of societal pressure. Emma believed that marriage to a man who shared her disability identity could be a solution. However, men with disabilities in Malawi often do not face the same level of difficulty in finding a non-disabled partner as women (Addlakha et al., 2017; Pal et al., 2015); their identity as a man is still "above" that of a woman (Addlakha et al., 2017). Due to this, men with disabilities will often choose not to partner with a woman who has a disability.

Beyond issues of relationships and abandonment, pregnancy and motherhood can compound financial struggles for women with disabilities. Malawian women with disabilities struggle to gain waged employment, and unmarried mothers may be seen as undesirable employees. Many of the women I spoke to discussed economic issues as a major constraint within their lives. Grace (D4) described women with disabilities' troubles as stemming from a "lack of capital." Ester (D3) felt that she was excluded from training in her workplace because of her disability. Doreen (D3) was fired from her job as a waitress due to her deafness, despite having successfully performed the required tasks. These stories demonstrate how women with disabilities were excluded from socially valued roles—however, these same women engaged in advocacy work that challenged this exclusion.

Emma, Doreen, Grace, Ester, and Lyness were all grassroots members of FEDOMA, as were the other women whose stories are drawn upon in this article. Many of these women held leadership positions within their local DDF chapters or their communities as activists. Advocacy work gave FEDOMA women a platform to centre themselves and their own embodied experiences. Women described their "advocate" identities as empowering, counteracting negative and dehumanising life experiences and stigma.

Saba* (D1) highlighted FEDOMA's focus on the empowerment of all people with disabilities as a move toward eliminating gender bias:

> I see FEDOMA as taking a good role. She [FEDOMA] is not gender-biased. She takes all people….I think it is good as FEDOMA to incorporate everyone who has a disability, so they can be well-empowered.

Like Saba, most of the people I spoke to, women and men, used woman—or *matri*—centric terms for FEDOMA, personifying the organisation as "she," the "mother organisation," "our mother," etc. FEDOMA's role in caring for the needs of persons with disabilities was portrayed by its grassroots membership as explicitly "womanly" and "motherly." This characterisation highlights a "feminisation" of the activism of a national advocacy organisation, crossing public—private boundaries and emphasising kindness, caring, and nurturing for building a successful movement. FEDOMA as a high-profile, public-facing representative of its membership, is anthropomorphised as a mother.

This emphasis on nurturing within the organisation was also found in the ways women expressed solidarity with one another. Relationship building was discussed seriously within FEDOMA's movement spaces as a way to expand empowerment and provide opportunities for women with disabilities. Women shared knowledge with other women as they attempted to grow the movement. Emma (D2) described the change she witnessed as her DDF's work took hold amongst women in the community:

> There has been a change. Because now we are seeing women standing and raise up their voices. Because we have advocated for them.

They created revolutionary spaces of mutual support in which women with disabilities educated one another on both the traditional roles they could "take back" *and* the new ones they created for themselves.

Mallory* D1's DDF chair, spoke about the impact of a mentor who had founded her DPO:

> She was a founder [of a DPO in D1]….She got transferred to MACOHA [Malawi Council for the Handicapped], where she was going to work, and when she was going…she told me: "I'm leaving to go to MACOHA—Are you interested [in taking] over?" I said yes, and I took over from her. Doing the same as she was doing up until the committee was established.

This founder, a woman who was herself moving up through the ranks of disability organisations in taking a job at MACOHA, handpicked her district-level successor. She ensured that the work she had begun in the district continued, in this case led by another woman with whom she worked. Now, Mallory is a leader within that DPO, chair of her DDF, and a sought-after expert representative for the disability community in Malawi.

In discussing her role as a leader, however, Mallory initially distanced these achievements from womanhood:

> I believe that, most of the times, hardworking spirit pays. I am not there because I am a woman, but…because of my work. Because day in and out, my home is like….We have an office for persons with disabilities. Today, one person come, and another day come. Hardworking spirit pays.

At the same time, Mallory "achieved" many of the traditional ideals of womanhood—she is married, a mother, and a teacher, an "acceptable" (and high-status) job for women. By engaging in these roles, she embodied women's success and resistance. Additionally, Mallory's approach to disability advocacy also emphasised positive traits associated with Malawian women. For example, in the quote above, Mallory presented her home as a place for persons with disabilities to seek counsel. In this way, Mallory extended her public advocacy work into her home—the space traditionally associated with women and their care work. Mallory extended the spaces of resistance and community care in her context, challenging public/private dichotomies. Using the home as an extension of their activist space was something only raised by women in interviews. Men focused on economic achievements outside of the house, as a public demonstration of the "ability" of people with disabilities, as well as emphasising their work within the DDF/ADFs out in the community, as did women. When men spoke of their home life, they were more likely to highlight challenges and/or feelings of shame:

> As a man of family…I do nothing. Everything, I depend on someone to support me. Because of my disability, I am failing to support my family. (Leo*, D1)

For some men, home as representative of a lack of opportunity to engage in expected waged labour roles, may have contributed to their being less likely to conceive of the home as a space of resistance and power in the same way some of the women did.

Despite emphasising her "hardworking spirit," Mallory discussed women's roles, which she believes make women well-suited to advocacy work:

> I was about to joke that Dads are not good, but Mom….Maybe it is good to empower both but more especially women. Because they have the spirit of a mother. That I cannot throw this one away. This one is my daughter, my son.

Mallory's father abandoned her family upon finding out that his daughter had a visible disability—he claimed that her mother must have slept with an English man, a common myth. This experience affected Mallory to the extent that it informed her priorities as an adult activist. Mallory de-emphasised her womanhood when discussing her position as a leader and public figure. However, she emphasised womanhood when discussing ideas like care work and its impact on persons with disabilities. Mallory's story demonstrates the personal nature of intersecting societal roles in influencing women activists, even those who do not intentionally perform intersectionality (i.e., not intentionally focusing on their own womanhood), in their activist storytelling.

Many participants raised the idea of belief in mothers' "[caregiving] spirit," introduced by Mallory above. Some women, including Saba (D1), used this identity, of woman and caregiver, to describe their approach to work on disability issues:

> As a woman….I don't consider myself. But I…see others' problems. So that they can be taken into consideration.

Saba pointed to women as selfless caregivers, using it to describe her own motivations for advocacy work. Connecting with and helping others was considered by many advocates to be "intrinsic" to women, and thus a "natural" part of women with disabilities' role, despite the denial of their womanhood in broader society. In using their intersectional identities as motivation for activism and practicing caregiving in their communities, they defied said constraints, engaged in everyday resistance, and transformed the traditional into the radical. In Saba's own words:

> It has touched me, as a woman. Because as women, we go through difficult situations. So being a woman, I feel it is really good to stand. And to share the responsibility. To empower someone. So, I am feeling good. I am doing a good job.

Like Saba, several of the advocates I spoke to saw their advocacy work as a responsibility. They believed in their (women's) responsibility to care for others and spread empowerment as an extension of that. Women advocates applied notions of familial caregiving to the DRM, substituting and/or extending their "mothering" into movement spaces. For some women, their focus was specifically on empowering other women with disabilities:

> I am happy, because I am fighting for other females with disability. So that they may also have access to education and some other services. I am so passionate about all people with disability….But most especially the women and the children. (Lyness, D2)

Women with disabilities working to empower their peers spoke with the authority of embodied experience and, in their speech and actions, they enhanced not only other women's sense of empowerment but also their own.

At the same time, women extended their participation in developing the movement through economic activities and applying women's work to the practicalities of creating better spaces. Elena* (D2) pointed out that the women of her DDF had been the ones to raise the funds for their building to have electricity through sewing and selling handbags:

> We do the work, and we deposit the money, and we use that same money to structure this building….So that's why you see the electricity facility there. Because of that money.

The building they support, a rare luxury for these grassroots groups, acts as a stable meeting point, enabling them to come together as a group and strengthen their work and relationships more easily.

Women disability activists also used community outreach to connect with women outside of the movement, particularly mothers of children with disabilities who were not already part of the DRM. For example, Ester (D3) connected with mothers she met through her job as a health worker. As a woman health worker and disability activist, Ester had a measure of social capital with women seeking that knowledge:

> I do go to the community, and chat with the pregnant women and give them guidance….On the date of delivery, if the child was born, with some difficulties…I went quite often to help, to take care of the children.

Ester's job allowed her access to women in the community and enabled her to care for children with disabilities (as well as their mothers) from birth.

Rhodah (D3) also took her experiences and learning within FEDOMA and used them to forge new relationships with others outside the movement, providing services and information, and inviting them in:

> In a local area, I brought together the teenagers. So that I can mentor them. About the sexual reproductive health….Especially for the women who are

> disabled, sometimes I might take them into another room and impart them there. Just to motivate them that….I am your model. So, don't worry.

Women with disabilities like Rhodah, who embraced their empowered role as rights advocates, offered themselves as role models. Rhodah took it upon herself to teach young women about sexuality. She prepared them for the traditional women's roles of wife and mother. In these talks, Rhodah incorporated her own learning from participation in the DRM, emphasising women's rights against abuse:

> They teach us that everyone has his or her own rights…we must not get married because someone has a passionate for us…our rights are…protected. Honoured.

She meaningfully engaged her audience of younger women growing up in an increasingly hybridised, neocolonial world—where tradition, human rights, and the intermingling of the two present a complex picture. Rhodah intends to pursue her work beyond local disability organising, with plans to run for political office and write a book about women with disabilities.

4. Discussion and Conclusions

In focusing on the experiences of women with disabilities in Malawi, we can gain a more complex understanding of mechanisms of marginalisation, resistance, and empowerment. Following calls to "de-model" (Araneda-Urrutia & Infante, 2020), "Africanize" (Hamel & Falola, 2021), and create "Afro-centric" (Haang'andu, 2020) disability studies, exploring movements within specific spaces, places, and times, with an intersectional lens, can help broaden the inclusivity and knowledge-base for disability organising worldwide. It also enables us to consider key social structures beyond the individual that contribute to the movement—in this case the familial, kinship-style networks that underpin organising for disability rights in Malawi, and the ways in which majority-world activists in this case both utilise and subvert traditional values, developing approaches to organising that reflect hybrid worlds with complex (neo)colonial histories.

Women with disabilities in Malawi experience abuse because of their embodied womanhood, but at the same time are perceived as "incapable" of engaging in traditional, valued social roles. As Tefera et al. (2018) point out, "society does not identify women with disabilities as capable of playing a valuable role….Adopting valued social roles…promotes self-esteem and confidence….Ultimately, participation in valued social roles can lead to the adoption of other valued social roles" (p. 82). In this article, I have explored examples of the way this plays out within Malawi's DRM. As part of their desire for inclusion, many Malawian disability rights advocates sought to engage in traditional women's roles and emphasised their ability as caregivers in their disability work. At the same time, their engagement in these roles led to them undertaking other types of social roles, including those that reflect the historical roles and resistance of women to limitations on their participation in society. Examples of this include taking on roles as chairs and vice chairs of DDFs and other community groups, Rhodah's plans to run for office and write a book, and using economic successes to improve movement infrastructure. At the same time, this engagement contributes to altering what it means to be a Malawian woman, by including women with disabilities in the definitional spaces of womanhood, and catalysing processes of empowerment that extend beyond the achievement of pivotal social roles of wife and mother.

Seeking valued social roles can be part of what motivates women with disabilities to engage with the DRM. Tefera et al. (2018) note that these are not the desired roles of all women with disabilities, but that these traditional roles are ones from which they are socially excluded if they do desire them, ultimately constraining their agency and self-determination. It is important to note that the participation of women with disabilities in these neo-traditional schemas may serve to reproduce gender inequalities. By engaging in valued social roles, there is a risk that the divisions between genders remain unchallenged. However, this also requires consideration of the intersectionality and practices of women with disabilities. Schriempf (2001) argues for "the recognition that women with disabilities…embody a complex of interwoven situations" (p. 67). Often having to fend for themselves, women with disabilities in Malawi seek to engage in waged labour work, blurring divisive gendered lines in practice. Additionally, as Adolfsson and Madsen (2020) found, the minority-world language of "gender," as a newer concept in Malawi's history, and tied to "women's empowerment" through NGO investment, may mean moving towards new ways of sharing different types of roles and responsibilities. In this, we see the term "gender" as impacted and moulded by Malawi's current and historical social structures into something with a new, more complex, and context-specific definition.

Women in Malawi have always engaged in roles that transgress minority-world conceptualisations of gender divisions and patriarchy, whether in central positions and key kinship roles in pre-colonial societies, or as a means of survival during colonialism, authoritarianism, and in the present day. While none of the activists interviewed for this study mentioned engagement with other emancipatory movements, including women's movements, their experiences, activism, and lives are contributing to a shift in Malawian womanhood, challenging women with disabilities' exclusion from this imaginary. By engaging in highly visible activist roles in the community, they also challenge the notion of women's domain as ending at the boundaries of the home, while simultaneously creating home and care work as spaces of activism. By constituting the personal and traditional as political, women contributed to longer-term social change, notwithstanding the tensions and contradictions that remain whilst doing so.

Across the stories of the women in this article, aspects of care became profound spaces of empowerment and engagement in social movements. The conceptualisation of FEDOMA as "mother" underscored the politicisation of home-based roles and the utilisation of home-spaces as sites of resistance and activism, and the transformation of this politicisation into a "feminine" politics of care that emphasises the "traditional" (community, caring, nurturing) and the "modern" (individual rights, women's empowerment, hybridity). In this way, the "feminised" public performances of the DRM counter mainstream Malawian political discourse's association of women with an apolitical view of the "traditional." Caring is connected to a "modern" Malawi, which incorporates individualised human rights into an ethics of community caring, expanding collective inclusion to the oppressed and marginalised. In particular, economic engagement and security, and related autonomy, are emphasised because they enable women to care for themselves and their families, reinvesting their economic successes into their communities—which in this case extend to activist networks and the kinship communities created in these networks.

The relationships between women within the organisation, combined with FEDOMA's personification as woman, emphasised the importance of nurturing and caregiving for empowerment within the DRM. However, this is also a heavy burden to place on the most marginalised people within a society, complicating the notion of caring for others as empowering. FEDOMA's women have developed collective structures as part of their support system for advocacy work and as a demonstration of members' adherence to collectivist notions of personhood, even if in practice they actually hybridise and subvert these notions. However, care must be taken with this approach to ensure that the voices of subgroups with different intersectional identities are heard and to prevent recreating oppressive structures within the organisation. Part of sharing this burden is in continuing to create spaces for activists to seek and provide collective support.

While this study contains many valuable stories, it focused on members of four of FEDOMA's district groups, and thus referenced only a fraction of the experiences of its membership and Malawi's DRM more broadly. In this article, I have not been able to engage with the full complexity of focusing on women's traditional roles in a positive way and the potential for reproduction of patriarchy; this study also lacks the experiences of LGBTQ+, non-binary, and gender non-conforming people, and the impacts of embracing societally prescribed gendered roles on related social movements. Finally, this study was conducted prior to the Covid-19 pandemic, which has changed so much about our world and about the spaces and circumstances in which disability activists, including those in Malawi, engage in their work, meaning that there may have been more recent changes to FEDOMA and its grassroots groups' systems of working and networks.

The disability rights work conducted by FEDOMA, and in particular the women activists within it, highlights the need for evolving approaches to disability activism and studies. Drawing on calls to Africanize, de-model, and contextualise disability studies, this work focused on the specific circumstances and forms of resistance engaged in by women activists in Malawi's DRM. Place-specific, localised, and de-modelled approaches can take us beyond hegemonic, Euro-and-USA-centric ways of knowing, exploring, and engaging with disability. This work is already being undertaken in the majority world, and minority world activists and scholars alike can learn from contextual, hybridised, and inclusive ways of creating and maintaining social movements.

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Conflict of Interests

The author declares no conflict of interests.

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Article

Disability, Religion, and Gender: Exploring Experiences of Exclusion in India Through an Intersectional Lens

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Abstract

Despite the existence of national and international laws and conventions to avoid discrimination in India, exclusion due to an intersection of disability, gender, and religious identity continues, resulting in marginalisation from society. This article investigates the lived experiences of people by exploring how aspects of their identity intersect to influence their inclusion or exclusion within society. Narrative interviews were undertaken with 25 participants with disabilities in the states of Tamil Nadu and West Bengal. This qualitative methodology was employed to allow the participants to recount their experiences (both positive and negative) in their own words. A thematic analysis of the data provided rich evidence of the complex social structure in India, manifested by the multifaceted intersectional nature of social inclusion and exclusion. Our research found that for our participants disability was the main factor upon which discrimination was based, but that this discrimination is often compounded for people with disabilities due to their minority religious status, or gender. Marginalisation of people with disabilities is shown to be exacerbated when these identities intersect. Action is needed to ensure the human rights of people with disabilities are realised and that discrimination and marginalisation are avoided for those who have different identities compared to the majority of the population.

Keywords

disability; gender; inclusion; India; intersectionality; marginalization; narrative interviews; religion

Issue

This article is part of the issue "Disabled People and the Intersectional Nature of Social Inclusion" edited by Alexis Buettgen (McMaster University), Fernando Fontes (Universidade de Coimbra), Susan Eriksson (South-Eastern Finland University of Applied Sciences), and Colin Barnes (University of Leeds) as part of the (In)Justice International Collective.

1. Introduction

Intersectionality is defined as a theoretical framework that considers the impact of heterogeneity across different intersections of social positions on lived experience (Bauer et al., 2021). The concept was first introduced by Crenshaw (1989) to explore experiences of marginalisation of Black women in the United States by drawing on theoretical understandings from Black feminism and critical race theory. Her ideas were further developed by considering how due to the intersection of their identity, Black women (and particularly those from disadvantaged communities) are often excluded from social movements and advocacy efforts (Crenshaw, 1991). Intersectional approaches have informed current understandings of how multiple and overlapping identities can reinforce deprivation and marginalisation, and may also strengthen divisions that exist between groups, and how these experiences may vary according to context and may change over time (Stewart, 2016). Building on her earlier work, Crenshaw (2015) argues that intersectionality is essentially a way of thinking about identity and its relationship to power.

Williams (1991) was among the first authors to consider how disability might intersect with other identities to shape how disadvantage is caused and experienced. Despite the clear potential that intersectional approaches have for disability-focused research, a paucity of evidence remains. The importance of intersectionality is reflected in the UN Convention on the Rights of Persons With Disabilities (CRPD), which became the first human rights treaty to acknowledge multiple and intersecting forms of discrimination (Kabir et al., 2022). Intersectionality is therefore increasingly recognised as an important topic in disability-focused research. Grech (2023) urges that more research explores intersectional dimensions to better understand the causes and consequences of people with disabilities experiencing poverty. Such research should consider history, power, inequality, and (geo)politics, as well as the impact of space and place.

India is a country with a rich social and cultural heritage, a complex class system and demography. In April 2023, India became the world's most populous nation, with 1.4 billion people living there. Population growth is in part driven by life expectancy continuing to increase, meaning the number of old people in India will continue to rise ("India poised to become," 2023). While united by their common nationality, the population is not homogenous with various aspects informing and affecting diverse identities. In India, interconnected and overlapping aspects of identity, including those linked to disability, religion, and gender, intersect and combine to affect and determine experiences of both inclusion and exclusion from society (Haq et al., 2020). Caste is intrinsically linked to religion and social class and is clearly influential in how inclusion and exclusion are experienced. There is an evidence gap relating to the complexity that accompanies the intersection of these identities and what this means for experiences of exclusion. This article contributes to what is known about how intersecting identities and the associated link to exclusion in India. We note that other aspects of identity are also likely to play a role, but the focus of the current study is on disability, religion (and caste), and gender. It is necessary to provide a brief background on each of these identities and why they are important before we analyse how these identities intersect.

1.1. Disability In India

Disability, as explained by the UN CRPD, is understood as a concept resulting from the interaction between impairment and attitudinal and environmental barriers that may impact their participation in society on an equal basis with others (UN, 2006). As per the social model of disability, it is conceptualised to be the manifestation of the interaction of a person's impairment with the environment they occupy. This might be the physical, cultural, or policy environment, or a mixture of all three (Mont, 2007). The global estimate for disability prevalence is 15% (WHO & World Bank, 2011). With its massive population, the prevalence of disability in India is estimated to be significant, but data remains limited and inconsistent. Estimates based on the last census held in 2011 reported a 2.2% disability prevalence rate (2.0% for women and 2.4% for men) (Leonard Cheshire, 2018). A systematic review of the prevalence of disability in India found the estimated ratio ranged from 1.6% to 43.3% (Ramadass et al., 2018). An estimated 70% of people with disabilities live in rural areas. More men have disabilities than women. Prevalence is also marginally higher for Scheduled Castes and Scheduled Tribes (Saikia et al., 2016). India signed and ratified the CRPD in 2007 and passed the Disability Rights Law in 2016. However, implementation is still a challenge with progress towards disability inclusion still limited with people with disabilities experiencing marginalisation in multiple spheres of life (Mehrotra, 2013). Negative and discriminatory attitudes towards people with disabilities continue to result in their exclusion from society (Pal, 2010, 2011).

1.2. Religion In India

Religion as a complex concept is understood to involve belief, faith, spirituality, institutions, behaviour, and practice (Tadros & Sabates-Wheeler, 2020). From both a historical and a contemporary perspective, religion plays a major role in shaping Indian society, with more than 99% of the population reporting having a religion; 80% of the population are Hindu. Muslims represent the largest minority religion with 14% of the population, with the remainder of people identifying as Christian, Sikh, Buddhist, Jain, or other religions (Ministry of Home Affairs, 2011).

Technically, according to its Constitution, India is a secular nation. Despite this, the links between religious identity and political power have become more pronounced in recent years (Robinson, 2010). The dominance of the Hindu majority is manifested in many aspects of life, including society, culture, and politics. Indian politics and religious affiliation have become increasingly intertwined, and under the leadership of the Hindu Nationalist Prime Minister Narendra Modi, there have been growing reports of discrimination, intolerance, and persecution of religious minorities (Haq et al., 2020; Kim, 2017). As well as the political sphere, religion also influences social experience in India. For example, the concept of Karma (which is grounded in Hinduism, Buddhism, Jainism, and Sikhism) shapes societal perception towards people with disabilities, resulting in their persecution and marginalisation (Ghai, 2015; Gupta, 2011).

Caste is the ancient and entrenched social system in India that provides groupings that are used to order society into a hierarchy (Das & Mehta, 2012). Caste is intertwined with religion—it is of Hindu origins. However, caste-related identity politics also impacts non-Hindus through social norms and practices. Vaid (2012, p. 396) states that even though "no caste has ever been homogeneous with regard to class criteria, congruence between the two has often been highlighted."

The relationship between class and caste is intricate and sensitive. However, it is clear that caste remains an important aspect of identity in India, influencing social and economic relations between social groups (Pal, 2011). Dalits are the lowest stratum in the system and represents 16.6% of the total population of India (Raghavendra, 2020). Caste-based stereotypes and stigma result in Dalits experiencing disadvantage, marginalisation, and exclusion (Pal, 2010). This caste-based discrimination has an impact on multiple factors including land ownership, employment, marriage prospects, and access to justice. Dalits are disproportionately poor, unemployed, and uneducated compared to others (Mehrotra, 2013). The prevalence rate of disability is also higher among Dalits compared with the general population, and they experience lower levels of education, employment, and poverty than people with disabilities from other castes (Pal, 2011).

