Collaborating with adults labelled/with intellectual disability to create disability support staff training materials.

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By

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Abstract:

Historically, people labelled/with intellectual disability in Canada have received institutionalized forms of care in which they were mistreated, abused, and controlled (Seth et al., 2015; Spagnuolo & Earle, 2017). Today, many people labelled/with intellectual disabilities live within the community and instead receive support from disability support workers in various settings, including within smaller-scale institutions such as group homes, supported independent living arrangements. In some instances, such settings continue to provide institutionalized forms of care (Spagnuolo & Earle, 2017). They may also be in receipt of disability support through involvement with various other community services, including education, employment and recreation. While this shift away from large-scale institutionalization has generally granted a greater level of autonomy for those so labelled than there was previously, the power differential between disability support staff and people labelled/with intellectual disability is such that many problematic support dynamics persist (Sagnuolo & Earle, 2017; Robinson et al., 2022; Antaki et al., 2007). This qualitive co-production project aimed to learn more about what people labelled/with intellectual disability wanted disability support staff to know about the provision of support and did so using a series of focus groups and individual interviews with a participatory component: the co-creation of a series infographics for training of support staff. Thematic analysis revealed two major themes in my data. The first, the ways that support was too often unhelpful or harmful, I broke down into three subthemes: variable treatment, assumptions of (in)capability, and directing or doing for participants leading to neglect of opportunities for skill development. My second theme described what the participants wanted to see from support instead, which also had three sub-themes: respect for boundaries, kind and compassionate treatment, and respect for individuality. My findings and the co-created infographics emphasized the importance of respecting the knowledge that people labelled/with intellectual disabilities have about their own needs, challenging social workers and other professionals to reflect upon their self-perceptions as experts.

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Introduction:

History of Support Services for People Labelled/With Intellectual Disability

For much of recent history, individuals labelled/with intellectual disabilities have lived in large-scale institutions (Seth et al., 2015; Spagnuolo & Earle, 2017). In these institutions, people were given no control over their daily schedule and were often treated very poorly by the staff providing their 'care', with survivors of these institutions describing a variety of different forms of physical, sexual, and emotional abuse (Seth et al., 2015; Rossiter and Clarkson, 2015; Hutton et al., 2017). In these settings, 'care' involved extremely dehumanizing treatment. As Peter Park, an institution survivor, describes it: "We weren't treated as human, in every single way" (Hutton et al., 2017, p. 39). Park described how he was not allowed to leave the institution once he was admitted, how there was no privacy, and that it was a "full system of total control" (p.44). Another survivor, Martin Levine, emphasized the intense physical torture that staff would inflict on him and other residents of the institutions as punishments for perceived wrongdoing (Hutton et al., 2017). Marie Slark, a survivor who helped instigate a class-action lawsuit against the Ontario government, also emphasized the control that staff had over residents: "the staff had total control. We had to do what they said, the way they said it, or else…We were told and not asked" (Seth et al., 2015, p. 62).

While the last remaining large-scale institution in Ontario closed in 2009, these institutions still operate in several Canadian provinces (Spagnuolo & Earle, 2017). This context is important to recognize, because, in Ontario, as described above, until very recently people labelled/with intellectual disabilities had been forced to live in large-scale settings where ‘expert’ staff controlled every facet of their lives (Seth et al., 2015; Spagnuolo & Earle, 2017; Rossiter and Clarkson, 2015; Hutton et al., 2017). Closure of these centres In Ontario has allowed many people labelled/with intellectual disabilities to live within their communities, but there are a number of service gaps that prevent deinstitutionalization from being fully realized (Spagnuolo & Earle, 2017). For example, a lack of resources available to people labelled/with intellectual disabilities can lead to institutionalization through the psychiatric or justice systems (Spagnuolo & Earle, 2017).

Spagnuolo and Earle (2017) argue that the shift from large scale institutions to smaller-scale group homes and supported independent living models has not significantly improved the quality of support that people labelled/with intellectual disabilities receive as they are still too often reliant on institutionalized forms of care and support. Rossiter and Clarkson (2015) highlight concerns that have been raised about the quality of service and amount of funding available to support people living in group homes, arguing that: “people who were vulnerable within institutions remain vulnerable within the context of community care” (p. 22).

Due to the history of institutionalization and the ways that people labelled/with intellectual disability are understood, the established dynamic is that people who are labelled/with intellectual disabilities too often continue to be granted limited power and control over their own lives. One reason for this is infantilization – those who are labelled/with intellectual disabilities are often constructed as being childlike, which is then used to undermine their capabilities and create and support the presumption that non-disabled others, such as medical professionals or caregivers, know best and thus are justified in assuming control over the lives of people so labelled (Mills & Lefrançois, 2018), dictating what care and support look like. Perceived vulnerability also plays a role in this; as Scully describes: “the more vulnerable a disabled person is believed to be, the less likely it is that others will treat the choices she makes or opinions she holds as worthy of respect” (Scully, 2014, p. 210). Stereotypic media and cultural representations of people labelled/with intellectual disability further reinforce perceptions that those so labelled are child-like and vulnerable (Fudge Schormans and Chambon, 2014; Fudge Schormans 2015). Self-advocates labelled/ with intellectual disabilities reported being troubled by the way mass-produced images often emphasized the dependence and vulnerability subjects labelled/with intellectual disabilities, stating they did not see themselves in these representations (Fudge Schormans 2015). Importantly, people labelled/with intellectual disability very rarely have control over the ways that they are represented. This matters as these representations significantly impact the way that people who are not labelled/with intellectual disabilities understand and treat those so labelled (Fudge Schormans and Chambon, 2014; Fudge Schormans 2015). This is relevant to deinstitutionalization because as Seth and colleagues (2015) put it: “we can close down all the institutions we want, but the mindset that created them still persists” (p. 67). Thus, unless perceptions of people labelled/with intellectual disabilities are shifted, they will continue to be understood as child-like and vulnerable, justifying the imposition of support that is neither wanted nor helpful by ‘experts’.

While working with allies and professionals in a class action lawsuit against the Ontario government for their role in creating and sustaining large scale institutions, self-advocate survivors expressed frustration that many of the people and services that were meant to be helping them both those inside and outside of the institution were controlling and condescending (Seth et al., 2015). These self-advocate survivors also described how difficult it was for them to get the support they needed in their day-to-day lives: “I don’t want to be talked down to, so I don’t ask for help” (Seth et al., 2015, p.64). When describing what she felt still needed to change, this self-advocate further elaborated that “you should be able to get emotional support and not have a worker who will just talk down to you and boss you around” (Seth et al., 2015, p. 65). Thus, although large-scale institutionalization of people labelled/with intellectual disabilities has ended in Ontario, people labelled/with intellectual disabilities are still not receiving the kinds of support that they need or desire. This demonstrates the importance of learning from people labelled/with intellectual disability about what they want disability support staff to know.

Situating Myself in the Research

Initially, when I began to develop the idea for my research project, I was coming at it from the perspective of someone who has worked in the role of an ‘inclusion counsellor’. I have worked steadily as an inclusion counsellor with children (6-12yrs), tweens (13-15yrs), and teens/young adults (16-21yrs) in recreation programs since 2017 (with some breaks for the COVID-19 pandemic and graduate school). In this role, staff provide support to disabled individuals that they are paired with. In the programs I have worked in, staff to client ratios range from 1:1 to 1:3. In recreation programs, staff often provide 1-1 support to disabled people. Some program examples include day camps, cooking socials, fitness socials, and swimming lessons. When working in these programs, such as day camp, staff also plan and facilitate activities for either groups of disabled participants, or for the individuals they are paired with. In my experiences as an inclusion counsellor, training provided to staff is very limited and the perspectives of people who are receiving this support are not considered. As a social work graduate student performing this role, I felt a need to critically examine the way I provided support. In order to do this, I wanted to work collaboratively with people labelled/with intellectual disabilities to learn more about what they wanted from support. I include this information about the context of support that I am familiar with because when I developed this project, I had intended it to focus on support in this field specifically. This shifted during the project – a shift that participants of the project requested, as they wanted to share their recommendations with a wider pool of staff than just those involved with recreation. Thus, the project now speaks to disability support more generally.

Research Problem

I made the decision to focus my research on learning from people labelled/with intellectual disabilities due to the ongoing and systemic issues that often prevent those so labelled from having their opinions are taken into account. Thus, I posed the following research question:

“What do people labelled/with intellectual disabilities want disability support staff to know in order to facilitate more respectful, equitable, and consistent support?”.

Literature Review

While conducting my literature review, I focused on three key areas: literature that indicates what might be considered ‘best practices’ for support in recreation, explores support relationships from the perspective of those being supported, and/or analyzes interactions between support staff and those receiving support. I started with literature that describes what is understood to be best practices for support in recreation in order to learn more about how disability support is framed in that industry. Initially, I had planned to focus my project on creating a training tool for support staff specifically in recreation, and thus wanted context related to that field. Although this project has changed direction since its conception, I still think this background information about what is understood to be ‘good support’ is relevant. Next, I reviewed literature that describes what support recipients want from disability support, as this is the perspective that I wanted to emphasize in my own project. Finally, I reviewed literature that analyzes the dynamics that occur between disability support staff and those being supported in order to learn more about the everyday impacts of these support relationships on those being supported.

