



Disability & Society

ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/cdso20

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To cite this article: Anna Sigrún Ingimarsdóttir, Kristín Björnsdóttir, Yani Hamdani & Snæfríður Þóra Egilson (2023): 'Then you realise you can actually do it': young disabled people negotiating challenges during times of transitioning into adulthood, Disability & Society, DOI: 10.1080/09687599.2023.2226317

To link to this article: https://doi.org/10.1080/09687599.2023.2226317

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Published online: 26 Jun 2023.

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'Then you realise you can actually do it': young disabled people negotiating challenges during times of transitioning into adulthood

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ABSTRACT

This study explored disabled people's reflections and experiences regarding the challenges they faced when negotiating transitioning to adulthood. It was informed by critical disability studies and youth studies. Four focus group interviews were conducted with altogether 21 participants, 10 men and 11 women with different impairments. A constructivist grounded theory approach was applied to categorise and synthesise data. Participants had faced a myriad of barriers while transitioning into adulthood, such as inaccessible environments, ableist ideas about disabled people as being dependent and childlike, lack of expectations and inadequate supports. Participants resisted these ableist ideals but simultaneously underscored their want to aspire transitional norms in order to live a valued adult life. The importance of having real choices and opportunities was pivotal. The findings underline the importance of dismissing the ableist ideas that persistently exclude young disabled people. Acknowledging different ways of being and doing is key at times of transitioning.

ARTICLE HISTORY

Received 16 August 2022 Accepted 13 June 2023

KEYWORDS

Transitioning; young disabled people; critical research; grounded theory; ableism

Points of interest

- This article looks at young disabled peoples' transitioning into adulthood from their own perspective.
- Participants' access to social spaces, activities, and opportunities typical for young people was often restricted or simply denied.
- Participants faced restricted choices that were not necessarily meaningful to them, did not reflect their lifestyle or identity and undermined the idea of who they wanted to become

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- The young people underscored desired ways of transitioning into adulthood emphasising justice, dignity, and being entitled onés own space, purpose, and opinions.
- The rigid ableist ideas about adulthood and disability that have persistently excluded young disabled people should be dismissed. Instead, opportunities for multiple ways for being an adult must be provided.

Introduction

Transitioning into adulthood is a complex process that happens over time (Stewart et al. 2014). Although it is generally understood as moving from one developmental stage to the next, there is in fact little consensus on when childhood ends, and adulthood begins (Hamdani and Gibson 2019; Valentine 2003). Transition can be linear, meaning that significant achievements take place rather continously or it can be back and forth, with progress and regression (Tchibozo 2013). Consequently, transitioning is a dynamic process that reflects individual interactions with societal patterns, wider cultural expectations, and historical context (Scott 2009), making it complex to conceptualise.

Traditional theoretical frameworks on development and transitioning have been dominated by psychological accounts, highlighting physical and cognitive aspects along with certain socially sanctioned milestones considered pivotal for entering adulthood (Priestley 2003; Steinberg 2016; Wyn and White 1997). Although these frameworks may give insights into the expectations for the daily life roles and activities expected of young people as they transition to adult life they can be potentially harmful for those who for varied reasons do not achieve 'normal' milestones (Hamdani and Gibson 2019; Priestley 2003). Approaching transitioning from a narrow understanding has been critisised for excluding marginalised populations whose access to resources often is limited (Gibson et al. 2014; Ytterhus et al. 2015). Many young people can experience anxiety, struggle, and grief as they try to achieve milestones that often are uncertain, hard to grasp and difficult to obtain (Hamdani and Gibson 2019; Smith et al. 2011).

Transitioning to adulthood can be particularly complicated for young disabled people (Gibson et al. 2014; Gorter, 2011; Meyer, Hinton, and Derzis 2015; Nguyen, Stewart, and Gorter 2018; Slater 2013). For example, stereotypical ideas about disabled people as dependent, passive, and childlike do not fit well with key notions about transitioning into adulthood as a push towards self-reliance (Fraser and Gordon 1994; Hamdani and Gibson 2019; Slater 2015). Nevertheless, many young disabled people live dynamic lives and like other young people have hopes and dreams for the future (Curran et al. 2021; Liddiard et al. 2019b).

