

Implications of internalised ableism for the health and wellbeing of disabled young people

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Abstract

When conceptualising health and wellbeing among disabled people, the experience of internalised ableism must be considered. In this article, we argue that internalised ableism is indeed a health and wellbeing issue that materialises in numerous complex psychological, social and physical consequences. For theoretical grounding, we utilise critical disability studies, feminist theorising about solidarity and disability activists' concept of 'disability justice'. We draw on data from focus-group interviews with disabled young people, comprising ten men and eleven women, with different impairment types. The focus-group discussions revolve around various aspects of their wellbeing and participation in society, and possible and actual threats to the wellbeing of disabled children and young people in general. The analysis reflects various negative effects of internalised ableism on the identity, health and wellbeing of disabled young people. Family support, access to safer spaces and positive peer interactions are factors defining how internalised ableism develops, is maintained or defied. Peer support and solidarity are strong indicators of

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promoting healing from internalised ableism. We argue that disability scholars need to address the health and wellbeing of disabled people in an ableist world.

KEYWORDS

disability, disability justice, health and wellbeing, internalised ableism, young people

INTRODUCTION

Over the last decades, disability activists and writers have spent much effort in moving away from the medical understanding of disability, emphasising the roles of political and societal factors that lead to barriers and disability discrimination (Garland-Thomson, 2009; Hughes, 2000). Due to disabled people's experiences of ableism and microaggression targeted at victimisation and pity, considerable resistance has revolved around focussing on the strength, joys and power of living in a disabled body (Garland-Thomson, 2017; Thomas, 1999). Although this focus has promoted changes in attitudes towards disabled people, as evident in policies and services, critical voices have emerged, for example, through feminist disability studies and activism, pointing out that it risks undermining the experience of living in a disabled body (Liddiard & Slater, 2018; Shildrick, 2002). This includes the physical and the emotional toll that can result from navigating an ableist world shaped for and by nondisabled people (United Nations, 2007). Although scholars within critical disability studies have directed their attention to the disabled body and pushed back against the ableist imperative that bodies should conform to normative ideas (Goodley et al., 2019; Meekosha & Shuttleworth, 2009), with a few exceptions (see, e.g. Brown & Leigh, 2018; Livingston & Boyd, 2010; Thomas, 2007), disability studies have refrained from discussing health issues—leaving it to other fields to set the agenda, which perpetuates the traditional medical understanding of disability.

We conceptualise health and wellbeing in broad terms, which includes psychological, social and physical dimensions that overlap and can contribute to an overarching sense of wellness when combined and balanced (Prilleltensky & Prilleltensky, 2003). In fact, this understanding is in line with the World Health Organization's (WHO 1946, p. 1) definition of health as "a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity". Furthermore, the preamble of the WHO Constitution states, "The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition" (WHO 1946, p. 1). We argue that disability studies should address health and wellbeing, such as by paying more attention to the relations between structure and subjective and bodily experiences (Charmaz, 2020) and acknowledging the effects of internalisation of ableism among disabled people (Campbell, 2009).

According to Campbell (2019), ableism is not simply a question of ignorance or negative attitudes towards disabled people; it is an unrealistic path of perfection and a deeply ingrained way of thinking about bodies. It feeds the idea that disability is negative and undesirable. In this paper, we aim to illustrate how internalised ableism is indeed a health and wellbeing issue, characterised by numerous difficult and complex psychological, social and physical consequences that intersect and overlap. To make our point, we draw on data from focus-group interviews with

disabled young people discussing aspects of their wellbeing. Building on the interviews, we also want to highlight the importance of solidarity for promoting positive intergroup contact and empowerment of disabled people as a group.

We begin by discussing the theoretical perspectives that we draw on and then introduce our study's design and methodology, followed by empirical examples reflecting internalisation of ableism by our participants. Lastly, we discuss some important lessons learned and implications that can be drawn from our study, such as in relation to policies and services for disabled people.