1.3. Gender In India

Gender equality is a central feature of the UN Charter agreed upon in 1945, yet the world remains deeply unequal with women and girls continuing to experience marginalisation due to their gender (UN, 2020). Socio-cultural traditions in India heavily influence how gender intersects with other identities resulting in complexities (Haq, 2013). Gender inequality is deeply entrenched in India's social and cultural fabric with division based on socially constructed predefined roles, which have an impact on various aspects of society including family life, work, and politics (Batra & Reio, 2016). In the Indian context, gender is often constructed heteronormatively, failing to recognise gender identity as diverse and fluid (Kakar et al., 2021). Kumar (2021) explains how women who have intersecting identities, such as caste and religious status, are often denied their social, economic, cultural, and political rights in India. Haq et al. (2020, p. 586) describe how "women are treated as second-class citizens facing multiple intersectional discriminations and limited individual rights within India's highly patriarchal and conservative societal norms." For women with disabilities in India, the situation is exacerbated, as they often experience a wide spectrum of violence including neglect, physical abuse, and denial of traditional duties such as marriage and motherhood on account of their intersecting identities (Jogdand & Narke, 2022). Singh (2017, p. 139) argues: "Traditional patriarchal customs and norms have relegated women to a secondary status within the household and workplace." Gender inequity in India, along with intersecting factors, is marginalising women, limiting their access to resources and opportunities.

1.4. Objective

The above identities are shown to influence experiences of exclusion and marginalisation; the evidence exploring the experiences of people with multiple identities remains relatively limited. Considering how multiple identities intersect allows researchers to navigate complexity. As Kabir et al. (2022, p. 6) argue: "Applying an intersectional lens helps connect human rights to the multiple forms of discrimination that people experience. It is essential to achieve equal outcomes for all in global efforts to fulfil the pledge to leave no one behind." As such, in this study, we apply an intersectional approach to better understand experiences of marginalisation in India, intending to inform action needed to improve societal inclusion for all, particularly for people with disabilities.

2. Method

2.1. Methodological Approach

Using a qualitative approach, data was collected between July 2020 and March 2022 via narrative interviews. As this study is concerned with disability and intersecting identities, we used a purposeful sample to ensure that all of our participants had multiple identities that are identified in the existing literature as commonly resulting in marginalisation (Haq et al., 2020). We used purposeful selection here as a mechanism to help *make* meaning, not just *uncover* it. We acknowledge that the results of our study are influenced and constructed through our choice of samples as well as how we interpreted the data (Reybold et al., 2012). The complexity of our study starts with our selection of location for the sample. All the participants came from Tamil Nadu and West Bengal, and a mixture of rural and urban environments. These states were selected because they have relatively high concentrations of minority religious populations—Christians in Tamil Nadu and Muslims in West Bengal (Kramer, 2021). We aimed for a diverse sample of people who, due to different aspects of their identity, belonged to multiple minority groups. In total, 25 participants chose to participate: 15 were from Tamil Nadu and 10 were from West Bengal. All of the participants had disabilities: 14 reported having physical impairments, six had visual impairments, three participants had multiple impairments, one had neurological impairments, and one had intellectual impairments. There were 14 Christians, nine Muslims, and two Jains. In terms of caste, eight participants were Dalit, 10 described themselves as being Backward Caste, two were Scheduled Tribe, and five described themselves as "other." Nine of the participants were women and 16 were men.

Prior to undertaking the narrative interviews, participants were invited to provide an account of their life history however they would be comfortable doing so with some options being provided. Some chose to just describe each significant phase of their life and what that meant for their identity. Others did drawings and others followed a "river of life" style approach (Howard, 2023). This provided some context for each participant but also acted to build a relationship with the researchers, helping participants "warm up" to participate and improve the subsequent interview (Palm & Hansson, 2018). The life history information provided here was translated, transcribed, and included in the analysis, which is described in the following sections.

A narrative interview approach was selected as its unstructured and depth-seeking format was deemed to be appropriate for gathering highly personal data from a group of marginalised individuals. Narrative interviews have been successfully used when gathering data about people with disabilities in other contexts, since they can ensure full and meaningful inclusion of all participants if they are carefully planned and implemented (Rohwerder et al., 2021; Thompson & Rohwerder, 2023; Thompson et al., 2021; Wickenden et al., 2021). Narrative interviews are subject-led, generating highly personal and individual, situational, emotional, and relational insights in a way that researcher-led interviews may not be able to. According to Jovchelovitch and Bauer (2000, p. 6), "conceptually, the idea of narrative interviewing is motivated by a critique of the question-response schema of most interviews." This approach allows the subject to select the topic and theme, as well as the order in which they reveal their narrative. Importantly (particularly for some people with disabilities), the participant responds in a way that they are comfortable with. Reasonable adjustments were made to ensure that everyone could participate and that any speech, language, or communication barriers were overcome. The interviews were conducted in the language that the participant was most comfortable with. The narrative interviews were as open-ended and unstructured as possible to minimize researcher influence. This aim was to record authentic accounts of people's experiences (Holt, 2010). This approach can empower people, as the participants develop agency as the authors of their own narrative (Overcash, 2003; Parker, 2004). The narrative interviews instigated a short introduction about how identity is made up of different aspects and how these can combine and intersect to influence social experiences. Participants were then asked a deliberately open question about how aspects of their identity had combined to influence inclusion or exclusion. After the participants had responded and stopped talking, further probing questions (where appropriate) were asked to prompt additional responses relating broadly to how intersecting elements of their identity had shaped their experiences.

The data were then translated into English, transcribed, and thematically analysed (Braun & Clarke, 2006) using an intersectional lens. The themes were generated purposefully focusing on experiences of exclusion and inclusion relating to different aspects of people's identities. The narrative interview approach was designed to allow participants to discuss what they felt was important in their lives with regards to identities intersecting, creating data on simultaneously lived experiences (Windsong, 2018).

The data was coded specifically under the following themes and order: (a) the intersection of religion and disability, (b) the intersection of gender and disability, and (c) the intersection of multiple (three or more) identities. As we analysed the data, it became clear that disability was by far the most dominant identity to be linked by participants to exclusion. We created a separate theme to reflect this and went back over all the data to ensure we had analysed it accordingly. We engaged with six disability activists who worked for local organisations of people with disabilities as a validation process. Section 3, on findings, is organised around these themes from the analysis. We recognise that life in India is complex and context is important. As such, our analytical strategy was designed to explore the complexity associated with experiences of multiple dimensions of social life (McCall, 2005).

2.2. Ethics

Ethics approval was granted by the Institute of Development Studies Research Ethics Committee. Careful thought was given to how the research was undertaken given the sensitivities relating to religious minorities. Also, in addition to the usual ethical considerations of undertaking any research with people, particular care was employed to ensure the process was accessible (including the consent process) and did not discriminate against people with disabilities or put them at any additional risk. Ensuring the strict anonymity of the participants formed part of this process.

2.3. Limitations

There were some limitations to this research, which we feel are important to reflect on. India is a huge country with a diverse population. While responses included in this study reflect individual and highly personal accounts of lived experience, more research is needed to explore the experiences of others with different intersecting identities in different spaces and states. We note that identity can be fluid and exploration of this is limited. For example, all our participants expressed their gender identity as either male or female, and discussions relating to how gender intersects with other identities were limited (by participants' choice) to focus on the female experience. We did not impose this as a restriction, but our sample size may have limited the diversity of experiences. Future studies could be more inclusive of people with non-binary gender identities. We recognise that by exploring participant experiences based on a combination of their characteristics, it is possible that we essentialise their experiences, reinforce stereotypes, and potentially exacerbate structures of power. John (2015) states that researching spaces where different identity characteristics intersect can obscure rather than illuminate what is known. This article aims to shine a light on marginalisation in India through an intersectional lens, but we recognise this approach is contested and welcome further theoretical debate, including a critique of our selected approach.

This research was undertaken as the Covid-19 pandemic was developing, which limited the number and diversity of participants who could be involved. Government restrictions meant reasonable adjustments to the protocol had to be made. Efforts were made to ensure diverse identities were represented, but some groups have greater representation than others. For example, while we included people with a range of impairments (including visual, intellectual, neurological, or multiple impairments), the majority of participants reported having physical impairments—although these varied in type and severity. Also, regarding religion, while Muslims and Jains were included, the majority of the participants were Christians. Sikhs, Buddhists, other minority religions, and people with no religion were not represented in this study, which is a limitation. A more nuanced sampling approach to caste (and class) identities could have been undertaken to ensure participants with a range of identities were included.

2.4. Positionality

In terms of the authors' positionality, the writing team is made up of one man and two women. None of us report having disabilities ourselves. Two of us are European, based in the UK, and are not involved in any organised religion. One of us is from India but does not disclose their religion or caste. Throughout the research process, we were reflective about our own positionality. We aimed to undertake the research from a neutral stance. During the planning phase, we recognised that we needed external advice to achieve this, so we engaged with an expert advisor, who was from India, belonged to a minority religion, identified as someone who had disabilities, and had a wealth of experience working in the field of disability inclusion. They had input into the research design and approach to the analysis. We were assisted with data collection by a researcher from India who identifies as a Dalit and belongs to a minority religion. They also contributed to advising about neutrality regarding the data collection.

3. Findings

Our research produced rich accounts of how people with various intersecting identities experience everyday life in contemporary India. As the highly personal responses were analysed, common themes emerged focusing on how aspects of identity intersect to exacerbate societal barriers. Despite the intersectional analysis of the data, it became clear that disability emerged as the perceived main driver of discrimination experienced by the participants. The following section explores the findings emerging from our data with regards to the intersectional nature of social inclusion, but also details how our participants reported disability as the dominant identity characteristic driving experiences of discrimination. Where possible we have used direct quotes from the participants to highlight these themes, intending to bring to the fore the voice of the participants in the research (Wickenden & Franco, 2021). The use of quotes is also in keeping with the philosophy of our methodological approach, as the narrative interview technique we used is designed for the participants to express their experiences in their own way (Holt, 2010). With regards to disability, where possible we have tried to disaggregate responses by impairment category or type, but specific impairment-related experiences were rarely mentioned by participants. This could have been in part due to our research approach, which—following the social model of disability—did not focus exclusively on impairment but rather on the response of society. The following subsections are organised around the main themes from the analysis.

3.1. Intersection of Religion and Disability

Involvement in religious communities was found to be desired by many participants and regarded as an important part of life. For some participants, their involvement in religion provided positive interactions and they felt accepted regardless of their impairments. For other participants, the situation was more complicated, with some experiencing exclusion due to a combination of their religion and their impairments. Identities of disability and religious belief intersected, resulting in exclusion from within their own religious community. This was in part found to be due to some religious beliefs commonly linking disability with shame, resulting in judgement from other members of the community and negative experiences for people with disabilities. For example, one Muslim man with physical impairments and diabetes discussed disability in the context of punishment from God/Allah, noting:

> If your body is not pious [because of disability] you should not read Namaz/Quran. I don't go to the *masjids* [mosque] very frequently as my body is not pious anymore. How can I go for prayer when my pants are getting wet every now or then [due to involuntary urination due to diabetes]?

Some participants reported excluding themselves from certain spaces due to their previous treatment by others due to a combination of their identities. Such self-imposed exile from religious spaces was reportedly due to links between disability and shame associated with particular religious identities. Such experiences were found to have been experienced across multiple religious settings and multiple impairments. A Christian man with physical disabilities noted:

> I avoided participating in social events, say, for instance, at the homes of the members of the church

> just for the fear of being a burden to them and so on. If I, in particular, go to any such events with my wife, the embarrassment is more pronounced [and] everyone will look at my wife with sympathy that she has to suffer because of her marrying a disabled person.

For other participants, exclusion from places of worship and religious activities due to aspects of their identity was imposed by others in the form of various barriers (both physical and societal). This was particularly pronounced for those with impairments that could not be hidden. Their religious beliefs were what motivated them to attempt to access religious spaces, but a combination of their disability, and the religious beliefs of others in their religious community resulted in them being excluded. As a result, they missed out on the social and spiritual benefits being part of a religious community can offer, which was found to have a negative effect on how they felt. A Muslim man with visual disabilities mentioned:

> I have heard of the Imams visiting the sick and the old in prayers and worship to help them at their homes. I feel they should have come to my home in search of me, [to help me] participate in daily prayers or weekly worships. All these [left] a bitter feeling, not only against the structure but against me as well.

A Christian man with physical disabilities reflected on his isolation:

> Since I was not frequenting the church like any other normal children, I did not have any friends there or any serious relationship with the priests or nuns over there.

As the data was gathered during the Covid-19 pandemic and people were subject to varying levels of social distancing rules, it is possible that feelings of isolation were heightened during this time. However, discrimination in minority religious settings appeared to have preceded the pandemic. Some participants mentioned others in their religious community only focusing on their disability rather than their personhood, or people assuming they are there to beg rather than to take part in a religious celebration. For example, a Muslim woman with physical disabilities noted:

> When I appear in such an event, they tell me: "Please leave, don't bother us now." They think I've gone there to ask for help, though I just visited them casually or just to have a friendly chat.

Some participants faced direct discrimination due to their impairments in their efforts to attend or be involved in leading religious activities. For example, one Christian man with physical disabilities had their reserved parking place taken away by their new parish priest, who also turned their face away from them whenever they met. Another Christian woman with visual disabilities reported:

> [I] was not allowed to be a part of Sunday Bible classes that will be organised after the main service, just because I am blind.

Another Christian man with a visual impairment reported being driven out of the church they set up "by a few members'':

> The reason [was] that I was blind and could not run the church, as it was growing. Nobody supported me and everyone was of the same opinion that a blind person cannot run a church independently.

For some people with disabilities, participation in a religious community has brought significant comfort and enjoyment, tinged by the negative experiences of inaccessibility and exclusion. One Christian man with physical disabilities, who feels included by their Pentecostal church noted:

> The foremost impact is that I have been given that worthy feeling that I am too a worthy creature of God and I deserve all the dignity to live as a normal human person. This did not happen overnight. All the worship methods, providing me with leadership opportunities and a place in the choir and even small positive gestures over a period of time gave me such a hope.

Other participants who were provided similar opportunities were also happy it made them feel (in their words) "normal." Kindness and inclusion from leaders in their religious communities and community members helped people feel more positive about themselves and their lives. Some participants changed their identity structure by converting to different religions in a quest to feel more included. In these cases, their disability status remained the same, but their religious status changed. Some converted because of the acceptance they felt from particular religious communities. For example, a formally Hindu man with physical disabilities said:

> I was amazed by the love and affection showered by the other members of the church on me as a disabled person and I started frequenting that church and was soon formally included as a member.

This presents an interesting finding in terms of fluidity of identity. While a person may not be able to change the status of their impairment, they may be able to choose to change their religion, which impacts how they experience inclusion and exclusion in different settings. Some people with disabilities noted that they felt their religious minority status meant that they experienced additional disadvantages compared to Hindus with disabilities. For example, a Muslim woman with physical impairment noted:

> Everywhere else disabled persons are being well-taken care of but not us. People from nearby Hindu localities are in a more advantageous situation than us.

The evidence showed that people with disabilities were struggling to access the social assistance they should be getting, and they believed this was due to their identity characteristics. For example, participants noted their difficulties accessing the disability card which enables their access to the relevant allowances and felt that these difficulties were caused by religious prejudice. A Jain man with a mother with intellectual disabilities noted:

> While I applied for the disability card for my mother, the social welfare officer did not want the issue after he came to know that we are Jains. He rejected my application and told me: "You are Jain, then why are you asking for Government support?"

Another Christian woman with visual disabilities also reported intersecting discrimination, saying:

> [I am] denied a cooking gas connection meant for the Hindu Dalits who are both abled and disabled. I was denied such a cooking gas connection and was told that, as a blind person, I cannot manage such a dangerous connection. I felt the undercurrent that I was denied because of being a member of a Christian community.

This evidence supports the research of Pal (2010, p. 23), who described marginalisation as having multiple bases in the social structure, involving various interrelated issues: "The situation of persons with disabilities among lower caste groups provides critical dimension to social discrimination, deprivation and exclusion.'' Marginalisation was found to be exacerbated by the intersection various aspects of social identity, resulting in certain groups (people who are Dalit and have a disability) being more likely to experience multiple disadvantages.

For some, the way that discrimination was experienced was clearly linked to different aspects of identity. For example, a Christian man with visual disabilities was assaulted by someone accusing him of trying to convert Hindus; he shared:

> Before I realised what was happening, he [a Hindu man] suddenly removed the belt from my hip and started to assault me using that belt. I was shocked. He, during the assault asked me if I am converting Hindus to Christianity. He started to beat me faster as I remained silent. I was rescued by the others who came across. What I mean here is that but for my disability he would not have had the courage to assault me.

Here, response to his minority religion instigated the reaction from someone from the majority religion, but then his disability resulted in his assault. Fear among the Hindu population of being converted to another religion well documented (Barua, 2015, for example, explores this issue in detail). However, in this case, while the response was caused by the participant's religious identity, the response was manifested in physical violence due to the participant's impairment.

3.2. Intersection of Gender and Disability

Our data produced limited evidence on how gender issues intersect with disability. However, where evidence was forthcoming, it indicated that gender and disability can intersect to impact negatively on all aspects of several of the female of the participants. Despite the majority of our participants being men, none of the male participants had anything to say about gender, with none of them reporting gender as a cause of discrimination, either when intersecting with another characteristic of identity, or on its own. However, many of the female participants were keen to discuss gender as an issue. Discrimination was found to be far more pronounced for women with disabilities than for men with disabilities. This is perhaps unsurprising and in keeping with evidence from the existing literature (Batra & Reio, 2016; Haq et al., 2020). Jogdand and Narke (2022) previously linked the explanation for such experiences to Indian culture and traditions, as well as attitudes and biases, which result in women with disabilities being disproportionately affected. Specific reference was made to the impact of gender issues for access to education for women/girls with disabilities. For example, one Muslim woman with physical disabilities who was taken out of school when she was eight said:

> In our Muslim community the way girl children are brought up is far different from the way boys are brought up. My parents would have given up the school education not only because of the accessibility but for the gender issues as well. They would have thought that it is enough for a girl child with disabilities.

This strong reaction to the negative treatment of women due to an intersection of gender and impairment resonates with the work of Jogdand and Narke (2022), who make the clear connection between the isolation of women with disabilities in India and experiences of low self-esteem and negative feelings. The evidence suggests discrimination experienced by women with disabilities was deeply entrenched in the social fabric, resonating strongly with the work of Batra and Reio (2016). Such discrimination based the intersection of gender and disability felt for many so regular and common that it had almost been accepted as "normal." The data indicates that women with disabilities face significant marginalization in India.

3.3. Intersection of Multiple Identities

The data showed that several participants faced discrimination due to multiple intersecting aspects of their identity. Exclusion was caused due to a combination of their impairment, their religious minority status, and in some situations their lower caste status. Such discrimination based on the intersection of identities appeared to be particularly prominent in the world of work, with participants discussing experiences of discrimination both in terms of getting a job, but also in terms of negative treatment from co-workers once employment was found. For example, a Christian man with a physical disability who is looking for a government job as a qualified teacher noted:

> I have to compete with the Hindus with disabilities. My being a Christian Dalit puts me in the Backward Class list and that delays the process of my getting a government job. [It] is a clear disadvantage to be a Dalit and a Christian. Had I been a Hindu with disabilities, then by this time I would have gotten the job.

Another Christian Dalit man with physical disabilities reflected on the discrimination based on multiple aspects of his identity:

> In my office I have been discriminated basically based on my disability, then on my being a Christian and then for being a Dalit.

Gender issues were also found to intersect with disability and religious identity. One Muslim woman who was visually impaired reported she was far more excluded than her brother who was also visually impaired and had an identical religious affiliation. She went on to say that the exclusion was so bad that she previously felt suicidal as a result of her exclusion and experiences:

> I feel like ending my life. There is no point in this life. Not a single day has passed where I haven't suffered.

The evidence showed that there was the perception that women with disabilities from religious minorities were found to face more pronounced disadvantages than other women. Exclusion was experienced due to the intersection of disability and minority religious status, but gender was the identity that defined experience.

There were instances where participants mentioned discrimination, but the situation appeared complex, with implicit or explicit motives being cited as the reason for the discrimination. For example, disability was used as an excuse to discriminate on the basis of caste. A Christian man with a physical disability reported:

> [I was] asked not to play for the choir, being [told] that it might be difficult for me as a disabled person to get to the church on time for the mass. I was heartbroken as I knew my handicap was not the sole reason, but it was my being a Dalit that resulted in my being expelled from the choir....The fact that I have been playing for the choir for many years did not seem to count for them. All of a sudden, they pretended to take cognisance of my inability.

This illustrates the complexity of social structures in India, as well as the attempt to assess what is happening through an intersectional lens. The nature of implicit discrimination and exclusion makes it particularly hard to analyse.

3.4. Dominance of Disability as the Identity Responsible for Most Discrimination

Although experiences reported were highly individual and shaped by varying and intersecting aspects of identity, discrimination based on disability identity emerged as by far the most reported cause of discrimination. Despite our study aiming to explore intersectionality, our analysis suggests that for our participants, the overwhelmingly dominant aspect of identity, which they reported as being the basis for experiencing exclusion by others, was disability. Their status as people with disabilities had far more of an influence than other aspects, including minority religion affiliation, gender, or caste. As shown above, we note that these aspects of their identity can and do intersect, contributing to discrimination, but that disability stigma, which appears to be deeply entrenched in Indian society, is the root cause of much societal exclusion for people with disabilities.

Feelings of exclusion due to disability status were commonly experienced across a range of aspects of life (including education, work, and homelife) and found to be both overt and covert. In some cases, it was made obvious that the discrimination was due to a person's impairment. In other cases, the discrimination was more veiled, but equally toxic. A Christian woman with physical disabilities noted:

> I have never felt included. Life has been one long journey of subtle exclusions.

Both overt and covert discrimination was found to be hurtful and had a negative impact on the lives of people with disabilities. Such discrimination based on disability was experienced across by participants across the range of other identities and appeared to take place regardless of religion, gender, or caste. Stigma around disability has resulted in people with disabilities being ignored and isolated by others.

Participants also detail experiencing abuse and mockery/laughter from others when they go out into society, which has led to isolation and some participants cutting themselves off from society. A Muslim woman with visual disabilities stated:

> People would hurl abuses at me due to my disability. That's why I don't go out.

Some people with disabilities responded to the stigma they face and the inaccessibility of their environments by excluding themselves from society. A Christian man with physical disabilities said:

> There are many instances when I self-excluded myself from attending to social and family events of church members, obviously because of my poor accessibility and the fear that I would attract sympathies from others.

The overriding perception from the participants was that their disability status was the reason why they were excluded, regardless of other aspects of their identities. While intersecting identities are undoubtedly important in terms of planning how to move towards a more equal society, it would appear that addressing marginalisation due to disability status should form the basis of any action that aims to be truly transformative in India.

4. Discussion

Intersectionality should allow researchers to explore how various identity systems mutually construct and influence one another and influence lived experience. However, as detailed by Erevelles and Minear (2010), there are various theoretical challenges of undertaking intersectional research, highlighted by questions such as whether some differences in identity should have prominence over others, or whether differences can merge to create a more acute form of oppression. Do some combinations of identity and context result in invisibility of certain aspects of identity? In an interview by Berger and Guidroz (2009), Kimberlé Crenshaw, who first coined the term "intersectionality," urges researchers to move beyond using intersectionality to just multiply identity categories, and instead use it as a framework to develop a structural analysis or a political critique. As such, intersectional analysis must consider how particular conditions are located within structures of power (Berger & Guidroz, 2009).