Disability Support in Recreation

The literature exploring the intersection of recreation and people labelled/with intellectual disability often concerns itself with maximizing social inclusion, a concept that is described variably in the literature. In their systematic review of studies that examined the experiences of social inclusion of people labelled/with intellectual disabilities in community recreation programs, Merrells et al. (2018), observed that none of the twelve studies that they included in their review clearly defined social inclusion. Within their own paper, Merrells et al., (2018) draw on previous work and describe social inclusion as “a core domain of quality of life” (p. 381) and “an interpersonal process allowing people with limitations or differences to feel acknowledged and valued” (p. 381). Merrells et al (2018) also suggest that belonging, relationships with others, and participating in society are important parts of social inclusion.

In addition to discussing recreation in relation to the domain of social inclusion, there is also a significant body of literature that discusses inclusive recreation. Inclusive recreation typically refers to recreation programs where disabled and non-disabled participants are in the same program (Mayer and Anderson, 2014). This is relevant because many of the studies that explore disability support in recreation are speaking specifically about support within these inclusive programs.

While most literature that discusses factors that facilitate social inclusion focuses on the perspective of staff or non-disabled participants, Edwards et al., (2021) is notable because it includes the perspectives of both disabled and non-disabled children participating in an inclusive recreation program. Edwards and colleagues (2021) aimed to determine what strategies could be used within inclusive recreation programs to promote social inclusion. They conducted two semi-structured interviews with each of their participants, eight of whom were disabled children between the ages of 8-18 years, and nine of whom were non-disabled children, also between the ages of 8-18 years. Of these eight participants that had disabilities, five of them were designated with cognitive disability. Edwards and colleagues (2021) gathered additional data through participant observation. Edwards and colleagues (2021) found that it is important for staff to be able to recognize diverse forms of communication and structure opportunities where everyone is able to express their preferences in order to support social inclusion. They also found that it was important for participants to be able to choose both which activities they took part in and their level of involvement with them. Their interviews with disabled participants particularly emphasized the need to be allowed to choose to take a break.

Weissman and colleagues (2022) conducted a recent study that investigated factors that led to quality participation experiences for adults labelled/with intellectual disability in inclusive recreation programs. Although Weissman and colleagues (2022) focused their inquiry on quality experiences in inclusive recreation programs rather than strategies that promoted social inclusion, their results were similar to those found by Edwards et al., (2021); Weissman et al., (2022) found that staff needed to be able to adapt to the communication styles and needs of the participants, and that friendly interpersonal styles allowed for rapport building. Weissman et al., (2022) emphasize that support staff also need to have knowledge related to the recreational activities, and that it is better if there is consistency with support staff. They also reported that it was important for staff to understand each participant's abilities through communication with caregivers or through documentation prior to the beginning of the recreation programs. Weissman et al., (2022) also noted several barriers to quality participation including variability in ways and extent to which staff engaged with participants, and participants being placed in programs that they were not interested in, however they did not report how frequently these barriers presented. While Edwards et al., (2021) were investigating contextual strategies to support social inclusion in inclusive recreation programs, Weissman et al., (2022) were investigating the factors that facilitated quality experiences in inclusive programming. Overall, both are recent studies that provide an overview of some of the strategies that might be understood to be best practices within the field of recreation. Both studies also included the perspectives of children or adults labelled/with intellectual disabilities to some degree. I found that, within the recreation-specific research literature, people labelled/with intellectual disabilities are rarely spoken to directly; staff or caregivers are often used as data sources instead. While Weissman et al., (2022) do include a few people labelled/with intellectual disabilities in their study, only four of the 21 people who were interviewed for the study were participants of the program. All others were caregivers or staff. Consequently, while Weissman et al., (2022) says a little bit about what people labelled/with intellectual disability might want from inclusive programs or support in recreation programming, much of the data in the study did not originate from the program participants labelled/with intellectual disabilities themselves. Although caregivers are often presumed to be able to provide data – more reliable and thus 'better' data - on the behalf of those they care for (Santinele Martino & Fudge Schormans, 2018), some studies, such as one by Froese et al., (1999) demonstrate that there can be significant differences between the opinions of people labelled/with intellectual disabilities and the people who provide care to them.

Disability Support from the Perspective of Those Being Supported

While literature exploring the efficacy of recreation support staff is limited, the body of literature that explores disability support relationships more generally is comparatively larger. Topping and colleagues (2022) conducted a constructivist grounded theory study to determine the factors that affect the quality of paid support for people with acquired neurological disability. This study stands out due to its centring of the perspectives of the people in receipt of support rather than those of staff or caregivers. Topping and colleagues (2022) found that the most fundamental factor in quality paid disability support as reported by the participants was that support staff recognized them as individual people with individual needs and preferences. All other reported factors required this as an underlying principle (Topping et al., 2022). For example, participants reported it was important that staff want to support the person with disability, treat them as a person, see them as an expert and respond to their individual needs. These findings align with work by Gridley et al., (2014) and Fadyl et al., (2011), two earlier studies that approached similar inquiries with people with severe/complex needs and their carers, and various groups of disabled people respectively. In a scoping review of the literature on the care of people with complex needs, Gridley et al., (2014) found that many of the publications they reviewed advocated for person-centred support. This is in line with what the participants of Topping et al., (2022) said, as they strongly emphasized the need for support that recognized them as individuals with individual needs. Fadyl and colleagues (2011) aimed to learn what disabled people believed determined ‘quality care’ through focus groups with several different groups of disabled people, including one group of people labelled/with intellectual disability. Overall, Fadyl et al., (2011) also found that there was a strong need for a humanizing approach to providing support services, which they defined as treating each participant as a person, allowing each person to be involved in their own care, listening to each person and taking them seriously.

Disability Support Dynamics

In addition to the literature that discusses quality care from the perspective of disabled people, I reviewed literature that examines relational dynamics between people labelled/with intellectual disabilities and support staff. Robinson and colleagues (2022) explored the support relationships of 42 participant pairs of support workers and young people aged 18-25 years labelled/with intellectual disability. In some of these pairs, the young person chose which support worker participated with them, while in others a service manager chose a support worker that the young person knew. Robinson and colleagues (2022) gathered data from a variety of sources including repeated interviews, social maps, and photo research, in order to learn about their support relationships. While Robinson and colleagues had initially been investigating more positive aspects of disability support relationships, when they analyzed their data they found a number of everyday ways that disability support staff perpetuated harm through the support relationship (Robinson et al., 2022). They found that the young adults labelled/with intellectual disability spoke about not being given choices or support for decision-making, and the harms of misusing humour. While humour was able to improve relationships when used well, participants reported that when misused, humour was experienced as mocking, insulting, and hurtful. The researchers also reported directly observing infantilizing treatment and demeaning language towards the people labelled/with intellectual disabilities from the support workers. They discussed the ways that the young people labelled/with intellectual disabilities were devalued by workers, noting that some support workers made demeaning comments about the eating habits or level of cleanliness of the people they were supporting. Another issue Robinson and colleagues reported on was how difficult it was for the young people to effectively object to elements of support that they felt were objectionable. They also addressed some of the institutional factors that can constrain disability support relationships, for example, being locked into goal setting frameworks by institutional mandates that do not fit what the young person labelled/with intellectual disabilities wants for themselves. Robinson et al., (2022) suggested that many of these negative practices were driven by the informal norms of the organizations, particularly in the absence of staff training or strong supervision.

These are also a number of studies that analyze video footage of staff and residents labelled/with intellectual disabilities to assess the relational dynamics that occur. Several of these studies, including those by Rapley (2004), Finlay et al., (2008), Antaki et al., (2007), and Antaki and Crompton (2015), emphasize the importance of analyzing day-to-day interactions as potential sites of autonomy, oppression, and resistance for people labelled/with intellectual disabilities. A study by Finlay and colleagues, (2008) considered issues of choice and control in the context of staff playing games with people who are labelled/with profound intellectual disabilities, a group of people for whom spoken language is not their primary means of communicating. Finlay and colleagues focused their research on games because they are a form of interaction where words are not always necessary, and this allows non-speaking people more control over what is happening. They emphasize how when trying to engage residents labelled/with profound disabilities in group homes with games, staff often treat ambiguous participation or non-compliance as temporary reluctance or a failure to understand. They also point out that there are strong institutional pressures on staff to continue with active engagement even when the resident does not show signs of enjoyment. When asked about factors that promoted positive experiences in inclusive programs, caregivers reported that they preferred when staff were persistent in their efforts to engage adults labelled/with intellectual disabilities during recreational programs (Weissman et al., 2022). Finlay and colleagues (2008) however problematize this staff practice and point out how persistence can undermine the autonomy of people labelled/with intellectual disabilities.