Much of the literature on young disabled peoples' transitioning has focused on transferring from child to adult-oriented services and often from service providers' viewpoint (Bagatell et al. 2017; Bekken, Ytterhus, and Söderström 2021; Gorter, Stewart, and Woodbury-Smith 2011). However, young disabled peoples' own perspectives and experiences are central in order to understand matters of importance to them at their time of transitioning into adulthood. The aim of this study was to investigate the challenges a group of Icelandic disabled people experienced during their transition to adult life. Fundamental is depicting how they understand and react to these challenges, such as the pressures involved with conventional social expectations. The following research question was posed: What are the main challenges disabled people experience when transitioning into adulthood and how do they negotiate these challenges?

Entering adulthood

Milestones into adulthood have been linked with attaining specific markers, sometimes termed the 'big five' (Settersten, Ottusch, and Schneider 2015, 3): 1) finishing education, 2) obtaining employment, 3) leaving the childhood home, 4) shifting to independent living, and 5) building romantic and peer relationships (Nguyen, Stewart, and Gorter 2018; Settersten, Ottusch, and Schneider 2015). These traditional markers have been questioned for being taken-for-granted as 'proper' achievements of adulthood for everyone (Hamdani and Gibson 2019; Zittoun 2012), unachievable (Ljuslinder, Ellis, and Vikström 2020), and heavily biased towards positioning ideas of independence as the ultimate objective (Priestley 2003). They often fall short when looking at the lived experiences of many young people who maintain and rely upon relationships with family of origin rather than living independently (Gillies, McCarthy, and Holland 2001; Holdsworth and Morgan 2005). Some research even suggests a growing need for parental support during young adulthood (Gillies, McCarthy, and Holland 2001), including young disabled people who identify their parents as vital at times of transitioning (Austin 2000; Sanders 2006; Shah 2010).

Young disabled people's ideas about becoming adults are often not in agreement with prevailing norms and ideas (Hamdani and Gibson 2019). This is due to the multiple forms of discrimination they are faced with, such as lack of opportunities and support (Nguyen, Stewart, and Gorter 2018) stereotypical ideas and oppressive structural arrangements (Jóhannsdóttir, Egilson, and Haraldsdóttir 2022). Furthermore, numerous young disabled people live with uncertainty regarding changing health status that can impact their future. Thus, transitioning into adulthood may be especially complicated for disabled people who may face multiple barriers due to inaccessible environments and inadequate supports (Bekken 2022; Bekken, Ytterhus, and Söderström 2021; Lindsay et al. 2019; Priestley 2003; Slater, Ágústsdóttir, and Haraldsdóttir 2018; Smith and Traustadóttir 2015; Stewart et al. 2014).

Critical perspectives within disability studies and youth studies

Critical approaches examine taken-for-granted assumptions and the effects of prevailing ways of thinking in society (Kincheloe, McLaren, and Steinberg

2011). Ontologically, critical approaches share the assumption that reality is based on hierarchies of power privileging some and excluding others, leading to discrimination (Creswell and Poth 2018; Eakin et al. 1996; Meekosha and Shuttleworth 2009). Implementing a critical lens means applying a certain scepticism to the societal status quo by elucidating multi-dimensional structures of inequality, such as disability, age, gender, race, geographical location, and class (Creswell and Poth 2018).

Within both disability studies (Goodley et al. 2019) and youth studies (Ibrahim and Steinberg 2014) critical perspectives are becoming more prominent. By centring on disability justice and involvement of disabled people (Meekosha and Shuttleworth 2009; Oliver 2013) disability research increasingly seeks out disabled peoplés input as experts in addressing the marginalisation and exclusion they encounter in society (Bekken 2022; Egilson et al. 2021; Goodley et al. 2019). Ableism is a central concept to critical disability studies. It is a set of practices and knowledge which feed the idea that disability is negative. This is reflected by society that is first and foremost organized around and built to serve nondisabled people (Campbell 2009; Fine 2019; Goodley et al. 2019). The relevance of ableism to the study of transitioning to adulthood is significant as it shifts the focus from impairments as barriers to successful transition toward the socio-cultural hindrances that shape young disabled people's experiences (Jóhannsdóttir, Egilson, and Haraldsdóttir 2022).

Traditionally youth studies have emphasised research where the adult researcher is an outsider looking in through an adult lens, rather than actively seeking out young people's voices and experiences (Best 2007; Ibrahim 2014; Kamp and Kelly 2014). Recently research involving young people has expanded (Bailey et al. 2015; Liddiard et al. 2019a) along with the heightened awareness of young people's voices and as social actors (Curran and Runswick-Cole 2014). Assumptions regarding capacity to participate in research has been affected by this change in the acknowledgement of young people as active participants and less as subjects (Liddiard et al. 2019a; Tisdall 2017). To deepen our understanding of the nuanced lives of young disabled people, we sought their input as experts in the marginalisation and exclusion they may face during transitioning to adulthood (Egilson et al. 2021; Bekken 2022; Goodley et al. 2019) as well as their reactions to their social situations. We focused specifically on how prevailing social values, beliefs and societal dynamics influenced the young peoples' possibilities for entering adulthood. In line with the aims of critical research we strived to unmask assumptions, especially ableism.