Using this framing, our analysis contributes to the evidence of how identities such as disability, gender, and religious minority status (and caste) intersect to impact lived experience. As explained by Kabir et al. (2022), considering where power lies allows us to explore structural barriers and to understand who is being left behind and why. India is a deeply unequal society, with gender continuing to be a major factor influencing marginalisation. Our findings resonated with existing research in that patriarchy is found to be deeply entrenched in Indian society (Singh, 2017). Women with disabilities are particularly marginalised and face societal challenges relating to both disability and gender. Saikia et al. (2016) described this as a double burden of discrimination. Marginalisation is further compounded for those who belong to minority religions, and those with lower caste status. In contemporary India, the line between politics and religion is becoming increasingly blurred, with the Hindu majority cementing their power under the governance of the Hindu Nationalist Prime Minister Modi (Haq et al., 2020; Kim, 2017). Despite recent progress towards disability inclusion in India in terms of the signing and ratification of the CRPD in 2007 and passed the Disability Rights Law in 2016, disability discrimination continues. The socially constructed barriers that result in discrimination against people with disabilities are in part shaped by religious beliefs (for example through the concept of Karma). In addition, the ancient caste system stratifies Indian society, with Dalits being the most powerless (Das & Mehta, 2012). As such, if you happen to be a woman with disabilities from an underprivileged minority (religion or caste) community in India, then you are more likely to face multiple forms of discrimination and experience extreme marginalisation and oppression.

Our findings suggest that discrimination due to disability clearly remains a problem in India, but that other factors such as gender, caste and minority religious status (which are arguably more entrenched in societal structures of power) also have an impact on when and where oppression is experienced.

Windsong (2018) urges researchers to engage with methodological challenges of intersectionality to avoid the research process becoming opaque and contribute in a transparent and honest way to how future research can be designed and conducted. Despite our efforts to investigate the intersecting nature of different identities in India, our results show that disability was the identity that resulted in the most significant marginalisation for all of the participants. Other identities were found to intersect to contribute to marginalisation, but disability status took prominence as the identity that resulted in universal marginalisation for our sample population. Despite this finding, our research does illustrate how useful using an intersectional lens can be for interrogating complexity. The interweaving of various aspects of identity is shown to feed into complex power structures and the creation of societal barriers, which if left unaddressed will result in the continued and exacerbated marginalisation of people with disabilities with certain identities, and social justice will remain unachieved.

Our research provides evidence focused on the intersectionality of lived experiences of disability in Tamil Nadu and West Bengal. It highlights the perspectives of underrepresented groups, and through an intersectional lens explores how identity can influence experiences of inclusion and exclusion. It has implications for future intersectional scholarship. While the findings draw on highly personalised experiences, they also have wider implications for addressing intersecting discrimination in India and beyond. It is clear that more research is needed to explore the complexities of how identities can intersect to exacerbate marginalisation. This is particularly important in a country like India, with its unique social, religious, and cultural history. In addition, there are also methodological implications, as innovative intersectional approaches are clearly needed to explore situations where a particular identity has a more pronounced impact on lived experience than other identities. Our research also has implications for the policy sphere. With disability emerging as the dominant factor that appears to be the root cause of discrimination ahead of other factors, policy makers must ensure that people with disabilities are considered at all stages of policy making. This is particularly important when making policies relating to minority religious status and gender, as our findings show that the marginalisation of people with disabilities is shown to be exacerbated when these identities intersect.

5. Conclusions

This study has contributed rich qualitative evidence that focuses on the drivers of marginalisation in Tamil Nadu and West Bengal. Using narrative interview methodology, we provided the people with disabilities who took part the opportunity to express their experiences of inclusion and exclusion in India in their own words. We encouraged them to reflect on how various aspects of their identity influenced their experiences. Our analysis suggests that social exclusion is highly contextual, complex, and influenced by a number of factors. However, for all of our participants, disability was the most prominent aspect of identity that resulted in marginalisation. Other aspects of identity (gender, minority religious affiliation, and caste) intersected to contribute to marginalisation. Despite being asked directly to comment on how various aspects of their identity intersect, most participants focused their responses on marginalisation resulting from disability. Societal attitudes and barriers that were influenced by entrenched power structures relating to religion, gender, and caste impacted the inclusion of people with disabilities in employment, education, and social spaces. In the context of our study, women with disabilities and Dalits with disabilities appeared to be particularly marginalised due to intersecting aspects of their identity. For some participants, their minority religious affiliation also influenced their experience of discrimination, but their impairment made them an "easier target" for abuse. Our study has highlighted that discrimination remains rife in India despite legislation existing to prevent it or respond to it. It is clear that the national law to prevent discrimination due to disability is not being implemented effectively. Different aspects of identity are shown to intersect with disability and result in compounded marginalisation. Action is needed to realise the rights of people with disabilities and ensure that they are included in all aspects of society, and to address intersecting discrimination due to any other aspect of their identity, including their caste, religion, or gender.

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Conflict of Interests

The authors declare no conflict of interests.

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Article

Intersecting Disability and Poverty in the Global South: Barriers to the Localization of the UNCRPD

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Abstract
The UN Convention on the Rights of Persons with Disabilities (UNCRPD) remains in place as the major disability rights instrument recognising that all persons with disabilities must enjoy human rights and freedoms as every other person. However, the CRPD does not automatically confer realization of these rights. In practice, its implementation is met by multiple hurdles, most pronounced at the local level in the Global South, where disability and poverty intersect. This article reports on findings from a study in five countries (Kenya, Philippines, Jamaica, Guatemala, and South Africa) looking at the extent to which the CRPD is being implemented locally in contexts of poverty, and the factors and processes impacting this localization. The findings highlight multiple barriers, becoming more pronounced in local rural areas. These include weak and fragmented organisations of persons with disabilities (OPDs), political and legal issues, and a siloed approach where disability is marginalised in mainstream areas, including development. These barriers are accentuated as intersectional dimensions are factored in, including indigeneity, age, gender, race, and ethnicity. Overall, each local context is left to its own devices, with urban stakeholders, unknowing of what life in poverty is like and how this reframes the CRPD in discourse and practice at the forefront. Our study concludes that there is a profound need for an informed, contextualized, intersectional, and geopolitical analysis where poverty is kept sharply in focus. This is essential to move beyond unrealistic assumptions about disability rights frameworks and to work towards truly localized and transformative efforts.

Keywords
disability rights; Global South; human rights; localization; UN Convention on the Rights of Persons with Disabilities; poverty

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1. Introduction

The intersections between disability and poverty have long been acknowledged in academic and practice circles. Often framed as a mutually reinforcing relationship, it is suggested that poverty exacerbates impairment, while disability intensifies poverty, especially in spaces and places where persons with disabilities confront disabling policies, discourses, attitudes, and practices (see Banks et al., 2018). Despite the continued lack of research into the dynamics operating in this relationship (Grech, 2023), it is often stated that persons with disabilities, especially those in the Global South, are among the poorest of the poor, whereby their rights are violated, in some contexts more than others (Banks et al., 2022; Benvenuto & Caulfield, 2019; Degener, 2016).

An important tool in seeking to redress these rights violations and breaking this disability/poverty cycle (at least at the level of discourse), has been the UN Convention on the Rights of Persons with Disabilities (UNCRPD, or simply CRPD). Opened for ratification in 2007, the CRPD sets out minimum standards for the rights of people with disabilities across a range of areas, for example, health and rehabilitation, inclusion in the community, accessibility and the right to life, alongside advocacy on the equalization of rights of people with disabilities. To date, over 185 states have ratified the convention. The references to the disability and poverty relationship are multiple in the CRPD. For example, the preamble highlights "the fact that the majority of persons with disabilities live in conditions of poverty, and in this regard recognizing the critical need to address the negative impact of poverty on persons with disabilities" (UN Nations, 2006, para. t). Article 28 lays out how states parties shall take appropriate steps "to ensure access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programmes and poverty reduction programmes" and "ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care." Together, the CRPD and a stronger global disability movement have sparked considerable developments in global norms and standards relating to persons with disabilities. These include work by the Committee on the Rights of Persons with Disabilities, political commitments made through the 2030 Agenda for Sustainable Development (and reflected in the 17 SDGs; UN, 2015), and guidelines on the inclusion of persons with disabilities in humanitarian action among others (UN, 2019).

The CRPD, though, does not automatically translate into benefits for persons with disabilities, especially for those caught in the disability/poverty bind in the Global South. As with other international human rights conventions, national governments are responsible for entrenching the implementation of the CRPD into their domestic systems and context in order to meet their obligations (Lord & Stein, 2008). Problems become accentuated as one moves from the international to the national and the local. There have been a number of critiques of international human rights law and international human rights conventions, including that they are often state-centric, top-down, do not allow for local values and cultural differences, and are "too technical—or abstract and aspirational, rather than practical and close to the people" (Durmuş, 2020, p. 36). Critics (see Harpur & Stein, 2022; Soldatić & Grech, 2014, 2022) also highlight how the CRPD may be a one-size-fit-all policy, ratified with ease, but with little alertness to how local contexts encounter, react to, and perhaps even resist it. Critical work has been growing, alerting that there may be multiple barriers that impact the extent to which the CRPD is being implemented and to what degree of success (see Grech, 2009; Najafi et al., 2021). Despite differences in opinion (see, for example, Crock et al., 2013), authors such as Pisani (2012), for example, have stressed how conventions such as the CRPD are also ultimately bound to citizenship, meaning that forced migrants for example are too often unable to claim their rights and left exposed. While the wording of the CRPD may be excellent at a macro level, it is at a local level that concrete barriers to implementation become manifest.

The term "localization" is increasingly being used by UN bodies (e.g., UNDP) and bilateral organisations (e.g., USAID) to point to the need to translate these international frameworks into reality in the daily lives of people in their communities beyond just creating national-level legislation and policies, which is often referred to as "domestication." Localization has recently been featured in international human rights law, understood as a process to support national, regional, and local governments, civil society, and service providers to develop mechanisms, partnerships, platforms, and strategies to effectively translate the CRPD into practice. We adopt this understanding of localization in this project and article.

The implementation of the CRPD is far from straightforward, and debates and evaluations of the implementation of the CRPD in local contexts, especially in the Global South, are still in need of research (Caldas de Almeida, 2019). To be clear, different authors in different contexts may use different words or framings, for example, "domestication" or "implementation of the CRPD," and we are therefore not suggesting that there is no research on the subject. In line with Faye Jacobsen (2022, p. 2), what we mean is that the state of research concerning localization more broadly is still a "very young object of study" where "empirical knowledge and understanding of human rights implementation at local level is still fragmented and scarce."

This article responds to these concerns, notably the gaps in critical research and understandings of the localization of the CRPD and the intersections with the disability–poverty nexus. It synthesizes findings from a broader study looking at the process of localization of the CRPD to understand the obstacles in local contexts in the Global South (see Weber et al., 2022). The need for a study on the process of localization across multiple contexts is long overdue, not as a mere research project, but to ensure that the CRPD does have power and relevance at the local level, where it actually matters, and importantly so that it can be genuinely transformative in the lives of persons with disabilities, particularly those in situations of poverty. In this regard, we hope that this study can serve as an impetus for further critical research and theory and policy development.

2. Methodology

This study, which was conducted in 2022, employs a qualitative approach foregrounding the views and perceptions of multiple stakeholders on the process of localization of the CRPD within their respective countries. Five countries in which the international NGO Christian Blind Mission (CBM) International has contacts and is active, were selected as sites for the study: Jamaica, South Africa, Guatemala, Philippines, and Kenya.

Interviewers, none of whom self-identify as persons with disabilities, conducted semi-structured interviews of approximately one hour online using Zoom or Microsoft Teams with each key stakeholder. All interviews were conducted in English or Spanish by the authors of this article and three other academic project collaborators in South Africa, Jamaica, and the Philippines respectively. Interviews were recorded with the permission of participants and then transcribed. Sampling was purposive, with a total of 40 participants of all genders recruited through the use of a collaboratively designed sampling frame for each country. See Table 1 below for a description of the participants. The objective was to have diverse views from different levels and phases of the localization process.

2.1. Data Analysis

The research team used thematic analysis (Braun & Clarke, 2006) to identify themes and patterns in the data that are pertinent to the research study objectives. It provided an inductive approach to engaging with data. The process involved manually identifying and coding key themes that would then lay out the thematic areas on which the findings below are based.

2.2. Ethical Procedures

Formal ethical approval was obtained from the University of Cape Town (Ref. HREC REF 275/2022). All ethical procedures were rigorously followed, including informed consent, confidentiality, voluntary participation, and anonymity in interviews while consistently highlighting the rights of all participants, including the right to withdraw from the study at any time. All names have been removed to protect the identity of participants.

2.3. Limitations of the Study

The first limitation is that the choice of countries was arbitrarily made from those with which CBM International has links, and therefore findings cannot be generalized. We are aware that every context is different and so are the processes of localization. The purpose of this study, though, is not to generalize, but to provide a snapshot of localization in the Global South that can inspire other research and possibly influence policy and practice on disability and poverty. The fact that interviews were conducted in dominant English and Spanish languages is another limitation, meaning that multiple voices and perspectives, especially those at the margins are excluded. This is especially the case when it comes to indigenous languages and perspectives where active efforts need to be in place for them to be heard and prioritized. Thus, the findings in this article are positioned and contextualized, and need to be read with this in mind. Finally, this article and the research project more broadly are limited conceptually. Localization as a concept related to the CRPD is severely under-researched and the concept itself scarcely developed theoretically,

Table 1. Description of participants.

Country	Organisational base of participants and number		Total
Guatemala	Disability Council member	1	7
	Organisation of persons with disabilities (OPD) members	3	
	UN official	2	
	Municipal office official	1	
Jamaica	Disability Council member	2	8
	OPD member	3	
	UN official	2	
	Municipal office official	1	
Kenya	Disability Council Member	2	9
	OPD member	2	
	Policy maker	3	
	UN Country rep.	1	
	Country rep.	1	
Philippines	OPD member	3	8
	Local government	3	
	Disability Council	1	
	National level policy consultant	1	
South Africa	Disability Council	1	8
	OPD member	3	
	UN official	1	
	Department of Social Development	2	
	Donor organisation	1	

leading to possible inconsistencies in its application by the research team.

3. Findings and Discussion

The following sections and subsections present and discuss the main findings from the thematic analysis, notably the key obstacles encountered in the local implementation of the CRPD. They navigate conceptual issues, followed by social, economic, political, and legal terrains, rights discourses and applications in practice, and organisational and representation concerns, rounding off with problems in mainstream areas and sectors.

3.1. Obstacles to Localization

3.1.1. Issues in Conceptualization

The first problem that deserves attention is a lack of clarity and agreement as to what localization actually means and involves concerning the CRPD, which implies that it remains uncertain as to what one is talking about or is meant to do:

> Honestly, I do not know what you mean [by] localization. Does it mean you have results locally, or is it more a process…of things you need to do, that you can implement it in a village, for example…? (Participant, Jamaica)

Participants expressed a range of views, such as that national ratification is localization in action, or that localization is a process or impact in local communities or a tool to push local government to consider the rights outlined in the CRPD:

> How I understand localization is that it is considering the capacities and culture of a community. (Participant, Philippines)

> Localization is bringing the CRPD to our national and local levels. (Participant, Kenya)

However, despite the diversity of views, there appeared to be some fluid patterns that illustrate limited reflection on what makes the localization of the CRPD particular and with its specific baggage of complexities and nuances. The following quote highlights this tendency towards simplification:

> Since it ratified—and [was] based on the Constitution—any treaties of international conventions we agree[d] to [make it] part of the law of the land. So basically, [the CRPD] also became part of the law of the Philippines. When it is part, then it is part, then it is included in our domestic legislation. (Participant, Philippines)

The tendency to see localization as a linear, somewhat organised one-way process from top to bottom to fit the CRPD within a national context, was a pronounced pattern in the data. This is despite the fact that, in practice, it is a complex, diverse, and dynamic process often determined by a range of connected and even conflicting factors (for more on these see Caldas de Almeida, 2019). A Filipino participant from an organisation of persons with disabilities (OPD) explained some of these interconnected factors:

> The context and capacity of the area are considered [in localization]. The culture, although possibly a barrier, should also be considered in localization. Financial constraints are also present. But part of the mandate of these duty bearers is to find resources to help society enjoy and exercise their rights.

3.1.2. Socio-Economic, Political, and Legal Contexts

What was evident in the data was that the CRPD and the processes of localization exist within and are conditioned by a complex ecosystem that is heterogeneous, dynamic and varies across contexts. What we present below are the main emerging themes.

3.1.2.1. Poverty and Its Limitations

Critics have often highlighted how the power of the CRPD is constrained in practice by multiple factors, not least the inequality it meets at a local level, especially in rural areas (Grech, 2015; Opoku et al., 2016). Evidence from this study suggests that the process of localization in some contexts is conditioned by the complexity, multidimensionality, heterogeneity, and dynamic nature of poverty. Indigeneity and other intersectional dimensions additionally create a complex web of hardships and oppression, as the following quote illustrates:

> Poverty means no money, no health care…long distances, and no support [from] anyone….You are alone…and indigenous, even harder, like with racism….So even making people aware of their rights is limited with no money. (Participant, Guatemala)

Interviews in this study highlight how practical needs can dominate strategic ones in contexts of poverty and inequality. This has serious implications including what realistically can be included and targeted and whether “higher order” needs and rights are of consideration in contexts of extreme deprivation. Poverty can influence how the process of localization happens, what can be invested, the barriers it meets on the ground, and what can realistically be achieved. A policy developer from South Africa explains the conundrum faced by poor persons with disabilities:

> Remember we live in a very difficult time, you cannot expect me to be at an awareness session for the whole 50 minutes knowing very well that within [those] 50 minutes I would have made maybe R 150 [USD 9] that I can buy food with later on for my family. So maybe that's why not everyone will be there; because some are looking at [the] time they are wasting at intervention sessions and the fact that they need to make money out there, and they have an impression that "being here will not benefit me in any way.''

One participant in Jamaica was rather direct in stating how in such dire circumstances and facing the quest to merely survive, the CRPD may well become superfluous, if not meaningless:

> You cannot go out and tell people about this CRPD if they are struggling to make ends meet. They need to survive. Who cares about a convention?

However, a local-level policymaker in the Philippines indicated how, despite the multiple limitations, the potential of the CRPD in challenging institutionalized discourse away from charity towards agency and the need to access social protection as a question of rights remains important:

> Persons with disabilities are not just objects and charity cases. That's what I learned from the training [on the CRPD]. [We don't aim for] special treatment, [but] social protection. What the CRPD is trying to convey is for us to be subject to what's within our community.

Findings from the study illustrate that while the political terrain is not the be all and end all of localization, it can affect multiple dimensions, including access to resources, accessibility to services, investment in infrastructure, and a change in attitude towards more inclusive politics.

3.1.2.2. Political Issues

In some cases, the disability agenda may be tarnished by partisan politics whereby only party-aligned people sit on disability affairs committees. Thus, they may not readily criticise the government when rights are violated or things are not working. Greed and corruption may also dominate as explained by this participant from the Philippines:

> Close to 15 years after ratifying the CRPD, it seems that we are still [at] square one because the CRPD has not really been institutionalized. Furthermore, our political culture here is that, if there are new officials, what they want to do is to make a name for themselves. They do not really examine or even continue on with the programs of their predecessors. Political ambition and greed get in the way. They want to be identified with their programs—"This is mine, this is my program"—even if the new programs are really useless and worthless.

As indicated by a participant in Jamaica, political actors are not always aware of the CRPD and do not know the implications for their own sectors. In addition, local and regional politicians may also not see disability as a priority:

> We have really always the same politicians, one or two, dealing with disability…the rest of them do not know anything about the field or are not interested.

In South Africa, one participant remarked how political players marginalise OPDs and engage consultants with no expertise on disability matters, reflecting a delegitimization of persons with disabilities in speaking about their own realities:

> When legislation and documentation or policies or implementation plans are drawn up, it often happens that the government appoints some consultants to do that work, and then…after the work has been done, the document gets sent to our organization and others like us [OPDs]…to give input. Then it often happens that people with disabilities, or we as organizations, have to almost re-write the document to get it in line with the CRPD….It feels as if the government doesn't have respect for persons with disabilities and the organizations, and then for the money part it goes to the fancy consultants; and when the real work needs to be done then it comes back to the sector.

The lack of funds for implementation is a serious concern given that the localization of the CRPD is a costly exercise. The perceived costs, it was suggested, may also be used as an excuse for inertia:

> They [politicians] always say: "No, disability is too expensive." So nothing is done…just a very cheap excuse. (Participant, Guatemala)

Traditional politics in many local contexts, especially rural areas in the Global South, are top-down and patronage-driven: This implies that, rather than a politics of rights, what drives the agenda is tokenism, favours, and *personalismos*. In fact, findings from the interviews highlight the multiple efforts that go into trying to warm up to local politicians—politics of favours, not rights—who act by personal choice rather than obligation. A participant from Guatemala went on to explain:

> Everything in Guatemala is about who you know and never about what you should get by right, by law…so we end up having to ask for favours, for pity, so someone finds it in his heart to help us

3.1.2.3. Legal Terrain and Justice

While the existence of legislation, policies, and plans does not guarantee implementation of the CRPD, they can provide an enabling framework that OPDs and civil society can use to hold the state to account. For this reason, laws, policies, and other state commitments are considered as a possible resource for the localization of the CRPD (see Faye Jacobsen, 2022; Pons et al., 2021; Rivas Velarde et al., 2018). However, in practice, the situation is extremely complex. In this study, participants highlighted how adapting local law requires legal as well as human and financial resources to be able to do this, as well as political openness and commitment to the process that may not always be present:

> Its application [of the CRPD] is very difficult and, in most cases, being able to push for inclusive public policies, to develop institutions, to assign a budget to advance the content to align with the preconditions of the CRPD, really is very difficult. (Participant, Guatemala)

In another example from this study, it is reported that some OPDs lack legal knowledge and legal support implying that they struggle to fulfil a monitoring role:

> How can an OPD actually understand the full legal text? We are supposed to give input to all kinds of reports, but we do not have a legal counsellor. What we need is access to legal advice first! (Participant, Jamaica)

A participant in the Philippines explained how domestic laws often prevail over international ones, however dated they may be and whichever conflicts they may have with the CRPD. In Guatemala, a participant commented on how there is a lack of legal identification of persons with disabilities as rights-holders in need of targeted protection.

At a practical level, the findings noted there are gaps when it comes to pro bono legal services. One major point here, and aligned with other literature (Grech, 2015; Soldatić & Grech, 2014, 2022) is the fact that persons with disabilities are hardly in a position to seek legal redress on account of their poverty. These include the fact that most do not have the resources to claim their rights, for example, to reach a major city for legal support, and importantly do not have time or financial means to sustain a court case because basic needs and survival need to be prioritised.