Rapley (2004) breaks down typical interactions between people labelled/with intellectual disabilities and group home staff into three main interactional styles: babying/parenting, instruction giving, and collaboration/pedagogy. Rapley observes that many of the ways that support staff interact with the residents of the group home construct residents as incompetent and place staff in positions of power. He notes that through babying/parenting and instruction giving, support staff presume that they have the right to tell the residents what to do and that the residents should follow these directions unquestioningly. Rapley (2004) contrasts babying/parenting and instruction giving with the final categorization, collaboration/pedagogy. He characterizes these interactions as ones where residents are involved in decision making, suggestions are given rather than instructions, and support staff speak to residents more like equals. These characteristics are similar to recommendations made by Antaki and Crompton (2015) in their analysis of conversational practices that can promote personal agency for people labelled/with intellectual disabilities. Antaki and Crompton (2015) first suggest that staff explain the overall purpose of the tasks that people are involved in. For example, if asking someone to put compost into flowerpot, explain that this is part of a larger goal of helping the plant grow. Their second recommendation is for staff to make requests and offer suggestions rather than giving directions. Thirdly, they recommend framing tasks as ones that have a joint purpose, where the people labelled/with intellectual disabilities being asked to perform a task have a stake in the reason the task being completed. Taken together, Rapley (2004) and Antaki and Crompton (2015) emphasize the importance of making suggestions rather than directing, explaining the purpose of tasks and why they are relevant to the individual, and involving people in decision making.

While digging into day-to-day interactions within a group home, Antaki and colleagues (2007) highlight how staff can interact with group home residents in a way that attributes to them a greater level of impairment than is appropriate. The researchers analyzed a session at a group home in the United Kingdom, where staff were meant to seek the views of the residents on their personal relationships. Rather than just finding out about their views, the staff began coaching the residents on who they should consider to be their friends. By providing coaching on this subject rather than seeking residents' opinions, staff are assuming that the residents would not be able to make this distinction themselves (Antaki et al., 2007). The researchers argue that since official discourse in the United Kingdom states that people labelled/with intellectual disability have the right to have a family, staff implying that residents are unable to identify who their friends are frames them as having fewer social rights than they are entitled to (Antaki et al., 2007). Staff also coached the residents into stating that staff were their friends, even though the residents themselves described the staff as "alright" and articulated that their role was that of a helper. One resident stated that the support staff "helps me" and was pushed into stating that a staff member was her friend. Antaki at al., further argue that these kinds of day-to-day interactions, where staff undermine the capabilities of people labelled/with intellectual disabilities, have larger implications for the realization of social policy or organizational mission statements. They point out these day-to-day interactions often act as sites of disempowerment and directly conflict with social policy in the United Kingdom.

The literature reviewed in this paper thus far has established a few common threads; studies such as those by Antaki et al., (2007) and Rapley (2004) demonstrate that dynamics between support staff and people labelled/with intellectual disabilities often involve producing incompetence and uneven power dynamics. Robinson and colleagues (2022) similarly point to how support staff often perform minor acts of harm in support relationships through undervaluing the people they're working with, misusing humour, and demeaning and infantilizing treatment. Finlay and colleagues (2008) pointed out that staff often treat disinterest as temporary reluctance and undermine the wishes of people labelled/with intellectual disabilities when playing games. Taken together, Rapley (2004) and Antaki and Crompton (2015) suggest that greater agency can be given to people labelled/with intellectual disabilities through making requests rather than demands, explaining why actions are being taken, giving people a stake in actions, and by creating space for people to make choices. Topping and colleagues (2022) determined that the most vital element of quality paid support was treating the disabled person as an individual with individual needs, a finding mirrored in studies by Gridley et al., (2014) and Fadyl et al., (2011). The recreation-specific literature often focused on social inclusion as a concept, with recommendations that included ensuring support staff had program specific knowledge, that they could adapt to a variety of communication styles and were given prior information about the participants that they were working with (Weissman et al., 2022). Edwards et al., (2021) found that it was important to allow participants to choose the activity and level of participation and recognize diverse forms of communication.

Literature Gaps

Generally, I found very few studies that draw from the perspectives and experiences of people labelled/with intellectual disabilities. This is supported by Merrells and colleagues (2018) systematic review of the literature discussing the involvement of people labelled/with intellectual disabilities in community recreational activities and their experiences. Despite the focus of their review, they noted that none of the studies that they included discussed the experiences of people labelled/with intellectual disabilities in depth. While several of the reviewed studies problematized relational dynamics that emerged between staff and people labelled/with intellectual disabilities, none engaged with people labelled/with intellectual disabilities specifically to determine what they wanted from support staff. The study being reported on in this thesis, centred on the research question, “what do adults labelled/with intellectual disability want disability support staff to know?” aims to begin to address these gaps by working directly with people labelled/with intellectual disabilities to create a resource that communicates what they feel staff should know in order to support them better.

Theoretical Framework

For this project I drew on critical disability perspectives and the feminist epistemological concept of epistemic injustice. This chapter will provide an overview of the theoretical perspectives I brought into this project, as well as some description of how I applied them.

Critical Perspectives on Disability

Critical thinking about ‘disability’ began with the disability rights movement and other forms of disability activism. According to Shakespeare (2013), “the disability movement has focused attention onto social oppression, cultural discourse, and environmental barriers” (p. 214). Another key facet of the disability rights movement is the idea of ‘Nothing About Us Without Us,’ which emphasizes the need for disabled people to have control in the matters that impact them (Charlton, 1998). One particularly influential model of thinking that arose from the disability rights movement is the social model of disability (Shakespeare, 2013). There are several key elements to the social model of disability. Firstly, the social model identifies a distinction between disability and impairment (Shakespeare, 2013). Impairments refer to embodied physical limitations, while disability is redefined as: “the disadvantage or restriction of activity caused by contemporary social organization which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities.” (UPIAS, 1975 as cited in Shakespeare, 2013 p. 215). This definition of disability places emphasis on the way that the social environment creates many of the challenges that disabled people face; rather than aiming to create change within the individual, it is society that must change under the social model of disability (Shakespeare, 2013). The social model can be contrasted with the medical model, which locates disability within individuals as biological, genetic, hormonal, neurological, or physiological problems (Goodley, 2014). Disability, when thought about through a medical model, encourages thinking about disability on an individual level (Goodley, 2014). Hughes (2007) points out that the subtext of most medical literature relating to disability is that the ‘normal’ and the ‘pathological’ are constructed as two opposites where the ‘pathological’ is understood to be a lesser existence. Rather than locating disability as an individual problem to be solved, the social model emphasizes the need to agitate for political change to address issues of systemic oppression (Goodley, 2014).

While the social model is very influential, there are a number of critiques. In his 2006 book *Disability Rights and Wrongs*, Shakespeare challenges the social model. He points out that impairment and disability are difficult to disentangle, that impairment plays a large role in the ways that disabled people experience their lives, and that disability cannot be entirely mitigated by social change (Shakespeare, 2006). Shakespeare outlines reasons why the dichotomy of ‘impairment’ as biologically determined, and ‘disability’ as socially constructed fails to hold up to analytical scrutiny. He points out that the social environment can often impact how impairments are experienced; one example that he uses is the case where pain or other symptoms could be remedied with access to medications or therapies, but they are not available due to social factors, such as low-income, or governmental policies. In that situation, the person’s experience of pain, which would typically be constructed as a biological impairment, is being worsened by social factors, thus entangling the two. Shakespeare also disagrees with the way that the social model undersells the impacts of impairment. Shakespeare (2006) emphasizes the importance of recognizing that impairment creates challenges that cannot be alleviated by social change because “even in the absence of social barriers or oppression, it would still be problematic to have an impairment, because many impairments are limiting or difficult not neutral” (p. 41). Some scholars, such as Eli Clare (2017), suggest that rather than dichotomizing impairment/disability and mind/body one can understand people using the frame of “body-mind” (p. xvi) or “body-mind differences” (p. xvi). Using language in this way resists separating the mind from the body and recognizes the interconnectedness of mind and body (Clare, 2017). Another critique of the social model is that it is rarely applied as a tool to understand the lives and experiences of people labelled/with intellectual disability (Chappell and Goodley, 2001). Instead, the problems people labelled/with intellectual disability face are often considered to be inherent to their impairments (Chappell and Goodley, 2001). In summary, these critiques of the social model concern themselves with the complexities of living with body-mind differences; they highlight how living with impairment is more complicated than the social model is able to conceptualize on its own.

