Exploring the Potential of Belonging:
A Participatory Study with Disabled Youth

by

Emily Eirikson

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We acknowledge and respect the Lək̓ʷəŋən (Songhees and Xʷsepsəm/ Esquimalt) Peoples on whose territory the university stands, and the Lək̓ʷəŋən and W̱ SÁNEĆ Peoples whose historical relationships with the land continue to this day.

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Abstract

Despite the prevalence of inclusion discourses and policies in education and disability services, some disabled youth continue to experience a lack of inclusion in educational and community spaces. Critical disability scholars and self-advocates have also raised concerns that dominant notions of inclusion continue to fall short and cause harm due to their underlying ableist assumptions. This participatory study engaged four youth with disabilities in focus groups to explore their experiences and perspectives of inclusion and belonging. Drawing on critical disability studies scholarship, reflexive thematic analysis identified two themes, (1) exploring belonging and (2) unpacking ableism, with interrelated subthemes. The findings indicate that the concept of belonging may provide a more meaningful and nuanced alternative to inform policy and practice, with the potential to disrupt the inequitable power relations inherent in inclusion rhetoric and shift power back into the hands of individuals with disabilities. The implications of this research inform how Child and Youth Care practitioners, public school educators, and professionals who support youth with disabilities in community and educational contexts can collaborate with disabled youth to foster their sense of belonging.

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Chapter 1: Introduction

This thesis research represents a collaboration with Canadian disabled[1] youth to explore their experiences of inclusion and how the concept of belonging may offer a meaningful and nuanced alternative. The research was inspired by my observations in the field as a youth outreach worker and my review of the existing literature; both of which indicated that despite the prevalent ideal of inclusion, some youth with disabilities experience a lack of belonging; that is, a lack of genuine reciprocal relationships and a valued place in the community (Renwick et al., 2019; Robinson et al., 2020; Salmon, 2013; Teachman et al., 2020).

While the physical presence of people with disabilities in the community has increased in recent decades, some continue to experience loneliness and isolation (Emerson et al., 2020; Gilmore & Cuskelly, 2014; Johannes et al., 2017; Kwan et al., 2020; Macdonald et al., 2018). Societal attitudes towards disability have been identified as an ongoing barrier to participation and belonging (Giles et al., 2020; Martin, 2019; Robinson et al., 2020; Teachman et al., 2020). The nondisabled[2] community's response to attempts at inclusion often reflects ableism; in other words, discrimination against disabled people in the form of various beliefs and practices that position one type of body as typical and fully human (Jenks, 2019). Ableism has also influenced the conceptualization of inclusion. Critical disability scholars have noted that inclusion has generally been defined by nondisabled adults as participation in mainstream (neoliberal, capitalist) society. As a result, disabled people often bear the burden of adapting and assimilating

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[1] While "person-first language" (i.e., "a person with a disability") is currently the primary language choice used by Canadian governments and many organizations, many self-advocates prefer "identity-first language" (i.e., "a disabled person") as the former suggests that disability is inherently negative and needs to be minimized or separated from the person (Titchkosky, 2001). Following their lead, I personally prefer identity-first language but will use both options interchangeably.

[2] I use the term nondisabled as an umbrella term for people who do not have physical, intellectual, or psychological disabilities. The more specific terms "able-bodied" or "neurotypical" will be used when relevant.

to the mainstream, while disability-specific spaces and relationships can be devalued and their own goals and desires overlooked in favour of nondisabled people's ideals (Renwick et al., 2019; Salmon, 2013; Teachman et al., 2020).

Defining Disability

My study is informed by critical theories and concepts such as ableism, intersectionality, and colonialism (Adjei, 2018; Dulwich Centre Foundation, 2015; Ineese-Nash, 2020; Meekosha, 2011). These concepts and other scholarship in the field of critical disability studies complicate the conceptualization of disability, expanding the definition beyond biomedical criteria to include social, political, and historical dimensions. In my thesis research, I view "disability" as a range of physical, intellectual, and psychological impairments and diversities while also acknowledging how disability is socially constructed and produced by the environment, and within Canadian/global settler-colonial contexts (Adjei, 2018; Ineese-Nash, 2020; Meekosha, 2011; Oliver, 1983; Titchkosky, 2001; Vehmas & Watson, 2014; Watson, 2018).

In North America, the dominant discourses surrounding disability predominantly rely on Euro-Western worldviews that position disability as an individual deficit and "largely fail to recognize the multifaceted disabling impacts of colonization on the health and well-being of Indigenous families and children" (Gerlach, 2018, p. 11). The construct of disability has been used in conjunction with race-based discrimination to advance colonial nation-building and uphold White supremacy and authority, harming Indigenous communities in the process (Roman et al., 2009). Indigenous scholars such as Nicole Ineese-Nash (2020) have critiqued the imposition of this pathologizing colonial construct on Indigenous children and communities, highlighting how the underpinnings of normativity and assimilation contradict the diverse understandings of disability held by Indigenous peoples across the globe that tend to embrace

and nurture the unique embodiment and gifts of each child and their place in the community. These Indigenous understandings of disability contrast with, and offer an alternative to, pathologizing dominant discourses.

My understanding of this colonial context shaped my orientation to the research even though none of my participants identified as Indigenous. I believe nondisabled people must take up the work of dismantling ableism in the same way that settlers need to take up the work of dismantling settler colonialism and White people need to take up the work of dismantling White supremacy (Mackenzie, 2019). At the same time, the work must be done in collaboration with disabled people, following their lead and desires—in this respect, the popular disability rights slogan “nothing about us without us” comes to mind.

My Journey to this Work

As I critically reflect on my life, I recognize that my attitudes towards disability have shifted significantly. Growing up I had very little exposure to or understanding of disability. As a first year Child and Youth Care (CYC) student seeking to narrow down the myriad career paths that all captured my interest, I declared to myself, “at least I know I’m not interested in working with kids with disabilities.” Facing my discomfort with disability seemed much less glamourous and appealing than the fields of mental health, addictions, and child protection that I was hearing about from the impressive guest speakers that visited my classes. My ideas began to change in the final year of my degree when I took a mandatory disability course that challenged so much of my ignorance and introduced me to concepts such as belonging and dignity that would become central to my praxis. Then, through the twists and turns of life, my first job post-degree was as a youth outreach worker for high school students with disabilities.

In this role I worked with families, staff, and volunteers to design and adapt social and recreational programs to be accessible for teenagers with disabilities. I first met Justin,[3] a young man with autism, when he attended a backyard movie night. Before screening the movie, a youth leader played a short clip advertising an upcoming summer camp trip. Justin commented that the video made camp look fun, but he was probably not invited since he did not attend the same school as the other teens. When he heard the camp was open to all teens, he exclaimed, “Then of course I want to come! Being part of this group makes me feel happy and alive.” Years later, this statement has stuck with me as one of the first times I realized how significant peer relationships and social opportunities can be for these teens—and how lacking. At the end of the night, when the movie was over and everyone was packing up, Justin glanced at his watch and remarked, “Wow, I’ve never been out with my friends past 9pm before.” Again, this statement struck a chord with me. Justin’s diagnosis did not make him incapable of having a movie night with friends, because here he was, doing just that. He had simply never been invited. I share this story not to evoke pity for Justin but to highlight the disconnect between prevalent ideologies of inclusion and genuine experiences of belonging.

My Masters-level coursework dove into critical disability scholarship, and my practice experiences steered me towards the literature on youth and inclusion. I learned about the limitations of inclusion and how youth voice is underrepresented in research (Biklen, 2020; Goodall, 2018; Koller & Stoddart, 2021; Robinson et al., 2020). I felt compelled to take on some of the work of identifying and combatting ableism to reduce its effects on the youth and families I had come to know and love. By bringing together a focus on youth voice and a critical awareness of ableism into an exploration of inclusion and belonging, my thesis work seeks to

[3] Name changed to protect identity.

help fill this niche. In sharing my journey, I hope that I can encourage fellow Child and Youth Care practitioners or anyone who works with this population to experience the paradigm shift that I did and to adjust their practice in response.

I see my role in this research project as a facilitator and translator of knowledge: I aim to bridge the gap between academia and "the real world," sharing critical concepts and language to help youth make sense of their lives and helping to elevate the voices of youth to accomplish social change (Loiselle et al., 2012). The findings are context-specific, borne out of critical relational praxis. By doing research with the youth and families I already know, the youth and I are "struggling and collaborating together in the specific locations and communities in which we work" (Loiselle et al., 2012, p. 200). That said, I recognize my limitations and biases as a nondisabled researcher. As such, I cite disability scholars and self-advocates who have spent their lifetimes and careers experiencing and theorizing on the topics of disability and ableism, inclusion and belonging, and encourage the reader to extend their learning through these references.

Research Questions

In a research article entitled "Interrogating Inclusion" that significantly inspired my own study, the authors came to the following conclusion:

> There is an urgent need for systemic shifts past idealized notions of inclusion as a journey by disabled persons towards mainstream, ableist social settings. Instead, attention should be paid towards studying and promoting social spaces where the status quo has been disrupted and alternative ways of being in the world are positively valued. (Teachman et al, 2020, p.1119)

The primary goal of my study is to identify situations in which youth experience genuine belonging and generate a deeper understanding of those experiences. **The overarching research question for this study is "What can we learn from youth with disabilities about experiencing and promoting belonging?"** I developed five sub-questions to further guide the study design:

1. How do disabled youth understand the concepts of inclusion and/or belonging?
2. In what situations and relationships do disabled youth experience genuine belonging?
3. How are disabled youth actively involved in seeking out belonging and resisting ableism, discrimination, or exclusion?
4. How do the perspectives and experiences of this study's participants compare to existing literature on belonging?
5. How might the concept of belonging enhance policies and practices related to inclusion (particularly for Child and Youth Care practitioners)?

Conclusion

My thesis study brings together my personal and professional experiences, a critical understanding of disability, and partnership with disabled youth to explore the rising critiques of dominant inclusion discourses and the potential of using the concept of belonging as a meaningful and nuanced alternative in theory, policy, and practice. The research questions seek to prioritize youths' voices, lived experiences, and agency within the context of existing literature and CYC practice. The next chapter summarizes relevant scholarship that informed my research.

Chapter 2: Literature Review

This literature review provides an overview of the concepts of inclusion, belonging, and ableism that frame my thesis. First, I historically locate the rise of inclusion ideologies then summarize some critiques of inclusion synthesized from critical disability scholarship. I introduce the concept of belonging as a more meaningful and nuanced alternative and explore how belonging has been employed and defined in research with disabled youth. Next, I outline the impacts of ableism on belonging for disabled youth. Lastly, I identify how ableism has shaped research trends and how recent research is using innovative participatory methods to resist ableist biases.

Contextualizing Inclusion

Disability has existed as a part of human diversity since the dawn of time; however, society's response to people with disabilities has shifted along with the rise and fall of various politics and ideologies. In Western nations institutionalization became the dominant approach from the 17th to 20th centuries (Cameron & Valentine, 2001). As industrialization and capitalism increased in the late 18th and early 19th century, the measures of how bodies were valued changed, with worth being tied to one's ability to "produce" or "contribute" (Jenks, 2019). Disabled bodies were characterized as passive, dependent, and therefore in need of special attention and care, which was purportedly best achieved by opening institutions and segregating disabled individuals from their communities (Conrad, 2020; Finkelstein, 1980). These notions are reflected in the medical model of disability, which focuses on individual impairment and views disabled people as "deficient, sick, afflicted, or suffering from a disability, and treatment and prevention are the primary goals" (Robertson, 2016, p. 53). Specialized institutions for people with intellectual and psychiatric disabilities opened in Canada in the mid-1800s (Dunn &

Langdon, 2016). There was no support provided to families who did not want to put their children in institutions, and individuals living in these settings often experienced overcrowded living conditions, poor nutrition, neglect, violence, and abuse (Dunn & Langdon, 2016).

In the 1960s and 1970s, the disability rights movement in North America gained momentum through the activism of disability organizations, parents, and, increasingly, self-advocates (Conrad, 2020; Dunn & Langdon, 2016). Ideals of inclusion took precedence alongside the independent living and community living movements and were eventually codified in international policy, such as the United Nations Convention on the Rights of Persons with Disabilities. The general principles of the Convention call for “full and effective participation and inclusion in society” (United Nations General Assembly, 2006, p. 5), and the document enshrines the right to living in community, inclusive education, equitable employment opportunities, and participation in political and cultural life, recreation, leisure, and sport. Significant advances in this era were informed by the emergence of a social model, first articulated by Mike Oliver in 1983 to identify how the limitations associated with disability are often the result of disabling barriers in society (Oliver, 2013). At the same time, insufficient social supports and resources resulted in “many people [becoming] institutionalized within the community, experiencing the same conditions of dependency, categorization, separation, isolation and stigma as individuals in institutions” (Dunn & Langdon, 2016, p. 35). These ongoing experiences reflect the prevalence of ableist attitudes and practices.

Today in British Columbia (BC), young people and their families continue to fight for access to inclusive education and equal life opportunities. In the 2023–2024 reporting year, Inclusion BC’s Community Inclusion Advocacy Support Program responded to over 1200 requests for support, of which 48% related to equitable access to K-12 education (Inclusion BC,

2024). BCEdAccess is a registered charitable organization that sheds light on the issue of inclusive education by tracking and reporting on hundreds of instances of educational exclusion each year (BCEdAccess Society, 2023, p. 3). These instances include students being restrained or secluded, sent home early, withheld from particular classes or experiences, or denied necessary physical care to make their attendance possible (BCEdAccess Society, 2023, p. 4). These instances occur despite BC's Inclusive Education policy, which "promotes an inclusive education system in which students with disabilities… are fully participating members of a community of learners" and outlines procedures and the responsibilities of parents, teachers, and the school board to make this a reality (Government of British Columbia, 2006). Exclusion is also experienced by people with disabilities of all ages in BC in terms of their access to employment, health and social services, and desired housing options (Inclusion BC, 2024). Interpreting and amplifying these personal experiences, critical disability scholars and self-advocates have raised concerns that dominant notions of inclusion continue to fall short and cause harm.

Critiquing Inclusion

Though the definition of inclusion may seem self-evident, a review of the literature identifies that there is no widely accepted, consistently applied understanding. On the contrary, critical scholarship illuminates how ableism is woven throughout various interpretations of inclusion, from the underlying theoretical assumptions to its enactments in practice.

First, inclusion has sometimes been narrowly defined as disabled and non-disabled people sharing the same space (Salmon, 2013). This framing can fail to acknowledge the barriers to participation and the formation of relationships such as physical inaccessibility, individual support needs, and, most importantly, ableist attitudes. When these barriers are not addressed,

people with disabilities may appear to be included but struggle to experience belonging. Research has repeatedly identified how "inclusive" settings can mask social hierarchies and exclusionary power dynamics. For instance, a study of relationships between disabled and nondisabled youth at a summer camp in the United States found that the nondisabled campers did not see any benefits of inclusion for themselves and described "allowing" disabled campers to participate with them (Devine & Parr, 2008). This choice of language seems to reflect a mindset in which disabled peers are deemed inferior, rather than equals with a right to community participation, and enables the nondisabled campers to hold ableist beliefs while seeing themselves as kind and benevolent.

In the North American school system, Koller and Stoddart (2021) observed that "despite the inclusion of children with disabilities in regular classrooms, research consistently presents children with disabilities as lonelier than their peers, less involved in their communities, and less likely to experience overall well-being" (p. 680). These authors noted that students with disabilities encountered more bullying and faced difficulties in building and maintaining friendships. A study of autistic boys in integrated physical education (PE) classes in the United States found that PE class, and specifically the locker room, was often a site of exclusion and bullying that led some students to self-isolate and even self-harm (Haegele & Maher, 2021). Similarly, autistic participants in Goodall's (2018) study in North Ireland found mainstream schooling did not meet their social, relational, or academic needs due to exclusion by peers, sensory overwhelm, and a lack of training to equip teachers and staff. These participants did not equate participation in mainstream schooling with inclusion; rather, they associated inclusion with feelings of happiness, recognition and respect as a person, and experiences of fairness and

equity. These findings indicate that genuine inclusion requires more than physical presence and must include addressing ableist attitudes and environmental barriers.

A more fulsome conceptualization of inclusion often encompasses independent living and paid employment along with participation in mainstream settings. However, a critical analysis of this definition identifies how these ideals are based on neoliberal values and may not align with the actual needs, desires, and realities of young people with disabilities who may enjoy living with their families, may frequently face job discrimination, and may appreciate the supports available in disability-specific contexts (Renwick et al., 2019). As Teachman (2023) has elaborated, “inclusion is often idealized in relation to deeply ingrained social values and beliefs about what people ‘normally’ can and should do in relation to their life stage, gender, and social class” (p. 6). Recognizing that some people lack the ability or desire to attain these societal ideals suggests that another definition of inclusion is needed—one grounded in the insights and lived experiences of people with disabilities.