Findings illustrated a tragic situation in South Africa where cases of rape are not reported or investigated by police, meeting ill-informed or generalized assumptions about persons with disabilities and their capacity to testify in a justice system:

> There's a lack of access to the justice system…the fact that various women and girls are raped and they don't get even as far as the support of the police to make a case…simply because of the non-willingness to "go the extra mile," [not] understanding…how people with certain impairments can actually go to court and testify, [making] wrong assumptions. (National OPD member, South Africa)

3.1.3. Individual Versus Family and Community Rights

Another emerging theme is the understanding of rights in the CRPD as *individual rights.* Participants highlighted how this is a serious problem in contexts where these individual rights are subsumed by communal ones. Within such spaces, it was suggested, families and communities may well have a critical impact on the possibilities of granting these rights to an individual, whether individuals even want individual rights, and/or would opt for the protection of their communities instead. One participant from Guatemala explains:

> On paper, you have an individual rights holder, but in many close-knit communities you have individuals who live with and through their communities. And whatever is on paper needs to go through families or communities or the village elders…because "life is community." This means the CRPD, just like disability laws, may not make much sense because they focus on the individual

The findings concur with Grech's (2015) that local dynamics and processes (community development) ultimately need to be influenced in contexts and cultures where rights are collectively framed and sought. Harpur and Stein (2022, p. 92) also explain how the CRPD text focuses on individual living rights, but this focus on rights from the Global North often clashes with the Global South's "communal and family focus."

3.1.4. The Problems With OPDs

The critical participation and assumed role of persons with disabilities and their respective organisations in the fight for rights, cross-cuts the text in the CRPD (see, for example, UN Nations, 2006, Articles 4 and 29). The role of OPDs on paper appears to be broad, including the compromise to engage in consultations with powerful stakeholders on policy and practice; to monitor the implementation of policies, and to push forward representation, especially of marginalized segments of the population with disabilities. Findings from this study reinforced the need for political participation and empowerment of OPDs and persons with disabilities who should own and define the rights agenda. However, a lack of knowledge of technical issues and language by smaller rural OPDs, especially indigenous ones, limits their ability to communicate on political issues. These meet gendered and other terrains of discrimination, including racism. An indigenous participant explains:

> There are many spaces where one does not feel…able to speak because people there speak very technically, the people there are supposedly very educated on the subject.…Sometimes I have been invited and I do not understand anything they are talking about because they are very technical…and I have been able to study, but others.…To be able to get involved in these political spaces.…It has been difficult being a woman with a disability, they always push you to the side. (Participant, Guatemala)

Findings indicate a situation of excessively high and unrealistic expectations of what OPDs can achieve in practice, especially the ones in poor rural areas in the countries studied here. The interviews illustrate a plethora of problems, both internal and external to OPDs, which seriously challenge the claims as to the potential of OPDs in leading the localization process itself. For example, OPDs frequently do not fully understand the process of localization or how to communicate with politicians in a way that can lead to potential change:

> Disabled people need to bring out a clear message. Politicians do not know about their situation, but their [disabled people] representatives often do not articulate what they actually want. You need to have a focused message to achieve change, not just complaints. (Participant, Jamaica)

> A participant from a poorer rural area in the Philippines indicated a lack of financial capital which could enable access to powerful people.…It is often difficult to move or do anything because there is no financial support. I have to dip into my own pockets. Thus, I sometimes feel so disheartened, especially when I request…support and the only word I get is that there are no funds available. (Participant, Philippines)

Evidence from the study also highlights a scenario of fragmentation between and within OPDs. For example, a local-level OPD member in South Africa explained:

> What I am also seeing is that [OPDs] no longer work together as they used to, like, Blind and Deaf Society is doing their thing, Autism South Africa is doing their thing. We do not have the platform, what was called the Federal Council on Disability.

Overall, this fragmentation challenges the discourse of joint and concerted action (see, for example, Löve et al., 2019).

Some participants noted how less powerful voices are frequently not heard or ignored, especially those in poor rural areas and indigenous people:

> Yes, [OPDs] probably make an impact, but where are they making this impact? Where is the funding? They are not making an impact. I mean, I am involved in [omitted] rural area, there are 240-something blind people and I go there to help them. Why? Because organisations are not reaching out to them. (Participant, South Africa)

Participants also mentioned that the goals of some OPDs are not necessarily the same as those of persons with disabilities and may indeed not represent the interests of the latter. In some instances, they may simply be about obtaining funds for their own benefit. This quote sums up these points:

> I don't think [OPDs] are doing justice…because they are after money. They are getting funding from whoever, Lotto and government and private funders and overseas funders and whoever. And then what happens is they want increases in their salaries and whatever, and they want to go and have lavish dinners in hotels and things like that, but then they want to charge for resources.…It is an NGO…you need to treat it as [such]. And if you go into that line [of work], you can't expect a salary of R 30 or R 40 thousand [USD 1790–2380]. Because that is not going to happen, or it shouldn't be happening. So, I believe that a lot of funds are being misused. (Participant, South Africa)

3.1.5. Lack of Awareness and Capacity Building on the CRPD

Two of the main mechanisms through which the CRPD can be localized appear to be awareness-raising and capacity-building for key stakeholders such as policymakers, development actors, OPDs, and municipal authorities concerning the assumed possibilities offered by the CRPD (Boucher & Fiset, 2015; Opoku et al., 2016; Rivas Velarde et al., 2018). A strong focus on capacity-building is a prerequisite for local acceptance and implementation of the CRPD. However, what emerges in the interviews is that there may be such a serious lack of knowledge on disability rights as well as the CRPD itself, including by UN agencies, and even more noticeable at a local level, that capacity building can only go so far:

> I do not think that people in local communities understand CRPD, what it means and what is its aim. (Participant, South Africa)

Socio-economic, cultural, and other barriers in communities on the ground in the studied countries mean that national laws and international frameworks are often neither known nor seen as relevant in local rural contexts including by those responsible for implementation such as local politicians. This supports findings in other studies (Chibaya et al., 2021; Grech, 2015; Guzu, 2015) suggesting that policies do not automatically mean that anything will be done in local contexts. The following quote highlights the situation in practice:

> You need to have a minimum of education for the CRPD to be relevant and this is the problem, that people do not have this minimum of education and so, if you go to [omitted rural area], for them [rural people] they couldn't care less whether you speak about the CRPD or not. (Participant, Guatemala)

Lack of awareness, as evidenced in the interviews, becomes even more pronounced in indigenous rural areas, where geographical, linguistic, economic, and cultural factors combine to produce a situation of critical isolation from a CRPD that is ontologically, materially, and even linguistically isolated. An indigenous woman with a disability from Guatemala presents a rather grim scenario:

> As women with a disability, indigenous…it is a challenge, it is survival….Many of us have not had the opportunity to study, we have no knowledge of anything…we cannot just turn up with a woman with a disability, from a rural area and speak to her about the CRPD, she will not even know what you are talking about….And the way of learning, the way of explaining it to this person, is going be different, there will always be different ways of learning and understanding what is being told to us…and another thing is the language…it is well complicated, all of this.

Despite the consistent calls for more awareness and capacity-building in the literature, the findings of this limited study reveal dramatic information gaps on the CRPD and how there are neither clear nor consistent guidelines on local implementation, nor informed and contextually sensitive strategies.

3.1.6. Siloed Approach: Lack of Disability Inclusion in the Mainstream

One theme that emerges with substantial force in the findings is how the almost sole focus on disability-specific interventions working within the CRPD, bypass the same mainstream, which is in fact the space that needs to be influenced and impacted because that is where effective alliances need to be built to ensure the CRPD can indeed be localized (see Skarstad & Stein, 2017). It is also where disabling and exclusionary practices may be located and hence need to be tackled. Participants explained how mainstream stakeholders (development-related, humanitarian, and others), as well as government ministries and those working across other thematic issues (e.g., gender, childhood, or indigeneity), are not actively involved in discussions or even reporting on the CRPD. This leads effectively to a siloed approach, where disability inclusion paradoxically operates in parallel to the spaces where this inclusion is meant to happen and where actual change is required:

> It is all disconnected, a disaster….Gender organisations, those working on poverty reduction, or any other thing, are disconnected from anything disability[-related]….And we, working in disability, are only talking to each other…and alone we cannot do much. (Participant, Guatemala)

This approach, as the participants discussed, has multiple repercussions. First of all, it leaves these other mainstream spaces, to an extent, "disability-free," lacking knowledge and understanding as to how to engage with disability and about the CRPD and its implications. This means that "mainstreaming" will effectively not happen:

> A main problem is, really, that in our catchment area there are a lot of NGOs, but none of them understands disability….They have often funds and political contacts that we do not have, but they do not include persons with disabilities….These NGOs could actually work much more efficiently than us sometimes. (Participant, Jamaica)

This siloed approach can result in a lack of social transformation that could provide the conditions for the effective inclusion of persons with disabilities as demanded by the CRPD.

3.1.7. Who Represents Who and How?

The issue of representation is as important as it is complex (see, for example, Jan, 2015). The findings of this study lay out a panorama of challenges when it comes to the representation of persons with disabilities that, participants stressed, impact the localization of the CRPD. OPDs are not always seen as representative especially at a local level, particularly by indigenous and rural persons with disabilities who may not feel represented by privileged urban non-indigenous OPDs. An indigenous participant from Guatemala expressed frustration with this situation:

> In OPDs, I believe there are always people speaking for us and this is not something good….I have had enough of this…they know nothing about us.

A participant from a rural OPD in the Philippines described how poorer and more isolated OPDs struggle when the cost of transportation to attend meetings is not covered:

> I am pushing to organize for persons with disabilities but it's too hard since there are budgetary constraints. Thus, it takes us a lot of effort to make the participants attend. It's frustrating and disheartening whenever we request [this] because they'll tell us that there's no available budget. And when they tell us that they want to meet the federation, I'll ask for transportation, since persons with disabilities won't agree to join if there is no transportation.

While a disability council, commission, or the equivalent is tasked with overseeing the implementation and monitoring of the CRPD, our findings highlight how these institutions may be dogged by problems such as lack of technical knowledge, incompetence, misuse of funds, power struggles, no representation, and active exclusion of poorer rural disability organisations, especially indigenous ones. In sum, those meant to play a critical role in the localization of the CRPD may themselves be a core part of the problem. This quote from a participant in Guatemala expresses sentiments about a national disability council perceived as one that has co-opted the disability space without delivering the goods and that disempowers persons with disabilities and their organisations:

> The council [CONADI] believes that its survival is at stake, so it resents persons with disabilities becoming empowered and becoming activists, to communicate with ministers and governors, because it thinks it is its executive role…it has a protagonism that is hegemonic…it has closed all the spaces for civil society participation in such a way that, if [other] organisations take their own initiative to speak to congress, with ministers, these will always tell us they "agree with CONADI"…but they are incompetent, even in the training they provide…they do not know the subject areas…the same CONADI is a barrier in our progress.

There is an assumption in the CRPD and in its interpretation at the national level that merely setting up such a post or role within these institutions will translate into local implementation of the CRPD and that these will impact other levels of relevance. Another observation here is that most of these focal points are located in urban places, especially at a regional level, the implication being that rural areas are hardly represented and covered. In a nutshell, there is profound urban-centrism.

3.1.8. Reflections on Intersectionality in Localization of the CRPD and the Disability–Poverty Nexus

Our findings provide opportunities for reflections on intersectionality. Localization of the CRPD is conditioned and impacted by complex dynamic interwoven factors that traverse personal, social, economic, political, cultural, ideological and religious, racial and ethnic, gendered, organisational, representational, technical, and also structural factors among others. These have serious impacts not only on the extent to which the CRPD is localized and how, but also on the disability–poverty relationship. More specifically, these intersectional dimensions bind localization–disability–poverty in a triple nexus, posing an intense challenge not only to the expectations and demands of the CRPD but also to discourses on poverty reduction among persons with disabilities when these complex and interconnected factors are not carefully understood and addressed—not individually but as jointly operating factors and processes.

4. Conclusions and Recommendations

This article has explored the various obstacles in place when it comes to the localization of the CRPD. The findings are clear in suggesting that localization is far from straightforward. To be clear, the CRPD, despite multiple hurdles, does have much merit, and as Bartlett and Schulze (2017, p. 3) remind us:

> While the difficulties in implementation are not to be underestimated, the CRPD offers a renewed opportunity to address those injustices. It should not be dismissed lightly as the treaty offers the best chance for at least a generation for a real, lasting and beneficial change in the lives of persons with disabilities.

However, much work needs to go into bolstering the CRPD's power to render disability visible, while tackling the issues that limit what it can do in practice to make the impacts stronger, more pertinent, and responsive to the local level.

A key conclusion is that we need a genuinely holistic, dynamic, ongoing, and responsive framing of localization that does not merely imply implementing a global framework that we assume somehow trickles down from international to national to local level. Instead, it means a cycle that is constantly being fed (and also at times interrupted) by multiple factors and processes within complex national, local, and geopolitical ecosystems that are themselves consistently changing and dynamic.

In conclusion, to effectively localize the CRPD beyond mere ratification, we need a political directorate familiar with the CRPD, the allocation of local budgets for its implementation, and a review of national policies in areas like justice and employment to address local disability needs. Access to justice must be universal, with structures in place for disability representatives in local offices. Crucially, OPDs need to be engaged as governance participants, community organizations must be bolstered, disability must be integrated into other practices, and partnerships fostered with OPDs and advocacy groups. Without this comprehensive approach, the CRPD's essence will likely remain unfulfilled in marginalized contexts.

It is also important to note that all contexts are heterogeneous and dynamic and therefore the process of localization can be neither generalized nor simplified. In fact, localization is itself in a state of constant flux and motion, is complex and not quite understood. At the most basic level, the findings in this study lay out a landscape that is still in need of much more research not as a mere academic project, but one that can work closely with policy development and practice as a project of praxis to ensure the CRPD does have impact at the most local levels in sensitive, adaptive and responsive ways.

Localization requires multiple and complex resources, both financial and representative voices, to include those that are most marginalised and for them to speak on their own terms. The process of localization is politically loaded and debates on localization cannot ignore the politics that frame and determine the boundaries and reach of the CRPD. As Dolmaya (2018, p. 343) stresses in the opening line to her chapter: "To discuss the politics of localization, we first need to define both politics and localization." Furthermore, there is no localization without the communities something is localized in. Systemic localization of the CRPD requires a "whole of society" approach and a transformation process in the way that international and national institutions, the private sector, and citizens collaborate to achieve the goals of the framework. Additionally, effective and meaningful localization is more than just the local implementation of the CRPD; rather, it is an ambitious and complex cycle and interplay of processes that include mechanisms from international to national and local and vice versa.

We need critical research to understand how the CRPD is being implemented across multiple local contexts, the factors and processes impacting implementation and the obstacles encountered as the CRPD "meets" local spaces imbued with intersecting historical, social, (geo)political, economic, cultural, and intersectional particularities and complexities. This means the need to engage with social, economic, political, cultural, ideological, and religious dimensions, including the complexities of livelihoods and infrastructure, alongside framings of disability in context. All these interact with multiple other dimensions to impact the extent to which the CRPD can be localized, how and to what extent, and with what effect in multiple areas. In particular, we need a consistent focus and emphasis on poverty that affects everyone indiscriminately, but whereby the barriers are intensified for persons with disabilities while creating new obstacles (see also Dziva et al., 2018).

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Conflict of Interests

There are no conflicts of interest to report.

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Article

Latin American Perspectives on Parenthood and Disability: Vulnerability, Risk, and Social Inclusion

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Abstract
Despite the growing recognition and acceptance of disabled people's sexuality, there are barriers to parenthood anchored in metaphors of vulnerability and risk. The social inclusion of disabled parents seems both desirable and risky, making disabled parenthood one of the current frontiers of inclusion for the disabled body. The interest in disabled parenting in Anglo-Saxon academic literature has barely been considered related to Latin American production. This article aims to address this gap by exploring the Latin American scientific community's understanding of parenthood and disability. To do so, we conduct a pragmatic discourse analysis of Latin American scientific articles in Web of Science (in English) and RedALyC and SciELO (in Spanish). Our findings show how the Latin American scientific community draws on different models of disability—in some cases introducing an intersectional perspective—that reproduce metaphors of vulnerability/risk regarding parenthood. We conclude by highlighting the importance of establishing dialogues between critical perspectives on disability from the Anglo-Saxon and Latin American contexts to address the complexities of the reproduction processes of disabled people. These dialogues can contribute to problematising the metaphor of vulnerability/risk currently associated with disabled parenthood.

Keywords
critical disability studies; disabled parenthood; Latin America; risk; vulnerability

Issue
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1. Introduction: Critical and Intersectional Perspectives on Disabled Parenthood

While critical perspectives on disability have gained influence in recent decades, social inclusion in the reproductive sphere still faces significant barriers. Greenspan et al. (1986, p. 2) consider disabled parenthood "the ultimate test of living in a free and humane society." Indeed, reproduction is considered "the ground zero of disabled peoples' foundational exclusion from modernity" (Mitchell & Snyder, 2019, p. xv), and this article addresses how the metaphor risk/vulnerability reproduces this exclusion within the matrix of modern rationality. According to Malacrida (2019), while people with all kinds of impairments experience parenthood exclusion, it is particularly poignant regarding intellectual, mental, and severe physical impairments. The internationally ratified United Nations Convention on the Rights of Persons With Disabilities (CRPD, 2006) includes the right to "make a family" (Art. 23). This has complicated the discursive exclusion of disabled parenthood as it currently revolves around an alleged conflict between "vulnerable subjects" whose rights are at risk. Both the disabled parents' right to form a family and their offspring's right to healthy development (allegedly threatened by parental disability) must be protected. There is little academic production on this subject: Guénoun et al. (2022) identified 16 articles in English and French, while

López Radrigán (2020) identified eight Latin American articles in EBSCOhost. In this article, we analyse Latin American scientific production around disabled parenthood, exploring similarities and differences between Anglo-Saxon and Latin American productions and contributing to the recent dialogue between critical disability studies (CDS) in these regions.

To contextualise CDS, we outline a brief genealogy of disability studies (DS). The social model of disability, the foundation of British DS, is based on the distinction between "impairments" (bodily defects) and disability or disablism (social oppression of people considered to be impaired; see Thomas, 2006). The social model made it possible to identify individual models of disability by contrast. Clare (2001) distinguishes between "medical, charity, supercrip, and moral models" (p. 359), while Palacios and Romañach (2006) differentiate between disposability models (the eugenic and marginalisation models) and the medical model. Disposability models (Palacios & Romañach, 2006) neglect disabled people because of alleged deficient social contribution and religious reasons. In this sense, the classical (Greco-Roman) eugenic model (Palacios & Romañach, 2006) considered the infanticide of disabled children because they were sinful. Marginalisation (Palacios & Romañach, 2006) and charity (Clare, 2001) models equal disability with poverty, treating disabled people as non-agentic objects of charity. Similarly, the moral model (Clare, 2001) understands disability as an indication of "moral weakness" (p. 360). More recent models of disability include the medical, where disability results from biological impairments, and the supercrip, where disability is a disposition to be overcome. In a previous study, we argued that the medical model seems to currently work with the other individual models (Sanmiquel-Molinero & Pujol-Tarrés, 2020).

Individual models are also intertwined with the social model and its derivatives. On the one hand, from the 1990s onwards, Finkelstein (2007) argued that the social model was depoliticised as it became a matter of "individual rights" sanctioned by states, thus dismissing the transformative vocation of the social structures of the original model. Similarly, in Latin America, Contino (2013) states that the inclusion of disability in the international development agenda led to practices, discourses, and policies that individualised the problem of the exclusion of disabled people. Furthermore, for López Radrigán and Ramírez Fuentes (2022), the popularisation of these models has generated a specific gap in contemporary post-colonial contexts. The global capitalist and colonial system perpetuates the endemic fragility and extreme precariousness of the Global South, as well as the disenfranchised sectors of the Global North. While rights are claimed for some disabled people, others are considered disposable.

On the other hand, the ramifications of the social model re-politicised aspects that the British social model had relegated to the personal sphere, such as reproduction, disabled motherhood (Malacrida, 2019; Thomas, 2006), or impairment. Thus, these scholars argued the need for an intersectional perspective. Notably, intersectionality is not exclusive to social models. When used in individual models, the intersectional perspective analyses how different subaltern identities add to disability as risk factors. In contrast, in derivatives of the social model, disability is understood as a form of oppression that intersects with other systems of difference, generating greater degrees of social vulnerability (Míguez, 2020). Interestingly, both individual and social intersectional approaches are based on the metaphor of multiple discrimination (McCall, 2005).

CDS is another transformation of the social model that incorporates the intersectional perspective. Its Anglo-Saxon version incorporates the notion of ableism. Ableism is the condition of possibility of disablism and also other systems of social differentiation, such as heterosexism, racism, classism, or ageism (Wolbring, 2008). Relatedly, Latin American CDS scholars (Gesser et al., 2020; Guedes de Mello, 2021) have also used the notion of ableism as the establishment of a normative ideal body for capitalist productivity. Not only is this corporeal norm the benchmark for disabled people but also poor people, blacks or mestizos, migrants from peripheral countries, or the rural population. Thus, ableism is strongly related to and mutually constitutive of other systems of oppression, such as sexism, racism, LGBTphobia, and classism. Gesser et al. (2020) introduce a systemic/structural notion of intersectionality to understand how these systems work to oppress particular groups, amplifying processes of exclusion. Other authors explore specific axis of domination. Inguanzo (2020) focuses on the intersection between disabled and indigenous identities, while Lopes (2018) explores how expectations about sexuality and motherhood are entirely different when gender intersects with disability. Other authors have argued that the exclusion of disabled parenthood is intertwined with modern rationality that produces multiple hierarchisations of bodies in terms of, for example, ability, gender, and race (Díaz, 2012; López Radrigán, 2020). Latin American intersectional perspectives are not homogeneous; they combine the metaphor of multiple discriminations with the metaphor of "interweaving" and the co-construction of oppressions (Lugones, 2008, p. 80).

The decolonial perspective explores the interrelationship between the coloniality of the self, the coloniality of power and the coloniality of knowledge (Pino Morán & Tiseyra, 2019; Villa Rojas, 2020). Following Ferrari (2020), the coloniality of ability considers individualisation as the only human possibility to face life and creates a "monoculture epistemology" (Díaz et al., 2021, p. 50) that naturalises difference and "others" the disabled subject. In addition, the Latin American intersectional perspectives incorporate some other perspectives besides the colonial analysis (López Radrigán & Ramírez Fuentes, 2022, p. 61) and develop understandings of anti-ableism from the Global South (Guedes de Mello, 2021; Munévar, 2021).

Anglo-Saxon and Latin American CDS provide valuable frameworks for problematising the notions of vulnerability and risk usually used in analyses of disability and reproduction. Shildrick (2000) argues that vulnerability is an inherently human feature that ableism projects onto "othered" groups (disabled people, pregnant women, children, or old people). Simultaneously, the normative (male, able, adult) body often refuses to openly recognise itself as "vulnerable" to the risk of being contaminated by these "othered" bodies. Regarding disabled motherhood, Fritsch (2017, p. 249) made an analogous argument when she claimed that the disabled body embodies the risks from which mothers are supposed to protect their children. Thus, disabled mothers are pressured to prove that they are not a risk to their "vulnerable" children, which, in turn, results in them not asking for support, and this makes them more vulnerable (Daniels, 2019). Recent Latin American CDS scholars have also problematised vulnerability or "fragility" by emphasising that not only are vulnerability and risk symbolically projected onto othered groups, but also in very material ways. In this sense, Vite Hernández (2020, p. 17) argues that feminist perspectives have analysed fragility from two standpoints:

> The first, based on what harms us from the outside, locating the structures that do not affect all of us in the same way, so that the lives and bodies of some individuals are more at risk than others due to the unequal management of how life is ensured, and the second, based on the shared ontological condition of fragility, it calls for the creation of relationships of interdependence and care.