The Icelandic context

Iceland is a high-income country and maintains a Nordic social welfare system where universal education and health care is provided, and disabled people are entitled to special services and assistance (Laws on services for disabled people with long-term needs for support, 2018). Although inclusive education is the guiding education policy (Bjarnason and Marinósson 2015) the inclusiveness of the system seems to fade out as students move through it with fewer inclusive settings for those students labelled as having 'severe' or 'profound' disabilities (Björnsdóttir 2017; Sverrisdóttir and Van Hove 2023). Relatively few disabled students attend higher education, and the dropout rates are high (Löve, Traustadóttir, and Sigurjónsdóttir 2010).

Historically, the labour participation of Icelandic youth is high and work status is among the generational identities of young Icelanders (Einarsdóttir et al. 2015). Despite legislative efforts to include and assist disabled people most young disabled adults neither attend school nor participate in the labour market (Tryggvadóttir, Snæfríðar Og Gunnarsdóttir, and Arnalds 2016). Reportedly this is in part due to stereotyped discriminatory views about disability held by educators and employers, who perceive disabled youth and young adults' life in terms of constrains and limits compared with their non-disabled peers (Rice and Traustadóttir 2011; Rice, Björnsdóttir, and Smith 2015). Other barriers to education and employment include a lack of adequate supports and services (Tryggvadóttir, Snæfríðar Og Gunnarsdóttir, and Arnalds 2016).

Materials and methods

This study was part of a larger research project focused on life quality and participation of children and young people in Iceland. The larger study design, and methodological and ethical considerations have been thoroughly described in an earlier publication (removed to avert identification).

Design

Guided by a constructivist grounded theory (CGT) framework proposed by Charmaz (2014), this qualitative study involved focus groups with young disabled people living in Iceland. Focus groups are a form of group interview that capitalises on communication among research participants to facilitate their exploring, clarifying and sharing personal views and experiences in ways that would be difficult in a one-on-one interview (Krueger & Casey 2014).

CGT begins with a broad topic that narrows as the research progresses. Research questions continually develop as they arise from issues of importance to the study participants. The implementation of CGT allows for inclusion of questions concerning social justice by supplying analytic tools that unfold how power, injustice, and marginality shape social conditions (Charmaz 2014, 2017; Charmaz, Thornberg, and Keane 2017). Unifying dimensions between CGT and critical studies are the ingrained focus on scepticism, the

rejection of a value-free inquiry, and the acknowledgment of societal positioning as a determining factor regarding outcomes in the empirical world (Charmaz 2014, 2017; Charmaz, Thornberg, and Keane 2017). CGT was chosen for this study as it focuses on dynamic social processes and allows for contextualising social justice and a close analysis of participants' own understandings of transitioning to develop.

Participants

Participants were recruited through advertisements on social media, personal networks within the Icelandic disability community and snowball sampling. We sought to recruit participants with a variety of backgrounds in terms of gender, age, residence, and impairment type that would reflect the multi-layered experiences of being disabled and young. Altogether four focus groups with a total of 21 individuals with various types of impairments (i.e. mobility, sensory, psychosocial or mild intellectual) were conducted. First, a pilot group of five people aged 30-50 years was conducted to refine and clarify the research focus and try out the initial interview guide. These participants discussed and reflected retrospectively on their transition experiences as youth. Their perspectives highlighted that transition is not a singular event or time point, but rather a continual process, which resonated with the experiences discussed by younger participants. Their pilot data provided rich descriptions about their transition challenges, thus a decision was made to include their data in the analysis. Data excerpts from pilot group participants are clearly specified in the findings.

The remaining three focus groups included disabled individuals aged 18–35 years. The second group included six people. To provide a safe space for discussing gender specific issues the third group included women only and the fourth group included men only with five participants in each group. Participants' genders were self-identified. Because of Iceland's small population, detailed description of participants is not provided to protect their identities.