Practices based on these ambiguous and unexamined notions of inclusion can have detrimental consequences for people with disabilities. On a theoretical level, the mere concept of “inclusion” relies on a binary opposition with “exclusion”, which upholds that there is a majority to which the minority should aspire to join. Teachman (2020) argued, “the unquestioned aims of most inclusion-focused programs and policies are to assimilate children into ‘normal’ spaces and thus efface their differences” (p. 1119). A critical review of 147 peer-reviewed studies on approaches aimed at promoting social inclusion for children with a range of disabilities seems to support this claim (Koller & Stoddart, 2021). The vast majority of the studies described interventions aimed at “fixing” the child in order to make them more socially competent in their environments. Specifically, 118 of the 147 studies incorporated social skills training, referring to

interventions that "normally consist of training coupled with reinforcement strategies to encourage the desired behaviour" (Koller & Stoddart, 2021, p. 684). The predominance of this approach calls for critical examination. Who determines what behaviour is desirable? Are the skills practiced through social stories or video modelling, for example, generalizable to real-life settings? Is removing children from the social context of their classrooms to "practice" their social skills through individual intervention effective or even logical? Only 32 of the 147 studies had any form of follow up to see if the interventions had a lasting impact (Koller & Stoddart, 2021). Even if these interventions are effective, the pressure to "fit in" or assimilate based on a biomedical framing of disability as an individual shortcoming may promote extraordinary rehabilitation efforts or medical or behavioural interventions (Teachman et al., 2020). Sasson et al. (2017) identified how negative impressions of disability may be founded on "subtle physical, dynamic, and auditory cues of presentation that can also include additional features, such as clothing choices, grooming habits, gaze patterns, or body posture" (p. 8). Some of these elements may be integral to a person's way of being in the world, and the effort to change them may be unreasonable when the problem is not necessarily the individual's behaviour or style of communication but rather how others perceive them.

These biomedical, individual interventions fail to account for the social and relational realities of disability, inclusion, and exclusion. More dignifying and caring alternatives include interventions that educate peers about disability, encourage them to reflect on their own behaviours, and facilitate the development of a peer support network for children with disabilities in structured and unstructured settings (Koller & Stoddart, 2021). Moreover, three studies found that training educators to support the social needs of children with disabilities had successful outcomes, and "teachers themselves identify a need for more training in inclusive

practices" (Koller & Stoddart, 2021, p. 691), which suggests this form of intervention could be a valuable avenue to pursue. The insidious nature of ableism requires a critical examination of inclusion efforts to ensure that they move beyond assimilation to recognize the dynamic social-relational aspects of disability and inclusion. In addition to burdening individuals with the work of fitting in, expectations of assimilation suppress human diversity and obscure the unique abilities and gifts of disabled individuals, perhaps because nondisabled society assumes that people with disabilities have nothing of value to offer.

In contrast, Hall's (2010) case studies of a theatre company and an arts organization in Scotland astutely outline the many benefits of disability-specific spaces where dynamics of exclusion are turned on their heads. These segregated spaces not only provide disabled artists with supportive, safe surroundings and opportunities for friendship, but also redefine inclusion beyond political ideals of employment and economic participation and reinscribe the social understanding and value of people with intellectual disabilities. Disability-specific contexts, "where the worth of disabled people is recognized and where impairments and differences are less stigmatized and may even be celebrated" (Teachman, 2023, p. 10), can be treasured sites of safety and belonging yet are often overlooked or dismissed when nondisabled people uncritically position mainstream participation as the defining criteria for inclusion. Proponents of inclusion must contend with the dissonance of expecting disabled individuals to expend enormous efforts to take part in an ableist society that is at best not designed for them and at worst overtly hostile. To mitigate the social, political, emotional, and physical harms of ableism, those who work with and care about people with disabilities must first acknowledge that ableism exists, not just as discriminatory behaviours but also as assumptions about what nondisabled people think disabled people may want or need.

In sum, the goals of the inclusion movement have yet to be fully achieved, and to make progress, self-advocates and disability scholars are increasingly critiquing and reformulating notions of inclusion. In a review of European literature on education and inclusion with a goal of "differentiating ideology from evidence" (p. 358), Limbach-Reich (2015) concludes,

> Given the large number of studies with their different scopes and the wide range of findings, it is very hard to summarise evidence for inclusion. The research cannot confirm that inclusion has a dominant and mainly positive effect for all children with disabilities, with positive effects on both academic outcomes and psycho-emotional dimensions… *One of the pitfalls of inclusion may be that it works but not for all, not at all times and not in all settings*. (p. 371, emphasis added)

Inclusion can "work" for some people, and these individuals and their families tend to champion inclusion efforts out of a desire to share the benefits they have enjoyed with others. The critiques raised in this thesis are not meant to discount such experiences but rather to recognize that not all disabled people have the time, energy, skills, or financial resources in their families or communities to overcome barriers and advocate for what they need and want. Acknowledging these complexities and examining other intersecting factors can deepen understandings of inclusion and lead to better outcomes for more people. Reviewing school inclusion in the United States, Biklen (2020) identified that it was most successful "when guided by the principles of presuming competence, belonging, and full citizenship, and informed by the experiences of students who have grown up within the change movement" (p. 233). The following sections of this chapter take up some of these ideas by exploring the possibilities that spring from embracing a paradigm of belonging that foregrounds the voices of self-advocates.

Introducing Belonging

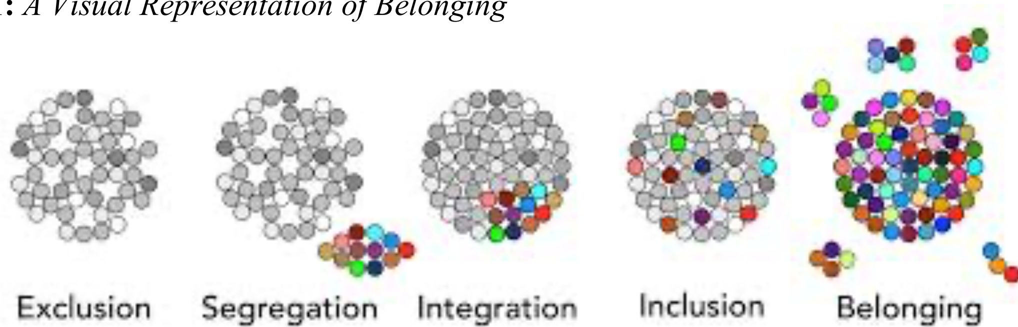
Many disciplines engage the concept of belonging with similar but varying emphases. To date, very little research exists that specifically investigates sense of belonging for people with disabilities (Gur & Bina, 2023). In a scoping review, Mahar et al. (2013) sought to develop a transdisciplinary definition of belonging that could be used to evaluate the effectiveness of community-based programs for people with disabilities. Based on literature that qualitatively explored the meaning of belonging or quantitatively measured sense of belonging, these authors concluded that belonging is "a subjective feeling of value and respect derived from a reciprocal relationship to an external referent that is built on a foundation of shared experiences, beliefs or personal characteristics" (Mahar et al., 2013, p. 1031).

Recent research has begun to explore what belonging might mean to young people with disabilities. Renwick et al.'s (2019) "Voices of Youth" study in Toronto, Canada recruited youth 13 to 24 years of age with intellectual and developmental disabilities and employed constructivist grounded theory to generate a theoretical framework for belonging. Belonging was found to be "an ongoing process experienced in four major ways: through engaging in social relationships, interacting with people who are similar, negotiating meaningful roles in the community, and through navigating norms and expectations – finding a good fit" (p. 951). The authors noted that this framing may represent "a departure from many westernized notions of inclusion that often equate inclusion to participation in socially normative activities (e.g., paid employment, independent living, presence in mainstream community settings)" (p. 961). As previously outlined, this limited view of inclusion may not correspond to the needs and desires of people with disabilities. In contrast, the Voices of Youth participants universally described belonging as desirable, important, and something they wished for, suggesting that the concept of

belonging may be more relevant and meaningful. A secondary study of the same data highlighted the significant role that family plays as a source and facilitator of, and occasionally a barrier to, belonging, in ways that are unique to youth with disabilities (DuBois et al., 2020).

Additional research aligns with these findings. In an Australian study that engaged 24 adults from disability self-advocacy organizations in focus groups to discuss the meaning of belonging, analysis identified four subthemes: belonging in relation to place, belonging as being part of the community, belonging as having relationships, and belonging as identity (Strnadová et al., 2018). Another Australian study with disabled teenagers and young adults found that belonging was multifaceted and included sentiments of being recognized, valued, welcomed, understood, accepted, and respected (Robinson et al., 2020). In addition, belonging was associated with safety, familiarity, comfort, continuity, fitting in, mutuality, and helpfulness to others, and participants reported finding belonging with friends, family, and support workers. Based on a lifetime of working with diverse community groups in the United States to increase belonging for members with disabilities, Carter (2021) crystallized his observations into ten "dimensions of belonging": being present, invited, welcomed, known, accepted, supported, cared for, befriended, needed, and loved. The figure below builds on this definition of belonging and effectively illustrates key differences between inclusion and belonging (Carter, 2022). Rejecting the implications of a same coloured "in group" tolerating the integration of diversely coloured outsiders, a paradigm of belonging asserts that all people are unique and find belonging in different ways, inside and outside of the mainstream.

Figure 1: *A Visual Representation of Belonging*



In research on sense of belonging for autistic university students, Pesonen et al. (2023) developed an understanding of belonging that incorporates the recurring themes of familiarity, comfort, security, and emotional attachment while adding a valuable emphasis on the affective and embodied dimensions of belonging. These authors posit that "belonging is not something that is accomplished or finally achieved, but something that is *felt* in some situations over others" (Pesonen et al., 2023, p. 741), acknowledging how a sense of belonging is socially negotiated and can vary across time and place. In the same way, individuals can also experience a felt sense of unbelonging (Puroila et al., 2021). My study embraces this view of (un)belonging as an embodied experience.

Collectively, the reviewed literature offers a rich and largely coherent definition of belonging, with some variation as expected due to the subjectivity of the concept. Several observations can be made. First, conceptualizations of belonging seem to be not only coherent, but accessible. For example, disabled adults participating in focus groups held "very lively discussions" about their sense of belonging or being excluded, suggesting that this language was understandable, familiar, and intuitive (Strnadová et al., 2018, p. 1094). Second, belonging encompasses some of the pieces that inclusion is missing. Belonging connotes an inherent condition rather than something to be bestowed, a sense of reciprocity and equality rather than heterogeneity and stratification, and a personalized approach without being overly

individualistic. Third, belonging is in some ways at odds with inclusion (at least in its predominant incarnations). In the words of Renwick et al. (2019), “many youths cannot achieve social inclusion based on neoliberal expectations of normalcy, or can do so only in ways that may undermine genuine belonging, as described by our participants” (p. 966). For example, masking their disability to fit in, forgoing needed supports, and sacrificing their desires to meet expectations of others does not promote a felt experience of safety, comfort, acceptance, care, or many of the other elements that have been identified as central to belonging.

Impacts of Ableism on Belonging for Youth with Disabilities

Participants in many of the studies cited previously shared examples of facing ableism in their everyday lives. In a Canadian study of disabled teens and friendship, “without prompting, all participants offered accounts of stigmatizing experiences both at school and in their communities” (Salmon, 2013, p. 351). Examples included teasing, mocking, verbal aggression, and being ignored, leading to progressive loneliness and exclusion. In another Canadian study, youth participants had numerous accounts of experiencing ableism in public, such as staring and rude behaviours (Teachman et al., 2020). The youth found this tiring and frustrating yet perceived it as inevitable; still, they attempted to avoid situations where they would be exposed to such behaviour since it made them feel unsafe. One young woman expressed awareness of being judged by her verbal abilities and by how she moved, as she was treated differently depending if she used an assistive communication device or not and if she used her walker or her wheelchair (Teachman, 2023). Some youth participants noted the impacts of ableism on the opportunities available to them, recognizing that as a wheelchair user it was harder to get a job compared to their peers (Renwick et al., 2019). Siblings of children with disabilities are aware of ableism too, noticing “name-calling, staring, patronising remarks, and misplaced sympathy”

(Stalker & Connors, 2004, p. 223). Some of the older siblings interviewed by Stalker and Connors (2004) recognized that these experiences went beyond individual bullying and connected them to broader societal discrimination against disability. All in all, research indicates that young people experience and recognize ableism in their day-to-day lives, though they may or may not have the language to name it.

Unsurprisingly, repeated experiences of discrimination have significant impacts on individuals' sense of belonging. When youth participants recognized exclusionary attitudes based on their impairment or perceived limitations, these negative responses impacted whether or not they felt able to engage with certain people or settings (Robinson et al., 2020). Analysis in the Voices of Youth study highlighted the impact of ableist attitudes by identifying that "belonging was tied to the quality of interaction and acceptance by others, rather than simply being included or invited" (Renwick et al., 2019, p. 953). Participants in this study wanted to feel noticed and valued, not judged. Some expressed feeling isolated within certain community experiences due to the way others acted towards them, demonstrating why simple measures of community participation may not correspond to a felt sense of belonging. Heartbreakingly, one participant reflected on the feeling that others "wanted nothing to do with [him]" (Renwick et al., 2019, p. 953). These researchers observed that "not having the desired number or quality of relationships led to isolation and loneliness" (Renwick et al., 2019, p. 953). Young people with disabilities in other studies also reported feeling excluded and having fewer friendships than they would like, particularly those "who thought others identified them primarily by their disability or who felt uncomfortable or vulnerable to prejudice outside home and disability specific settings" (Robinson et al., 2020, p. 63). A compounding pattern was observed in that "actual or feared

experiences of negativity or harm by others led some people to exclude themselves" (Robinson et al., 2020, p. 64).

Experiencing a lack of belonging or relationships may be positioned as an individual failing through the framing of social impairment. This perceived deficit in relationship skills has become heavily associated with certain diagnoses. Autism Spectrum Disorder (ASD) is frequently characterized by social impairments, resulting in smaller social networks, loneliness, isolation, and a reduced quality of life—in other words, a lack of belonging (Sasson et al., 2017). The coupling of ASD with poor social skills is an excellent example of how ableism is invisibilized, as "social interaction by definition involves more than one person" (Sasson et al., 2017, p. 1). Drawing together three independently conducted studies, researchers found,

> First impressions of individuals with ASD made from thin slices of real-world social behaviour by typically-developing observers are *not only far less favorable* across a range of trait judgements compared to controls, *but also are associated with reduced intentions to pursue social interactions*. (Sasson et al., 2017, p. 1, emphasis added)

In other words, snap judgements based on ableist biases were seen to obstruct opportunities to form friendships. The autistic stimulus participants were evaluated as awkward, unattractive, unintelligent, untrustworthy, and unlikeable, resulting in a reduced desire on the part of typically-developing[4] peers to initiate conversation, spend time together, or even live near them (Sasson et al., 2017). These negative impressions were formed in seconds and were only associated with audio and visual stimuli. The transcript alone was not negatively rated, indicating that the issue is not the substance of the communication but the way it is delivered. These findings also hint at a vicious cycle, as "the reluctance of [typically-developing] individuals to engage in social

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[4] Language from the study

interactions with their ASD peers further limits the opportunities for individuals with ASD to practice their already fragile social skills" (Sasson et al., 2017, p. 8). In sum, this study provides concrete evidence of blatant ableism and correctly identifies a lack of relationships as "a bidirectional problem" (Sasson et al., 2017, p. 1).

Identifying and Resisting Ableism in Research

Ableism can also be observed in research trends. Self-advocates in the disability rights movement have asserted their right to be involved in conversations and decision-making about their lives, as captured in the popular slogan "nothing about us without us." Yet, many scholars have identified that youth voices are missing from the literature on inclusion (Biklen, 2020; Goodall, 2018; Koller & Stoddart, 2021; Robinson et al., 2020). Salmon (2013) identified an adult-centric bias when she noted that "most research attends to friendships between disabled children and their nondisabled peers… this connection appears to be the gold standard for inclusion from the perspective of many parents, policy makers and researchers" (p. 348). Furthermore, studies often define inclusion by the extent of participation in mainstream society and focus on the barriers and facilitators of this participation—by measuring engagement in community-based leisure activities, counting interpersonal relationships, and surveying the attitudes of staff and the public—rather than asking people with disabilities for their opinions on what constitutes inclusion (Renwick et al., 2019). This lack of participation in research can be linked to many factors, ranging from logistical barriers and limitations in individual ability or interest to ableist assumptions and gatekeeping (Crook et al., 2016). Nonetheless, with creativity and attention to ethical considerations, participatory research has been successfully conducted with this population, as outlined below.