Expanding further on the construction of disability, Meekosha and Shuttleworth (2009) discuss the importance of bringing elements of critical social theory to understanding disability. Like Shakespeare (2006), they challenge understanding impairment and disability as discrete, binary concepts. Meekosha and Shuttleworth highlight the importance of recognizing how time and place impact the way that disability is theorized, bringing attention to the euro-centric viewpoint that academic approaches to disability often take. They also emphasize the importance of linking theory with action in order to enact social change, the need to recognize cross-cultural understandings of disability, and the importance of understanding complex social relations (Meekosha and Shuttleworth, 2009). Specifically, Meekosha and Shuttleworth suggest that intersectionality is an important lens for critical disability studies to incorporate. Intersectionality, originally developed by Crenshaw in 1991, theorizes that interlocking social identities are oppressed in unique ways (Crenshaw, 1991). This can be contrasted with a multiplier or additive model of understanding interlocking social oppression, which Meekosha and Shuttleworth state had been used to conceptualize aged, racialized, or gendered experiences of disability previously. Bringing these principles, particularly intersectionality, into analysis of disability is important because experiences of disability are not monolithic. Recognizing intersectionality, as well as the impact of time and place, is necessary to understand varied disability experiences.

While intersectionality gives shape to the ways that people with interlocking social identities are oppressed differentially, ableism and disablism add specificity to conceptualizing oppression that disabled people face. Campbell defines ableism as a "a network of beliefs, processes and practices that produce a particular kind of self and body (the corporeal standard) that is projected as the perfect, species typical and therefore essential and fully human" (Campbell, 2008, para. 7) and disablism as "a set of assumptions (conscious or unconscious) and practices that promote the differential or unequal treatment of people because of actual or perceived disabilities" (Campbell, 2008, para 3). In other words, ableism is a system that produces what is understood and accepted as the ideal; this identifies so called 'able' bodies and minds as the preferred standard, the norm, while disablism refers to the unequal ways that people with non-normative bodies and minds are treated, in ways that work to disable them. Campbell argues that this distinction is an important one, as primarily focusing on disablism fails to attend to the ways that ableism produces disability as inherently negative. In essence, changing the disabling ways that disabled people are treated does not change the ways that disability is thought of or spoken about. Merely challenging disablism invites change at the individual or organizational level rather than the societal or ontological (Campbell, 2008).

Critical disability theorizing was important for a number of reasons applicable to this project. Firstly, it informed the language that I am using throughout this thesis. I am using the language of 'labelled/with intellectual disability', following the lead of others such as Kuri and Fudge Schormans (2022). This language is used in order to recognize that there are many different language choices that people understood to have intellectual disability use (Kuri and Fudge Schormans, 2022). As they explain (p. 1):

> we use the political term people labelled/with intellectual disabilities. The slash between the words labelled and with recognizes that while some people may claim this label, others understand the label to have been

imposed upon them (McClelland et al., 2012), identifying this imposition as a practice of oppression that works to disable them (Titchkosky, 2001). Identifying the participants in this research as people labelled/with intellectual disability requires engagement with the idea that these labels are socially constructed rather than understanding ‘intellectual disability’ to exclusively be a set of medicalized criteria. Using a slash for labelled/with recognizes that some individuals who have this label understand their impairments to be a significant source of difficulty in their lives, and thus do not wish to reject the label of ‘intellectual disability’, even though others find the imposition of this label oppressive.

This project also drew on Meekosha and Shuttleworth’s (2009) assertion that critical disability theory or scholarship should be connected with action. This influenced the methodology I chose for this project, which will be expanded on in greater detail in that chapter. Critical conceptions of disability also greatly informed my data analysis, particularly the concepts of ableism and disablism as defined by Campbell above. Understanding ableism as a system which produces non-disabled people as the ideal (Campbell, 2008), allows one to recognize how people labelled/with intellectual disability are understood by non-disabled support staff. Disablism, meanwhile, gives language to the unequal and unfair ways that people labelled/with intellectual disability are treated both in general, and within disability support relationships. Disablism was visible in many of the experiences with disability support staff that the participants described in this project. Ableism, meanwhile, appeared to play a significant role in the power dynamics between staff and participants; since ableism produces non-disabled people as the species standard ideal, non-disabled support staff were constructed as superior to the people that they are supporting, reflected in the ways that they are understood to be ‘experts’ and ‘in charge’.

Feminist Epistemology – Epistemic Injustice

Epistemology is a branch of philosophy concerned with understanding the nature of knowledge (Joy, 2022). Feminist epistemology proposes that knowing is an exercise of power and is necessarily a political activity (Code, 2014). Epistemic injustice is one concept that has arisen from philosophical premises of feminist epistemology (Code, 2014; Schweiker, 2022). Popularized by Miranda Fricker, epistemic injustice proposes that it is possible to undermine people in their capacities as knowers, and that this harm can have many secondary impacts due to the importance of knowledge in the social world (Fricker, 2007). In her book *Epistemic Injustice: Power and the Ethics of Knowing,* Fricker theorizes two different kinds of epistemic injustice: testimonial injustice and hermeneutical injustice (Fricker, 2007). Fricker describes testimonial injustice as a wrong that occurs when a person’s statements are granted less credibility than they should be, which she describes as a “credibility deficit” (2007, p. 18). She exemplifies this concept by referring to how the white jury members in Harper Lee’s novel, *To Kill a Mockingbird,* refuse to accept Tom Robinson’s testimony that he is innocent due to their prejudices against black men. Fricker also highlights how perceived credibility deficits can lead to people not being asked about what they know because they are not considered to be good informants. She refers to this phenomenon as pre-emptive testimonial injustice (Fricker, 2007).

The second form of epistemic injustice that Fricker describes, hermeneutical injustice, occurs when people are unable to make their experiences intelligible to others due to a lack of understanding or terminology to describe those experiences. She exemplifies this through an overview of how the idea of ‘sexual harassment’ came to be a part of the public consciousness (Fricker, 2007). When women began to work outside of the home, many women experienced sexualizing and degrading treatment from male co-workers or supervisors. However, until many women came together to discuss these shared experiences, each woman understood this as an individual issue, and did not have words to describe this situation to others. Fricker argues that:

> it was no accident that their experience had been falling down the hermeneutical cracks. As they struggled in isolation to make proper sense of their various experiences of harassment, the whole engine of collective social meaning was effectively geared to keeping those obscured experiences out of sight (p.153).

In other words, Fricker argues that a lack of understanding or terminology to understand sexual harassment was a direct result of women’s systemic marginalization and an unequal ability to contribute to the way that the world is understood. Speaking more generally, Fricker conceptualizes inequities in ability to contribute to the way the world is understood, or the collective hermeneutical resource, as the primary source of hermeneutical injustice (Fricker, 2007).

Since 2007, numerous scholars have taken up epistemic injustice, in ways that challenge and expand on Fricker's original ideas. Several have critiqued Fricker's original conceptualization of the term. Dotson for example, (2012) expands the scope of epistemic injustice by introducing the concept of contributory injustice. Dotson suggests that different groups of people have access to different hermeneutical resources. Marginalized people often have access to hermeneutical resources that allow them to make sense of their social worlds that privileged people do not. Dotson proposes that rather than experiencing injustice due to a lack of hermeneutical resources, marginalized people may instead be harmed by a lack of recognition or uptake of their hermeneutical resources. Dotson calls this form of epistemic injustice contributory injustice.

Additionally, while Fricker discusses the potential for credibility excesses, where people are considered more credible than they should be, she argues that these excesses are not a form of epistemic injustice (Fricker, 2007). This premise has been contested, notably in the context of medical settings where doctors and other healthcare professionals assume positions of epistemic privilege over ill people (Carel and Kidd, 2014). Carel and Kidd (2014) propose that ill people are often undermined as knowers due to the amount of epistemic privilege health professionals assume over them within healthcare systems and dyadic encounters. Carel and Kidd highlight how ill people within the healthcare system are often not taken seriously when they report symptoms, and doctors have the power to decide which testimonies to take seriously and which to ignore. This reflects an epistemic power dynamic where medical professionals, as experts, are able to dismiss and undermine the knowledge that ill people have about their own experiences (Carel and Kidd, 2014). Thus, ill people's knowledge about their own bodies are often discredited due to testimonial injustice, or they experience hermeneutical injustice and are unable to articulate their symptoms and experiences (Carel and Kidd, 2014).

