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Thesis for the degree of PhD

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Ungt fatlað fólk á vegferð til fullorðinsára: Úrlausnarefni og áskoranir

´Mér er alveg sama hvað þeim finnst, ég er sátt við mig eins og ég er´

Anna Sigrún Ingimarsdóttir

Ritgerð til doktorsgráðu í fötlunarfræði

Leiðbeinandi

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Ágrip

Unglingsárin marka tímabil mikilla breytinga þar sem einstaklingur færist frá því að vera barn yfir í að verða fullorðinn. Umbreytingar unglingsáranna geta falið í sér að ná tilteknum áföngum er varða þroska eða sjálfræði og endurspegla breytta stöðu einstaklingsins í félagslegu og menningarlegu samhengi. Markmið þessarar doktorsritgerðar var að skoða reynslu ungs fatlaðs fólks af þessu lífsskeiði með það fyrir augum að draga fram og miðla upplifun þess og reynslu af því að feta veginn til fullorðinsára. Ennfremur að skoða hvaða hugmyndir og væntingar þau höfðu um það að verða fullorðin, áskoranirnar sem þau tókust á við á þeirri vegferð og áhrif þessa á sjálfsmynd þeirra og sjálfskilning.

Rannsóknin samanstendur af fjórum fræðigreinum. Sú fyrsta fjallar um hvernig fötluð börn og ungmenni upplifa möguleika sína til þátttöku heima fyrir, í skóla og í samfélaginu og hvað þau töldu mikilvægt til að lifa góðu lífi. Jafnframt er horft til þess hvernig félags- og efnislegir þættir mótuðu aðstæður þeirra. Önnur greinin beinir sjónum að ungu fólki, hvernig það tókst á við margþættar hindranir á vegferðinni til fullorðinsára og fann sinn sess í lífinu. Þriðja greinin beinist að þátttöku unga fólksins á djamminu, mikilvægum félagslegum vettvangi sem þeim reyndist oft erfitt að fá aðgang að. Þar er rýnt í merkingu djammsins í lífi unga fólksins og hvernig það tókst á við hindranir. Doktorsverkefnið er hluti rannsóknarverkefnisins Lífsgæði og þátttaka barna og unglinga: Umbreytingarannsókn (LIFE-DCY) sem var styrkt af Rannís (174299-051) og í fjórðu greininni er fjallað um rannsóknarverkefnið í heild og helstu niðurstöður þess. Þar er jafnframt greint frá hugmynda- og aðferðafræði rannsóknarinnar og siðferðilegum álitamálum sem henni tengdust.

Rannsóknin var byggð á blönduðu rannsóknarsniði þar sem meðal annars var notast við tilviksathuganir með fötluðum börnum á aldrinum 11 til 15 ára. Einnig var stuðst við rýnihópaviðtöl með ungu fötluðu fólki á aldrinum 18 til 35 ára. Rannsóknin byggði á grundaðri kenningu, innan ramma félagslegrar mótunarhyggju, og var unnin í anda gagnrýninna fötlunar- og ungmennafræða. Lykilhugtökin, adultismi og ableismi, voru nýtt til að rýna í viðteknar hugmyndir um ungt fatlað fólk og hvernig þær spegluðust í reynslu þátttakenda. Raddir og reynsla unga fólksins voru miðlægar í rannsókninni allri.

Unga fólkið vildi takast á við hefðbundin fullorðinshlutverk og láta að sér kveða á félagslegum vettvangi en þeim mættu marglaga hindranir sem drógu verulega úr aðgengi þeirra og tækifærum til þátttöku til jafns við jafnaldra. Félagsleg viðurkenning var unga fólkinu mikilvæg og mörg lögðu hart að sér til að fá samþykki. Sú viðleitni gat skapað togstreitu þar sem þau fundu sig knúin til að fela eða afneita fötlunartengdum þörfum sínum til að mæta normatífum viðmiðum. Þetta úrlausnarefni var mörgum þungbært.

Niðurstöður rannsóknarinnar sýna glögglega hvernig ableismi og adultismi birtist í daglegu lífi ungs fatlaðs fólks, bæði leynt og ljóst. Helsta nýnæmi þessarar rannsóknar er umfjöllun um samlegðaráhrif ableisma og adultisma sem leiddu af sér flóknar og þversagnarkenndar áskoranir. Til var ætlast að unga fólkið tæki þátt í aldurstengdum verkefnum þótt þau fengju hvorki svigrúm né nauðsynlegan stuðning til þess. Taumhald hinna fullorðnu, sem hafði gjarnan aðrar hugmyndir og væntingar en unga fólkið sjálft, takmarkaði frelsi þess til að prufa sig áfram.

Rannsóknin sýnir hvernig ráðandi hugmyndir um vegferðina til fullorðinsára mótast af ableískum og adultískum hugmyndakerfum sem undanskilja og útiloka mannlegan margbreytileika, svo sem meðal fatlaðs ungs fólks sem ekki getur fylgt þessum fastmótaða ramma. Óaðgengilegt umhverfi, óviðunandi þjónusta og kerfisbundnir fordómar gagnvart fötluðu fólki skapa hindranir og grafa undan möguleikum þess að njóta áheyrnar og að fá réttan stuðning á eigin forsendum.

Lykilorð:

Ungt fatlað fólk, breytingar, ableismi, adultismi, áskoranir

Abstract

Transitioning into adulthood presents challenges for all youth, but particularly so for young disabled people, whose lives are shaped by normative expectations around age and ability. This doctoral research explores young disabled people's reflections and lived experiences regarding the possibilities and challenges they faced before, during, and beyond their transitions into adulthood. It investigates how deeply embedded societal assumptions about disability and youth shape their pathways, opportunities, and self-image during these critical life stages.

This study comprises four articles. The first one explores how disabled children and youth understand their possibilities for participation and wellness at home, in school, and in their communities, and how socio-material conditions intersect to shape their situations. The second article highlights the views of young people currently navigating transitioning to adulthood well as those reflecting on their experiences retrospectively. It provides a broad view of the transitioning process by capturing both individual and shared experiences. The third article offers insights into young disabled people's partying experiences, to understand what partying meant for them and how they navigated party spaces. The fourth article draws on the larger LIFE-DCY project and provides a reflexive account of its methodological, conceptual, and ethical considerations and synthesizes of key findings.

The study was conducted within the framework of the LIFE-DCY project, funded by the Icelandic Centre for Research (174299-051), and employed a qualitative, multi-method research design. It included in-depth case studies with disabled children aged 11–15 and key figures in their lives, as well as focus groups with young disabled people aged 18–35. The research was informed by constructivist grounded theory and emphasized the co-construction of meaning between the researcher and the participants. Inspired by critical disability studies and youth studies, the research drew on the concepts of ableism and adultism to illuminate how normative structures and beliefs systematically constrained the young people's experiences. In keeping with the principles of critical disability studies, the research was committed to centering on the voices and experiences of the young people, who were seen not only as participants but as experts with vital insights into their lives.

The young disabled people actively sought to engage in transitional milestones and peer activities, which they saw as essential during their transition to adulthood. However, participation often involved navigating a range of barriers—such as inaccessible built environments, pervasive stereotypes, low expectations, and inadequate support. The findings showcase the widespread impact of ableist and adultist attitudes that shaped interactions in schools, services, and public life, often in ways that reduced opportunities for participation, belonging, and recognition. Whether, and to what extent, the young people were able to participate alongside their peers depended on socio-material arrangements such as access, the availability of appropriate support and how well they were able to assimilate taken-for-granted norms. While many sought to meet these norms to attain a valued adult life, they also pushed back against the ableist ideals underpinning them.

The analysis yielded three key insights. First, the young disabled people had to navigate complex barriers - including inaccessible systems, low expectations, and limited opportunities to participate in meaningful settings. These challenges disrupted their transition to adulthood and hindered their efforts to move forward. Second, they were caught in a double-bind of ableism and adultism as they were simultaneously held back and held to impossible standards—expected to ‘act their age’ while being denied the support and freedoms typically associated with that age. Third, structural gaps and poorly aligned services compounded the young people´s marginalization, making it difficult for them to participate meaningfully in society on their own terms. These structural failures often had significant consequences for their sense of self, social inclusion, wellness, and their experience of emerging adulthood.

The study highlights how dominant narratives about transition and adulthood draw upon rigid, linear, and able-bodied timelines that fail to account for the diversity of young people’s lives. Inaccessible environments, fragmented services, and normative assumptions create barriers that undermine young disabled people’s efforts to be seen, heard, and supported on their terms. Ultimately, this dissertation study contributes to ongoing discussions and debates in disability and youth research, advocating for a reimagining of transition frameworks, calling for more inclusive, flexible, and justice-oriented approaches that recognize the structural, cultural, and relational dimensions of growing up disabled.

The findings highlight how ableist assumptions, often reinforced by inaccessible environments and a lack of awareness about their needs, continue to shape how YDP are seen and treated in ways that undermine their emerging sense of self.

Notions regarding transitioning and emerging adulthood are rigid and ingrained with unfair and often unrealistic markers that may fit some but not all.

Keywords:

Young disabled people, transitions, ableism, adultism, challenges

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Contents

List of Abbreviations

AI	Artificial intelligence
CDS	Critical disability studies
CGT	Constructivist grounded theory
CRC	UN Convention on the Rights of the Child
CRPD	UN Convention on the Rights of Persons with Disabilities
LIFE-DCY	Life Quality and Participation of Disabled Children and Youth: A Transformative Study
YDP	Young disabled people

List of Original Papers

This thesis is based on the following original publications, which are referred to in the text by their Roman numerals (I, II, III and IV). In articles I, II and III, I served as first author where I collected the data and had a leading role in data analysis, writing and editing. My contributions in article IV included collaborative development of conceptual frameworks, participation in qualitative analysis, and involvement in writing and editing. This consisted of assisting in refining the narrative, clarifying implications, and ensuring coherence throughout the paper.

I. Ingimarsdóttir, A. S., & Egilson, S. T. (2024). "I just want to live my life": Young disabled people's possibilities for achieving participation and wellness. *Social Sciences*, *13*(1), 63. https://doi.org/10.3390/socsci13010063

II. Ingimarsdóttir, A. S., Björnsdóttir, K., Hamdani, Y., & Egilson, S. Þ. (2023). 'Then you realize you can actually do it': young disabled people negotiating challenges during times of transitioning into adulthood. *Disability & Society*, *39*(11), 2775–2795. https://doi.org/10.1080/09687599.2023.2226317

III. Ingimarsdóttir, A. S., Björnsdóttir, K., Hamdani, Y., & Egilson, S. Þ. Let us talk about our party stories: Young disabled people out on the town. Submitted for publication in the International Journal of Disability & Social Justice.

IV. Egilson, S. T., Ólafsdóttir, L. B., Ingimarsdóttir, A. S., Haraldsdóttir, F., Jóhannsdóttir, Á., Gibson, B. E., & Hardonk, S. (2021). Life quality and participation of disabled children and young people: Design and methods of a transformative study. *International Journal of Qualitative Methods*, *20*. https://doi.org/10.1177/16094069211016713

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1 Introduction

The importance of supporting young disabled people (YDP) to live well and participate fully in society is firmly established in international human rights frameworks, including the Convention on the Rights of the Child [CRC], (1989) and the Convention on the Rights of Persons with Disabilities [CRPD], (2006). Despite these commitments, YDP remain among the most marginalized and disadvantaged groups globally (United Nations [UN], n.d.-b). They continue to face persistent barriers to acceptance and inclusion, and prior research highlights significant disparities in their opportunities for participation and wellness compared to their non-disabled peers (Bedell et al. 2013; Egilson et al. 2017, 2018; Hamdani et al. 2018, 2022; Imms et al. 2017; Ólafsdóttir et al. 2019; Pearson et al. 2025). There is a growing recognition of the importance of promoting the social participation and wellness of YDP and children (Egilson et al. 2018; Hamdani et al. 2018, 2022; Krieger et al. 2018; Ólafsdóttir et al. 2019; Smith et al. 2021). A key dimension of this effort involves understanding how YDP navigate the transition into adulthood and the barriers they are met with.

In research traditions, the transition to adulthood is frequently associated with achieving a set of milestones—sometimes referred to as the 'Big Five' (Settersten et al., 2015, p. 3): (1) finishing education, (2) obtaining employment, (3) leaving the childhood home, (4) shifting to living independently, and (5) building romantic and peer relationships. However, conceptualizing these transitions is complex with underlying ideas laden with normative assumptions – grounded in nondisabled experiences (Smith & Dowse, 2019). Furthermore, transitions are not experienced in a vacuum but are deeply shaped by social, cultural, and institutional contexts, which influence what is considered a 'successful' path to adulthood. Successfully approximating these markers depends on a range of interrelated factors, including access to personal, familial, and social resources, the quality of support received, and the dynamic interaction between individuals and their environments (Furlong et al., 2011; Priestley, 2003; Woodman & Bennett, 2015).

At the time of writing, we are living through turbulent times marked by global uncertainty in the wake of the COVID-19 pandemic, ongoing conflicts, and economic instability. While these challenges affect many, disabled people continue to be disproportionately affected due to entrenched structural inequalities, under-resourced systems, and persistent ableism (Bixby, 2024; Goodley, 2025; Wong, 2020). In this context, it is vital to amplify and critically engage with the concerns and lived experiences of disabled communities. This PhD project contributes to the ongoing conversation focusing on YDP prior to and during transitional periods by critically examining the societal structures and social relations that shape their experiences and opportunities as well as the assumptions made about them. Grounded in a commitment to disability justice, I hope this research will inspire critical awakening.

The research was conducted as part of a larger project titled "Life Quality and Participation of Disabled Children and Youth: A Transformative Study" [LIFE-DCY] (Egilson et al., 2021). The purpose of the LIFE-DCY project was twofold: firstly, to evaluate children's and YDPs quality of life as reported by themselves and their parents, and secondly, to locate commonalities, differences, and conflicting issues in the processes that may influence disabled children's and YDPs' life quality and participation. The LIFE-DCY research was funded by the Icelandic Research Fund (grant number: 174299051) and the University of Iceland Research Fund (2018—2019). This PhD project was furthermore granted funds from the research fund Vísindi og velferð: Styrktarsjóður Sigrúnar og Þorsteins in 2025.

1.1 Purpose and aims

The purpose of the PhD project is to critically explore the complex nuances of transitioning from childhood into adulthood. Grounded in the experiences of YDP, with additional insights from their parents and teachers, it furthermore aims to capture the issues that YDP deem important and illuminate how societal structures impact their lived experiences before, during and beyond this transition. The research questions evolved in tandem with my growing understanding of the research topic and its findings, and are as follows:

1. How do children and young disabled people navigate transitioning and make meaning of their path within a broad socio-material context?
2. How do ableist understandings of adulthood influence young disabled people's experiences?
3. How does adultism intersect with ableism to impact young disabled people's experiences of transitioning into adulthood?

To address these aims and questions, a qualitative inquiry was conducted, guided by a critical disability studies (CDS) lens (Goodley et al., 2019). The data collection involved focus groups and individual interviews with YDP, and case studies with children aged 11-15 years, their parents and teachers. Document reviews and participant observations were part of the data-gathering process. The data analysis followed constructivist grounded theory (CGT) (Charmaz, 2014) which has proven to be well-suited for critically informed research (Charmaz, 2017, 2019; Meekosha & Shuttleworth, 2009). In order to incorporate critical social contexts, the data were analysed through the lenses of ableism (Wolbring, 2008) and adultism (Bell, 2003). These frameworks helped illuminate both overt and subtle forms of discrimination, including microaggressions, that often go unnoticed but have a cumulative impact on disabled people (Kattari, 2019).

The findings are presented in four academic articles:

Article I, "'I just want to live my life': Young disabled people's possibilities for achieving participation and wellness'" features case studies with children and younger adolescents and sheds light on how they experience and understand key aspects of growing up. Although participants' reflections centered on the present, many also expressed curiosity about their futures, wondering what they might do later in life and how to pursue their goals. They expressed desire to be included in social activities, particularly alongside their peers, and emphasized the importance of support in enabling participation and overall wellness. The findings, grounded in the insights of younger participants, offer a valuable entry point to understanding how early experiences shape the broader transition to adulthood.

Article II builds on the foundation established in the first article but shifts the focus to participants aged 18–35 who were either actively navigating transitions or reflecting on them retrospectively. The article titled "'Then you realize you can actually do it': Young disabled people negotiating challenges while transitioning into adulthood" provides a broad view of transition by capturing both individual and shared experiences. To explore these experiences, a series of focus group discussions was conducted. Across all focus groups, participants reported similar challenges, including inaccessibility in the built environment and enduring ableist assumptions. These issues proved particularly challenging for participants to navigate in their journey into adulthood.

In the focus group discussions, participants were invited to reflect on what they considered essential to a good life as young adults. A recurring topic raised in the groups was the importance of partying and socializing downtown with peers. Thus, the focus of the research shifted toward partying experiences of YDPs, with the aim to understand what partying meant for them and how they navigated party spaces. Article III, "'Let us talk about our party stories': Young disabled people out on the town", delves into participants' partying experiences and – through the lenses of ableism and adultism – sheds light on how social forces impacted these experiences. The findings show partying as an exciting opportunity to be and connect with peers and their larger environment, which becomes increasingly important at times of transitioning into adulthood. The article furthermore delineates how access to this social setting is frequently restricted by structural factors and stereotypes.

Article IV, which is the final article of the dissertation, is titled "Life quality and participation of disabled children and young people: Design and methods of a transformative study". It offers a broader perspective on the LIFE-DCY project as a whole, discussing the research journey, the methodological approaches and key lessons learned. Grounded in a mixed-methods design, the article draws on extensive quantitative and qualitative data to offer a comprehensive view of the life quality and societal participation of disabled children and YDPs. Unlike other articles in this dissertation, which focus primarily on pre-teens, youth, and young adults, this article includes the experiences of younger children.

1.2 Positionality and terminology

My interest in young people and the transition into adulthood began when I was a social work student in 2010. As a young disabled woman with chronic illness, the issues facing disabled youth resonated deeply with me. This was the inspiration for my BSc project, which focused on how chronically ill youth transition from children's hospitals to adult wards (Ingimarsdóttir, 2010). While working on the BSc, I encountered a wealth of literature that framed transition not as a single handover from children to adult services, but as a continuous, multifaceted process. This perspective emphasizes the importance of considering psychosocial, educational, and vocational dimensions alongside those of healthcare (Bekken et al., 2021; Gorter et al., 2011; Nguyen et al., 2018). These insights sparked a lasting interest in the topic, particularly from the perspective of my lived experiences as a YDP.

The term young disabled people (YDP) is used throughout the dissertation, referring to individuals aged 15-30 who identify as disabled or chronically ill. According to the UN, (n.d.-a), those aged 15-25 fall under the definition of youth. However, the concept of youth is fluid, shaped by cultural and contextual factors that can expand or narrow the age range it encompasses (UN, n.d.-a). Accordingly, this project does not focus solely on chronological age but instead considers how presumed incapacity for autonomy is culturally assigned, particularly to those who are both young and disabled (Moore, 2020; riley, 2023). Furthermore, the term YDP corresponds with the project's theoretical framework, acknowledging that disability results from the interaction between young individuals with impairments and their environments. An exception to this terminology is made when referring to individuals with intellectual disabilities and children on the autism spectrum, for whom people-first language is used as is customary within disability research. In contexts where bodily characteristics are in focus—the term impairment is used instead.

1.3 Overview of the thesis

The thesis is structured into six chapters. The following chapter, Chapter 2, lays the groundwork by introducing the theoretical frameworks and core concepts that underpin the project along with human rights treaties and legislation important to the topic. In Chapter 3 the study context is explored and key literature on the experiences and identities of YDP discussed as well as literature addressing the transition to adulthood. Chapter 4 outlines the methodology and methods employed in the research and considers the ethical considerations as well as the strengths and weaknesses of the research project. Chapter 5 presents a concise summary of the findings of the four peer-reviewed articles. Finally, Chapter 6 delves further into the findings, offering deeper analysis and interpretation.

2 Theoretical framework

This chapter introduces the theoretical framework and the core concepts that shaped the project. It begins by briefly discussing the social understanding of disability (Oliver, 2013) which provided the foundation for evolving CDS, the main perspective underpinning this research. The chapter then explores key constructs central to critical inquiry, including ableism (Wolbring, 2008), adultism (Flasher, 1978) and microaggression (Kattari, 2019; Sue, 2010). These concepts offered essential analytical and critical insights throughout the project, shedding light on the nuanced challenges and everyday barriers that YDP encountered during their transitions into adulthood.

Additionally, the chapter introduces the concepts of wellness (The Global Wellness Institute, n.d.) and participation (Imms et al., 2016). Both are understood as socially situated and embedded within broader human rights discourses. To frame these ideas within a rights-based perspective, the project also draws on the CRPD and the CRC. These influential human rights treaties affirm YDP's rights to self-determination and full participation in society.

2.1 Critical disability studies

Critical disability studies (CDS) is a growing field of social research that seeks to go beneath surface appearances by critically examining dominant assumptions that marginalize, exclude, and fail to accommodate or value disabled people (Goodley et al., 2021; Harvey, 2018; Kincheloe et. al., 2011). CDS engages with the contemporary complexities of disability, emphasizing the social, political, and relational dimensions that influence disabled people's lives (Goodley et al., 2021).

CDS builds on the foundational work of scholars such as Oliver (2009), Thomas (2004), and Mercer and Barnes (2010) as well as the British social model of disability, which is rooted in materialist and neo-Marxist traditions. The British social model represented a significant shift in how disability was understood, identifying physical and social barriers, along with cultural and policy frameworks, as the primary causes of disabled people's exclusion (Mercer & Barnes, 2010; Oliver, 2009; Shakespeare, 2014). In addition to the British social model, other significant socially contextualized approaches have been developed. These perspectives share a focus on how disability is produced through the interaction between individuals and their environments, rather than being rooted solely in bodily impairments (Shakespeare, 2014).

The social understanding of disability was fundamental in identifying barriers to participation as rooted in society rather than within the individual. However, it increasingly faced criticism for oversimplifying the complex quandaries of living with impairments (Crow, 1996), and for downplaying the significance of embodied experiences in shaping disabled people's lives (Flynn, 2021; Meekosha & Shuttleworth, 2009; Vehmas & and Watson, 2014). Feminist and poststructuralist perspectives have built on earlier social models by drawing attention to the role of power, discourse, and embodiment. These contributions have led to a more relational understanding of disability, viewing it as arising from the dynamic interactions between bodily experiences, social structures, and cultural meanings (Thomas, 2004, 2007). Within this framework, disability emerges from the mismatch between an individual's needs and a society that fails to accommodate human diversity. This social-relational perspective has long been prominent in the Nordic countries (Tøssebro, 2004; Traustadóttir et al, 2015) and is emphasized in the preamble of the CRPD.

CDS is situated within a broader movement of critically oriented research that emphasize the role of oppressive social dynamics and power hierarchies, in which some individuals are privileged, and others are marginalized (Creswell & Poth, 2018; Eakin et al., 1996; Meekosha & Shuttleworth, 2009). Correspondingly, it critiques the normative assertions rooted in the medical understanding of disability, which underlie much of what is traditionally held as right regarding disability; framing disability as individual deficits and overlooking society's role in perpetuating discrimination (Goodley, 2025; Meekosha & Shuttleworth, 2009; Shildrick, 2019). A key aspect of CDS is exploring how disability relates to and intersects with other marginalized social positions or privilege (Goodley, 2025; Meekosha & Shuttleworth, 2009). Moreover, sharing foundational ties with other critical perspectives such as youth, feminist, race, queer and mad studies, CDS is open to various avenues of inquiry to enhance a nuanced understanding of oppressive arrangements that have marginalized disabled people throughout history (Goodley, 2013; Shildrick, 2019). Importantly, by examining disability as a cultural, economic, and political phenomenon, it raises provocative questions about society, culture, community, media, family, education, and everyday relationships (Goodley, 2025).

As Meekosha and Shuttleworth (2009) note, to effectively examine and counteract discrimination that disabled people are subjected to, it is pivotal to delve into the sociopolitical context of disability and investigate how oppressive power dynamics are produced and reaffirmed. Thus, CDS underscores the important relationship between knowledge and action, viewing research as a vital tool to challenge oppressive systems and disrupt power dynamics (Goodley et al., 2019; Liddiard et al., 2019; Meekosha & Dowse, 2007; Morley & Macfarlane, 2014). It calls for research to be attentive and accountable to those most marginalized in society, and to amplify voices often overlooked (Meekosha & Shuttleworth, 2009; Oliver, 2013). It furthermore highlights the importance of centering lived experiences in this endeavor, recognizing disabled people as experts in identifying and addressing marginalization (Bekken, 2020; Egilson et al., 2021; Goodley et al., 2019).

Ableism is a core concept within CDS (Fine, 2019; Goodley et al., 2019) and serves as a tool to delineate how normative unfavorable societal norms affect YDP lives. The subsequent subchapter focuses on ableism, its manifestations and its role in reaffirming and maintaining systemic inequalities.

2.1.1 Ableism

Ableism, as a concept, took shape during the disability rights movements of the 1960s and 1970s in the UK and USA (Levi, 2005). It refers to a pervasive form of prejudice and bias that privileges nondisabled people and socially valued abilities, often at the expense of those whose ways of moving, thinking, or being, fall outside dominant ideals of ability (Sandberg et al., 2021). The term ableism gained recognition in the early 1980s, particularly among feminists. It has evolved from a definition focused on discrimination to a broader understanding in disability studies, where ableism is seen as a cultural system that establishes and maintains hierarchies of ability (Campbell, 2009). Importantly, ableism is a complex societal problem and has a foothold in more than just individual attitudes. It operates through a complex network of beliefs, practices, and institutional processes that shape how people understand themselves, their bodies, and their place in society (Chouinard, 1997; Wolbring, 2008).

Ableism shifts focus to the privileges of nondisabled people, particularly those who are white, economically advantaged, and heteronormative (Goodley, 2025). This is important as ableist ideology has historically profited dominant social groups and legitimized their privilege and superior status over other groups (Reed, 2025; Wolbring, 2008). While its manifestations vary, ableism profoundly shapes the lives of disabled people, including how they perceive themselves and navigate the world (Jóhannsdóttir et al., 2024). Discriminatory attitudes and practices that perpetuate unequal treatment of disabled people often mirror those found in other systems of oppression, such as sexism, racism, and adultism. Yet, ableism remains one of the most pervasive and socially accepted forms of prejudice (Charlesworth & Banaji, 2019; Kattari et al., 2018; Wolbring, 2008; Wolbring & Lillywhite, 2023). This widespread prevalence can be traced to the fact that ableist rhetoric is embedded in scientific and medical norms that frame disabled people as defective, reinforcing deficit-based views throughout society (Goodley, 2025; Wolbring, 2008). Furthermore, there is a general lack of awareness and public dialogue about the discrimination disabled people face and their social marginalization (Ford, 2009). As a result, ableism becomes especially difficult to dismantle, operating as a form of taken-for-granted common sense (Levi, 2005).

Despite the growing recognition of ableism's impact, further research is needed to deepen understanding of how it is experienced in everyday life, particularly among those with less visible impairments or chronic illnesses, and how it operates in conjunction with other marginalized identities (Kattari et al., 2018). While manifestations of ableism may change over time, its ongoing impact is a significant concern. It continues to affect the lives of disabled people of all ages, including YDP, in often overlooked ways, as will be discussed in later chapters.

2.1.2 Adultism

Collins (2020) points out the persistent tendency to overlook age as a meaningful axis of marginalization, particularly when overlapping with other forms of oppression. To address this gap, the concept of adultism has emerged as a valuable analytical tool. It refers to the systematic oppression and marginalization of young people and children by adults and adult-centric institutions (Bell, 2003; Bell, 2018; Douthirt-Cohen & Tokunaga, 2019). Coined by psychologist Jack Flasher in 1978, the term has since been taken up by scholars and advocates in the fields of children's rights and the sociology of childhood, where it serves to challenge adult-dominated assumptions about competence, autonomy, and participation (Flasher, 1978; LeFrançois, 2011). Adultism emphasizes the importance of specific socially valued abilities required to acquire rights and status as an adult. Due to young age and inexperience, young people are often perceived as lacking abilities but having the potential to develop them as they transition to adulthood (Delgado & Staples, 2008; Kafer, 2013; Wolbring, 2008). This positions young people as opposite to adults, who are commonly seen as more intelligent, competent, civilized, and self-controlled (Liegghio, 2016). The perception of inferiority contributes to a social hierarchy that justifies the disproportionate authority adults exercise over youth. As a result, a wide range of restrictions are legitimized, reinforcing systemic youth oppression (Bell, 2003; Corney et al., 2022; DeJong & Love, 2015). As adult-centric assumptions sideline young people's perspectives and marginalize youth voices, adultist discrimination is reinforced and perpetuated (Bell, 2003; Douthirt-Cohen & Tokunaga, 2019).

The younger years are often romanticized as the 'age of possibilities,' a period characterized by freedom, exploration, and a focus on the present (Arnett, 2004; Lesko, 2012; Syed, 2015). Yet, young people are also expected to 'behave themselves' whilst preparing for responsible adulthood, one rooted in self-reliance and productivity (Edmiston et al., 2017). This creates a contradiction: While youth is celebrated as carefree, they are simultaneously burdened with pressure to 'grow up'. This may leave little room for play or spontaneous enjoyment — like partying. Adults who engage in such activities are commonly negatively labeled, such as 'party animals' or told to 'grow up' (Balducci, 2016), reflecting a belief that play belongs to children (Brown & Stenros, 2018). For YDP, these tensions are heightened by the intersection of adultism and ableism. At the same time, they are held to heightened expectations of rationality, control, and competence —expected to manage their impairments while contending with pervasive stereotypes. This compounded scrutiny leaves them even less room to make mistakes or deviate from normative ideals of maturity and independence (Ágústsdóttir et al., 2025; Slater, 2015).

Combating adultism requires more than simply recognizing the rights of young people, it involves actively promoting their meaningful participation and autonomy. Adults have a crucial role in this effort by acknowledging their responsibility to challenge adultism where applicable. By listening attentively, valuing young people's input, allowing for mistakes, and encouraging their independence, adults can become strong allies in dismantling adultist barriers and facilitating genuine youth participation (Bell, 2018; Lansdown, 2005). This is particularly the case for YDP, who often rely on their parents for support and encouragement (Austin, 2000; Shah, 2010).

Adultism has a significant impact on society, influencing public policies, laws, institutions, and societal attitudes. Importantly, though, no single act, belief, custom, or policy is inherently adultist (Bell, 2003, 2018). Preventing adultism requires age-appropriate engagement between young people and adults as the latter must attune their expectations to young people's abilities and competencies (Pasupathi & Löckenhoff, 2002), while also respecting them as rights-holders (Vranješević, 2020). This means recognizing young people as social actors in the present, not simply as adults in the making (Liegghio, 2016).

2.1.3 Microaggression

Microaggressions are common expressions of ableism, adultism, and other forms of oppression. They occur at the interpersonal level and include everyday verbal, nonverbal, or environmental slights—whether intentional or not—that convey hostile, derogatory, or dismissive messages based on a person's marginalized identity (Sue, 2010). Microaggressions play a crucial role in discussions about oppression, as they represent subtle but persistent ways through which inequality is reinforced. Although they are often difficult to identify, repeated microaggressions can accumulate over time, leading to significant long-term effects (Kattari, 2019, 2020; Keller & Galgay, 2010). This is partly because they often go unnoticed, as they are delivered by well-meaning people who are unaware of their harmful effects (Sue et al., 2007; Gonzales et al., 2015; Olkin et al., 2019). The cumulative harm caused by repeated microaggressions has been described as 'death by a thousand paper cuts' (Sue, 2010). Though the phrase may seem extreme, it underscores the severe toll of subtle, ongoing oppression. Because microaggressions are often minimized or misunderstood by those in privileged positions, YDP are left to navigate their effects alone, placing an unjust burden on them, while those in privileged positions remain untouched and unaccountable (David, 2014; Kattari, 2020; Kattari et al., 2018)

Microaggressions against disabled people can take the form of social rejection, bullying, lowered expectations, harassment, and objectification (Olkin et al., 2019; Keller and Galgay, 2010). This can result in feelings of anticipated mistreatment, a need to hide one's minority identity, and the internalization of negative societal attitudes (Beagan et al., 2021; Hoy-Ellis, 2023). The emotional toll of dealing with microaggressions is increasingly recognized in research (Beagan et al., 2021; Gonzales et al., 2015; Jóhannsdóttir et al., 2024; Kattari, 2020; Keller & Galgay, 2010; Miller & Smith, 2021; Olkin et al., 2019). When it comes to YDP, specifically, the effects of microaggressions are wide-ranging and often deeply felt. YDP are frequently treated in ways that diminish their autonomy and maturity, often being perceived as overly innocent, dependent, or in constant need of help (Keller & Galgay, 2010). Such persistent patterns call for greater awareness and deliberate efforts to challenge the subtle yet harmful biases embedded in everyday interactions.