Studies in this small but growing body of research were designed to accommodate diverse forms of participation, for instance by inviting communication partners to be present in interviews, using images and plain language in study materials, and incorporating visual methods such as photovoice or pictorial mapping to facilitate data collection with participants who may have limited verbal expression or comprehension (Renwick et al., 2019; Robinson et al., 2020; Strnadová et al., 2018; Teachman et al., 2020). Another theme is efforts to involve youth as researchers in advisory positions. For example the Voices of Youth study gathered a research team of three academic researchers, three community collaborators, and three disabled youth consultants (Renwick et al., 2019). The youth consultants helped to develop the methods, procedures, recruitment materials, and interview questions; provided consultation on data analysis; and participated in creating a video to share the findings. Robinson et al.'s (2020) participatory study on disabled youths' sense of belonging also consulted with young people for guidance throughout the process: participants were actively involved in photographic data collection, data analysis via group discussions, and dissemination of results through selecting images for public exhibition. However, even this carefully designed participatory study encountered accessibility challenges. Twelve of the 28 participants who were asked what belonging meant to them were not able to answer the question directly because it was too abstract (Robinson et al., 2020). Nonetheless, barriers such as this should not inhibit researchers from engaging with disabled participants since creative solutions can often be found. Robinson et al. (2020) demonstrated that non-speaking participants can be involved in data analysis:

> [One participant] progressively selected his preferred images by choosing from sets of three related photos he had taken… images were offered more than once in different

> groupings to test his preferences and he reliably chose the same images, firmly pushing away the ones he did not like (p. 56)

Undertaking these efforts to centre the voices of disabled youth in discourses that shape their lives is a crucial step in counteracting the harms of ableist biases in (well-intentioned) research.

Conclusion

This literature review has identified how dominant notions of inclusion are not well-defined, can perpetuate inequitable power dynamics, and uphold normative ideals rather than prioritizing the needs and desires of disabled people. Emerging research on belonging for youth and adults with disabilities suggests that belonging is a subjective and embodied experience grounded in social relationships. Disabled youths' experiences of inclusion and belonging are significantly impacted by ableism, which has also influenced research with this population by limiting youth involvement. The next chapter will describe how my study contributes to existing scholarship by embracing a critical, participatory research design.

Chapter 3: Methodology & Methods

This chapter outlines the overarching research approach and orientation of my study as well as the methods used for recruitment, data generation, and analysis. I describe the steps I took to ensure the research was ethical, credible, and rigorous. To conclude, I summarize my plans for knowledge mobilization.

Participatory Research Design

This study sought to address the lack of youth voice in inclusion literature by embracing a participatory research design that views youth as experts on their own lives who are capable of critical thinking and working for social change (Ozer, 2016). This approach to research builds on my background in youth work which has affirmed that youth have important things to say about their life experiences. In my research, I sought to combat a "misguided developmental approach that assumes children and youth do not or cannot understand the systemic injustices they experience every day" (Loiselle et al., 2012, p. 179)—an assumption that may be even stronger when it comes to young people with disabilities. Loiselle et al. (2012) argue that youth are not only aware of the structural forces that shape their lives but are actively engaged in resisting them. Correspondingly, this study was premised on a belief that young people with disabilities experience, understand, and resist ableism (Renwick et al., 2019; Robinson et al., 2020; Salmon, 2013; Teachman et al., 2020). This critical perspective informed the research questions, research design, and data analysis.

My study draws on the principles and practices of Youth Participatory Action Research (YPAR), a subset of Participatory Action Research (PAR). PAR approaches have been used with populations who experience systemic oppression and marginalization to work collaboratively to identify issues and potential solutions in their communities through iterative cycles of research

and action (Ozer & Piatt, 2017). Emerging in the early 20th century, action research has since been adopted to study issues of women's and Indigenous peoples' rights, environmental activism, adult literacy, male-to-female violence, HIV/AIDS prevention, and more (Kemmis et al., 2014; McIntyre, 2008). A strength of PAR is that it connects "ordinary" people with the larger social movements that are changing the communities and societies around them, making the personal political (Kemmis et al., 2014). YPAR is a specific subset of PAR designed to involve young people in research and social change projects (Foster-Fishman et al., 2010; Ozer, 2016; *YPAR Hub*, 2015). YPAR as a methodology aligns with the critical orientation of this study as it "embodies a deeper epistemological approach in asserting that young people are experts who can create knowledge leading to empowerment and social justice" (Ozer, 2016, p. 263). Therefore, I drew on elements of YPAR to inform the design of this research given the parameters of a master's thesis study. In accordance with these participatory principles, this chapter outlines how youth were involved at various stages of the study from design to implementation to analysis. I also recruited a youth co-researcher who acted as a collaborator and advisor throughout the project in addition to being a participant.

Working with the Youth Co-Researcher

Youth researchers are well-positioned to gather information and provide insights on issues that are often hidden from adults, such as the intricacies of teen social relationships, based on their lived experiences (Ozer & Piatt, 2017). In this study, it seemed particularly important to fill this role to help counteract my biases and assumptions as a nondisabled adult. The youth co-researcher, Jade[5], was a young disabled woman I had known for multiple years through my employment as a youth worker. Jade self-identifies as a disability advocate and was eager to

[5] All names are pseudonyms.

share her thoughts and experiences throughout the research process in her dual roles of co-researcher and participant. Over the years I have known Jade, we have had many critical conversations about her struggles with ableism and accessibility and had worked together to develop inclusive programs for youth with disabilities and their families within the context of my broader work in a youth outreach organization. I had been hired when the organization's disability branch was just beginning and met Jade early on. As such, we were both in pioneering roles. Jade became the first high school student with a physical disability to volunteer at summer camp for a month, and this position provided many opportunities for her to give feedback to senior staff on making this leadership development program and the camp property accessible. In our local programs, she also served as a student leader and helped design activities for our weekly youth group nights. When I told Jade that I was doing a research project on inclusion, she was keen to help in any way she could. Together we determined that as a youth co-researcher, her role was to provide consultation at key points in the study. Her role continued to evolve as the study progressed in response to group dynamics and the preliminary findings and analysis. Jade's contributions at each stage are outlined throughout this chapter.

Ethical Considerations

The University of Victoria Human Research Ethics Board granted ethics approval for this study (#21-0483). Beyond this institutional requirement, my practice and research are informed by situational and relational ethical perspectives that prioritize ongoing critical reflexivity, relational accountability, and high standards of care, reciprocity, and dignity (Banks, 2016; Campbell, 2015; Chazan & Baldwin, 2021; Wilson, 2016). These principles align with an "ethical commitment to doing CYC practice as politicized, critical, and radical social change

work alongside children, youth, families, and communities" (Loiselle et al., 2012, p. 180), a commitment that applies to my research as well.

Relational Accountability

Attention to ethical considerations were woven throughout the research process and grounded in my relational accountability as a nondisabled person working in this field, wanting to use the opportunities and positionality I held to contribute towards change and justice for the youth, families, and communities I have come to know and love. Drawing on an Indigenist research understanding, relational accountability refers to the responsibilities that come with relationships and is built upon principles of respect and reciprocity (Wilson, 2008, 2016), that hold researchers responsible to their participants and the participants' communities (Reich et al., 2017). My relational accountability to the youth participants in my study stems from my role in the community and pre-existing relationships with them and their families. Over the years I have spent getting to know them I have earned trust, and I committed to upholding my responsibility for their care and wellbeing while they were participating in my research project and beyond. In this way, my relational accountability supported an ethic of care. I extended acts of care to the youth participants throughout the research process by practicing active listening, attending to their unique needs, and seeking to create a comfortable space, as described later in this chapter (Chazan & Baldwin, 2021).

In maintaining an ethic of reciprocity, I sought to avoid research that was exploitative or extractive (Chazan & Baldwin, 2021; Reich et al., 2017). I wanted the youth who participated to experience both tangible and intangible benefits, from honoraria in recognition of their time and

knowledge, to having opportunities to connect with other youth and gain self-advocacy skills[6]. Reciprocity also encompassed the bidirectional nature of our relationships, in which I as a researcher am learning from and being changed by the youth (Wilson, 2008). In the hopes of inspiring change that would positively impact the youth, I sought to use my skills and positionality to disseminate their lived experiences and stories to a broader audience through the ideas for knowledge mobilization described later in this chapter.

Guided by the principle of dignity (Richardson & Wade, 2010), I recognized and honoured the inherent worth, autonomy, and personhood of the youth. I valued and respected their insights and perspectives, and did not dismiss their experiences based on their age or ability. I prioritized dignity in our interactions, for instance by providing time for youth to communicate or do a task at their own pace without jumping in to do it for them (unless they asked for help).

Practicing Reflexivity

Reflexivity can be described as "honesty and authenticity with one's self, one's research, and one's audience" (Tracy, 2010, p. 842), particularly regarding one's strengths, weaknesses, beliefs, and perspectives. I enacted critical reflexivity with a continued attentiveness to my social location and use of self throughout my engagement with the research study, beginning with my motivations to do this work. I believe ableism is a problem for nondisabled people to address rather than leaving disabled people to shoulder the burden of simultaneously living under and fighting against inequitable social conditions. As a nondisabled graduate student and youth worker practicing in the disability community, I felt uniquely positioned to take up this research.

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[6] Interviews with long-term adult members of a self-advocacy group in Australia suggest that involvement in self-advocacy promotes a sense of belonging, social connections, and purposeful occupation (Frawley & Bigby, 2015).

I also recognized that as a nondisabled adult, I would bring certain biases into the work. I took measures to recognize and address these limitations, such as writing reflective field notes in my research journal and consulting with the youth co-researcher.

I started my research journal when I was in the earliest stages of conceptualizing this study in October 2020, to capture the ideas, hopes, and values I wanted to carry into this work. Throughout the process, I recorded my interpretations, questions, challenges, and decision-making. I documented moments when my thesis timeline and requirements led me to deviate from a fully participatory approach. I also took notes during and after conversations with the youth researcher and my thesis committee members, as well as documented my reflections during key stages of recruitment, data generation, and analysis. Some of my reflections were based on personal experience and field observations made possible by my existing relationships with the youth that led me to interact with them in their daily environments (school, home, community) on a regular basis. I returned to these notes often during the analysis and writing stages to inform and further refine my interpretations.

My identity as a nondisabled person, my Child and Youth Care practice experience, my existing relationships with the youth participants and commitments to the community, and my critical theoretical orientation outlined earlier in this chapter all significantly shaped my stance as a researcher in this project as well as my analysis and findings. Similarly, Jade's lived experience of disability and personal circumstances also shaped her contributions and perspectives in her dual role as youth participant and co-researcher. I plan to continue practicing reflexivity when sharing the findings through published articles, conference presentations, or other methods of knowledge mobilization by locating myself within the research, sharing why and how I found myself doing this work, and relating some of the considerations from this section.

Participant Recruitment and Consent

This study sought to engage a sample of four to six youth between the ages of 13 and 21 who self-identified as disabled, neurodivergent, or having a disability, and lived in the Greater Victoria area. In her role as youth co-researcher, Jade provided consultation on the recruitment poster and information letter (see Appendices). I sent these recruitment materials to key contacts at community organizations in Greater Victoria where I had built relationships previously as a volunteer, inviting youth to share their experiences and opinions on inclusion and belonging. These contacts forwarded the recruitment materials to parents via email, who then reached out to me to express interest. I also directly contacted the parents of some youth I knew. I met with interested participants in their homes or on Zoom to provide more information, answer questions, and obtain informed written consent from the youth. I used purposive sampling to curate a diverse participant group. For example, because the first two participants were female and close in age, I then sought to recruit male participants of different ages. There was also one youth who attended a recruitment interview but decided not to participate in the study.

The Tri Council Policy Statement does not dictate a particular age of consent and advises researchers to determine ability to consent on a case-by-case basis, depending on a participant's ability to understand the nature and consequences of the research (Canadian Institutes of Health Research et al., 2018). Appendix D outlines some questions that helped me to determine each participant's capacity to consent. I decided to seek the written consent of a parent or guardian for participants under the age of 19, which is the age of majority in British Columbia. Therefore, the parents of the two younger participants were present for the recruitment interviews while the parents of the two older participants were not present but were aware and supportive of their children's involvement. To support good comprehension and informed consent, I used plain

language in the recruitment materials and during my conversations with the youth and took time to elicit and respond to their questions and concerns.

My ethical standard for consent went beyond making sure all the right forms were signed. The consent process was ongoing, relational, and contextual (Chazan & Baldwin, 2021). Building on my pre-existing relationships with the participants, I invested time in "the creative processes of building trust, connection, care and self-awareness, which are the foundation of practising ethical, reciprocal consent" (Chazan & Baldwin, 2021, p. 115). Drawing on my experience and skills as a youth worker and counsellor, I continuously assessed, solicited, and respected consent throughout the study. In the focus group conversations and meetings with the youth researcher, this process included having explicit dialogue and paying attention to nonverbal communication to ensure that the topics of conversation were safe for all involved and that everyone had positive feelings about their participation and contributions. I also checked in to confirm consent at key points in the data generation process.

Navigating Multiple Relationships

I had pre-existing relationships with all four of the youth in the final participant group through my employment as a youth outreach worker. The youth also knew each other through school and community programs. There is not much written about the complexities of doing research in the context of multiple relationships. However, scholarship in the fields of counselling, social work, and other human services provide some ethical guidelines and acknowledge that multiple relationships may be inevitable when working within certain communities (Everett et al., 2013; McDougall, 2023). This literature offers insights on navigating the various roles and relationships in a responsible and ethical way (McDougall, 2023).

Drawing on these insights and the way I work with youth in my professional role, in this research I sought to mitigate inequitable power dynamics related to multiple relationships by openly discussing boundaries with the youth, practicing informed consent that could be withdrawn at any time, planning together how to protect confidentiality across contexts, and seeking guidance from my supervisor regarding the potential harms and benefits for the participants (Everett et al., 2013). I recognized that the youths' participation could be impacted by a desire to help me or please me. For instance, I imagined they might be uncomfortable saying no or voicing disagreement with my ideas. While recruiting and seeking consent, I took care to communicate to the youth that there was no pressure from me to join the study, and that their decision would not impact my working relationship with them. During data generation, I made space for diverse viewpoints by using phrases such as "everyone's answer can be different" and "I want to hear what you really think" and did not push youth to share when they said they were done or when they seemed hesitant. When I brought my preliminary analysis to the youth for their feedback, I invited them to tell me what I needed to change, add, or remove rather than simply asking if they agreed. The youth set boundaries with me when they did not want to share and told me when they did not agree with or relate to the ideas being discussed.

Multiple relationships may in fact promote increased honesty and sharing, integrity and responsibility, connectedness and healing (Everett et al., 2013). Rather than viewing multiple relationships as a liability, I believe these relationships strengthened my study by promoting relational accountability and effective research (Everett et al., 2013; McDougall, 2023). In an article written by youth community researchers reflecting on their involvement in a participatory project, the youth concluded, "the most important thing academic researchers have to understand is the importance of building trust with youth when you want to learn about their lives and

experiences in their communities" (Reich et al., 2017, p. 9). I had already spent years building trust with the youth participants and their families, and this foundation of comfort and accountability enhanced our ability to collaborate. Furthermore, I was familiar with each of the youth's communication styles and had some knowledge of the broader context of their lives, which facilitated data generation and strengthened analysis.

Data Generation Methods

My study employed focus groups and photo elicitation as two participatory methods of data generation, supplemented by the field notes described above. In addition, all participants were asked to complete a brief sociodemographic information form to help provide context for the findings and promote a deeper analysis. This information is summarized in Table 1.

Table 1: *Summary of Youth Participants' Self-Reported Sociodemographic Information*

<table>
<tr><td rowspan="2">Gender</td><td>Male</td><td>2</td></tr>
<tr><td>Female</td><td>2</td></tr>
<tr><td>Age</td><td colspan="2">15-20 years old</td></tr>
<tr><td>Disability</td><td colspan="2">• Cerebral Palsy
• Don't Know
• Intellectual Disability
• Moderate Intellectual Disability</td></tr>
<tr><td>Ethnicity</td><td colspan="2">• Canadian
• Ukrainian
• White
• English
• Scottish</td></tr>
</table>

Focus Groups

Focus groups have been used in previous studies to engage adults with disabilities (Jóhannsdóttir et al., 2022; Strnadová et al., 2018). I utilized three semi-structured focus groups to enable participants to build on each other's ideas, to recognize that they were not alone, and, as a relatively informal method of data generation, to feel more at ease in sharing their perspectives (Acocella & Cataldi, 2021). The interaction between participants in focus groups elicited additional details, clarifications, questions, and challenges, bringing forth shared social knowledge while also allowing for a diversity of voices and meanings to emerge (Acocella & Cataldi, 2021). Furthermore, focus groups provided participants with an opportunity to connect with others who could relate to their lived experiences and to develop a sense of solidarity and collective identity (Jóhannsdóttir et al., 2022). I planned for multiple focus group meetings to promote increased relationship-building and deepening conversations. I incorporated discussions, visuals, and interactive activities to engage different styles of expression and communication as well as to offer participants multiple opportunities to share in a way and time that was comfortable for them.