Finally, in her 2020 paper discussing epistemic injustice and people labelled/with intellectual disability, Catala critiques Fricker's focus on language-based propositional knowledge. Catala argues that: "a fundamental premise underlying this literature is that epistemic injustice is normatively problematic because it undermines individuals' epistemic agency, i.e., their ability to produce, convey, or use knowledge" (2020, p, 756). Catala points out that standard conceptions of both testimonial and hermeneutical injustice focus on language-based, or logocentric, exchanges of knowledge. She argues that this focus on logocentric knowledge implies that those who do not communicate through language are not defined as epistemic agents and are therefore unable to experience epistemic injustice. To counter this, Catala argues that it is possible to express epistemic agency through non-propositional knowledge domains such as practical (knowing-how), tacit (common-sense), affective (emotional-knowing) and embodied (knowledge from the body). She proposes that each of these knowledge domains has its own form of epistemic agency, and that agency can be expressed by “doing something that involves its corresponding epistemic object, i.e., the type of knowing it concerns: e.g., producing, conveying, or using that particular type of knowing” (Catala, 2020, p. 763). Thus, epistemic agency can be expressed using non-verbal modes of expression, as non-propositional knowledges can be produced, conveyed, or used, without using language (Catala, 2020). For example, swimming is a skill that requires practical knowledge. Swimming across a pool demonstrates this practical knowledge and represents a form of practical epistemic agency that does not require spoken language. By increasing the number of knowledge domains that convey epistemic agency, Catala expands the scope of epistemic agency to include people who do not use spoken language (Catala, 2020). In addition to expanding the scope of epistemic agency to include non-propositional knowledge, Catala proposes that there can be different types of epistemic injustice relating to these differing knowledge domains. Catala points to how this is particularly relevant for people labelled/with intellectual disabilities as they are discredited as knowers in many domains beyond spoken statements due to presumptions of incapability. “For example, an undue credibility deficit might occur in the context of practical epistemic agency when displaying skilled know-how that is inadequately recognized, thereby yielding what I call practical testimonial injustice” (Catala, 2020, p. 768). In summary, Catala argues that centring only spoken testimony or understanding when considering epistemic agency and injustice is highly limiting. It is necessary to recognize the non-verbal ways that people can express agency, especially when considering people labelled/with intellectual disabilities (Catala, 2020).

Epistemic injustice has been applied to experiences of disability in general (Scully, 2018), and to mental disabilities in particular (Dohmen, 2016). Scully (2018) argues that there are “distinctive features of disabled life that, because they shape the processes through which knowledge is gathered, evaluated, judged, and disseminated, also influence the ways in which epistemic injustice is experienced by disabled people” (p.106). Scully notes that disabled people often have to interface with medical or social care systems that assume epistemic privilege over them, and that disabled people must learn how to communicate in the ways that these systems deem appropriate, or not be taken seriously. She also discusses the idea of “global epistemic incapability” (p. 116), or the idea that “the fact of impairment by itself is taken to render someone incapable of being a source of reliable knowledge, irrespective of whether the impairment itself might reasonably be expected to do so” (p. 116). Scully highlights the patronizing way that nondisabled people often address questions towards companions or support staff rather than disabled people, reflecting an assumption that the disabled person does not know or cannot communicate for themselves. This is an issue that Dohmen (2016) also makes note of; he highlights an account by an autistic self-advocate who reports that her support staff is assumed to speak for her, even though she is able to communicate for herself through the use of communication technology. Similar to Scully (2018), Dohmen discusses the epistemic privilege that professionals have over people deemed to have mental disabilities and introduces the ways that decision-making power is regularly stripped from people labelled/with intellectual disabilities due to epistemic injustice. He describes an example where someone labelled/with intellectual disability wanted to marry her partner, but her family and the staff at her housing and employment agencies determined that she needed to live with her partner for two years before getting married. “It seemed like they were making decisions for us. They would talk about you like you weren’t even in the room… I felt I did not have any say about how I wanted to live my life” (Hageman, 2009, as cited in Dohmen, 2014). Dohmen also describes how those advocating against institutionalization have faced persistent testimonial injustice, as their accounts of institutionalization are taken to be untrustworthy, and it is assumed that non-disabled allies must be manipulating the disabled organizers. He explores how these epistemic injustices can lead to further harms, such as creating doubt about whether self-advocates can trust their own knowledge and make their own decisions. This is understood to be caused by the erosion of a trait known as “epistemic courage” (p. 672), which refers to one’s ability to feel confident about their knowledge even when it is challenged (Dohmen, 2014).

Bringing concepts relating to epistemic injustice and epistemic agency into my data analysis is an important frame for analyzing participants’ experiences and interactions with disability support staff. It is also important to recognize undue epistemic privilege as theorized by Carel and Kidd (2014) and highlighted by Scully (2018), and Dohman (2016), which speaks to the related problem of staff or professionals being assumed to ‘know best’ while people labelled/with intellectual disability are presumed to ‘not know’. Pre-emptive testimonial injustice, where a person’s knowledge is never sought out because they are not considered to be good informants (Fricker 2007), is particularly relevant to this population in relation to academic research. Santinele Martino and Fudge Schormans report that one of the authors was asked by an ethics committee member: “whether there really was any benefit to interviewing labelled people as they supposedly ‘cannot provide good data’” (2018, p. 10). People labelled/with intellectual disabilities are frequently excluded from research and other forms of knowledge production (Santinele Martino and Fudge Schormans, 2018).

I believe epistemic injustice as a theoretical concept frames the importance of asking people labelled/with intellectual disabilities about what they want staff to know because it articulates ways that exclusion from knowledge production is harmful. Similarly, contributory injustice as theorized by Dotson (2012) suggests that people labeled/with intellectual disabilities are harmed by a lack of uptake or understanding of their knowledge and experiences. Both of these theoretical principles highlight the importance of giving credence to and prioritizing the perspectives of labelled/with intellectual disabilities. Including epistemic injustice as part of my theoretical framework for this project synergizes well with the use of a critical disability orientation; critical disability approaches emphasize the need to agitate for social justice for those with stigmatized body-minds, and epistemic injustice identifies a particular form of social injustice that this project attends to. Epistemic injustice was also highly visible in my data, which will be explored during the discussion chapter.

Methodology:

The methodology and methods for this project are influenced by two methodologies: inclusive research and critical disability studies. The conceptualization of critical disability studies (CDS) as a methodology is described by Minich (2016). Minich proposes that:

> The methodology of disability studies as I would define it, then, involves scrutinizing not bodily or mental impairments but the social norms that define particular attributes as impairments, as well as the social conditions that concentrate stigmatized attributes in particular populations (p. 3).

Minich (2016) emphasizes the importance of social justice work to critical disability studies and proposes that disability scholarship should: “occur not for its own sake but with the goal of producing knowledge in support of justice for people with stigmatized bodies and minds” (p. 3). Schalk (2017) further suggests that critical disability studies can be understood as a “methodological approach to studying power, privilege and oppression of bodily and mental norms which is not dependent upon the presence of disabled people, yet is informed by their perspectives, practices, and concerns about disability” (para. 3). Taken together, these perspectives suggest that research can be aligned with critical disability studies by orienting to social justice, being concerned with the social conditions that stigmatize and oppress people who deviate from the norm, and is informed by the perspectives, practices, and concerns of disabled people.

Heilig and Sandell Hardesty (2024) draw on Margaret Price (2012) to describe four areas where critical disability methodological approaches and goals can be directly applied: access, activism, identification, and representation. Prioritizing access involves considering how to facilitate inclusive participation and present research accessibly (Heilig and Sandell Hardesty, 2024). The second area of potential application, activism, encourages researchers to translate their research into action. Identification involves contextualizing oneself within the research, whether that is as a disabled researcher, or a sympathetic ally. Heilig and Sandell Hardesty note the interconnectedness of identification and representation when working from this methodology; “a disability studies approach to identification connects to representation in qualitative work, as it necessitates more attention to the imaginary boundaries between those researched and those who are researched” (2024, p. 6). Thus, representation can become a part of critical disability studies projects by capturing the nuances of researchers’ subjectivities in addition to communicating the views and experiences of those participating in the research.

This project is also influenced by the methodological principles of inclusive research – an approach to research with people who are labelled/with intellectual disabilities that is rooted in goals of social justice, of identifying and challenging oppressive stereotyping and pathologizing responses to people labelled/with intellectual disabilities (Walmsely and Johnson, 2003; Bigby et al., 2014; Garatt et al., 2022). Inclusive research as originally defined by Walmsely and Johnson (2003) refers to research that:

> includes or involves people with learning disabilities as more than just subjects of research. They are actors whose views are directly represented in published findings in their own words but – and this is important – they are also researchers playing an active role as instigators, interviewers, data analysts or authors (pp. 61-62).

While Walmsely and Johnson were the first to coin the term ‘inclusive research’, and their definition remains influential twenty years later (Garatt et al., 2022), there are a number of approaches to inclusive research (Bigby et al., 2014). Following a comprehensive review of the peer reviewed literature surrounding inclusive research available at the time, Bigby et al., (2014) identified three approaches to inclusive research: advisory, leading and controlling, and collaborative group. In the first approach, advisory, people labelled/with intellectual disabilities act as advisors to the research team, making decisions about research priorities, funding, or other elements of the project (Bigby et al., 2014). When projects use a ‘leading and controlling’ approach, they aim to give people labelled/with intellectual disability ownership of the research process (Bigby et al., 2014). This means people labelled/with intellectual disabilities initiate, lead, and execute the research (Bigby et al., 2014). Finally, collaborative group projects involve people labelled/with intellectual disabilities working in collaboration with community groups or academic researchers. Bigby et al., (2014) define collaborative groups as “partnerships or collaborations in which people with and without disabilities who work together have both shared and distinct purposes which are given similar attention and make contributions that are equally valued” (p. 8).