2.2 Wellness

Over the last decades, there has been a rise in research on wellness within the social sciences (Ciziceno, 2022) and among healthcare scholars (Gibson et al., 2023). This development aligns with the heightened awareness of questions related to the constitution of what a 'good life' entails in different settings (Ciziceno, 2022; Ryan & Deci, 2001). The Global Wellness Institute (n.d.) defines wellness as 'the active pursuit of activities, choices, and lifestyles that lead to a state of holistic health'. This definition highlights a balance between multiple interconnected areas, physical, social, psychological, intellectual, emotional, cultural, and spiritual. Thus, wellness reflects individuals' overall satisfaction across different life dimensions (Adams et al., 2000; Wellness Alliance, 2025; The Global Wellness Institute, n.d.). These personal evaluations are shaped by evolving sociocultural contexts, as well as by immediate circumstances, opportunities, emotions, and mindsets (Gibson, 2016; Gibson et al., 2023). Accordingly, wellness is not only about individual feelings or life satisfaction but shaped by broader sociopolitical forces, including dominant ideas about what constitutes a 'good' life and which lives are considered valuable or well-lived.

Because their experiences of wellness often diverge from dominant norms, YDP may find that their wellness is not fully recognized or socially validated (Gibson, 2016; Moons et al., 2006). Acknowledging the sociopolitical influences on wellness allows for a more nuanced understanding that reflects the complex interplay between individual experience and societal expectations (Gibson, 2016; Hamdani et al., 2022; Prilleltensky & Fox, 2007; Prilleltensky et al., 2001).

Although the term 'wellness' may partly overlap with concepts such as participation and inclusion, it can provide essential insights into how people experience their environments (Ciziceno, 2022; Gibson et al., 2023; Teghe & Rendell, 2005), particularly when examined together with life quality (Medvedev & Landhuis, 2018). Like wellness, the concept of life quality entails how and to what extent individuals experience satisfaction with their lives (Moons et al., 2006). Life quality has been defined by the World Health Organization [WHO] (n.d.) as the 'perception of position in life, in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns ...'. Life quality is not a central concept in this project, although it was key to the broader LIFE-DCY research (Egilson et al., 2021).

In recent years, important research has focused on YDP's perspectives, highlighting aspects that matter most in their lives, such as access to meaningful activities, diverse social relationships (Jóhannsdóttir et al. 2022; Melbøe & Ytterhus 2017), being treated with respect (Byhlin & Käcker 2018; Jóhannsdóttir et al. 2022; Smith & Traustadóttir 2015) and maintaining stable health (Hamdani et al. 2018, 2022; Rachele et al. 2014). Gaining a deeper and more nuanced understanding of YDP's perception of wellness is essential to recognize and respond to their needs in ways that maximize their goodness of life.

2.2.1 Participation

Participation is a key concept when examining disabled people's experiences. Like wellness, participation is multilayered and holds different meanings. Broadly speaking, participation refers to an individual's active involvement in various social settings (Piškur et al., 2013; WHO, 2001), encompassing everyday functioning and the activities people engage in within their environments (Imms et al., 2016). Two main aspects of participation are often identified. The first relates to the objective experience of 'being there,' which considers whether an individual attends and engages in routine social activities within a given setting, as well as the nature of that engagement. The second aspect captures a more subjective, 'in-the-moment' experience, encompassing an individual's sense of engagement, belonging, and satisfaction with their involvement (Anaby et al., 2013; Anaby et al., 2015; Imms et al., 2016; Imms et al., 2017; Powrie et al., 2015).

Research has primarily focused on observable factors like attendance in activities, rendering the subjective aspects, such as individuals' feelings about their involvement and sense of appreciation, acceptance, and inclusion, often overlooked (Adair et al., 2018; Imms et al., 2016; Imms et al., 2017). While attendance is a prerequisite for participation, presence alone does not ensure inclusion (Adair et al., 2018). Therefore, exploring subjective experiences is essential to understanding how individuals value their participation. Additionally, it is vital to highlight society's responsibility in fostering inclusion by creating equitable opportunities that embrace diversity, enabling everyone to thrive (Cameron, 2014).

Participation is widely recognized as a critical foundation for wellness (Kuykendall et al., 2018), especially for disabled children and young people. It supports growth and development by enhancing social skills and fostering meaningful interactions (Bedell & Dumas, 2004; Piškur et al., 2013). Beyond this, participation increases young people's visibility and can affirm their value as members of the community whose voices and rights matter. It can be a powerful force, not only for social change, but also by supporting their transition into adulthood (Vranješević, 2020).

Studies exploring YDP's perceptions of participation have shown that they place significant importance on having choices about activities and being able to control with whom, how, and whether they participate (Jóhannsdóttir et al., 2022; Ólafsdóttir et al., 2024). These are all fundamental prerequisites for experiencing wellness, aligning with the essential aspect of participation as an opportunity to connect with others on a deep and dynamic level (Hall, 2010; Hammell, 2015; Manoj et al., 2022). However, many barriers persist despite ongoing advocacy and established legal initiatives, such as the CRPD and CRC, aimed at promoting the participation of YDP and children. A range of environmental dimensions continues to limit their opportunities for meaningful participation, such as negative attitudes, inaccessible built environments, and a lack of time and opportunities. In addition, systemic issues such as ineffective policies, fragmented services, and unaccommodating institutional structures further restrict participation (Anaby et al. 2013; Egilson et al. 2017, 2018; Hodge & Runswick-Cole 2013; Krieger et al. 2018; Ytterhus et al. 2015). The effects of these barriers are evident in the fact that YDP and children participate less frequently than their peers and are less involved in valued community-based activities (Byrne, 2024; Egilson et al., 2017; Melbøe & Ytterhus, 2017).

2.3 Important human rights treaties and legislation

The CRPD and the CRC are significant human rights treaties that collectively affirm the rights of YDP's to self-determination, wellness and full participation in society. Central to both frameworks is a commitment to removing barriers that hinder the full realization of the rights of YDP. Furthermore, two Icelandic legislations are specifically relevant to this research, as they reflect the ideology of the CRC and CRPD and address the importance of preparing and supporting YDP in their transition into adulthood. In the following subsections, both treaties and the Icelandic regulation are explored in greater detail.

2.3.1 The CRPD and the human rights approach

The CRPD (2006) is a groundbreaking human rights treaty that redefined the understanding of disability in the context of human rights. It asserts that disabled people have the right to participate fully and equally in society and prohibits discrimination based on disability (Degener, 2016). The CRPD is a binding international treaty, which means that all signatories are required to put its principles into practice and ensure that the rights it outlines are respected (United Nations & Inter-Parliamentary Union, 2007). In its preamble, it recognizes that 'disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others'. By adopting this perspective, the CRPD places the responsibility on signatory states to address disability-related exclusion, thereby underscoring the role of society in counteracting barriers

(Degener, 2016, 2017). It furthermore illuminates what reforms are needed to uphold and realize equality and justice for disabled people (Davy et al., 2022).

Importantly, the CRPD refers to all disabled people, but it is especially protective of disabled children and young people. Article 7 affirms their rights and calls for decisive action to guarantee they enjoy their human rights, including social inclusion. Furthermore, it states that it must be ensured that disabled children 'have the right to express their views freely on all matters affecting them, their views being given due weight per their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right'. Thus, the CRPD brought attention to the rights of this group, marking a significant shift in perspective and recognizing children as rights holders (McCallum & Martin, 2013). Iceland signed the CRPD in 2006 and ratified it in 2016 (Stjórnarráð Íslands, n.d.). However, as of August 2025, it has yet to be fully incorporated into domestic law and the pace of implementation has been slower than expected (Brennan et al., 2018; Davy et al., 2022; Jónasdóttir et al., 2020; Traustadóttir & Brennan, 2020).

Although the human rights approach is explicitly used in the analytical framework of only one article of this PhD research, its core message, that disabled people have the right to participate and live well, underpins the entire project.

2.3.2 The CRC and young disabled people

The CRC (1989) marked a pivotal shift in how children and their rights are understood. It introduced a transformative view of children not as passive recipients of adult authority and ownership, but as active social actors with their own needs, interests, and capacities to shape and contribute to their environments (Gísladóttir, 2020; Varadan, 2019; Vranješević, 2020). Since its ratification in Iceland in 1992, and its direct incorporation into national law in 2013 (Althingi, 2013), it has significantly influenced legislation, policy, and legal practice. The CRC positions children as rights-holders entitled to participate in decisions affecting their lives, recognizing childhood as a meaningful phase. Article 23 of the CRC affirms that disabled children have the right to live independently, with access to the support that enables their participation and dignity in society. Historically, this article is important, as prior to the CRPD, the CRC was the only international treaty to include a specific article on the rights of disabled children. It was among the first instruments to recognize disability as a human rights issue explicitly and to address the unique experiences of disabled children as a distinct concern (McCallum & Martin, 2013).

Although the CRC does not explicitly mention adolescence or youth, it recognizes the evolving needs of older children as they approach key transitional milestones. This is evident, for example, in Articles 12 and 5, which affirm children's rights to express their views and have those views given due weight. Article 5 further highlights the principle of evolving capacities, recognizing that as children grow, they should be granted increasing autonomy while being protected from the full responsibilities of adulthood (Lansdown, 2005). These core ideas have been further developed through the emergence of childhood studies (James et al., 1998) and youth studies (Ciesliek & Simpson, 2013), both of which emphasize the need to prioritize the perspectives of children and young people to understand their lived experiences better. This shift has expanded the scholarly lens beyond individual development to encompass the broader societal, historical, and cultural contexts of growing up, and in doing so, has helped reveal the severe impact of societal marginalization on these groups (Best, 2007; Ibrahim, 2014).

Importantly, the CRC affirms that children's precarious position must never be equated with lesser value, as all children hold equal worth, regardless of ability. This foundational pillar resonates strongly with the principles of CDS, which underpin the perspective taken in this project.

2.3.3 Icelandic legislation important for this research

Icelandic legislation includes two significant acts that are centrally focused on the objective of facilitating independence for YDP, fostering their growth and inclusion and promoting their full participation in society.

Firstly, the Act on services for disabled people with long-term support needs no. 38/2018 (Althingi, 2018) is a framework law that outlines broad obligations and guiding principles, intended to inform national-level practice and policy. The law, among other things, emphasizes the importance of personalizing services to meet users' needs, circumstances, and preferences, allowing them to thrive on their terms and reach their fullest potential.

Secondly, the act on integrated services in the interest of children's prosperity no. 86/2021 (Althingi, 2021) is a recent act, adopted with the aim to strengthen the wellness of children and young people (Parliamentary document no. 440/2020-2021). Partly inspired by the Scottish framework Getting It Right for Every Child [GIRFEC], the goal of the law is to provide children in need of special services, along with their families, with integrated services. The legislation emphasizes the importance of collaboration between children, parents, and care professionals. As the law is relatively new, its practical impact has yet to be fully realized, and it remains to be seen how effectively it will ensure the continuity of services in practice. Importantly to the issue of transition into adulthood, Article 22 of the act emphasizes the development of an individual support plan that includes preparation for the transition to adulthood, aiming to prevent gaps in services. On the same note, Articles 13 and 19 of Act No. 85/2018 underline the importance of ensuring that YDP have access to appropriate and continuous support as they reach adulthood.

3 The study context

This chapter discusses previous research and writings that have contributed to a broader understanding of the historical, structural, and social factors that shape the lived experiences of YDP. A key theme in the literature underpinning this project is the recognition of YDP and children as knowledge holders and experts in their own lives (UN, 1989; Ibrahim, 2014; James et al., 1998). Their insights are therefore considered essential and irreplaceable to this project. The chapter is divided into two sections. The first explores key literature on the experiences and identities of YDP. The second section examines the transition to adulthood, first from a general perspective and then with a focus on the Icelandic context.

3.1 Growing up with disability

The youth years are often recognized as a time of 'in-between' when young people find themselves caught between the dependencies of childhood and the expectations of adulthood. In this phase, individuals navigate physical, emotional, and social changes while also making sense of their developing identities and figuring out their place in the wider world (Tilleczek, 2014). For many, this journey can be complex; however, for YDP, it is often made even more challenging by additional barriers that complicate their paths forward (Pearson et al., 2025; Zukerman et al., 2024).

A substantial body of research has shed light on the multiple and compounding challenges YDP frequently encounter at times of transition (Gibson et al., 2014; Gorter, 2011; Lindsay et al., 2017; McLaughlin, 2025; Nguyen et al., 2018). Service transitions, such as those involving health- or social care (Beresford & Stuttard, 2014; Hanghøj et al., 2017; Pearson et al., 2020 Östlie et al., 2007) or school-to-work pathways (Halpern, 1994; Lindsay et al., 2016; Wei et al., 2014), are frequently described as fragmented and lacking coordination. There is a growing consensus on the need for a more nuanced and holistic approach that moves beyond narrow, service-led framing to also consider how cultural, social, and economic contexts shape access to meaningful opportunities and participation (Pearson et al., 2025; Pearson et al., 2020; Wood et al., 2018).

Past and present experiences significantly shape how young people navigate their way into adulthood, influencing not only the paths they take but also how they perceive themselves along the way (Kelly & Kamp, 2020; McLaughlin, 2023; Slater, 2013). Thus, opportunities for meaningful participation become central to how young people experience and shape their transition. Participation in this sense is not only a goal, but also a process through which young people develop autonomy, a sense of belonging, and confidence in their abilities — all of which are vital for continued engagement and personal growth (Bentzen & and Malmquist, 2022; Imms et al., 2022). Therefore, it becomes essential to explore the everyday activities, relationships, and environments that influence YDP in order to develop a comprehensive understanding of their transition (McLaughlin, 2025).

In the following chapters, issues related to the transition into adulthood from the perspective of YDP will be explored.

3.2 Transitioning into adulthood

Transitioning into adulthood has long been framed as a linear, step-by-step process with a predetermined outcome (Settersten et al., 2015; Smith & Dowse, 2019). Across OECD countries, ideas of youth transitions remain grounded in traditional markers of adulthood, such as obtaining full-time employment, achieving financial independence, forming a long-term relationship, and becoming a parent (Ravenscroft et al., 2017). Since the 1970s, significant socio-economic changes have transformed the conditions under which young people can access these markers. Changes include shifts in labor markets, rising job insecurity, extended participation in education, and regressive welfare reforms (Furlong et al., 2011; Holdsworth & Morgan, 2005; Pearson et al., 2025). As a result, pathways into adulthood have become more complex and uncertain, yet the pressure to reach these traditional markers remains strong (McLaughlin, 2025; Pearson et al., 2020). These markers, often viewed as prerequisites for a 'successful' adulthood, have been widely criticized for reinforcing universalized, taken-for-granted expectations that fail to reflect the complexity and diversity of young people today (Hamdani & Gibson, 2019; Woodman & Bennett, 2015; Zittoun, 2012). While such conventional markers may provide insights into young people's activities, they also reflect an unjust and rigid societal value system that favors those with greater resources while limiting opportunities for those less privileged (Kelly & Kamp, 2020; McLaughlin, 2025; Wyn & White, 1997). In response to these critiques, there has been a call for a more holistic approach to understanding transitions, one that not only considers the broader social and structural context but also critically examines the oppressive aspect of normative markers and how young people negotiate them (Johansson & Herz, 2019; McLaughlin, 2023). Essentially, this involves viewing young people from a broader perspective, analyzing how the interactions between individuals, activities, contexts, and socio-political conditions influence and are influenced by the transitions they undergo (Hedegaard & Edwards, 2019; Macdonald et al., 2013).

As a marginalized group YDP are often overlooked and their opportunities for participating in society limited, especially when they occupy other disenfranchised positionalities, such as on the grounds of their race and gender (Bell, 2003; Jóhannsdóttir et al., 2024). This is because prevailing frameworks for understanding transitions are rooted in taken-for-granted assumptions that do not account for YDP's varied needs and priorities (Hamdani & Gibson, 2019). These norms can be exclusionary, and even harmful (Ljuslinder et al., 2020) as they commonly assume a linear, future-oriented trajectory that privileges independence and long-term planning. Yet, this vision does not align with the lived realities of all YDP. As a result, young people can feel caught between competing demands. For example, those who live with short life spans or uncertainty regarding their health may benefit more from focusing on the present and engaging in activities that bring them fulfilment, rather than concentrating on preparing for a distant or uncertain future (Abrams et al., 2020; Gibson et al., 2014). Similarly, YDP's daily schedules are often filled with tasks designed to help them become self-reliant and capable of managing on their own. While these activities are intended to support independence, they can come at the cost of participating in meaningful youth experiences, such as spending time with friends, enjoying leisure activities, or simply having fun, ultimately leading to social exclusion and feelings of being left out (Curran et al., 2020; Slater, 2013).

Studies have highlighted the critical role of family support in navigating transitions, showing that a supportive home environment can help counter structural barriers and enable YDP to participate more equally in everyday life (LeFrançois, 2011; McLaughlin, 2023, 2025). However, normative transitional markers have historically positioned independence as the goal of adulthood, overlooking the value of interdependence and the diverse ways people can live rich, fulfilling lives through mutual support, shared responsibility, and community engagement (Hamdani et al., 2015; Priestley, 2003; te Riele, 2004). Furthermore, dominant individualist rationality has been further reinforced by the rise of neoliberalism (Edmiston et al., 2017) and the marketization of public services, which have intensified these ideals by introducing strict eligibility criteria and placing greater conditions on access to support (Snæfríðar- og Gunnarsdóttir et al., 2025). This is reflected in prevailing narratives overemphasizing autonomy and personal responsibility, obscuring structural barriers and unequal access to opportunities (Pearson et al., 2020, 2025). Thus, the responsibility for navigating the transition to adulthood often falls on the individual. For YDP, this frequently means managing without the support they are entitled to — support that is essential for ensuring access to meaningful opportunities and transitional activities (Stewart et al., 2010). Due to the focus on individual responsibility, broader discussions about transitioning often adopt a deficit-oriented framing. In this view, young people, particularly those who do not meet conventional milestones, are seen as 'the problem'. Consequently, interventions tend to focus on fixing individuals to fit predetermined norms, rather than confronting discrimination or addressing the societal inequalities that restrict equitable transitions (Bell, 2003, 2018; Nalani et al., 2021).

The transition to adulthood exposes the values and systems that define what is considered a 'successful' life. Research shows that YDP's aspirations and concerns about the future are shaped more by social and structural conditions than by their impairments, highlighting the need for society to take greater responsibility in creating inclusive and equitable pathways (Shah, 2008).

3.2.1 Transitioning into adulthood within the Icelandic context

Iceland is a high-income nation characterized by a Nordic welfare model, in which universal access to education and healthcare is central, and disabled people are entitled to specialized services and support (Althingi, 2018). Although legal frameworks and policies increasingly affirm the rights of disabled people to an accessible environment and appropriate accommodations, significant gaps between policy and practice continue to hinder the societal participation of YDP (Brennan & Traustadóttir 2020; Jónasdóttir et al. 2020). For example, while Iceland has ambitious goals for inclusion, implementation often falls short due to imprecise and vague definitions of key concepts, constrained budgets, and inconsistent enforcement. As a result, initiatives frequently fail to tackle discrimination or remove barriers to meaningful participation (Brennan et al., 2018; Traustadóttir & Egilson, 2025). These shortcomings are particularly evident when YDP attempt to navigate socially-accepted transitional milestones or engage in other meaningful activities on their path to adulthood, as the following section demonstrates.

3.2.1.1 Education

Iceland's national educational policy emphasizes principles of inclusive education and equal access for all students (Althingi, 2008a; Althingi, 2012). This implies that all students should have access to education that meets their individual needs and learning styles. Nevertheless, the journey towards achieving these goals has not been without controversy, with ongoing debates surrounding the implementation of the policies and how effectively they address the diverse needs of all students (Gunnþórsdóttir & Jóhannesson, 2014). These controversies are especially evident when it comes to the educational opportunities of YDP's and children, who continue to encounter barriers that limit their full and equal access at all levels of schooling[1] (Björnsdóttir & Jónsson, 2025).

In an international context, Iceland is often presented as an example of a highly inclusive education system, with nearly all children aged 6 to 15 enrolled in compulsory schools (Óskarsdóttir et al., 2019b). However, high enrollment rates alone are not sufficient to ensure true inclusivity within the system (Gunnþórsdóttir & Jóhannesson, 2014; Óskarsdóttir et al., 2019b). Inclusive education is often understood as merely involving the presence of students with special educational needs in mainstream

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[1] Iceland´s educational system operates mainly within the public sector and is divided into four levels: playschool (for ages 18 months to 5 years), primary and lower secondary schools (compulsory for 6- to 16-year-olds), upper secondary schools (for ages 16 to 19) and higher education.

schools, rather than an approach that applies to all students (Gunnþórsdóttir et al., 2024). Segregated units for students with special educational needs are well-established, reflecting a prevailing belief that some students are better served in separate educational settings outside the mainstream (Gunnþórsdóttir & Jóhannesson, 2014). This understanding aligns with ableist assumptions that link limited participation within education primarily to the YDP's and children's impairments rather than to systemic or environmental barriers (Egilson, 2016; Marinósson & Bjarnason, 2016). Despite policy commitments toward inclusive education, it is paradoxical that recent years have witnessed a rise in segregated and/or specialized educational offerings within compulsory schools (Björnsdóttir & Jónsson, 2025).

Similar challenges persist within upper secondary education, which, in practice, falls short of being inclusive. One key barrier is that schools are permitted to restrict admission based on academic performance, disproportionately affecting disabled students who may not fit narrow academic criteria. As a result, students with lower grades or those who do not meet compulsory school competency levels face limited access to continued education (Sverrisdóttir & and Van Hove, 2023; Sverrisdóttir & Jóhannesson, 2018). Furthermore, many upper secondary schools are ill-equipped or unprepared to accommodate the needs of pupils with disabilities, leading to instances of delayed admission (Björnsdóttir & Jónsson, 2025; Gunnþórsdóttir et al., 2024). Students labeled with intellectual impairments face limited educational options, being directed into segregated programs within mainstream schools. Almost all upper secondary schools offer special programs designed to address the diverse needs of the student body — not only for disabled students but also for those who face challenges for other reasons, such due to language barriers (Gunnþórsdóttir et al., 2024). This development reflects both the evolving societal conceptions of inclusion (Marinósson & Bjarnason, 2016) and broader societal changes in recent years, during which upper secondary school students have become a more diverse group than they were before (Reynisdóttir & Jóhannesson, 2013).

Due to inefficiencies and exclusionary practices at the compulsory and upper secondary levels, disabled students are often inadequately prepared or unable to meet the formal criteria required to pursue higher education. Furthermore, the university arrangement is characterized by speed and efficiency, providing an environment that may not be conducive to the needs of disabled students who require support and accommodations (Björnsdóttir & Jónsson, 2025). The University of Iceland offers one diploma program for students labeled with intellectual impairments, preparing them for roles in kindergartens, after-school programs, libraries and self-advocacy. All the courses are shared with nondisabled peers (Stefánsdóttir & Björnsdóttir, 2018; The University of Iceland, n.d.). Although the program is limited regarding choice of study it represents a significant step in advancing disability rights (Stefánsdóttir & Björnsdóttir, 2018). In fall 2025, the University of Akureyri, situated in the northern region of the country, launched a pilot diploma program for students labeled with intellectual impairments. The program aims to prepare students for careers in services for children and adults, including roles in education, leisure, sports, day services, and non-governmental organizations (University of Akureyri, 2025).

A key prerequisite for implementing inclusive education is a comprehensive understanding of inclusive pedagogy across all levels of education. However, university faculty members often lack formal teacher training and are therefore ill-equipped to support diverse learning needs and, furthermore, lack opportunities for professional development in this area (Gunnþórsdóttir et al., 2023; Óskarsdóttir et al., 2019a). There is a pressing need for further research on the experiences of disabled students in higher education in Iceland. Studies from other Nordic countries have yielded important information, highlighting disabled students' call for greater flexibility, such as increased distance learning options, alternative assessments, and accessible course materials (Magnus & Tøssebro, 2013). Research has also shed light on the multiple systemic barriers students encounter – many of which are embedded in the very structure of support services. The current model of personalization of the services places responsibility on students themselves to identify their needs, seek out accommodation, and navigate unfamiliar and often opaque systems. Limited access to information leaves many unaware of the support available or their rights, resulting in delays or missed opportunities (Langørgen & Magnus, 2018). To access services, the disabled students are typically required to provide documentation or undergo assessments to prove their eligibility (Althingi, 2010), which can be both burdensome and stigmatizing. Once approved, support is often fragmented and unreliable. Consequently, disabled students must invest significant time and energy into overcoming institutional barriers—labor that is both invisible and undervalued (Ágústsdóttir & Jónsdóttir, 2023; Langørgen & Magnus, 2018).

3.2.1.2 Work

Employment holds substantial symbolic and practical value in Icelandic society (Einarsdóttir et al., 2015). For many young people, entering the workforce is a natural step into adulthood, and Iceland has historically maintained strong youth employment figures. Between 1991 and 2023, the average unemployment rate for people aged 15 to 24 was around 9%, noticeably below the global average of 16% (TheGlobalEconomy.com, n.d.). However, when focusing on YDP aged 18 to 30, the picture shifts substantially, as only about 17% of them are employed (Gísladóttir & Staub, 2023). Research shows that employment is significant to disabled people, not only for financial benefits but also a sense of identity, purpose, and social connection (Hardonk & Ingvarsdóttir, 2021; Hardonk & Jónasdóttir, 2025).

In Iceland, there are complex and multilayered barriers to achieving full work inclusion for disabled people. This includes a deeply ingrained belief that disabled people, especially those with intellectual impairments, are better suited for segregated work settings (Hafsteinsdóttir & Hardonk, 2023; Hardonk & Jónasdóttir, 2025). Prejudiced attitudes are common among employers, coworkers, and even job counselors tasked with supporting disabled people's workforce transitions. These include stereotypical ideas about disabled people's capabilities being less than those of their nondisabled peers (Goodall et al., 2024; Hardonk & Halldórsdóttir, 2021; Hardonk & Ingvarsdóttir, 2021). Recent Icelandic research highlighted the barriers autistic women experienced in the workplace due to a lack of understanding and appropriate support. Instead of receiving the necessary flexibility and awareness, they were expected to conform fully to neurotypical norms, which often resulted in exhaustion, distress and job loss among the women (Nikolova-Fontaine & Egilson, 2023).

In recent years, various labor market initiatives have aimed to strengthen disabled people's rights and promote their inclusion, such as supported employment programs grounded in laws about support to disabled people (Althingi, 2018) and wage subsidies where the state covers part of the salary (Althingi, 2006). Despite ongoing efforts, many disabled people struggle to find and maintain meaningful employment due to structural inequalities and ableist assumptions that limit access to work and hinder full participation (Hardonk & Jónasdóttir, 2025; Shamshiri-Petersen & Krogh, 2020).

3.2.1.3 Living independently

As previously noted, traditional milestones associated with adulthood commonly include a shift to living independently (Settersten et al., 2015). Disability studies scholars have critiqued this framing for promoting simplistic notions of increasing independence as the ultimate goal (Gibson et al., 2014; Hamdani & Gibson, 2019). While dependency is generally accepted in childhood, dependent adults are often framed as problematic—seen as deviating from normative ideals of the self-sufficient adult (Priestley, 2003). As a result, YDP are expected to pursue independence—ideally with as little support as possible. This mindset continues to limit YDP' s possibilities for reaching their kind of independence.

The term independent living has a special meaning within the scope of disability studies, referring to the groundbreaking movement that emerged from disability activism. The Independent living ideology acknowledges that support is often a prerequisite for disabled people to live independently and participate fully in society (Morris, 2004). It emphasizes the right of disabled people to make decisions about where, how, and with whom they live, and to exercise control over the services they receive and their own lives (Ratzka, 2007).

The independent living ideology has had a significant impact on the development of support available to disabled people in Iceland, as personal assistance and direct budgets have become established services. However, access to these services is often delayed due to prolonged waiting periods and insufficient funding. Additionally, finding suitable housing, that would support YDPs' transition out of the parental home, remains a significant challenge due to the scarcity of new accessible housing (Jónsson et al., 2022; Öryrkjabjandalag Íslands, 2023). These barriers disproportionately affect YDP, many of whom remain in their childhood homes longer than their nondisabled peers, despite their desire to establish independent households (Öryrkjabandalag Íslands, 2023). Furthermore, many YDP struggle to make ends meet. A recent report revealed that close to six in ten are forced to rely on financial support from family members to get by (Gísladóttir & Staub, 2023). Such conditions pose a serious barrier to living independently, as they undermine YDP's right to self-determination and financial autonomy.

3.2.1.4 Sex and relationships

Social and cultural barriers also limit YDP's participation in intimate relationships. Icelandic research has illuminated how young disabled people are desexualized and not expected to be able to or be interested in sexual behavior, making it difficult for them to engage fully in the social world of intimacy (Ágústsdóttir et al., 2020; Jóhannsdóttir & Ágústsdóttir, 2024). This is particularly evident among individuals labeled with intellectual impairments who commonly experience belittling attitudes, paternalism, restricted autonomy, lack of privacy, constant monitoring and are often perceived as 'eternal children' (Björnsdóttir et al., 2017; Björnsdóttir & Stefánsdóttir, 2020). Those who reside in assisted living residences have described how their need for privacy is often compromised, making it difficult for them to figure out and test their sexual identities. Many have voiced a desire for sexual education that could help them better understand themselves and navigate intimate relationships (Björnsdóttir, 2022).

In a similar vein, YDP in Iceland also face multifaceted and ethically questionable barriers when it comes to experiencing parenthood. Recent Icelandic research indicates that disabled women's fertility is undermined as they are coerced to take contraceptive measures or undergo abortions (Björnsdóttir et al., 2017; Björnsdóttir & Stefánsdóttir, 2020). Disabled people who need fertility assistance or want to foster children are also faced with ableist attitudes where their impairments or living conditions are seen as risky to children's welfare (Pálsson, 2021). Disabled parents face prejudice and are often met with suspicion, as evidenced by their disproportionate reporting to child protection services, frequently over minor incidents (Sigurjónsdóttir & Rice, 2023).

3.2.1.5 Technology

While the exploration of technology and AI's impact is beyond the scope of this project, it is worth noting that AI is increasingly embedded in everyday systems, including digital platforms that often remain inaccessible (Margrétar Bjarnadóttir, 2023). AI-enabled assistive technologies hold potential to support YDPs' autonomy and participation in areas such as education, employment, and independent living. Without inclusive design and critical oversight, AI risks becoming yet another layer of systemic discrimination (Maitreya, 2024; Quinn, 2021). This is particularly relevant for YDP and children, whose protection remains inadequate within AI systems; thus, they may face risks such as covert surveillance, data misuse, and exposure to digital harm (UNICEF, n.d.). The increasing use of AI thus raises urgent questions for disability and youth studies.

4 Study design and methods

This chapter introduces the methodology and methods employed in the research, its aims, and an emphasis on the experiences of YDP transitioning into adulthood. The research questions evolved throughout the course of the project. In the following subchapters, the questions are revisited and discussed, highlighting how they were answered. The next subchapter provides information on the participants, the data gathering and the analysis. Lastly, ethical considerations and the strengths and weaknesses of the research project are discussed.

4.1 Aims and research questions

This project aimed to critically explore the complex nuances of transitioning from childhood into adulthood for YDP and how ableist and adultist societal norms influenced their lived experiences prior to, during, and beyond transitioning. As described in Chapter 2, CDS guided the research and served as a foundational framework for the overall project. The research questions evolved in tandem with my growing understanding of the research topic and its findings. Furthermore, maintaining broad research aims and questions was instrumental in opening unexplored and nuanced dimensions. For instance, the significance of adultism in the lives of YDP did not become apparent until the writing of the third article, and accordingly, was addressed in a research question formed later than others.