Regarding disabled parenthood, the notion of vulnerability is polysemic, as it implies different subjects are "put at risk" by different agents. We analyse vulnerability/risk as a metaphor for disability where disability is equated with "vulnerability/risk" so that all or some of the characteristics of the "vulnerability/risk" binomial are indirectly transferred to disability, establishing a field of possibilities and impossibilities for the disabled person (Edwards, 1997). Vulnerability "puts at risk" or threatens the integrity of a subject who inherently does not have sufficient resources to face a threat and is, therefore, vulnerabilised. Moreover, the "vulnerability/risk" metaphor assumes a threatening agent that will inevitably hurt those who do not have sufficient resources. So, if "disability is vulnerability/risk" and "disability" means something different depending on the model of disability, it is relevant to ask what the risk and the subject of vulnerability are in different models of disability in Latin American studies on parenthood and disability.

2. Method

Metaphors are crucial in the inception, dissemination, and production of scientific knowledge (Quale, 2002). This article conducts a pragmatic analysis (Mey, 2001) of the interrelation between the metaphor vulnerability/risk and disabled parenthood in Latin American scientific literature. Pragmatic analysis identifies the social implications of statements beyond their manifest meaning through a contextualisation of the statement (Duffy, 2008) that is necessarily theory-based. Following anticipatory pragmatics, which seeks to promote non-oppressive uses of language (Mey, 2012, p. 705), we contextualise the statements following the CDS perspective. We do not intend to support a particular disability model but contribute to the dialogue between CDS perspectives.

Regarding the sample, we conducted an initial search ("disability and parenthood") on Web of Science. Latin American institutions only developed 1/300 articles. We used SciELO and RedALyC, databases that disseminate Latin American science. Searches for the expressions "paternity and disability," "maternity and disability," "disabled mother," "disabled father," "father with disability," and "mother with disability" yielded 23 scientific articles. We removed seven: five outside Latin American institutions, one translated from English, and one that was a review of other articles. The selected 16 articles and the main model of disability they use are in Table 1.

The analytical procedure proceeded as follows:

1. Coding of the article: We coded each article using the following categories: explicit model of disability; presence—or not—of an intersectional

Table 1. Articles and their main model.

No. Article	Model	Article
1	Medical	Alarcón, J., Castro, M., Frites, C., & Gajardo, C. (2015). Desafíos de la educación preescolar en Chile: Ampliar la cobertura, mejorar la calidad y evitar el acoplamiento [Challenges of preschool education in Chile: Expanding coverage, improving quality, and avoiding encopling]. *Estudios Pedagógicos*, *XLI*(2), 287–303.
2	Rights	Basaure Miranda, I. M. (2017). Situación del derecho a la maternidad de las mujeres con discapacidad mental en Argentina [Situation of the right to motherhood for women with intellectual disabilities in Argentina]. *Derecho Global. Estudios sobre Derecho y Justicia*, *3*(7), 117–139. https://doi.org/10.32870/dgedj.v0i7.117

Table 1. (Cont.) Articles and their main model.

No. Article	Model	Article
3	Moral	Baudoin, N. (2020). Crafting for change: Dos experiencias de creación participativa en Francia y Argentina [Crafting for change: Two experiences of participatory creation in France and Argentina]. *Economía Creativa*, *13*, 68–123.
4	Social	Block, P. (2002). Sexuality, parenthood, and cognitive disability in Brazil. *Sexuality and Disability*, *20*(1), 7–28. https://doi.org/10.1023/A:1015230303621
5	Social	Cárcamo-Hernández, O., & Rovira, J. P. (2022). Cuando la exclusión escolar se presenta como ‘oportunidad’: Una aproximación etnográfica a la Movilidad Interescolar Temprana (MIET) [When school exclusion presents itself as an “opportunity”: An ethnographic approach to early inter-school mobility (EISM)]. *Revista Colombiana de Educación*, *85*, 121–142.
6	Medical	Castro, L. R., & Zúñiga, O. M. (2002). Principales dilemas bioéticos en las personas con discapacidad prolongada [Main bioethical dilemmas in individuals with long-term disabilities]. *Acta Bioethica*, *8*(1), 127–135.
7	Social	Cisternas, M. S. (2013). Salud global, género y derechos humanos [Global health, gender, and human rights]. *Revista Enfoques: Ciencia Política y Administración Pública*, *11*(18), 153–186.
8	Social	Cruz-Pérez, M. d. P. (2014). Mitos acerca de la maternidad en mujeres con discapacidad [Myths about motherhood in women with disabilities]. *Perinatología y Reproducción Humana*, *28*(2), 91–96. https://doi.org/10.1016/j.rprh.2015.06.001
9	Rights	Cruz-Pérez, M. del P. (2015). Acceso a derechos sexuales y reproductivos de las mujeres con discapacidad: El papel de las y los prestadores de servicio [Access to sexual and reproductive rights of women with disabilities: The role of service providers]. *Revista de Estudios de Género. La Ventana*, *42*, 7–45.
10	Eugenic	Figari, C. E. (2009). Más allá de las sexualidades posibles Dilemas de las prácticas incestuosas [Beyond possible sexualities: Dilemmas of incestuous practices]. *Desacatos. Revista de Ciencias Sociales*, *30*, 129–146.
11	Rights	Garrido, L. A. (2018). Las políticas de conciliación de la vida familiar y laboral en España y sus avances en la equidad de género [Family and work reconciliation policies in Spain and their progress in gender equity]. *Revista Interdisciplinaria de Estudios de Género de El Colegio de México*, *4*.
12	Social	Herrera, F. (2022). ‘La mamá soy yo’: Experiencias parentales de madres y padres con discapacidad en Chile [“La mamá soy yo”: Parental experiences of mothers and fathers with disabilities in Chile]. *Psicologia em Estudo*, *27*. https://doi.org/10.4025/psicolestud.v27i0.58850
13	Supercrip	Mata, R. M. H. (2019). Las madres solteras universitarias: Redes de apoyo social e identidad materna [Single mothers who are university students: Social support networks and maternal identity]. *Intersticios Sociales*, *17*, 203–231.
14	Rights	Proenza-Pupo, J. R., Enríquez-Lozano, C. A., & Serrano-Galindo, S. A. (2020). Herramienta tecnopedagógica, para el aprendizaje de la metodología de investigación científica, en estudiantes sordos [Technopedagogical tool for learning scientific research methodology in deaf students.]. *Luz*, *19*(4), 97–105.
15	Eugenic	Valdés, E., & Puentes, L. V. (2018). El bioderecho y sus aportes a los ordenamientos jurídicos colombiano e interamericano. A propósito de una decisión peligrosa de la Corte Constitucional y su coincidencia con la jurisprudencia de la Corte Interamericana de Derechos Humanos [Biolaw and its contributions to the Colombian and Inter-American legal systems. On a dangerous decision of the Constitutional Court and its coincidence with the jurisprudence of the Inter-American Court of Human Rights]. *Boletín Mexicano de Derecho Comparado*, *51*(153), 673–710.
16	Eugenic	Yupanqui-Concha, A., Aranda-Farias, C., & Ferrer-Pérez, V. A. (2021). Violencias invisibles hacia mujeres y niñas con discapacidad: Elementos que favorecen la continuidad de la práctica de esterilización forzada en Chile [Invisible violence towards women and girls with disabilities: Elements that foster the continuity of forced sterilization practices in Chile]. *Revista de Estudios Sociales*, *77*, 58–75.

perspective; the article’s aims and general implications; and use of the metaphor risk/vulnerability.

2. Coding of the excerpts: We selected 178 excerpts referring to disabled parenthood and coded them as follows: article; model of disability; subjects involved; the excerpt’s objective; and implications. For implications, we focused on identifying how models of disability and vulnerability/risk metaphor worked in each excerpt.
3. The three authors independently coded the excerpts and then reviewed any coding differences.

Table 2 illustrates the disability models identified in the excerpts. The most frequently used models are eugenic, medical, and social. Supercrip is the least frequently used.

The disabled woman and the disabled person are the most frequent main subjects implied in the excerpts, accounting for over half the excerpts. There are a few excerpts where disabled people’s families appear as the main subject; usually, the family appears as a secondary subject (Table 3).

We applied the following criteria of rigour (El Hussein et al., 2015): (a) fitness, through the theoretical analysis of the implications; (b) auditability, making the analysis procedures explicit; (c) credibility, reviewing the inter-researcher coding; (d) trustworthiness, making the research perspective explicit and contrasting the results with scientific research; and (e) saturation, including in the analysis all scientific articles that meet the search criteria.

3. Results

While articles can be classified by their primary disability model (“M. article” column in Table 4), the articles include references to different models of disability (“Model” columns in Table 4). An article can: (a) ascribe to one model and simultaneously adhere to the postulates of other models; (b) include references or arguments from other models to reinforce or criticise them. This result would be congruent with the dialogical character of language and the multiple voices that traverse it (Bakhtin, 2010; Danow, 1991).

In the analysis, we have identified two ways of using the vulnerability/risk metaphor: (a) disability as vulnerability/risk for disabled people (see Table 5), and (b) disability as vulnerability/risk for other subjects, including the developing child, the disabled person’s family, or the social body as a whole. We present these results using

Table 2. Articles and their main model.

Model	No. excerpts	Percentage of total
Eugenic	51	27.7%
Medical	35	19.0%
Moral	27	14.7%
Rights	29	15.8%
Social	36	19.6%
Supercrip	6	3.3%

Table 3. Frequencies of the subject.

Main subject	No. excerpts	Percentage of total
Disabled people	48	26.1%
Disabled women	51	27.7%
Legal	54	29.3%
Professionals	26	14.1%

Table 4. Cross-modelling of articles and excerpts.

	Model					
M. Article	Medical	Rights	Social	Moral	Eugenic	Supercrip
Eugenic	14.1%	9.4%	15.3%	14.1%	41.2%	5.9%
Medical	17.2%	0.0%	34.5%	6.9%	41.4%	0.0%
Rights	20.7%	55.2%	13.8%	10.3%	0.0%	0.0%
Social	0.0%	0.0%	0.0%	0.0%	0.0%	100.0%
Social-rights	30.8%	12.8%	23.1%	25.6%	7.7%	0.0%
Supercrip	0.0%	0.0%	0.0%	0.0%	100.0%	0.0%
Total	19.0%	15.8%	19.6%	14.7%	27.7%	3.3%

Table 5. Summary of (a) disability as vulnerability/risk for disabled people.

	Disability as vulnerability/risk for disabled people	
Model	Risk factor	Vulnerabilised subject
Medical	Motherhood	Biologically deficient subject
Rights	Agents (e. g., states) that enforce disabled people's rights to parenthood	Impaired subject as a subject of parental rights
Social	Physical and social disabling barriers to parenthood	Impaired subject who is trying to become a parent
Moral	Disabled people's lack of moral judgement or agency	Impaired subject who is amenable to becoming pregnant as a result of sexual assault
Supercrip	Disabled people's lack of moral strength to overcome impairment and disabling barriers	Impaired subject who is trying to become a parent
Eugenic	—	—

excerpts identified with the article number (following the order in Table 1) and the corresponding excerpt number.

3.1. Disability as Vulnerability/Risk for Disabled People

Disabled people are usually considered vulnerable. In the case of reproduction and parenting, this vulnerability falls especially on women (Table 3).

From the medical model, disabled women are conceived as "biologically deficient" and, therefore, motherhood is thought to put the woman at risk (Daniels, 2019; López Radrigán, 2020). For example, one doctor advised a disabled woman to have an abortion, considering her pregnancy "risky" because of her disability. In another case, a mother was recommended sterilisation because "both the use of contraceptive methods and the pregnancy could be very dangerous in [her] condition" (9/89). An interviewed professional expressed something similar (16/143): "As long as the risk of the [disabled] patient becoming pregnant is high, then it is better to operate [sterilise]."

The moral model questions the disabled subject's ability for moral judgement; they are considered vulnerable to abuse by able-bodied people as a result (6/56):

> People with mental disabilities…do not have sufficient ability to criticise the behaviours or opinions indicated to them by the people around them; this is, inter alia, one of the causes that can lead them to constitute a group vulnerable to abuse in society.

Constructing disabled women as lacking (moral, sexual, and reproductive) agency allows professionals to justify forced sterilisation as a way of preventing the vulnerability that allegedly arises from sexual abuse-related pregnancy (not sexual abuse in itself): "Forced…sterilisation is justified as…a way of preventing greater vulnerability to a possible pregnancy" (16/146). Alternatively, some professionals suggest that disabled/vulnerable women should be adequately trained to measure risks to compensate for their lack of agency: "There are many abusers. They are sick, and they only take advantage [of disabled women]. You know, these women's need for affection is so big….This is why discussing this subject is crucial to help them measure risks" (9/80).

Notably, excerpts 6/56 and 16/146 question disabled people's moral judgement faculties while not questioning the moral judgement of those who "abuse." This naturalises the risk factor (abuse) as a morally neutral

Table 6. Summary of (b) disability as vulnerability/risk for other subjects.

	Disability as vulnerability/risk for other subjects	
Model	Risk factor	Vulnerabilised subject
Medical	Parental biological deficiency	Disabled people's offspring
Rights	Disabled people as subjects of parental rights	Disabled people's offspring
Social	Disabling physical and social barriers to parenthood	Disabled people's offspring
Moral	Prospective disabled parents' lack of moral judgement or agency	Disabled people's offspring and able-bodied society (relatives, states)
Supercrip	Disabled people's parents lack of moral strength to overcome impairment and disabling barriers	Disabled people's offspring and able-bodied society (relatives, states)

result of physical or intellectual superiority while obscuring the fact that violence is only possible inasmuch as the abuser's position in class, race, gender, and ability axes is legitimised (García-Santesmases, 2023). In contrast, excerpt 9/80 pathologises the attraction and affection towards a disabled female body (vulnerable as she is "in need of affection") as immoral. Disabled people are, in both examples, at the mercy of the moral judgement of non-disabled people (Longmore, 1997, p. 136), and paradoxically, the disabled subject is held morally responsible for not being sufficiently prepared to avoid vulnerability.

According to the social model, disabled people's vulnerability is caused by social barriers that put them at risk. Mothers and fathers encounter environmental and social impediments, and society is often unwilling to make reasonable adjustments to enable them to exercise their parenthood (12/105). The narrative of barriers, specific to the social model, is incorporated by the individual supercrip model by making the disabled subject responsible for "overcoming" both their impairment and the barriers imposed on them, which means embodying "intensive mothering" (12/101):

> Mothers with disabilities develop everyday strategies of resistance to counteract negative views of their disability. These strategies range from presenting a highly disciplined public image of motherhood ("super mums" who embody the values of intensive mothering) to avoidance tactics that allow them to protect themselves from possible assault (anticipating discrimination). These strategies have high emotional and physical costs.

The rights model recognises disabled people's right to create a family, which is explicit in the excerpt: "[Under the CRPD] children with disabilities or parents with disabilities shall not be separated from their parents or children, respectively" (14/116). However, the unwillingness or ineffectiveness of actors that should legally protect disabled people are considered risk factors that render the disabled body vulnerable. For example, excerpt 2/12 quotes the UN Committee in charge of monitoring compliance with the CRPD in Argentina, stating: "The Committee expresses its concern at the existence, in the country, of sterilisation practices of persons with disabilities without their free and informed consent." Another excerpt about Chile states: "In the majority of the interviewees, negative perceptions are evident regarding the defence of the rights that the state should guarantee to this population group, as it fails to fulfil its protective role and allows institutional violence against them" (16/171). Both examples can be interpreted within the particular contexts in which they are set. For Danel (2019), in Argentina, the foundations of social intervention to restore injustices were lost during the dictatorship, and the work of the state towards disability has been shaped by certain breaks with dictatorial authoritarianism, but also by surreptitious continuities that weaken people's access to rights. Furthermore, the dictatorships in the Southern Cone, especially in Chile, firmly implanted an economistic rationality, weakening state action (Núñez Parra, 2020).

As with the social model, health professionals sometimes use the individual models alongside the rights model: "The disabled person becomes a more vulnerable human being, which makes it necessary to adopt special measures…to protect their rights as a person, in the face of decisions affecting him or her in the field of health" (6/53).

Paradoxically, protecting disabled/vulnerable subjects' right to make decisions entails their substitution in decision-making, which fits in with the individual model's conception of the disabled subject as "morally or biologically deficient" to decide autonomously for a course of action:

> This human faculty must be protected in persons with disabilities.…By the principle of autonomy, the patient could refuse treatment, but by the principle of non-maleficence, the professional could be compelled to provide it. In this confrontation of values, third parties (responsible family members, for example) often act to resolve the conflict. (6/54)

Finally, the intersectional perspectives identified in the articles analyse vulnerability/risk from a summative perspective, considering that, in terms of violence, disabled women are more vulnerable than able-bodied women or disabled men. For example: "It should be noted that the gender profile will be the sum of the conditions of vulnerability experienced by women and girls due to the particular situations they experience because of their age, maternity, ethnicity, disability or other" (7/64). This summative perspective also applies to indigenous or impoverished women's rights: "A mother with a disability belonging to an indigenous or impoverished group who does not meet the high expectations of intensive mothering is likely to alert state institutions and face serious threats to her parental rights" (12/114).

Disability is both a matter of vulnerability and a risk factor in the reproductive processes of people, especially disabled women.

3.2. Disability as Vulnerability/Risk for Others

Individual models, unlike social models, not only consider the disabled person as vulnerable and put at risk by their impairment but also see this vulnerability as a risk or threat to offspring, the family environment, and the social body (Burghardt, 2013). Resorting to the "moral" model, professionals argue that the disabled person (again, especially women) is "unaware of risks" or a "whimsical" subject, selfish in wanting a child for which she cannot care. Excerpt 9/75 quotes Matilde, a 36-year-old sociologist:

> I think that we should talk about it, make them aware of the risks and it also depends on who the person is, because then it is a mere whim and then their family faces the consequences of their pregnancy…and they don't think about the children either.

Disabled women are aware of professionals' dismissive attitude. Excerpt 9/74 quotes 37-year-old Adriana, who has spina bifida:

> [They said] that I shouldn't think about that, that I should think about fulfilling myself in another way, or by adopting. Of course, they knew as well as I did that the DIF [integral family development] wouldn't give me a baby for adoption because of my condition.

The above reference to adoption clarifies that what professionals wish to avoid is biological motherhood because of the "risk" it poses to child development, exemplifying the connection between the moral and eugenic models. Maternal disability is not only seen as a risk for young children but also for school-age children, who are categorised as disabled because of maternal disability (5/49), and even adults when they are allegedly prevented from pursuing their work projects because of maternal disability (3/20). In some quotes, professionals justify preventing disabled women from reproducing without these women's consent in terms of risk calculation with "unwanted disabled children" in mind:

> The decision to force [non-permanent] contraception…is because [the health care team] does a kind of proportionality between risks and benefits: Which is riskier, that an unwanted possibly disabled baby is born or that the woman or girl gets an intrauterine device installed without their consent? (16/161)

In this eugenic calculation, the object of risk is clearly "the children's body." The alleged irresponsibility of disabled mothers is greater if disabled offspring are sought intentionally. The subsequent fragments suggest the social model is "dangerous" as it contradicts the principle of "procreative beneficence," in which parents are legally and morally obliged to choose the "best possible child, without mental or physical impairments" (15/138). The authors equate "children without impairments" with "those expected to have the best possible life, or at least as good a life as everyone else in the world" (15/120). The salience of the eugenic model has its historical roots in the conceptions of the nation's perfectibility lying on the foundations of Latin American nation-states. The constitution of a stronger, healthier, and better-looking population in opposition to bodies considered inferior—such as indigenous, black or mestizo—reproduced the parameters of modernity/colonialism (Block, 2002; Danel, 2019).

Remarkably, excerpt 15/120 homogenises "able-bodied people" as if the quality of their life depended entirely on the presence of "impairments," excluding other factors such as social class, gender or race. Thus, a quasi-anti-intersectional perspective is manifested, where disability operates as a master status that justifies the erasure of any other structural ascription that could condition well-being. By contrast, we could say that the following excerpt argues for an intersectional perspective, attentive to different power matrices when it states that:

> For much of the twentieth century, individuals stigmatized by gender, race, poverty, disability, or sexuality were subject to extreme methods of social control in the United States and Europe….Practices perpetrated on these women [with cognitive disabilities] included compulsory institutionalization and sterilization, as policymakers focused on ways to reduce perceived threats to the social order. (4/46)

Finally, the medical model also uses the rights model regarding "disability as a risk to the body of the vulnerable child." The following excerpts denounce that, although parental rights are recognised in Article 23 of the CRPD, an Argentinian court decreed "the state of abandonment and adoptability of the child" based on the child's "right to a healthy existence." Another excerpt notes that "the reasoning of the sentence is clear: Due to her disability, [the disabled woman] is unfit to exercise motherhood" (2/10). Here, a mother's and a child's rights are violated through "the invocation of the best interests of the child to be placed in a situation of adoptability, without the corresponding assessment of the harm it will cause" (2/14). Thus, the coexistence of the individual and social models produces a conflict between the child's rights "to a healthy existence" (which the maternal disability would put at risk) and the mother's rights to form a family.

The analysis suggests the medical, moral, and eugenic models converge in considering disabled parenthood as a moral irresponsibility both for the offspring and the social body.

4. Conclusions: Problematising Vulnerability/Risk in Disabled Parenthood

The findings show that the vulnerability/risk metaphor constitutes the pivotal axis of the individual and social models. Furthermore, in the individual models, disability constitutes a moral and biological defect that makes the disabled body vulnerable to others. The interventions proposed from these models are aimed at preventing the reproduction of the "deficient body," achieving its rehabilitation, or supervising parenting abilities and the ability to manage all these risks individually. Otherwise, drawing on the child's rights, removal from home is suggested. These interventions align with contemporary intensive mothering imaginaries (Hays, 1996).

Moreover, social models advocate the right of disabled people to exercise parenthood (CRPD, 2006).

In this framework, these people are also seen as vulnerable: the risk comes from physical, social, and legal barriers imposed by states, able-bodied society, families, and professionals. Proposed interventions in the analysed fragments are awareness-raising programmes against stigmatisation, initiatives to support disabled parenting or training programmes for disabled people and health and social professionals. Notably, while these interventions point to the social nature of vulnerability, they act on the individual. Latin American decolonial perspectives counter this colonial individualism and argue that (a) the rights model endorses the ideal individualised subject of coloniality (Díaz et al., 2021; Pino Morán & Tiseyra, 2019) and (b) the uncritical acceptance of the social model contributes to the invisibility of structural inequalities and the colonial origin of "disabling structures" (Pino Morán & Tiseyra, 2019, p. 512). Although some excerpts highlight the importance of considering the particularities of disabled indigenous mothers (Herrera, 2022), none of the extracts adopts an explicitly decolonial framework of analysis. Conversely, neither have most of the studies conducted from a decolonial perspective on disability (Díaz, 2012; Ferrari, 2020) explicitly addressed parenthood. While one should not assume that all Latin American scholarship on disability and parenthood should adopt a decolonial perspective (or vice versa), it is an intersection worth exploring.