All youth participants took part in three 90-minute, in-person, audio-recorded focus group sessions that took place in a private room in a local recreation centre. The room was set up to promote a conversational atmosphere, with a couch and chairs circled around a coffee table with snacks and drinks. I developed session outlines (see Appendices) informed by similar research studies (Robinson et al., 2020; Sigstad & Garrels, 2021) and in consultation with the youth co-researcher Jade. The first session generated initial conversation and ideas around belonging and inclusion and introduced photo elicitation, which I describe below. In the second session, youth shared and discussed the photos they had chosen. In the third session, which took

place almost one year later[7], youth provided feedback on the themes identified in my preliminary analysis. As an unforeseen benefit of all the participants already knowing each other, the youth often encouraged each other to share and added details to each other's stories. In line with the participatory design of the study, I transparently communicated aspects of the methodology and research process to the youth as the study progressed.

Photo Elicitation

First named by photographer and researcher John Collier in 1957, photo elicitation gained popularity in the fields of anthropology and sociology as a data collection method that facilitated the expression of tacit knowledge and a deeper understanding of the phenomena under investigation (Harper, 2002; Romera Iruela, 2023). Photo elicitation originally consisted of the researcher choosing photos to guide and enhance interviews, but evolved over time and now refers broadly to any method of incorporating photos in research interviews, whether the photos are chosen by the researcher or the interviewee (Romera Iruela, 2023).

Within the broader umbrella of photo elicitation, photovoice is a method that actively engages participants in the generation and interpretation of photographic data related to the research topic (Shaw, 2021). Originally developed by Wang and Burris (1997) in the context of participatory community needs assessment, photovoice methodology is based in a critical research paradigm and is inherently participatory, political, and change-oriented (Romera Iruela, 2023), which aligns with the aims of this study. Loiselle et al. (2012) articulated the value of photovoice by describing it as "a participatory method that uses photography and critical analysis to disrupt dominant narratives and re-center Othered bodies and perspectives" (p. 183), since this method allows participants to bring forward the images and narratives that are important to them.

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[7] Transcription and analysis took longer than anticipated because I was working full time and pregnant!

Photovoice and photo elicitation methods have been used in studies on inclusion, belonging, and community participation with disabled participants as a helpful tool for those who have difficulty with verbal expression (Heffron et al., 2018; Ile, 2020; Robinson et al., 2020). In addition to increasing accessibility by using visual methods, “the practice of art in research… seeks difference and multiplicity rather than an answer” (Loiselle et al., 2012, p. 188), making space for the uniqueness and complexity of youths’ experiences to come through. However, effective employment of photovoice requires a significant time investment of training the participants as co-researchers and photographers and working with them to prepare photos and narratives to be shared with policymakers (Wang & Burris, 1997). As such, I modelled this study’s version of photo elicitation on the principles and practices of photovoice with some modifications to suit the scope of a master’s thesis project.

After I facilitated an initial brainstorming activity to familiarize participants with the concepts of inclusion and belonging, I gave the youth a handout with instructions for taking photos. This document is provided in the appendices and included headings of “What photos should I take?”, “What will we do with the photos?”, and “Some ideas if you need them”. The use of prompts is an adaptation on the traditional open-ended photovoice methodology that researchers have used with participants with intellectual disabilities (Robinson et al., 2020; Sigstad & Garrels, 2021).

To demonstrate how we would use photographs in this study, the youth co-researcher Jade and I each brought a photo to this first session and presented it to the group, sharing how the photo represented our experiences of inclusion and belonging. In the second session, the youth (including Jade) brought their own photos and took turns sharing using a simple “who/what/where/when/why” formula and asking each other questions. Three of the participants

did not end up taking photos specifically for this project but rather brought in existing photos of friends and family from their family albums. Due to the complexities of gathering informed consent from all the people represented in the youths' images, the photos were only used during the sessions and for data analysis and cannot be included in the findings. Photovoice holds an explicit goal of reaching policymakers (Wang & Burris, 1997), and in the third session I asked participants if they had ideas about who we could share the findings with, but they did not articulate an answer.

Data Analysis

I followed the process of reflexive thematic analysis as described by Braun and Clarke (2006, 2019), which consists of six recursive steps that I will outline below. Thematic analysis is an accessible method for beginning researchers and useful for participatory research projects (Braun & Clarke, 2006). Reflexive thematic analysis centres researcher reflexivity, subjectivity, and creativity, viewing these dimensions as " a resource, rather than a potential threat to knowledge production" (Braun & Clarke, 2019, p. 591). Recognizing that the analyst plays an active role in generating themes informed by their epistemological positioning, I acknowledge that I drew from a critical paradigm in which knowledge is socially constructed and influenced by power relations, with attention to underlying ideas, assumptions, and ideologies that shaped the data (Patel, 2015).

First, to familiarize myself with the data, I listened to and manually transcribed the audio recordings of the sessions and reread the transcripts multiple times. I had invited the youth to choose pseudonyms for themselves and replaced all names in the transcripts with pseudonyms to protect privacy. Second, I generated initial codes based on my research questions and familiarity with the data using a software program called Dedoose. Some examples of these codes were

“family”, “friends”, “gender”, “being known”, “choice” and “assumptions”. Alongside the transcripts, I reviewed and analyzed the photos and recorded my observations, impressions, thoughts, and questions in my field notes. Third, I began to search for themes, guided by the research questions. At this point I shared my preliminary analysis with the youth co-researcher, the youth participants, and my supervisory committee to get their feedback, which significantly shaped further analysis and development of themes. The fourth, fifth, and sixth steps of reviewing themes, defining and naming themes, and producing the report were concurrent and iterative. My analysis continued throughout the writing phase as I continued to reflect on converging, contrasting, contradicting, and deepening data points.

Collaborative Analysis with Youth

Consistent with my YPAR methodology, thematic analysis also involved a collaborative process with the youth participants and the youth co-researcher (Cornish et al., 2014; Ozer & Piatt, 2017). Jade participated in debriefing meetings for all three sessions, and her feedback significantly shaped data analysis. The themes generated by my preliminary analysis were then shared and further refined in the third session with participants, in which I utilized visuals and an interactive activity to elicit feedback and involve the youth in analysis. I presented each of the subthemes I had developed with a brief description and image, then posted the titles and images on the wall. I asked the youth to revisit their pictures and tape them up next to the subtheme that seemed most relevant. This activity provided valuable insights: some of the subthemes did not have very many pictures associated with them, which suggested that these subthemes were less accessible or relevant for the youth. This observation influenced my decision to use participant quotes to name the themes throughout my findings, which supported the research goal of foregrounding youth voice while also including more accessible language. The youth also placed

quite a few photos in the space between two subthemes, highlighting the close relationship between those ideas. Due to the limited time frame, it was not possible to elicit extensive engagement on every theme, but the session provided a valuable opportunity to uphold informed consent throughout the research process.

As I worked to develop themes, I struggled with the tension between representing the youths' stories in the way they had been shared with me and presenting a more critical interpretation. Teachman et al. (2020) argue that it is "equally important to go beyond 'giving voice' to interpret how youths' presentations of their lives and their understandings of inclusion were shaped by their social positions, and by the values, norms and beliefs that underpin calls for inclusion" (p. 8). As such, my initial analysis adhered closely to what the youth had said, while later iterations included more of my interpretations, questions, and interaction with extant literature.

The theme of ableism was central to the findings. At the same time, it was challenging to introduce and discuss ableism in accessible terms that did not feel alienating or stigmatizing. My motivation to overcome this discomfort came from the excellent work of Loiselle et al. (2012), who offer this argument:

> By withholding concepts and analytical tools… because they seem too complex or too theoretical, we deny the complexity of [young people's] experiences, prevent generative ways to understand their social conditions, and fall back on problematic assumptions about age, capacity, and timely development. (p. 195)

And,

> It is not “in the best interests” of children, youth and families to maintain a practice of convenient silence and inaction; assuming they do not want to have these conversations maintains our comfort with the status quo, not theirs. (p. 201)

I wanted to create space for the youth to understand and articulate their lived experience in new ways and hoped that doing so would help us work together to make change, and this commitment superseded my fear of awkwardness or discomfort.

Rigor and Credibility

At each stage of the research process, I took measures to enhance the study’s rigor and credibility. According to Tracy (2010), rich rigor develops from strategies such as gathering enough data through sufficient time in the field, creating detailed and accurate transcriptions, and employing effective and thorough analysis procedures; while credibility refers to findings that are trustworthy enough to use as a basis for action and decision-making. Alhough I draw on some of Tracy’s (2010) concepts, I do not believe that universal criteria define or ensure rigor. Rigor cannot be “achieved” and truth cannot be “found” by simply executing the right methods or fulfilling the right criteria, however, the intentional and committed implementation of certain practices can contribute to more intellectually robust qualitative research (Smith & McGannon, 2018).

By drawing on Youth Participatory Action Research, the overall research design contributed to the study’s trustworthiness in that “YPAR can improve the rigor, relevance, and reach of science by affording insider expertise not only in the identification of questions that are important to study but also in enhancing the quality and validity of data and interpretation” (Ozer, 2016, p. 8). The youth researcher’s involvement offered this kind of insider expertise. YPAR also supports multivocality, which enhances credibility (Tracy, 2010). During participant

recruitment, I sought to engage a diverse group of youth to represent a range of experiences and opinions. The group ended up being balanced in terms of age and gender but was homogenous in cultural and socioeconomic background. Though the participant group was small, this sample size can be appropriate for qualitative research that seeks to be intensive rather than extensive, and to indicate key insights rather than conclusive findings (Crouch, 2006). Prioritizing depth over breadth helps to add nuance and complexity to exploratory studies (Boddy, 2016).

As the participants shared their stories and perspectives, I endeavored to attend to divergent viewpoints and convey them in the findings. As previously described, I had pre-existing relationships with the participants and I believe this foundation of trust and comfort strengthened the study. In an intergenerational, cross-cultural storytelling research workshop, "many participants expressly stated that their decision to participate was connected to knowing and trusting the researcher who invited them" (Chazan & Baldwin, 2021, p. 107), supporting the idea that relationships can be instrumental when doing research with populations who historically do not engage in research.

I sought to enhance rigor during data generation by gathering multiple kinds of data (session transcripts, youths' photos, field notes) over the course of extended engagement with the participants (Tracy, 2010). The guidance of the youth co-researcher Jade broadened and deepened the data generated as well as the quality of analysis, as she noticed gaps and advised on how to address them. Furthermore, Jade's lived experiences and relationship to inclusion differed from the other participants, and this diversity of perspectives added strength to the findings.

Keeping field notes from research inception supported reflexivity and credibility by documenting reflections, observations, and decision-making (Tracy, 2010). For example, this

field note from January 17, 2023, captures some of my wondering and planning during the recruitment phase:

> Field note: *Finally beginning to recruit participants! It is very hard, already getting questions about "will my child be able to participate?" and there is no easy answer to that… it all depends who agrees to participate and then hopefully I can adjust the session outlines to fit them well. I am very glad I planned for multiple sessions because the first session will allow me to get to know participants and then adjust accordingly for second session if needed. Also good questions coming up around the limitations of a study/gathering knowledge when some people experience inclusion and exclusion but may not have the ability to express their thoughts and opinions about those experiences. How to make sure my research is representative? How to achieve equity for those who express themselves [in ways other than verbal speech]?*

Finally, I engaged in collaborative analysis to enhance trustworthiness by getting participant feedback on the preliminary themes, which further refined my analysis and framing of findings. Tracy (2010) described this practice as "member reflections", which are designed not to test if the findings are true but rather if they are comprehensible and meaningful, and to provide an opportunity for further collaboration and elaboration. As Smith and McGannon (2018) explained, input from participants at this stage "help[s] create a meticulous, robust, and intellectually enriched understanding through generating additional insights and dialogue" (p. 117). In this vein, my third session with the participants helped me to determine which themes resonated most and which themes required further clarification.

Knowledge Mobilization

In line with the participatory nature of this study and my goal to involve youth at all phases of the process, I will offer to share the findings with the youth participants in an accessible format, such as a one-page plain language brief or short video. At this point I will ask the youth if there is anyone else they would like me to share the findings with such as their parents or teachers. To disseminate the findings to a broader audience, I plan to submit a peer-reviewed research paper summarizing this study to the *Canadian Journal of Disability Studies*, an open-access online publication. I would also like to partner with the youth researcher to design a presentation for Inclusion BC's annual "Everybody Belongs" conference. To accompany the presentation, I would create a one-page brief with key messages from the study that I could distribute to conference attendees. This brief could also be circulated in the Inclusion BC monthly newsletter and sent to the Ministry of Education and Child Care inclusion branch.

Conclusion

This methodology chapter described a participatory research design in which I partnered with a youth co-researcher and utilized focus groups, photo elicitation, and collaborative analytical methods to explore the research questions. I also described how my pre-existing relationships with the youth and the community strengthened the rigor, credibility, and ethical foundation of the study. The next chapter outlines the findings.

Chapter 4: Findings

My thematic analysis of the data, guided by the research questions, identified two interrelated themes divided into nine subthemes. I included quotations from the youth co-researcher that exemplified each subtheme in the titles to foreground youth voice and incorporate more accessible language. I also integrated literature to help interpret the findings.

Exploring Belonging: "Everything About Me Should Be Accepted, Loved, and Respected"

The findings in this first theme serve to elucidate how the youth in this study understand and experience a sense of belonging. Analysis identified four contributing elements: (1) safety and comfort, (2) unconditional acceptance, (3) companionship and community, and (4) making a contribution. Figure 2 below depicts a collaborative analysis activity from the third session in which youth revisited their pictures and matched them with the subthemes from my preliminary analysis. Many of the photographs youth shared included multiple family members and friends, and it was not possible to gain everyone's consent to publish them. As a result, the contents of the pictures are hidden. However, the distribution of photos demonstrates how certain subthemes were perhaps more relevant and meaningful to the youth as well as how certain subthemes were closely related. This information shaped the final framing of the findings.

Figure 2: *Collaborative Analysis Activity*

Safety and Comfort: "Cause If You Don't Feel Safe You Don't Feel Like You Belong"

The first group session incorporated a brainstorming activity inviting the youth to share whatever came to mind when they heard the word "belonging". Part way through the brainstorming, I asked the youth what it felt like to belong. "Comfortable" and "safe" were two of the feelings the youth named, and the youth researcher Jade summarized "cause if you don't feel safe you don't feel like you belong". Further discussion identified that this sense included both physical and emotional experiences. Youth reported feeling a sense of emotional safety, ease, and authenticity when spending time with friends and family who knew them well. Finn shared that he particularly enjoyed spending time with his cousins with whom he got along easily. When asked why he had chosen to share a photo of his extended family gathered at Christmas time, Finn stated,

Finn: Well because it's… it reminds me like… I belong with everybody in this picture.

Emily: Hmm… that's a time that you feel like you belong, some people you belong with?

Finn: Mhmm. And I'm safe with everybody.

For Jade, a youth with a mobility impairment, it was important to surround herself with people who would listen to her limitations and not pressure her to do things that made her feel physically unsafe or uncomfortable. She asserted, "people need to understand that we're not joking around when we say that we can't. If we can't do that, we can't do that."

Some of the youths' photographs and stories suggested that it was easier for them to feel safe and comfortable with people who were similar to them. Analysis identified three relevant areas of similarity: ability, gender, and language/culture. The youth did not explicitly name (dis)ability as an area of commonality, but many of the friends described in their stories of belonging were classmates with disabilities from their specialized "inclusive" education classes. For example, two of the participants Finn and Larry met in elementary school then continued to have classes and spend lunch hours together. Their families got to know each other and, at the time of this study, they frequently spent time together outside of school, for instance to celebrate their birthdays. Olivia described a similar relationship with her friend Jay, whom she met in the first year of high school and shared classes with until graduation.

As the conversation moved to explore other facets of identity, the youth described mixed experiences and opinions about whether gender dynamics impacted their sense of belonging. Olivia expressed a wish for more girls in her college class so that she could "make more friends that are girls" and found it "overwhelming" to not have as many girls in the group with her. At the same time, she was good friends with multiple male classmates from high school. Finn described enjoying his time with male and female classmates in different settings: "I like hanging

out with Larry sometimes… Charissa can join when we're eating lunch and me and Larry can hang out when we're doing our project in form design." As the youth discussed which gender dynamics were more comfortable and why, Jade suggested the boys enjoyed hanging out together "cause you can talk a lot more about boy stuff!". This statement elicited laughter amongst the group and Finn quickly responded, "Girls talk about girl stuff!", suggesting that there is a deeper level of comfort and ease when interacting with peers of the same gender.

The conversation about gender reiterated a perception that a sense of physical safety is important for belonging and shed light on the intersecting elements of gender and disability. Jade shared,

> *I actually prefer hanging out with males… it's more a protection thing… Even though I'm friends with them and I like hanging out with them, it's more like if anything goes wrong, they are there to, you know, step in, you know, in front of me to say, "uh uh, no way!"*

Regarding language and culture, Jade reflected on moving to Canada as a child and how she experienced being different from others as a barrier to belonging:

> *That's another thing about inclusion… when you come from a completely different language, completely different alphabet, a completely different people entirely… in my case it was really hard to become, to feel like I belonged, for a really long time, because the language barrier… that was put in front of me was very thick and very big.*

Coincidentally, all four participants had moved to Victoria from another city, province, or country, and reflected together on what it was like to leave a place where they felt they had belonged and to develop a sense of belonging in a new place. They all agreed that it took them time to settle in, get to know people, and build up a sense of familiarity, safety, and comfort.