The research questions in the dissertation are as follows:

1. How do children and young disabled people navigate transitioning and make meaning of their path within a broad socio-material context?
2. How do ableist understandings of adulthood influence young disabled people's experiences?
3. How does adultism intersect with ableism to impact young disabled people's experiences of transitioning into adulthood?

The project comprises four papers, 1) "'I just want to live my life': Young disabled people's possibilities for achieving participation and wellness", 2) "'Then you realise you can actually do it': Young disabled people negotiating challenges during times of transitioning into adulthood", 3) "'Let us talk about our party stories': Young disabled people going out on the town", and 4) "Life quality and participation of disabled children and young people: Design and methods of a transformative study". The first three articles focus on specific and targeted issues aiming to shed a light on YDP experiences regarding transitioning into adulthood and how they navigated their social environments, while article IV is a methodology paper which describes the larger LIFE-DCY project (see table 1 below).

Table 1. Overview of papers within the PhD

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	1. Article	**2. Article**	**3. Article**	**4. Article**
Title	'I just want to live my life': Young disabled people's possibilities for achieving participation and wellness	'Then you realise you can actually do it': young disabled people negotiating challenges during times of transitioning into adulthood	'Let us talk about our party stories': Young disabled people going out on the town	Life quality and participation of disabled children and young people: design and methods of a transformative study.
Aims	To explore disabled children's and adolescents' possibilities for participation and to identify the practices and policies that affect their participation and how these are enacted.	To examine the challenges young disabled people face when transitioning into adulthood and how they navigate these challenges.	To explore how partying opportunities for young disabled people are influenced by assumptions rooted in ableism and adultism.	To outline the study design, methodology, and methods of the LIFE-DCY research project, and to address methodological and ethical concerns, as well as lessons learned.
Research questions	1,2	1,2	1,2,3	1,2
Participants	Seven case studies were conducted with disabled children and adolescents. Each case included interviews with the young person, their parents and teachers, participant observations and document analysis.	Four focus groups were conducted with a total of 21 participants. Three included participants aged 18-35, and one (pilot focus group) included participants aged 30-50.	Twenty-one disabled people aged 18-35 participated in four focus groups, which included a pilot focus group with participants aged 30-50. Four follow-up interviews.	The study was conducted in two phases. Altogether 209 disabled children and their parents participated in 1. (quantitative) phase. The 2. (qualitative) phase included 14 case studies with children and youth and focus groups with young disabled people aged 18 to 35. Three included participants aged 18-35, and one (pilot focus group) included participants aged 30-50.
Analysis	Qualitative analysis was inductive and data-oriented, involving an in-depth examination of the data.	Constructivist grounded theory was initially applied during the analysis, followed by a critical lens in the final steps.	Constructivist grounded theory was initially applied during the analysis, followed by a critical lens in the final steps.	The initial analysis (2. phase) was inductive, followed by critical and transformative lenses.
Main findings	Complex dynamics between personal circumstances, social structures, and material conditions shaped participants' opportunities for participation. The enactment of their disability-related rights often hinged on parental system knowledge and broader sociocultural contexts.	Participants faced varied barriers while transitioning into adulthood, including inaccessible environments and ableist attitudes. Participants resisted these unfair norms yet simultaneously expressed their aspirations to achieve them.	Going out was an essential opportunity to connect with peers. However, they encountered various barriers that limited their access to party spaces, including inaccessible environments, ableist/adultist attitudes, and microaggressions.	Intersecting social, cultural, and temporal factors shaped how disabled children and young people experienced life quality and participation. The findings reveal how childhood disability is constructed through knowledge, power, and prevailing social norms.

2

4.2 Critical qualitative lens

When conducting studies of any kind, it is pivotal to ensure that chosen interpretive frameworks and associated philosophical beliefs align with the research aim and direction (Creswell & Poth, 2018). Using CDS afforded me a critical stance in the project, setting out to question taken-for-granted assumptions, as well as disassembling and uncovering forms of oppression and injustices (Charmaz, 2017; Gibson, 2016) faced by YDPs before, during, and beyond transition into adulthood. To gain the necessary in-depth data to do this, I employed a qualitative research inquiry (Charmaz & Belgrave, 2018; Eakin & Gladstone, 2020). The critical lens guided the analytical focus and interpretations of data, generating valuable insights that deepened the analysis and sharpened the interpretative focus of the findings. In line with the framework of CDS, the young people who participated in the study were recognized as eminently qualified and irreplaceable sources of knowledge (Best, 2007; Liddiard et al., 2019). Their input informed the entire research process, anchoring the study in the lived realities, perspectives, and aspirations of those at its core.

4.2.1 Grounded theory - a critical tool

Since the inception of grounded theory in 1965 (Bryant, 2020), the approach has become a well-established qualitative inquiry, appreciated for its thoroughness, flexibility, and ease of use (Charmaz, 2014). CGT provides a means for a thorough exploration of social processes and action, through the simultaneous collection and analysis of data in an iterative process. It relies on comparative methods and provides tools for developing, checking, and enhancing innovative analysis, ultimately leading to the construction of a theoretical perspective that offers an in-depth understanding of the meanings underlying various social phenomena (Charmaz, 2014; Charmaz & Belgrave, 2018; Charmaz et al., 2017; Gibbs, 2013).

CGT begins with an inductive approach, where the researcher engages with the data with an open mind, aiming to gain a broad understanding of what is happening (Bryant, 2020; Charmaz, 2014; Charmaz et al., 2017; Morse & Clark, 2019). As patterns and findings emerge, CGT shifts toward deductive reasoning. At this stage, the researcher strives to interpret and contextualize the data by drawing on similarities and differences in the analysis and integrating relevant theories or concepts that may offer insight (Charmaz, 2014). By testing and refining possible explanations, the researcher gradually arrives at the most plausible interpretation, leading to a deeper and more nuanced understanding of the meanings behind social phenomena (Charmaz,2008, 2014; Charmaz & Belgrave, 2018; Charmaz et al., 2017).

In CGT there is a clear political undertone that aligns well with the aims of CDS. CGT encourages critical inquiry into power dynamics, such as by questioning who defines and controls core social processes, under what conditions, and to whose advantage (Charmaz, 2006; Oliver, 2011). It also emphasizes that power is dynamic and socially negotiated, highlighting that existing social arrangements can be challenged and changed (Clarke, 2003). According to CGT, knowledge is co-constructed, shaped by the interaction between researchers and participants, each bringing their own experiences and perspectives to the process, which inevitably influences the process and the eventual outcome of the study (Charmaz, 2014; Charmaz et al., 2017; Clarke et al., 2018). Employing CGT involves being aware of one's limitations and recognizing that a researcher's values and social position inherently shape what they notice in the data (Charmaz, 2014). The aim is not to erase the researcher's presence but to make their theoretical stance and positioning explicit (Bryant, 2020; Charmaz, 2014; Oliver, 2011). This requires reflexivity—an examination of how the researcher's worldview and experiences influence the research process, emphasizing the importance of critical self-awareness (Charmaz, 2017). To this aim, CGT urges researchers to write memos to elicit analytical reasoning and, at the same time, prompts the researcher to reflect on preconceptions, feelings, and views about the data. This echoes CDS's focus on the researcher's self-reflection and awareness of status and location within research, such as their complicity in creating and reaffirming oppressive power structures (Charmaz, 2014, 2017, 2019; Goodley, 2016; Goodley et al., 2019).

4.2.2 Forms of data

Qualitative interviews are a vital tool for gathering in-depth insights about specific phenomena, grounded in participants' knowledge and lived experiences (Charmaz, 2014; deMarrais, 2003; Roberts, 2020). In this project, individual interviews were used as the primary method of data collection in Article I and also featured in Article III. Focus group interviews, by contrast, center on collective discussion among individuals who share common interests or characteristics. These discussions create dynamic spaces for addressing societal issues of concern and for participants to co-construct meaning around shared experiences (Rowe & Frischherz, 2022; Yin, 2009). As a method, focus group interviews are compelling in making visible the experiences of marginalized groups, validating their perspectives, and highlighting both individual and collective strategies of survival and resistance (Munday, 2006; Wilkinson, 1998). Focus group interviews served as the primary method of data collection in Articles II and III, offering rich insights into the social and relational dimensions of YDP's lives.

In participant observations, researchers systematically document actions, behaviors, and interactions, generating detailed insights into social settings and how people relate to others (Floersch et al., 2013; Hennink, 2011). This method is especially useful for understanding complex social processes and dynamics (Adler & Adler, 1994; Charmaz, 2014). Alongside interviews, participant observations were key data collection methods in Article I and are referenced in Article IV.

Documents, both written and visual, are frequently employed in research as they offer access to contextual data that might otherwise be unavailable, (Campbell et al., 2017).

All four articles draw on multiple sources of documents in both textual and visual formats, such as international human rights treaties, domestic legislation, reports, participants' individual plans and education plans, school assignments, photos, videos, drawings, and art crafts.

4.3 Methodology

The case study approach was employed with participants aged 11—15 and focus groups were conducted with those aged 18—35. Recruitment was carried out through invitation letters from our collaborating institutions, advertisements on their websites and social media platforms, as well as referrals from key informants in the disability sector, such as activists and service providers. Aiming for diversity in terms of gender, age, residence, and types of impairment, the study also employed snowball sampling, where those recruited recommended others who might be suitable candidates for the research. The case studies and focus groups were conducted between 2017 and 2020. Additionally, four individual follow-up interviews were conducted between 2021 and 2023 as part of theoretical sampling, helping to clarify findings and illuminate unresolved categories (Charmaz, 2014).

4.3.1 Case studies

To gain a comprehensive understanding of transitioning into adulthood, it was essential to include YDP of different ages, providing insight into the early stages of this journey. Accordingly, article I and IV focused on the experiences of disabled children aged 11 to 15. The case study approach was chosen because it offers opportunities to explore the diversity, complexity, and richness of disabled children's experiences in-depth, while also drawing on stakeholders' perspectives to deepen understanding (Yin, 2009). The case studies were designed to shed light on the multilayered contexts and arrangements surrounding the children's aspirations, self-image, daily structures, and the roles of significant actors in their lives. In line with the case-study approach, multiple sources of information (Yin, 2009) were gathered. Article I is based on seven case studies conducted by me and my fellow researchers in the LIFE-DCY project, while article IV refers to the 14 case studies that constituted the larger project.

Each of the seven case studies utilized in article I centered on a disabled child (aged 11-15) and included interviews with the child and at least one parent and one teacher, along with observations and document analysis. Particular emphasis was placed on engaging children who are frequently overlooked from research due to assumptions about their ability to speak for themselves (Teachman et al., 2014), such as children with autism spectrum disorder (ASD), communication impairments, and/or mild intellectual disabilities. A total of three girls and four boys participated. All but one had more than one diagnosis, five were diagnosed with ASD, three had mobility impairments, and another three had other types of neurodevelopmental or invisible impairments. All except one lived in the capital area, where approximately 70% of the Icelandic population lives.

A total of 13 parents took part, six fathers and seven mothers. The parents had a diverse range of educational backgrounds and professions. Most had office jobs, three worked in trades, and one mother was a stay-at-home parent. No parent identified as LGBTQ; all were white and of native Icelandic origin. Thus, it can be argued that they were predominantly middle-class or upper-middle-class. Altogether, seven teachers were interviewed.

4.3.1.1 Interviews

The interview guides for the children, parents and teachers (see Appendix D) were formulated by the LIFE-DCY team, informed by its prior work and knowledge on YDP's and children's wellness and participation (Egilson et al., 2021). The interview topics encompassed the children's wellness and participation, such as their opportunities to take part and sense of belonging in various settings. All guides were open-ended to facilitate natural and creative discussions. The goal was for the interviewees — children, parents, and professionals — to express themselves in their own way. Thus, the questions were intentionally broad and exploratory, allowing for a wide range of responses.

As a rule, we began by interviewing parents to gather background information, which helped establish trust and ensure our familiarity with topics and issues of value to their children (Teachman & Gibson, 2012). Then we met with the children on several occasions at their chosen location. Efforts were made to meet the children's needs and preferences in the interviews. We informed them beforehand about the research, including the topics to be discussed and the duration of the interviews. Participants also shared documents, including the child's individual education plan, school assignments, photos, and drawings. Later in the process, interviews with teachers helped to situate the children's accounts within the everyday context of school life and peer interactions.

During interviews with the children, we encouraged them to reflect on their vision of a 'good life' and where they envisioned themselves in 15 years. This gentle and lightly guided structure was key to building trust and enabling participants to share personal thoughts, ultimately allowing for authentic and meaningful insights that may not have surfaced in a more controlled setting. Most participants enthusiastically shared their accounts, even on complex and sensitive subjects such as bullying or violence. They rarely needed prompting to maintain flow, though I remained mindful of active listening – nodding, using facial expressions and offering clarifying responses such as 'Did I understand you correctly' or 'Do you mean that'. Participants' insights often emerged most vividly toward the end of interviews, when they were invited to share anything they felt had been overlooked or required clarification. Many, particularly parents who had been 'battling the system,' used this opportunity to express their experiences.

Each interview lasted approximately 60 minutes and was transcribed verbatim afterwards. To meet the children's needs and to avoid overwhelming them, we took breaks during the sessions. Approximately six months after the last interview, the children received accessible summaries to review and discuss with us, which also allowed them to provide additional feedback. About five such comments were received and were included in the data.

4.3.1.2 Observations

Observations took place in the children's usual environments, including their homes, schools, and recreational settings. A total of 12 participant observations, lasting from two to six hours, were conducted as part of the seven case studies, six in schools and six during leisure activities. The first observations typically took place at the children's school after interviewing their parents at home. The time and place of later observations were determined in collaboration with the child and, sometimes, their parents, and usually involved valued activities, such as after-school clubs, sports practice, or dining at restaurants. When approaching the observation sites as a stranger, such as at school or sports practices, I tried to blend in without disturbing or interfering. The observations focused on the interaction between the child and their peers, as well as the child's interactions with adults who were present. When in less formal settings, my engagement became more active, which at times revealed unexpected insights, as my proximity allowed me to witness firsthand some of the challenges faced by the children and their families. A pivotal moment occurred when a father jumped fully clothed into a pool to rescue his son, who had a seizure while swimming. The father had accompanied his son to swimming lessons for years because there were no other support options available. Another observation took place at a popular coffee house, offering a glimpse into how one participant became conscious of herself when she saw a cute boy. As a researcher, I felt the dynamic between us change as I became a co-conspirator and a confidant she confided in about boys. This joint experience helped to understand her better and provided insights that I believe deepened the data analysis. During the observations, I took brief notes in real-time, which were later expanded into detailed field notes that captured both descriptive accounts and reflective insights after each session.

4.3.2 Focus groups

Focus group interviews with YDP served as the foundation upon which articles II and III were built, while article IV also draws on the same data. The aim was to explore the diverse perspectives and experiences of YDP in relation to their journey into adulthood. Participants were invited to share their views on what constitutes a good life, what supports their happiness and wellness, and how they navigate challenges and setbacks along the way.

A total of four focus groups were conducted, involving 21 individuals, ten men and eleven women, aged 18–35. A wide age range was considered pivotal to situating the YDP transitional experiences within a larger societal and cultural context, while also taking note of possible generational differences. Two of the groups were mixed gender, the third group comprised disabled women, and the fourth group included disabled men. Two participants were identified as members of the LGBTQ community, and one participant identified as having a brown skin tone. All were of native Icelandic origin. Most participants were recruited from the greater capital area, although a few were raised in rural municipalities. The participants self-defined as disabled, which included a wide range of physical, intellectual, and hidden impairments or a mix of many. Some were still in upper secondary school or university, others were job searching, and a few had stable employment. Most participants had not been successful in finding a job that matched their needs or interests. Thus, the participants reflected a broad spectrum of experiences and knowledge on YDP issues.

At the outset, a pilot group of five disabled participants aged 30 to 50 had been assembled to help refine the research focus and test the initial interview guide. The pilot participants were asked to reflect on past transitions, and the discussions offered insight into persistent structural and attitudinal barriers. As their experiences contributed to important perspectives on enduring societal inequalities and closely echoed those of younger participants gathered in the following focus groups, their narratives were included in the overall analysis.

The focus groups were co-facilitated by me and Freyja Haraldsdóttir, a fellow disabled woman and researcher. Each session lasted approximately 1,5 and 2 hours. To create a welcoming atmosphere and help participants feel at ease, we provided light refreshments and ensured that everyone had the space and time to share their thoughts. Our role was to act as facilitators, guiding the discussion gently to allow for a productive, participant-led flow. This balance was crucial, as many participants shared deeply personal and complex stories. We were also mindful that some topics could be emotionally challenging; therefore, participants were reminded that they were under no obligation to discuss anything that made them uncomfortable. The interview guide and structure reflected this approach (see Appendix D). Sessions began with brief introductions, which often led to deeper conversations. We then moved to more targeted questions, such as: 'How would you describe a good life?' and 'What do you think is needed to achieve that?'

Before the focus groups, we, the moderators, decided to be open about our positioning as disabled women. As strong advocates of the principle 'nothing about us without us' (Oliver et al., 2012), we felt it was crucial to take the journey with the participants by being transparent about our own disability identity. This disclosure appeared to foster a sense of solidarity, enhancing participants' trust and mutual understanding, which in turn facilitated the depth of discussions. It also allowed us to meaningfully relate to participants' experiences, notably when they referenced places, people, or practices that might be unfamiliar to outsiders.

To document emerging reflections and ideas during the sessions, I took notes, which I then reviewed with my fellow moderator, ideally the same day or the day after. These conversations allowed us to share initial impressions and determine the next appropriate steps, such as arranging follow-up interviews or considering whether a participant might require further support.

4.3.3 Data analysis

All field notes were written immediately after observations, and interviews were transcribed verbatim shortly thereafter. Documents, fieldnotes, and interview excerpts were uploaded into ATLAS.ti-8 for Windows (Friese, 2014), which allowed easy access to both transcribed material and participant-generated visuals. Following Charmaz's (2014, p. 15) CGT approach, the first seven of her nine analytic strategies (see Appendix A) guided the analytical process. Furthermore, CGT's iterative approach enabled flexibility between analytical steps, which proved helpful in navigating the complexity of the data.

Firstly, the data was read thoroughly to build familiarity, and this early engagement helped surface initial insights and shape emerging analytical themes. In line with Charmaz (2014), the data were coded using initial line-by-line coding focusing on actions, processes, relationships, and emotions. Verbs were especially useful in staying close to participants' meanings. I approached the data inquisitively, asking analytical questions such as, 'What is happening here?' and 'How does this connect to the participant's experience?' Particular attention was paid to how environmental structures aligned with YDPs' needs, as well as to contradictions or negative cases that seemed at odds with the major pattern accounting for most of the data (Charmaz, 2014).

Documents collected in the data generation phase served as a valuable supplement to other focus groups and interview data. These were, for instance, crafts and photos shared by case-study participants, highlighting talents and strengths that might otherwise be overlooked. In some cases, these documents revealed contradictions, such as a girl proudly presenting self-portraits of her scars, while her parents expressed concern and a desire for surgical correction to make her look more normal. As discussed in article I, documents also exposed a clear gap between the goals of disability legislation and the lived realities of children and families who did not receive the services they were entitled to.

As the analysis progressed, its focus sharpened, and tentative categories began to take form. The most significant and frequent initial codes were further synthesized by comparing codes with other codes, codes with data, and later comparing the data sets and memos with the emerging findings. Gradually, the analysis became more deductive and theoretically driven, drawing on critical perspectives. I employed theoretical sampling (Bobbink et al., 2024; Charmaz, 2014), revisiting the data and literature to develop emerging insights further. Using a CDS lens and theoretical concepts like ableism and adultism helped refine my understanding of the YDP's multilayered experiences and the complex societal forces shaping their transitions into adulthood. Discussions with fellow LIFE-DCY members also supported this process by helping to sharpen our collective critical perspective through shared reading and dialogue around each other's findings.

In keeping with the commitment to CDS and CGT, a research journal was maintained throughout the research period. This involved writing memos to document research decisions, address dilemmas and contradictions, and capture insights on the emerging analysis. Reflecting on personal feelings was especially important when participants shared difficult experiences, such as neglect and abuse. Engaging with these emotions helped me acknowledge the weight of their stories more effectively while situating my responses.

While the critical lens helped clarify the YDP's experiences, interpreting data on partying and 'adult play' proved particularly challenging. Existing literature on this topic remains limited and often presents conservative views. However, partying emerged as a significant activity for participants, which prompted further exploration in the third article. Following Charmaz's (2014) advice, I revisited focused coding to identify leads and patterns. To better align with participants' accounts, I turned to alternative sources, such as the Disability After Dark podcast and Open Future's Facebook posts, which provided essential insights missing from the academic literature. Building on these perspectives, I also involved a small number of participants in the analysis, whose reflections helped deepen the interpretation and spark new ideas.

As the research evolved, I appreciated how CGT and CDS complemented each other, enabling me to stay anchored in the participants' accounts while also exploring the broader societal structures and power dynamics that influenced their lives (Charmaz, 2011, 2017, 2019; Charmaz et al., 2017). This critical framework was particularly valuable in highlighting concepts such as ableism and adultism, which were essential for understanding the complex social realities of YDP and revealing the power hierarchies that shaped their experiences (Charmaz, 2014, 2017, 2019).

4.4 Ethics

Various ethical aspects became prominent due to the sensitive nature of the study, which involved a marginalized group whose participation included sharing personal and sometimes difficult experiences. In addition, Iceland's small population necessitated careful consideration to ensure participants' anonymity.

As part of the LIFE-DCY project, we initially applied the qualitative aspect of our research to the National Bioethics Committee and the Data Protection Authority. This application was approved with reference numbers VSN-16-187/-VI/-V2. Before conducting interviews and focus groups, participants received an introductory letter that explained the purpose of the research and emphasized that their participation was voluntary. Participants also signed informed consent forms (see Appendix C). At the beginning of each session, we reiterated key information and confirmed that participants understood their involvement. By fostering trust and transparency, we aimed to establish an ethically sound research framework that respected participants' rights and enhanced the credibility of the research process.

In Article I the information from parents and teachers was used to provide valuable contextual insights about the child but was not treated as a substitute for the data collected directly from the children. The children's and YDP's perspectives remained central and were consistently prioritized throughout the study.

A core value of this project and of CDS more broadly is to uncover and challenge the power relations and social hierarchies that sustain injustice (Meekosha & Shuttleworth, 2009). In this context, it was essential to reflect on and disclose my positioning. As a disabled young, white, heterosexual cis woman and a social worker, I had insights and experience from both sides of the table. This background was valuable but also came with challenges. I had to be mindful of my position and impact on the research process and progress, as well as of myself as a figure of power. To mitigate this, I drew on the principles of CDS, which foreground participants' voices and recognize them as experts in their own lives. In addition, drawing from a wide range of data sources enriched the analysis and supported a more grounded, credible, and nuanced representation of their experiences.

Producing critical knowledge, requires a careful and comprehensive reflection on how research actions and decisions may contribute to or challenge existing oppressive arrangements (Charmaz, 2014; Creswell & Poth, 2018; Madison, 2011). One prominent ethical dilemma in this project was how to balance the fine line between respecting and describing YDP's experiences of risky behavior, such as drinking and going downtown, while also being mindful of the inherent risks that such activities can entail. When presenting this aspect of the research, some people questioned the appropriateness of exploring such issues, citing the heightened risks YDP may face, including their increased risk of – or vulnerability to - abuse. While such concerns are understandable to a degree, they often reflect a protective, paternalist mindset shaped by ableist and adultist assumptions. In contrast, many YDP described these experiences as sources of joy, connection, and autonomy, and actively resisted being excluded from them. As Hollomotz (2009) argues, 'we must see beyond 'vulnerability' and aim to eliminate conditions that create risk.' Guided by this perspective, I found it ethically necessary to respect YDP's self-determination and to take seriously their desire to participate in activities that some adults may view as inappropriate or risky.

4.5 Strengths and weaknesses

Studying societal phenomena involves navigating a dynamic and constantly evolving social landscape. Consequently, the knowledge acquired is inherently shaped by specific contexts, times, and circumstances. This reality holds for the current project, which, while offering significant insights into YDP issues, is still bound by its time, place, and participants. The findings provide insights that are responsive to shifts in societal developments. While these constraints can be viewed as weaknesses, they simultaneously present an opportunity to understand current societal problems deeply and how subtle nuances in behaviors and attitudes manifest in social processes (Rubin & Babbie, 2009). Furthermore, it should be recognized that most participants in the study were white, native Icelanders from middle-class backgrounds living in the greater capital area. Therefore, the study does not capture the experiences of YDP who are multiply marginalized due to their social positioning.

The CGT design and data generation method helped ensure that participants' subjective realities were interpreted and represented as accurately as possible, thereby enhancing the trustworthiness of the study. Few have explored issues related to YDP through the lenses of ableism and adultism. By doing this, the research generates new understandings, offering valuable insights into the lives of young people. By highlighting the systemic gaps and barriers faced by YDP, it has the potential to inform policy reform and influence decision-making aimed at advancing disability equality.

5 Summary of findings

The main findings of the dissertation are presented across four peer-reviewed articles. This chapter offers a concise overview of those findings and how each article contributes to the project's overarching analysis.

5.1 Article I. 'I just want to live my life': Young disabled people's possibilities for achieving participation and wellness

This first article is grounded in case studies with disabled children and youth and focuses on their preparation for transition to adulthood. It was published in *Social Sciences* in 2024. The article explores how the children and youth understand their possibilities for participation and wellness at home, in school, and in their communities, and how social, cultural, and material conditions intersect to shape those opportunities. Data was gathered from the children, their parents and teachers, each group expressing a strong and mutual desire for the disabled child to be included in everyday social life, especially in peer settings. Additionally, observations took place in the children's usual environments. The findings demonstrate how underlying structural dynamics and normative traditions influence whether and how opportunities for participation are realized. They furthermore underscore the importance of providing adequate and responsive support to enable disabled children to exercise their rights to inclusion and community participation. These rights are enshrined in international human rights treaties such as the CRC and CRPD, both of which inform Icelandic policy and practice. However, their implementation proved inconsistent and often inadequate.

Whether or not the families received their rightful support largely depended on several intersecting factors. This included how well parents understood and could navigate the welfare system, which effectively placed the burden of finding appropriate solutions on the families themselves. This burden was compounded by austerity measures and cutbacks within the municipalities responsible for service delivery. The outcome was a patchwork of support, in which families had to 'make do,' with limited resources and, as a result, the children and youth were frequently excluded from meaningful social experiences.

5.2 Article II. 'Then you realize you can actually do it': Young disabled people negotiating challenges during times of transitioning into adulthood

Building on focus group discussions with YDP aged 18-35, this article highlights the views of those currently navigating transition markers as well as those reflecting on their experiences retrospectively. The analysis aimed to gain a nuanced understanding of participants' experiences by examining both shared patterns and individual aspects. Focus groups discussions proved to be an effective method for achieving this goal. Notably, all participants, regardless of age, reported common challenges and priorities, as they navigated efforts to align with valued transitional markers. Participants described encountering barriers in the built environment alongside deeply ingrained ableist attitudes that uncritically portrayed them as incapable. These kinds of views made it more difficult for them to be recognized and supported as adults, contributing to their marginalization. Their experiences reveal a double bind: while their opportunities to achieve traditional transition milestones, such as employment, were limited, they simultaneously faced criticism and stigma for receiving disability benefits. The normative expectations imposed on the YDP often required them to meet specific goals – such as securing employment - without providing the necessary access, resources or opportunities to do so. They experienced significant frustration in the face of these rigid barriers. Despite these challenges, many found comfort and strength in connecting with disabled peers who were dealing with similar situations. This sense of solidarity was sometimes profoundly affirming for participants, providing them not only emotional support but also a collective resilience. A key takeaway from this study is the importance of shared understanding and mutual recognition in helping young disabled people navigate the often complex journey into adulthood. The article was published in *Disability & Society* in 2023.

5.3 Article III. 'Let us talk about our party stories': Young disabled people out on the town

In the focus group discussions, participants were asked to reflect on what it meant to live a good life as young adults. Across all focus groups, they consistently emphasized the importance of social activities, particularly partying and going downtown with peers, as a key component of a fulfilling life. This pronounced and somewhat unexpected focus on partying prompted a deeper investigation into what such social spaces meant for YDP and how they navigated them. This became the primary focus of the third article, which has been submitted to the *International Journal of Disability and Social Justice* and continues the exploration of YDP's experiences during the transition to adulthood. The findings show that 'going out' provided new and exciting opportunities for YDP to express themselves, strengthen peer connections, and engage with their broader environment. Partying was an essential part of YDP's lives and vital for making valued connections with peers and exploring their identity. However, participants' experiences were shaped by persistent ableism and adultism, which surfaced through inaccessible venues, stereotyping, and negative assumptions about their capacity to participate. Participants frequently encountered microaggressions in these social settings, for example, being ignored at bars, questioned about their presence while drinking, or facing unwanted attention and scrutiny. These forms of exclusion - subtle in appearance yet overt in impact - created numerous obstacles, ultimately limiting YDP's ability to participate equally in nightlife settings. The findings clearly demonstrate that partying is a significant and meaningful site of participation for YDP and that research focusing on the topic, centering YDP's voices and priorities, can render important insights into their social lives. Interestingly, though, this remains an area that has received limited attention in scholarly work.

5.4 Article IV. Life quality and participation of disabled children and young people: Design and methods of a transformative study

The fourth article was published in the *International Journal of Qualitative Methods* in 2021. It synthesizes key insights from the larger LIFE-DCY research project and provides a reflexive discussion of the project's methodological, conceptual and ethical aspects. The LIFE-DCY project had two main objectives: first, to assess life quality as reported by disabled children and their parents, and second, to identify commonalities, differences, and tensions in the processes that shape participation and wellness. To this end, both quantitative and qualitative methods were employed in two phases. In phase one, two instruments were used to measure life quality, participation and environment (KIDSCREEN-27 and Participation and Environment Measure). Altogether 209 disabled children and their parents, and 335 children in a control group and their parents (paired reports) participated. Phase two consisted of 14 case studies with disabled children aged 8—18 and focus groups with 21 disabled young adults aged 18—35. This broad age range provided insight into both current experiences and retrospective reflections on growing up disabled. The qualitative analysis was inductive and data-driven and later guided by critical and transformative perspectives to examine how social and environmental contexts shape life quality and participation. Furthermore, how such contexts are susceptible to change within different environments and at various times.

The article highlights the central role of theory and ethical considerations throughout the LIFE-DCY project, which this dissertation is a part of. It discusses key methodological and ethical challenges related to power, representation, and the social construction of disability and childhood. Thus it places the empirical findings from my doctoral research in a larger context and offers insights that contribute to a broader discussion about 'normality' and its impact on the lives of disabled children and young people. As such the article provides valuable lessons for future research and practice.

6 Discussion

Anchored in a critical disability studies perspective (Goodley et al., 2019, 2021), this project set out to examine the complex and nuanced processes involved in the transition from childhood to adulthood for YDP, and how ableist and adultist societal assumptions shaped their lived experiences during these times of change. A key focus was exploring how participants understood and made meaning of their trajectories within an unjust society and highlighting, on the one hand, dominant assumptions about the abilities and position of YDP and children, and on the other, the influence of normative ideas about growing up and entering adulthood on their opportunities to participate meaningfully. This chapter synthesizes the central findings across the articles and the dissertation as a whole.

6.1 Navigating barriers that undermine transitioning pathways

The overall findings of the dissertation show that YDP and children encounter a range of persistent and complex barriers that shape their opportunities, wellness, and ultimately their transition to adulthood. In line with previous research (Bagatell et al., 2017; McLaughlin, 2025; Pearson et al., 2025; Priestley, 2003; Stafford et al., 2017), the findings document inaccessibility of the built and natural environment, as well as deeply embedded stereotypes, assumptions, traditions, and attitudes that YDP have to navigate to gain access to meaningful activities and spaces. They furthermore provide an important insight into how these barriers interact with the process of identity formation.