Data gathering and analysis

The focus group interviews were conducted between September 2017 and September 2019, each one lasting approximately two hours. Topics for discussion included the participants' experiences related to transitioning to adult life, as well as their perspectives on their wellbeing, life situations and future goals. The discussion guide was open and fluid, providing for interactive space and allowing participants' stories to emerge (Charmaz 2014). The focus groups were transcribed by the researchers. The transcripts were then checked for accuracy and anonymised. The interviews were in Icelandic and excerpts were translated to English by the authors, care was taken to maintain their meaning.

Data gathering and analysis were performed concurrently in an iterative process of constant comparison between data, emerging codes and analysis. This involved extensive categorisation of data and identifying key concepts (Charmaz 2014). In keeping with Charmaz (2014), CGT analysis started following the first focus group session with a thorough reading of data and memo writing that continued for the remainder of the research project. Tentative categories and their properties were elaborated on, and data gaps were addressed in later focus group sessions. The software package ATLAS.ti-8 (Friese 2019) for Windows was used to keep track of the data, codes and memos.

Initially, data were coded by scanning for processes, actions, relationships, and emotions. Focused coding followed in which preliminary codes were examined and compared, and preconceptions of emerging topics were checked - unearthing codes with the most analytical potential, (Charmaz 2014). The major findings emerged after comparing the data sets and memos with the participants' lived experiences of transitioning. Instead of proceeding to theoretical coding, as described by Charmaz (2014) a critical lens was applied in the final analysis underscoring the multiple disadvantages and mutual processes of exclusion that affected the young disabled people's transitioning into adulthood and the way in which they negotiated these challenges.

Ethical issues

The informed consent process included giving participants written and verbal information about the purpose of the study, confidentiality, and anonymity and what their participation would involve. Afterwards, the participants confirmed their voluntary and informed consent by signing a form. Throughout the study measures were taken to protect the participants' identities. All identifiable information were removed such as by using pseudonyms. Emphasis was placed on complying with access needs, considering participants' different abilities and preferences, and giving them sufficient time and space to express themselves. To accomplish this, interviewers simplified language when necessary and, when called for, used sign language interpreters.

Data were gathered by two researchers who both identify as disabled and one of them, the first author, grew up chronically ill. Researchers' reflexivity was incorporated into the study process to raise preconceptions and power imbalances to a conscious level for scrutiny about how they might shape analysis. This involved extensive memoing to recap methodological issues and reflect on analytical dilemmas and directions. Memoing also included the

first author's brainstorming and experience of doing the study, as suggested by Charmaz (2014). Furthermore, the study process was regularly discussed with fellow researchers in the larger team and co-authors.

The research was approved by the Icelandic National Bioethics Committee (approvals no. VSN-16-187/-VI/-V2).

Findings

Participants in this study experienced and navigated several challenges during their transition to adulthood. These challenges are presented in four categories: 1. Being side-lined and excluded, 2. Facing doubts and negative assumptions, 3. Facing restricted choices, and 4. The quest for acceptance.

Being side-lined and excluded

All participants had encountered situations where they felt side-lined or excluded from spaces and activities associated with their age and life stage between childhood and adulthood. Hekla a 22-year-old woman labelled with intellectual impairment, said: 'nondisabled people look past us, we are invisible [and issues important to us as young adults] not spoken about.' For her and some other participants, such exclusion occurred routinely as their presence in adult spaces was not necessarily expected nor accounted for and their views and opinions of their future were not elicited or considered. Consequently they felt overlooked, and insignificant. Having limited power and say regarding their futures reinforced the tension between hopefulness regarding their future and feelings of alienation.

Being side-lined and excluded took on many forms. For example, participants with physical impairments emphasised how inaccessible physical environments hindered them in travelling freely and partaking in social activities and spaces for young adults, such as dating, clubbing, and work. Hera (27 years old) said: 'buildings [that] usually are not built for all body types', limited their access to many adult places. Examples of being denied access to social activities and spaces were also shared up to the point of a blatant refusal. Tara (43 years old) from the pilot group who identified as DEAF described the traumatic experience of having doors closed in her face at a social event during her high-school years, and then being asked by the organizer to leave the premises as she had no business of being there. Hekla had also been left-out and shared her experience in conversations:

Hekla: I think nondisabled people often do not bother to listen to us.Interviewer: Can you talk a bit more about that?Hekla: If I am talking to you and you just leave and I need to repeat myself...Interviewer: Do you mean that people do not stop to listen?

Hekla: Yes and I think it is so distressing and frustrating ... it has happened very often ... I am talking about something and they say 'yes okay' and leave. It makes me feel like they do not want to.

Steinn aged 24 also reflected on how he had been excluded based on his impairment:

Some people do not want to give me a chance ... When I have applied for jobs that I really want, it [the physical impairment] has been a barrier, people's attitude changes when they hear the word disabled, then they think: 'he is useless'.