THEORETICAL FRAMEWORK

Theoretical discussions about internalised oppression grow from the soil of critical race theory (Crenshaw et al., 1996) and postcolonial theory (Hook, 2012) but have implications for other marginalised groups as well (David, 2013). Our theoretical underpinnings stem from Campbell (2009) who analysed the internalisation of ableism as well as from David (2013) who investigated internalised oppression among different marginalised groups such as women, queer people, disabled people and aboriginal people. Campbell (2009) pointed out that to gain the same respect accorded to nondisabled people, disabled people must “overcome” their disability. The “nondisabled gaze” marks ableism as the gaze of the impeccable body through which everything is decided (Hughes, 2000). This deeply embeds ableism within our culture—where disability is, at its best, tolerated and never celebrated (Campbell, 2008). Therefore, internalisation of ableism is almost inevitable.

Oppression can occur not only at an institutional level, such as through laws and policies, but also through social norms. Such an oppression may be more common in the present Western world and can be hard to notice (David, 2013), often resulting in microaggression (Sue, 2010). Microaggression occurs as intangible discriminating and prejudiced interactions, whether intentional or unintentional. Because of the hidden nature of microaggression, people who experience it are often compelled to question their perception of it through microinvalidation, which can lead to self-blame. Microaggression therefore contributes to the internalisation of ableism (David, 2013).

Internalised oppression can appear as an uncritical devaluation of one's own group (David, 2013). This devaluation can be passed on, both across generations and among people through socialisation, such as when exclusion becomes taken for granted. It should be noted that internalised oppression can exist and operate outside people's awareness, intentions or control. However, it has immense influence on how people think and feel about themselves and other members of their group. Rosenwasser (2000, p. 1) describes this as:

... an involuntary reaction to oppression which originates outside one's group and which results in group members loathing themselves, disliking others in their group, and blaming themselves for the oppression – rather than realizing that these beliefs are constructed in them by oppressive socio-economic political systems.

Scholars researching internalised oppression have found that it can contribute to mental health concerns, such as anxiety, depression, isolation, feelings of inferiority, powerlessness and a negative body image (David, 2013). Livingston and Boyd's (2010) meta-analysis has uncovered a striking negative relation between internalised stigma for people living with mental illness and “lower levels of hope, empowerment, self-esteem, self-efficacy, quality of life and social support” (p. 2157) and a

positive association with psychiatric symptom severity. In a similar vein, Reeve (2000) points out that disabled people often experience oppression in counselling, which may hinder them from establishing a positive sense of identity and working through their internalised oppression.

The internalisation can begin at a young age and depends on the environmental context, such as how people have been raised and what messages they receive about themselves and others (David, 2013).

Campbell's definition of internalised ableism

Campbell (2008, 2009) argues that the internalisation of ableism consists of a two pronged strategy: “the distancing of disabled people from each other and the emulation by disabled people of ableist norms” (2008, p. 155). We find this distinction overlapping when used with empirical examples, as distancing from the disabled identity often entails emulating the norm. We therefore use them interchangeably.

The distancing of disabled people from one another is what Campbell (2009, p. 22) calls “tactics of dispersal”. The individualisation of disability makes it difficult to form a common identity where the shared histories of disabled people, negative ontologies and the absence of strong oppositional role models are not easily available to disabled people. Thus, disabled people have had very few opportunities to “develop a collective conscious, identity or culture” (Campbell, 2009, p. 22).

When emulating the norm, the disabled person is required to embrace an identity that is not one's own. As stated by Campbell (2009, p. 25), “one must constantly participate in the processes of disability disavowal, aspire towards the norm, reach a state of near-ablebodiness, or at the very least to affect a state of ‘passing’”. According to Leary (1999, p. 85), “passing occurs when there is perceived danger in disclosure (...). It represents a form of self-protection that nevertheless usually disables, and sometimes destroys, the self it is meant to safeguard”.

Ahmed (2017) points out that when a body does not fit a norm, for example, due to race or disability, it becomes questionable. The person therefore needs to either settle with being othered or defend one's way of being by inhabiting a norm, to become something that the person is not. Passing is not only performed to avoid discomfort in questionable situations but often is a matter of surviving and securing safety (e.g. from street harassment). Passing takes much effort, and if one fails, it can come with a cost (Ahmed, 2017).

Emulating the norm can also materialise in ‘defensive othering’, that is, people distancing themselves from the devalued identity imposed by the dominant group and assuming the legitimacy of the dominant group (Campbell, 2009). It should be noted that disabled people do not absorb negative representations of disability uncritically and passively; rather, their responses are often contradictory. Reacting to these ambiguous responses, disabled people are shamed into unwittingly performing ableism, further establishing impairment as unattractive and undesirable. Emulating the norm can lead to burnout, risking safety issues and other health-related issues (Campbell, 2009).