Participants described a recurring disconnect between how they understood themselves and how others perceived them, often through a narrow, deficit-based lens. This mismatch led many to feel sidelined, misunderstood, or reduced to their impairments, which overshadowed their broader identities, aspirations, and personal strengths. Participants shared experiences of being treated as inferior, or even invisible, particularly in contexts where they sought to approximate traditional transitional markers (Settersten et al., 2015) or participate in meaningful activities. They recounted instances of intrusive encounters, such as unsolicited questions about their impairments, violations of personal space, and condescending or dismissive attitudes – and how they navigated them. Microaggressions also appeared in media portrayals, where stereotypical representations of disabled people were often treated as laughable—or even depicted as 'better off dead.' At times, the cumulative effect of these interactions became emotionally exhausting, reinforcing feelings of alienation and undermining their sense of self-worth and even posed a threat to their safety. This led some to feel that withdrawing from participation was their only option. At times, this meant downplaying or concealing their needs to avoid the emotional toll of constant scrutiny or confrontation. Yet this self-suppression was neither passive nor taken lightly; it was a deliberate strategy, a way to preserve access to valued spaces and activities, and to claim brief reprieve from ableist judgment.

Although discriminating encounters caused them mental exhaustion and lowered their sense of wellness, at the same time, many YDP actively resisted ableism. Far from being silent or submissive, they expressed a strong desire to participate as their authentic selves and to be accepted on their terms. As one participant put it, 'I don't care what they think—I'm happy with who I am.' This kind of self-acceptance is a form of resistance. As Hitselberger (2020) explains; 'The way you exist in the world is political—especially if you are marginalized. Society has decided that some bodies and ways of being are more valuable than others. Pushing back against that is a revolutionary act.' In this light, YDP's refusal to conform to narrow expectations and their insistence on being visible, present and proud is a powerful assertion of self-determination.

6.2 The double-bind of ableism and adultism

YDP face a dual challenge due to their identities as both young and disabled. This puts them at risk of experiencing ableism and adultism, resulting in a complex form of marginalization. On the one hand, society expects YDP to prepare for adulthood by becoming more independent, entering the workforce, and assuming roles that are valued in adult society (Bell, 2003). On the other hand, they are commonly perceived as too vulnerable, dependent, or sick to engage in many of the very activities that signify and support this transition, such as managing finances, making decisions about education or employment, or moving out of the family home.

Research on intersectionality indicates that overlapping forms of marginalization often exacerbate the barriers individuals face, as each form introduces its unique challenges and implications (Collins, 2020; Collins & Bilge, 2016). For the participants in this project, navigating the layered and often contradictory demands of growing up proved especially strenuous, frequently leaving them feeling dismissed or misunderstood. As aforementioned, dominant ideas about adulthood tend to rest on rigid, narrow and ableist assumptions; there was limited recognition of YDP's diverse ways of becoming and belonging and little space for alternative trajectories. Participants felt their contributions undervalued or overlooked simply because they did not align with prevailing norms. Ironically, at the same time, they were held accountable to those very norms.

The project's main findings, therefore, highlight the way in which the interplay of adultism and ableism creates a double-bind for YDP: they are expected to conform to conventional standards of adulthood, yet are systematically denied the opportunities and resources necessary to do so. Participants described not being offered a meaningful curriculum at school, lacking support to develop their talents, and being denied the freedom to make mistakes, often in the name of protection. A significant aspect of the double-bind was such overprotection which proved to be a defining feature of the broader pattern of ableism that shaped how YDP were treated across social contexts. Another facet was the ongoing experience of subtle yet pervasive discrimination, particularly in the form of everyday microaggressions. These constraints not only limited their autonomy and growth but also reinforced the very barriers they were expected to overcome. This was deeply concerning for many, and one participant captured the dilemma vividly: 'It is as if birds were not taught to fly—how can they leave the nest?'

The YDP in this study aimed to approximate traditional transitional markers while also highlighting their own approach, which was tailored to their needs and lifestyle. Owing to ableist and adultist connotations, this aspiration was generally difficult to achieve.

6.3 Lack of support facilitates exclusion

When examined through a critical lens, the exclusion experienced by YDP stems less from their impairments and more from the societal structures and relations that shape experiences, opportunities and assumptions made about them. One area where this became particularly visible is in the support systems intended to facilitate their participation. These services often fail to meet their objectives. Participants described them as inadequate, fragmented, and inconsistently delivered, with unclear standards and little guidance for navigating a complex system, as depicted in prior Icelandic research (Brennan and Traustadóttir, 2020; Jónasdóttir et al., 2020; Jónsson et al., 2022). These limitations were further reflected in how support interventions are typically designed from the top down, without genuinely consulting the YDP they intend to serve. Assistance is commonly tied to institutional settings, such as schools, and personal support is typically limited to just a few hours, far from sufficient to meet YDP's broader social and age-related needs. This lack of support became increasingly problematic as the children grew older and sought to engage in a wider range of activities, particularly socializing with peers away from adults' watchful eyes, where they could, as one participant put it; 'let loose and be teenagers.' Such peer interactions are not just recreational, they allow young people to test boundaries, assert independence, and challenge adult authority, actions that are themselves key markers of the transition to adulthood (National Research Council, 2013).

The findings raise important questions about how Iceland's obligations under the CRPD and the CRC are being translated into practice, and more specifically, how recent legislation intended to support YDP and children (Lög 85/2018; Lög 86/2021) is implemented. So far, implementation has been slow, raising concerns that these legal reforms, though promising on paper, remain delayed or uneven in practice. Despite these initiatives emphasizing the right of YDP and children to participate fully in society, access appropriate support, and have a say in decisions affecting their lives, the lived experiences shared by participants in this project highlight a significant gap between these commitments and everyday realities. This disconnect appears to be driven by a combination of limited political will, under-financed services, and a lack of clear mechanisms for ensuring consistent, rights-based implementation across national and municipal levels. Brennan et al. (2018) suggest that it is challenging to change an established welfare system, particularly when the system itself maintains control of services. These difficulties stem not only from budget constraints but also from perspectives that prioritize non-disabled, adult viewpoints. When YDP are not seen as active participants, services are more likely to be designed for them rather than with them, reinforcing adult-led models of control and stifling opportunities for shared decision-making, flexibility, or youth-driven goals. The greater the divide between the socially constructed roles of children and adults, the more difficult it becomes to bridge transitions in practice with support they are entitled to (Benedict, 1976; Vranješević, 2020). YDP's voices are essential to design services that truly reflect their needs, rights, and lived realities. Catino et al. (2018) state that when young people play a central role in developing solutions to the inequities they encounter, the implementation improves for all stakeholders involved.

Despite the obstacles the YDP in this research faced, all in all they led vibrant lives and expressed contentment with their circumstances, particularly when they had access to the support and accommodation needed to participate in ways that affirm their worth and equality. These opportunities allowed them to step outside imposed ableist and adultist roles and experience life as young people—curious, social, and eager to engage with the world on their terms. Participating in such activities was not only vital to their wellness and personal growth but also contributed to developing resilience and confidence, which helped them navigating the ableist and adultist barriers they regularly encountered.

6.4 Concluding comments

Transitioning into adulthood is a complex yet profoundly significant participatory experience for YDP, as they begin to navigate the adult world. As Imms et al. (2022) note, 'Participation is an essential driving force of life-span development, providing opportunities to develop autonomy, belonging, and learning which in turn support ongoing participation'. In other words, participation is not only an outcome but also a vital mechanism for personal development, self-determination, and overall wellness, particularly during periods of transition. Conversely, and similar to the findings of Pearson et al (2025), the YDP who participated in this study were largely unaware of having had any conversations about or involvement in their support and future plans.

The YDP in this study aimed to approximate traditional transitional markers while also highlighting their approach, tailored to their needs and lifestyle. Owing to ableist and adultist connotations, this aspiration was generally difficult to achieve. Recognizing the durability and adaptability of ableism is key to challenging it in all its forms (Wood et al., 2018). A part of what complicates and stifles YDP's pathways during transitions is the persistent ableist stereotypes attached to their identities. Assumptions about their inherent vulnerability are particularly problematic, as they stem from and reinforce both ableist and adultist perspectives. Although often framed as protective, an overemphasis on vulnerability can lead to unnecessary restrictions and a denial of autonomy. A vital first step is to critically examine vulnerability, not as an individual trait, but as a socially constructed phenomenon, scrutinizing the broader social processes that produce and sustain discrimination based on its premises (Hollomotz, 2009). These processes are deeply rooted in normative underpinnings that privilege typical bodies and abilities, effectively marginalizing those who do not fit within these narrow expectations. By reframing our understanding of vulnerability in this way, we can challenge discriminatory practices and advocate for a more inclusive society.

Achieving equitable opportunities for YDP during their transition to adulthood requires coordinated action across all levels of society. This includes advocating for rights-based approaches, implementing policy frameworks that promote inclusive and participatory service delivery, fostering cross-sector collaboration, supporting families to reduce stress and build capacity, and ensuring that YDP are meaningfully supported within the life contexts that matter to them (Imms et al., 2022). The policy environment around transitions for young disabled people is problematic, and contradictory, and too often disabled people are overlooked in policy and planning (Pearson et al., 2025; Wong, 2020). This holds especially true for YDP and children, who face the compounded risk of being excluded due to the intersecting forces of ableism and adultism. To address this, their perspectives must not only be acknowledged but actively integrated into the systems and decisions that shape their lives. YDP must be engaged not just as sources of insight, but as active collaborators and leaders who bring first-hand knowledge of how to use resources to make informed choices and decisions about how to achieve and sustain wellness. Only then can the commitments Iceland has made under the CRPD and CRC be meaningfully fulfilled.

While strong leadership from YDP in shaping their own lives and influencing decisions that affect them is vital for ensuring better wellness and participation outcomes during transitions, it does not imply that adults should take a passive role. Young people still require support, and it is the responsibility of adults to promote their wellness by providing appropriate guidance and encouragement. This includes supporting YDP who are new to self-advocacy and decision-making. Parents are often YDP's greatest advocates at times of transition (Shah, 2010) but like others, parents can also hold ableist and adultist ideas. Therefore, it is essential to support parents in tackling the systematic and structural arrangements that are the roots of so many of the challenges their disabled children face on their road to adulthood (Jóhannsdóttir et al., 2022).

I agree with Goodley (2025), who states that we live in rapidly changing times that demand critical knowledge about disability and the socio-economic, cultural, and political conditions that contribute to disability exclusion. The rapid rise of often inaccessible digital technologies, including AI-driven systems, poses new challenges for YDP who frequently rely on such systems as recipients of disability-related services. Continued research, monitoring and advocacy are essential to ensure that these technologies do not deepen existing inequalities or create new barriers to participation.

Although much progress has been made in advancing rights, evident in legal frameworks, policies, and shifting societal attitudes, significant challenges remain. YDP still encounter systemic barriers that limit their full inclusion in meaningful activities and environments. A key intersection of this project is the need to deepen the collective understanding of how ableism and adultism intersect and shape the transitional experiences of YDP. Continued dialogue, research, and action are essential for transforming recognition of rights into lived realities.

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Paper I

Paper I

social sciences

Article

"I Just Want to Live My Life": Young Disabled People's Possibilities for Achieving Participation and Wellness

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Abstract: This study aimed to (a) explore disabled children's and adolescents' possibilities for participation and (b) identify the practices and policies that affect their participation and how these are enacted. Case studies were conducted with seven children and adolescents with various impairments. Each case included interviews with the young person, their parents and teachers, as well as observations in their usual environments. The interview topics covered the young people's participation, their sense of belonging and aspects that were pivotal to their engagement and wellness. The observations focused on their possibilities for participation and interactions with peers and adults. These young disabled people's possibilities for participation at home, in school and in their neighbourhoods were affected by complex dynamics between personal and environmental factors. Whether and how the young people's disability-related rights were enacted depended on the socio-cultural–material arrangements and parents' knowledge of the welfare system. To better understand and act on the complex and marginalised position of young disabled people, more focus should be directed at policies that affect their rights and possibilities for participation and how these are enacted in practice. Knowledge needs to be expanded to scrutinise the disabling hindrances hidden in social and structural spaces and implemented in services.

Keywords: disabled children's rights; socio-material arrangements; services; accommodations; case studies

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1. Introduction

The significance of promoting and ensuring that disabled people have the opportunities to live well and participate in all areas of society is emphasised in international policy and human rights treaties (Convention on the Rights of the Child (CRC 1989); Convention on the Rights of Persons with Disabilities (CRPD 2007)). The current research has identified various challenges to the opportunities of disabled children and adolescents to participate in social activities and to experience wellness, in comparison with their nondisabled peers (Bedell et al. 2013; Egilson et al. 2017a, 2018; Hamdani et al. 2018, 2022; Imms et al. 2017; Ólafsdóttir et al. 2019). Increasingly, the importance of focusing on ways to promote disabled children's and adolescents' social participation and wellness has been highlighted (Egilson et al. 2017b; Hamdani et al. 2018, 2022; Krieger et al. 2018; Ólafsdóttir et al. 2019; Smith et al. 2021).

Participation is a multi-dimensional construct, with two main dimensions typically identified—an objective dimension reflecting whether someone is included in the routine social activities of a particular setting, how and with whom, and a subjective dimension reflecting a person's engagement, sense of belonging and contentment with one's involvement in that setting (Anaby et al. 2013; Imms et al. 2017; Powrie et al. 2015). In line with the normative understanding that considers disability as being, first and foremost, within the person (Oliver 2013), disabled children's and adolescents' lack of participation has often been regarded as directly linked to their individual impairments. Increasingly, the various environmental factors that influence these young people's opportunities for participation have been stressed, such as attitudes, the design of built environments, policies, services and systems (Anaby et al. 2013; Egilson et al. 2017a, 2018; Hodge and Runswick-Cole 2013; Ingimarsdóttir et al. 2023; Krieger et al. 2018; Ytterhus et al. 2015). Thus, personal and socio-cultural factors appear to intersect to mediate these children's and adolescents' participation in various situations (Egilson et al. 2021). This resonates with the relational understanding of disability put forward in the preamble of the CRPD (2007), where disability is described as "the result of the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others".

Similar to participation, the concept of wellness can have varied meanings, which nevertheless all emphasise the importance of being able to draw on personal strengths and capabilities in order to live the best life possible (Hamdani et al. 2018, 2022; Rachele et al. 2014). The Global Wellness Institute (n.d.) defines wellness as "the active pursuit of activities, choices and lifestyles that lead to a state of holistic health". How people perceive wellness is considered to be based on their satisfaction relating to the interplay of various dimensions, that is, physical, social, psychological, intellectual, emotional and spiritual (Adams et al. 2000; Global Wellness Institute n.d.). The concept of well-being is often used interchangeably with wellness, although well-being also extends to society's role and emphasises societal responsibility (World Health Organization 2021). In a scoping review focusing on the wellness of young people with developmental disabilities, Hamdani et al. (2018) found that the concept was often ill defined, making it complex to untangle and compare. Overall, disabled children's and adolescents' ideas about wellness underscore their desires to have meaningful opportunities to take part in activities, have a variety of social relationships (Ingimarsdóttir et al. 2023; Jóhannsdóttir et al. 2022; Melbøe and Ytterhus 2017), be respected as individuals (Byhlin and Käcker 2018; Jóhannsdóttir et al. 2022) and have stable medical health (Hamdani et al. 2018, 2022; Rachele et al. 2014).

Ample research demonstrates that these young disabled people's[1] ideas of participation and wellness issues may differ from those of their parents and other adults (Egilson et al. 2017b; Emerson et al. 2023; Hamdani et al. 2019; Hemmingsson et al. 2017; Ólafsdóttir et al. 2019; Silva et al. 2019). Nevertheless, including the perspectives of parents and other key stakeholders may enable the development of a better understanding of a young person's ability to participate and be included in various contexts and to experience wellness (Egilson et al. 2021; Teachman and Gibson 2013).

This research is part of a larger study which focussed on the life quality and participation of disabled children and young people in Iceland (Egilson et al. 2021; www.life-dcy.is). This part of the study aimed to expand prior knowledge on disabled children's and adolescents' possibilities for achieving wellness and participation in valued settings and activities. It also explored how practices, policies, physical layouts, sensory qualities, social relations and attitudes, such as ableist assumptions that favour typical bodies and abilities, shape their opportunities for participation and inclusion. The research questions were the following:

- How do young disabled people perceive their possibilities for participation and wellness at home, in school and in their communities?
- How do socio-cultural–material arrangements, such as policies and practices, intersect to shape these young people's opportunities for participation and inclusion?

1.1. Political Environment, Rights and Policies

The CRPD (2007) is a treaty on human rights that reframes disability with respect to human rights and establishes the norm of the societal participation of disabled people on an equal basis with others. The treaty directs policy focus towards human rights and social perspectives on disability, where more attention is paid to the contextual factors shaping disability rather than to individuals and their impairments. The rights to services that support participation in the community, as well as to make decisions and choices in one's own affairs, are enshrined in the CRPD (Devi et al. 2011; Löve et al. 2018). By signing and ratifying the CRPD, authorities have recognised the importance of their obligations to prevent discrimination and provide opportunities for disabled people of all ages to be active members of society.

Article 7 of the CRPD (2007) focuses on disabled children and emphasises that all necessary measures must be taken to ascertain their full enjoyment of all human rights, including facilitating social inclusion. It similarly states that it must be ensured that disabled children "have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right". These emphases are consistent with and further outline the provisions of Article 23 of the CRC (1989), which focuses on disabled children's rights to special care and support to ensure that they can live full and independent lives. Furthermore, Article 31 of the CRC highlights all children's right to participate in leisure and recreational activities appropriate for their age, as well as the importance of access to equal opportunities.

Achieving equality for young disabled people is often a matter of having access to the necessary accommodations that may enable them to participate fully in all aspects of life (Navarro 2014). However, reasonable accommodation, as defined in Article 2 of the CRPD (2007), should not "impose a disproportionate or undue burden" on other social actors. Grue (2023) points out that this restriction creates what appears to be an underlying contradiction in the convention. While the right to full and equal participation is nominally absolute, in practice, it depends on a heavily qualified right to reasonable accommodation. Consequently, this principle of "undue burdens" may result in important accommodations not being provided in practice (Grue 2023, p. 2).

1.2. The Icelandic Context

As one of the Nordic countries, Iceland has received international attention for its high standard of living, emphasis on human rights in policies and legislation, extensive public welfare provisions and gender equality (Kangas and Kvist 2018). The responsibility for most disability services was transferred from the Icelandic state to municipalities in 2011 to create more cohesive services offered closer to users (Lög um breytingu á lögum nr 59/1992, um málefni fatlaðra, með síðari breytingum, No. 152/2010). Primary schools and lower secondary schools are also funded and administered by municipalities. An approved diagnosis from the authorised organisations is typically required to be eligible for specialised services and support inside and outside of school (Lög um samþættingu þjónustu í þágu farsældar barna 86/2021).

In 2016, Icelandic authorities ratified the CRPD (Stjórnarráð Íslands [Government Offices of Iceland] n.d.), indicating their commitment to implementing the treaty's obligations. Subsequently, the legal framework started to integrate a relational understanding of disability, along with the goals and requirements outlined in the CRPD. Although legal texts and policies increasingly proclaim disabled people's rights to an accessible environment and necessary accommodations, the gaps between policy and practice still pose a threat to the societal participation of disabled people, as is evident in recent research (Brennan and Traustadóttir 2020; Jónasdóttir et al. 2020). This relates partly to the lack of awareness about disability issues and the poor financial situation of many Icelandic municipalities, and it has been pointed out that both state and local authorities have underestimated the scope and costs of the transfer of disability services to the municipalities (Ríkisendurskoðun [The Icelandic National Audit Office] 2021). Moreover, the legislative wording and exemptions allow interpretations and implementations that are not in line with disabled people's core rights, as put forward in the CRPD (Jónasdóttir et al. 2020).

Personal assistance (PA) for disabled people is offered in most European countries and has been considered an important tool for empowerment, independence and participation (European Network on Independent Living 2020). Although traditionally designed for adults, in a few countries, such as Norway and Sweden, PA has been extended to disabled children and their families (Jenhaug and Askheim 2018). In Iceland, PA payments for disabled children and adolescents had been awarded only in exceptional cases, but in 2022, Úrskurðarnefnd velferðarmála [Welfare Appeals Committee] (2022) decided that applications for PA for children under the age of 18 could not be denied on the basis of age.

2. The Study

This study is part of a larger project focusing on young disabled people's lives. The design and methods of the larger study are thoroughly described in an earlier publication (Egilson et al. 2021). This part consisted of case studies with seven young disabled people and focused on their wellness, as well as the intersecting environmental effects on their rights and possibilities for participation. Case studies (Creswell and Poth 2017) can promote an understanding of the context in which young disabled people's lived experiences take shape, such as the structure of their daily lives, their aspirations and agency and the role of important actors in their lives. Moreover, this methodology facilitates building trust with participants using a stepwise approach in addressing sensitive issues that may arise.

2.1. Participants and Procedures

Altogether, seven young disabled people (aged 11–15), as well as key actors in their lives, participated in the study. Five participants were recruited through informants in the disability sector and two through snowballing. Table 1 summarises the key participants' main characteristics. The majority were diagnosed with autism spectrum disorder (ASD) in addition to another type of impairment. Apart from Helgi, who lived in a rural area, all the participants lived in the greater capital area, where approximately 70% of the Icelandic population lives.

Table 1. Key participants.

Pseudonym	Age (Years)	Gender *	Impairment Type
Saga	11	F	Physical
Gunnar	11	M	Physical, ASD
Helgi	12	M	ASD, ADHD
Gísli	15	M	ASD, Neurodevelopmental Syndrome
Atli	15	M	Physical, ASD
Elín	14	F	Invisible, ASD
Hanna	15	F	Invisible, Physical

* Each participant's gender is self-identified.

The data were gathered in 2018–2020. In line with the case study approach, we drew on multiple sources of information (Creswell and Poth 2017; Yin 2009). Each case included three to five interviews with the young disabled person and at least one parent and one teacher, along with observations and document analyses. The interview guides covered various aspects of the young people's participation in different settings, their wellness, friendships and sense of belonging. Additionally, the young people were encouraged to choose conversation themes that they found important. The interviews lasted about one hour each and the observations lasted from two to six hours.

Typically, we started by interviewing the parents to gather background information that would better enable us to build trust, establish a rapport and ensure that we focused on the topics and issues that were relevant to their children (Rasmussen and Pagsberg 2019; Teachman and Gibson 2013). Then, we met with the young disabled person on several occasions. We told them ahead of time what we would ask about in the interview and how long it would last. The interviews with the young people started with simple, precise and structured questions, followed by more open-ended questions. To avoid jumping to conclusions, we emphasised probing and asked directly about certain events and experiences, such as how they understood some incidents that we had observed. The teachers were typically interviewed last. The observations took place in the participants' homes and schools and focused on their possibilities for participation and their engagement and interactions with peers and adults within these environments. Observations in recreational settings were also planned, but due to the COVID-19 outbreak, only a few were carried out. The participants also shared documents, such as school assignments, photos and drawings, with us. Approximately six months after the last interview, the young people received accessible summaries to review and discuss with us, which also gave them an opportunity to provide additional comments, either in person or online. About five such comments were received and then included in the data.

2.2. Data Analysis

The interviews were recorded with the participants' permission and then transcribed verbatim by the authors or the members of the larger team. Each transcribed interview and set of observation notes was reviewed and reread iteratively to determine its accuracy (Brinkmann and Kvale 2015). The data were then grouped and organised according to the characteristics in ATLAS.ti (Friese 2014; Seidel 1998) using a coding system consistent with the research objectives. The initial analysis was inductive and data-oriented (Alvesson and Skjöldberg 2018). By comparing and contrasting the young people's experiences, we focused on the commonalities and differences regarding their possibilities for achieving participation and wellness. Both authors then re-read the coded transcripts multiple times to capture the conflicting issues in the mechanisms that appeared to either facilitate or restrict the young people's participation and wellness and the ways in which their rights were enacted or otherwise.

2.3. Ethics

All participants were informed about the purpose of the study and willingly participated. They received an introduction letter and a written consent form, which informed them about the aim of the study, interviews and observations, as well as their ethical rights. Each consent form was signed by the researcher, the young person and the other participants (parents and teachers) before the interviews and observations took place. An emphasis was placed on trust and anonymity, such as by using pseudonyms for people and places. The study was approved by the Icelandic National Bioethics Committee (VSN-13-081/16-187-V2).

3. Findings

To illustrate how the young people who participated in our study perceived their possibilities for participation, we provide short descriptions and larger vignettes (Boxes 1 and 2). All emphasised being able to participate in social activities and everyday events along with their peers, but they often experienced limited opportunities due to physical, attitudinal or structural restrictions. The barriers they encountered intersected according to different contexts, such as inaccessible physical layouts, inflexible systems and ableist attitudes, and typically, a more complex picture arose during adolescence. For example, Helgi lived in a rural area and travelled 40 km to and from school on a school bus. After-school activities and outings with friends required preparation in terms of transport, but due to strict procedures and the lack of funding, the municipality did nothing practically or financially to accommodate him and his family. As Helgi came closer to adolescence, he also became more interested in all kinds of social encounters, but had few options, except social media.

Negative attitudes, along with rigid ideals and traditions, were reflected in how the young people's capabilities were not necessarily given credit in the school environment. Elín was very artistic and resourceful and had learned (on YouTube) different crafts that she proudly showed the first author during their first encounter, and also beat the latter in complicated strategic board games. However, these strengths appeared to be unappreciated in school. Her main teacher was pessimistic about her potential and stressed that her work was not in line with the educational standards. She explained, "We have not found Elín's strengths, and I do not know if we will." Because of this negative attitude, Elín was unable to develop her artistic talents with support from the school. An important opportunity to build up her strengths to the fullest appeared to have been lost.

Obtaining the right kind of support and services (self-defined) was central in all accounts. Typically, assistants were part of the school staff and controlled by the school, leaving the young people with hardly any voice on the matter. Outside school, Atli, Gísli and Elín had support workers who met with them once a week to do something "fun together like going to the movies or cafés" (Gísli). They liked this arrangement and wanted to meet their support workers more often but claimed that the support was often unreliable, such as when the latter cancelled a meeting or resigned. Elín said, "I get upset when she [the support worker] is not going to make it." Difficulties in reaching the "right support person" and high staff turnover limited the usefulness of this arrangement, thereby reducing the young people's opportunities for social participation. In contrast, Gunnar and Saga had recently received PA services, which greatly increased their opportunities to participate inside and outside of school, along with their peers.

Box 1. Receiving the right kind of service: "How the PA contract changed my life".

Gunnar was a well-spoken young man and a talented student. Due to his physical impairment, Gunnar used a walker and wheelchair interchangeably for travel, depending on the situation. Some areas in the school were quite inaccessible for him, such as a fenced-in court in the schoolyard where his peers commonly gathered during recess. From a young age, Gunnar had assistants in many situations in school, provided mainly on the school's terms. Beyond school hours, limited support was available other than that provided by his family. Although after-school services were offered in his school district, these were mainly intended for and used by children aged 6–9. As the years passed, Gunnar and his family increasingly questioned this arrangement, which made Gunnar feel left out in valued after-school activities. As Gunnar described, "I could not do the same things as my classmates, like go to birthday parties and such."

A lot changed for the better when Gunnar got a PA contract at the age of 11, which gave him and his parents control over how the support was provided, when and by whom. He vividly described these changes in a presentation, which he named "How the PA contract changed my life". Consequently, Gunnar was able to take part on his own terms, making him feel much more independent, self-sufficient and happy. He said, "Now I can do the same things as my classmates, although I may do them a bit differently." Gunnar received PA every day except Sundays, focusing on helping him go home after school, attending physiotherapy, engaging in sports activities and visiting friends. Gunnar and his family prioritised hiring "young guys". According to Gunnar, this was because he needed help with personal issues, such as "going to the restroom", and that they "understood him" and thus could talk to him "about personal stuff". Gunnar was quite comfortable with the young guys joining him to meet his peers in situations where adults were usually not visible. His mother Tinna added, "At this age, you don't necessarily want your mother around." Gunnar claimed that he felt "in control", not only because he could now participate in the way he wanted but also because his parents did not have to help him out during the daytime. He said, "My parents have important jobs, and I want them to be able to work without having to worry about who helps me during the day." Evidently, Gunnar was proud of his parents and found it important that they were given time to work and contribute to society. However, receiving PA did not come naturally, as Tinna described, "We were never informed about the possibility of PA assistance; only because I heard about it from somebody did we think about applying for PA on Gunnar's behalf. But when we applied, we were well received."

When the study was conducted, Saga had recently received a PA contract, which provided her with much more control over the way in which she was provided support. Just as in Gunnar's case, Saga's parents had not been informed about the possibility of PA services but heard about this option by chance. The PA services provided Saga with opportunities to be more independent in her peer relations and—as her mother emphasised—take more responsibility for her actions. Her mother continued, "The [assistants] are not the ones who bring her up; that is my job. They help her with things [that] children typically do. And if Saga skips school, I scold her, not the assistant." Saga and her family found the PA services pivotal to her wellness as they provided her with freedom, autonomy and independence at the important stage between childhood and teenage years. Other participants did not have PA services, but then again, none of them had extensive physical impairments, which seem to be the criteria for Icelandic children to receive PA contracts (personal communication).

The families of the other young disabled people had also often not been informed about their rights and subsequently missed out on the disability-related support that might have increased the children's possibilities for participation and their parents' possibilities for supporting them. This was a source of frustration for many, including Gísli's mother, who claimed to be exhausted because of all the work involved in dealing with the system. She stated, "If only we had been offered more supports, if only I had known (about our rights)!"

Box 2. Atli: Opportunities for participation: "I am not going to accept any segregation".

> Similar to Gunnar, Atli was a bright young man, and due to his physical impairment, he used a walker in physically demanding situations. Atli also had an ASD diagnosis and was particularly sensitive to sounds and crowds. Atli found it important to be socially active and included but claimed that he had often been sidelined and not listened to in school. For example, a few years earlier, school officials had decided one-sidedly that due to his impairments, he was better off in a separate classroom, away from his peers. Atli and his family objected. His mother said, "He was in a class with 50 students, and the noise was just too much for him; decreasing the number of students to, say 20, would have been the solution." For his part, Atli claimed that this shift was due to bullying, and he felt that it was unfair that he was the one made to leave: "Instead of the teachers confronting the bullies, I was removed from the class!" Because of this, Atli felt discriminated against and not respected on equal grounds with his peers. He claimed: "I do not have the right to say 'no'; they just take me away when I just want to live my life like everybody else."
>
> When opportunities for participation were presented and Atli felt respected and included, he also felt that life was good. At the time of this study, he worked at a specialty shop after school and had been invited to be a spokesperson for young disabled people at a few conferences. Having valuable and respected roles improved his sense of wellness because he felt accepted and heard. Being vocal and visible helped him gain confidence, especially getting a platform in his political party, where he was well received. Atli's self-worth increased as he recognised new possibilities for the future and started to plan his political career, already at age 15. He claimed, "My dream is to be a minister."

Differences in the views of young people and their parents on which opportunities for participation to pursue were occasionally observed. Because of health reasons, Hanna could not attend football practice with her schoolmates. This was a major concern for her parents, who feared that Hanna might be lonely and sidelined by her peers. Hanna regarded the situation differently since she had found new friends in school who did not like football. She was also active on social media, where she reached out to a community of young queer people. Contact with the queer community was a momentous experience for Hanna's identity formation as she was figuring out her sexuality, but she had not yet disclosed this part of her life to her parents.

4. Discussion

This study explored young disabled people's possibilities for participation and wellness. Two research questions were posed: (1) How do young disabled people perceive their possibilities for participation and wellness at home, in school and in their communities? (2) How do socio-cultural–material arrangements, such as policies and practices, intersect to shape these young people's opportunities for participation and inclusion? The findings are discussed in detail below.

The young people perceived their possibilities for participation and wellness differently, depending on the time and the context. The younger participants focused on the present and underscored having opportunities to be included in social settings and activities, along with their peers. These were often complicated by inaccessible built environments or by limited, or not the "right kind", of support. Being able to participate without the presence of their parents or other authoritative figures opened opportunities to develop and strengthen their relationships with their peers, which became increasingly important as the years went by. To a certain extent, the younger children's social environment was not much different from that of other children, and they were involved in activities similar to those of their peers the same age. They were nevertheless left out in certain contexts, such as in the schoolyard. Similar to other studies' findings (Andersen and Dolva 2014; Bekken 2017), initially, the younger participants were not very critical of their limited possibilities for participation and appeared to take the status quo for granted. However, when faced with new options, such as PA, they emphasised the positive impacts of these supports on helping them lead better lives and participate along with others. Indeed, perceptions of what is ordinary or "enough" are not created in a vacuum but formed in relation to the social environments in which people are immersed (Gibson 2016), in this case the children's lack of familiarity with other ways of living. Examples of having more choices and flexibility regarding social participation with peers, as well as the importance of not being "burdens" so that their families could participate in the labour market, were shared. Disabled children are in fact often perceived as burdens on their family (McLaughlin et al. 2016; Runswick-Cole 2013), and it can be difficult to form a positive identity and experience wellness under such circumstances.