Hekla's and Steinn's discussions of their experiences echo the ableist view that disabled people are less worthy due to their impairments.

In some instances, participants did not attend social gatherings to avoid being disappointed, as they were afraid of being excluded or that their needs for access would not be met. They described how the arrangement and structure of events and activities are often ableist in nature, e.g. when events for young people are advertised with short notice, then disabled people may be prevented from attending. Brynja aged 21 who has a hearing impairment said: 'sometimes I just decide not to even try to book interpretation because I know there is no chance, I will get it [with a short notice], so why bother.' In short term not attending, or self-excluding from social events could minimise the effects of feeling othered when not accounted for. However, repeated experiences of this kind strenghtened participants' feelings of being side-lined and excluded from adult spaces and activities in the long run.

Facing doubts and negative assumptions

Ableist assumptions and attitudes had negative consequences for participants' opportunities and access to adult roles and activities . Participants described how their capabilities were often ignored and that they were more strictly controlled and under surveillance by adults compared with their nondisabled peers. They often experienced ableist attitudes based on doubts about their abilities, reflecting negative presumptions about disabled people. Also, there was limited tolerance for behaviours which were considered 'atypical' such as regarding how to move, dress and behave in social situations. Gunnur, a blind woman in her forties who participated in the pilot group, reflected on her past experiences and stressed how ableism had influenced her possibilities at the labour market since youth:

I have always felt society thrusts disability upon me. I just have to disagree; I am aware that I do not have the same opportunities as nondisabled people in the labour market. However, this is also a question of attitude ... making conditions better, if they were better, I could work. I will not be a pilot or a truck driver there are limits [said in a sarcastic tone], but they are far fewer than people generally assume.

Most participants wanted to work but felt they were given limited opportunities. When Snorri aged 30 and with physical impairment reflected on his employment participation, he described how his first employer initially was hesitant to give him responsibilities. However, the employer's daughter supported Snorri in overcoming barriers at the workplace, which contributed to a positive experience. He said:

During the first months at the shop the employer was hesitant asking me to do stuff, rather she would do it herself. Her daughter is amazing, and she fought for me to get the job ... today my employer trusts me with anything.

When given opportunities Snorri and others were often able to demonstrate their competencies. However, even when participants were actively participating and visible in everyday spaces and activities, doubts of other about their abilities persisted. Arnar a 23-year-old man with physical impairment had repeatedly met customers who did not understand that he was an employee at a speciality shop:

I work as a shop assistant and customers never come and ask for my help because they cannot fathom, that I work there ... I always have to seek out customers and prove that I actually work there, and people always go: 'What, ehh, yes, assistance?' [said in an embarrassing tone]. Once I offered someone assistance and they thought I was asking for help going out the door [Arnar smirks].

Similarly, participants who received disability benefits discussed experiencing negative beliefs about their misuse of such benefits. Steinn had applied for disability benefits because he was only able to work part time. On top of that, he had to argue and prove that he was eligible for these benefits, even to people close to him: 'Not only were my opportunities limited because of my impairment but I also had to debate my disability benefit with a friend of mine because he thought me having them unfair'. Thus Steinn suggested that his friend held ableist beliefs about what counts as being disabled with respect to being eligible for benefits.

Such ableist ideas about typical ways of being and doing did not allow for fluid capabilities and even thrusted participants into roles seen as less worthy. This was most notable among people with intellectual disabilities who often were infantilised, and among participants with dynamic disabilities who had to justify their fluid situations to escape being marked as 'lazy welfare system cheaters' (Steinn's words). Being treated with suspicion and negativity, was emotionally draining and it in some cases affected participants sense of worth.

Facing restrictive choices

All participants described having restricted choices when transitioning into adulthood. Vilmar aged 23, captured the general sentiments of many

participants when he said, sarcastically: 'it should be okay to allow us to choose what we want to do, and where we feel at our best.' His account suggested that family members, service providers and others often manipulated or restricted the choices he had regarding what to do and how to do it.

Having choices regarding activities, events and other forms of adult socializing was seen as fundamental. Due to the participants' different characteristics, situations and preferences there was a great diversity in the examples they brought up. Most preferred to socialise with friends who had similar interests and did not specifically seek out disabled friends. Few, most notably those labelled with intellectual disabilities, valued being with disabled peers in certain circumstances, a safe space where they could be free from ableist judgements and comments. In the youngest participant and Hekla from the women's focus group discussed this:

Ína: I am learning to be a trainer [names sport] and I want to have classes only for disabled people ... and provide a safe space where no one judges you.