The driving force of shame

The negative consequences of internalised ableism on health and wellbeing are also related to shame (Velotti et al., 2017). Shame is the effect of alienation and defeat (Slobodin, 2019) and

strongly influences how people move and act in the world, often unconsciously. Another article based on the same data sources as those used in this article (Jóhannsdóttir et al., 2021) reveals how social determinants and powers affect disabled young people's experiences and identities. Shame is externally imposed through the message that being disabled is an invalid social position, which is then reinforced and internalised by the young people.

Shame is linked to anxiety proneness and symptoms, as well as to depressive symptoms (Giordano, 2018). According to Goldberg (1991), one of the primary incentives for shame is being treated as inferior or considering it a threat against the integrity of one's identity. This is what Ashley (2020, p. 5) calls "core shame identity", characterised by an overarching fear of being exposed as deficient and flawed, which again may result in a persistent feeling of unworthiness, unlovability and disconnection. In an unfriendly environment, empathy for the self is often lost (Ashley, 2020). These have serious consequences, such as depression and a desire to hide and withdraw, as the rage that shame inherently causes is directed inwards to oneself (Goldberg, 1991). As Ashley (2020) argues, "shame eventually becomes internalised within their personality, and the narrative shifts from 'I did something bad' to 'I am bad'" (p. 4).

Being accepted by others, sharing feelings and building relationships based on caring can promote relief from shame (Goldberg, 1991). Through the social support of others with similar experiences, shame can be diminished.

Solidarity and disability activism

Hemmings (2012) developed a useful concept that she calls "affective solidarity", where the dissonance of one's being can be transformative. She states that the "lack of fit between our own sense of being and the world's judgements upon us constitutes a kind of feminist reflexivity" (Hemmings, 2012, p. 149). In other words, our experiences of our sense of self, such as feeling ill-fitted with social expectations and undervalued, produce affects, such as anger, shame, frustration, rage, misery and passion. This might evolve into a sense of injustice and then possibly a desire to rectify that injustice. This possible evolution, what Hemmings (2012) calls affective solidarity, is "the desire for transformation out of the experience of discomfort, and against the odds" (p. 158). It is against the odds because this realisation does not always lead to affective solidarity. It is even more against the odds in relation to the solidarity of disabled people, who have had fewer opportunities (compared with other minority groups) to develop a collective identity or culture (Campbell, 2009). However, it is important to keep in mind bell hooks' (2015) statement that marginality is more than a site of deprivation. It is a place of resistance and an opportunity for a counter-hegemonic discourse, therefore often a nourishing site, enabling people to resist. This is what Piepzna-Samarasinha describes in her book, *Care Work: Dreaming Disability Justice* (2018), noting that although solidarity and care among disabled people may not be perceived as 'real activism', they are nevertheless radical and powerful. The term 'disability justice' originated from "the Black, brown, queer and trans members of the original Disability Justice Collective, founded in 2005 by Patty Berne, Mia Mingus, Leroy Moore, Eli Care and Sebastian Margaret" (p. 15), as a framework centering the lives and needs of disabled, queer, trans, black and brown people, already marginalised from the mainstream disability rights movement. In a world, where people have been taught that their care needs are burdens and that they should not take up too much space, disabled and sick people have built care webs for one another (Piepzna-Samarasinha, 2018). When such solidarity emerges, it can act as a sanctuary for healing internalised oppression (Campbell, 2009).

It is of the utmost importance not to feed the idea that there are ‘those who can cope’ and ‘those who cannot’. Being resilient is easier in some contexts than in others—easier at some points in people’s lives but harder at other times. Thus, it is unhelpful to adhere to the dichotomy of the strong and the weak (Giordano, 2018). Rather, it is important to resist the shame of internalisation of ableism through the solidarity of disabled people and their allies.

Resilience and pride require constant negotiation, especially in individuals who have experienced social rejection and abuse. But this negotiation should not rely only on individual skills: social support must be a part of the process. Empowerment should not be an aim on its own: social (and political) action is needed concomitantly, to reduce shame.

(Giordano, 2018, p. 17)

This understanding fits well with the transformative methodological approach (Mertens, 2017) used in the larger research project (Egilson et al., 2021) on which this article is based. The project addressed discrimination, marginalisation, oppression and social justice, with the overall aim of achieving changes at both the community and the institutional levels.