Olivia: That's me when I first moved here… I wasn't belonged here, but I got used to here, then I belonged.

Finn: Yeah like for me like when I just moved from that place to here, I [did] not belong here but I was just like, you know like, just settled in and just enjoy myself here.

Part of the process of acculturation included getting used to the physical location:

Emily: What were some of the things that happened to make you eventually feel like you belonged?

Olivia: Getting used to the city for me, because I moved from a really snowy place to not so much snow.

The youth also reported that developing new relationships was a significant component:

Olivia: When I was in [name of province], I feel like I was with a lot of friends and family but here I don't have much family, but more friends… But all my family are in [province] and I have no family here so it's hard.

A sense of place was quite central to some youths' understanding of belonging. When the topic of belonging was initially introduced, Olivia's first response was "for me, belonging is you belong somewhere." Part of her sense of belonging in Victoria was tied to having "a nice house to live in." Other youth expressed that they felt they belonged in places such as their homes or at a familiar summer camp. In contrast, leaving a place or community they found safe and comfortable brought up some uneasiness, such as when Olivia shared "I was nervous because I was finishing high school."

The importance of feeling safe and comfortable in order to experience belonging was echoed by youth in other studies (Robinson et al., 2020; Teachman, 2023). The youth in this study did not explicitly discuss any difference in their experiences in mainstream settings

compared to disability contexts, but extant literature has identified how some disabled young people have reported feeling unsafe and uncomfortable in mainstream spaces, impacting their sense of belonging (Goodall, 2018; Haegele & Maher, 2021; Robinson et al., 2020; Salmon, 2013; Teachman et al., 2020).

Unconditional Acceptance: "They're Not Going to Judge You"

Building off a sense of safety and comfort, the youth described how their closest relationships were characterized by unconditional acceptance. The stories and photos youth shared highlighted their feelings of being seen, known, and loved for who they are. After the first two sessions, while Jade and I reflected on what the group had discussed, she offered the following definition of belonging: "physically, mentally, emotionally, everything about me should be/could be accepted and loved and respected," which eloquently expressed the desire to be her authentic self and be accepted and included just the way she is. The youth agreed that because of each person's individuality, people find belonging in different places and situations, ranging from "a circus" (for a fun energetic personality) to their bed at home!

When I asked the youth about people who "loved them no matter what," Larry and Olivia named their families. Youth descriptions of their relationships with family members conveyed a certain depth and simplicity in which the youth could just *be*. For example, Larry's favourite picture showed him collecting shells on the beach with his grandma, and while he had difficulty verbally articulating what the photo meant to him, the image exuded a sense of peace and happiness. In the third session during the analysis activity, Larry chose to place this photo in the space between "safety and comfort" and "unconditional acceptance". Pets were also present in many photos and identified as important family members who were unconditionally accepting.

In fact, it was while the youth were discussing their beloved pets that Jade articulated the special kind of emotional support pets can provide, by knowing "they're not going to judge you".

In contrast, Jade felt that she did not belong in her family and described finding unconditional acceptance with friends instead. She sensed her family members did not fully accept all aspects of her identity, did not support her desires for independence, and had different perceptions of her level of competence. When it came to career planning and dreaming about the future, Jade described feeling frustrated when her parents did not believe she could accomplish her goals and made undesirable decisions on her behalf. While belonging within her family was lacking, Jade described a photo that demonstrated inclusion, togetherness and acceptance with her college classmates by saying,

> *We're together, we're a community, we're a family, quote on quote. So this is what inclusion for me would look like. They included me in the photo, they made sure that I was seen. You can't really see my walker that much, but you can see the handles right here.*

Jade mentioning that her walker was included in the picture points to the significance of her disability being acknowledged and welcomed rather than suppressed or stigmatized. In the same vein, establishing unconditional acceptance as a contributor to a sense of belonging conflicts with the unspoken expectations of assimilation that often underpin dominant discourses of inclusion (Graham & Slee, 2008; Koller & Stoddart, 2021; Teachman et al., 2020). Resisting these assimilative pressures, the youth co-researcher wisely remarked, "it's not all about the individual fitting in. If society wants these people to be included, they have to step it up!" At the same time, she expressed insecurity about the perceived value of disabled people, wondering,

"how much does society actually want people like ourselves with different abilities… to be part of society? How much are they willing to change for the people who cannot change?"

Companionship and Community: "Friends Are Sometimes Like Your Lifeline"

Social relationships with friends and family were central to the youths' experiences of inclusion and belonging and ranged from close-knit bonds to broader forms of community affiliation. In fact, Olivia initially defined inclusion as "new friends," then later expanded her definition to include gathering with other people, whether she knew them well or not. It seemed that she associated a sense of inclusion with being with other people and not alone. In addition to being surrounded by community, companionship reflects the importance of having people to go through life with. Analysis of the youth's stories and pictures suggested that belonging develops through shared experiences, from major milestones to day-to-day life. Youth shared many memories recalling time spent with family and friends including going on trips, celebrating birthdays and holidays, having sleepovers, meeting new baby cousins, attending weddings, graduating high school, going to summer camp, participating in community events, attending class or after school programming, and just hanging out.

Some youth seemed to value a sense of affiliation or membership with a larger group, as evidenced by Olivia and her high school graduation class. It was very meaningful for Olivia to participate in the graduation group photo and dinner/dance event, and she was quite upset to miss participating in the ceremony due to being sick. She repeatedly referred to this group as "all my grads." While some of them were her close friends or peers that she had been in class with, there were many students that she would have barely known but still felt a sense of affinity with. Furthermore, the youth participants often alluded to a sense of companionship in relationships with friends, even though they could not always articulate the meaning behind their photos. For

instance, when asked why they had chosen to share a certain photo, Larry stated simply "cause I'm hanging out with my friends" and Finn proclaimed, "because it's fun to show you and me!" Nonetheless, the joy and significance of these relationships shone through, especially when the photo included the person they called their best friend. Participants were visibly excited when sharing memories about friends and identified the same feelings of happiness, excitement, and having fun when brainstorming our group definitions of belonging and inclusion.

Close friends were described as a "support system" or "lifeline," highlighting the special importance of companionship in times of hardship. Jade shared how much she appreciated the close friends who would notice, check in, and care for her when she was struggling:

> *They're the people who will literally like call you or text you and say "hey, what's up? You ok? Wanna talk, or me to call you? Wanna hang out? Wanna, you know, do something?" … Your friends know you, know who you are and what's normal for you and what's not.*

Though the youth all named at least one close friend and expressed greatly valuing their peer friendships, deeper analysis suggested that their social experiences may have been shaped by ableism and disability stigma in ways that the youth may or may not have been aware of, able to articulate, or willing to acknowledge. The stories and photos the youth shared indicated that participants formed the strongest sense of belonging and reciprocal relationships with family members, peers with disabilities, or support staff and volunteers. To illustrate, of the 29 photos shared, 15 featured family members and 7 featured friends, peers or classmates with disabilities[8]. Olivia spoke enthusiastically about her friendship with Sarah, a staff person she met and enjoyed spending time with at summer camp, while Finn shared multiple photos depicting fun times with

[8] The remaining 7 photos were of the youth alone or had no one at all in the picture (a picture of a place or object).

his cousins, who he described as funny and easy to get along with. In contrast, none of the youth showcased a relationship with a nondisabled peer in their pictures. Some named nondisabled peers as friends but did not have stories or pictures of hanging out with them outside of school. The predominance of family and staff relationships is one way in which belonging for teens with disabilities differs from their nondisabled peers, who may more frequently find belonging in large social networks that are independent from their families. This trend may conflict with youth desires for peer friendships. For instance, Olivia showed a picture of her new friends at summer camp and talked about preferring to spend time with them rather than her mom.

It is worth noting that the youth did have opportunities to engage with nondisabled peers at school. In fact, due to the modified course load that many students with disabilities are given, the mainstream classes they participated in were often elective courses such as art or woodworking that may have offered more chances for social interaction than academic classes. In a one-on-one conversation reflecting on the second group session, I asked the co-researcher Jade about peer relationships, and she shared that some peers would refuse to associate with her or seemed to not know how to interact with her. She said that sometimes it could become very awkward, "to the point where it's like, are you ok? I'm not going to bite!" This reflection suggests that the lack of genuine reciprocal relationships with nondisabled peers may be due to their peers' awkwardness and discomfort around disability.

In contrast, Olivia shared a photo from a Halloween dance hosted by an adaptive arts organization where she was having fun with some of her friends from school who also have intellectual disabilities. They were in a space that was designed just for them, surrounded by people (again, disabled peers, family members, staff, and volunteers) who were willing and even eager to engage with and befriend people with disabilities—an attitude that appeared to support

Olivia's sense of belonging. These conditions seemed to open up opportunities for reciprocal relationships in which both parties genuinely appreciated the other's company and contributions, rather than a one-way relationship in which the disabled person is only seen as a passive recipient of care, support, or pity. These findings underscore the value of disability spaces and align with previously cited research, in which community members' attitudes towards disability seemed to be key in promoting or inhibiting a disabled individual's sense of belonging (Renwick et al., 2019; Robinson et al., 2020; Strnadová et al., 2018; Teachman et al., 2020).

Making a Contribution: "Even the Smallest Things Can Feel Big"

The data in this final subtheme illustrates how youths' experiences of having a valued role to play supported their sense of belonging. The youth offered multiple examples of how they contributed to the relationships and communities around them. Olivia shared a favourite memory of serving as the maid of honour in her cousin's wedding. She described the day as "very special" and recalled that she "was really nervous but [she] did really well!", indicating that it was important for her to do a good job in this trusted role. Finn reflected on his experiences at a summer camp he had visited multiple times over many years. In addition to being a place where he had fun and felt safe and comfortable, he shared excitedly about his new role serving in the kitchen and dining hall:

> *This summer I'm going to camp [name redacted] and actually working there… I'm gonna go to the kitchen, clean up the kitchen, make up the seats for the people to come in and start cooking, and you know, like set the tables and make them clean.*

Jade recounted an opportunity to take leadership for a pizza sale at school and reflected on what this experience meant to her:

> *I was chosen to help out with pizza day at the college… Because I was the only one who knew how to operate [the cash machine], I said yes… [and] I did it! I proved to people that I can be a leader or that I can be the person they, you know, thought I could be… even the smallest things can feel big.*

These stories represent the youth feeling proud of their roles and contributions, which was another emotion that the group identified and associated with belonging in the brainstorming activity.

The youths' desire to make a contribution can also be seen in their decision to participate in this study, as they expressed wanting their voices to be heard. In the first session, the youth agreed that listening to one another and letting everyone have their say was a key group guideline. During an early planning meeting, Jade expressed concern that readers "might not take [the findings] seriously because we're young adults" or might think "you don't know anything about this because you haven't lived enough." However, she also asserted passionately that "we lived through it, we know what we're talking about, even if we're young." She wanted her lived experiences to be heard and valued but anticipated a dismissive response based on her age.

Held together, the findings in this subtheme highlight youths' desire to be valued and seen as competent, with their skills and contributions being recognized, validated, and trusted. More than just being physically included, belonging seemed to comprise a sense that one's presence and contribution mattered and would be missed.

Overall, the findings in the first theme provide insights into how belonging was primarily experienced in friendships, family relationships, and disability communities that were characterized by safety and comfort, unconditional acceptance, companionship, and opportunities to make meaningful contributions. These themes coincide with the findings of

similar qualitative studies in Canada and Australia, conducted with small groups of youth with disabilities on the topic of belonging (Renwick et al., 2019; Salmon, 2013; Strnadová et al., 2018; Teachman et al., 2020). This conceptualization of belonging is not unique to youth with disabilities; indeed, people of all ages and abilities would likely find that feeling safe, comfortable, accepted, and valued contributed to a felt sense of belonging (Allen et al., 2021; Baumeister & Leary, 1995). Furthermore, the youths' perspectives were not solely defined by their disability: other aspects of their identity such as gender and culture also shaped their experiences and perspectives (Gerlach et al., 2024; Goodley et al., 2019; Puroila et al., 2021). These findings are reflective of this group of participants, who were relatively privileged and well-connected socially. Nonetheless, elements such as ableism and limited abilities add nuance to these findings, and the concept of ableism is explored in the following theme.

Unpacking Ableism: Experiences of "A Society Not Suited for You"

As described in the findings so far, the youths' photographs primarily showed positive instances of inclusion and belonging in which the youth were having fun with their friends and family. The youth did not show photographs that represented experiences of exclusion or unbelonging, and only a few were taken in a school setting. This observation is not surprising considering their photographs were selected from their families' existing albums. The youth co-researcher was the only one who took new photographs that represented inaccessibility, exclusion, and her positive and negative experiences at school. Nonetheless, as a whole, the youth did not present themselves as being marginalized or excluded. Some participants regarded the word disability as a label that people used for them but that they were deeply uncomfortable with, while other participants seemed to not be as acutely aware of their disability. This range of

perspectives made it difficult to focus on disability-related exclusion and ableism in our conversations.

After the first two group sessions, youth co-researcher Jade reflected that the group's discussion seemed incomplete in that it only explored the positive side of inclusion and belonging. To bring a more nuanced perspective, she volunteered to share more about her lived experiences of facing physical barriers and social stigma, needing to advocate for herself and others, and navigating identity, relationships, and family expectations. We arranged an additional one-on-one interview for her to share her lived experience of facing exclusion and encountering barriers to belonging. My analysis of this data, and a review of the group session transcripts, identified a recurring theme of ableism which I organized into the following five subthemes.

Physical Accessibility: "You're Too Much of a Hassle"

The youth co-researcher, who uses a walker, shared many examples of physically inaccessible environments and how they impacted her. Jade found that universities and colleges often lacked elevators or ramps where she needed them, noting that even her college's Centre for Accessible Learning was a bit of a challenge to access physically, because she had to go all the way around a building and up a hill. She shared that it is hard to feel like you belong in a place you cannot enter. Indoors, Jade described how counters, cupboards, and other objects were often placed out of her reach. When spaces were not automatically accessible, she had to wait for someone to help her or struggle with all her might to do it on her own, putting her in situations that were uncomfortable at best and unsafe at worst. She also described how the attitude of people around her could sometimes place the exclusionary consequences of physical accessibility on her shoulders, further increasing her sense of being unwelcome: "They go, you're too much of a hassle, we can't."

Jade often thought about ways to address the physical inaccessibility around her. She wished for simple fixes in the environment, at one point giving the following example about her high school Foods classroom:

> *I'm not saying to gut the kitchen and restart again. It would be nice if that was the case, but you don't have to. All you have to do is make sure the microwave is on the counter and not up on the oven, and make sure most of the stuff is lower on the shelves. It's simple. It doesn't need to be complicated.*

She also expressed the value of having high-quality, personalized technology to increase her access to certain places and communities and help her to "be at [her] best" despite living in "a society not suited for [her]". When she switched to a new walker that supports her from behind rather than in front, it gave her the freedom to do more of her desired activities, like play soccer. She spoke about how this directly impacted her sense of inclusion:

> *Sometimes for inclusion you need a vehicle or a tool to feel included. So without this, without my walker, I feel like half of the time or most of the time I don't feel very included. Cause, then it's, you know, I'm not able to move… Some people help me out or try to help me out but then that kind of defeats the purpose of being independent.*

Jade valued and connected independence and self-reliance to a feeling of inclusion, perhaps because her family and others around her were not always supportive of the ways and places in which she wanted to be included, so she felt like she had to be able to do it herself.

A lack of physical accessibility can impact the types of social interactions that can occur and reinforce messages about who belongs in that space (Salmon, 2013). Drawing on Jade's reflections on her college campus, these implications could be quite limiting in terms of her access to higher education and the social and career networking associated with this stage of life.

Furthermore, ignorance and ableism may be perpetuated through practices of physical separation that limit opportunities for the formation of relationships between people of differing abilities.

The Stigma of Disability: "I Understand What It's Like… to Not Be Seen the Way You Want to Be Seen"

Jade further described various dimensions of exclusion that highlighted ableist attitudes and prevented her from feeling welcomed and cared for. Reflecting on times she had been invited into a space but subsequently ignored, she differentiated this experience with the term "mental inclusion:"

> *Like yes, you're included in a situation, but they ignore you… if people don't ignore you and include you in the conversations or in the games or things like that, they're mentally including you. They are thinking about you and how you can be involved.*

Her participation had often been limited by assumptions about her level of competence. When she was younger, she attended a birthday party where there was an opportunity to try horseback riding and felt hurt and excluded when,

> *Without knowing, without asking me whether I can or cannot, [the friend] assumed that I cannot. So in that way it was non-inclusive, and felt very demeaning. It's like "you can't do this; you can't do that." Ask first, before you assume things.*

It was within this context of not having her competence recognized that she expressed "I understand what it's like… to not be seen the way you want to be seen". Now, as a job-seeking college student, Jade also feared that employers would make assumptions about her abilities. In contrast, she was very appreciative "to be looked at as an adult" in certain situations. Reflecting on a visit from the college president who spoke to her class about their educational experiences and how they could be improved, her initial feeling of nervousness gave way to a sense of

validation because "he was talking to us like adults and not children, which was nice. Sometimes people talk to us like children, and it's not nice. We're not five."