Critical disability studies and inclusive research are two methodological approaches that draw on guiding values to shape the research; the creation of knowledge that benefits those with stigmatized body-minds (Minich, 2016; Schalk, 2017), and collaboration with people labelled/with intellectual disability during the research process (Walmsely and Johnson, 2003; Bigby et al., 2014) respectively. One way of applying these principles is to draw on methods that align with these values, such as participatory research methods. Participatory research “argues in favour of the possibility, the significance, and the usefulness of involving research partners in the knowledge-production process” (Bergold and Thomas, 2012, p. 192). In order to be understood as a participatory project, research partners must have some degree of control and decision-making power over the process and outcomes of the project (Bergold and Thomas, 2012). Thus, participatory research and inclusive research, while not synonymous, both prioritize involving those who choose to be a part of the research as collaborators rather than subjects.

In order to apply the principles of critical disability studies and inclusive research, I conceptualized my MSW research project as extending beyond the limits of an academic thesis. In addition to writing a traditional thesis, this project also includes a participatory component: the co-creation of a training tool for disability support staff. This training tool complements my chosen research question: what do adults labelled/with intellectual disabilities want disability support staff to know to facilitate more respectful, equitable, and consistent support relationships? I wanted to co-create this training tool with the participants so that their knowledge regarding disability support could be shared with staff directly by sharing the tool. Collaborating with the participants of my project in this way allowed me to action my chosen methodologies, critical disability studies and inclusive research. Working with the participants to co-create a training tool reflects the collaborative group approach to inclusive research described above, where academic researchers and people labelled/with intellectual disability have shared and distinct purposes during the research process (Bigby et al., 2014). Since the research question identifies staff behaviour as potentially problematic, the aim for the co-creation of this tool was to influence staff behaviour and affect change directly. In doing so, this project aligns with a critical disability studies methodology by using research to affect change in support of people labelled/with intellectual disabilities.

Methods:

Recruitment, On-Boarding, and Informed Consent:

This research project made use of purposive sampling. Potential participants were contacted through developmental service organizations and self-advocacy groups in the Southern Ontario region, excluding Hamilton, Ontario. I recruited participants from outside of Hamilton because I had worked as an inclusion counsellor for five years and I wanted to avoid recruiting anyone that I knew, or who might have contact with programs that I work for. My thesis advisor, Ann Fudge Schormans, who has been involved in many inclusive research projects, provided me with email addresses for staff contacts at organizations such as Respecting Rights, Christian Horizons, and the Participatory Action Research Network. I sent an email to each of these contacts, attaching my plain language Letter of Information (LOI), recruitment poster, as well as templates for talking to potential participants about the study by phone, email or directly (in-person). Initially, I had intended to recruit young adults 18-29 years old for this project, so I requested that information about my study be shared with service recipients that were 18-29 years old that they knew to be able to consent to the research. I requested that the information be shared with potential participants in the way(s) that were most accessible to them, drawing on the scripts I had created for communicating about the project via phone, email or in-person. I asked staff contacts to provide my email address and my temporary phone number to potential participants so they could contact me if they were interested in participating. I chose to sample from a relatively large region so I could reach out to as many organizations as possible.

Recruiting participants was difficult; I had to make two amendments to my sampling strategy before I was able to recruit participants to this project. First, I expanded my sampling region from the Niagara and GTA region to anywhere in Southern Ontario. I did this fairly early in the recruitment process, only a week after first sending out my initial contact email. I made this change to avoid excluding potential participants from the wider region of Southern Ontario. I used virtual methods for collecting data, which meant that I did not need to worry about managing physical distances between myself and the participants, or between participants. Even after expanding my sampling area, only one potential participant reached out to me during the first three weeks of recruitment. I then submitted a second amendment that increased the honorarium I was offering (from $50 to $60) and age range (from 18-29 to 18+) for the project. Following this second amendment, eight additional individuals reached out to express interest in this project through phone or email. Three of these individuals were not recruited into this project for various reasons: one declined to participate for personal reasons, another had a scheduling conflict, and a third was under the age of 18. Thus, I recruited six participants into this study in total. It is important to note that the participants for this project self-selected and had control over whether to participate. Rather than collecting any information regarding particular diagnoses, I relied on organizational contacts' determination, and participants' expressed interest in the project as confirmation of eligibility.

Once potential participants expressed interest, I booked an initial meeting over Zoom. While booking the meeting, I sent a copy of the LOI via email, to ensure that they had received it. During the initial meeting, we reviewed the LOI and I obtained and documented their oral consent to the research. The participants also chose pseudonyms for use in publications, and we discussed whether they wanted to be credited for their work on the training tool. This initial conversation focused on the potential costs and benefits of being credited, specifically that by putting their name on the training tool others would be aware that they had participated in this project. I also stressed that this decision could be changed any time until the training tool was published and would be revisited closer to the publication of the tool.

In light of dominant assumptions that people labelled/with intellectual disabilities are unable to consent to research, it is extremely important to attend to informed consent when performing research with people labelled/with intellectual disabilities (Knox et al., 2000; Santinele Martino and Fudge Schormans, 2018). This requires ensuring everyone understands both their role in the project and their rights as participants (Knox et al., 2000). One approach to realizing informed consent is to understand consent as a process rather than a one-time declaration (Knox et al., 2000). The initial meeting that I booked was an important part of this process. It allowed me to confirm that potential participants understood all the information contained within the LOI. I also used this meeting to assess the potential participant's comfort level with the project and make them aware of the types of issues that we would be discussing. We talked about potential upset that may have arisen as a result of these discussions; for example, discussing negative experiences with staff could bring back memories of troubling experiences. This served as an opportunity to establish boundaries around discussing these more troubling topics. One participant mentioned how they had personal and traumatic experiences that they did not want to bring forward in any detail. Having a conversation about this prior to obtaining consent to participate in the research was important because it reinforced an important aspect of informed consent for participation in this project; the right to not answer questions that felt too sensitive or disclose any information that the participant did not want to. In addition to obtaining oral consent during the on-boarding session, I reviewed consent and the participants' rights at the beginning of every focus group or interview session. This review emphasized that they were free to decide not to participate, to stop participation at any time, to refuse to answer specific questions, or to not take part in specific discussion they found too sensitive. Participants were also reminded of their rights to privacy and confidentiality. This review provided space for participants to ask questions and confirmed that everyone was comfortable proceeding. By approaching consent in this way, I ensured that everyone had time to think about their participation in the project and were regularly reminded of their rights as participants.

While I did not collect demographic data, it is notable that all but one of the participants were involved with the same agency. I am unsure how many of these individuals attended the same branch of this agency. I do not know why individuals from this agency, but not other organizations, decided to join my project. There were pre-existing relationships between three of the members of the focus group, as they talked about being in the same group home together. At least two different branches of this agency were involved however, and not all of the participants knew each other. This speaks to potential limitations in my recruitment sampling, as participants may have shared characteristics because they received services from the same agencies. Their experiences of support may have also had more in common than they would otherwise, since they received support from the same organization, or even the same individuals. Thus, experiences that appeared as themes in my data may be more reflective of the culture of this agency than disability support as a whole. Similarly, participants may have had higher levels of agreement on what the ‘dos’ and ‘do nots’ should be due to their common experiences, potentially reducing the generalizability of this tool.

Data Collection:

In order to determine the best form of data collection for this project, I drew on the literature surrounding inclusive research methods. Nind et al. (2022), argue that focus groups can be an especially good way to perform research with people labelled/with intellectual disabilities. They note that focus groups allow for diverse forms of participation and can allow participants to learn from each other. Specifically, Nind et al. (2022) suggest that repeated focus groups with people labelled/with intellectual disabilities can be helpful because they allow time for reflection on discussion prompts, reduce pressure to respond to questions quickly, and allow for trust to be built between participants. Following these principles, this project utilized successive focus groups in its design; data collection took the form of three successive focus groups and two separate individual interviews. The individual interviews were conducted with the same participant and a support staff that facilitated his participation in the project. I interviewed this individual separately because he received services from the same agency as several other participants and I was concerned that there could be a pre-existing relationship between the support staff and these participants. Although I was recruiting participants to my study through contacts at various agencies, I had committed to not revealing the identities of study participants to agency staff. Therefore, I interviewed this individual separately in order to uphold confidentiality.

Data collection took place between July 2nd 2023 and Sept. 3rd 2023. I conducted the three focus groups and two individual interviews virtually using Zoom. I chose to use virtual focus groups and interviews because I was sampling from a large area outside of the city that I lived in. While some of the participants lived near each other, most did not, and using virtual methods made getting this group together possible. My data collection sessions served two purposes. The first was to gather qualitative data regarding what the participants wanted support staff to know in order to facilitate more respectful, equitable and consistent support. Secondly, I needed facilitate the collaborative creation of a staff training tool. The focus groups were sequential, typically taking place with the same participants each time. One participant was unable to attend the first focus group but attended the second and third focus groups. Thus, the first focus group had four participants, while the second and third focus groups had five. These five participants chose the pseudonyms, Emma, Jessica, Jewel, Jamie Daniel, and Grim Reaper. The individuals participating in these focus groups did so without support staff present. A sixth individual, pseudonym Superman, was interviewed twice, separately, with a support staff present.