METHODS

This study is part of a larger research project that focussed on the life quality and participation of disabled children and young people in Iceland (Egilson et al., 2021). As part of that project, four focus-group sessions with young people—who all identified themselves as disabled—were conducted to explore their views and experiences. A focus group is a form of group interview that capitalises on communication among research participants to facilitate exploring, clarifying and sharing their views, knowledge and personal experiences (Krueger & Casey, 2014).

Participants

The participants in the first focus group were recruited through a convenience sample as the intention was to clarify the focus and the questions in the draft interview protocol. The participants in the remaining three focus groups were recruited through key informants in the disability sector, personal contacts and snowballing (Brinkmann & Kvale, 2014), with the intention of obtaining a varied sample in terms of gender, age and impairment types. Altogether, ten men and eleven women [each participant’s gender was self-identified], aged 18–35 and with different impairment types (e.g. mobility, sensory, intellectual and psychosocial), participated in the focus-group interviews. Approximately 80% of the group had been disabled from birth. The first two groups comprised mixed genders. To detect and accommodate possible gender preferences during discussions, the third group had disabled women participants only, and the fourth had disabled men participants only.

Data generation

Two researchers who both identify as disabled moderated the focus-group interviews, which took place between the spring of 2018 and the autumn of 2019 and lasted 1.5–2 hours each. The

informants were asked to reflect on their childhood and adolescence, how they viewed their life and wellbeing, and in hindsight, what they considered the most important factor for enabling disabled young people to participate in society and enjoy wellbeing, as well as which aspects they considered threats to disabled people's wellbeing and life quality.

The focus-group sessions were recorded with the participants' permission and transcribed verbatim. To analyse internalisation, we drew from David (2013) who investigated internalised oppression among marginalised groups, as well as from Campbell's (2009) definition of internalisation of ableism—emphasising its implications for the wellbeing of disabled people. We thus used a theory-driven thematic analysis, approaching the data with specific questions in mind (Braun & Clarke, 2006). We read the interview transcripts repeatedly, keeping in mind the theoretical concepts that would promote sensitivity to the topic and enable us to detect similarities and differences in the participants' experiences. The overall research design, methodology and methods are thoroughly described by Egilson et al. (2021).

Methodological and ethical concerns

All participants were well informed about the purpose of the study and willingly participated. During the interviews, attention was paid to power relationships, and emphasis was placed on developing trust and security in interactions, feeling shared comfort and safety and minimising the distance between the researchers and the participants. Multiple measures were put in place to accommodate individual participants' needs. These included preparing thoroughly and taking into consideration their abilities and preferences, such as giving them enough time, simplifying the language and using the services of sign-language interpreters. The transformative focus allowed sharing and scrutinising complex experiences and realities during the group discussions. Identifiable information was removed to prevent the results from being traceable. The study was approved by the Icelandic Bioethics Committee (VSN-16–187-V2).

FINDINGS

The start of internalising ableism

As David (2013) states, the internalisation of ableism starts early, even before the birth of a disabled child. Having a disabled child is typically considered a tragedy and a burden on the family, and much of the attention centres on the child's impairments and specific care needs (Fisher & Goodley, 2007; McLaughlin, 2012; Ytterhus et al., 2015). These beliefs were also evident in our data. Our participants described their parents' encounters with doctors, where they were made to feel that the birth of their disabled child was indeed a tragedy. This was discussed both in relation to personal experience and on a more general level, such as by Ingvar in the men's focus group:

It's like if you are born disabled, your parents need education on everything their child can do. Not that the doctor comes and says, "This is what is wrong, and this ... and this... and this." Too often, a grim picture of the baby's condition is painted. When rather someone should come and say, "These are the resources available for you Your child can do this ... and this ... and this." The focus is too often on what is wrong with the baby but not what the baby is capable of.

Some participants mentioned how through a huge effort, their parents actively fought against these stereotypical ideas to ensure that their child had the same rights and opportunities as every other child. This also entailed inadequate expectations towards their disabled child, which negatively affected the child's possibilities to develop and use his or her potential. Júlía said:

There are often too little expectations towards disabled children. You know, many parents really have to fight in order to have the same expectations aimed at their disabled child as any other child. This can affect parents in that they become incredibly tired and bitter.