A more complex picture arose during adolescence, when the young people faced increased educational demands in school, along with their changed experiences, priorities and a wider field of activity. One participant not only had to negotiate her disability but was also figuring out her sexuality; another emphasised making his political mark in the world. Opportunities for young disabled people to explore their possibilities are pivotal, especially if they belong to multiple minority groups, which can make their social position more precarious (Delgado and Staples 2007; Toft et al. 2019). It is well known that adolescence can be an especially difficult time for disabled individuals, who may experience anxiety, struggles and grief when they try to reach normative milestones that are often rigid, inflexible and difficult to obtain (Hamdani and Gibson 2019; Jóhannsdóttir et al. 2022).

In all seven cases, various socio-cultural–material arrangements intersected to shape the young people's opportunities to participate and experience wellness. Many of the hindrances they faced were rooted in policy or service implementation, which did not accommodate their need for support. For example, assistants were typically employed by schools or social services and according to these systems' specific terms. Other barriers included inaccessible built environments and negative attitudes, such as when the young people's non-academic talents were not valued in schools, as well as the way in which the schools dealt with bullying.

Our findings also showed the striking lack of information provided to the young disabled people and their families regarding various disability-related rights. Consequently, a few families had to actively seek out and negotiate support to facilitate their children's participation and wellness. The parents vividly described how they had been unaware of their rights and that service providers did not initiate contact with information regarding services. In some instances, this absence of an incentive led to a lack of important accommodations that could have benefited the young person and their family for years. This echoes the findings from previous research with young disabled people and their families, which has consistently shown a notable shortage of information and the difficulties in accessing support from the systems with which and professionals with whom the families interact (Egilson et al. 2017a, 2018; Tøssebro and Wendelborg 2015). This work of having to find services and support is arguably one form of what Grue (2023, p. 2) calls "undue burdens", referring to the often-invisible work imposed on disabled people and their families to ensure their participation.

Although the parents were the young people's strongest allies and worked hard to provide their children with opportunities for participation and autonomy, there was not always a consensus on how to act or what to prioritise. On some occasions, the parents' stance appeared to be affected by normative thinking, such as when they wanted their children to join peers in particular activities, while the young people had different priorities.

It is well known that young disabled people's ideas on wellness issues tend to differ from those of their parents (Egilson et al. 2017b; Hemmingsson et al. 2017; Ólafsdóttir et al. 2019; Silva et al. 2019) and—with good intentions overruled—ableist ideas may surface (Fine 2019; Goodley et al. 2019; McLaughlin 2023) because of the effects of living in an ableist society.

Although in this paper we have mainly focused on socio-material arrangements from a perspective based on human rights, we also want to point out the significance of the ways in which bodies appear and function regarding whether they are perceived as fitting in. Different kinds of impairments may lead to various forms of prejudice because of normative ideas about how bodies should appear and behave (McLaughlin et al. 2016). Arguably, personal and environmental dimensions uniquely interacted in forming the young people's experiences of participation and wellness. In general, more accommodations were provided in terms of the challenges faced by our study's participants due to visible physical impairments, although, in many cases, they took a long time to be implemented, such as PA services. This is important since without mobility, young disabled people can be excluded from everyday activities that support wellness and engender a sense of belonging (Smith et al. 2021). The participants' less visible impairments and characteristics, such as those due to ASD, were typically met with less understanding, and the interviews with their teachers conveyed that these students were occasionally regarded as a nuisance to a smooth-running classroom. Our survey studies on the participation of young autistic people (Egilson et al. 2017a, 2018; Jakobsdóttir et al. 2015) revealed a confluence of environmental factors that strongly affected their possibilities for participation. Similar findings were identified in a scoping review focusing on environmental aspects that either supported or hindered young autistic people's relationships and participation in social activities (Krieger et al. 2018). This directs attention towards how young disabled people are made to feel out of place through the ways that schools and other settings in which they typically interact are designed and organised, and where conformity is emphasised (McLaughlin et al. 2016).

PA services for persons under 18 are exceptions in Iceland and elsewhere (Jenhaug and Askheim 2018). These PA services' positive impact on increasing participation and wellness is clearly reflected in a participant's description: "How the PA contract changed my life." This related to minimising stigmatisation so that the young person—together with an assistant—could have experiences similar to those of their same-aged peers, such as going to and from school, being more responsible and independent and venturing beyond the family sphere. Similar aspects have been raised in other studies (e.g., Jenhaug and Askheim 2018), although publications on PA for disabled children and their families have typically focused on the effects on the families, not on the benefits for the disabled young people. There is a need for more studies on PA services' impacts on young disabled people.

The findings from our previous studies underscored young disabled people's sense of belonging and acceptance as the cornerstones constituting the goodness of life (Egilson et al. 2021; Ingimarsdóttir et al. 2023; Jóhannsdóttir et al. 2022). Hence, whether and how practices and policies facilitate young disabled people's wellness and participation in valued activities needs to be further scrutinised and acted on.

Given the small sample size, our findings cannot be generalised to the broader population of young disabled people. Moreover, due to the COVID-19 pandemic, we were unable to focus as much on participation in community settings as planned. We also acknowledge our Western perspective and that some of the issues raised in this paper may not apply to other cultures where young disabled people's possibilities for participation and wellness may be even more limited than in Iceland (World Health Organization 2011, 2022).

5. Conclusions

The young disabled people and their families worked hard to ensure their participation in valued activities. Access to the relevant accommodations and support provided participation opportunities and promoted a sense of wellness so that the young people felt that they had a place in the world. However, the burden of finding accommodations was typically imposed on the parents, who had to work extra hard to ensure that their children could participate along with their peers. Translating the CRPD's (2007) human rights perspectives effectively into practice so that policy and service implementation aligns with its principles requires an emphasis on the ways in which important information is provided and the availability of the necessary support when and where needed.

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Notes

[1] In line with our theoretical standpoint, the term young disabled people is used throughout this article to signify that disability arises in the interaction between young people with impairments and their environments. Young people with impairments may indeed have considerable abilities. Although they may be disabled they do not "have" disabilities.

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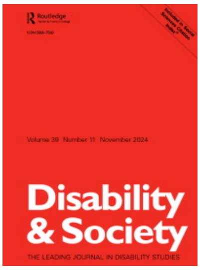
Paper II

Paper II



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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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'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.

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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, thereby marginalizing, excluding, and often dehumanizing disabled 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 non-disabled 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. Ína 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 Ína 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. Ína 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 Líf 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 quest 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.

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Paper III

Paper III

‘Let us talk about our party stories’: Young disabled people out on the town

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Abstract

Partying is a controversial yet typical activity among young people that holds significant social value. This study explored young disabled people’s partying experiences, aiming to understand what partying means for them and how they navigate party spaces. Critical disability studies and youth studies informed the study, and we used ableism and adultism to explore how social forces impacted young people’s partying experiences. Data were generated through focus groups and individual interviews with young disabled people. The findings showed that ‘going out’ was a new and exciting opportunity to be and connect with peers, which became increasingly important at times of transitioning into adulthood. Nevertheless, barriers rooted in ableism and adultism restricted the young people’s access to partying in a myriad of ways, such as inaccessible built environments, negative attitudes, stereotyping, and microaggressions. The findings underline the importance of deepening understanding of young disabled people’s partying experiences, preferably emphasizing young voices.

Introduction

Partying is a valued and normalized social activity for young people in most countries (Ander and Wilińska, 2020). The term is used for a spectrum of enjoyable activities and entertainment during free time (Demant and Østergaard, 2007; Kleiber, Hutchinson and Williams, 2002). Party settings often offer more flexibility in terms of social rules and expectations, allowing people more leeway to let loose and act more freely compared to other social settings (e.g., school, work, family life) (Ander and Wilińska, 2020; Aresi and Pedersen, 2016; Demant and Østergaard, 2007. Engaging in partying and cultural life is an intrinsic part of life for disabled people, as it is for all people, and a human rights issue (Leahy and Ferri, 2024). Article 30 of the Convention on the Rights of Persons with Disabilities (CRPD, 2007) highlights disabled people's and children's right to participate in cultural activities, including leisure and recreational activities.

Research has studied young people's nightlife experiences and settings, such as exploring their motivations for partying (Geisner et al., 2017), meaning it holds for them (Beccaria and Sande, 2016), place and/or space (Ander, Abrahamsson and Bergnehr, 2017), and drinking behavior (Ander and Wilińska, 2020; Aresi and Pedersen, 2016). Collectively, these studies suggest that party spaces can play an immense role in young people's lives, as they try to make sense of their place in the world, discovering who they are and what that means in relation to a broader society. Although partying is a well-established social activity, little research has explored the experiences of young disabled people, who like nondisabled peers, also participate in and benefit from partaking in varied social activities during the transitional years (Anaby et al., 2015). This article explores young disabled people's partying experiences in Iceland, aiming to understand what partying means for this group and how they navigate party spaces.

Previous studies have mainly focused on negative aspects of partying, such as alcohol misuse often aiming to identify preventive strategies to control drinking and irresponsible behaviors (Ander, Abrahamsson, and Bergnehr, 2017; Ander and Wilińska, 2020; Demant and Østergaard, 2007; Nofre, 2023). We do not dispute the negative sides of alcohol use nor the detrimental effects young people's alcohol consumption can have on their health and social development (Berk, 2018). Despite these potential hazards, partying and nightlife activities have social significance in young people's lives (Aresi and Pedersen, 2016; Demant and Østergaard, 2007; Garcia, 2013; Nofre, 2023). Partying can encompass more than just fun and socializing. It can also be an expression of control, a sense of responsibility, the exercises of personal agency, and the establishment of personal boundaries (Ander, Abrahamsson and Bergnehr, 2017; Aresi and Pedersen, 2016; Percy et al., 2011,). It can have a symbolic role in transitioning into adulthood as it signifies the fading of parental control, thus marking ever looming adulthood and more autonomy (Ander, Abrahamsson and Bergnehr, 2017; Demant and Østergaard, 2007; Robinson, 2009).

More knowledge about young people's viewpoints on partying is needed because their voices may tell a different story compared to those of adults (Ander, Abrahamsson and Bergnehr, 2017; Ander and Wilińska, 2020; Demant and Østergaard, 2007; Nofre, 2023). This is in line with recent developments within youth studies and disability studies, where the heightened focus has been put on seeking out young people's voices rather than relying on adults' perspectives to understand youth issues (Kamp and Kelly, 2014; Liddiard et al., 2019; Corney et al., 2022, McLaughlin, 2024). This may apply especially to young disabled people whose voices have received limited attention within youth studies (McLaughlin, 2024).

Young disabled people are subjected to ableist assumptions throughout their lives and across social contexts (Jóhannsdóttir, Ágústsdóttir and Björnsdóttir, 2023; Hamdani and Gibson, 2019; Calder-Dawe, Witten and Carrol, 2020) which can lead to experiencing disability stigma, discrimination, and exclusion. In addition, they must deal with adult-centric ideas, which typically portray young people's partying activities as a societal problem (Ander and Wilińska, 2020). Thus, accessing party spaces can become quite complex for young disabled people who face layered impairment and age-related stigma (Ingimarsdóttir et al., 2023; Toft, Franklin and Langley, 2019). Our critical theoretical standpoint aims to expose, oppose, and redress forms of oppression, inequality, and injustice (Charmaz, 2016), with a focus on ableism and adultism as forms of oppression. By utilizing ableism, a central concept in critical disability studies (Goodley, 2013), and adultism (Bell, 2003), we aim to unpack how young disabled people's possibilities for partying are affected by taken-for-granted assumptions about disability and adulthood (Amundson and Taira, 2016; Campbell, 2008; Corney et al., 2022; DeJong and Love, 2015). Both concepts elucidate discriminating belief systems which manifest in multiple injustices and social dynamics (Campbell, 2009; Delgado and Staples, 2008). Taking a critical stance can give insights into how young disabled people understand, react to, and resist ableism and adultism when partying. Our research questions were as follows: 1) What role does partying play in the lives of young disabled people? and 2) How do young disabled people navigate the effects of ableism and adultism when partying?

Ableism and adultism

Ableism

Simply stated, ableism draws attention to prejudice and bias in favor of nondisabled people who possess socially valued abilities (Sandberg, Rosqvist and Grigorovich, 2021). The term has been defined as 'a network of beliefs, processes and practices that produce a particular kind of self and body' (Campbell, 2001, p. 44) and as 'a set of beliefs, processes and practices that produce – based on abilities one exhibits or values – a particular understanding of oneself, one's body and one's relationship with others ... and includes how one is judged by others' (Wolbring, 2008, p. 252). Ableism is grounded on the general expectation of able-bodiedness and able-mindedness as socially valued and preferred, which produces, among other things dominating assumptions about disabled people as flawed (Goodley et al., 2019; Chouinard, 1997).

Historically, various social groups have explicitly used ableism to legitimize privilege and superior status over other groups (Wolbring, 2008). How ableism operates varies, but its impact is considerable and widespread in the lives of disabled people, such as when ableism is internalized and shapes the individual's self-perception and behavior (Jóhannsdóttir, Ágústsdóttir and Björnsdóttir, 2023). David and Derthick (2014) suggest that such internalization occurs when individuals unconsciously devalue their own social group due to societal norms and exclusion.

One way ableism is enacted is through microaggressions, which have been defined as interactions that can appear as 'everyday verbal, nonverbal, and environmental slights, snubs, or insults, whether intentional or unintentional, that communicate hostile, derogatory, or negative messages to target persons based solely upon their marginalized group membership' (Sue, 2010, p. 3). Kattari (2020) emphasizes that microaggressions should be included in any general discussion of ableism, as they are a way in which ableism is perpetuated more implicitly. Examples of such microaggressions against disabled people can consist of social rejection, bullying, disregard, lowered expectations, harassment, and objectification (Olkin et al., 2019, Keller and Galgay, 2010). Given their subtle nature, they can be difficult to spot because they are often delivered unconsciously by well-intentioned individuals unaware of their harmful impacts (Sue et al., 2007; Gonzales et al., 2015; Olkin et al., 2019). Keller and Galgay (2010, p. 249) compiled several common sentences that illustrate how microaggressions can occur in the lives of disabled individuals. See Box 1 below.

BOX 1. Examples of ableist microaggressions

'Let me do that for you.'

'You people are so inspiring.'

'I would never date someone who uses a wheelchair.'

'What happened to you?'

'Come on now, we all have some disability.'

While such incidents may seem trivial, their cumulative impact on marginalized groups can be substantial (Sue, 2010; Keller and Galgay, 2010). Throughout this article, we use the concept of ableism to explore how ableism was embedded in young disabled people's accounts of their party experiences.

Adultism

Adultism is a concept that helps to define and understand the systematic oppression and discrimination of young people by adults (Bell, 2003; Bell, 2018; Douthirt-Cohen and Tokunaga, 2020). Adultism underscores the importance of certain socially sanctioned abilities required to obtain rights and status as an adult. Due to their youth and inexperience, young people are perceived as lacking these abilities but as having the potential to attain them when transitioning from immature childhood to mature adulthood (Delgado and Staples, 2008; Kafer, 2013; Wolbring, 2008). In society, younger people are often compared to adults, who are seen as more intelligent, competent, civilized, and in control (Liegghio, 2016). As a result, young people are viewed as inferior to adults, leading to various restrictions (Bell, 2003; Corney et al., 2022; DeJong and Love, 2015).

The concept of adultism revolves around the belief that young people should be under the authority of adults (Corney et al., 2022). Moreover, adult-centric ideas do not take young people seriously and disregard their input regarding decisions, even about their own lives (Bell, 2003; Douthirt-Cohen and Tokunaga, 2020). As a result, young people are accustomed to adult control and expect dominance, leading them not to see themselves as equals to adults (Punch, 2002).

Adultism can manifest in overt and covert ways. Delgado and Staples (2008) referred to microaggressions they view as indicative of adultism (see Box 2 below).

BOX 2. Examples of adultist microaggressions

'You are so smart for your age.'

'You are not old enough to understand.'

'We know what is best for you.'

'Act your age.'

'What do you know about life?'

Adults' responsibility in young people's lives cannot be overstated as adults are obliged to provide young people and children with support and protection in line with their developmental needs at different times. This includes acknowledging their cognitive capacity, ensuring their safety, providing guidance, and allowing for gradual independence and opportunities of decision-making as years go by. Understanding and detecting adultism can thus be complex and noteworthy, no single act, belief, custom, or policy is inherently adultist (Bell, 2003). For behavior to be considered adultist it must involve a consistent pattern of disrespect or mistreatment, that undermines young people's intelligence or autonomy (Bell, 2018; LeFrançois, 2014). The key to mitigating adultism is age-appropriate engagement between young people and adults. The latter must hold appropriate expectations based on the young people's abilities and competencies (Pasupathi and Löckenhoff, 2002), and respect for them as rights-holders (Vranješević, 2020), positioning them as social actors in the present rather than as future adults (Liegghio, 2016). Through the lens of adultism, we examine how assumptions about young people as being incapable of making autonomous decisions are reflected, reproduced and/or resisted in young disabled people's accounts of their party experiences.

Methods

This article reports on a qualitative study based on focus group and individual interviews with young disabled and chronically ill people. The study was developed using a constructivist grounded theory (CGT) (Charmaz, 2014), a method aimed at systematically analyzing social processes and actions and evolving understanding and theory grounded in the data. CGT researchers involve simultaneous data collection and analysis and constant comparison between the two to understand the research topic from the participant's point of view. CGT was chosen as it allows thorough data analysis and is considered fitting for explorative research looking at dynamic social processes where prior knowledge is scant (Charmaz, 2014; Charmaz, 2016; Charmaz, 2019).

Participants and data

Twenty individuals aged 18-30 years old participated in the study, 16 in focus group interviews and four in individual interviews. Participants were mainly recruited from Iceland's greater capital area, but a few were raised in rural municipalities. The recruitment was through advertisements on social media, personal networks within the Icelandic disability community, and snowball sampling. Participants had to identify as either disabled or chronically ill, and we strived to include young people with varied impairments to mirror a breadth of experiences. Because of Iceland's small population, detailed descriptions of participants were omitted to hide their identities.

The focus group data were gathered by two researchers who both identify as disabled, and one of them, the first author, grew up chronically ill. Altogether, three focus groups were conducted. The first group included three women and three men, the second group included women only, and the third group had men only, with five participants in each group. Participants' gender and disability were self-identified. The focus group interviews lasted approximately two hours each and were recorded with the participant's permission. Topics for discussion included the participants' perspectives and experiences related to transitioning into adulthood, focusing on aspects of their social lives, partying in particular. The discussion guide was open and fluid, providing interactive space and allowing participants' stories to emerge (Charmaz, 2014). Our initial plan was to interview the young people about their quality of life and what they considered a good life (Citation removed). However, the discussions in all four focus groups consistently shifted towards partying, indicating its significance in the young people's lives and sparking our interest in the subject. To follow up on accounts from focus-group participants, four individual interviews were conducted to explore the topic further.

Data analysis

The first author transcribed the data; the transcripts were checked for accuracy and anonymized. Consequently, the data were read thoroughly and then coded line-by-line along with the writing of reflective memos. This led to the formation of tentative codes and emerging categories. Focused coding furthered the synthesis by unpacking data with the analytical potential to explicate participants' experiences. The software program ATLAS.ti-8 for Windows was used to code and organize the data (Friese, 2019).

Instead of advancing to Charmaz's steps of theoretical coding, we then applied a critical lens to explore our generated categories, defining and elucidating the effects of ableism and adultism on the young people's meaning-making when partying and how they made sense of their partying experiences.

The researchers' position was reflected throughout the study, including preconceptions, research directions and rational interpretation, and coding and forming categories. Furthermore, the study process was consistently shared with fellow researchers in a larger team. Preliminary findings were presented at seminars attended by disabled people of all ages and fellow researchers. Their input and discussion helped further the development of the analysis.

Ethical and methodological considerations

All participants signed an informed consent form after being given written and verbal information about the purpose of the study, confidentiality, and ways to ensure anonymity. They were also told that taking part was voluntary, that some of the issues to be discussed might be sensitive, and that they were free to take a break or withdraw from the study at any time. Also, emphasis was put on complying with access needs. This included careful preparations and adjustments, considering participants' different ages, abilities, and preferences, and giving them sufficient time and space to express themselves. To accomplish this, interviewers simplified language and, when called for, used sign language interpreters. The interviews were conducted in Icelandic, and the authors translated excerpts into English. Out of respect for participants and to increase clarity, some interview excerpts were slightly edited to shorten their length. Care was taken not to disrupt their meaning.

The research was approved by the Icelandic National Bioethics Committee (approvals number removed).

Findings

The young people who participated in this study considered partying a vital part of their social and leisure activities and enthusiastically shared their experiences. They furthermore emphasized the many aspects and nuances they faced when navigating the party space at different times and contexts. The findings are presented in four categories: 1) Partying as feeling as part of society, 2) Physical and attitudinal barriers to partying, 3) Facing microaggressions and degrading attitudes, and 4) Not being accepted as adults.

Partying as feeling as part of society

Feeling part of society was an essential outcome of partying for young disabled people. Participants described partying as a pleasant and exciting experience where they interacted with peers and other partygoers, aiming to bond and have fun. Partying was also described as a means to 'let go' and 'let loose' of daily strains and demands. Emma, who was blind, said: 'For me, it is all about dancing in clubs and just letting go of hard things.' Relaxing with friends was highlighted, as well as 'taking a break' when they felt tired or stressed. Helga, with a physical impairment, said: 'There is just something [special] about the smoking room,' referring to the many discussions and fun encounters she had had in the smoking zone. Overall, the participants stressed that partying was a central aspect of their social lives and just as important to them as to other young people. Partying took place within a context, such as the young people's age, the occasion, and with whom they went out. Whatever the context, participants emphasized doing it on their terms: when and where they wanted to and with whom they chose.

Because of their age, the younger participants were considered by adults as 'too young to party' and found cunning ways to evade adults' judgment and supervision. They typically met in their homes, peers' houses, or outdoors. Klara, who described herself as having a nonapparent impairment, reflected on the lengths she went to in her late teens: 'I remember we put on our nicer clothes and went outside and into the lava, it was so cold. I even snuck out the window of my room.' Here Klara describes an Icelandic youth experience when young people party outside in nature, in a local lava field, which provided a good hiding spot to party without being noticed by adults, who they feared would not accept their partying. For her and other younger participants, partying typically took place out of adult sight, for instance, when home alone.

Those who had reached the legal drinking age were more accepted by adults when they went partying. Accordingly, party spaces for this group were more formal and organized, such as bars, clubs, music festivals, and concerts. Partying was sometimes associated with other social activities and relations, such as workplace staff meetings, team-building activities, or end-of-season festivities. Schoolmates often partied to celebrate graduation, test scores, and term conclusion milestones. Most participants occasionally drank alcohol while partying, but a few did not[2], and the reasons behind not drinking varied. For Erla, it was a personal decision: 'Drinking is just not my thing.' A few explained that due to the danger of mixing alcohol and their medications, they opted not to drink.

The socializing and interacting dimensions were a focus in the young people's accounts, as they used partying for social gain, such as to kindle new connections and foster established ones. A few acknowledged partying to meet potential sexual partners, as they felt it was easier to overcome social awkwardness and shyness in such situations. Moreover, when partying, peers seemed more relaxed, open, and willing to understand and accept participants' diverse needs and identities. This was immensely important to the young people who all had experienced being overlooked and shut out at some point. Ronja, with a nonapparent impairment, said: 'It is like they have more courage to engage with you.' A few others also claimed that after-hours peers seemed more interested in them and their opinions, making them feel more welcome and providing opportunities for sharing and making new and exciting connections.

Hence, partying was a prioritized and diverse social space the young people navigated with peers during their free time. While partying, they felt a sense of belonging and that they were accepted as they were. However, as described below, examples of the opposite also occurred, and the young people had to deal with various barriers.

Physical and attitudinal barriers to partying

Physical and attitudinal barriers hindered access to and experiences of partying. All participants encountered barriers when navigating the party scene and vividly shared examples when their presence was not accounted for or expected. They emphasized the effects of physical and attitudinal barriers and how they felt unwelcomed and stigmatized in inaccessible environments where they required extreme effort, time, or energy to navigate party spaces.

Participants with physical impairments and chronic illnesses reflected on the inaccessible locations and layouts of bars and clubs. This included old buildings with small and narrow spaces, often without elevators and with entryways that did not account for wheelchairs. Axel said: 'Sometimes you are just stuck, which can be annoying when girls you are talking to go down the stairs.' He was excluded from following his peers because he could not move freely within many bars.

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[2] Participants did not discuss other recreational substances.

Traveling between places was also challenging. ‘Pub crawling’ was an integral part of ‘going downtown’, referring to when participants went out and ‘strutted’ between bars. However, Laugavegur, the main party street in Reykjavík, is located on a hill, which was a nuisance for those who could not travel long distances. Thus, some of the young people unwillingly stayed put, like Axel, who felt he was missing out when friends went pub crawling. Vala, with a chronic illness, claimed it was just’ too much work’ traveling between bars, especially during cold and snowy winters. She added ‘Laugavegur is so horrible I get so tired [when I walk there].’ Neurodivergent participants described how crowds, bright lights, loud music, and chatter overwhelmed them and complicated their access to the party scene.

Hekla, who had a stoma, emphasized her need always to have a restroom nearby. She described herself as the ‘toilet expert’ because when preparing for a night out, she had to find out beforehand the location of accessible restrooms. She said: ‘I know where all the best toilets are, and I usually go to bars where there is a decent toilet ... I really do not want an accident to happen’. Few bars offered accessible restrooms, and long waiting lines caused problems for her and others who needed quick access. Consequently, these young people felt left out when their peers wanted to go somewhere with scarce or inaccessible restrooms. They described music festivals and concert areas as notorious for lacking accessible restrooms. As a result, stoma/catheter users often skipped these events to avoid uncomfortable or potentially dangerous situations. Klara said: ‘If I do not use the bathroom, my bladder could explode, it could be life-threatening.’

For young people who had apparent impairments, accessing alcohol could be challenging due to the ableist beliefs they faced about who is allowed to drink, even though they had reached the legal drinking age. For instance, they mentioned not being invited to parties or offered drinks. Tanja described encounters with skeptical servers who doubted their ability to drink:

> Once, I went to this restaurant and wanted to order a glass of wine. The server did not serve me because he thought I was too sick to drink, so we argued about it. Eventually, he served me, though. After a few years, I returned, and he remembered me and served me this time. He was still a little hesitant.

Tanja’s description of the server’s reaction suggested that the server held ableist beliefs about disabled people being unable to do certain things, like drink alcohol, because of their impairments. This is an example of how disabled people may be excluded from partying. This situation was deeply unsettling for Tanja and her friends who witnessed the encounter. Interestingly Tanja was in the company of disabled people, but her impairment was the only one visible. To the server, Tanja’s friends’ presence was less disruptive, and apparently, he did not view them as disabled.

The lack of necessary adjustments to make partying accessible and limited understanding about disability evoked complex feelings such as being a burden and their needs not being significant enough to bother friends and fellow partygoers. When Vala's friends opted to stay with her instead of going to inaccessible bars, she occasionally took a pass on the invitation because she feared she was 'holding her [non-disabled] friends back as they felt obligated to dawdle over her.' She did not want to cause problems or a scene. The fear of being humiliated and having peers treated with suspicion because they encouraged participants' 'bad behavior' when using alcohol or being out after midnight was emphasized. Kolbeinn, with a physical impairment, said: 'c.'

In the short term, pulling out of inaccessible party spaces could minimize the conundrum and humiliation the young people faced. However, because of ableist assumptions the young people repeatedly felt pressed into withdrawing from events due to not being accounted for, which negatively affected their self-perception and self-worth.

Facing microaggressions and degrading attitudes

Ableist assumptions manifested in multiple ways, perpetuating how participants were received by able-bodied people in party spaces. Some of the young people experienced microaggressions so frequently that they did not notice them unless others pointed them out. Karl, with a physical impairment, reflected on buying beer at the mall:

> Once I went to the mall with my female friend, we went to the liquor store. Then we walked out, both holding a case of beer. When we returned to the car she said, 'did you notice there were at least fifteen people staring at us?' [said in a shocking tone] I just said 'no' because I have learned to ignore it ... she, of course, is non-disabled and she was like: 'shhhit I was not aware of this.'

Karl's discussion of this experience sparked a thought-provoking discussion about microaggressions, as other group members also strongly related to being stared at in situations where their presence was not expected. However, due to the commonplace and subtle nature of microaggressions, they were challenging for many of the participants to spot. Two blind women, Karen and Emma, described receiving compliments for attending parties:

> Karen: I have been praised for being good at drinking [everybody laughs], and wow, I would make so many people happy if I were an alcoholic.

> Emma: Also, you are even better if you are hung over the next day [said sarcastically].

The young women's accounts are examples of how disabled people are recipients of praise for doing things that are generally considered unremarkable for most people their age. They suggested that being praised for completing ordinary tasks was condescending and reflected ideas about disabled people being incapable of doing the same things as their able-bodied peers.

Participants with invisible impairments often experienced changing capabilities from day to day which presented as fluctuations in energy levels, stamina and experience of pain. As they did not fit the traditional stereotype of disability, their peers and other partygoers made assumptions that they were able-bodied and capable and did not need any help because of their impairments. Consequently, their needs were overlooked or disregarded. Gunnur, who experienced episodes of body stiffness and fatigue due to her impairment, illustrated her double bind situation. 'When I meet new people, I must start by asking if they could help me stand up, if not I am stuck. "Do I want to go out with you tonight? Sure, but only if you can help me get out of chairs"'. Gunnur dreaded having to prove her impairment to strangers, especially when she was expected to explain her personal situation in detail. However, she had no other choice if she was to get the help she needed. Paradoxically, when she disclosed her disability, people often did not take her seriously or diminished her experiences. This complicated the decision to disclose her impairment even further.

Even though most participants wanted to shift the focus away from their impairments, a few with invisible impairments emphasized 'coming out' as disabled. They felt that their impairments were a hidden but essential part of their identities and wanted to be embraced as disabled. Because partying was a social space where 'anything goes' it offered a valued opportunity to disclose issues such as having an impairment, which generally was not regarded as socially acceptable to share. Although generally well received, sharing information also carried risks, as some recipients disregarded boundaries and breached trust. For example, Ronja was devastated when an acquaintance revealed that she used a stoma, which led to her being bullied and nicknamed 'pussy-bag' at a party at a friend's house. In the aftermath, Ronja felt she had no choice but to keep her stoma a secret out of fear of ableist violence and to protect herself.

All in all, participants underscored their wish to be accepted and valued as disabled people, rather than being compared to nondisabled 'standards'. However, navigating party spaces with its many microaggressions was a complicated task and despite their efforts to secure access, the young people could not count on being accepted. This fact affected them in varied ways, they experienced self-doubt and felt devalued, making it difficult for them to find inner peace and feel comfortable in their social environments.

Not being accepted as adults

The young people not only had to deal with ableism and microaggressions when partying, but they also grappled with the impacts of adultism. This was evident in stereotypical ideas about how adults should look, a disregard for their wants and priorities, negative assumptions about their lack of capabilities, and unfair treatment. Many examples of how young people were discriminated against based on stereotypical ideas about disability and adulthood were shared. Those who appeared young for their age particularly faced doubts and intimidation when trying to enter age-restricted venues. Klara with a chronic illness said:

> Usually, bouncers tediously investigate my card to see if it is fake, scrutinizing whether it was truly me. One time, I was accused of using my older sister's ID. Another time, the bouncer wanted to confiscate my credit card because he said it was not me in the picture. Thankfully, he did not; otherwise, I would not have been able to pay for the taxi ride home.

Regarding adultism (Bell, 2003; Delgado and Staples, 2008), the bouncer from Klara's example, an authoritative adult figure, felt justified in confiscating her card. Klara felt powerless as her only proof of age was being questioned. This situation exemplifies an assumption that young people are up to no good, which typically justifies an adult's interference. The bouncer's actions seemingly demonstrate this notion as he disregards Klara's legal ID and her pleas, resulting in unjust treatment. Furthermore, because of her impairment, she felt that her security was threatened, as it would have been difficult for her to get home without the card. If she had a health episode, it could have had serious implications.