Jade described feeling disrespected due to her disability: "[People] have this idea of 'you're different, you're weird, therefore I can't respect you'." She shared her experiences of being explicitly mistreated and excluded due to her disability. While growing up in an orphanage (not in Canada), she remembered feeling like "a piece of garbage", left behind alone and closed in a room while everyone else went out. On the other hand, being surrounded by people who were socially inclusive, who listened to her, and who looked out for her needs promoted a sense of belonging. She referenced a meaningful moment while volunteering at a summer camp when her team rallied around her so that she could join them to hike a mountain. The group had an empowering attitude and worked proactively to address barriers and find individualized solutions, which made her feel cared for. All in all, Jade's stories and reflections demonstrate the impact of varying attitudes towards disability on experiences of belonging.

Assimilation Disguised as Inclusion: "I Don't Want to Fit in a Box"

Jade shared many thoughts around how the concept of fitting in relates to genuine belonging. She was clear in her desire to be seen as an individual and appreciated for who she is, as demonstrated by this statement:

> *I don't always need to fit in… I want to be my own individual person with my own opinions, with my own looks on the world, with my own understanding of it. If I change who I am in the core, my core self, I'm no longer myself. I'm just a puppet.*

She also wanted to have the space to express her unique needs and did not want to "fit in so much that there's no understanding [that] we need things; we need help, we need you to understand that we're not the same as other people." In one particularly powerful exchange, Jade

articulated that the perceived consequences of not doing the work to fit in or suppress her needs would be judgement and exclusion:

> *Jade: Like most of the time I'm like, "I'm fine!" when in reality, most likely, I need a hand. But I'm not doing it for my sake, saying I'm fine. I'm doing it because society makes me believe that you have to pretend to be fine to be seen as quote on quote, normal.*
>
> *Emily: Right, yeah. Everyone's gotta be independent and capable and productive…*
>
> *Jade: If you're not, you're out of here. You're trash.*

Changing oneself to be a part of the group can sometimes be an unarticulated requirement for inclusion (Teachman et al., 2020), but does not correspond to this study's findings on belonging. During our group sessions, the youth described experiencing belonging when they felt safe and comfortable to be their authentic selves. In the third session, I asked if any of the youth besides Jade had experienced the pressure to fit in. The boys did not relate to this feeling. Olivia disclosed that it could be hard to make new friends at college and empathized with a Deaf classmate who was often left out by teachers or peers who did not know about or were not willing to accommodate her impairment. Although this classmate could speak out loud, it was easier for her when the people around her used sign language to communicate. Olivia acknowledged that it was sometimes difficult to include this classmate but wanted to do what she could, representing an awareness of the unfair expectations of assimilation and a willingness to help mitigate the load. In response to this story, Jade reflected on her own experiences and feelings and explained "if they don't shift to what you need you feel like you are a burden rather than a part of the community." This quote exemplifies how a sense of belonging can be jeopardized when the onus is placed on the individual to do the work of fitting in.

Jade also acknowledged and resisted society's limiting perceptions of what it means to have a disability by declaring, "I don't want to fit in a box that society puts in front of me." She observed that people with invisible disabilities are sometimes put in positions to act a certain way to "prove" the legitimacy of their disability, whereas obvious physical disabilities are more easily seen as valid. Again, she questioned this dichotomy and argued that there is no one way to "look disabled," advocating for the freedom to be herself.

Fighting for Equality: "I Call Myself an Advocate for People With Disabilities"

Jade often referenced her desire and sense of responsibility to use her voice and personal experiences to make change. She could list many examples of things she had already advocated for, such as installing automatic doors at her high school and filming videos with an assistant to highlight accessibility issues on her college campus. Due to this, she was proud to "call [herself] an advocate for people with disabilities". Despite these successes, she was also aware of the obstacles that come with social change work and was particularly sensitive to how others perceived her advocacy efforts. To manage the perceptions of the people around her, she described modifying her advocacy strategy. For instance, Jade made comments like "oh man, wouldn't it be nice to have an automatic door?" rather than asking directly, since she worried that being too direct would not be well-received. This phrasing represents Jade's skillful navigation of power imbalances, inviting the recipient to consider how the accommodation might benefit them too. Though her strategy was effective in addressing the issue at hand, it failed to identify or disrupt the "benevolent" nondisabled majority with the power to grant or deny such requests. Jade also recognized structural issues such as a lack of funding that could prohibit accessibility improvements and brainstormed more manageable fixes that could still make a difference.

Despite her passion, Jade expressed struggling with the burden of advocacy. While she generally encouraged people to approach her to ask questions when appropriate, there were times when she found questions off-putting, invasive, or wished she did not have to explain herself. For instance, while writing her resume in her college employment program, she wished she did not have to disclose her diagnosis to potential employers and ask for accommodations, and that businesses would take on the work to be more universally accessible. She wanted to minimize how much she stood out and to feel like she could simply go to work and feel comfortable without people asking a lot of questions. Jade voiced her desire for more people to share the load of advocacy, asking "why don't other people take some of that responsibility on themselves? Why can't able-bodied people take someone else's perspective… and try using a wheelchair to get around?"

Left Out of the Conversation: "Teachers Do Say 'You Are Included'... but They Don't Actually Know What That Is"

While reflecting on their understanding of the term "inclusion," the youth concluded that conversations about inclusion mostly took place in education settings. They identified teachers, educational assistants, school counsellors, and college professors as people who talked about inclusion. However, the youth had difficulty reiterating exactly what was said in those conversations, indicating that whatever was discussed or decided did not fully sink in or make an impact on them. In fact, when I first asked the youth to raise their hands if they had heard the word "inclusion" before, not one of them did, exemplifying their unfamiliarity with the term. Outside of school, the youth could not think of times that they explicitly talked about inclusion with their families or friends either. Jade explained, "families don't tend to talk about those kind of things… because we're a family we're supposed to be naturally inclusive."

Jade reflected, "Teachers do say 'you are included' or 'we're trying to make it inclusive' but they don't actually know what that is, I don't think," suggesting that she experienced a disconnect between what she was being told and how she actually felt. In describing her teachers' approach to inclusion, Jade shared "it's like, well, there's supports for you to get if you are not included." Her tone of voice suggested that this approach was not helpful.

As a researcher who knew the youth and their families outside of the study and had opportunities to observe them in their daily lives, I came to realize that my assumptions and ideas about inclusion as a nondisabled adult differed at times from the youths' perspectives. I often struggled with the tensions between what the youth said in these sessions and what I had perceived or assumed to be true about their lives, and this struggle was captured in my research field notes:

> Fieldnote: *When I hear [Olivia] talk about her graduation over and over, I can't help thinking of going with her to prom as her date. I saw the friends she is speaking about, and they would come up to say hi and take a picture or dance with us for a few minutes. But then they'd go back to their other friends and she'd come back to our table with all her classmates with disabilities (and one mom, also present as a prom date!). I am struck by the difference in her prom experience compared to her nondisabled peers. At the same time, I know she genuinely enjoyed herself. I just don't want to paint a picture that she has all these friends at school and is well-connected when my perception is that they actually don't value the friendship in the same way, i.e. she is not truly "included." But then who am I to prioritize my interpretation over her telling me that night was a valued experience of belonging for her?*

In this fieldnote, my perception of exclusion (not being included as an equal in her nondisabled peers' graduation festivities) exists alongside Olivia's experience of belonging at her graduation. My understanding of the situation was shaped by my perspective and life experience as a nondisabled adult, and likewise, Olivia spoke from her contextualized lived experience.

Similarly, Finn and Larry were self-described "best friends" who shared multiple pictures and stories of their time spent together, overall conveying satisfaction with their social relationships and sense of belonging. I had the opportunity to observe them regularly in a school setting at lunchtime, and they would typically eat together in the study centre with a few other friends and classmates while supervised by an educational assistant. Again, I struggled with my perception that they were segregated from their nondisabled peers who filled the hallways and various other, more central, gathering spaces in the school, even though this perceived segregation appeared to be Finn and Larry's choice. I also observed some resistance to being seen in their school's learning support classroom where peers with higher support needs would hang out, especially at lunch time. After some reflection and interrogation of my biases, I now interpret their lunchtime arrangements as a way of defining their identity and finding their place in the world in a way that makes sense to them. It is worth noting that dominant discourses about where and with whom it is desirable to be included may have influenced their choices. Overall, the findings in this subtheme explore the discrepancy that can exist between youth and adult ideas about inclusion, demonstrating the critical importance of listening carefully to young people and supporting their choices and agency.

In conclusion, the findings in the theme of "Unpacking Ableism" examine how disabled youths' sense of belonging can be impacted by experiences of physical inaccessibility, social stigma, and assimilative pressures, which have been identified in similar literature (DuBois et al.,

2020; Robinson et al., 2020; Salmon, 2013; Strnadová et al., 2018; Teachman et al., 2020). The last two subthemes indicate how nondisabled adults and peers could help to mitigate the impacts of ableism and promote belonging by sharing the burden of advocacy and listening to young people's opinions and desires.

Conclusion

My analysis of the youths' stories and pictures identified four elements that contributed to their sense of belonging: safety and comfort, unconditional acceptance, companionship and community, and making a contribution. In general, the youth in this study expressed satisfaction with their social relationships and sense of belonging, however a critical perspective inspired by the youth co-researcher's lived experiences suggests that the youth's experiences may still have been impacted by their disability, ableism, and disability stigma. In the following chapter I bring these findings into conversation with existing literature to discuss the implications for understanding and promoting disabled youths' sense of belonging.

Chapter 5: Discussion

This study sought to answer the overarching research question "What can we learn from youth with disabilities about experiencing and promoting belonging?" Drawing together the findings of this study and the reviewed literature, in this final chapter of my thesis I argue that promoting belonging for disabled youth requires a critical examination of how inclusion discourses and practices may be causing inadvertent harm. I also explore how a paradigm of belonging offers the potential to disrupt ableist power structures. Based on the lived experiences of young people with disabilities, I articulate a conceptualization of belonging as embedded in social relationships. Grounded in this understanding of belonging and critical orientation towards inclusion, I offer specific recommendations for parents, teachers, Child and Youth Care Practitioners, and researchers. Lastly, I reflect on the limitations of this study and some lessons learned along the way.

Illuminating the Harms of Inclusion

In this section I critically examine how inclusion discourses and practices can cause inadvertent harm to youth with disabilities through processes of assimilation and disempowerment.

Maintaining the Invisibilized Centre

The concept of inclusion implies a "bringing in" (Graham & Slee, 2008, p. 278), thereby maintaining inequitable power relations between "the included" and "the includers". Edwards et al. (2001) identify how notions of benevolence obscure this hierarchy: "For even as 'we' become more responsive and inclusive, 'we' remain the centre, extending the embrace to ensure that the centre holds and things do not fall apart" (p. 426). In the context of my study, the youth valued their experiences of being part of a group or community and did not present themselves as

excluded, in other words, as being in need of inclusion. This self-assessment may reflect the fact that the youth participants were relatively well-connected socially but may also indicate a reluctance to self-identify as marginalized. The inherently othering rhetoric of inclusion may pose a barrier to exploring the concept of inclusion in conversations, planning, and decision-making *with* disabled youth who may not see themselves as excluded.

Furthermore, by casting the focus on those on the outskirts who need to be brought in, inclusion discourses invisibilize the centre "from which all exclusions derive" (Graham & Slee, 2008, p. 278) and conceal the untenable nature of what is being positioned as the norm: "Although predicated as natural and true, the rule of the norm is statistically derived, negating the diversity to be found within nature and the naturalness of diversity" (Graham & Slee, 2008, p. 281). This observation raises questions as to how approaches to education, healthcare, and social change might be transformed by positioning disability as a natural and expected part of human diversity rather than grounds for discrimination or a problem to be fixed. Currently, dominant discourses that uphold the "inclusive" centre create pressures to assimilate to this fictional norm. Disabled youth may exert costly efforts to reach unattainable normative ideals in their quest to find belonging, rather than embracing themselves the way they are (Teachman et al., 2020). In contrast, the youth in this study valued the freedom to be themselves and find acceptance and belonging, without changing in any way.

The most insidious cost of changing oneself to fit in may result from the inadvertent messaging that disabled youth should *want* to be part of the mainstream or to become "normal" because the way they are is not good enough or worthy of inclusion. Youth researcher Jade recalled being told that her physical accessibility needs made her "too much of a hassle". Drawing on concepts informed by critical disability studies including the social model and the

right to be disabled (Dulwich Centre Foundation, 2015; Oliver, 1983, 2013), the "hassle" described by Jade stems from inaccessible environments and a lack of appropriate tools, technology, or motivation to meet her support needs. Nonetheless, Jade's words demonstrate how discourses that locate the problem of disability within the individual are perpetuated "in the real world" and how these messages are personally experienced and internalized by young people. The reluctance of some of the youth participants to discuss their disability may represent further evidence of internalized ableism. These prevailing messages of disability stigma and assimilation can be unintentionally perpetuated through inclusion discourses (Graham & Slee, 2008; Koller & Stoddart, 2021; Teachman et al., 2020).

Diminishing Youths' Voices and Choices

Findings in the subtheme of "Left Out of the Conversation" suggest that the youth participants had largely been excluded from meaningful conversations or decision-making about what inclusion looked like, or could look like, in their own lives. Even though inclusion is the current dominant discourse in the education of youth with disabilities, the focus group sessions in this study appeared to be one of the youths' first chances to talk about their views of inclusion and share their thoughts and experiences with peers. More broadly, researchers have repeatedly identified the lack of youth voice in literature about inclusion (Biklen, 2020; Goodall, 2018; Koller & Stoddart, 2021; Robinson et al., 2020). This lack of input from youth signifies that the power to determine what inclusion will look like remains in the hands of educators and policymakers, who are likely nondisabled adults, while disabled youth are positioned as passive and disempowered.

A failure to attend to youths' voices may also result in ineffective inclusion efforts that do not consider the complexities of youths' experiences. My self-reflective field notes about

Olivia's graduation events and Finn and Larry's lunchtime arrangements illustrate how adult assumptions about inclusion can differ significantly from youths' felt experiences of belonging, corresponding to how dominant discourses of inclusion can frequently depart from the needs and desires of people with disabilities (Renwick et al., 2019). Autistic youth in Ireland have advocated for the importance of choice in their educational journeys, noting that mainstream educational placements may work for some youth who have access to appropriate supports, but not for all (Goodall, 2018). Disabled youth accessing social services in Canada expressed preferences for either inclusive groups or disability-specific groups (Cairns, 2015). Though disability-specific groups may be disparaged for perpetuating segregation, Salmon (2013) eloquently described the difference between youths' experiences of imposed segregation and self-exclusion: "choosing to be with similar others was a self-affirming choice for these disabled teens, albeit within the context of oppression against disability, and offered them freedom from normative judgements about behaviour, conversation, and interaction" (p.353). In the same vein, although the concept of choice invokes notions of freedom, autonomy, and opportunity, it is important to acknowledge how choices are contextually situated. Social, historical, and political factors constrict the choices that are available or seem possible to young people, especially in marginalized communities (Galvaan, 2015).

Recognizing ableism as one of these constricting factors, there are various ways to interpret youth choices and what they say about them, which has been discussed by the authors of comparable studies with Canadian disabled youth (Renwick et al., 2019; Salmon, 2013; Teachman et al., 2020). In my study, only the youth researcher directly described feelings and experiences of exclusion and unbelonging (Gerlach et al., 2024; Puroila et al., 2021), leaving unanswered questions about the other youths' experiences. It is possible the other youth felt

excluded but were not comfortable sharing these feelings or had come to think of this way of being as necessary and unchangeable. Alternatively, they may be content with their social arrangements and even consciously choose segregated spaces that are safe and comfortable to avoid the stress and discomfort of navigating ableism in mainstream spaces. The complex influences of disability stigma and the diversity of youths' relationships to their disability, the disability community, and inclusion demonstrate the need to listen carefully to each youth's voice and choices rather than making assumptions or maintaining a prescriptive approach to inclusion (Renwick et al., 2019; Strnadová et al., 2018).