Others were raised in families that in their opinion had identified more with dominating ideas and unintentionally—and even in good faith—echoed the tragedy discourse to their children from an early age. The notion of being vulnerable and somehow incompetent or “not good enough” often contributed to these young people's social exclusion and marginalisation from mainstream society, in their opinion. Other discriminatory factors, such as gender, social status and place of residence, also played a role in feeling othered whilst growing up. This came up repeatedly in the women's group, where they shared experiences of sexual harassment and violence, racism and lack of sexuality. Júlía expressed her experience of the intersection of disability and sexuality:

For me, it is complicated to discuss relationships because I am a lesbian. (...) people connected that to my disability, saying that I just knew myself as a woman. And that I did not know men. That is why, according to them, I am attracted to women because it is the only thing I know! (*everyone laughs*)

The ever-present tragedy discourse was central in the young people's accounts. Furthermore, they described how it had gradually and increasingly affected their sense of self during their adolescence and adult years. A few participants specifically used the concept of internalised ableism and regarded it as the main barrier to their wellbeing later in life.

Tactics of dispersal and emulating the norm

Our participants described numerous examples of tactics of dispersal from an early age. Some of these were initiated by parents, others by professionals. Árni described how the “good” paediatrician put a stop to his socialising with other disabled children:

I had a very good paediatrician who fought for me to not associate with other disabled children, that is, I would not go to a special school, not go to the summer camps for disabled children, like my brothers. And yes, I spent much more time around non-disabled children.

Nevertheless, this distanced Árni from the group, and as shown in the next quote, he spoke of controversial and negative experiences when he was with other disabled children:

I started experiencing that when I was around disabled children. I did not understand what they were going through... I did... I disregarded my disability. Mine was not as important/valid as that of others.

Although the first example is an important acknowledgement of Árne's place in society, the second example shows how being separated from other disabled children may have diminished his opportunities to establish relationships with them. Ultimately, it may have hindered him from identifying with other disabled people and creating a positive disabled identity. In hindsight, Árne and a few others emphasised that disabled children should have the possibility to socialise with both disabled and nondisabled children.

The tactics of dispersal were also initiated by the disabled children and youth themselves and often in relation to the perceived hierarchy of disability, where intellectual disability was considered less valued than physical disability. Tinna provided a relevant example of how she had tried to distance herself from intellectual disability:

I have experienced, and my uncle – who also has a physical impairment. People see how he walks and start to talk to him in this tone, like he has an intellectual disability. You have a physical impairment, and people assume that you also have an intellectual disability, but it doesn't have to be so. And it is frustrating because you always feel like you have to prove yourself. People treat me like I am stupid, which ... which, of course, I am not.

Tinna echoed the common view that people with an intellectual disability are stupid and less worthy. Such distancing is yet another aspect that may complicate the possibility of developing a positive disabled identity and solidarity, which again may act as a buffer against prejudice and stereotyping (Branco et al., 2019).

Many participants shared disempowering experiences of being in summer camps for disabled children. Hildur's account illustrated the complexities of developing a positive disabled identity when placed in a challenging situation and having no voice:

Just really hard summers ... where we, as young children, experienced the vulnerability of other children in this place. It kind of sticks with me, this vulnerability and aloneness of the other children. We were not experiencing one another's strengths, you know. There is a huge difference between experiencing peer support through strength and empowerment and enduring what we experienced in that summer camp.

At a certain age, Hildur decided that she did not want to be like the disabled children at summer camp; instead, she wanted to be like the kids in her neighbourhood:

I came home and somehow muddled with many different feelings and ... went to the living room to my mum and said, "I don't want to be the way I am... I want to be like all the other kids in the playground." And, you know. I had this conflict of suddenly not wanting to be myself. This is somehow a very defining moment in my life.

These examples reflect distancing of disabled youth from one another, which both relate to and possibly reflect aspects of ableism. The main reasons are experiences of not being valued, the

hierarchy of different types of disabilities and—most importantly—the vulnerability of disabled children who find themselves in a disempowering situation. The key factor here is the forced segregation that the young people experienced as children in the summer camp. On one hand, being forced together, even without explanations, can bring about feelings of shame and anger that recrudescence towards other disabled people. This involuntary reaction, as Rosenwasser (2000) puts it, may easily lead to internalisation of ableism. On the other hand, if Hildur also had a real choice of establishing meaningful relationships with other disabled youth in an empowering environment, her experience might not have been so devastating. Such an example is provided later on.