Deepening the already initiated dialogue (Pino Morán & Tiseyra, 2019) between Anglo-Saxon and Latin American CDS can help us to study the mutual construction of the race, gender, and disability categories in relation to parenthood in specific historical and geopolitical locations. It also problematises how the medical-moral-eugenic device of "truth" disproportionately vulnerabilises disabled mothers, constitutes them as risky parental subjects, and generates political horizons. In contrast to the exaltation of modern/Western standardisation, CDS perspectives should uphold the plurality of ways of being, the potency of bodily, functional, and sensory diversity, and collaborative ways of parenting. In this sense, decolonial perspectives propose the idea of "ecological dialogue" (Díaz et al., 2021, p. 47). That is, incorporating multiple voices and localised knowledges while giving a privileged space to disabled people. This is in line with the proposal of Daniels (2020), who highlights that there exist forms of disabled parenting in which the children are not constituted as vulnerable. Rather, there is a mutual adjustment between the child and the parental figure.

Lastly, Anglo-Saxon and Latin American CDS (Núñez, 2020; Shildrick, 2000; Vite Hernández, 2020) acknowledge the constitutive vulnerability of every human being as an ontological, ethical, and political argument to question the univocal relationship between vulnerability and disability (Burghardt, 2013). Nonetheless, disability is transformative since all bodies are vulnerable as potentially disabled. We, therefore, wonder whether the argument of the universality of disability is lexicalising the metaphor "disability is vulnerability/risk." As Edwards (1997, p. 31) says, "what is dangerous is when the metaphorical nature of the enterprise is forgotten, and domain A is talked about in terms of domain B as if it were not a metaphor at all." The analysis suggests that the reviewed models reproduce the vulnerability/risk metaphor. Future studies addressing the social inclusion of disabled parenthood should explore the possibility of thinking about disability or childhood without resorting to the metaphors of vulnerability/risk. Recent developments in CDS have advanced both "vulnerability" and "eco and interdependency" as key concepts for a critical perspective on the conditions of possibility for human existence (Pié Balaguer, 2019, p. 27). While vulnerability implies that a subject might be at risk, interdependency raises concerns about the conditions that make disabled parenting possible and the effects of relying on ableism, heterosexism, classism, or racism. The metaphor of "disability as interdependency" thus challenges the prevailing colonial individualism present in mainstream disability perspectives, reproduced in Latin American academic, social, and political spheres. Incorporating multiple voices and local knowledge in an intersectional ecological dialogue on disabled parenthood has the potential to address subjective and structural inequalities. Such a critical perspective not only acknowledges the transformative nature of disability but also fosters more inclusive and empowering approaches to disabled parenthood. In sum, future research should explore whether the metaphor "disability as interdependency" has the potential to address the above-considered pitfalls of vulnerability/risk.

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Conflict of Interests

The author declares no conflict of interests.

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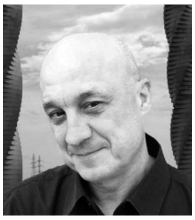

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Article

Person-Centred Planning in Centres of Activities for Inclusion

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Abstract

Person-centred planning includes the active social participation of individuals with intellectual and developmental disabilities (IDD) and is the fairest path towards assuring human rights and citizenship among people with IDD. Semi-structured interviews were undertaken with four technicians from centres of activities in Portugal, four family members, and four adults with IDD to observe the best practices that facilitate/hinder the implementation of person-centred interventions. Several discrepancies were identified regarding inclusive practices in centres of activities and capacity building, associated with the sense of mission, vision and perspective of technical structures, the bureaucratic weight that conditions the transition between intervention models, the participation and positioning of families regarding their representation of the centres, as well as the investment these centres make concerning effective and fair inclusion in surrounding communities. Still far from successful implementation, a person-centred approach must be considered and include all participants' perspectives to build robust and integral life projects.

Keywords

CACI; capacity building centres; diversity; inclusion; intellectual disability; organisations; person-centred planning; Portugal

Issue

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1. Introduction

Disability inclusion is understood as the experience of participation, in different settings, of each person with disabilities, promoting human rights and creating more supportive structures that ensure equal access to all societal contexts (United Nations, 2019). The inclusion process is developed via a conceptual change from medical to biopsychosocial models (Purdue, 2009), stressing the human rights of the disabled person (Bray & Gates, 2000) and focusing not just on the obstacles to individual health/medical conditions, but on services and support, and on the external factors that surround an individual's life (Koller et al., 2018). Broader expressions such as intellectual and developmental disabilities (IDD) are part of this inclusive approach (e.g., Schalock et al., 2019), combining the fields of intellectual disability and developmental disabilities. IDD comprises significant limitations in intellectual functioning and adaptative behaviour manifested before the age of 18 (intellectual issues) and/or chronic issues manifested before the age of 22, which results in substantial functional limitations in three or more life activities and requires long-term supportive services (developmental issues). In Portugal, youths and adults with IDD can be placed in social centres during the day with the intention of promoting their sense of belonging to the community and their skills by carrying out activities that enhance their self-determination, the establishment of interpersonal relationships, and the undertaking of valued social roles.

According to Simplican et al. (2015), community participation occurs in three different contexts: segregated, semi-segregated, or mainstream. These social structures can, therefore, have different organisational practices, from those more focused on traditional models, more segregated from the community to practices based on person-centred planning and focused on achieving inclusion for all adults. However, research on this topic lacks greater depth, namely concerning how person-centred intervention has been implemented in organisations that support adults with IDD (Torres, 2015) and how these promote effective inclusion in the community.

Person-centred planning comprises tools and strategies to improve the quality of life of the patients/users and promote changes in these individuals' lifelong project (Neto, 2019; Ratti et al., 2016). This systemic intervention, based on the biopsychosocial model (M. G. Pereira & Smith, 2006), is implemented in social centres that seek to meet the needs of each person in collaboration with their families and their community, constructing a project around patients' participation in the centre with the goal of including them socially.

The construction of a life project can be defined as the construction of an individual's identity in mapping possible future identities. Everyone, whether with disabilities or not, may build their identity through social relationships. Person-centred planning proposes that the work developed in social centres promotes a series of competencies that facilitates social interaction and individual growth: self-determination, interpersonal relationships, and valued social roles (Beadle-Brown et al., 2012; Kaehne & Beyer, 2014). These competencies' aim has brought new challenges to organisations, shifting from work more focused on disability and behavioural interventions, based on the medical model, to core values of inclusion, providing service users and their families power over their lives (Iriarte et al., 2017), in a positive vision of the future, reinforcing strengths, preferences, and the capacity to gain new abilities (Holburn, 2002). Self-determination and interpersonal competencies, among other competencies, promote the most significant inclusion in the community (Santos, 2017). Wehmeyer et al. (2011) defined self-determination as the individual's ability to achieve goals autonomously. In a centre with adults with IDD, self-determination can play a crucial role in finding a job outside the organisation, choosing the activities to be performed inside the centre, or joining a group of self-advocates (Heller et al., 2011). To contribute to self-determination in centres with person-centred approaches, Abery et al. (2008), assuming an ecological model of self-determination, developed, for this purpose, training for staff members. Results revealed that adults with intellectual disabilities living in community-residential settings exercise greater self-determination than peers in similar settings where staff have not been trained. Adults with IDD could also be trained in self-determination through self-directed support. In randomised trial studies, causal effects were observed with the training of adolescents with IDD in self-determination (see Wehmeyer & Abery, 2013).

Furthermore, person-centred interventions reinforce interpersonal relationships, as having a prominent role in human development and learning (Marques, 2017). Activities promoting interpersonal relationships enable community proximity (McCausland et al., 2018). In this approach, individuals must engage in meaningful experiences from an early age with parents, friends, and the most prominent community members. In adulthood and organisational contexts, the interpersonal relationships of people with IDD are crucial on a daily basis (Marques, 2017), as relationships can often have an impact on the quality of life, as those who are included in a more significant number of networks and peer groups have a better outcome, avoiding situations of segregation and solitude (Fiori et al., 2006). People with IDD often have smaller social networks and participate less in friendship activities, as Emerson and McVilly (2004) reported in their study with a sample of 1,542 adults with intellectual disabilities. The median interactions were two activities with other adults with intellectual disabilities and zero activities with friends without disabilities in a period of four weeks.

Moreover, interpersonal relationships are mainly maintained with the staff from centres, with literature on person-centred planning recommending informal relationships with staff and recognising the strengths and needs of the person with a disability (Iriarte et al., 2017). Clarkson et al. (2009) analysed the perceptions of a group of 11 adults with an intellectual disability concerning the support of the staff. Through semi-structured interviews, participants highlighted honesty, trust, and nurture as the most significant traits to build positive relationships.

The relationship between adults with IDD and family plays a crucial role in creating interpersonal relationships and may often be one of the most significant factors (Kozma et al., 2009) for the quality of implementation of person-centred planning (McCausland et al., 2021). Person-centred planning improves communication and family participation (Claes et al., 2010), reinforcing staff-family relationships. However, several potential barriers can arise in the staff-family relationship, when families are placed in a passive position (Rasheed et al., 2006), with only an occasional sharing of specific vocabulary with staff (Chambers & Childre, 2005) or of organisational procedures.

Besides self-determination and interpersonal relationships, valued social roles are also a priority in person-centred planning (Bradley, 1994). According to one of the precursors of social role valorisation (Wolfensberger, 1972, 1983, 2000), people generally define themselves according to the roles they occupy in the community. When only allowed to occupy marginal societal roles, adults with IDD feel undervalued (Fontes, 2016). Iriarte et al. (2017) presented significant support indicators for valued social roles through person-centred planning concerning paid employment or voluntary work. On the other hand, the social participation approach demands full community engagement and less segregated services, requiring monitoring systems and the support of individual needs (Bertelli et al., 2015).

Due to these changes in the social structures' working paradigm, this study aims to understand the practices and policies connected with implementing person-centred planning intervention (several competencies such as self-determination, interpersonal relationships and valued social rules), highlighting the facilitating aspects and constraints from the perspective of the technicians, families, and adults themselves, adopting an analysis from individual to organisational and intervention characteristics.

1.1. Centres of Activities and Capacity Building for Inclusion

There are several responses among centres to support youth and adults with IDD in Portugal, namely family foster care for adults with disabilities, home support, residential homes, and centres of occupational activities (CAOs, after the Portuguese *centros de actividades ocupacionais*; see Decreto-Lei n.º 18/89, 1989). According to the Portuguese Social Security, CAOs—later renamed CACI for centres of activities and capacity building for inclusion (after the Portuguese *centros de atividades e capacitação para a inclusão*)—have as their main aim the promotion of activities for adults with moderate disabilities. Ordinance Law no. 70/2021 (Portaria n.º 70/2021, 2021) describes CACI as social services with a community basis to develop occupational activities for adults with disabilities (18 years or older), seeking the promotion of their quality of life, access to the community, and to the resources and activities that support inclusion, based on their needs and capacities.

As centres of occupational activities, these structures can offer several activities: occupational and therapeutic, socially valuable, interaction with the social context, and qualification for social and professional inclusion. Centres have different spaces, commonly divided into occupational rooms and socially valuable rooms. The work developed in these rooms has distinct objectives to respond to different challenges. The occupational rooms aim to ensure that individuals with IDD remain active and interested in performing previously defined activities (Veiga et al., 2013). As for the socially valuable rooms, the aim is to further adults' professional integration into the labour market, promoting social and professional abilities. Nevertheless, according to article 8 of Law no. 70/2021, socially valuable activities should be preferentially implemented in the community and not in the centre, as practised commonly.

To guarantee the quality of the implementation of person-centred interventions, factors that hinder and facilitate intervention have already been investigated in several social and health contexts (Collins, 2014; de Silva, 2014; Morgan & Yoder, 2012). However, according to Scholl et al. (2014), research results concerning the effectiveness of person-centred interventions are contradictory. These results' inconsistency could be explained by the different methodologies used to analyse the effectiveness of an intervention (Damschroder et al., 2009). Hower et al. (2019) analysed the implementation of patient-centred care intervention, identifying the organisational determinants considered by decision-makers as barriers/facilitators based on the Consolidated Framework for Implementation Research (CFIR; for a complete description see the Supplementary File), which was also implemented in the present study.

Therefore, the following research questions were formulated: Which competencies (self-determination, interpersonal relationships, valued social roles) are the most worked on within person-centred planning in CACI? What are the factors that facilitate/hinder the implementation of person-centred planning at different levels (perceptions of intervention characteristics, the organisational level, and the individual level)?

2. Method

2.1. Participants

The sample of the study is composed of 12 participants, namely four technicians (A-D), four family members (A-D), and four adults with IDD aged between 20 and 40 years old (A-D). These participants are connected to four CACI in the north/centre of Portugal, selected by convenience through a list of institutions previously analysed. The directors of each CACI indicated the technician to be a participant in the study, and the technician named the adult with IDD and the member of the family who had more contact with the centre. The technicians have a background in psychology and social education. Technician A has a background in clinical psychology in the health area, as a specialist in psychological intervention in mental illness, with five years of work in a CACI. Technician B has a degree in clinical psychology, in the branch of systemic and family intervention, with six years of training in disability. Technician C has a degree in social education and has been working at a CACI for one year. Technician D has a degree in psychology and a post-graduation in management of social enterprises. Technicians A and B are females, C and D are males.

Family members are listed as Family Member A, Family Member B, Family Member C, and Family Member D. Family Member A (male) is a car upholsterer with primary schooling (four years of schooling). Family Member B (female) is a technical assistant in a higher education institution with secondary education (12 years of schooling). Family Member C (female) is a manager of a cosmetics shop, who attended the first year of a nutritional sciences degree (degree not completed). Family Member D (female) is a dental assistant with a degree in environmental engineering. The adults were listed as Adult A (male aged 34, 16 years in a CACI), Adult B (male aged 23, three years in a CACI), Adult C (male aged 32, nine years in a CACI), and Adult D (female aged 37, 19 years in a CACI).

2.2. Data Collection

The data collection instruments used in this research study were interviews conducted by the same researcher. Due to pandemic contingencies, the interviews took place face-to-face, through videoconference. Three different scripts were created, one for the technicians (14 questions), one for the adults with IDD (13 questions), and the other for their family members (12 questions). The questions focused on categories such as the role played by adults with IDD in the CACI; the influence of self-determination skills, interpersonal relationships, and valued social roles in the way the CACI operates; the implementation of activities at the CACI based on the person-centred intervention; the participation of the community in the CACI's activities; the role of the family in the way the CACI works; the construction of life projects. These interviews were previously tested with a technician, an adult with IDD, and a family member to validate the questions and to adapt language. For adults with IDD, the questionnaire was adapted with several examples to assist in the understanding of the questions, the interviewer was trained previously, and staff from the centre/members of the family assisted in the preparation of the online session, easing the communication process.

The directors of the CACI signed a favourable authorisation to implement the research study. To implement the research study, a request for collaboration and informed consent was made to family members and senior technicians, as reference figures of adults with IDD. A request for consent was also made to the adults, and oral authorisation was requested for the recording of the interview, given the possibility that they might not master reading and writing skills, and in conjunction the favourable opinion of their legal guardians was sought.

All ethical issues were safeguarded, and all participants were duly informed of the study's aims. The ethical committee from the university approved the present study. The interview with technicians took an average of 40 minutes, the family member interview took an average of 30 minutes, and the interview with adults with IDD took an average of 10 minutes.

2.3. Data Analysis

All the interviews were transcribed and qualitative content analysis (Bardin, 1977) explored participants' perspectives. Categories were extracted from the questions asked. We also based our analysis on the CFIR (Damschroder et al., 2009), a coding frame including core elements of person-centred intervention, combining deductive and inductive approaches. The CFIR is a well-established framework that proposes a list of constructs that influence (positively or negatively) the effectiveness of an intervention. The CFIR comprises five significant domains: intervention characteristics; outer settings; inner settings; characteristics of the individuals involved, and the implementation process. Two trained researchers assessed all transcribed interviews (L. C. and L. A.). Disagreements were solved through discussion. The final version is presented in Section 3, with a short definition and textual fragments of participants' narratives to exemplify. The textual fragments were translated into English.

3. Results

A total of 12 interviews were analysed and the results are structured according to the research questions and CFIR domains, enabling the following categories: (a) intervention characteristics, (b) outer setting, (c) inner setting, and (d) characteristics of the individuals involved. These are described and explained in detail in the following sections, with the results for every group of interviewees.

3.1. Intervention Characteristics

In what concerns the intervention implemented in each CACI, several subcategories were found and consolidated to deepen and clarify the analysis of the results.

3.1.1. Strength, Quality, and Adaptability

This subcategory refers to the perception of the quality and validity of the intervention undertaken in each CACI to achieve the expected results and the extent to which it can be adapted to meet specific needs. Our results clearly show concern on the part of the technicians associated with ensuring multidisciplinary work and with providing varied experiences to the CACI's users. Some of them try to make these users aware of all the services of the CACI, with the perspective of users' active participation in preparing the respective allocations and selection of activities, but always with the need to justify that they also benefit from those moments to assess the skills and needs of the users "to allocate them better": "We have a very, very large multidisciplinary team with different areas of expertise, which enables us to meet what they ask us to do, but also to meet the needs we identify" (Technician A).

Furthermore, families and the users themselves seem to have little involvement and little critical approach regarding the strength, quality, and adaptability of the intervention provided, as only one family member commented on having felt improvements in the general behaviour of her family member, as mentioned by Family Member C: "I have lost count, but he has been there for many years. I have noticed that he has become more agile; he improved without a doubt."

3.1.2. Complexity

The subcategory analysed here refers to difficulties in implementing the intervention. Our results reflect not only the immediate difficulties and concerns, depending on the type of interviewee, but also a wide variety of barriers and potential inhibitors to the intervention's success.

Besides the complexity associated with the intervention, other difficulties experienced are linked to the diversity of the characteristics of users (high heterogeneity), the dimensions of the CACI itself, the management of expectations regarding the results of the intervention (namely on the part of family members and sometimes of the users themselves), and an unfavourable ratio between technicians and users (high number of users), reflecting a panorama of global disinvestment in the social and disability area:

> Then there is the bad habit of the state…of thinking that a methodology that works very well in Finland, Norway, or Denmark, will also work very well here [Portugal]. However, they are given 1000 euros per month in support, and we have 200 euros. They have technicians and support staff of almost one-to-two, or one-to-one many times, and here we have one-to-ten. (Technician D)

Family members recognise the challenges associated with the intervention and appreciate the work undertaken by technicians with their relatives. However, they also signal their need for knowledge associated with the nature of the intervention itself. According to Family Member A:

> So, I know he has support, he has various kinds of support, but sometimes I do not know what subjects he has, what support he has. Yes, I cannot decipher what they are, he sometimes tells me, he shows me the papers, so I can read them, but there are so many things.

3.1.3. Planning of an Intervention: Change of Paradigm

Regarding the perception of innovation in the intervention paradigm, our results point to a progressive (though slow) replacement of the traditional biomedical intervention paradigm by the person-centred model, adjusted to emotional and motivational needs and personal preferences. These results show that this is a transversal perspective of technicians and families:

> I think there is this change, and we are thinking about it and what I said to you during the interview. We are increasingly valuing the tastes, the choices of the person, and not focusing so much on what the technical part thinks. (Technician B)

> She [the user] always had the opinion, the final decision has always been hers, however much they may sometimes disagree, they [the technicians] may try to make her understand. However, the final decision is always hers. (Family Member D)

3.2. Outer Setting

Several subcategories also emerged when considering the local community and social context.

3.2.1. Social Inclusion and Stereotyping

Despite the shortage of detailed data, our results point to the existence of prejudice against people with IDD, namely within the family itself:

> Because he [the user] had problems, the other brother was smarter than him, and sometimes there was interference because one knew more and the other knew nothing. Moreover, he began to feel inferior to his brother and put himself aside. Moreover, I always tried to…call him…pulled him to the other side, so he did not care too much about that. (Family Member A)

Technicians are the ones who position themselves most critically, reflecting on the implementation of the inclusion model in other places that impact lifelong development, such as schools:

> At this moment, it is the phase of integration in schools that they call inclusion, which for us often makes no sense because we are talking about a relative inclusion. We are talking about schools with a little room called multi-disability room where young people are placed and do little, but they call it inclusion, unfortunately. (Technician D)

3.2.2. External Policies in Disability

In terms of government policies and regulations, technicians refer to the weight of bureaucracy—besides lack of financial investment—as negatively impacting processes associated with the work of the CACI in terms of promoting a person-centred intervention:

> Here [Portugal], getting a wheelchair is a lengthy process, a complex process, which often fails to produce results, and maybe abroad they have the right and the facilities, and then have an adapted wheelchair that costs 3,000 or 4,000 euros. (Technician D)

3.2.3. Rights of Adults With IDD

Although not consistent or conclusive, our data concerning this matter indicates some failures in the assertion of some rights of people with IDD, often associated with a certain paternalism:

> From the general population of our CAO, the dimensions that are most worked on are, I think, the emotional well-being dimension and the physical well-being dimension. The dimension we have the

> most difficulty working on is the person’s rights. (Technician A)

3.2.4. Peer Pressure and Similar Centres

Regarding the competitive pressure to implement an intervention, because another similar centre is also implementing it, our results are consistent concerning the absence of this comparison. Each CACI is centred on its own reality and users’ characteristics, developing a network of activities for them.

3.2.5. Adults With IDD’s Engagement With the Community

When considering the involvement and inclusion of people with IDD in the communities, two approaches emerge. On the one hand are the efforts that derive from strategies undertaken by centres and headed by the technicians, which seek to promote these realities—whether in more concerted initiatives, or occasional events:

> We will always seek to provide answers outside our micro-community…because the goal is that….[In the centre] it’s inclusion, work on the skills and meet the[ir] needs, but it is a false inclusion. So, we try to take them and insert them into the community, which is real inclusion. We have an excellent relationship with the community: local businesses, vets, city council, bakeries, factories. (Technician A)

Along the same line is the positive recognition by families concerning the CACI for all these initiatives:

> Certain projects that they create, like this one, for example, about the integration of the disabled into society, which makes them, now I am missing the word, which makes them value themselves even more. (Family Member D)

On the other hand, the users of the CACI do not recognise or cannot position themselves as actively participating members of their surrounding communities:

> Interviewer: Do the activities essentially take place in the centre, or do you also do them around your community?
>
> Adult D: In the centre, we have an event that we do every year involving the whole community.

An exchange with another participant resulted in the following dialogue:

> Interviewer: Are the activities you usually do always in the centre, or do you also do activities in the community, in the area where you live?
>
> Adult C: No. It is only in the centre.
>
> Interviewer: You never had activities with the community?
>
> Adult C: No. Not that I remember.

3.3. Inner Setting

Regarding internal context, organisational structures, and characteristics of the CACI, we present here the categories found.

3.3.1. Structural Characteristics and Organisational Resources

Analysing the interviewees’ perspective on the characteristics of the CACI, aspects such as social architecture, age, maturity and size of the centre, resources, and work management are co-articulated for a global service. We found indicators that allow us to assume a convergence between technicians, families, and users, aimed at the diversity of the offers and the concern of the user’s characteristics and needs.