Adultist ideas about supposed adults' capabilities, looks, and behaviors perpetuated how the young people were received by peers in party spaces. Even though the young people criticized and resisted these ideas, they also conformed in order to live a 'valued lives'. Kristín, who has a physical impairment and a short stature, often faced unwelcome attention from fellow partygoers who assumed she was younger than she was:

> When I drink and have hardly taken a sip of my first beer and lose my footing or move too fast because I am always trying to be better at looking normal ... Then you get these comments; 'jeez you need to drink less, how many have you had?' Nevertheless, this did not happen because of drinking; I still would have bumped into things due to my [impairment-related] uncontrolled movements.

Kristín and other youthful-looking participants described how fellow partygoers watched and surveilled them. The young people dreaded and found overbearing the well-intentioned but ableist and adultist interventions, rooted in the understanding that nondisabled people and adults know what is best for them. To avoid ableist comments and questions, Kristín felt compelled to hide her impairment and attempted to pass as a nondisabled adult thus adhering to adultist and ableist 'norms'. Karl had a similar experience to Kristín when partygoers questioned why he was out so late. To mitigate such demeaning situations, he changed his attire to look older and mask over his impairment. Ironically, while passing, Kristín and Karl avoided unwanted attention, but maintaining the facade of being 'worthy adults' in party spaces became physically and emotionally draining.

Most of the young people claimed they had good relationships with their families and valued their guidance in dealing with things, impairment related and otherwise. However, when it came to partying, the young peoples' priorities sometimes clasped with those of their parents whom they felt did not understand their need to party so the young people did not get the support they wanted. They described how their parents stressed the importance of acquiring skills to prepare for the future, which the young people agreed with. But the young people desired more leeway to make mistakes and missteps, as well as opportunities to push limits, explore their identity, and reach their potential despite repercussions. Partying provided a valuable platform to act out and explore themselves. This difference in ideas occasionally resulted in conflicts between young people and their parents. Vala described a night out that did not go according to plan:

> One time I went out and drank too much, my friends had to help me empty my stoma ... I remember how outraged my parents were because of my irresponsibility and how annoyed I was, one mistake and everybody freaks. I have helped nondisabled friends puke, and nobody was shocked then.

In a follow-up interview, Vala further explained that even though the incident was serious, today she sees it as a part of her growing up. She added: 'Mistakes are not necessarily bad, we all make them. I just happen to be chronically ill and of course I will make mistakes in relation to that'. Vala's sentiment echoes most participants' understanding that making mistakes was an important life lesson. They believed young disabled people should have opportunities to try, fail, and learn from experience. However, due to adultism and ableism the young people faced limited opportunities which restricted their choices when transitioning into adulthood.

Discussion

In this article, we have delved into the partying experiences of young disabled people in Iceland. By exploring how they navigated party spaces, we sought to understand how their experiences are affected by ableist and adultist assumptions. Two research questions were posed: 1) What role does partying play in the lives of young disabled people? 2) How do young disabled people navigate the effects of ableism and adultism when partying? The findings are discussed in detail below.

The young people's partying had multiple manifestations, depending on the time and the context. Being socially active became increasingly important as they entered young adulthood, partying with new choices, new people, and alluring activities played a pivotal role. Research has long recognized that peer relationships gain more significance during adolescence and young adulthood (Berk, 2018). The young people in this study strongly emphasized building their social networks and peer relationships. Party spaces functioned as a means to establish and enhance these connections while such opportunities were not as readily available in other settings, such as at home, within the structured school environment, or in the workplace. Moreover, partying provided opportunities for the young people to practice their personal and social skills while also testing boundaries and challenging the adults' authority. The attainment of autonomy from parental control is often considered a milestone in transitioning into adulthood (Gibson et al., 2014) and that was certainly the case in our study. Consistent with earlier research on non-disabled youth (Ander and Wilińska, 2020; Aresi and Pedersen, 2016; Beccaria and Sande, 2016; Demant and Østergaard, 2007; Geisner et al., 2017) partying served multiple functions in the young people's lives due to the social benefits they provided.

Prior research has reflected on the lack of relevant opportunities for young disabled people to participate in important social environments (Priestley, 2003; Gibson et al., 2014; Castle, Burland and Greasley, 2022), such as live music events. This was also evident among the young people in this study. Barriers embedded in various socio-cultural-material environments often posed challenges in accessing party spaces and related activities. The physical environment was a major barrier for those with limited mobility, particularly during wintertime. Going out usually involved traveling long distances and party venues seldom fulfilled accommodation needs. As in previous research (Castle, Burland and Greasley, 2022; Slater and Jones, 2018) finding accessible toilets impacted decision-making regarding whether or where to go as insecure access to such facilities meant the young people could not go out without risking health or public embarrassment. Lack of accessible toilets appears to be an overlooked and disregarded problem that needs closer attention as they clearly have a role in ensuring equal access and participation possibilities (Slater and Jones, 2018).

A significant hindrance was the negative attitudes and stereotyping of fellow partygoers towards the young disabled people. These attitudes manifested in apparent and more subtle microaggressions, as seen in how fellow partygoers reacted to the young people when they were out and about. For example, when they were treated as if they should not be there. In the most extreme cases, staff refused their entrance into clubs for no apparent reason other than how they perceived that they did not meet the presumed characteristics young people should uphold. The contradiction of these presumptions became evident when the young people had to deal with microaggressions stemming from being held to unfair double standards, as they simultaneously were praised for their presence at parties, even for drinking alcohol, yet criticized as reckless for putting themselves in danger. The joint influences of ableism and adultism crystallized in the young people's experiences. This aligns with previous studies examining how interweaving identities can compound and further impede access and equality (Travis and Leech, 2014; Bell, 2003).

Fellow partygoers often held ableist and adultist understandings they clung to justify their exclusionary attitudes and behaviors, such as by viewing young disabled people as too sick to a party or as burdens. These stereotypes made it difficult for the young people to present themselves as capable and fit to party. These assumptions reflect age-old ableist generalizations held about disabled people as tragic and incompetent (Oliver, Sapey and Thomas, 2012). Dealing with inflexible attitudes of ableism and adultism led to conflicting feelings. Adhering to ableist standards increased their chances of joining party spaces. Still, it could also mean giving up their desires and requirements, such as when they concealed their impairments or downplayed their accommodation needs. Mingus (2011) described this dilemma as the seduction of ableism, when disabled people are compelled to choose between access or connection with the community as their needs for accommodations are not understood or acted on.

Thus, the young people had little choice but to conform to ableist and adultist assumptions to gain entrance and feel accepted in party spaces, albeit often at a high cost to their mental wellness. They felt angry, exhausted, and undervalued, having to suppress their needs and conceal their identities. It was particularly difficult for those who could not conform, like young people with apparent impairments, who consequently felt even more alienated. This aligns with previous research indicating that failing to conform to norms can inadvertently exacerbate social exclusion and marginalization (Gibson et al., 2014). Despite this, the young people resisted ableism and adultism in varied ways, such as by criticizing the limited options and condescending attitudes they faced. They expressed a strong desire to participate as their authentic selves and to be accepted as they were. This attitude fueled their determination to challenge ableism and adultism while claiming their presence in party spaces.

An important aspect of addressing ableism and adultism in 'adult play' such as partying involves recognizing and translating article 30 of the CRPD (2007) into practice. Thorough discussions about the barriers faced by young disabled people are an important first step, highlighting the young people's ideas and visibility. Young disabled activists and disabled people's organizations can amplify the call for changes by petitioning for improved access to party spaces, such as by organizing public campaigns that raise awareness, advocate, and contradict biased ideas about young disabled people as different and unfit to party. Although young disabled people's parents (Ingimarsdóttir et al., 2023; Shah, 2010), can offer valuable support and allyship, parental interference remains a sensitive issue. The priorities of young people and those of their parents can be difficult to balance, not the least when it comes to partying with its associated risk and danger (Ingimarsdóttir et al., 2023; Jóhannsdóttir, Egilson and Haraldsdóttir, 2022; Shah, 2010). Treading the fine line between providing guidance and protection against potential harm and yet allowing young disabled people the freedom to figure out their independence appears to be complex. In our larger study (Citation removed) some young disabled people claimed that their families perceived them as vulnerable and incapable. In contrast, others described their parents as their greatest advocates who actively fought with them against stereotypical ideas to ensure that they had the same rights and opportunities as their non-disabled peers. Those who claimed that their parents had supported them and given them leeway to test their limits seemed to fare best and were most content as young adults (Citations removed).

As staunch allies of young disabled individuals, we believe parental support is vital for improving access to important social environments during adolescence and beyond. Concurrently, parents may not receive adequate assistance in this regard, leading to stress and tension within the family, resulting in communication clashes and further barriers. Therefore, it is also essential to consider how to support young disabled people's parents, who themselves also grapple with changed roles.

Conclusion

The young disabled people in this study strongly desired to socialize and party with their peers. Partying offered them numerous opportunities for self-exploration and connecting with peers and communities. However, navigating party spaces was commonly challenging due to barriers, such as lack of access within the built environment, microaggressions, and other ableist attitudes. Ableism and adultism deeply impacted the young people's experiences, and despite their efforts, they often struggled to gain acceptance and participate in party spaces. It is important to deepen our understanding of ableism and adultism to better act on the barriers young disabled people encounter in party spaces. This requires ongoing discussion and research, ideally led by young disabled people with the support of adults.

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Life Quality and Participation of Disabled Children and Young People: Design and Methods of a Transformative Study

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Abstract

The LIFE-DCY research project has two aims. First, to evaluate disabled children's quality of life (QoL) as reported by themselves and their parents, and second, to locate commonalities, differences, and conflicting issues in the processes that may influence disabled children's life quality and participation. This paper describes the study design, methodology, and methods along with lessons learned. In addition various methodological and ethical concerns are raised. A sequential mixed-methods design was applied. In Phase one (mapping) we used KIDSCREEN-27 to study how disabled children evaluate their QoL compared with the perspectives of their parents and those of non-disabled children and their parents. Using the Participation and environment measure we also studied parents' perspectives of their children's participation in different social contexts. Altogether 209 disabled children and their parents, and 335 children in a control group and their parents (paired reports) participated in phase one. Phase two (unpacking) consisted of 14 case studies with disabled children aged 8–18 years and focus groups with 21 disabled people aged 19–35 years. The initial analysis was inductive and data-oriented. We then used critical and transformative lenses to shed light on how meaning was made of life quality and participation in relation to the context in which study participants found themselves. The LIFE-DCY research promotes an understanding of how important aspects of life quality and participation may intersect within different contexts and at different times. The theoretical understandings from this study may also help unpack various aspects of childhood disability in terms of knowledge and power and enhance understandings of how ideas about normality and childhood disability are constructed.

Keywords
case study, critical theory, focus groups, methods in qualitative inquiry, mixed methods, ethical inquiry

Introduction

Research into the life quality and participation of disabled children and young people[1] has been fragmented and spread over different disciplines and has mainly consisted of small-scale qualitative studies (Stalker, 2012) and a limited number of large survey studies (Silva et al., 2019). Many of these studies provide partial and/or descriptive perspectives, which limit the possibility of scrutinizing the complex dynamics involved in participation of disabled children and young people along with their life quality[2] (Tisdall, 2012; Watson, 2012). Furthermore, due to the lack of necessary adaptations, disability is often poorly presented in research that aims to provide important insights into children's and young people's well-being and social contexts. This was the inspiration for a study on life quality and participation (LIFE-DCY) that sought to evaluate disabled children's life quality as reported by themselves and their parents. This paper describes the study design, methodology, and methods along with lessons learned. In

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addition, we discuss various methodological and ethical concerns and how they were addressed in relation to our use of a critical disability studies perspective (Goodley et al., 2019) in combination with a transformative mixed-methods design (Mertens, 2007; Mertens et al., 2013).

The intersecting dynamics of disabled children's life quality and participation, which are the hallmarks of our project, are arguably best studied through a mixed-methods design that allows extensive quantitative and rich qualitative data to be produced and compared. Our point of departure was that, although life quality and participation measures are important in enabling the comparison between the ratings of disabled and non-disabled children and their parents, they nevertheless have shortcomings since they do not take into account each child's unique perspective on the relevant significance of a measure's set options in relation to their life (Gibson, 2016). Thus, in order to scrutinize the commonalities and differences between disabled and non-disabled children's and young peoples' experiences, we integrated quantitative measures with stakeholder perspectives through creative, participatory methods. By comparing and contrasting different types of datasets, we aimed to provide a broad spectrum of insights into aspects that facilitate or restrict the life quality and participation of disabled children and young people. We also aimed to identify recommendations for increasing their opportunities for participation and living a "good life."

Theoretical Perspective

The complexities of evaluating life quality and participation pose challenges to research design and methodology, particularly when research aims to generate both generalizable knowledge and in-depth understanding of the ways in which an individual's experiences take shape within certain contexts.

Our theoretical perspective played an important role in our study design aimed at addressing these challenges. We framed the study within a critical approach to disability (Goodley, 2014; Goodley et al., 2019; Meekosha & Shuttleworth, 2009) that promotes an understanding of and challenges exclusionary and oppressive practices associated with ableism, and aims to unpack the ways in which these may intersect with other forms of marginalization, such as class, gender, and ability. What unites critical disability study theorists is an agreement that disabled people are undervalued and discriminated against and that this cannot be changed simply through changing legislation and policy (Goodley et al., 2019). Instead, new forms of knowledge are needed that value disabled people's experiences as experts in helping to address marginalization and exclusion. In line with this approach, this study focuses on the multiple disadvantages and mutual processes of exclusion which may affect disabled children and young people's life quality and participation. Moreover, we sought to explore the possibilities for living well in non-normative bodies and to push back against the imperative that bodies should conform to normative ideas. Through this critical lens, the body, emotions, and affect are surfaced while cultural and structural systems that get in the way of living well with disability are critiqued (Goodley et al., 2019; Meekosha & Shuttleworth, 2009; Meekosha et al., 2013).

A second pillar of our theoretical perspective is a transformative framework that focuses on generating knowledge that pertains to societal contexts and emphasizes social justice, the role of power differentials in the definition of reality, and specific issues of importance to marginalized groups (Mertens, 2007; Mertens et al., 2013; i.e., disabled children and young people). This is consistent with our critical approach and foregrounds the importance of designing studies around building trust with participants and transparency of goals and strategies through partnerships and dialogues between researchers and disability communities. Our study was inspired by the fact that, although Article 7 in the Convention on the Rights of Persons with Disabilities (United Nations, 2007) states that disabled children's perspectives are to be given due weight, on an equal basis, with those of other children, there are indications that, they may not be heard or their concerns may not be acted upon in research and practice (Andersen & Dolva, 2014, Bekken, 2017; Einarsdóttir & Egilson, 2016; Wickenden, 2019). In our study, we specifically aimed to include children and young people who are typically excluded from research and to learn from their experiences as a basis for societal change. A transformative framework requires that dissemination of findings is conducted in ways that encourage them being used to enhance social justice and human rights (Mertens, 2007; Mertens et al., 2013; Sweetman et al., 2010), something we have implemented throughout the research process.

By focusing on uncovering processes of knowledge, power and exclusion, the two frameworks contributed to a holistic understanding of disabled children's and young people's experiences that helped us interrogate the key constructs of our study and generate new types of knowledge with transformative potential.

Life Quality and Participation

The two constructs, life quality and participation, are often ill-defined or inadequately defined with different researchers and disciplines having different understandings of what is desirable and important and what constitutes a "good life" (Coster et al., 2012; Dahan-Oliel et al., 2012; Dijkers, 2007; Fayers & Machin, 2016; Gibson, 2016; Haraldstad et al., 2019). However, most scholars agree that life quality is a multidimensional construct that reflects on the individual's perception of his or her life and well-being (Whoqol Group, 1995). Use of quality of life (QoL) measures is important in enabling comparison between groups, such as between the views of disabled and non-disabled children and their parents (Ravens-Sieberer et al., 2005).

Such measures, nevertheless, presuppose that life quality is a pre-existing stable object, altogether discoverable and amenable to measurement. Standardization unavoidably imposes particular normative ideas about what constitutes a good life by offering set options that do not take into account individuals' perspectives on the relevant significance of each of these options in relation to their lives (Gibson, 2016). Ideas of what constitutes a good or poor life are part of a larger repertoire of socially embedded beliefs that mediate how persons come to understand themselves and others (Bourdieu, 1977). Although subjective satisfaction with life has been promoted as the most important conceptualization of life quality, it should be acknowledged that individual determinations of satisfaction do not occur in a social vacuum but rather are shaped by prevailing normative discourses of normality and disability. Thus, personal judgments of the goodness of life are always formed within sociocultural environments across time and place, as well as by immediate circumstances, opportunities, emotions and state of mind (Gibson, 2016).

Participation is also a multi-dimensional phenomenon and is commonly described a person's involvement in a life situation (World Health Organization, 2001), highlighting everyday functioning and social roles. Lack of conceptual clarity and operationalization of the meaning of participation has been pointed out (Maxwell et al., 2012; McConachie et al., 2006; Piskur et al., 2014), but two main dimensions are typically described, an objective dimension reflecting whether someone is included in the routine social activities of a particular setting, how and with whom and a subjective dimension reflecting engagement, sense of belonging and satisfaction with the extent of one's involvement within that setting (Anaby et al., 2014; Coster et al., 2012), acknowledging the informal and social aspects of the construct (Horgan et al., 2017). In line with our theoretical perspective, this study specifically considered the social and material features of the children's and young peoplés typical environments at home, school and in their communities (e.g., social relations, attitudes, practices and traditions, physical layout, sensory qualities and aspects of nature), to determine to what extent they were able to participate within different settings. Also, how these environmental features affected the development of accommodations and acceptances that could promote the children's and young people's participation (Egilson & Hemmingsson, 2009; Egilson, Jakobsdottir, et al., 2017; Egilson et al., 2018; Imms & Granlund, 2014; Krieger et al., 2020).

Study Aims

Drawing from this combination of critical disability studies and transformative approaches, we designed a study that aimed to develop understanding and knowledge about Icelandic disabled children's and young people's life quality and participation. While foregrounding the views and perspectives of disabled children and young people, we also included the perceptions and expectations of their parents and other key stakeholders to develop insights into the role of the social contexts in which the children's experiences were formed. This included decisions regarding participation made by different stakeholders and structures and processes that facilitated or restricted disabled children's and young people's participation, inclusion and overall life quality and well-being.

Our focus on the interplay between social and material features and processes that impact disabled children's and young people's experiences of life quality and participation was operationalized through specific emphasis on (1) the role of agency and resistance, (2) the role of language in interactions between children/young people and other stakeholders, (3) the interplay between the children's experiences of being disabled and the environments in which they participated, and (4) the intersection of disability with other dimensions of the children's and young people's lives. In order to meet our aims, we developed eight research questions, four quantitative and four qualitative/mixed-methods questions.

1. How do disabled children rate their QoL as compared with non-disabled children?
2. How do disabled children rate their QoL as compared with their parents?
3. How do parents of disabled children rate their children's QoL as compared with parents of non-disabled children?
4. How do parents of disabled children rate their children's participation and environment supports as compared with parents of non-disabled children?
5. How do the perceptions of disabled children and young people about their life quality differ from that of family, friends and teachers and how can this be understood/explained?
6. How do the socio-cultural-material environments interrelate with disabled children and young people's life quality and participation?
7. How are disabled children and young people actively involved in important (personally defined) aspects of their lives?
8. How do the constructs of life quality and participation interrelate in the lives of these disabled children and young people?

Study Design and Methodology

Scholars have pointed out that mixed-methods designs are uniquely suited to providing a multifaceted picture of life quality and participation (Carroll et al., 2018; Gibson et al., 2014). Applied to our study, this resulted in a sequential transformative explanatory design (Creswell, 2014; Mertens, 2007) in which quantitative measurement of children's life quality and participation was followed by a range of qualitative methods in an effort to extend the breadth and range of inquiry, and complement and bridge objective and subjective ways of knowing.

We initially used surveys in our "mapping phase" to compare QoL ratings between disabled and non-disabled children, between disabled children and their parents, and between parents of disabled and non-disabled children. We then followed with an "unpacking phase," consisting of qualitative case studies and focus group interviews in order to yield rich information about the situations and perspectives of disabled children

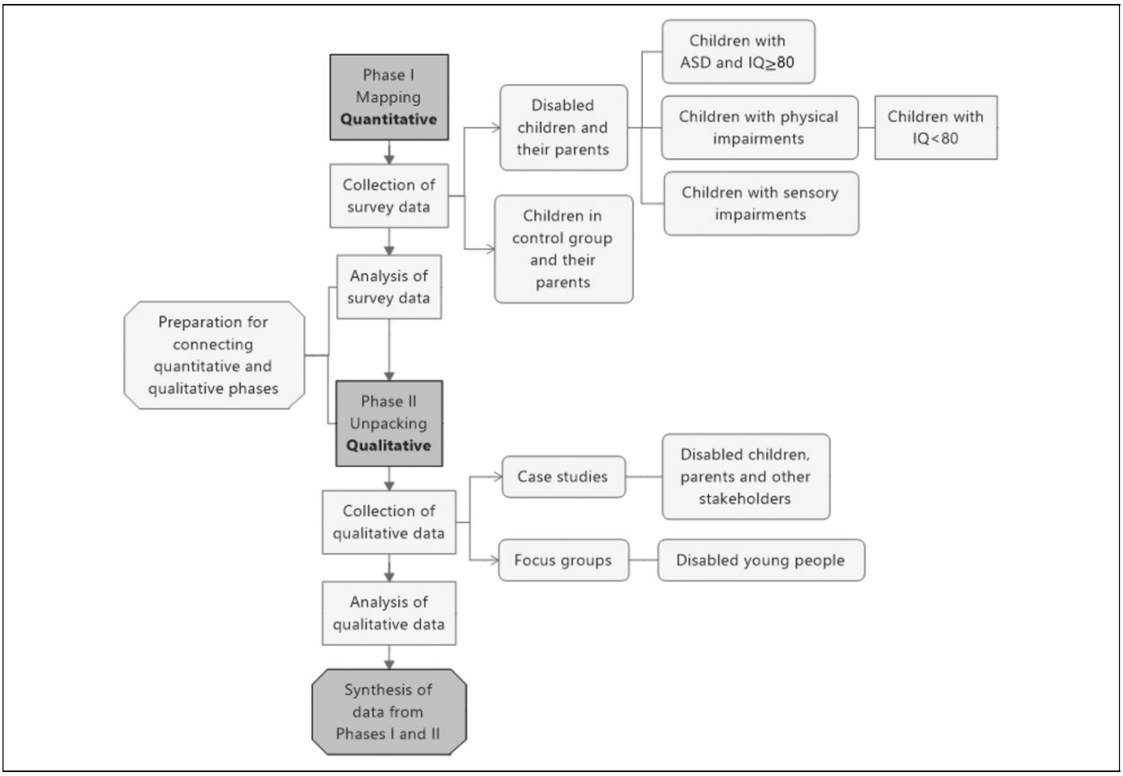

Figure 1. Theoretical stance: Critical and transformative.

and young people. The survey data in the mapping phase were gathered in 2015–2018, although preparations started as early as 2013 by translating, culturally adapting and piloting the two measures and setting up an electronic platform (Egilson et al., 2013; Egilson, Jakobsdottir, et al., 2017; Egilson, Ólafsdóttir, et al., 2017; Egilson et al., 2018; Jakobsdóttir et al., 2015; Ólafsdóttir et al., 2014). The qualitative data in the unpacking phase were generated in 2017–2019. Analyses are ongoing, particularly those building upon the entire dataset. Figure 1 presents the components of the study design.

The study was approved by the Icelandic Bioethics Committee (VSN-13-081/16-187-V2).

Phase I—Mapping

This phase was designed to provide statistical information about the QoL, participation and environments of disabled children aged 8–18 as compared with children of the same age from the Icelandic national registry—in order to answer the first four research questions. Thus, we examined how disabled children evaluated different aspects of their QoL and compared this with the perspectives of their parents and of non-disabled children and their parents to convey existing similarities and differences. We also gathered data on parents' perspectives of their children's participation in different environmental settings.

Measures

Two measures, KIDSCREEN-27 (KIDSCREEN Group Europe, 2006) and the Participation and Environment Measure [PEM-CY] (parent report; Coster et al., 2011, 2012), were used.

KIDSCREEN-27 is a generic QoL measure designed for children aged 8 to 18 that can be self-completed or used as a parent-proxy report. This measure was chosen as it provides a broad perspective on the understanding of QoL and focuses more on how the child feels than on what he or she can do. Furthermore, the measure is child-friendly and easy to complete (Ravens-Sieberer et al., 2006). KIDSCREEN-27 includes five dimensions: physical well-being (five items), psychological well-being (seven items), autonomy and parent relations (seven items), social support and peers (four items), and school environment (four items). Either the frequency of feelings or behaviors or the intensity of an attitude is assessed. Each item is scored on a 5-point scale and the recall period is one week (KIDSCREEN Group Europe, 2006). The measure has been translated and validated for more than 40 countries (Silva et al., 2019). It has good psychometric properties and excellent cross-cultural comparative validity (Ravens-Sieberer et al., 2014).

The PEM-CY is designed for parents of children aged 5–17 and examines children's participation and the effect of the environment on participation at home, in school and in the community (e.g., community events, organized or unstructured physical activities and getting together with other children). In the PEM-CY, parents are not only asked to identify how frequently their child participates but also how involved the child typically is while participating and whether the parent would like to see the child's participation in this type of activity change and how. In the environment section, parents report on whether and how environmental characteristics such as physical layout, sensory qualities, attitudes, and cognitive and social demands of activities have an impact on their child's participation at home, in school and in the community. Furthermore, parents' views on structural and social aspects are included through questions about the availability and adequacy of resources in these three settings, such as, services, information, time and money. The PEM-CY fits well with our theoretical perspective as it links the impact of the environment to participation within a particular setting, focusing simultaneously on participation and environmental factors (Coster et al., 2011, 2012). The PEM-CY has been translated and culturally adapted into a number of languages (Krieger et al., 2020).

Participants and Procedures

Disabled children aged 8–18 were recruited from the registry of the State Diagnostic and Counselling Centre (SDCC), which keeps diagnostic records of the great majority of children and young people diagnosed with neurodevelopmental disabilities in Iceland. Initially, data were gathered on children with ASD with an IQ $\geq$ 80. In order to get a more varied sample, we then included children with physical impairments and children with an IQ < 80. Many children were diagnosed with more than one type of impairment. In order to reach out to children with sensory impairments, we also collaborated with institutions providing services for children with vision and hearing impairments. Consequently, the KIDSCREEN-27 platform was adapted in order to accommodate children with vision impairment and translated to sign language in order to reach deaf or hard-of-hearing children. Survey data from a control sample from the Registers Iceland allowed for comparison between disabled and non-disabled children and their parents. Although the survey data were not gathered simultaneously but in three phases and then amalgamated, the exact same procedures around data gathering and analyses were implemented all three times. The KIDSCREEN was first sent out electronically to children and their parents, and 8 weeks later, parents had the option of answering the PEM-CY.

Information on altogether 209 disabled children and their parents and 335 non-disabled children and their parents (paired reports) were gathered. Overall, the sample was varied and considered representative by our partnering institutions.

Most of the information about data gathering, analysis and accessibility procedures within the mapping phase has been thoroughly described in our earlier publications (Egilson, Jakobsdottir, et al., 2017; Egilson, Ólafsdóttir, et al., 2017; Egilson et al., 2018; Ólafsdóttir et al., 2019). Key findings reflect that disabled children rated their QoL lower than the children in the control group but nevertheless mostly within the average range. Parents of disabled children evaluated their children's QoL lower on all dimensions than did parents of children in the control group, and the difference was substantially larger than for the childreń s self-reported scores. Finally parents of disabled children rated their children's QoL considerably lower than the children did themselves, even if they were asked to answer "just as their child would."

According to their parents, disabled children participated in fewer activities and were less involved than their peers at home, within school and the community. Parents of disabled children desired more change in their child's participation than did other parents. Also, parents of disabled children much more often reported that characteristics of the environment made participation harder (Egilson, Jakobsdottir, et al., 2017; Egilson, Ólafsdóttir, et al., 2017; Egilson et al., 2018; Ólafsdóttir et al, 2019).

Comparing the answers from parents on KIDSCREEN-27 and PEM-CY is ongoing and will allow for a better understanding of their reasoning at the time and place of assessment, that is, whether or how their understanding of their disabled child's participation and environmental supports may possibly explain how they answered questions about their child's QoL. Forthcoming papers present the correlation between parent's ratings of the two instruments along with the psychometric properties of the Icelandic version of KIDSCREEN-27.

The survey results provided important pointers for targeting recruitment of participants and refining the focus of the next phase, unpacking.

Phase II—Unpacking

This phase was designed to explore in-depth the diversity, complexity and richness of disabled children's lives. It took place after most of the survey data had been collected and consisted of (a) case studies with disabled children age 8–18 years and (b) focus groups with young disabled people age 19–35. In this phase we aimed to follow-up on and better understand some of the key-findings of phase I, such as the different views of parents and their children about the children's life quality, and the effect of different environments on the childreń s possibilities for participation.

Case studies (Creswell, 2014; Yin, 2009) can promote an understanding of the context in which disabled childreń s lived experiences take shape, such as the daily structure of the children's lives, their aspirations and agency, and the role of important actors in their lives. Moreover, this methodology made it possible to build a relation of trust with the children, and to apply a step-wise approach in addressing sensitive issues. The components of the two surveys proved helpful in broadening

Table 1. Characteristics of the Disabled Children and Young People Who Participated in the Unpacking Phase of the Study.

	Case Studies Age 8–18	Focus Groups Age 19–35	
Characteristics	Frequency	Frequency	Total
Gender			
Male	8	10	18
Female	6	11	17
Impairment type[a]			
Mobility	5	14	19
Sensory (sight, hearing)	3	5	8
Autism	6	3	9
Intellectual	3	3	6
Other[b]	4	7	11
Residence[c]			
Capital area	13	22	35
Other	1	4	5

[a]Some participants had more than one type of impairment. [b]Refers to various hidden impairments and long-term illnesses. [c]Altogether 75% of the Icelandic population lives in the capital area.

the scope for the children's reflections on their life quality and participation.

In addition, focus groups were conducted in order to further reflect on the survey findings and on the meaning of the two key-constructs in the lives of disabled children and young people. This method departs from a retrospective approach that allows for considering aspects of life quality and participation within the context of participants' life stories and experiences. Also, group dynamics support participants in exploring and clarifying their views in ways that would be difficult in an individual interview (Krueger & Casey, 2009). Participants were recruited through invitation letters from our collaborating institutions, ads on their websites and other social media, and through key informants within the disability sector, such as disability activists and service providers. In order to obtain a varied sample in terms of gender, age, residence and impairment types, snowballing recruitment followed through existing study participants.

Altogether four children in the case studies and 10 participants in the focus groups were recruited through snowballing and key informants within the disability sector. We emphasized reaching out to youth who are often excluded from research on the grounds that they cannot speak for themselves (Teachman, 2014), such as children and young people diagnosed with ASD, communication and sensory impairments and/or mild intellectual disabilities. Table 1 summarizes the main characteristics of the participants in this phase.

Participants and Procedures

Case-studies. Each case centered on a disabled child and included interviews with the child and at least one parent and one teacher, along with observations and document analysis. In line with the case-study approach, we drew on multiple sources of information (Creswell, 2014; Yin, 2009). Interview guides for children, parents and key actors such as teachers and therapists were developed by the research team. The interview guides were informed by the main components of and our analysis of the two surveys in order to connect the two phases of our data collection. Thus the interview topics covered various aspects of the child's participation in different settings, their involvement and sense of belonging, friendships, and what they identified as key aspects of a good life. In addition, the children were encouraged to choose conversation themes that they found important.

Typically, we started by interviewing parents to gather background information that would better enable us to build trust and establish rapport with their child, and ensure that we focused on topics and issues that were relevant to their child (Teachman & Gibson, 2013). Then we met with the child on several occasions. For children with difficulties expressing their views and feelings, we opened the dialogue by talking about something that she or he enjoyed (Skovbo Rasmussen & Pagsberg, 2019) and then used the questions in the KIDSCREEN-27 to initiate conversations about life quality and experiences of participation in different settings. We told the children ahead of time what we would ask about in the interview and how long it would last. In order to avoid jumping to conclusions, we emphasized probing and asked the children directly about certain events and experiences through questions such as "Why did you do it that way?" "What were you thinking when . . . ?" "How did you feel when . . . ?" Stakeholders such as teachers and therapists were typically interviewed last.