Impacts on health and wellbeing

The participants also directly discussed how negative representations of disability affected their wellbeing. Ása and Sólrún, both women with an intellectual disability, discussed the core of the psychological aspect:

Ása: There is a connection between depression and anxiety and for example, disability. And you know, it is most likely because society has a negative view of disability.

Sólrún: I think that society could be more positive. “Yes, okay, you are like this!”

Researcher: Can I ask you, Ása, when you say the connection between depression, anxiety and disability is because of society, can you name an example?

Ása: Just prejudice towards disability.

Researcher: Exactly. That people ...?

Ása: That people just get scared, they do not think they are acceptable, and then they isolate themselves and become anxious.

Sólrún: I became depressed because of my disability, but also because of prejudice from others.

This isolation that Ása described can be linked to what Ashley (2020, p. 5) refers to as “core shame identity”, meaning a persistent feeling of unworthiness, unlovability and disconnection, resulting in deep shame. The internalisation of ableism can slip into every part of the young people’s lives, as Eggert explained:

I understand it; I don’t know if I would date me, with everything that comes with it.
So, I understand people, even if it is not the right attitude, or maybe not very modern.
I cannot get frustrated or angry with people because I understand it 100%.

When asked why no one would want to date him, Eggert said that dating him would be too much of a burden. One part of people’s wellbeing is having a meaningful relationship with other people. In Eggert’s case, he did not consider that a viable option. Again, it was a persistent feeling of undesirability and unlovability, with the internalisation of shame as the core identity (Ashley, 2020).

Halla described her view that disabled children should work at double speed:

Yes, I have strong opinions about not wrapping your kids in cotton wool. Just let them have challenges and just ... yes, they have to work twice as hard, just work harder.

Although this can be perceived as part of internalising ableism, it is nevertheless complicated and paradoxical. Often the expectations towards disabled people are extremely low, which may result in them feeling the need to prove others wrong and work at double speed. Such a response may lead to exhaustion and internalise the idea that they are never good enough. However, it is important to provide disabled children and youth with opportunities to try new things, as offered to other young people. Jón described the freedom he experienced as a child as he was allowed to explore the rugged terrain relatively far from his home:

I had a lot of freedom at our farm and sometimes got myself in dangerous situations. That was solved by equipping my wheelchair with a radio transmitter. Then I could go as far as I wanted and was able to call for help if needed.

Jón felt that being able to explore on his own and take risks was an important part of his childhood, a positive experience that he drew on as an adult.

Ása's, Sólrún's and Eggert's experiences of being treated as inferior and unworthy entrenched shame, which again enforced the internalisation of ableism. In contrast, Jón's childhood experience was valuable in creating his positive identity.

Resistance, solidarity and the importance of safer spaces

Resistance to internalisation of ableism relies on access to safer spaces, as well as solidarity and support. We deliberately use the word 'safer', not 'safe', since spaces that disabled people regard as safe are fluid and can quickly become unsafe due to access issues, ableism, microaggression or violence. Therefore, disabled people must always be on guard and prepared for anything. This reality was described well by Anna, one of our participants:

My best days are the days when I don't have to keep my defensive wall up. And I admit that there are days, not many, because I always have to be dealing with this, (...) I often shun from certain scenarios and circumstances. Just because I am so tired from always keeping up this defensive wall.

Anna found it important to be able to let go and not always be prepared for ableist microaggression or dismissal, that is, not having to spend so much energy on fighting stigma and stereotyping or answering inappropriate questions. Other participants echoed similar concerns and referred to space as safer if they could be sure that the people around them would not judge them or deprive them of their power to define their own bodies and needs. Such 'care webs' (Piepzna-Samarasinha, 2018) were not always available, and sometimes, the only way out was simply to isolate themselves from other people.

Although a safer space was often found in the family, this was not always the case. Instead of being supported by her mother, Sólrún experienced being occasionally belittled: "My mum also sometimes tears me apart and says, 'You cannot do this' [or] 'This you cannot learn.'" As Sólrún could expect ableist aggression in her family, she always had to keep her guard up.

In contrast, Ingibjörg described how her mother helped her resist and fight exclusionary attitudes and behaviours.