The first focus group guide (Appendix A) involved answering questions regarding what participants wanted from support, including what they wanted new staff to know, what they considered to be ideal support, and how the support they received differed from the support that they would like. These questions aimed to generate data about what the participants wanted staff to know about support, and since the intention was to create a training tool, I emphasized what new staff needed to learn. At the end of the group, I asked what form the training tool should take, and a participant suggested making a series of 'dos' and 'do nots' for the staff. This was something that others agreed with, and several ideas for 'dos' and 'do nots' were proposed. During this group, while I had control over the questions that I asked, the participants were the ones who suggested the form that the training tool should take. This was one of the ways the participants had direct control over the output of this project; this decision determined how the knowledge co-produced through this project would be communicated.

In between the first and second focus group, I edited the Zoom auto-transcript, created a summary of the main points, and wrote some draft ‘dos’ and ‘do nots’ based on my summary. Due to the time constraints of my master’s program, I was unable to use a collaborative approach for this stage of the work. I also developed my second set of focus group questions (Appendix B). While creating these questions, I had several goals. I wanted to make sure my summary was accurate, get feedback on the ‘dos’ and ‘do nots’ that I had made from my summary, and gather any additional thoughts the participants wanted to share. I also wanted the participants to give me as much direction as possible regarding the appearance of the infographics, not just the ‘dos’ and ‘do nots’. I had a couple of different ideas about how to gather feedback about the layout and appearance of the infographics. The first was to show examples of other ‘do’ and ‘do not’ infographics that I was able to find through *Google Image Search*. These infographics were on unrelated topics and had different approaches to conveying information. I showed these infographics to the participants and asked what they did or did not like about them. I aimed to learn about how the participants wanted the infographics to be presented. The participants wanted the infographics to be eye-catching, colourful, and have pictures to represent each point. Multiple participants emphasized the importance of the images, wanting the infographics to be understandable even if literacy was not a strength for the viewer. All of these directions were very important to me, and I prioritized them during the draft creation process.

My second idea for gathering feedback about the layout was to share a whiteboard on Zoom that all participants could edit. In theory, this allowed participants to brainstorm layout ideas for the infographics, however, in practice, it proved somewhat frustrating for the participants. While several participants were eventually able to communicate some of their ideas through this medium, they also experienced frustration with the unfamiliar tool not behaving in the ways they expected. While facilitating this part of the focus group, I held back on jumping in to 'fix' these challenges. I offered to help, but I did not do anything for the participants unless they asked me directly. This was important because, as I learned from participants during the first focus group, help, when given without having been asked for, takes control away from those being helped, and would have conflicted with the principles of my methodology, which emphasizes giving participants as much choice and control as possible (Bigby et al., 2014; Bergold and Thomas, 2012). Although this made the session more challenging, I think it was important to prioritize the participants' self-determination and control during this process. The participants demonstrated on the whiteboard that they wanted to use green checkmarks to denote the 'dos' and red x's to denote the 'do nots', which I incorporated into the draft infographics. They also demonstrated formatting the dos/ do nots on one large page, with 'dos' on the left side and 'do nots' on the right side. I tried to replicate this when I made the draft infographics, but I found that this was not feasible; there were too many points for one page. When I made the drafts, I used 12 pages to ensure readability. The participants also decided on the main title for the infographics: Communication Keys. In summary, during the second focus group the participants confirmed what they wanted the dos and do nots to be, emphasized the importance of bright colours and accessibility, demonstrated some layout ideas, and decided on the title for the infographics.

The first individual interview occurred in between the second and third focus groups. Although I received ethics clearance for support staff to participate in the focus groups, I interviewed Superman separately. As previously mentioned, this was because there was an overlap in service providers between several of the focus group participants and Superman. Consequently, despite the support staff having signed an Oath of Confidentiality, bringing Superman's support staff into the focus groups carried a risk of making the identities of study participants known to their service providers, breaking confidentiality. In the interview, the support staff primarily assisted Superman in setting up Zoom. They also assisted by asking Superman follow-up questions and ensuring that Superman understood the questions I was asking. This interview combined questions from the first and second focus groups: I asked the first set of focus group questions and I also asked for feedback regarding the example do/do not infographics. I modified the third phase of the second focus group. Instead of asking Superman to directly make changes to the shared whiteboard from focus group 2, I showed it to him, summarized the design choices the group had made, and asked if he had anything else he wanted to add. I made this modification because it became apparent that Superman was getting tired, and I knew directly editing the whiteboard could be very challenging. He said that he agreed with the focus group's feedback and that he wanted the infographics to be colourful but did not have anything else to add about what the infographics should look like.

The third focus group took place five weeks after the second focus group. This gave me time to complete a number of tasks, including editing the Zoom auto-transcript from the second focus group, facilitating and editing the auto-transcript of the individual interview, and creating mock-ups of the do/do not infographics. To create the mock-ups, I started by creating a list of the 'dos' and 'do nots' identified by the participants. In addition to using the items the participants agreed on during the focus groups and interviews, I reviewed the completed transcripts to ensure that any new points were also represented. After I had created the list of dos and do nots, I printed them out and arranged them into clusters. I clustered the dos and do nots that I thought complemented or contrasted each other; for example, one cluster was about not making assumptions, and what staff could do instead of making assumptions. These clusters became the basis for each individual infographic. At this stage, I decided that *Canva* was the best fit for creating the infographics. Using *Canva* granted access to a number of images that I was able to use in the infographics, which was beneficial due to the limited variety of images available through creative commons search engines such as *Wikimedia Commons*. I then created the drafts for a series of twelve infographics where several “dos” and “do nots” were clustered together for each, and all of the “dos” and “do nots” were paired with images available through *Canva*. I incorporated feedback that the infographics should be colourful and eye-catching by using different coloured backgrounds with gradients to give each infographic distinct visual flair.

Following the creation of the draft infographics, the third focus group and second individual interview involved soliciting feedback regarding these drafts. During the group, I shared my screen with the participants so that they could directly suggest changes to the mock-ups. I was able to make the changes that participants requested in real time. This was very helpful because it meant I was able to share control over the editing process; although I was making the changes on the infographics, the participants were the ones directing me on what they wanted changed, and how I should change it. For example, when participants wanted to change the images that were being used in the infographics, I was able to show them the assets that were available and they were able to decide which images they preferred. This part of the process was very important for realizing my goal of using a collaborative group method of inclusive research; we worked together towards a common goal in editing the infographics, and while we had separate roles in this process, both were important. The participants also made the decision that the full title for the infographics should be ‘Communication Keys: DOs and DO NOTs for providing support for individuals with disabilities’. This title reflected two important changes. The first was that language surrounding ‘support in recreation’ was removed; the participants felt that these infographics were applicable to a wide range of settings and wanted to see them implemented everywhere. The second change was to the language describing who was receiving support. Rather than using the language of ‘labelled/with intellectual disability’ or ‘disabled people’ the participants felt most comfortable using ‘individuals with disabilities’.

The final point of data collection was the follow-up individual interview with Superman and his support worker. Like the third focus group, this interview involved gathering feedback regarding the infographic mock-ups. I used the same method, of screen-sharing and inviting feedback on the infographics, as I did for the third focus group. Following the conclusion of the focus groups and individual interviews, all participants received a $60 honorarium for their time. Participants received these honorariums by e-transfer, or through mail via cash or gift cards. I also confirmed how each individual wanted to be credited on the infographics. One individual chose to use their initials, another their full name, and the other three are credited by their pseudonyms. I had a conversation with the individual who wanted to use their full name, and they were adamant that their full name be used so that they could be credited for their work.

One key direction that the participants gave during the infographic creation process was that they wanted the infographics to be accessible. To honour this request, I kept accessibility principles that I was already aware of, such as maintaining high colour contrast between text and backgrounds, and using large, sans-serif fonts in mind. I also met with Nusrat Mir, McMaster's accessibility specialist in order to learn more about how to ensure the infographics were accessible. She gave me tips on how to write good alternative text for the images in the infographics, and also helped me adjust some of the layouts to make them easier to understand. My supervisor, Ann Fudge Schormans, also helped me create appropriate alternative text for the infographics in *Microsoft PowerPoint*. I licensed the infographics under a creative commons, attribution-noncommercial-noderivs license prior to distributing them. This means that people are free to share this work, with credit, without using it for commercial purposes or making changes to them. I will expand further on my distribution strategy for these infographics in my discussion chapter.