Hekla: We need more classes only for us like CrossFit.

Although Ina and Hekla wanted the possibility of disabled-only events they also emphasised having more choices as becoming adults. As an example, their choices regarding education were restricted since they lacked formal access to the higher education system and the available options were not necessarily meaningful to them. Ina continued:

I am excited about the University and the diploma but simultaneously I find it unfair that this is the only study course open for disabled people. In this course they are preparing you for work in preschools, after school clubs or in libraries, all jobs that are fine with me. But still choices are being made for us, where we are supposed to work ... I am a bookworm and would like to learn social studies.

Participants with mobility impairments emphasized how inaccessible built environments hindered their access to adult spaces which limited their possibilities for participating in chosen activities and with chosen people. For participants with hearing impairments having access to and choices regarding sign-language interpretation was paramount to ensuring their independence and possibilities to engage in valued roles at present and to prepare for the future. Ella aged 20 who had a physical and hearing impairment reflected on the importance of choice regarding personal assistance and sign-language interpretation:

I do not want to be dependent on my parents, I do not want to be a burden, I ask them [parents] for assistance on matters not concerning my disability. For instance, my dad is a financial advisor and I ask him about finances, and we argue about it because both of us are financial nerds. But for everyday living I want my own assistants and sign-language interpretations and to choose who assists me because I do not want to be with just anybody, no thank you!

Although Ella liked to do certain things together with her family, she found it important to live independently and be in control over her daily activities with the support of her personal assistants. Similarly Lena, aged 28, valued her family's support but wanted someone else than her mother to assist her with finances:

Lena: I really want to try to take care of my finances, but I think that I will make a mess of it. Interviewer: You have not been doing that? Lena: No, my mother has been doing it for years. Interviewer: What is needed for that to be possible? ...

Lena: Assistance with money ... It is so embarrassing. If I go to the shop and there is not enough credit on my card, I always need to call my mother [lowers her voice]. 'Mum can you add credit to my card?' I feel like a baby [when this happens].

It is uncertain whether Lena's mother took care of Lena's finances because there was no other assistance available, or because she believed Lena was childlike, incapable, and dependent, and therefore could not take care of her finances on her own. Either way Lena's ideas and wants were dismissed which restricted her choices regarding reaching independent adulthood.

Ableism shaped what choices were possible and allowable for participants. Anna aged 29 labelled with intellectual impairment initially claimed she did not want to become a mother. After some discussions with the interviewer, she revealed that it was not really about her own wishes but instead about her mother being worried that the burden of childcare would fall on her because she did not believe Anna was capable of taking care of a child. When asked if she wanted to become a mother if sufficient support was available Anna answered, 'yes of course'. Nevertheless, she didn't believe that was a realistic option.

Overall, strong concerns were raised about how young disabled people were not consulted, their needs and wishes not acted on and their choices for adult life such as regarding education and parenthood were restricted.

The quest for (self)-acceptance

Being accepted and valued as a disabled person, rather than in relation to nondisabled people, was identified as important by all participants. However, ableist norms constrained and limited their opportunities for participation in valued adult roles as well as their acceptance in society. In some cases such norms had also influenced participant's acceptance of self as a result of living in an ableist world. In retrospect, pilot group participants and some of the others regarded transitioning successfully into adulthood as finding and using their own voice and being socially accepted. Nevertheless, this was not something that could be taken for granted but typically required: 'double effort and hard work' (Tara's words). Örn aged 26 from the men's group who had physical impairment had recently moved to the capital area where he applied for jobs without success. In his earlier job applications, he had always disclosed his impairment but one day he changed his tactic:

I went and told the guy that I had not wanted to disclose beforehand that I am a wheelchair user, and he goes: 'I would have offered you the job anyway. I know where you have worked and where you are from. People from there I know are hard workers.' I was like [in a frustrated tone]: 'why did I not disclose my disability?'

So, after many earlier rejections Örn was finally offered a job. Örn's experience also underlines the importance of social networks, and if he had been from another town the outcome might have been different. Alma, aged 25, reflected on ways of transitioning into adulthood as a disabled person:

Disability is a part of you just like being blond ... but what most people see as disability is its connection with difficulties doing or not being able to do something. The dream is to take part ... and not having to prove yourself all the time, that you being there is just natural. Not having to hang on to disability quotas ... there should not have to be a special treatment to ensure disabled people's participation [at times of transitioning].