Observations took place in the children's usual environments, such as, within their homes, their schools and in recreational settings, and focused on the children's possibilities for participation and their engagement and interactions with peers and adults. Participants also shared with us documents such as the child's individual education plan, school assignments, photos and drawings. Approximately 6 months after the last interview, participants received accessible summaries to review and discuss, which also gave them an opportunity to provide additional comments to the researcher either in person or on-line.

Altogether, 14 case studies were carried out, each including four to seven interviews with a child, his or her parents and teachers, and two to four observations. The interviews typically lasted about 1 hr each and the observations lasted from two to six hours. More data were generated with the participants aged 8–13 than with those aged 14–18. Although these older participants shared their views openly, they were not as keen on having us researchers observe them in schools and leisure settings, which we respected.

Focus groups. Four focus groups with a total of 10 disabled men and 11 disabled women, aged 18–35, were conducted to (a) place participants' childhood experiences in larger context of experiences later in life, and (b) to jointly reflect on the results of Phase I and the two key constructs of the study. Two of the groups were mixed gender, the third group consisted of disabled women and the fourth of disabled men. Participants' gender was self-identified. Two research group members, who both identify as disabled, moderated the focus groups, which lasted between 1.5 and 2 hr each. The participants were asked to reflect on their childhoods and adolescence, how they viewed their life in terms of its quality, and on their possibilities for participation and sense of belonging in different environments. Based on their experiences, participants were asked what they considered to be the most important aspects of enabling disabled children and young people to participate in society, and which aspects they considered to be barriers to their participation and well-being.

Data Analysis

Interviews from case studies and focus groups were recorded with the participants' permission and then transcribed verbatim. Each transcribed interview and observation note was reviewed and reread iteratively by the researchers to determine its accuracy (Brinkmann & Kvale, 2015). Then, the data were grouped and organized by characteristics in ATLAS.ti in line with the noticing, collecting, thinking (NCT) model of qualitative data analysis (Friese, 2014; Seidel, 1998) using a flexible coding system consistent with the research objectives and conceptual framework. Thus, the initial analysis was inductive and data-oriented (Alvesson & Skjöldberg, 2018), highlighting processes and transitions within and across cases. By comparing and contrasting participants' experiences, we strived to locate commonalities, differences and conflicting issues in the mechanisms that facilitate or restrict life quality and participation.

Initially, the team reviewed observation notes and interview transcripts together and established a joint coding list to identify patterns in the entire dataset. This coding list was applied to the data, allowing for identification of areas for further inquiry. Subsequently the researchers jointly reviewed the list by comparing interpretations and code definitions, resulting in merging of similar codes and creation of new ones. To ensure consistency, at least two researchers applied the joint coding list to all qualitative data and performed comparisons. This approach ensured that the data was scrutinized and interpreted on a thematic level in a collaborative way, thus supporting trustworthiness of our analyses. This work provided the foundation for subsequent inductive and descriptive analyses that are the subject of presentations and publications (e.g., Egilson, 2021).

To answer the last four research questions, we then used the critical and transformative lenses described above to shed light on how meaning was made of life quality in relation to the contexts in which our study participants found themselves. Critical analytical questions guided the analysis, for example: How do participants understand and talk about life quality? What discourses, ideas, values and subject positions do they reproduce in their talk? How do they reproduce or resist common ways of understanding disability? How do characteristics of the children's environments, e.g., age, class, residence, gender, sexuality, impairment type, social and material arrangements, expectations, and practices, intersect to enable or constrain the children's daily pursuits? Common in our analysis was the aim of uncovering processes by examining everyday practices and asking why they persist and to scrutinize current conceptualizations of the constructs of life quality and participation

To further develop our critical disability studies lens in line with study aims and analysis of data (Goodley, 2014; Meekosha & Shuttleworth, 2009; Meekosha et al., 2013), we drew on specific critical concepts such as Bourdieu's (1986) central concepts of habitus, capital and field. These concepts were used to unpack how children come to see themselves as disabled or included/excluded and the complex social forces that appear to produce participation, life quality and differential access for disabled children and youth. Through this analytical frame, we strived to develop a nuanced and detailed picture of the complex web of individual and social structural barriers faced by disabled children and how they accommodate or resist these in their talk and actions. The scrutiny of the complex dynamics and interplay of different elements that together construct disability within a specific social field were particularly useful. Although the disabled young people might possess sufficient symbolic and cultural capital to succeed in a field such as elementary school, they could be ill-prepared, ill-equipped and out of place in a field (Bourdieu, 1986; Cregan & Cuthbert, 2014) such as attending university and in obtaining employment.

Different analyses from Phase II are presented in published and forthcoming papers. One paper explored the negative effect of shame on young disabled people psychological wellbeing, life quality and participation (Jóhannsdóttir et al., 2021), using Wetherell's (2012) notion of affective practices. Another paper focused on how microaggressions appear in the day to day life of young disabled people using the definitions of Keller and Galgay (2010) on manifestations of microaggressions towards disabled people as well as Goffman's (1959) theories on social interaction and stability (Ágústsdóttir et al., 2020). Forthcoming papers explore for example disabled siblings' possibilities for participation, their interactions with peers and adults and the essence of the therapy services they received (Egilson, 2021); young disabled peoples' reflections on transitioning to adulthood, extracting how they negotiate and make-meaning out of entering adulthood; their experiences of internalisation of ableism (Campbell, 2009) and how it affects their health and well-being; the way in which young deaf people with cochlear implants experience their life quality, with particular emphasis on the relation between their identities and their perceptions of what constitutes life quality; and the social participation of children on the autism spectrum in school, using some of Bourdieu's (1977) key-concepts to analyse the children's situation.

Accessibility, Voice and Ethics

A core value of the research project was to ensure that anyone who was interested in participating was able to participate. Ethical issues around and accessibility of the surveys in the mapping phase have been described in our earlier publications

(Egilson, Jakobsdottir, et al., 2017; Egilson, Ólafsdóttir, et al., 2017; Egilson et al., 2018; Ólafsdóttir et al., 2019). Particular measures were taken to ensure the access of children and youth with sensory impairments. In the unpacking phase, multiple measures were put in place to adapt methods to individual participant's needs. These included preparing thoroughly and taking into consideration participants' different ages, abilities and preferences by giving enough time, simplifying language and the use of sign-language interpreters, drawings, and photography (Carroll et al., 2018; Einarsdóttir & Egilson, 2016; Gibson et al., 2013). In line with the transformative research approach (Mertens et al., 2013; Sweetman et al., 2010), attention was paid to power relationships and a strong emphasis was placed on participants' involvement in the decision making about their participation, trust and security in interactions with the researchers and the transparency of research goals and methods. This included seeking informed consent from the children as well as from their parents about decisions on whom to interview and whether, when and where observations should take place.

Throughout the research process, we were aware of the complexities of the much debated notion of "giving voice to children" (Facca et al., 2020; Spencer et al., 2020; Spyrou, 2011; Tisdall, 2012) Within the research processes, we acknowledged disabled children's and young people's voices and experiences as complex constructions "where meanings are always situated and open to multiple interpretations" (Facca et al., 2020, p. 9). Also, we acknowledged that our research, like most if not all research, is an interpretive process that necessarily involves carving out and/or foregrounding pieces of data that we ourselves selected, edited and drew on for our theoretical arguments. Therefore we placed emphasis on encouraging participants to reflect on ideas and notions related to goodness of life and participation that often have taken-for-granted meanings in professional and academic circles.

A challenge was how to respect the children's and young people's agency while simultaneously acknowledging their fluid and shifting positions within different environments and at different times. As in previous research (Gibson, 2018, p. 1), we noted how participants "actively worked to construct preferred identities and resist others." Similarly, many of the disabled children who participated in our research strived to present themselves as capable and in control although they faced various challenges, discrimination and injustices, as was evident in our findings.

Participants in the focus groups described how they, as teenagers, had downplayed most challenges in an effort to present as strong and/or competent. When entering adulthood, they increasingly acknowledged the various hardships they had faced, including the oppression of stereotypes and disabling material and social environments, leaving them often with feelings of being inadequate and/or flawed (Jóhannsdóttir et al., 2021). While they had become increasingly critical, they also did not want to be seen as victims of any sort. It was challenging at times to respect participants' agency in conveying their stories while simultaneously underlining the disabling structures they encountered in their daily lives. Our transformative focus helped better understand participants' complex realities, such as the discussions in the focus groups which allowed for sharing and scrutinizing complex childhood experiences. In line with our critical approach, our study did not set out to expose life quality and participation in terms of a singular reality, rather we aimed to uncover the contradictions and fluid interpretations that characterise disabled children's lived experiences. This contribution to scholarship and practice, opens opportunities for reflections about life quality and participation when considered on the children's terms.

Discussion

In this section, we discuss methodological lessons learned by highlighting some key findings. Our study addresses an important challenge in childhood disability research, i.e. implementing a comprehensive theoretical and methodological approach aimed at uncovering the perspectives and experiences of disabled children and young people on their life quality and participation. As aforementioned, we also paid attention to the perspectives of parents and other key actors, as well as to the structures disabled children and young people encounter within different social and material environments.

It is well known that the views of disabled children and their parents tend to differ (Davis et al., 2007; Egilson, Ólafsdóttir, et al., 2017; Hemmingsson., 2017; Ólafsdóttir et al., 2019; Silva et al., 2019; Upton et al., 2008). Nevertheless, including the perspectives of parents and other key stakeholders enabled us to better understand how key actors in the children's lives make meaning of the child's life quality and participation and how this was interrelated with the way in which the children perceived their own situations.

Our explanatory mixed-methods approach allowed for important comparisons within and between datasets to interrogate similarities and differences based on a clearly developed theoretical framework. Large scale surveys such as the ones undertaken in our mapping phase provide important overviews and make it possible to compare findings on structural variables relevant for policy and practice, e.g., in relation to allocating resources. For example, the lack of availability and adequacy of environmental resources reported by parents of children with autism (Egilson, Jakobsdottir, et al., 2017; Egilson et al., 2018) poses a serious concern and highlights the need for considering policies and processes that create inequity and exclude families of disabled children.

The comparison with non-disabled children was also an effective part of our study design, especially regarding the child self-reported data which placed the experiences of disabled children in a wider context (Dickinson et al., 2007; Ytterhus et al., 2015) and served to counteract normative ideas of what a good life should entail. For example, on KIDSCREEN-27, the disabled children and young people as a group had relatively high scores on the psychological well-being dimensions that focused on positive emotions, satisfaction with life and absence of feelings of loneliness and sadness. This is an important message to parents who rated their children's psychological well-being much lower, even when they were asked to answer as their child might (Egilson, Ólafsdóttir, et al., 2017; Ólafsdóttir et al., 2019). Comparing the answers of parents on KIDSCREEN-27 and PEM-CY also allowed for a better understanding of their reasoning at the time of assessment, that is, whether or how their understanding of their disabled child's participation and environmental supports might explain how they answered questions about their child's QoL. This will be described in a forthcoming paper.

The pairing of the answers from the children and their parents along with comparisons with a group of non-disabled children helped inform the focus and questions in the unpacking phase (Egilson, Jakobsdottir, et al., 2017; Egilson, Ólafsdóttir, et al., 2017; Egilson et al., 2018; Jakobsdóttir et al., 2015). The use of creative participatory methods within that phase (e.g., the thorough discussions in the focus groups and creating opportunities for children to express themselves in relation to the two Phase 1 surveys of life quality and participation) allowed for scrutinizing the commonalities and differences between disabled children's and young people's experiences, making meaning of life quality in context. The mixed-methods approach thus enabled participants to engage with our findings, which they co-interpreted and expressed through contextualization, deeper insight and critical reflection.

Having facilitators with lived experience of disability in the focus groups was a foundation for building shared comfort and trust with the participants, and the emphasis on creating a safe-space promoted rich discussions where young disabled people openly shared, compared and contrasted their childhood experiences, which often led to new insights. As an example, in one of the focus groups, participants shared that having attended a summer camp for disabled children had been a devastating experience for some, while others had thrived and made important and lasting friendships in the same camp. These different experiences enabled reflection and discussion among focus group members, encouraging them to make sense of their experiences in relation to other aspects of their lives and the environments in which they grew up.

The generation of rich and varied qualitative data was important as, at times, we aquired certain information in one interview with a young child and then got a different viewpoint in the next. This reflects a central challenge for life quality research, recognizing that life quality is not experienced as a stable reality that can be consistently conveyed by either children or adults. The same applies to participation as individual wishes regarding inclusion, involvement and interactions may be formed by environmental features such as available opportunities to participate and make meaningful choices, in addition to preferences and state of mind, which may vary across time and place. Moreover, the research and interview contexts inevitably shape participant narratives. Thus, the multiple points of contact provided a depth and richness to the data that would be difficult to achieve otherwise. Being flexible and using a range of methods and adjustments to accommodate different accessibility needs enabled us to work effectively and respectfully in both phases. Thorough adaptations of the KIDSCREEN-27 enabled us to reach out to disabled children who are typically not included in large scale survey research, and, consequently to make comparisons with non-disabled children and their parents. Extensive preparations before and during the qualitative phase, e.g., in relation to building trust, creating a mutual dialogue, customizing communication, and drawing on knowledge about autism and working with interpreters, helped ensure a relatively smooth implementation.

The use of critical and transformative lenses helped us conduct a nuanced in-depth analysis of the intersecting sociocultural mediators of young people's self-understandings of their life quality and participation (Ágústsdóttir et al., 2020; Curran & Runswick-Cole, 2013; Goodley et al., 2019; Jóhannsdóttir et al., 2021; Meekosha & Shuttleworth, 2009). Combining quantitative and qualitative perspectives provided a broad spectrum of insights (Mertens, 2007), including different contextual viewpoints by which to interpret the findings (King et al., 2013) and propose recommendations. In line with our transformative focus, an effort has been made to target political decision makers at various levels, such as by disseminating the findings to policy makers in Iceland and other Nordic countries (Nordic Welfare Centre, 2021), organizations for disabled children and families, practitioners, and other stakeholders. We have in particular emphasized ways to promote participation and remove barriers for disabled children and young people, based on our findings. In addition, many of our participants have shared their views and experiences at national seminars and dissemination events. Publications in Icelandic are also part of our transformative focus, a way to make the outcomes of our research more accessible within the local community and to further a social justice agenda (Ágústsdóttir et al., 2020; Egilson, 2016; Jakobsdóttir et al., 2015, 2017; Ólafsdóttir et al., 2014).

Finally, scrutiny of our data reflects the dynamics of the different elements that intersect and constitute goodness of life and a feeling of involvement within different environmental settings. Typically, a sense of belonging and acceptance were highlighted and defined as the most important markers. As stated by one of the focus group members:

The best moments in my life are when I am allowed just to be myself, not only the disabled me. These are the moments when people are open to accepting me for who I am, not only seeing my disability.

The theoretical understandings and implications from our study will be further explored and presented in future publications focusing on specific aspects of participation and life quality of disabled children and young people, as well as the interplay of the two constructs.

Conclusion

By contributing insights from our study, this article responds to a call by scholars to pay close attention to methodological and conceptual issues when planning studies on life quality (Haraldstad et al., 2019) and participation (Dahan-Oliel et al., 2012). Our methodological approach allowed for comparisons within and between datasets to convey similarities and differences about how key issues of life quality are understood by disabled children and young people and relate to one another. It also allowed for a conceptual elaboration of the complex construct of participation. The LIFE-DCY research promotes an understanding of how important aspects of life quality and participation may intersect within different contexts and at different times. In addition, exploration of the similarities that exist between disabled and non-disabled children may serve to demystify important aspects of disability, normality and the goodness of life. The theoretical understandings from this mixed-methods transformative study may help unpack various aspects of childhood disability in terms of knowledge and power and enhance understandings of how ideas about normality and childhood disability are constructed (Curran & Runswick-Cole, 2014; Gibson, 2016; Runswick-Cole et al., 2018). In addition to contributing to developments in scholarly work, our study has the potential to inform the reflexivity of policy makers and professionals who organize and provide support to disabled children and their families.

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Notes

1. In line with our theoretical standpoint, the term disabled children/people is used throughout this article to signify that disability arises in the interaction between children and young people with impairments and their environments. Children with impairments may indeed have considerable abilities. Although they may be disabled they do not "have" disabilities.
2. In this paper, we use the abbreviation QoL when addressing information gathered through measures but use the term "life quality" when referring to the concept in broader terms, embracing the individual's understanding of the goodness of her or his life within her or his context.

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Appendix A – Charmaz's nine-step research strategy

A slightly abridged version of Charmaz's nine-step research actions.

1. Conduct data collection and analysis simultaneously in an iterative process.
2. Analyze actions and processes.
3. Use comparative methods.
4. Draw on data to develop new conceptual categories.
5. Create inductive and abstract, as well as analytic categories through systematic data analysis.
6. Focus on theory construction for a deeper understanding.
7. Engage in theoretical sampling.
8. Look for variations within the studied categories or processes.
9. Aim to develop categories rather than simply covering a specific empirical topic.

Appendix B – Introductory letters

HÁSKÓLI ÍSLANDS
FÉLAGS- OG MANNVÍSINDADEILD

Kynningarbréf vegna tilviksathugunar :

LÍFSGÆÐI OG ÞÁTTTAKA FATLAÐRA BARNA OG UNGLINGA: UMBREYTINGARANNSÓKN

LIFE-DCY

Halló!

Vilt þú taka þátt í rannsókninni minni um líðan og þátttöku barna? Ég leita að áhugasömum börnum og unglingum á aldrinum 8-18 ára til að hitta og ræða við um daglegt líf þeirra. Ætlunin er að tala við 16 íslensk börn og fjölskyldur þeirra.

Ef þú vilt taka þátt þá mun ég taka 1-3 viðtöl við þig, foreldra/forráðamenn þína og aðra aðila sem þú og fjölskylda þín tilgreinið. Það geta til dæmis verið kennarar eða stuðningsaðilar. Hvert viðtal er um það bil klukkustundar langt. Ef þú leyfir mun ég líka koma í heimsókn til þín, heimsækja þig í skólann og á annan stað þar sem ég fæ að fylgjast með þér, svo sem í tómstundaiðju. Heimsóknirnar verða ákveðnar í samráði við þig og fjölskyldu þína. Loks mun ég óska eftir að fá að skoða skrifleg gögn sem þú átt, til dæmis frá skólanum þínum.

Allt sem fer fram okkar í milli er leyndarmál, líka nafnið þitt. Ég er bundin þagnarskyldu sem þýðir að ég má ekki segja neinum það sem þú segir mér, ekki einu sinni foreldrum þínum. Ég mun passa vel upp á allar upplýsingar sem ég fæ frá þér og öðrum. Allar upplýsingar verða varðveittar á öruggum stað meðan á rannsókninni stendur og eytt þegar búið er að vinna úr þeim.

Á næstu dögum mun ég hringja í þig og foreldra þína til að kanna áhuga ykkar á þátttöku og finna tíma fyrir fyrsta viðtal. Þú

Nánari upplýsingar um rannsakendur, rannsóknina og birtingar niðurstaðna má finna á heimasíðu verkefnisins:

www. lifsgaedarannsokn.is

Ábyrgðarmaður rannsóknar:

dr. Snæfríður Þóra Egilson,
prófessor við Háskóla Íslands,
sími: 862 2725,
netfang: sne@hi.is

ræður hvort þú tekur þátt í rannsókninni eða ekki og þú getur hætt hvenær sem er án útskýringa. Ef þú finnur fyrir vanlíðan eftir viðtal eða heimsókn getur þú haft samband við Helgu Þorleifsdóttur félagsráðgjafa hjá Greiningar- og ráðgjafarstöð ríkisins og rætt við hana um líðan þína.

Ég hlakka til að heyra frá þér,

Nafn rannsakanda

Greiningar- og
ráðgjafarstöð ríkisins

Samskiptamiðstöð
heyrnarlausra og heyrnarskertra

HÁSKÓLI ÍSLANDS
FÉLAGS- OG MANNVÍSINDADEILD

Kynningarbréf vegna tilviksathugunar :

LÍFSGÆÐI OG ÞÁTTTAKA FATLAÐRA BARNA OG UNGLINGA: UMBREYTINGARANNSÓKN

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sími: 862 2725,
netfang: sne@hi.is

Kæra foreldri/forráðamaður

Takk fyrir að sýna rannsókninni okkar áhuga. Rannsóknin er framhald af áralöngu rannsóknarstarfi þar sem lífsgæði, þátttaka og umhverfi fatlaðra og ófatlaðra barna voru skoðuð með tveimur spurningalistum. Nú er fyrirhugað að gera tilviksathuganir (case studies) til að fylgja eftir niðurstöðum spurningalistanna og rýna nánar í lífsgæði og þátttöku fatlaðra barna. Alls munu 16 íslensk börn og fjölskyldur þeirra taka þátt í þessum hluta rannsóknarinnar.

Rannsóknin er unnin í samstarfi við Greiningar- og ráðgjafarstöð ríkisins, Þjónustu og þekkingarmiðstöð blindra og sjónskertra og Samskiptamiðstöð heyrnarlausra og heyrnarskertra. Rannsóknarteymið samanstendur af Snæfríði Þóru Egilson iðjuþjálfa og prófessor við Félags- og mannvísindadeild Háskóla Íslands (HÍ), Stefani C Hardonk lektor við sömu deild, Lindu Björk Ólafsdóttur iðjuþjálfa og Önnu Sigrúnu Ingimarsdóttur félagsráðgjafa en báðar eru þær doktorsnemar í fötlunarfræðum við HÍ. Rannsóknin er styrkt af Rannsóknarsjóði, *verkefnastyrkur nr. 174299-051*.

Við leitum eftir fötluðum börnum á aldrinum 8-18 ára og fjölskyldum þeirra til að taka þátt. Þátttakan felur í sér að rannsakandi tekur 1-3 viðtöl við barnið, foreldra/ forráðamenn og aðra lykilaðila sem fjölskyldan tilgreinir. Það geta t.d. verið kennarar eða stuðningsaðilar. Hvert viðtal er u.þ.b. klukkustundar langt. Auk þess er áformuð heimsókn (þátttökuathugun); 1) á heimili fjölskyldunnar, 2) í skóla barnsins og 3) á annan stað þar sem rannsakandi fær að fylgjast með þátttöku barnsins utan heimilis, t.d. í tómstundaiðju. Tilhögun heimsóknanna verður ákveðin í samráði við fjölskylduna hverju sinni, s.s. hvar og hvenær. Loks verður óskað eftir að fá að skoða skrifleg gögn sem endurspegla samskipti við þjónustukerfið, líkt og einstaklingsnámskrár.

Öll viðtöl verða hljóðrituð, afrituð orðrétt og upptökunni síðan eytt. Allar upplýsingar sem fram koma í viðtölum og þátttöku-athugunum verða meðhöndlaðar samkvæmt ströngustu reglum um trúnað og nafnleynd og farið að íslenskum lögum varðandi persónuvernd, vinnslu og eyðingu frumgagna. Rannsóknargögn verða varðveitt á öruggum stað meðan á rannsókn stendur og eytt að lokinni úrvinnslu, eigi síðar en fimm árum eftir rannsóknarlok. Niðurstöður rannsóknarinnar verða gerðar ópersónugreinanlegar. Leyfi Vísindasiðanefndar og Persónuverndar liggur fyrir (nr. VSN-16-187)

Á næstu dögum mun [nafn rannsakanda] hafa símleiðis samband við þig til að kanna áhuga ykkar á þátttöku og finna tíma fyrir fyrsta viðtal. Tekið skal fram að þér og ykkur ber ekki skylda til að taka þátt og þið getið hætt hvenær sem er án fyrirvara eða útskýringa á ákvörðun ykkar. Einnig er þér frjálst að neita að svara einstökum spurningum. Ef eitthvað sem kemur fram í viðtalinu veldur þér eða barninu þínu vanlíðan gefst ykkur kostur á að ræða við Helgu Þorleifsdóttir félagsráðgjafa hjá Greiningar- og ráðgjafarstöð ríkisins ykkar að kostnaðarlausu.

Með bestu kveðjum og kæru þakklæti,

Snæfríður Þóra Egilson,
Stefan C Hardonk
Linda Björk Ólafsdóttir &
Anna Sigrún Ingimarsdóttir

HÁSKÓLI ÍSLANDS
FÉLAGS- OG MANNVÍSINDADEILD

Kynningarbréf vegna tilviksathugunar :

LÍFSGÆÐI OG ÞÁTTTAKA FATLAÐRA BARNA OG UNGLINGA: UMBREYTINGARANNSÓKN

LIFE-DCY

Kæri kennari

Takk fyrir að vilja leggja rannsókninni okkar lið. Rannsóknin er framhald af áralöngu rannsóknarstarfi þar sem lífsgæði, þátttaka og umhverfi fatlaðra og ófatlaðra barna voru skoðuð með tveimur spurningalistum. Nú er fyrirhugað að gera tilviksathuganir til að fylgja eftir niðurstöðum spurningalistanna og rýna nánar í lífsgæði og þátttöku fatlaðra barna. Alls munu 16 íslensk börn og fjölskyldur þeirra taka þátt í þessum hluta rannsóknarinnar.

Rannsóknin er unnin í samstarfi við Greiningar- og ráðgjafarstöð ríkisins, Þjónustu og þekkingarmiðstöð blindra og sjónskertra og Samskiptamiðstöð heyrnarlausra og heyrnarskertra. Rannsóknarteymið samanstendur af Snæfríði Þóru Egilson iðjuþjálfa og prófessor við Félags- og mannvísindadeild Háskóla Íslands (HÍ), Stefani C Hardonk lektor við sömu deild, Lindu Björk Ólafsdóttur iðjuþjálfa og Önnu Sigrúnu Ingimarsdóttur félagsráðgjafa en báðar eru þær doktorsnemar í fötlunarfræðum við HÍ. Rannsóknin er styrkt af Rannsóknarsjóði, *verkefnastyrkur nr. 174299-051*.

Í rannsókninni taka þátt fötluð börn á aldrinum 8-18 ára og fjölskyldur þeirra. Þátttakan felur í sér að rannsakandi tekur viðtöl við barnið, foreldra/forráðamenn og aðra lykilaðila sem fjölskyldan bendir á. Þú ert einn af þessum aðilum sem tilgreindir voru og óskum við því eftir að fá að ræða við þig.

Ef þú samþykkir að taka þátt mun rannsakandi taka eitt viðtal við þig, u.þ.b. klukkustundar langt, um þátttöku og aðstæður barnsins. Jafnframt óskum við eftir að fá að fylgjast með barninu í skólanum. Tilhögun heimsóknarinnar verður ákveðin í samráði

Nánari upplýsingar um rannsakendur, rannsóknina og birtingar niðurstaðna má finna á heimasíðu verkefnisins:

www. lifsgaedarannsokn.is

Ábyrgðarmaður rannsóknar:

dr. Snæfríður Þóra Egilson,
prófessor við Háskóla Íslands,
sími: 862 2725,
netfang: sne@hi.is

við þig, barnið og fjölskylduna (s.s. hvar og hvenær).

Öll viðtöl verða hljóðrituð, afrituð orðrétt og upptökunni síðan eytt. Allar upplýsingar sem fram koma í viðtölum og þátttökuathugunum verða meðhöndlaðar samkvæmt ströngustu reglum um trúnað og nafnleynd og farið að íslenskum lögum varðandi persónuvernd, vinnslu og eyðingu frumgagna. Rannsóknargögn verða varðveitt á öruggum stað á meðan rannsókn stendur og eytt að lokinni úrvinnslu og eigi síðar en fimm árum eftir rannsóknarlok. Niðurstöður rannsóknarinnar verða gerðar ópersónugreinanlegar. Leyfi Vísindasiðanefndar og Persónuverndar liggur fyrir (nr. VSN-16-187).

Á næstu dögum mun [nafn rannsakanda] hafa símleiðis samband við þig til að kanna áhuga þinn á þátttöku og finna tíma fyrir viðtal. Tekið skal fram að þér ber ekki skylda til að taka þátt og þú getur hætt hvenær sem er án fyrirvara eða útskýringa. Einnig er þér frjálst að neita að svara einstökum spurningum.

Með bestu kveðjum og kæru þakklæti,

Snæfríður Þóra Egilson,
Stefan C Hardonk
Linda Björk Ólafsdóttir &
Anna Sigrún Ingimarsdóttir

Greiningar- og ráðgjafarstöð ríkisins

Samskiptamiðstöð
heyrnarlausra og heyrnarskertra

HÁSKÓLI ÍSLANDS
FÉLAGS- OG MANNVÍSINDADEILD

Kynningarbréf vegna tilviksathugunar:

LÍFSGÆÐI OG ÞÁTTTAKA FATLAÐRA BARNA OG UNGLINGA: UMBREYTINGARANNSÓKN

LIFE-DCY

Kæri viðtakandi

Ég heiti Freyja Haraldsdóttir, er þroskaþjálfi og kynjafræðingur, og vinn nú að rannsókninni Lífsgæði og þátttaka fatlaðra barna og ungmenna (LIFE-DCY) ásamt hópi fræðimanna við Háskóla Íslands. Undanfarin ár höfum við unnið að rannsóknum á lífsgæðum fatlaðra barna og þátttöku þeirra við mismunandi aðstæður.

Tilgangur rannsóknarinnar er að skoða upplifun fatlaðra barna sem eru búsett á Íslandi á lífsgæðum sínum og þátttöku á ólíkum sviðum samfélagsins samanborið við jafnaldra. Jafnframt að kanna hvernig foreldrar fatlaðra barna meta lífsgæði barna sinna til samanburðar við foreldra ófatlaðra barna. Einnig skoðum við hvort fötluð börn meti lífsgæði sín með öðrum hætti en foreldrar þeirra.

Í tengslum við rannsóknina er áformað að hafa rýnihópa þar sem við biðjum ungt fatlað fólk að líta til baka til barnæsku sinnar og unglingsára með hugtökin lífsgæði og þátttöku í huga.

Með þessu bréfi vil ég kanna hvort þú hafir áhuga á að taka þátt í slíkum rýnihópi. Um er að ræða eitt rýnihópaviðtal sem tekur u.þ.b. tvær klukkustundir. Í hópnum taka þátt 6-7 ungar fatlaðar manneskjur. Við viljum biðja þátttakendur að skoða með okkur reynslu sína af lífsgæðum, velsæld og tækifærum til þátttöku á ólíkum sviðum og kanna þann skilning sem þátttakendurleggja í hugtökin. Við iljum ræða hluti eins og:

- hvað eru lífsgæði?
- hvað er gott líf?
- hver eru tækifæri fatlaðra barna og unglinga til að taka þátt við mismunandi aðstæður?
    - Hvað gengur vel?
    - hvað gengur síður?
- hvað felur það í sér að taka þátt við mismunandi aðstæður?

Nánari upplýsingar um rannsakendur, rannsóknina og birtingar niðurstaðna má finna á heimasíðu verkefnisins:

www.lifsgaedarannsokn.is

Ábyrgðarmaður rannsóknar:

dr. Snæfríður Þóra Egilson,
prófessor við Háskóla Íslands,
sími: 862 2725,
netfang: sne@hi.is

Öll rýnihópaviðtöl verða hljóðrituð, afrituð orðrétt og upptökunni síðan eytt. Allar upplýsingar sem fram koma í rýnihópaviðtölum verða meðhöndlaðar samkvæmt ströngustu reglum um trúnað og nafnleynd og farið að íslenskum lögum varðandi persónuvernd, vinnslu og eyðingu frumgagna. Rannsóknargögn verða varðveitt á öruggum stað meðan á rannsókn stendur og eytt að lokinni úrvinnslu, eigi síðar en fimm árum eftir rannsóknarlok. Niðurstöður rannsóknarinnar verða gerðar ópersónugreinanlegar. Leyfi Vísindasiðanefndar og Persónuverndar liggur fyrir (nr. VSN-16-187)

Ef spurningar vakna ekki hika við að hafa samband við mig á netfangið nafn@hi.is og í síma xxx-xxxx.