My mum is so stubborn, and when I was a teenager, I often got in trouble in school because I did not accept the service I got there. Mum said, “Okay, Ingibjörg, you have these needs, and you should just tell the school that you have these needs.” So, in my eighth grade, I went to the principal and explained my case and everything. And my mum supported me. (...) and she taught me not to be ashamed of it.

Ingibjörg’s account shows how vital family support can be in resisting the internalisation of ableist shame. As Hemmings (2012) argues, it is not given that a group experiencing internalised oppression has the opportunity to experience joint solidarity. With disabled people, the chances are less than with other minority groups (Campbell, 2009). It is therefore essential that the planning of social spaces be empowering, as evident in Hildur’s story, mentioned earlier. For disabled people, the chances may be fewer than for other minority groups, depending on the accessibility and inclusiveness of social spaces. Hildur continued to discuss her experience from the summer camps:

If we as kids would have felt empowered in our situation, that would have been a totally different thing. But the knowledge back then was not there.

The access to spaces where disabled children and youth feel welcome, where people embrace them, understand and support them is vital for establishing solidarity.¹ In fact, such spaces were described by some of our participants. In a summer camp for deaf children, Andri experienced great joy and empowerment:

I am absolutely certain that for Deaf kids who use sign language, the best thing for them is to go to summer camps with other sign-language speaking and other Deaf people. I went to an ordinary summer camp, and yes, it was fun, and I participated in games and the curriculum. But I was always outside of it. When I went for the first time to a summer camp for Deaf kids, it was totally different. I was immediately involved in everything and experienced just ... understanding; we understood each other. That was very empowering. Having such peer support just changed everything and was so empowering.

The difference in Hildur’s and Andri’s experiences of attending summer camps was immense and ultimately affected their possibilities of experiencing solidarity in shared disabled identities.

In their adulthood, some participants were given the opportunity to meet other people with the same impairments as theirs. They described how empowering it was to see these people having families, spouses and careers—helping them develop a stronger disabled identity and a sense of belonging, as well as gain access to a safer space:

In my twenties, I again started to accept myself. I came to the city and gained access to sign language again. I started having different communications than before – where it was always just one on one – and could see other people debate and argue and just talk about numerous things in sign language. Just sharing what happened yesterday and so forth. Totally different communication than I had experienced before. I got to know new people that could speak to me in sign language.

Thus, the importance of belonging and having access to a safer space is unquestionable, whether it be in the family, as Ingibjörg described, or in the Deaf family, as in the preceding extract. Peer

support and solidarity can have life-changing effects. As our examples show, when such solidarity emerges, it can counteract internalised ableism so that people can heal and even flourish.

DISCUSSION

Campbell (2009) argued that there is a “critical need to investigate internalised ableism and its effects on the psychic life of our (disability) community” (p. 29). In our study, numerous examples reflected how internalised ableism from an early age had rippling negative effects on the health and wellbeing of the disabled young people. The internalisation took place through interactions with external structural arrangements, which often maintained and reinforced their devalued positions, such as being stereotyped as deviant and inferior. Ableism made the young people’s impairment a sensitive marker of something ‘abnormal’ and ‘undesirable’, which again made them even more aware of their physical, psychosocial and intellectual differences and negative portrayal in society. However, participants’ experiences were neither fixed nor stable, and positive experiences were also shared.

Fighting the notion of normality, prejudice and stigma was burdensome for the young people in our study and manifested in exhaustion, anxiety, depression and isolation, among others. Consistent with other researchers’ findings (Smith & Traustadóttir, 2015; Teachman et al., 2020), many participants referred to their adolescence as being an especially difficult time when they had increasingly experienced social exclusion due to the lack of accessible activities and social settings. Dealing with people’s stares, patronising comments and other types of microaggressive or explicitly aggressive moves was challenging as well.

In many instances, shame had regulated and disciplined the disabled young people towards internalisation of ableism. For example, the isolation, disconnection and unlovability described by some participants appeared to be persistent and ever-present. Being constantly treated as inferior triggered feelings of being unworthy of love and belonging, which again reinforced their shame. In line with our prior findings (Jóhannsdóttir et al., 2021), we argue that by disciplining and regulating the young people in our study, shame became a driving force in their internalisation of ableism. Shame also appeared to be strongly linked to the mental health issues and negative body image that many of our participants described.