Alma's discussion explicates that although measures need to be taken to facilitate transitioning into adulthood so that young disabled people can access and maintain valued roles, such measures and quotas also position them as 'in need of' intervention. It does not come automatically or 'naturally' compared to non-disabled people, which again reflects embedded assumptions of ableism.

Participants underscored their desired ways of transitioning into adulthood and emphasised justice, dignity, and being entitled onés own space, purpose, and opinions. Líf a woman with physical impairment who participated in the pilot group reflected on being disabled and still considered worthy. She called this social safeness, which afforded her with validation, security, and goodness of life:

Social safeness ... when you are entitled to your space, and you have a purpose, and you can hold opinions. As a disabled woman I have had to fight for it [since my teenage years]. You have to be inventive finding resources for gaining and finding social safeness ... and when you have found it that is an incredible feeling of serenity, then life is good.

When Lif reflected on the process of transitioning she came to the conclusion that social safeness was the ultimate goal for successfully reaching adulthood and ultimately living a good life where you are accepted by yourself and by the environment.

Although accounts of not being valued or fully accepted as adults were prevailing, examples of the opposite were also shared. In fact, almost all the

pilot group members had come to terms with their transitioning experiences and found valued paths. They underscored disability solidarity and peer support as a vital part of transitioning successfully into adulthood. All the participants in this study emphasized the importance of being accepted for who they were and to have opportunities and safety equal to others – to be valued as part of human diversity.

Discussion

This study explored young disabled people's main challenges when transitioning to adulthood and how they negotiated these challenges. Below the findings are discussed in more detail.

The young disabled people in our study faced myriad of barriers when transitioning into adulthood, which is consistent with other researchers' findings (Bekken 2022; Gibson et al. 2014; Lindsay et al. 2019; Priestley 2003; Slater, Ágústsdóttir, and Haraldsdóttir 2018; Smith and Traustadóttir 2015; Stewart et al. 2014). This included inaccessible physical and social environments, discriminatory attitudes, lack of expectations, limited choices, and inadequate supports. Due to these barriers traditional transitioning trajectories: finishing education, obtaining employment, leaving the childhood home, shifting to independent living, and building romantic and peer relationships (Nguyen, Stewart, and Gorter 2018; Settersten, Ottusch, and Schneider 2015) were not achievable to many participants. And although most participants criticized these markers as being rigid, they had in fact all strived hard to reach them.

Our findings highlighted a complex dynamic in which ableist ideas about disability associated with inaccessible structural arrangements often perpetuated beliefs about participants as unworthy and unable to undertake adult roles and responsibilites (Campbell 2009; Jóhannsdóttir, Egilson, and Haraldsdóttir 2022). For example, disabled people trying to work was difficult because of automatic assumptions portraying disabled people as unable to fullfill duties In other instances the opportunities available failed to meet their wants and needs. All had experienced that other people were fixated on their impairments, overlooking their other personal traits.

Numerous examples of being side-lined and excluded were shared such as being seen as inferior, and on occasions as invisible. Access to social spaces, activities, and opportunities typical for young people was often restricted or simply denied. Trying to gain access could be stressful and involved the risk of being hurt as it was unclear whether one would succeed or fail because of other peoplés lack of expectations, limited flexibility or will to accommodate their needs. Success often depended on support from family and friends who vouched for participant's capabilities, which coincides with previous research (Austin 2000; Shah 2010). Although the support of others was often appreciated, most participants emphasised their want to succeed on their own merit. This demonstrates the importance of being in control in onés life as an important marker of reaching adulthood. Simultaneously it may also reflect underlying ableist assumptions which value highly all forms of independence. As stated by Campbell (2012, p. 212) 'We all live and breathe ableist logic', which may affect disabled people just as much as other people.

Whilst the support from family was often considered valuable, there were also examples in which family support was lacking but desired. Earlier research has demonstrated that family members can act both as a source of support (Austin 2000; Sanders 2006; Shah 2010) and a hindrance (Mitchell 1999; Priestley 2003) at times of transitioning. This was especially complicated when family members on whom the youth counted on for support, demonstrated ableist beliefs about disability (Bell 2018) such as doubting their abilities, were overprotective, or showed forceful behaviour towards their strive towards the adult role. This was most notable among young people labelled with intellectual disabilities although similar stories were shared by other participants. This can best be described as complex interplay between support and independence. Too much parental involvement easily undermines one's sense of independence while lack of support can lead to failure to succeed in new roles and responsibilities (Holdsworth and Morgan 2005; Priestley 2003).