Hægt er að lesa um rannsóknina á heimasíðu okkar: www.lifsgaedarannsokn.is

Með kæru þakklæti og bestu kveðjum,
Freyja Haraldsdóttir og Anna Sigrún

HÁSKÓLI ÍSLANDS
FÉLAGS- OG MANNVÍSINDADEILD

Introductory letter about participating in case study research:

LIFE QUALITY AND PARTICIPATION OF DISABLED CHILDREN AND YOUNG PEOPLE: A TRANSFORMATIVE STUDY

LIFE-DCY

Hello

My name is (researcher‘s name), and I am a researcher currently working on the project *Life Quality and Participation of Disabled Children and Young People: A Transformative Study* (LIFE-DCY), together with a team of researchers at the University of Iceland.

This study aims to explore the experiences of disabled children and adolescents living in Iceland, focusing on their life quality and participation in various aspects of society. We wish to examine whether disabled children experience their quality of life and participation similarly or differently from their parents and children who are not disabled.

As part of the study, we will be forming focus groups with young disabled people. In these groups, participants will be invited to share their experiences growing up, particularly in relation to life quality and participation. For example, we will discuss topics such as:

- How do you define life quality?
- What is a good life?
- What opportunities exist for disabled children and young people to participate in school, family, and social life?
    - What are the positive aspects?
    - Which areas need improvement?

I am reaching out to see if you would like to participate in a focus group. This focus group interview will last approximately two hours and will include 6-7 young disabled people.

We will record all focus group interviews and transcribe them to ensure we capture everything the group discusses. After transcribing, all recordings will be destroyed. Those of us

Further information about the research, researchers and findings can be found at our website:

www.lifsgaedarannsokn.is

Principal Investigator:

dr. Snæfríður Þóra Egilson,
professor at the University of Iceland,
sími: 862 2725,
netfang: sne@hi.is

conducting the research will keep everything confidential, and we will not disclose any individual comments. When we report our findings, we will ensure that no one can identify the participants. The research has been approved by the Icelandic National Bioethics Committee (protocol code no. VSN-16-187).

If you are interested in participating in the study, please email me at name@hi.is or call me at xxx-xxxx. You can also reach out via email or phone if you have any questions. Please don‘t hesitate to ask for assistance if you need help contacting me.

For more information about the research, please visit our webpage: www.lifsgaedarannsokn.is

We appreciate your consideration, all the best
Freyja Haraldsdóttir og Anna Sigrún

Appendix C – Informed consent

HÁSKÓLI ÍSLANDS
FÉLAGS- OG MANNVÍSINDADEILD

Life quality and participation of disabled children and young people: A transformative study

Informed consent

I agree to participate in the study *Life quality and participation of disabled children and young people: A transformative study*.

I will participate in a focus group interview that lasts approximately two hours. The purpose of the focus group is to explore the experiences of young disabled people regarding their life quality, wellness, and opportunities for participation during childhood and adolescence:

- How do you define life quality?
- What is a good life?
- What opportunities exist for disabled children and young people to participate in school, family, and social life?
  - What are the positive aspects?
  - Which areas need improvement?

All information will be treated as confidential, and steps will be taken to ensure that no data can be traced back to individual participants. For example, all names and place names will be anonymized during the transcription process. The original data will be securely stored and destroyed after the study is completed, and no later than five years after its conclusion.

You may choose to withdraw from the study at any time, without having to provide a reason.

_______________   _____________________________________
Date   Participant‘s signature

The undersigned researcher confirms that they have provided complete information about the nature and purpose of the study, in accordance with the laws and regulations governing scientific research.

____
Researcher‘s signature

HÁSKÓLI ÍSLANDS
FÉLAGS- OG MANNVÍSINDADEILD

Lífsgæði og þátttaka fatlaðra barna og unglinga: Umbreytingarannsókn

Upplýst samþykki

Ég undirrituð/undirritaður veiti samþykki fyrir því að ég og barnið mitt tökum þátt í rannsókninni *Lífsgæði og þátttaka fatlaðra barna og unglinga: Umbreytingarannsókn*, eins og henni er lýst í kynningarbréfum og ef barnið sjálft samþykkir þátttöku sína.

Þátttaka í rannsókninni felur í sér að rannsakandi tekur 1-3 viðtöl við mig og barnið mitt. Hvert viðtal er u.þ.b. klukkustundar langt. Ég mun einnig tilgreina annan/aðra aðila sem eru hluti af lífi barnsins og gott væri fyrir rannsakanda að ræða við. Auk þess mun rannsakandi koma í heimsókn til okkar, í skóla barnsins og á annan stað í samfélaginu þar sem barnið er þátttakandi. Í þessum heimsóknum mun rannsakandi fylgjast með barninu í leik og starfi. Tilhögun heimsóknanna verður ákveðin í samráði við mig, barnið og aðra viðeigandi aðila hverju sinni (s.s. hvar og hvenær). Ég gef rannsakanda einnig leyfi til að skoða skrifleg gögn sem endurspegla samskipti okkar við þjónustukerfið, líkt og einstaklingsnámskrá barnsins.

Farið verður með allar upplýsingar sem trúnaðarmál og þess vandlega gætt að ekki verði hægt að rekja þær. Til dæmis verður öllum nöfnum og staðarháttum breytt við afritun viðtala. Frumgögnum verður eytt að rannsókn lokinni og eigi síðar en að fimm árum liðnum.

Okkur er frjálst að hætta þátttöku í rannsókninni á hvaða stigi hennar sem er án útskýringa né nokkurra eftirmála.

______________ ____________________________________
Dagsetning Undirskrift foreldris/forráðamanns

Undirritaður starfsmaður rannsóknarinnar staðfestir hér með að hafa veitt upplýsingar um eðli og tilgang rannsóknarinnar, í samræmi við lög og reglur um vísindarannsóknir.

____
Undirskrift rannsakanda

HÁSKÓLI ÍSLANDS
FÉLAGS- OG MANNVÍSINDADEILD

Lífsgæði og þátttaka fatlaðra barna og unglinga: Umbreytingarannsókn

Upplýst samþykki

Ég undirrituð/undirritaður veiti samþykki fyrir því að taka þátt í rannsókninni *Lífsgæði og þátttaka fatlaðra barna og unglinga: Umbreytingarannsókn*, eins og henni er lýst í kynningarbréfi.

Þátttaka í rannsókninni felur í sér að rannsakandi tekur viðtal við mig sem er u.þ.b. klukkustundar langt um þátttöku og aðstæður barnsins. Einnig samþykki ég að rannsakandi komi í heimsókn á vinnustað minn og fylgist með þátttöku barnsins í því sem fram fer.

Farið verður með allar upplýsingar sem trúnaðarmál og þess vandlega gætt að ekki verði hægt að rekja þær. Til dæmis verður öllum nöfnum og staðarháttum breytt við afritun viðtalsins. Frumgögnum verður eytt að rannsókn lokinni og eigi síðar en að fimm árum liðnum.

Mér er frjálst að hætta þátttöku í rannsókninni á hvaða stigi hennar sem er án útskýringa né nokkurra eftirmála.

______________ ____
Dagsetning Undirskrift foreldris/forráðamanns

Undirritaður starfsmaður rannsóknarinnar staðfestir hér með að hafa veitt upplýsingar um eðli og tilgang rannsóknarinnar, í samræmi við lög og reglur um vísindarannsóknir.

____
Undirskrift rannsakanda

HÁSKÓLI ÍSLANDS
FÉLAGS- OG MANNVÍSINDADEILD

Life quality and participation of disabled children and young people: A transformative study

Informed consent

I agree to participate in the study *Life quality and participation of disabled children and young people: A transformative study*.

I will participate in a focus group interview that lasts approximately two hours. The purpose of the focus group is to explore the experiences of young disabled people regarding their life quality, wellness, and opportunities for participation during childhood and adolescence:

- How do you define life quality?
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- What opportunities exist for disabled children and young people to participate in school, family, and social life?
    - What are the positive aspects?
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You may choose to withdraw from the study at any time, without having to provide a reason.

________________ ____

Date Participant‘s signature

The undersigned researcher confirms that they have provided complete information about the nature and purpose of the study, in accordance with the laws and regulations governing scientific research.

____

Researcher‘s signature

HÁSKÓLI ÍSLANDS
FÉLAGS- OG MANNVÍSINDADEILD

Life quality and participation of disabled children and young people: A transformative study

Informed consent

I agree to participate in the study *Life quality and participation of disabled children and young people: A transformative study*.

My involvement will include the following: 1) the researcher will conduct 1 to 3 interviews with me, 2) the researcher will visit me at home, at school, and at another location chosen by my parents and me, and 3) the researcher will review written records I have, such as those from my school.

All information collected during the study will be kept strictly confidential and securely stored. You may choose to withdrawn from the study at any time, without having to provide a reason.

______________ ____

Date Child's signature

The undersigned researcher confirms that they have provided complete information about the nature and purpose of the study, in accordance with the laws and regulations governing scientific research.

____

Researcher's signature

Appendix D – Interview guides

HÁSKÓLI ÍSLANDS
FÉLAGS- OG MANNVÍSINDADEILD

Lífsgæði og þátttaka fatlaðra barna og unglinga: Umbreytingarannsókn

Viðtalsvísir fyrir börn og foreldra

Í upphafi:

- Stutt kynning á rannsókninni og tilgangi viðtalsins.
- Fara yfir samþykkisyfirlýsinguna með viðmælanda.
- Ítreka að fulls trúnaðar sé gætt og að viðkomandi megi hætta þátttöku hvenær sem er.
- Fá undirskrift barns, foreldra og annarra viðeigandi aðila.

Börn

<u>Heimili</u>

Segðu mér frá sjálfum/sjálfri þér
(Hvað ertu gamall/gömul? Í hvaða bekk ert þú?)

Segðu mér frá fjölskyldunni þinni
(Hverjir búa heima hjá þér? Áttu systkini? Gæludýr? Hvað gerir fjölskylda þín saman?)

Segðu mér frá deginum þínum
(Hvað gerir þú fyrst á morgnana? Hvað gerir þú þegar þú kemur heim úr skólanum? Hvað gerir þú á kvöldin? Hvað viltu helst gera heima, með hverjum?)

Hvað finnst þér skemmtilegast að gera?
(Er eitthvað heima fyrir sem lætur þér líða vel?)

Er eitthvað sem þér finnst ekki skemmtilegt að gera?
(Er eitthvað heima fyrir sem truflar þig?)

Hverjir aðstoða þig ef þú þarft hjálp við eitthvað heima hjá þér?
(Fjölskyldumeðlimir? Aðrir?)

Hjálpar þú til heima við heimilisstörfin? Hvernig?

Segðu mér meira frá áhugamálum þínum
(Hvenær sinnir þú áhugamáli þínu? Hvers vegna finnst þér það skemmtilegt? Þekkir þú aðra með svipuð áhugamál? Er eitthvað erfitt við áhugamálið?)

Samfélag

Segðu mér frá krökkunum sem þú hittir reglulega
(Segðu mér frá skólafélögum þínum. Ert þú að hitta aðra krakka en skólafélaga þína? Átt þú vini? Hver er besti vinur þinn? Af hverju er hann/hún besti vinur þinn? Hvað gerið þið saman?)

Hvað gerir þú þegar þú ert ekki heima og ekki í skólanum?
(Hvað gerir þú í frítíma þínum? Ertu í íþróttum eða félagsstarfi? Hvernig gengur? Hverjir taka þátt með þér? Ertu ánægð/ánægður með það sem þú ert að gera? Er eitthvað sem mætti vera öðruvísi?)

Er eitthvað í umhverfinu sem hefur áhrif á það sem þú gerir utan skólans og heimilisins?
(Kemstu allt sem þú vilt fara? Af hverju ekki? Hvernig ferð þú á milli staða? Er eitthvað sem mætti vera öðruvísi?)

Ferð þú einhverntímann og gistir annarsstaðar en heima hjá þér? Til dæmis hjá vinum, ættingjum, stuðningsfjölskyldu, á sambýli eða spítala þar sem þú ert ekki heima yfir nótt?
(Hvað finnst þér um það? Hvernig líður þér með það? Er eitthvað sem mætti vera öðruvísi?)

Skólinn

Segðu mér frá skólanum þínum
(Hvernig gengur þér? Hvernig finnst þér í skólanum? Hvað finnst þér skemmtilegt? Er eitthvað sem er ekki skemmtilegt? Hvað gengur vel? Eitthvað sem er erfitt?)

Segðu mér frá kennurum þínum
(Hvað gera kennarnir? Hvernig hjálpa þeir þér að læra? Er eitthvað sem þeir gætu gert öðruvísi?)

Færðu sérstaka aðstoð í skólanum?
(Hvernig aðstoð færð þú? Hvernig aðstoð myndir þú vilja fá? Hvar (við hvaða aðstæður)?)

Hvað gerir þú í frímínútum?
(Ein/n eða með öðrum?)

Er eitthvað sem truflar þig eða gerir þér erfitt fyrir í skólanum?
(Er eitthvað sem þér finnst vont eða óþægilegt? Kemstu þangað sem þú vilt fara?)

Að lokum

Segðu mér hvernig góður dagur er
(Hvað gerir þú, hvar, með hverjum?)

Hvað finnst þér vera gott líf, hvað gerir þig sérstaklega glaða(n)/hamingjusama(n)?
(Af hverju? Hvað þarf að vera til staðar? Er eitthvað sem lætur lífið ekki vera gott?)

Hvað (ef e-ð) þarf að vera til staðar svo þú getir tekið þátt í því sem þú þarft og vilt gera?

Ef þú ættir eina ósk, hvers myndir þú óska þér?
(Ef þú ættir töfrasprota sem þú gætir veifað og allt það sem er erfitt hyrfi, hvernig væri lífið öðruvísi? Hvað gerðirðu þá?)

Foreldrar

Heimili

Segðu mér frá fjölskyldu þinni
(Samsetning fjölskyldunnar, bakgrunnur, hvað gerið þið saman?)

Segðu mér frá barninu þínu
(Aldur, persónueiginleikar, styrkleikar, áhugamál, hvernig barnið tjáir sig, félagstengsl, heilsufar, skerðing og/eða greining, hjálpartæki)

Hvernig er dæmigerður dagur í lífi barnsins þíns?
(Hvað gerir barnið heimavið? Hvað er skemmtilegt/leiðinlegt? Hlutverk á heimilinu, heimilisstörf)

Hvernig eru samskipti barnsins við þig og aðra fjölskyldumeðlimi?
(Hvað er rætt við barnið og hvað ekki? Fær barnið tækifæri til að taka ákvarðanir?)

Hvað gerir þú og aðrir í fjölskyldunni til að stuðla að þátttöku barnsins heima fyrir?
(Reglur, umbunarkerfi, aðstoð)

Er eitthvað í umhverfinu sem hefur áhrif á þátttöku barnsins heima fyrir?
(Hönnun, skipulag, búnaður, tími, þjónusta)

Telur þú barnið vera sátt við heimilislífið og þátttöku sína heima fyrir?
(Líðan þess, væntingar, áhugi)

Er eitthvað sem þú myndir vilja hafa öðruvísi?

Samfélag

Segðu mér frá öðrum börnum sem barnið hittir reglulega
(Skólafélagar, vinir, hvenær hittast þau? Hvað gera þau saman? Samskiptin, frumkvæði, undirbúningur)

Hvað gerir barnið þegar það er ekki heima og ekki í skólanum?
(Íþróttir, félagsstarf, afþreying í nærumhverfi, hvernig gengur? Er eitthvað sem mætti vera öðruvísi?)

Er eitthvað í umhverfinu sem hefur áhrif á þátttöku barnsins utan skólans og heimilisins?
(Hvernig fer það milli staða? Kemst það leiða sinna? Hönnun, skipulag, þjónusta, fjárráð, viðmót annarra, veðurfar, öryggi, er eitthvað sem ætti vera öðruvísi?)

Hvað gerir þú eða aðrir í fjölskyldunni til að stuðla að þátttöku barnsins í samfélaginu?

Telur þú barnið vera sátt við þátttöku sína í samfélaginu?
(Líðan þess, væntingar, áhugi)

Dvelur barnið þitt einhvern tímann annarsstaðar en heima hjá sér?
(Hvar? (ættingjar/vinir, stuðningsfjölskylda, sambýli, spítali) Hversu oft? Líðan þín og barnsins? Er eitthvað sem mætti vera öðruvísi?)

Skólinn

Segðu mér frá skóla barnsins
(Rýmið, aðgengi, kennarar, nemendur, námið, aðstoð, þjónusta, aðlögun, útisvæði, íþróttasvæði)

Hvernig eru samskipti barnsins við kennara og annað starfsfólk skólans?
(kennsla, aðstoð, þjónusta, upplýsingar, hvað er rætt við barnið/hvað ekki? Ákvörðunarvald barnsins)

Hvernig eru samskipti barnsins við aðra nemendur?
(Er hvatt til þeirra sérstaklega?)

Hvernig eru samskipti þín við skólann?
(fundir, samráð, upplýsingar)

Er eitthvað í skólaumhverfinu sem hefur áhrif á þátttöku barnsins í skólastarfi?
(Hönnun, skipulag, stefna/verklag skólans, tæknileg úrræði, lýsing, hávaði, viðmót, samgöngur)

Hvað gerir þú og aðrir í fjölskyldunni til að stuðla að þátttöku barnsins í skólanum?

Telur þú barnið vera sátt við þátttöku sína í skólastarfinu?
(Líðan þess, væntingar, áhugi)

Er eitthvað sem þú myndir vilja hafa öðruvísi?

Viltu bæta einhverju við varðandi aðstæður barnsins þín og fjölskyldunnar í heild?

Að lokum vil ég ræða aðeins við þig um hugtökin þátttaka og lífsgæði
(Merking þeirra, hvað hefur áhrif? Hvað hefur ekki áhrif? Hvað þarf til þess að taka þátt? Hvað finnst þér vera gott líf?)

Lykilaðilar sem fjölskyldan tilgreinir

Hver eru tengsl þín við barnið og fjölskyldu þess?
(Ástæða samskipta, upphaf, saga ykkar, hversu oft hafið þið samskipti?)

Hvernig myndir þú lýsa barninu?
(Persónueiginleikar, styrkleikar, áhugamál, hvernig barnið tjáir sig, félagstengsl, heilsufar, skerðing og/eða greining, hjálpartæki)

Segðu mér frá stundum ykkar saman
(Staður, tími, tilgangur/markmið, þátttaka barnsins, hvað gengur vel/illa?)

Hvað gerir þú til að ýta undir þátttöku barnsins?

Er eitthvað í umhverfinu sem hefur áhrif á þátttöku barnsins?
(Hönnun, skipulag, aðgengi, stefna/verklag, tæknileg úrræði, lýsing, hávaði, viðmót, samgöngur)

Telur þú barnið vera sátt við þátttöku sína?
(Líðan þess, væntingar, áhugi)

Er eitthvað sem mætti vera öðruvísi?

Er eitthvað annað sem skiptir máli eða þú vilt bæta við?

Viðtalsrammi

Skólaumhverfi fatlaðra nemenda

Skóli og nám

1. Hvað eru margir nemendur í bekknum?
2. Hvernig nemandi er hann?
    a. Hvernig gengur honum að tjá sig?
    b. Hvernig gengur að taka þátt í hópverkefnum?
3. Notar hann hjálpartæki í skólanum?
4. Segðu mér frá hvernig honum gengur í misjöfnum námsgreinum?
    a. Er munur á milli námsgreina?
        i. Ef já hver telur þú að ástæðan sé?
    b. Geturu sagt mér frá þeim tímum sem hann sækir annað, þá hvert og hvað er hann að gera?
        i. Hvað eru bekkjarfélagarnir að gera á meðan?
5. Hvernig er með aðgengið í skólanum?
    a. Bekkjarstofa?
    b. Gangar?
    c. Salerni?
    d. Matsalur
    e. Skólalóð
    f. Geturu sagt mér aðeins frá því sem þú ræddir við mig á kennarastofunni um lyftuna?
6. Hvernig gengur í frímínútum?
    a. Er hann með aðstoð í frímínútum?
7. Hvernig er með vettvangsferðir?
8. Hvernig er samband hans við bekkjarfélaga?
9. Hvernig aðstoðar þú hann í kennslustundum?
10. Fær hann sérstaka aðstoð í skólanum?
    a. Hvernig er aðstoðinni háttað?
11. Hvernig gengur að koma til móts við þarfir hans og bekkjarins í heild?

    a. Hefur hann aðgang að nauðsynlegum upplýsingum eða stuðningi?

12. Er komið til móts við þarfir hans og bekkjarins við stundatöflugerð?

    a. Ef já þá hvernig
    b. Eru mikil ferðalög?

13. Hvað réðiði því að þið eruð í þessari stofu núna?

Lífsgæði og þátttaka fatlaðra barna og unglinga: Umbreytingarannsókn

Viðtalsvísir rýnihópa

Um leið og við bjóðum ykkur velkomin viljum við þakka ykkur fyrir að gefa ykkur tíma til að taka þátt í þessu rýnihópaviðtali í dag.

Við heitum Freyja og Anna Sigrún og vinnum hjá Rannsóknasetri í fötlunarfræðum. Kynna okkur stuttlega.

Tilgangur rannsóknarinnar er að:

- skoða upplifun fatlaðra barna sem eru búsett á Íslandi á lífsgæðum sínum og þátttöku á ólíkum sviðum samfélagsins samanborið við jafnaldra
- kanna hvernig foreldrar fatlaðra barna meta lífsgæði barna sinna til samanburðar við foreldra ófatlaðra barna.
- skoðum við hvort fötluð börn meti lífsgæði sín með öðrum hætti en foreldrar þeirra.

Við viljum ræða hluti eins og:

- hvað eru lífsgæði?
- hvað er gott líf?
- hver eru tækifæri fatlaðra barna og unglinga til að taka þátt við mismunandi aðstæður?
    - Hvað gengur vel?
    - hvað gengur síður?
- hvað felur það í sér að taka þátt við mismunandi aðstæður?

Á meðan á viðtalinu stendur skiptir máli að öllum geti liðið sem best. Það gerum við með því að:

- Hlusta vel hvert á annað,
- bera virðingu fyrir hvort öðru, t.d. með því að virða ólíkar tilfinningar og skoðanir,
- vera meðvituð um að umræðuefnið getur verið viðkvæmt og því þurfum við að gæta þess að það sem sagt er hér inni fari ekki lengra,
- virða ólíkar leiðir til tjáskipta og gefa öllum þann tíma sem þau þurfa til þess að koma máli sínu á framfæri,

- virða ólíka reynslu, einstaklingsbundnar upplifanir og persónulegar skoðanir,
- virðum þarfir líkamans, hér er allt í lagi að hreyfa sig, standa upp, halla baki á hjólastól o.sfrv.

Einhver kann að hafa persónulega erfiða reynslu af hvers konar misrétti. Engum er skylt að deila þeirri reynslu en öllum er þó frjálst að segja frá því sem þau vilja. Þið megið líka hætta og fara hvenær sem þið viljið.

Að viðtali loknu munum við afhenta ykkur upplýsingar um hvert þið getið leitað um frekari aðstoð og stuðning.

Nánar um praktísk atriði og trúnað

- Við erum með upptökutæki, það er bara svo við munum betur það sem þið segið.
- Við munum ekki segja neinum frá því sem þið segið hér og nafnið ykkar kemur hvergi fram. Þetta er alveg nafnlaust.
- Slökkva á farsímum.
- Fylla út upplýst samþykki

Fara yfir samþykkisyfirlýsinguna með viðmælendum og fá undirskrift.

Byrja á að allir kynni sig.

Opnunarspurningar	
1. Aldur, búseta, fjölskylda 2. Hvernig talar fólk um hugtakið fötlun í kringum ykkur? 3. Hvernig upplifið þið hugtakið fötlun? 4. Notar annað fólk hugtök um ykkar fötlun eða ykkur sem fatlað fólk sem þið notið ekki sjálf?*	1. Áhugamál, menntun, atvinna, annað 2. Notið þið það? Notið þið önnur hugtök? Hafnið þið hugtökum? Hvernig? Hvar? Hvers vegna? 3. Hefur það breyst í gegnum frá barnæsku? 4. Hvaða hugtök? Hvaða áhrif hefur það á ykkar líðan? Skipta hugtök máli? Hefur notkunhugakana afleiðingar? Ef svo hver þá? * Rannsóknin sýnir að fötluð börn og foreldrar þeirra nota ekki alltaf sömu orðræðu og börnin þeirra, hvað teljið þið að valdi því?
Lykilspurningar	
Lífsgæði 1. Hvað finnst ykkur vera gott líf? 2. Haldið þið að hugmyndir annarra um gott líf hafi áhrif á hugmyndir, líðan og líf fatlaðra barna og unglinga? 3. Haldið þið að hugmyndir annarra um lífsgæði fatlaðs fólks (barna og fullorðinna) hafi áhrif á hverju fötluð börn og unglingar deila með öðrum (t.d. reynsla og tilfinningar?)Ef þið gætuð ráðlagt foreldrum, t.d. farið aftur í tímann og ráðlagt ykkar eigin, hverju vildu þið koma á framfæri? 4. Ef að þið mynduð eignast (fötluð) börn, hvað finndist ykkur mikilvægt að hugsa um sem foreldrar svo þau geti átt gott líf? 5. Nú kemur það fram í rannsókninni að fatlaðar stúlkur meta lífsgæði sín verr en fatlaðir drengir á sumum sviðum. Hvað teljið þið að geti verið þess valdandi?	*Lífsgæði* 1. Haldið þið að aðrir, t.d. foreldrar, systkini, vinir, ókunnugir, hafi svipaðar eða ólíkar hugmyndir um gott líf? Af hverju eru þær hugmyndir öðruvísi ef svarið er að þær séu ólíkar? 2. Hvernig? Hverjir? Hvenær? Hvar? 3. Hvernig þá? Afleiðingar ólíkra hugmynda um hvað sé gott líf og hver geti sagst lifa því??? Þöggunin þegar norminu er mótmælt... 4. Hvaða hugtök mynduð þið nota? Hvað mynduð þið leggja áherslu á í þátttöku? Og aðgengi?
Líðan 1. Hvar og með hverjum líður ykkur vel?	*Líðan* 1. Hvers vegna?

2. Eru einhver ákveðin rými (vettvangur eða aðstæður með ákveðnu fólki) sem eru óþægilegri en önnur? 3. Er einhver sérstök framkoma annarra óþægileg/styðjandi? 4. Hefur framkoma annarra og almenn viðhorf í samfélaginu breyst frá barnæsku og þá hvernig?	2. Hver og hvað einkennir þá?' 3. Hvers vegna? 4. ...
Þátttaka 1. Hvað þýðir það í ykkar huga að taka þátt (í samfélaginu)? 2. Hvaða þættir í umhverfinu og viðhorfum fólks voru frelsandi/hamlandi fyrir þátttöku ykkar í samfélaginu sem a) börn b) unglingar? 3. Munið þið eftir aðstæðum sem börn/unglingar þar sem þið gátuð/fenguð ekki að taka þátt í tilteknum aðstæðum? 4. Hvaða áhrif teljið þið að aðgreining, t.d. sérskólar, sérstakir vinnustaðir, sumarbúðir og tómstundastaðir hafi áhrif á lífsgæði fatlaðra barna og unglinga? (dæmi: stuðningsfjölskylda, sumarbúðir fyrir fötluð börn, skammtímadvalir, ferðaþjónusta)	*Þátttaka* 1. Hvernig var þátttakan í barnæsku? Heimili, í skólanum, í félagslífi, nærumhverfi (hjá vinum), menningu, á persónulegum sviðum, t.d. ástarsamböndum? 2. Voru einhverjar aðstæður/félagsskapur þægilegri en annar? En kvíðvænlegri? 3. Hvernig tilfinningar vakti það? 4. Áhrif þjálfunar á sjálfsmynd og lífsgæði?
Lokaspurningar	
Framtíðarsýn 1. Hvernig haldið þið að líðan fatlaðra barna og unglinga sé þegar þau hugsa um framtíð sína? 2. Hvernig töluðu aðrir um framtíðina ykkar? 3. Hvaða tilfinningar vakti það? 4. Er eitthvað sem þið viljið bæta við áður en við hættum í dag?	**Framtíðarsýn** 1. Hvernig sáuð þið framtíðina ykkar? Varð hún eins og þið ímynduðuð ykkur? Hefur það breyst í gegnum tíðina? Voru hugmyndir annarra um ykkar framtíð í sömu línu eða sambærilegar við ykkar sýn (aka litlar væntingar) 2. ...

Life quality and participation of disabled children and young people: A transformative study

Interview guide for focus groups

Thank you for joining us today for this focus group interview. We appreciate your time and participation.

We are Freyja and Anna Sigrún, and we work at the Center for Disability Studies—short introduction.

The purpose of the study is to:

- Investigate the experiences of disabled children and youth in Iceland concerning their life quality and participation in various areas of society compared to their peers.
- Examine how parents of disabled children and youth perceive their children‘s quality of life in relation to parents of non-disabled children.
- Explore whether disabled children evaluate their life quality differently from their parents.

We want to discuss topics such as:

- How do you define life quality?
- What is a good life?
- What opportunities exist for disabled children and young people to participate in school, family, and social life?
    - What are the positive aspects?
    - What areas need improvement?
- What does it mean to participate in various situations?

During the interview, it is important for everyone to feel as comfortable as possible. We achieve this by

- Listening attentively,
- respect one another, including different feelings, perspectives, and opinions.
- Be mindful that some topics may be sensitive; therefore, please ensure that what is shared within the group remains confidential.

- Acknowledge and respect different ways of communicating, and allow everyone the time they need to express their thoughts.
- Respect your body‘s needs; it is absolutely fine to move, stand, adjust your position, or lean back in a wheelchair — whatever helps you feel comfortable.

We recognize that some participants may have personal experiences with injustice. You are never required to share these experiences unless you wish to. You are free to express yourself in the way that feels right for you, and you can choose to pause, take a break, or leave the group at any time.

At the end of the interview, we will provide you with information on where to find further help and support, should you need it.

More about practicalities and confidentiality

- We have a recording device, so that we can remember what you say better.
- We won‘t tell anyone what you say here, and your name won‘t appear anywhere. This is entirely anonymous.
- If possible, please turn off your cell phones or set them to silent so we can avoid interruptions.
- Fill out an informed consent form.

Review the consent form with the interviewees and obtain their signatures.

Start by having everyone introduce themselves.

Opening questions	
1. Age, living situation, family 2. How do people talk about the term disability around you? 3. How do you perceive the concept of disability? 4. Do those around you use the same concepts as you do?	1. Hobbies, employment, work, school, leisure ... 2. Do you use other terms? Do you reject certain concepts? How, where and why? 3. Has it changed since childhood? 4. Which terms? How do they impact your feelings? Terms, do they matter? If so how?
Key questions	
Life quality 1. What does having a good life mean to you? 2. Do the opinions others have about the life quality for disabled people (children or adults) influence what disabled children and adolescents feel comfortable sharing about their experiences and feelings? If you could advise parents—perhaps even to your own parents in the past—what would you want to tell them? 3. If you were to have disabled children, what aspects should parents consider to ensure they lead a good life?	*Life quality* 1. Do you think that parents, siblings, friends, and strangers have similar or different ideas about what constitutes a good life? If they are different, what are the reasons behind those differing ideas? 2. How? Who? When? Where?
Feelings 1. Where and with whom do you feel comfortable? 2. Are there particular places or situations—maybe with certain people—where you feel more uncomfortable than others? 3. Has it changed since childhood?	*Feelings* 1. Why? 2. Who are the people, and what are the things, that make these situations uncomfortable? 3. How?
Participation 1. What does participating in society mean to you?	*Participation* 1. What was your participation like during childhood? You might

2. Thinking about your experiences, what aspects of the environment or people's attitudes helped you participate, and what made it more difficult, as a) a child and b) an adolescent? 3. Can you recall any situations during childhood or adolescence where you were able—or not allowed—to take part in certain activities or events?	think about areas such as home life, school, social interactions, your local environment with friends, cultural activities, or personal aspects like romantic relationships. 2. Were some situations or groups of people more comfortable for you than others? Did any make you feel anxious or uneasy? 3. What feelings did these experiences bring up for you?
Concluding questions	
Aspirations for the future 1. How do you think disabled children and adolescents feel about their future? 2. How did or do other people talk about your future? 3. What emotions does this bring up for you? 4. Before we finish, is there anything you would like to add? Are there any topics we haven‘t discussed that you would like to address?	**Aspirations for the future** 1. How do you envision your future, particularly in terms of transitioning into adulthood? Has your life turned out as you had imagined? Has your perspective on adulthood changed over time? Were others’ expectations about your future aligned with your own hopes and vision for growing up? (expectations) 2. ...