Various contextual factors, such as family support, access to safer spaces, positive peer interactions, networks and knowledge, appeared to affect whether and to what extent internalised ableism developed and was maintained. We acknowledge that disabled people are of course entitled to consider their own impairments in different ways. As an example, when some participants commented that they would like to be nondisabled, it could not automatically be classified as internalised ableism. Nevertheless, the manifold and complex feelings and experiences that were shared in the focus groups appeared to strongly reflect internalised oppression and ableism, although only a few directly used these terms. In this context, it is important to note that internalised oppression may operate beyond people’s awareness or control and consequently influence how they think and feel about themselves and their group members (Rosenwasser 2000).

Keeping in mind WHO’s (1946) definition of health and given the lack of mental and social wellbeing described by our participants, the negative implications of internalised ableism on their health and wellbeing seem evident. In the disabled young people’s opinion, the prerequisite for pleasant social interactions and experiences was having other people respectfully listen to and validate what they had to say. In other words, the focus would not just revolve around their impairments or the assistance they needed. Whilst reflecting on their shared understanding, they often experienced valuable peer support through which a safer space could be established and

solidarity achieved. Such disability justice care webs (Piepzna-Samarasinha, 2018) can promote healing from internalised ableism, through strong positive intergroup contacts and joint empowerment, which can also be characterised as affective solidarity (Hemmings, 2012). Thus, one of the most efficient ways to resist internalised ableism may be to offer positive intergroup contacts (Branco et al., 2019). Our participants stressed the need for both positive intergroup contacts and interactions in the society at large. This is echoed in the Convention of Rights of People with Disabilities (CRPD), article 24, (United Nations, 2007), which emphasises disabled people's full and equal participation in education and as members of their community. To this end, appropriate measures must be taken, such as facilitating diverse means of communication and mobility, as well as providing peer support and mentoring.

Our findings have implications for policies and practices in health and social services for disabled people. The effects of dominant perspectives on perpetuating stigma and exclusion and the way that these are played out through interactions and structural arrangements in services should be acknowledged and counteracted wherever possible. As stated in the CRPD, article 8 (United Nations, 2007), it is important to combat stereotypes, prejudices and harmful practices and instead foster respect for the rights and dignity of disabled people. Professionals in health and social services need to acknowledge disabled people's history of oppression and their individual and collective trauma stemming from such experiences. They also need to recognise society's and their own ableist thinking, which ultimately affects the way that services are designed and delivered (Charmaz, 2020; Reeve, 2000).

CONCLUSION

At the beginning of this paper, we pointed out that for the most part, scholars engaged in disability studies have refrained from discussing health issues. Thomas (2007) claims that this is because the core message of disability studies has been to challenge the idea that being disabled is all about impairments and defects. This hesitation in the field of disability studies is understandable in light of the medicalisation of most aspects of disabled people's lives throughout the decades. We nevertheless think that it is timely and important that disability scholars focus more on the relation between structure and subjective experiences (Charmaz, 2020), such as by investigating the physical and psychological strain of navigating a world designed for and run by nondisabled people. In our larger research project (Egilson et al., 2021), we have addressed discrimination, marginalisation, oppression and social justice, with the overall aim of achieving changes at both the community and the institutional levels. This paper fills in a gap in disability studies by addressing and uncovering the internalisation of ableism and its possible implications for the health and wellbeing of disabled people.

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AUTHOR CONTRIBUTIONS

Ásta Jóhannsdóttir: Formal analysis (equal); Methodology (supporting); Validation (equal); Writing – original draft (lead); Writing – review & editing (equal). **Snæfríður Þóra Egilson:** Funding acquisition (lead); Methodology (equal); Project administration (lead); Validation

(equal); Writing – original draft (supporting); Writing – review & editing (equal). **Freyja Haraldsdóttir:** Data curation (lead); Formal analysis (equal); Validation (equal); Writing – original draft (supporting); Writing – review & editing (supporting).

DATA AVAILABILITY STATEMENT

Due to the nature of this research, participants of this study did not agree for their data to be shared publicly, so supporting data is not available.

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ENDNOTE

- ¹ The documentary Crip Camp shows how solidarity and empowerment can be fostered. It also depicts how the experience of these camps affects the life of disabled youth, not just there, but onwards in their lives (CRIP CAMP: A DISABILITY REVOLUTION | Official Trailer | Netflix | Documentary, 2020).

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