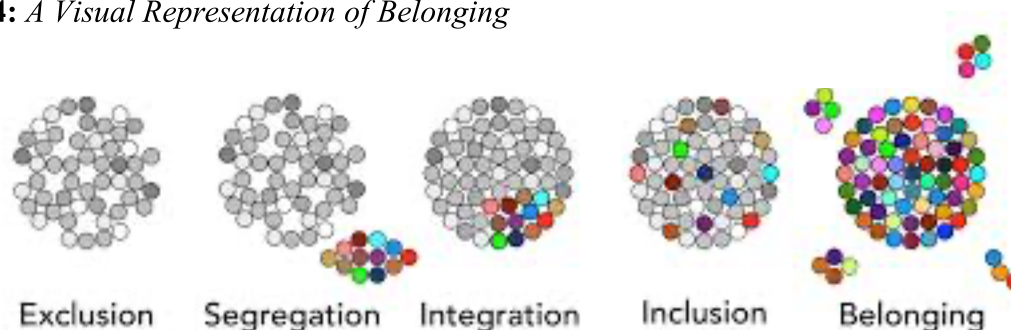
Exploring the Potential of Belonging

In recognition of the power dynamics inherent in dominant notions of inclusion, Graham and Slee (2008) suggest reformulating the goal from "how do we move 'towards inclusion'?" to "what do we do to disrupt the construction of centre from which exclusion derives?" (p. 279). I contend that embracing a paradigm of unconditional belonging can illuminate opportunities to disrupt these inequitable relations and shift power back into the hands of individuals with disabilities.

Embracing New Paradigms

The following visual representation of belonging developed by Carter (2022), that I previously introduced in my literature review, invokes how a paradigm of belonging can help to flatten ableist power hierarchies.

Figure 4: *A Visual Representation of Belonging*



This view of belonging shatters the dichotomy between the included/excluded and the includers. All individuals are represented by coloured dots, indicating that disability is a natural part of human diversity that does not impact one's intrinsic worth, dignity, or place in the community. Belonging becomes the unspoken starting point, rather than a conditional status that can be bestowed or revoked by those in power. This paradigm shift from "we will include you" to "we all belong" engenders a significant restructuring of power dynamics and ultimately represents a change of heart and radical shift in mindset. Embracing and enacting this paradigm shift constitutes an ongoing process of practicing humility and unlearning ableist biases. For example, the good intentions behind inclusion efforts may stem from a desire to rectify past wrongs or avoid inflicting the pain of exclusion and segregation. However, the assumption that everyone wants to—or should want to—be included in the same spaces in the same way exudes a lack of critical thinking at best and arrogance at worst.

Figure 1 also represents how all individuals are welcomed into the centre, while acknowledging that some individuals may choose to find belonging in other spaces. This recognition points to the value of the disability community. Renwick et al. (2019) have referred to the commitments and supports that characterize disability contexts, which in my professional experience includes the presence of people who are willing to listen and engage patiently and

non-judgementally. These characteristics seem to promote the experiences that disabled research participants have reported of finding belonging and feeling understood, accepted, respected, valued, and cared for within disability organizations and communities (Renwick et al., 2019; Strnadová et al., 2018). In my study, youth had positive experiences and formed valuable social relationships in disability contexts, whether they self-identified as disabled or not. Spending time in the disability community, or in similar spaces that welcome youth as they are and offer affirmative messaging about disability, may help youth to develop a more positive self-image that integrates their disability (Renwick et al., 2019). The opportunity to discuss their experiences and opinions about inclusion with peers in the focus group sessions also hints at the political significance of the disability community. Many key activists in the American disability rights movement point to their early experiences of meeting other young people with disabilities at a summer camp and realizing they were not alone in their struggles as the catalyst for later advocacy efforts, which ultimately culminated in the passing of the ground-breaking Americans with Disabilities Act in 1990 (Lebrecht & Newnham, 2020). Overall, the findings of this study and related literature support the importance of promoting the disability community and a positive disability identity.

Embodiment and Empowerment

I propose that belonging is best understood as an embodied experience—one that is multidimensional, highly subjective, and deeply felt (Pesonen et al., 2023; Strnadová et al., 2018). On a foundational level, the feelings of safety and comfort that underpinned a sense of belonging for the youth in this study are experienced in the body, in and through the nervous system. Furthermore, the youths' subjective perceptions of their social relationships were what determined their sense of belonging, more so than an outsider's evaluation of their

circumstances. Conceptualizing belonging as embodied and subjective suggests that only the individual can define what belonging looks like for them, which helps to shift power back into the hands of young people (Gerlach et al., 2024).

Supporting a youth's embodied sense of belonging requires careful attention to the diverse ways that each person experiences disability, strengthening the rationale for youth and their families to hold increased power in planning and decision-making. Within the education system, unexamined assumptions about where disabled students belong can lead to nonsensical outcomes such as one physically impaired student watching his educational assistant make sandwiches as part of a standardized life skills curriculum designed for students with disabilities, never mind the fact that this student would never be physically capable of making a sandwich on his own (Teachman et al., 2020). Centring the voices, desires, and expertise of youth and their families can lead to more personalized, contextualized approaches rather than "one size fits all" solutions. Cultivating experiences of belonging for youth with disabilities requires considerable and ongoing investments of time, effort, and intention to learn and respond to individual needs and preferences, which may not always be possible in an industrialized capitalist education system in which teachers are frequently overloaded and burnt out.

Understanding the Relational Dimensions of Belonging

The youths' pictures and stories illustrate how a wide range of relationships, from casual acquaintances to intimate bonds, were central to their sense of belonging. By examining the intricacies of disabled youths' social relationships, while attending to the elements of belonging identified in this study and the impacts of ableism, this section outlines how the findings in my study align with existing research to provide a cohesive and nuanced understanding of belonging for youth with disabilities.

Known and Valued in the Community

For the youth in this study, a sense of group affiliation and connection to place contributed to their sense of belonging. Their sense of safety and comfort was built up with familiar people and places over time, such as their school environment or hometown. Similarly, disabled youth and adult participants in studies on belonging have identified their homes and neighbourhoods as important sites of belonging or not belonging and feeling safe and comfortable. Participants valued being recognized and greeted in the community, for instance by neighbours and public transit drivers (Renwick et al., 2019; Robinson et al., 2020; Strnadová et al., 2018). These examples broaden notions of belonging by demonstrating that simply sharing community spaces and being acknowledged can support a sense of being known and belonging to a community.

Participants with disabilities in the Toronto-based Voices of Youth study reported that they enjoyed having active, defined roles in the community, for instance through working or volunteering. Some of the participants also described the importance of being a good friend and providing support to their friends (Renwick et al., 2019). In the same vein, adults with intellectual disabilities have expressed the significance of "being a contributing and valued member of the community" and having "respectful and reciprocal relationships" for their sense of belonging (Strnadová et al., 2018, p. 1095). These findings correspond to this study's findings on youths' desires to make a contribution. The examples shared by the youth, such as serving as a maid of honour or volunteering at a beloved summer camp, contrast with neoliberal framings of inclusion that emphasize paid employment and economic participation and offer alternative ways of conceptualizing contribution (Renwick et al., 2019).

Accepted and Supported by Family Members

Family was often an important site of belonging for the youth in this study, who shared many stories about time spent with cousins, grandparents, aunts and uncles, and this trend represents a prevalent theme in related literature. Another Canadian study found that "overwhelmingly, participants indicated they felt most included within the familiar and safe social space of family" and that getting together with extended family was a favourite activity (Teachman et al., 2020, p. 1114). The researchers of the Voices of Youth project also identified that family members constituted a significant portion of the youths' social networks when compared to their nondisabled peers. As an illustration, the study invited participants to identify a friend to participate in one of the interviews with them, and many of the participants who could not identify a friend asked to have a family member participate instead (DuBois et al., 2020).

Adolescence is often conceptualized as a period of growing independence and socialization with peers, outside of the family (Güroğlu, 2022; Salmon, 2013). For youth with disabilities, this trajectory may be impacted by the realities of impairments that require parental support and by disability stigma and ableism, whether it is real, perceived, or feared. As Salmon (2013) observed, "because of stigma, it seemed that disabled youth were not recognized as potential friends by nondisabled peers" (p. 351). In contrast with these attitudes, Teachman et al. (2020) have suggested that family members of young people with disabilities may come to view disability in more neutral or even positive terms over time, as their familiarity with impairment increases. Similarly, in a study of children's perceptions of their disabled siblings, one participant summarized their view of their sister by saying "she's different, but it's normal for us" (Stalker & Connors, 2004, p. 225). Disability was "accepted as an integral part of the child" that made them who they were, not viewed as a tragedy but simply a fact of life (Stalker &

Connors, 2004, p. 228). These perspectives align with the belief that disability can be a natural form of human diversity, which in turn supports the kind of unconditional acceptance that youth in my study associated with a sense of belonging and often experienced in their families.

Family members can also facilitate or inhibit belonging in the greater community. As DuBois et al. (2020) explained, "recent policy shifts towards deinstitutionalization and neoliberalism in Westernized nations have led to families taking on increased roles as both the main caregivers and decision-makers in the lives of youths and young adults with [intellectual and developmental disabilities]" (p. 2924). Therefore, youths' belonging in the community was heavily dependent on "interactions and activities that family members did together or through networks they had set up for the youths within the community" (p. 2928), and youth relied on their parents and family members for scheduling and transportation to support their community engagement. Parents' practical, emotional, and financial supports significantly facilitated community involvement, and youth who did not have this support from any family members "struggle[d] to attain access to college, work, volunteering, and social relationships" (Dubois et al., 2020, p. 2930). At the same time, this level of parental control over access to friends and activities can cause tension and pose a barrier to belonging when youths' opinions about living arrangements, friendships, and types of support needed differ from their parents'. Multiple researchers have noted that friendships seem to be more important to youth when their family relationships and sense of belonging are strained by conflict, judgement, abuse, trauma, loss, or grief (DuBois et al., 2020; Robinson et al., 2020), which aligns with Jade's reflections on finding belonging more with friends than with her family.

Invited and Cared for by Friends

The youth in my study described positive experiences with friends and seemed satisfied with their close relationships with disabled peers as well as their more casual relationships with nondisabled classmates. These findings depart from those of similar literature that speak to the challenges of friendship for youth with disabilities. Youth with disabilities in other research reported forming friendships with disabled peers who they met in group activities or shared classes (Salmon, 2013; Teachman et al., 2020). However, in an Australian study that asked disabled youth about experiences of "not-belonging", "many young people spoke openly about feeling lonely, and their desire to have more or deeper friendships" (Robinson et al., 2020, p. 63). Youth felt discouraged by friendships that did not feel reciprocal, for instance if they thought they were close to a peer but did not receive invitations to get together (Renwick et al., 2019; Robinson et al., 2020). This social imbalance may be due to peers' awkwardness, discomfort, or negative perceptions of disability (Salmon, 2013; Sasson et al., 2017). In light of these findings, supporting youth to foster the peer relationships they desire while addressing any disability-related stigma their nondisabled peers may hold would be a worthwhile target for intervention.

Literature also indicates that young people with disabilities often consider their support workers as friends. Some youth expressed appreciation for support workers who put effort and creativity into facilitating meaningful experiences that made them feel known, respected, valued, and confident (Robinson et al., 2020). Other found their friendships with support workers especially valuable when the staff were of a similar age and they could engage in shared interests without parental involvement (Teachman et al., 2020). In this study, Olivia's stories and pictures portrayed cherished friendships with support staff and program volunteers who supported her sense of belonging.

Recommendations

This section specifies how practitioners, parents, researchers, and allies can support disabled youth in experiencing belonging.

Child and Youth Care Practitioners and Educators

1. Involve youth in conversations about what inclusion looks like in their lives. Co-create plans for education and community participation *with* youth, not for youth.
2. Prioritize relational practices and relationship-building to learn with and from youth. Invest the time to get to know each youth and their unique needs and desires and work collaboratively with them to cultivate a sense of belonging.
3. Take steps to address power inequities in decision-making, for instance by identifying biases and assumptions stemming from one's position as a (nondisabled) adult and instead prioritizing youths' self-identified needs, desires, and opinions. Ask where, when, and with whom they experience belonging, and seek to promote these circumstances.
4. Offer choices and opportunities rather than prescriptive ideas of what inclusion should look like. Developing policies and frameworks can support systemic changes to promote inclusion and belonging but personalized and contextualized approaches are also needed.
5. When evaluating inclusion policies and practices, ask critical questions like "whose interests are being served?" and "into what do we seek to include?" (Graham & Slee, 2008, p. 290)
6. Acknowledge and address the potentially ableist attitudes of peers and community members when designing and implementing inclusion policies and practices.
7. Protect and promote disability spaces that can offer a key site of belonging for youth with disabilities. Seek to expose youth to positive messaging about disability and disabled role

models to support the development of a positive disability identity. At the same time, respect youths' evolving preferences regarding how they understand and relate to their disability, such as their preferred language choices.

8. Recognize and value each youths' strengths and contributions.
9. Support key life transitions, for instance from adolescence to young adulthood. Graduation from high school represents a major shift as many relationships, supports, and services change or end. Initiate proactive conversations and planning to nurture long term relationships and community.

Parents and Family Members

1. Encourage youths' belonging to the disability community by identifying positive role models, facilitating introductions and opportunities, connecting with self-advocates, and providing (social) media representation. These steps can help to combat internalized ableism and promote a positive sense of self that integrates their disability.
2. Recognize that parents and family members hold power to influence what youth see as possible, normal, and expected for their lives. Reflect on your own hopes, fears, assumptions, and biases. Ask youth what they desire in terms of their community involvement and what they envision for their future. Connect with other parents and families who are on the same journey to share ideas and support.

Researchers

1. Involve youth in the co-design of participatory and collaborative research projects to elicit youths' perspectives on issues that affect their lives.
2. Embrace a research orientation informed by critical disability studies that does not automatically position disability as a problem that needs to be fixed.

3. Seek to capture diverse perspectives by engaging individuals with a wide range of disabilities, as well as individuals with different social identities and locations such as Indigenous, newcomer, and/or LGBTQ+ youth with disabilities.
4. Continue to explore spaces, communities, and relationships where ableist power hierarchies have been disrupted and disability is positively valued.

Nondisabled Allies

1. Listen to people with disabilities and ask questions when appropriate, rather than making assumptions about their needs or desires.
2. Get comfortable with being uncomfortable! Though interacting with people who move, behave, or communicate differently than you may feel awkward at first, your familiarity and sense of ease will increase over time, providing opportunities for the development of reciprocal relationships, new mindsets, and belonging for all.

Lessons Learned

In conducting this study and writing my thesis, I learned so much about the research process, including how things do not always go to plan! I initially intended to use photovoice as a method of data generation since the participatory, critical, and change-focused nature of this method appealed to me as an idealistic graduate student eager to make a difference in the world. However, when writing my methodology chapter in consultation with my supervisory committee, I realized that the method of data generation that transpired is best defined as photo elicitation. I thought I had provided clear instructions to the youth in terms of how to take pictures, but in the end, Jade was the only one who followed photovoice procedures—that is, she took pictures throughout her week that related specifically to the research topic, in contrast with the other participants who brought in existing pictures from their photo albums of family and

friends with whom they felt they belonged. As a result, most of the photos could not be included in the dissemination of findings due to issues of privacy and consent. The photos the participants provided were still a useful tool to start and deepen our conversations. Nonetheless, if I were to conduct a photovoice project in the future I would do two things differently: ensure there was sufficient time allotted to train youth as photographers and co-researchers and supply cameras for each youth to use. I assumed that the youth would all have their own devices capable of taking photographs but now realize they may not have been allowed to bring or use those devices in certain contexts such as school or extracurricular activities. Furthermore, I suspect that being given a camera specifically for this project would have increased their motivation and helped them to remember to take pictures.

Throughout the research process I also learned to continuously evaluate and let go of my assumptions and biases. In particular, my understanding of belonging was repeatedly challenged and expanded. I initially believed that reciprocal relationships characterized by mutual respect and value were essential to belonging, a belief that positions the ableist attitudes of nondisabled peers as a significant barrier and disabled youth as disempowered and victimized. In holding this belief, I was reinforcing the notion that relationships with nondisabled peers are "the gold standard for inclusion" (Salmon, 2013, p. 348), even though I directly critiqued this mindset in my literature review.

During my analysis and writing, I came to understand how affiliation with a group and simple social interactions like saying hi to a bus driver are also important contributors to a sense of belonging. This realization helped me to develop a conceptualization of belonging as embodied and subjective. As I have argued in this discussion chapter, an individual's felt sense of belonging matters more than an outsider's perception. I needed to take my own advice and

listen to youth to understand and respond to the complexity of their experiences. This takeaway brings to mind the words of Jim Anglin, an early mentor of mine: “Child and Youth Care isn’t rocket science. It’s far more complex than that!”

Limitations

The primary limitation of this study is the small amount of data that could be collected from a group of four participants over three focus group sessions. Conducting participant recruitment in the fall of 2022, shortly after the Covid-19 pandemic, likely influenced the number of interested youth and families. My sample group was also limited in that all four participants were of White European background and similar socioeconomic status. Their stories and experiences represent a certain level of privilege and do not necessarily reflect the experiences of disabled youths from other backgrounds. Nonetheless, the relatively small sample size was appropriate for the scope of a qualitative, independent, master’s research study.