Participants described their experiences of dealing with patronising comments and practices as challenging and tiresome. They also discussed that subtle and more aggressive provocations threatened their identity and well-being. Examples of internalising ableism (Jóhannsdóttir, Egilson, and Haraldsdóttir 2022) were reflected in some of the young people's accounts about limited faith in their abilities. A few people labelled with intellectual disabilities described being stuck in stagnant childlike roles (Björnsdóttir, Stefánsdóttir, and Stefánsdóttir 2015) which they nevertheless actively resisted by their critical stance of status quo. Similarly, participants with dynamic disabilities were often met with the disbelief of others about their fluctuating capabilities, and constantly needed to justify their fluid situations, even to people close to them.

Most of the young people in this study faced restricted choices that were not meaningful to them, did not reflect their lifestyle or identity and undermined the idea of who they wanted to become (Priestley 2003). This was notable regarding finances and social events but also in relation to their education and the labour market. To some extent, participants accepted having restricted choices, especially those labelled with intellectual disabilities, who occasionally did not question limited options or other people's interference and involvement in their choice-making. Prior research has shown that such experiences can lead to diminished self-confidence and self-esteem (Björnsdóttir, Stefánsdóttir, and Stefánsdóttir 2015) and even cause the self-exclusion which some of the young disabled people in our study practiced to avoid disappointments.

In Icelandic society successful transition into adulthood is associated with implicitly agreed upon characteristics of a 'proper' adult status, not the least in terms of labour participation (Einarsdóttir, Einarsdóttir, and Rafnsdóttir 2015). This was a major dilemma for many of the young people in this study who had faced barriers in the labour market due to negative stereotyped attitudes about disability. These findings align with previous Icelandic research that demonstrate that most young disabled people are unemployed and rely on disability pension (Tryggvadóttir, Snæfríðar Og Gunnarsdóttir, and Arnalds 2016). By doing so they take a marginalized position in society, often associated with prejudice and negative attitudes (Rice and Traustadóttir 2011). Some participants had also been denied access to adult roles such as parenthood and living independently which in their opinion reflected their unsuccessful transition into adulthood. They emphasised their longing for more opportunities and to be accepted for who and as they were. They desired respect and validation instead of being seen as less or dismissed based on their impairment. A few participants termed this guest for meaningful choices and being on equal terms in interpersonal relationships without having to fight or prove their worth as the attainment of 'social safeness'. It should be noted that consistent with previous research (Curran et al. 2021; Liddiard et al. 2019b) many participants lived active lives, had plans for the future, and some had in fact experienced the social safeness they regarded as a precursor for successful transition. However, they had all worked extra hard to prove themselves to others and had themselves been influential in creating safe social spaces.

Overall, trust, solidarity and disability pride characterized the focus group discussions where participants with different types of impairments found closeness in discussing the challenges they had encountered during their transitioning to adulthood. Although many of their experiences differed mutual understandings, respect and safety facilitated rich discussions about sensitive issues, not the least in the women's group. Thus an important lesson to be learned from this study is how powerful such shared understandings can be and possibly act as a protective factor on the road to adulthood.

As aforementioned, although the young disabled people criticized the narrow and ableist norms of being and doing, they nevertheless wanted to approximate them, and to have choice and opportunities for living a valued adult life. The critical disability studies lens helped illuminate the intersecting sociocultural mediators that affected the young people's transition possibilities, and problematise the taken-for-granted norms of becoming an adult.

It is important to widen understanding and acceptance of difference and diversity (Hamdani and Gibson 2019) such as by recognizing and legitimatizing different ways of being and doing in the world.

Concluding remarks

Transitioning into adulthood is complicated for all youth but particularly so for marginalised young people, such as young disabled people (Priestley 2003; Smith et al. 2011). We argue that the added challenges young disabled people experience during their progression from childhood to adulthood are based on ableism, lack of opportunities and other injustices which influence how other people perceive them and respond to their circumstances. However, since transitioning into adulthood is strongly influenced by cultural and historical factors (Priestley 2003; Scott 2009) it is amenable to change, as ideas for what counts as an adult have changed and transformed over time, as well as ideas about disability. We underline the importance of dismissing the rigid ableist ideas about adulthood and disability that have persistently excluded young disabled people and instead provide opportunities for multiple ways for being an adult. It is important to consult with young people on how to promote necessary changes and provide adjustments and supports to facilitate their strive for adulthood.

Disclosure statement

No potential conflict of interest was reported by the authors.

Funding

Icelandic Centre for Disability Research

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