Some technicians still refer to the large number of adults with IDD and the low financial resources as real barriers to the personalisation of the therapeutic and occupational services of the CACI:

> We have 165 users in four CAOs, so there are inevitably different reactions. However, for example, based on one of the CAOs where more people are supported, we have three typically occupational rooms. Then we have two rooms for socially useful activities. The work tends to focus more on well-being or purely occupational activities in the typically occupational rooms. And then, in each room, some employees provide more occupational activities, and others provide more welfare-related activities. (Technician C)

Family Member B mentioned:

> We were talking and seeing how they could work differently with my son….Because he likes football and cooking, they think he can [create] a blog as he enjoys doing recipes and all that; blogging about cooking, recipes, and sports, but for now, this is on standby.

An exchange with another participant resulted in the following:

> Interviewer: Do they give you the freedom to do an activity that the centre does not plan?
>
> Adult A: Yes….Swimming pool.

Adult C, when asked if they had a choice in planning activities, also said: “Yes. Yes, I do.”

3.3.2. Internal Communication, Conflict Management, and Collaboration

There were two lines of approach regarding the importance of communication within the centre for effective intervention, the organisation socially constructed norms and values, and the capacity to minimise conflict and absorb change. Regarding managing conflicts between users and between these and the technicians, management seems relatively peaceful, as mentioned by Family Member D: “It was good, I noticed great companionship between her and her colleagues”. However, occasional altercations were noted: “We know that there are conflicts between colleagues, between users and staff, and they dislike being called to account, they dislike certain things that they see and observe” (Technician B).

3.3.3. Professionals’ Training

Concerning the CACI’s focus on the valorisation and professional training of its assets (technicians, staff), we understand that few contributions in our sample allow us to establish a strong position. Only one of the technicians directly referred to this investment:

> As team members, one thing that is also part of our practice is that we promote the training of our monitors….Since 2019, we have started training sessions about the importance of self-determination. We went around the different rooms and the different locations to be able to show them [staff] that it was possible to let the person be a participant, even if not self-determined in some issues, in some cases [major disabilities], but an active participant in their life. (Technician A)

3.4. The Characteristics of the Individuals

Person-centred care is based on the individual characteristics of users, their personal attributes, and the development of features aligned with life projects.

3.4.1. Adults’ Needs, Interpersonal Relationships, and Internal Resources

Regarding the personal needs of the CACI users, their resources and personal characteristics, and the way these translate into their interpersonal relationships, we have observed that families are susceptible to the work developed in the centres, as this promotes feelings of inclusion, a sense of belonging and perceived personal “usefulness,” and supports a continuous work on their autonomy and constant investment in their skills. The technicians’ perspectives fit into this search for personalized/personalisation and intensive work directed towards their users:

> Our role here is to promote…skills, not only professional skills, such as writing, reading, [but] personal and social skills [as well]….Essentially, our objective and what we work towards is that the activities we develop…be aimed at promoting these skills and also their happiness. (Technician B)

3.4.2. Professional Training and Development

Regarding the development of professional skills and competencies in adults with IDD, the perspectives of the interviewees are aligned in the sense that, whenever possible, this can be implemented in articulation with the community:

> Strategies such as meetings with people who have nothing to do with the centre [on behalf of] integration in society; for example, for years she has had a job for two days a week, in an office…and some activities are entrusted to her alone. I think this is also very important, what they [the centre] do. (Family Member D)

The adults interviewed were clear when they expressed the goal of finding a job:

> My goal is to be a worker in a car wash workshop, which is what I am doing now….It is about they [technicians] being there for a while to see the work, if I am doing it well or not. Moreover, giving a helping hand, maybe, when necessary. (Adult C)

3.4.3. Psycho-Emotional and Functional Well-Being

In this subcategory, several issues arise as families’ concerns (or priorities) tend to differ from the ones expressed by the technicians. Aspects of behavioural nature, emotional stabilisation, self-esteem, integration, and autonomy were consistently pointed out by families.

Technicians, on the other hand, show a growing concern with the real personalisation of intervention towards a better quality of life, “to meet their preferences and what is useful and has a significant impact on their rehabilitation or simply on improving their quality of life” (Technician A).

3.4.4. Involvement of Family and Friends in an Individual’s Intervention

Reflecting on the articulation between families and technicians in the sense of promoting the continuity of intervention strategies, we verified that there are many gaps in the families’ knowledge about individual plans and (personal, structural, financial) resources, which could hinder the results outside of the centre: “They explain what is going to happen, what they are going to do about…and explain how he [adult] has been doing. Because that is the way it is, I often do not read” (Family Member A).

Most of the time, technicians are aware of these difficulties:

> Parents also have difficulties; sometimes they do not have the active role that we would like them to have.…We try our best not to institutionalise the client from the onset…to promote the active role of the family. (Technician A)

3.4.5. Self-Determination

Regarding the capacity of choice of the activities that compose users' days, we can find some discrepancies as interviewees present different discourses. Our results tend to show that users do not have the full power of choice, nor do they enjoy the personalisation of care that the technicians were talking about throughout the interviews, often being "fitted" into the available activities or where it is more practical (from the organisational point of view) for them to be: "Speaking on the issue of self-determination, I think we are very far, I think we are far away" (Technician C).

Some technicians tend to acknowledge this more than others, and we can state that some centres are starting to create formal opportunities (e.g., periodic meetings) to listen to their users, but these seem to have no strategic mediation or any implementation in practice:

> Interviewer: They help. And do you have, for example, youth meetings?
>
> Adult B: No.
>
> Interviewer: So, you do not do that kind of…you have nothing, you just share your problems, is that it?
>
> Adult B: Yes.

3.4.6. Individuals' Life Projects

Concerning the co-construction of individual life projects, the results obtained highlight minimal and erroneous perspectives on what they are and their nature/objectives. Families seem to be attached to a merely occupational approach for their relatives: "I do not think he has any objectives other than those he is achieving there. He likes it there, he loves it, he likes his friends, he likes all the staff" (Family B).

A technician was not clear about the true meaning of the construct "life project," it being tied to a subjective, almost philosophical approach: "We are focusing on dreams. We want to focus on what is meaningful to that service user and [to his dreams]" (Technician B).

4. Discussion

Implementing person-centred interventions comes with increased pressure on the day-to-day practice of organisations such as CACI. This study aimed to explore the facilitating/constraint determinants of person-centred implementation from the perspectives of technicians, family members, and users, assuming the inclusion perspective and answering two main questions: Which competencies (self-determination, interpersonal relationships, valued social roles) are the most worked on within person-centred planning in CACI? What are the factors that facilitate/hinder the implementation of person-centred planning at different levels (perceptions of intervention characteristics, the organisational level, and the individual level)?

As regards the first question, our results could have been more conclusive. The new paradigm brought a more profound concern for self-determination, quality of life, life projects, well-being, community inclusion, and socially valued roles mentioned by technicians. However, it needed to be clarified how these domains were worked on, with explanations mainly focused on the several constraints pointed out to implementing person-centred interventions. As mentioned by Ratti et al. (2016), person-centred planning is a complex multi-component intervention with the potential to impact an individual's quality of life. It comprises individually tailored approaches and techniques to support people with IDD to develop a lifestyle based on choices, preferences, shared power, rights, and inclusion (Ratti et al., 2016), while decision-making is driven by the individuals themselves and by those who care about them, with a particular emphasis on personal assets such as self-determination, choice, and autonomy. Furthermore, if some centres demonstrate that there is a concern with person-centred planning, showing the need to undertake more activities within the community, help adults search for a job and assist in their daily routines, or even take part in international training to improve staff development, others are still attached to traditional routines, with adults with IDD mainly divided into different rooms, executing several activities without a proper aim to their life project. This organisation could also be partially explained by the difficulty that some technicians felt in defining each concept properly and how to operationalise it in daily activities.

In implementing person-centred planning—and concerning our second research question—several factors were identified and organised partially according to the CFIR scheme (Damschroder et al., 2009; Hower et al., 2019), including intervention characteristics, outer settings of organisations, inner settings of organisations and individual factors. Individual factors were the most mentioned, especially by family members and adults with IDD. Even family members needed to be made aware of all the activities and procedures undertaken in the centres. This factor refers to specific characteristics of adults with IDD that could facilitate or hinder intervention, such as internal resources, psycho-emotional and functional well-being, the involvement of family and friends in their life project, and self-determination. Firstly, it should be noted that technicians make more references to self-determination, individual plans, and establishing a relationship with the community than family members. Furthermore, as mentioned in previous studies (Emerson & McVilly, 2004; Fiori et al., 2006), adults with IDD lived isolated from the community, with the centre staff, family members, and other adults from centres as the main elements of their circle of relationships. Though this could be a limitation for their emotional and psychological well-being, centres are increasingly aware of the relevance of users' well-being, promoting several therapeutic activities (e.g., physical activities, psychological support) recognised by family members and users as positive.

In inner settings, since each CACI has the necessary tools and equipment to promote intervention and multidisciplinary teams with increasing specialisation, interventions could be easily implemented but can be hindered by a lack of adequate internal communication or by conflicts. On the other hand, the need for more staff trained in this domain seems essential for adequate care (O'Brien & O'Brien, 2000). Promoting staff training in inner settings and expanding political and financial support for disability in outer settings, in line with previous studies (Hower et al., 2019), is still needed. This lack of financial support to centres (e.g., outer settings) impacts organisational issues (e.g., inner settings). One of the mentioned issues is the need for more technicians and educational/monitor staff that support adults daily. Person-centred intervention is particularly demanding in terms of personnel, as it requires technicians available to support adults in their lives in the community.

Regarding intervention characteristics, staff and family members recognised that the person-centred planning model aims to reduce segregation and social isolation, providing new opportunities and developing skills necessary for the social inclusion of adults with IDD. Interviewees reveal the importance of implementing this planning to build life projects, giving them a perspective of inclusion in a global society. The community's support corroborates previous studies on the same topic (Becker & Pallin, 2001; M. Pereira, 2014). Families recognise the effort of staff members and in some situations refuse to undertake this monitoring, leaving this task to the technician. The lack of family support and involvement could compromise the quality of the intervention (McCausland et al., 2021), as family plays a crucial role in creating interpersonal relationships (Kozma et al., 2009).

5. Conclusions

This study is one of the first studies in Portugal to explore the factors that facilitate/hinder the process of person-centred planning implementation, presenting at the same time the opinions of technicians, family members, and adults with IDD. A deeper understanding of how four centres organise daily activities while promoting self-determination, interpersonal relationships, valued social roles, and community inclusion is critical, particularly given the increased interest in person-centred interventions in practical contexts.

The analysis of this data led us to conclude that there is still much work to be done in transitioning from traditional planning to person-centred planning, as factors related to intervention characteristics, outer settings, inner settings, and individual characteristics are seen as hindering the process rather than facilitating it. The process is slow and lengthy, developed in different stages for each centre. Future studies are needed to understand this phenomenon from a larger perspective, with more centres and other intervening parties such as community members, directors of companies, or technicians from entities such as Social Security. In that case, a specific study on terminology and best-practice methods could contribute to optimising person-centred implementation. Moreover, questions about how technicians and organisations are prepared to help adults build a larger network of relationships, including members who are not paid to be in their lives, could be discussed. Training in this area could be an asset, with the selection of centres where the person-centred approach is already being implemented as case studies for other centres. Sharing knowledge and experiences among professionals with international and national colleagues would be useful for the implementation of the person-centred approach.

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Conflict of Interests

The author declares no conflict of interests.

Supplementary Material

Supplementary material for this article is available online in the format provided by the author (unedited).

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Article

Intersectional Praxis and Disability in Higher Education

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Abstract

This article explores whether intersectional praxis can be discerned in the provision of disability/accessibility resources in higher education in Sweden and the United States. Analysing interviews with administrative staff based on hypothetical scenarios (vignettes) that could qualify as situations of disability discrimination, this article identifies several situations of (missed) opportunities for intersectional praxis. It then proceeds with a discussion of participants' conceptions of disability and organisational possibilities for collaborations with other offices at their university or college. Although opportunities for intersectional praxis are generally absent or missed in both countries, the article argues that American participants were closer to such critical praxis because they tended to consider disability in terms of barriers and as a structural issue, and advocated for the recognition of disability as diversity. By contrast, the Swedish participants seemed further away from an intersectional praxis because they tended to view disability as a difficulty that requires individualised support measures and as a situational issue regarding the learning environment. The article proposes that these differences are connected to differences regarding disability and anti-discrimination politics in both countries. In the US, disability politics have been characterised by a civil rights and social justice approach, while in Sweden disability politics have been conceived in terms of welfare services and a relational approach to disability. This article concludes that the conception of intersectionality as a critical praxis offers an original lens to gain new insights into how disability inclusion is promoted in different contexts.

Keywords

accommodations; anti-discrimination; disability; diversity; equity; higher education; inclusion; intersectionality; praxis; Sweden; United States

Issue

This article is part of the issue "Disabled People and the Intersectional Nature of Social Inclusion" edited by Alexis Buettgen (McMaster University), Fernando Fontes (Universidade de Coimbra), Susan Eriksson (South-Eastern Finland University of Applied Sciences), and Colin Barnes (University of Leeds) as part of the (In)Justice International Collective.

1. Introduction

Addressing this thematic issue's call to consider disability in relation to the intersectional nature of social inclusion, this article explores whether intersectional praxis (Collins, 2015; Townsend-Bell, 2011) can be discerned in the provision of disability/accessibility resources in higher education in Sweden and the United States. Higher education is an interesting case for analysis because it is an area where social inequalities are produced and reproduced but also combatted and potentially evened out. Yet little is known as to whether and how disability is included as a matter of social justice in higher education, and the existing research usually focuses on one national context (Aquino, 2022; Shallish, 2015, 2017). Since axes of inequality are considered differently in different settings, it is relevant to adopt a comparative approach (Montoya, 2021; Townsend-Bell, 2011). The choice to study Sweden and the United States is motivated by the contrasting legacies of disability and anti-discrimination politics in the two countries, which reflect differences regarding both how disability has been conceived and how social inequalities have been addressed.

This article starts by asking how intersectionality is related to disability in higher education (Section 2). It proceeds by outlining the processes through which disability anti-discrimination laws were passed in Sweden and the United States, and highlighting differences in conceptualisations of disability in the two countries (Section 3).

Section 4 contextualises the organisation of disability resources in Swedish and American higher education. Section 5 presents the research design and Section 6 the findings of an empirical study of the implementation of disability anti-discrimination laws in Sweden and the United States. The study is based on interviews with staff working with disability/accessibility resources at universities and colleges, who were asked to describe their work and comment upon hypothetical scenarios (vignettes) of situations that could qualify as discrimination based on disability. The findings of the research are further discussed in the final section of this article (Section 7).

This article does not aim to provide a systematic comparison between Sweden and the United States. The comparative approach is used as a heuristic tool to gain new insights into current practices and the potentiality of intersectional praxis regarding disability in higher education.

2. How Does Intersectionality Relate to Disability in Higher Education?

Emerging from the work of US Black feminist communities in the 1960s and 1970s, the idea of intersectionality was outlined in a position paper by the Combahee River Collective in 1982, which argued that Black women's experience could not be grasped by race-only or gender-only frameworks because it is shaped simultaneously by race, gender, social class, and sexuality (Collins, 2015). This critical idea was subsequently coined as the concept of intersectionality by Crenshaw (1991). Thirty years on, intersectionality has been adopted by a range of disciplines and has been used by scholars employing different definitions and methodologies (Collins, 2015; McCall, 2005). Some of these developments have been criticised for losing their critical edge. Reviewing the intersectionality literature in higher education studies, Harris and Patton (2019, p. 361) observe that "higher education scholars consistently focused on the intersections of social identities, while missing Crenshaw's…call to connect these everyday identity specific experiences to intersecting structures of oppression." Moreover, although researchers have demonstrated the significance of conceptualising disability as an axis of social inequality (Shifrer & Frederick, 2019), it is often missing from intersectional research. This article positions itself in the body of research that examines intersecting structures of oppression in society from a social justice perspective and seeks to place disability at the heart of intersectional inquiries.

Next to being an analytical strategy and a field of study, intersectionality can be approached as a form of critical praxis, which "sheds light on the doing of social justice work" (Collins, 2015, p. 16). The concept of intersectional praxis was developed by Townsend-Bell (2011), who observed that the axes of difference that matter in intersectionality are contingent on a certain context and are deployed differently by different activists. Building on these insights, Montoya (2021, p. 9) suggested that "comparative analysis may be helpful for determining the conditions that constrain or facilitate intersectional praxis." This article asks whether and how disability matters as an axis of intersectional praxis in Sweden and the United States. While previous research on intersectional praxis has examined social movements (Evans, 2022; Montoya, 2021; Townsend-Bell, 2011), this article scrutinises the work of administrators implementing disability anti-discrimination law in institutions for higher education. It asks whether disability/accessibility resources staff consider disabled students' positionalities regarding different axes of inequality, how they understand disability, and how they report on organisational opportunities for intersectional praxis at their institutions.

Most studies on disability in higher education are concerned with disabled students' experiences of barriers and discrimination or with the attitudes of faculty and staff regarding disability (Moriña, 2017). This literature tends to be limited to one national context. A notable exception is the study of Järkestig Berggren et al. (2016), who compared the experiences of disabled students in Sweden, the Czech Republic, and the United States. Scholars have also highlighted faculty's experience of disability discrimination and criticised ableism in academia (Dolmage, 2017). Further, some research examined disability/accessibility services in higher education. However, a review of this literature pointed to a general lack of conceptual frameworks that would enable a critical examination of these services (Madaus et al., 2018). This article addresses this research gap by drawing on intersectionality as a critical conceptual framework to analyse whether and how social justice informs praxis in the context of service provision in higher education.

Scholars have claimed that intersectionality is paramount to realise justice for disabled students (Kim & Aquino, 2017; Knoll, 2009; Liasidou, 2013; Peña et al., 2016). The few studies that use intersectionality in empirical research on disability in higher education highlight that disability is generally perceived as different compared to other characteristics (Abes & Wallace, 2018; Kimball et al., 2016; Shallish, 2017). Examining disability as identity, Kimball et al. (2016, p. 92) show that "disability is all-too-often treated as distinct from other college student identities." Abes and Wallace (2018) report that students with physical disabilities experience "intersectional erasure" because their disability is only viewed as a need for an accommodation, which negates their other identities (Abes & Wallace, 2018, p. 551). Other studies investigate whether disability is viewed as part of student diversity at universities and colleges. A key observation is that disability is largely absent from diversity policies in higher education aiming to promote the inclusion of students from minority and marginalised groups in society (Aquino, 2022; Shallish, 2015, 2017). Based on interviews with diversity workers at six college campuses in the northeast

United States, Shallish (2017, p. 19) observed that disability and diversity “continue to remain separate concerns,” but that some administrators fight to recognise disability as part of diversity (Shallish, 2017). Similarly, Aquino (2022) found that postsecondary administrators working at a private, medium-sized university located in the Mid-Atlantic region of the United States tended to forget disability when asked to define student diversity, but that, “when asked if disability should be included in postsecondary diversity, all participants expressed the importance of including it” (p. 1568). These studies suggest that disability remains overlooked or treated as a different category but that efforts are made to place it more clearly within the scope of diversity work in higher education. This article adopts a comparative perspective between Sweden and the United States that further elucidates the importance of considering a critical intersectional praxis in the study of service provision in higher education.

3. Disability Models and Anti-Discrimination Rights in Sweden and the United States

In the United States and the Nordic countries, disability studies developed as research fields in the 1990s. While there have been dialogues between the two regions, American and Nordic disability studies have remained distinct fields, which developed in relation to their social, cultural, legal, activist, and academic contexts (Traustadóttir, 2009). Both fields are grounded in social perspectives on disability and reject the conception that disability is an individual and medical issue. In the United States, this social perspective took the shape of a “minority model of disability,” which conceives disability in terms of discrimination and positions disabled people as a minority group (Hahn, 1996). By contrast, the Nordic countries developed a “relational model of disability,” defining disability as a situational misfit between the individual and the environment (Tøssebro, 2004). While both perspectives can be considered as variations of the social model of disability (Traustadóttir, 2009), they are also different: The American minority model presents disability as an issue of social injustice that can be combatted through civil rights and anti-discrimination measures; the Nordic relational model views it in terms of situational disadvantages that can be compensated through welfare measures and changes in the environment. The relevance of using different models of disability has been much discussed in disability studies (Shakespeare, 2006). Although recent disability research tends to adopt more complex definitions of disability, the original models arguably reflect differences in how disability studies developed in the two contexts. The findings of the study presented in this article suggest that they continue to inform how disability is conceptualised in Sweden and the United States.

Since anti-discrimination laws provide the legal basis for disabled students’ right to accommodation in higher education in Sweden and the United States, it is worth looking at the ways in which they were adopted in the two countries. In the United States, anti-discrimination laws were pushed by the activism of the Black Civil Rights Movement and other citizenship movements, including the disability rights movement (Scotch, 2001; Skrentny, 2002). As such, the adoption of American anti-discrimination laws followed a bottom-up process. The first American federal law banning discrimination based on disability is the Rehabilitation Act of 1973, which prohibits disability discrimination in services and programs receiving federal funding. The scope of this prohibition was extended through various laws and, in particular, through the Americans With Disabilities Act of 1990, which was the world’s first comprehensive civil rights law concerning disabled people. By contrast, the adoption of anti-discrimination laws is a more recent phenomenon in Sweden, where disability politics has traditionally been focused on social welfare rights. The first Swedish anti-discrimination law regarding disability concerned discrimination in the workplace and was passed in 1999. The main driver behind the passage of this law was the European Union Treaty of Amsterdam of 1997 and the anticipation of the EU Employment Equality Directive of 2000, which urged EU member states to strengthen their protection against discrimination in employment (Lappalainen, 2020). Hence, the passage of anti-discrimination laws followed a top-down process in Sweden. In the following years, Sweden adopted other laws banning discrimination on various grounds and in different areas of society. These laws were merged into the Swedish Discrimination Act in 2008, which prohibits discrimination on seven grounds, including disability. Since the 2014 amendment to the Discrimination Act, lack of accessibility is recognised as a form of discrimination. This amendment was advocated for by the Swedish disability movement, which started promoting the use of anti-discrimination legislation as a tool for social change after the passage of the 2008 Discrimination Act (Sépulchre, 2021; Sépulchre & Lindberg, 2020).

4. Disability Resources in Swedish and American Higher Education

In Sweden and the United States, students with disabilities have the right to accommodation and support measures to access higher education. This right is stipulated by the main disability discrimination laws in both countries—the Americans With Disabilities Act and Section 504 of the Rehabilitation Act in the United States; the Discrimination Act in Sweden.

Disabled students represent an important part of the student population: Nineteen percent of undergraduates in the United States reported having a disability in 2015–2016 (National Center for Education Statistics, 2018), and this number amounted to 26 percent of all students registered at a Swedish institution for higher education in spring 2016 (Universitets- och högskolerådet, 2018). However, reports show that many students needing support related to disability refrain from asking for such support (National Center for Education Statistics, 2022). It is also true that all disabled students do not need accommodations in higher education—for example, a wheelchair user does not need to use disability resources regarding physical access if the campus is accessible.