Conclusion

My critical analysis of the lived experiences of four Canadian youth with disabilities constitutes a meaningful contribution towards understanding and promoting disabled youths’ sense of belonging. The study arose from my personal and professional experiences and relationships, and a review of critical disability scholarship that highlighted the limitations of dominant inclusion discourses and practices. The participatory research design generated findings that can be summarized in two themes: (1) exploring belonging and (2) unpacking ableism. These findings indicate that embracing a paradigm of unconditional belonging has significant potential to disrupt ableist power hierarchies and reorient inclusion policies and practices to be grounded in relationships and to centre youths’ voices and choices.

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Appendices

Appendix A: Email Scripts

For Organizations

This script will be sent to contacts at organizations where Emily has volunteered in the past, such as Community Living Victoria, Power to Be, and Embrace Arts Foundation

Hello (contact's name),

(insert personal greeting)

I am currently completing a Masters degree in Child and Youth Care at the University of Victoria. As part of my thesis requirements, I will be conducting a research study to gather the perspectives of youth with disabilities on inclusion and belonging. I was hoping that you could help me connect with potential participants. I have attached a recruitment poster designed to be hung up in any physical spaces or shared in a digital newsletter. I have also attached a detailed information letter that could be forwarded to specific families that you think might be a good fit.

Please let me know if you are willing to pass on this information, and if you have any questions or feedback.

Take care,
Emily

For Families Emily Knows

Hello parents!

Some of you may know that in addition to my work with Young Life Capernaum, I am also currently completing a Masters degree in Child and Youth Care at the University of Victoria. As part of my thesis requirements, I will be conducting a research study in the new year to gather the perspectives of youth with disabilities on inclusion and belonging. I have attached an information letter that explains the study in detail. I would like to invite your teens to participate and/or for you to pass on this information to anyone else that you think may be interested. That being said, please feel no obligation to participate! Choosing to join the study or not will not affect your teen's participation in Capernaum or my relationship with them. I am also recruiting participants through other community organizations that I have connections with.

Let me know if you have any questions or feedback,

Emily

Appendix B: Recruitment Poster

Share your thoughts on inclusion and belonging!

WHO: Youth ages 13-21 who have a disability or are neurodivergent, and live in the greater Victoria area.

WHAT: Three 1.5 hour group sessions with discussions, arts-based activities, and snacks!

WHY: We want to know what youth with disabilities think about their experiences of inclusion, and their ideas of how we can help everyone experience belonging.

WHERE: G.R. Pearkes Recreation Centre

WHEN: Saturday February 25th and March 11th, 2-3:30pm
Third date TBD

HOW: Contact Emily at [redacted] or ehellard@uvic.ca
to find out more or to take part in the study

You will receive a gift card to thank you for participating!

This research study is supervised by Dr. Alison Gerlach
in the School of Child and Youth Care at the University of Victoria
and is funded by the Social Sciences and Humanities Research Council of Canada

Appendix C: Information Letter

Beyond Inclusion: What do Youth with Disabilities Think about Belonging?

Principal Investigators:

Emily Eirikson, Masters Student
School of Child & Youth Care, University of Victoria
Phone: [redacted] | Email: ehellard@uvic.ca

Dr. Alison Gerlach, Assistant Professor
School of Child & Youth Care, University of Victoria
Phone: [redacted] | Email: alisongerlach@uvic.ca

[name redacted], Youth Community Researcher

Why are we doing this study?
This research is inspired by professional experience and a review of the literature which both reveal that in spite of the prevalent ideal of inclusion, some youth with disabilities experience a lack of belonging; that is, a lack of genuine reciprocal relationships and a valued role in community. Youth voices are also missing from the research on this important topic. Therefore, the purpose of this study is to explore the perspectives of youth with disabilities on inclusion and belonging to see what practitioners, policy makers, and parents might be able to learn.

The Social Sciences and Humanities Research Council of Canada is funding this study.

Why are we inviting your child to participate in this research?
Your child is invited to participate in this research because they are between the ages of 13 and 21, live in the Greater Victoria area, and have a disability or are neurodivergent. We are seeking a small, diverse group of teens to participate in this study, of various ages, genders, ethnicities, and abilities.

What does participating in this study involve?
Taking part in this study will involve participating in three group sessions that use discussions and photo-based activities to share stories about inclusion and belonging. The group sessions will last 90 minutes and will be held in a private room at a rec centre. In the sessions participants will be asked about their definitions of disability, inclusion, and belonging; examples of times they have experienced inclusion and belonging; ideas of what gets in the way of inclusion and belonging, and about other similar themes. The sessions will be audio-recorded for the purpose of making a transcript that will be analyzed for the research. The recordings and any photos shared with the group will only be shared with Emily, Alison, and the youth community researcher. Participants will also be asked to complete a form to gather anonymous information about their age, gender, disability, and ethnic background.

What if you change your mind?
Taking part in this study is completely voluntary. Your child is free to not answer any question(s), to leave a session, or to withdraw from the study at any time without giving a reason. Their decision to not participate in this study or to leave the study will be kept confidential. If your child decides to leave the study after a group session, they will be asked if we may use the information they have shared or if they would like to withdraw the information altogether. We will respect their choice.

What are the benefits of taking part in this study?
We believe that youth with disabilities have key insights about their experiences that can inform practice and policy to promote inclusion, belonging, and holistic wellbeing, and their perspectives are currently underrepresented in research literature. We hope that participants will benefit from the opportunity to grow in their self-advocacy and leadership skills and to build relationships with other youth.

Are there any risks in taking part in this study?
We do not think there is anything in this study that will be harmful or distressing for your child. The questions and activities are open-ended so that participants can share as much or as little as they wish. However, if at any point they feel uncomfortable and want to end their participation, they can let the researcher know immediately and their wishes will be respected. They do not have to give an explanation.

In light of the ongoing Covid-19 pandemic, participants will be advised if they have or may have come into contact with an individual who has been infected with COVID-19. Contact information for participants will be stored in a separate file from research data in the event that follow up is needed.

How will your child's identity and privacy be protected?
All of the information that may identify your child in this study will be kept strictly confidential and will not be shared with anyone. Your name, the name of your child, the names of anyone they mention, and your exact location will not be included in any written materials. All the information and data collected for this project will be stored securely through UVIC's online network storage for a 5 year period, in keeping with the University of Victoria data collection policy. At the end of 5 years, all collected data and related information will be disposed of appropriately (e.g., delete electronic files; confidential shred of hard copies).

How will the results of this research be shared?
You and your child will receive a summary report of the findings written in accessible language. The youth participants will be invited to suggest ideas of how the findings of the study could be shared to promote change, for instance sending a report to school administration and their teachers, creating an art piece or a video to be distributed online, or designing a presentation for a conference. These methods of sharing the findings will not include any identifiable information such as recordings or photos from the sessions unless a participant would specifically like to be involved, in which case additional informed consent will be requested. The study findings will also be shared in a published academic article as part of the requirements for Emily's Masters thesis, and will be available online via the UVIC library.

Will you receive any payment for taking part in this study?
Participants will receive an honorarium in the form of a gift card to acknowledge the important contribution of their time and insight. If they change their mind and withdraw from the study part way through for any reason, they will still be compensated for their participation up to that point. Participants will receive a $50 VISA gift card for each session they attend, up to $150 for participation in all three sessions.

Who can you contact if you have any questions about this study?
If you have any questions or concerns about what we are asking, you may contact Emily Eirikson by email at ehellard@uvic.ca; or by phone at [redacted]. In addition, you may confirm the ethical approval of this study, or raise any concerns you have, by contacting the UVic Human Research Ethics Office at 250-472-4545; or ethics@uvic.ca.

To help youth decide if they want to participate, this is how the study will go:

1. Emily will meet you in person to explain more about the study, let you ask questions, and then ask if you agree to be part of the study or not. You can choose not to be part of the study OR you can agree. If you agree, you can change your mind at any time and that is okay. If you agree, then Emily will ask you a few questions about your background (age, gender, diagnosis, ethnicity). Your answers will be kept anonymous and will help Emily understand more about how inclusion and belonging may be different for different people.

2. Then, everyone who has agreed to be part of the study will meet together for the first time. We will get to know each other, share some of our ideas about inclusion and belonging, and give some instructions to prepare for the next session. This will include taking pictures or finding images that you think can help us understand more about inclusion and belonging from your point of view. This meeting will be audio recorded.

3. We will all meet a second time a few weeks later to show each other our pictures and talk more about inclusion and belonging. You can share as much or as little as you like and you can take a break or stop participating if you want. This meeting will also be audio recorded.

4. Emily will take the recordings of the meetings and start to analyze them to look for themes and put together some ideas about belonging and inclusion.

5. We will meet for a third and final time and Emily will share the themes and ideas that she has found so far in the analysis. You can tell Emily if you agree, if you have anything to add, or if you want her to change some of the ideas if they are not quite right. You can also give some ideas of who we should tell about the findings of our study, like parents, teachers, respite workers, or people who run programs for youth with disabilities. This meeting will also be audio recorded.

6. Emily will put together all the ideas including the feedback from the group. She will write about them and publish an article as part of her Masters degree. She may also share the ideas at a conference, in a video, in a letter, or in some other way so that more people can learn from the study. Your photos and the recordings from the sessions will not be shared unless you specifically agree to it.

Thank you for thinking about participating in this study!
Please contact Emily if you are interested and would like to meet in person.

Appendix D: Determination of Capacity to Consent

Prior to seeking consent in the initial meeting with potential participants, the investigator (Emily Eirikson) will determine if the youth is capable of providing consent.

Process

Review the information letter and study details in conversation with both the youth and a parent. Encourage and answer all questions and re-explain any information that is not clear.

Through this conversation determine the youths' capacity. Questions to help assess capacity may include:

- Who can be a part of this study?
- What will you do in the study? What else? Do you want to do all these things?
- What if you start and decide you don't want to do it anymore?
- Who will know what you say?
- Why do you think we are doing this study?
- Will I use your name when I write a report?
- Do you have to do this?
- Will taking part hurt you in any way?
- Who can tell you more if you have questions?

Note: an 'incorrect' answer will not necessarily be construed as incapacity but will serve as a cue to re-explain and reassess.

Appendix E: Consent Form

Beyond Inclusion: What do Youth with Disabilities Think about Belonging?

By signing this form, I agree that:

- A member of the research team has explained this study to me.
- I read the Information Letter dated January 14, 2023 and understand what this study is about.
- All my questions regarding the study have been answered.
- I understand how I will be involved.
- I understand that I may drop out of the study at any time.

Yes, I agree to participate in this study.

______________________________	____________________________	______________
Participant's Name (please print)	Signature	Date

I understand what this study is about. I support my child's decision to take part in this study.

______________________________	____________________________	______________
Parent's Name (please print)	Signature	Date

______________________________	____________________________	______________
Name of person obtaining consent (please print)	Signature	Date

A copy of this consent will be given to you and a copy will be kept by the researcher.

Appendix F: Demographic Information Form

Please fill out this form to give some background information about you and your family. Your answers will be kept anonymous. You can ask your parents to help you fill out this form. If you do not feel comfortable answering a question you may leave it blank.

1. How old are you? ____________________

2. What gender do you identify with? ___________________________

3. How would you describe your disability? ______________________________________
   (you can write a specific diagnosis or a general category ie. "intellectual disability")

4. What ethnic or cultural background do you/your family members identify with?

   ____

Thank you for taking the time to fill out this form!

Appendix G: Session Outlines

Session 1: Introduction to the study (90 min)

Supplies needed: flip chart paper, markers, Photovoice handouts, audio recorder, snacks

Introduction (15 min)

- Welcome each person into the room, get settled, seated in a circle, give snacks (5 min)
- Remind sessions will be audio recorded – gain consent to record, start recording (2 min)
- Research sounds really official… but this is gonna be fun!
- Go over some ground rules (visually represented on poster) (8 min)
    - Listen to each other when speaking
    - What is shared in this group stays in this group
    - Only share as much as you want
    - Let Emily know if you need a break

Discussion: Inclusion & Belonging (45 min)

- The topic of my research is inclusion and belonging. I think it's really important for every person to experience true inclusion and belonging. But those two words can mean a lot of different things to different people, so the first thing I want us to do as a group is to decide what inclusion means to us. A lot of adults have written about it and shared their ideas but not many teens… and YOU know things that adults do not.
- Raise your hand – who has heard the word inclusion before?
- Raise your hand – who thinks they can give a definition of inclusion?
- Where have you heard the word inclusion? Who says it? Where did you first hear it?
- Let's start brainstorming. When you think about inclusion, what does it look like? How does it feel? Why is it important? IS it important?
- Is it different for belonging? Is there anything you would add or change if we did a brainstorm for belonging? Where are some places that YOU belong? Or who are some people that you belong with? How does it feel when you are in those places or with those people?
- Do you ever feel like you don't belong? When/where/with who? How does that feel? What gets in the way of belonging?
- Is it harder for people with disabilities to be included or to feel like they belong? Why or why not?
- What else might make a difference in how people feel included and feel belonging?
- Do you think it makes a difference to inclusion and belonging if you are a boy or a girl, if you speak English or a different language, if you are Canadian or come from a different country?
- What advice would you give a teenager starting high school to make friends, be a part of things?

Photovoice (30 min)

- Introduce Photovoice and the plan for next session, answer questions (20 min)
    - Distribute handout with Photovoice guidelines and ideas

  - Share my photos and youth researcher's photos as examples
  - I will ask a lot of follow up questions and be very nosy!
  - Emphasize: need consent if people are going to be in the photos you are taking!
- Wrap up (10 min)
  - Any last thoughts to share? And thank everyone for their time

Session 2: Photovoice (90 min)

Supplies needed: poster with group guidelines, flip chart paper, markers, audio recorder, snacks

Introduction (10 min)
- Welcome, get snacks, review consent & group guidelines, start recording

Discussion (70 min)
- Sharing of photos (60 min)
  - Each person picks their favourite photo to share first and go around the circle
  - Tell us about the photo – Who/what/where/when?
  - WHY did you take this photo – What does it tell us about inclusion or belonging?
  - Space for comments from others – what thoughts, feelings, or questions come up when you see this photo?
  - As time permits, go around the circle multiple times so that each person can share at least 2 or 3 photos
  - Take a 10-minute break halfway through to stretch, get another snack, go to the bathroom – to help maintain ability to engage fully

Conclusion (10 min)
- Talk about the plan for next session – Emily will analyze, then you will have an opportunity to give feedback and talk about who we should share this information with
- Ask for gift card locations again (for honoraria)
- Ask for "code names" (for pseudonyms)
- Any last thoughts to share?
- Thank everyone for their time

Session 3: Feedback (90 min)

Supplies needed: posters with ground rules, flip chart paper, markers, audio recorder, snacks, visuals of belonging subthemes

Introduction (10 min)
- Welcome, review consent, recording, ground rules (10 min)

Discussion (75 min)
- Emily shares update on her process over the last year (aka why it has taken so long) (5 min)
- Emily introduces belonging and subthemes (15 min)
- Photo sorting activity (30 min)

    - Can you match your photos to the subthemes?
    - It is ok if they do not fit in any subtheme, or more than one subtheme
    - What is missing? What would you say differently? Is anything not quite right?
- Emily briefly summarizes youth voice and ableism themes (10 min) and assesses youth comprehension and resonance
- Brainstorm ways to share findings (15 min)
    - Emily will write an article that will get published in a journal
    - Who do you think needs to hear this information?
    - What is the best way to share it with them?
    - Do you want me to send it to your parents?

Conclusion (5 min)

- Wrap up (5 min)
    - Thank you SO MUCH for participating!
    - Distribute gift cards
    - If you have any questions or concerns you can contact me

Appendix H: Suggestions for Taking Photos

What photos should I take?

- Take pictures of people, places and activities that tell something about inclusion or belonging
- You can also choose photos from your family photo albums
- You can take the photos or ask someone else to take them for you. But you should decide what photos to take.
- You can be the director and put yourself in the photos!
- There is no right or wrong. Anything is welcome. Be creative!
- Try to bring 4-6 photos to the next session

What will we do with the photos?

- When we all get together next time, we will show each other our photos and explain what they say about inclusion and belonging
- Please bring a printed copy of the photos that you can give to Emily to keep for her research OR email her the photos ahead of time and she will get them printed
- These photos will not be shared with anyone besides Emily, Alison (her supervisor), and [name redacted] (the youth community researcher)

Some ideas if you need them…

- A place where you like to hang out with your friends
- A really fun or special memory with your friends
- A favourite family memory
- A place where you feel like you can be yourself
- A place where you feel important
- Someone that you really trust
- A time when you were proud of yourself
- A place where you *don't* feel like you belong
- A time when you did *not* feel included
- Something that gets in the way of inclusion

** IMPORTANT **

You NEED TO explain the study to anyone you want to include in your photographs and get their permission first. You can tell them that you are participating in research to learn more about inclusion and belonging in the lives of teens with disabilities.
If they don't agree, DON'T include them in your photo.

CALL OR EMAIL ME IF YOU HAVE ANY QUESTIONS

Emily Eirikson ehellard@uvic.ca