Universities and colleges typically have specialised staff concerned with accessibility and accommodations for disabled students. In the United States, this staff is part of administrative offices that are commonly called "accessibility resources" or "disability resources." Most of these offices are located under divisions of student affairs, but they can also be part of other divisions, for example, divisions focusing on diversity, equity, and inclusion. The Swedish equivalent of accessibility/disability resources staff are commonly called "coordinators for targeted pedagogical support" and are also included in divisions of student affairs. For reasons of readability, this article refers to staff in both countries as disability/accessibility resources staff.

The general task of disability/accessibility resources staff is to administer different types of support and accommodations. The practical procedure varies between institutions, but it follows a similar pattern. It starts with a student requesting accommodations or support measures based on disability. Unlike other anti-discrimination statutes, legal protection from disability-based discrimination only applies to individuals who qualify as disabled people. In higher education, this qualification is established through affiliation to a disability/accessibility resources office, which often requires a medical certificate or equivalent documentation by an expert. In the United States, this requirement has been relaxed since the 2008 Amendment of the Americans With Disabilities Act, which specifies that, rather than focusing on whether an individual qualifies as a person with disabilities, legal investigations need to concentrate on whether disability-based discrimination has occurred. By contrast, presenting a valid certificate of a lasting impairment is an essential requirement to obtain accommodations and support in higher education in Sweden.

Once the student is affiliated, the disability/accessibility resources staff meet with the student to discuss their experience and needs in the context of higher education. During these meetings, staff recommend, in dialogue with the students, the type of support measures and accommodations that may be appropriate. Anti-discrimination law in both countries stipulates that support measures and accommodations cannot lower the level or modify essential requirements of a course. Disability/accessibility resources staff can suggest a series of accommodations but the final decision regarding academic accommodations is taken by the course's instructor.

Three further contextual aspects regarding the organisation of higher education in the two countries are worth mentioning. First, students must pay tuition and fees to access higher education in the United States. In Sweden, higher education is free of charge for individuals with a permanent Swedish residence permit and citizens of the EU and the European economic area. However, disabled students in Sweden report having financial difficulties to finish their education, among other reasons because they do not have the time to engage in paid work during their studies or because they do not manage to take enough courses to be eligible for a study loan from the Swedish Board of Student Finance (Universitets- och högskolerådet, 2018). A second aspect relates to the scope of disability/accessibility resources. In the United States, these resources concern the overall campus experience of disabled students, ranging from accommodations in the classroom and the dormitories to parking permits and dietary requirements. In Sweden, the disability/accessibility offices are only concerned with students' learning experience in the classroom and examinations. Finally, many American institutions of higher education have cultural centres, which are spaces for community building and activism centring on various cultural minorities. A few American institutions also have disability cultural centres (Chiang, 2020). By contrast, cultural centres are not typically found on Swedish campuses, but Swedish students organise into student unions.

5. Research Design

Following the methodology of intersectional research that acknowledges its social construction, I would like to start the presentation of the research design with a disclosure of my positionality. I identify as a white, cis-gender, non-disabled, woman, who is committed to social justice. I am a European immigrant who has been doing research and teaching at various Swedish universities and was affiliated with an American university during the time of this study. This positionality implies that I am familiar with the context of higher education but that I also have an outsider position because I did not grow up in Sweden or the United States.

The data for this study were generated through vignette interviews. Vignettes are hypothetical situations that are presented to the participants during the interview. Vignette interviews are well-suited to examine how people in different contexts reflect about a given topic (Križ & Skivenes, 2013; Saguy, 2000). Five vignettes describing common situations pertaining to the implementation of disability rights in higher education were constructed for this study. The following excerpt of one vignette exemplifies the type of scenarios that were brought up in the interviews:

> A student with ADHD asks a teacher to make their PowerPoint slides available before the lectures because that helps them to focus. *What do you think the teacher will answer?* The teacher says that they

> understand but that, unfortunately, they cannot provide the PowerPoint slides beforehand because they have no time and because they often need to make last-minute changes in the lectures. *How do you interpret this reaction?* (Vignette 1)

The vignettes focused on interactions between students and teachers. They did not include any background information about the participants, except for the disability-related characteristics concerning the need for a particular accommodation. In addition to the vignettes, the interview guide comprised questions about the participants' professional role, the procedure to request disability resources, and the relation between the disability/accessibility resources offices and other offices at the university or college.

A pilot interview was conducted to test the interview guide. Thereafter, 16 interviews were realised (seven interviews in the United States and nine in Sweden), with a total of 18 participants (one interview included three participants). The participants were recruited through purposive and snowball sampling to interview staff members working at institutions of higher education of different sizes and geographic locations. This limited sample is not representative of all disability/accessibility resources staff in Sweden and the United States, but it includes participants from five different American states and nine different Swedish counties. In the United States, most participants held the position of assistant director or director of a disability/accessibility resources office, and one participant was working at the Office for Diversity, Equity, and Inclusion. In Sweden, disability/accessibility offices have a flat structure and there are no directors. One of the Swedish interviews included three participants and one interview was with a participant working as a legal advisor for an institution of higher education. In the two countries, there is no formal education to become an administrator of disability/accessibility resources. Participants had degrees in various academic disciplines, such as occupational therapy, rehabilitation sciences, higher education, sociology, psychology, and law.

All the interviews took place via Zoom between November 2021 and May 2022. Online interviews via Zoom are considered a good way to collect data (Archibald et al., 2019) and this digital tool was particularly advantageous for the realisation of interviews with individuals located thousands of kilometres from each other towards the end of the Covid-19 pandemic. The interviews lasted between 1 and 2,5 hours. They were recorded with the consent of the participants and transcribed verbatim.

Qualitative thematic analysis (Nowell et al., 2017) was used to analyse the interview material. The analysis followed a combination of inductive and deductive steps. Step 1, I (the author) wrote down initial analytical reflections during the process of conducing and transcribing the interviews. Step 2, I annotated each interview transcript with open codes. Step 3, to get an overview of the interviews, I summarised each interview in a memo, together with quotes and analytical reflections. Step 4, I returned to each interview transcript to inquire about intersectional praxis more specifically. This second round of coding was guided by the following analytical questions:

- Do staff working at disability/accessibility resources consider disabled students' positionalities regarding different axes of inequality?
- How do staff working at disability/accessibility resources offices understand disability?
- How do staff working at disability/accessibility resources offices consider the role and position of their offices within the organisation of the university or college?

6. Findings

Overall, the analysis indicates that the disability/accessibility resources staff rarely referred to intersectionality in their interpretation of the vignettes. While this finding may have been influenced by the design of the research—which did not prompt the participants to reflect on intersectionality—other factors seemed also to have played a role, including the participants' conception of disability and the organisational features of their institution of higher education.

6.1. Looking for Traces of Intersectionality

Five traces of intersectionality were identified in the interviews, alluding to inequalities pertaining to socio-economic and geographic background, transgender identity, parental responsibilities, status of foreigner (international students), and race and ethnicity. The first trace concerns the difference between students with and without documentation of their impairment, which gestures towards the intersection between disability and socio-economic disparities regarding social class. Affiliating to the disability/accessibility resources office generally requires medical documentation but, as one American participant noted, obtaining a diagnosis is influenced by access to socio-economic resources:

> A lot of students [are not affiliated to the disability/accessibility resources office], and, in order to even get a diagnosis, that also can mean time and money. (US, interview 6)

As mentioned previously, this requirement has been relaxed in the United States in recent years, but providing documentation of an impairment is a critical condition to request disability accommodations in Sweden. Consequently, the students who do not possess such documentation do not get access to these resources:

> I have many [students] who contact me who want to get support without having an impairment…then I often have to explain that: This support is based on having documentation [showing] that you have a lasting impairment. (SE, interview 15)

Some participants remarked that access to medical evaluations varies between different Swedish regions. They stated that they consider this geographic inequality when assessing the documentation provided by the students, for example regarding neuropsychiatric diagnoses:

> We approve [the documentation] even if you are waiting for an evaluation…then you use your referral as a certificate [of your impairment]. (SE, interview 14)

A second trace of intersectional praxis was found in an interview with an American disability/accessibility resources staff member who mentioned that they had acquired more knowledge about transgender expression and identity to improve their service to disabled students:

> There is so much more in that conversation with students than just the disability piece…several students that have either transitioned or are in the process of transitioning or, you know, like we talked about, this is a place where the students can be themselves and maybe need different pronouns. I have quite a few students in that realm and so, as a professional, I had to get more comfortable having these conversations and learning more of these resources to be a better ally and support for the student. (US, interview 1)

The three remaining traces of intersectionality identified in the interviews suggest missed opportunities for intersectional praxis. One instance concerns the situation of disabled students who are parents and sought accommodations during the pandemic. A Swedish staff member explained that they denied the requests regarding “care for sick children” (which in Swedish takes the acronym VAB) because they estimated that these were not based on an impairment. The Swedish acronym VAB refers to the possibility for parents to stay at home to care for their sick children and get financial compensation from the Swedish Social Insurance Agency:

> Another thing I thought about with the pandemic is this eternal caring-for-sick-children for some students…mainly those who perhaps have had [difficulties with] with concentration, planning or when they have a lot of emotions and such…students who have felt stressed because they cannot put that time on the studies because they have to stay at home with their sick children…which has put them in quite a stressful situation, which in itself may have caused them to ask for support. And then I may have felt: uhm, but in a situation like that, we are not talking about an impairment, it is not because of an impairment that you have ended up in this situation. And then I can feel that it sucks that I can’t offer more support, but at the same time, it’s not your impairment that is decisive here. But then I understand that it is a contributing factor. (SE, interview 14)

The quote suggests that the staff member felt torn about this decision because, although they had decided that disability was not the main factor causing the need for support, they recognised that it did play a role in the situation of the student. As such, this situation can be interpreted as a missed opportunity for intersectional praxis regarding the resources needed by disabled students who have young children.

Another missed opportunity for intersectional praxis concerns international disabled students who do not receive adequate resources because the Swedish offices of disability/accessibility resources in higher education are limited to learning situations, that is, studying, classroom interactions, and examinations:

> I also meet many international students with disabilities…and I have actually had many students from the US….From the students’ perspective, it is worse here….When it comes to housing, when it comes to healthcare. It doesn’t work well at all in some cases…but that kind of lies outside of the university….We must at least inform them properly about how it works when you come here. (SE, interview 11)

The quote suggests that the Swedish participant identified the need for intersectional praxis because they observed that the difficulties experienced by international students were caused by a lack of attention to their particular situation.

Although disability/accessibility resources have a wider scope in the United States, the American participants deplored that disabled students often remain excluded from some spaces on campus. In the following quote, a staff member observes that disabled students may be excluded from ethnic and cultural community centres because of inaccessibility:

> If the students went to the Native American house or you know, in the multicultural student affairs or that sort of thing, those may not be accessible, or maybe only the first floor is accessible. That is a major way that, unfortunately, a lot of schools like ours discriminate, I mean, we can get pretty close with their housing usually, and their dining and their classes. But their day-to-day experience? Probably not! (US, interview 7)

This quote highlights the lack of consideration of the intersection between race or ethnicity and disability. The next section digs further into actual and potential intersectional praxis regarding disability by analysing how disability/accessibility resources staff in both countries conceive of disability.

6.2. Understanding Disability: A Situational Disadvantage or Structural Inequality?

The analysis suggests that there is a difference between the conceptions of disability among the Swedish and American participants. In Sweden, the disability/accessibility resources staff tend to view disability as a situational difficulty that needs to be compensated for through individual measures, which highlights a relational model and deficit model of disability:

> I usually say to the student: "You must all go to the finish line." Or: "You must all jump over this bar." This is the course goals or the finish line, it will never be pulled closer to you, it will never be lowered, but your impairment implies that you start behind them [the other students] in a, shall we say, 100 m race. You start 10 m behind, and it's not fair. So, then I try [to tell the disabled student] in this conversation, that we aim to close this gap as best as possible so that you come up as close as possible…but we can never lower that bar. In this case, we are a public authority and there must be a legal certainty in how we evaluate students, and we can never jeopardise that. (SE, interview 8)

As illustrated by this quote, "legal certainty" was viewed by many Swedish participants as a key principle guiding their work, indicating a procedural justice approach to the provision of disability/accessibility resources. This position differs from the following quote in which an American staff member explains that they take a social justice approach to their work:

> I see disability…as part of human variation and the structure that we create is very ableist. Essential work that I do is anti-ableist work. (US, interview 2)

Although not all the American participants referred to ableism, the interviews in the United States suggest an overall understanding of disability in terms of structural inequality. By contrast, the Swedish participants tended to use a relational understanding and endorse a deficit view of disability. This appears in the following quote, in which a Swedish participant explains their perception of the attitudes of non-disabled students towards disability resources.

> Most people seem to understand that these students [disabled students] do not get advantages. It is to compensate for difficulties. (SE, interview 15)

This understanding of disability as a difficulty in need of compensation is also reflected in the following quote, in which a Swedish disability/accessibility resources staff states that they use the term "functional impairments" rather than "functional variations." The term *funktionsnedsättning* (functional impairment) is used to refer to disability in the Swedish Discrimination Act. The term *funktionsvariation* (functional variation) is a more recent addition to the Swedish language. Since it refers to "variation" instead of "impairment," it is considered less stigmatising and has been introduced as the politically correct way of speaking of disability in the last decade. The Swedish disability/accessibility resources staff were aware of this terminology but explained that they commonly use the term "functional impairment" because the purpose of their work is to tackle students' disability-related difficulties in higher education:

> We speak about functional impairments and it concerns, well, we are speaking about [that] when it is an impairment in relation to the studies, it is actually a difficulty in that case. (SE, interview 11)

It is noteworthy that there is no equivalent for the term "ableism" in the Scandinavian languages (Lid, 2022), which arguably affects their possibilities to signify disability in terms of social justice. Overall, the Swedish participants viewed disability as a difficulty that arises in relation to the students' learning environment. They recognised the importance of improving the general accessibility of universities and campuses but typically added that this was not the role of their office because they had to take care of individual accommodations first. This focus on a narrow aspect of disability/accessibility resources, which is encouraged by the organisational structure, can be interpreted as limiting opportunities for intersectional praxis in higher education:

> Individual support always comes first. It is the exercise of public authority, we must handle things quickly, the students have the right to their accommodations. So, meeting with departments and talking [about the need to improve accessibility], unfortunately, comes in second place. It is a wish, I would perhaps wish that there were more resources for the accessibility work itself. (SE, interview 10)

In the United States, the disability/accessibility resources staff similarly described individual measures as the most important task of their office. However, rather than speaking of individual difficulties in need of compensation, they generally used the language of eliminating barriers. The reference to barriers suggests an understanding of disability according to the social model, which posits disability as a dimension of structural inequality and oppression, in line with the language of intersectionality. This shows in the following quote in which a participant explains why they meet with each student:

> A lot of the work that we do is about identifying: what is the actual barrier of access?…We can't get that information from, you know, a letter from a doctor

> that says a student has ADHD or anxiety or whatever, even if you get a psycho-educational evaluation from a student who has a learning disability, that can tell you quite a bit about their mental functioning but it doesn't really tell you about their experience and that's really an important aspect to understanding what they may need or would work. (US, interview 3)

The interviews with the American staff show a difference between offices focusing on disability and those focusing on accessibility. In the following quote, an American participant explains that they changed the name of their office to "accessibility resources" to make it more inclusive of all people needing accommodations:

> Our name is just adaptability and flexibility and meeting folks where they're at and some people very readily identify as a person with a disability or disabled person, however they choose to identify. And some folks are just not there yet on their journey, or they say "nope, I just need accommodations in the moment because I had a car accident," or "I'm having a surgery," so, for us, it's about meeting folks where they're at. (US, interview 5)

As exemplified by this quote, many American participants viewed disability as an identity that people can have and, which some participants added, should be celebrated on campus. In the same vein, many American disability/accessibility resources staff argued that disability should be considered as diversity:

> We endeavour in our office to work through a disability justice model or social justice model, but I would, I wouldn't be…universally it's still very much working through a compliance, you know, compliance model: What do we have to do? We're working hard to try to kind of try to shift that perspective and shift the perspective of disability as deficit to disability as part of diversity, innovation. (US, interview 2)

The interviews suggest that disability is not recognised in terms of diversity in most institutions of higher education in the United States, but that some disability/accessibility resources staff push for this recognition, which is further evidence of the potential for intersectional praxis. This appears in the following quote, in which a participant was asked about the advice they would give to new faculty members:

> I would advise them to think about disability as an aspect of diversity and to think about, you know, how the choices that we make in designing our courses can contribute to access and equity. (US, interview 4)

Besides promoting the conception of disability as diversity, American disability/accessibility resources staff emphasised the (intersectional) need to improve the overall accessibility of higher education, for example by encouraging faculty members to create their courses according to the principles of universal design for learning (UDL).

> You may want to think about the next time you offer this course, making these changes so that you don't need to make accommodations anymore. (US, interview 4)

This idea was also found in some Swedish interviews, although they did not commonly refer to the terminology of UDL:

> There is something called, perhaps, universal design for learning, I think, universal design for, well, something like that, how do you think, how do you get them [disabled students] into teaching from the beginning, I think. Because then I think we will get those exceptions to be much fewer.…Prepare so that you don't have to deal with all the exceptions. (SE, interview 11)

It is worth noting the contrast between the wording of the American and Swedish quotes, referring to the need to make "accommodations" and deal with "exceptions," respectively. The former relates to a social model conception of disability, while the latter refers to an individual and problem-based deficit approach to disability. The argument that disability should be recognised as diversity was not present in the Swedish interviews. Instead, the dominating conception was that disability requires support or accommodations to compensate for difficulties. Viewed in this light, UDL was understood as a practical measure in Sweden because, as argued in the quote above, it reduces the number of "exceptions" that need to be made. By contrast, the same principle of UDL seemed to be perceived in terms of social justice and as a tool for structural change in the American interviews that were underpinned by a more intersectional social model of disability.

Overall, the analysis suggests that the Swedish disability/accessibility staff used a relational model and deficit model of disability, and that procedural justice was the main principle guiding their work. By contrast, the American disability/accessibility staff conceived of disability through a social model and minority model, placing their work in the intersectional realm of social justice. Because it centres social justice, the work of the American disability/accessibility resources staff can be interpreted as laying closer to intersectional praxis compared to their Swedish counterpart.

6.3. Contrasting Organisational Possibilities for Disability/Accessibility Resources Offices

Taking another step in the analysis of intersectional praxis, this section sheds light upon the ways in which the disability/accessibility resources staff viewed the place of their office in the broader organisation of their university or college. In general, staff from both countries stated that they had few contacts with other divisions, except for other offices providing learning support for students. Yet the participants recognised the potential and/or need for collaborations with divisions working with equality, inclusion, and diversity:

> Formally, like our offices, we report to separate people…even at a small university we still have these silos and still like, work in our own little bubble. (US, interview 6)

> It's a bit unfortunate that those roles, perhaps, are not closer to each other at our university because I see a lot of synergy, that we could collaborate in a better way and I think there are conditions for that, but unfortunately, it's not like that at the moment. (SE, interview 8)

The interviews suggest that some universities and colleges in Sweden and the United States are moving towards increased collaboration between the disability/accessibility resources offices and other offices on campus, because of organisational changes and because the disability/accessibility resources staff are increasingly invited to represent accessibility issues in various committees:

> It feels more like we were a small, isolated island in the beginning, but we have tried to kind of get out there, so that people know what we do, that we collaborate and sit in some reference groups….Just to include the accessibility issues. (SE, interview 15)

Similarly, American participants mentioned an increased interest in accessibility by faculty and other staff at their university or college. Besides accessibility, some American participants referred to changes regarding the recognition of disability as diversity, for example in the policy documents of their institution:

> Disability at [name of the university] is actually considered part of diversity itself. In our definition of disability, in our diversity strategic plan, disability is considered part of that and so has a seat with all the other types of diversity groups. (US, interview 3)

Next to formal structures, some participants pointed to the organisational culture at their university or college and explained that a small institution, with people who know each other, facilitates collaboration between offices and divisions, which enables a broader consideration of disability.

In sum, the interviews suggest that disability is typically considered an issue separate from other social justice concerns at Swedish and American institutions of higher education, but that this situation is changing in some places. A main change in both countries concerns an increased interest in accessibility, among others, through universal design, which mainstreams disability in various domains of higher education. In addition, some disability/accessibility resources staff in the United States noted an increased recognition of disability as diversity. While both developments—in terms of accessibility and diversity—address the inclusion of disabled students in higher education, it is the framing of disability in terms of diversity that mostly opens avenues for intersectionality as a critical praxis. This is because, as the following quote suggests, it makes the link between disability and other efforts toward social justice apparent:

> People are very excited about diversity and inclusion and social justice and, I think, once they realise disability can also be part of those efforts and part of that work it's like: "Oh, of course," and, like, they want to learn more. (US, interview 4)

7. Conclusion

This article explored whether intersectional praxis can be discerned in the provision of disability/accessibility resources in higher education in Sweden and the United States. The empirical analysis suggests that, although opportunities for intersectional praxis are generally absent or missed in both countries, the American participants were closer to such critical praxis because some of them placed their work in the realm of social justice and advocated for the recognition of disability as diversity. Recognising disability as diversity opens the door to intersectional praxis because it positions disability on par with other dimensions of structural inequality and oppression. By contrast, the Swedish participants seemed further away from intersectional praxis because they tended to view disability as a difficulty in need of compensation through support measures and as a situational issue regarding the learning environment.

To understand these differences, it is useful to consider the context of disability politics in both countries. In the United States, disability politics have been characterised by a civil rights and social justice approach; in Sweden, disability politics have been conceived in terms of welfare services and a relational approach to disability. As described in this article, anti-discrimination rights were adopted through a bottom-up process in the United States and followed a top-down process in Sweden. The empirical analysis indicates that these different approaches to disability politics and anti-discrimination rights are reflected in the ways in which American and Swedish disability/accessibility resources staff members talked about their work. While American participants referred to social justice and the importance of countering inequalities resulting from ableism, Swedish participants highlighted the importance of procedural justice and legal certainty. The latter suggests that the right to non-discrimination based on disability is interpreted in

Sweden as a means to determine access to welfare provisions rather than as a tool to combat structural inequalities rooted in ableism. This interpretation would benefit from future research on intersectional praxis and the implementation of anti-discrimination rights in Sweden and other European countries whose disability politics have traditionally been organised through the welfare state, as well as on the consequences that these different approaches have in practice.

This article highlighted the role of organisational structures. In line with previous research (Aquino, 2022; Shallish, 2015, 2017), this study found that disability is often considered a separate issue in higher education, which offers few organisational possibilities for intersectional praxis. Yet the interviews indicate that changes are occurring in some places. The first change concerns increased attention to and a mainstreaming of accessibility issues at Swedish and American universities and colleges. Whether various initiatives regarding accessibility strive toward social justice and imply intersectional praxis are important questions for future research. The second change, which was only mentioned in the American interviews, regards the promotion of disability as diversity. This article argued that this perspective opens avenues for intersectional praxis because it facilitates the inclusion of disability in other work concerning social justice in higher education. The American participants remarked, however, that the recognition of disability as an issue of social justice is far from established in higher education in the United States, suggesting the need for more research in this area.

The findings of this small-scale explorative study cannot be generalised, but they offer insights that are worth exploring further. This article proposes that, besides scrutinising different conceptions of disability, we need to examine how social justice in general and anti-discrimination laws in particular are understood in different national contexts because these understandings arguably influence opportunities for intersectional praxis and disability inclusion in higher education and other societal arenas.

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