In summary, throughout the creation process I found ways to ensure that the participants were directing how the infographics were made. The participants proposed what kind of infographics we should make, shared their ideas about what the dos and do nots should be, directed that accessibility should be prioritized, and provided ideas about how the infographics should be designed and laid out. They determined that the infographics should speak to 'providing support for individuals with disabilities', choosing both the language and context of the infographics. When reviewing the draft infographics, participants chose how the infographics should be edited, directing me to make the changes that they wanted from the available options. Finally, they made the choice regarding how they wished to be credited for their work on the infographics.

Data Analysis:

I performed initial iterative analysis concurrently with data collection from July- September 2023. First, I edited the Zoom auto-transcripts by reviewing the video recordings of the focus group and interview sessions after each session was completed. This involved carefully ensuring that the words written on the transcript were accurate, in addition to making editorial choices regarding the punctuation that was used. After each session, once I had completed the transcripts, I performed an initial analysis by summarizing the data. This was necessary to facilitate the creation of the infographics. I also did this so that I could discuss these summaries with project participants during the follow-up focus groups and interviews; I wanted to ensure that they agreed with how I had understood their points. Clustering the ‘dos’ and ‘do nots’ was also a form of data analysis, since I was making judgements about how various points should be grouped together to make the infographics. I also sought feedback regarding these groupings from project participants.

Following the data collection phase in September 2023, I began thematic analysis, following the guidelines for thematic analysis first outlined in Braun and Clarke in 2006, and expanded upon in their 2022 textbook which goes into greater detail regarding reflexive thematic analysis. To begin the process of thematic analysis, I read over the completed transcripts several times. I used an inductive method to generate a list of codes from the data. Rather than pre-generating a list of codes, I generated my codes from the data (Braun and Clarke, 2006). I then printed out paper copies of each of their transcripts and coded them manually. Once all my transcripts were coded, I compiled a list of all the codes in Microsoft Excel. I looked for similarities and grouped related codes together into clusters. While my clustered codes did not translate directly into my chosen themes, I used these clusters of codes to identify common recurring elements within the data. I then wrote out these elements on a whiteboard and identified connections between them. I then condensed these connections into three initial potential themes: how support could be unhelpful, how support relationships could be challenging, and what made good support. Analysis continued as I organized and wrote up my data. I found there was a lot to be said about how support was unhelpful, and that participants spoke more about they wanted from support, particularly through the dos and do nots, than they did about what made good support. Thus, I restructured my themes to focus on these two elements, drawing on the completed infographics to demonstrate some of the ideas participants had about what they would like to see from support.

Challenges/Limitations:

There were a few challenges that I encountered during this project. Firstly, not all participants were able to participate fully in the focus group conversations. One participant of the focus groups was significantly less communicative than the others. While they occasionally joined the conversation to say a few words, or provide short answers in the chat, the use of online focus groups made it very hard to learn more about their thoughts and opinions. There were a few times when I asked this individual specific questions and they gave one-word answers, or very short written answers sent to me as private messages in the chat. At one point early in the first focus group, other group participants were instructing this person on how to write a response in the chat, when they had already sent an answer to me privately. As a facilitator this was difficult to manage, since I did not want to address private messages publicly, but the conversation had stopped completely, focusing on instructing this person on how to do something they were already doing. This made me very uncomfortable, and it made me feel like I was singling them out, since trying to learn more had caused the entire conversation to shift, becoming about this person rather than the intended topic. In addition to this person not speaking or using the chat very much, there appeared to be other communication barriers; I found their spoken language difficult to understand, nor was it always clear to me if they were able to hear the conversation. There were also times when it was possible to hear other things that were going on in the background, which appeared to be a further challenge. After the first focus group, I sent an email to all the participants and encouraged them to reach out by phone or email if there was anything else they wanted to say, and that it was okay if talking one on one was more comfortable. I received no response to this. While I could have been more direct in addressing this issue, this person had not consented to being contacted for follow-up discussions or focus groups, indicating instead that they were “not sure” when I asked about this during the oral consent process. Due to this, I felt it was appropriate to reach out to everyone in a general way, but not to request a follow-up interview with this person specifically. With the knowledge that I have now after completing this project, I think that an individual interview would have been a more appropriate way to collaborate with this person; this way I could take as much time as needed to ask the right questions to learn more about their thoughts without causing an entire group of people to focus on them. I could have addressed this during the on-boarding process, by asking how best to provide support, and whether they would be more comfortable with an individual interview.

A second limitation was the challenge associated with gauging and sustaining engagement with participants for the duration of each focus group, which lasted approximately an hour and twenty minutes. Using online focus groups made this harder to deal with, as participants were able to turn off their cameras, making it impossible to gauge body language. I also had no control over their environments, and it was possible to overhear a number of background distractions. At one point during the second group another participant fell asleep for a portion of the discussion. A second participant, who was in the room beside this participant, tried to wake them up but was not successful in doing so. Afterwards, I reached out to them to ask if they wanted to discuss any parts that they might have missed while asleep, but they were not interested. While this was the most extreme example of participant disengagement, it was sometimes hard to tell, particularly when soliciting feedback, whether agreement was entirely due to genuine agreement or instead because of lack of engagement.

Thirdly, the presence of the support worker influenced how the individual interviews with Superman proceeded. Although the support worker made including Superman in this project possible, they also actively participated in the conversation, offering their opinions and making comments throughout. When they offered their opinions, they often invited Superman to respond, or to disagree with them if their statements were incorrect. Thus, while the support worker seemed to make an effort to not speak over Superman, they still influenced the conversation by participating in it. Consequently, Superman's interviews were not purely reflective of his thoughts and opinions.

Findings:

This project involved six participants with different experiences of support in their lives, and this is reflected in my findings and subsequent analysis. While I did not collect demographic information, five of these individuals, Jamie Daniel, Grim Reaper, Superman, Emma and Jewel were affiliated with an organization that provides paid daily living support. Jessica, meanwhile, did not receive daily living support from paid staff, instead receiving support primarily from family members. While Jessica spoke of her lived experiences as someone with visible and invisible disabilities, she also had experience working as a disability support staff. Thus, throughout the focus groups she drew on her observations from work in addition to her experiences with people in public, and her support experiences with her family.

Initially, I had planned to focus my project on disability support in recreation, but this did not unfold as I had originally intended. When I first began asking questions about what kinds of support in recreation everyone had experience with, it seemed that only Grim Reaper, Jewel, and Superman were regularly engaging with recreation activities where paid support staff were present. Grim Reaper identified a recreational program run by a local social service organization that he attended, while Jewel said that she regularly attended a community centre that ran recreational programs for disabled people. Superman indicated that he received support with recreational activities on a regular basis. Jamie Daniel and Jessica had experience with recreation, but only distantly; Jamie Daniel described going to swimming lessons as a child, and Jessica mentioned being involved in Special Olympic sports events when she was in high school. Emma indicated that she did not have experience with recreation programs. While some had more recent experiences with disability support in recreation than others, my plan to discuss support specifically in the context of recreation fell apart quickly; when I asked about ‘support’, the experiences that were most salient to participants were the ones that they experienced most regularly, in most cases, their experiences of daily living support. Rather than trying to redirect the conversation so that it was specific to recreation, as I had originally intended, I felt it was more aligned with my methodological approach to allow the project to go in the direction that the participants believed it was most important to discuss.

After conducting thematic analysis on the transcripts from the three focus groups and two individual interviews, I observed participants identified various ways that they found support was too often unhelpful or harmful. This was my first major theme, which I broke down into several subthemes: variable treatment from staff, assumptions of (in)capability, and directing or doing for participants leading to neglect of opportunities for skill development. While participants had a lot to say about these negative experiences with support, they also had ideas for alternative staff practices. Some of these alternatives were spoken about directly, while others were presented through the co-developed infographics. Thus, my second theme reflects what participants wanted to see from support staff. I have broken this down into the following sub-themes: respect for boundaries, kind and compassionate treatment, and recognition and respect for individuality. My two major themes and the associated subthemes were highly interconnected, as what the participants wanted to see from support staff was directly contrasted with the ways that they found support unhelpful or harmful. This interconnection is also reflected on the infographics developed collaboratively with the participants, as many of them present both things that they did not want support staff to do, and what they wanted them to do instead. I present a selection of the infographics in this findings section, and Appendix C includes the full collection.

Theme One: Ways that support was often unhelpful or harmful.

During the interviews and focus groups, participants discussed ways in which support could be unhelpful or potentially harmful in both the short and long-term. Unhelpful help can be broken down into three key elements, a) variable treatment from staff, b) being assumed to be (in)capable, and c) directing or doing for participants leading to neglect of opportunities for skill development. Overall, these ways that support could be unhelpful came up frequently during the first two focus groups; even questions that had been intended to elicit information about positive aspects of support tended to return to discussion of how support could be unhelpful or harmful.

Sub-theme a) Variable treatment from staff.

One key issue that repeated throughout both focus groups and individual interviews was that there was a high level of variance in the quality of staff support, reflected in the differing ways they treated participants. This issue first emerged when I asked whether participants felt like staff treated them with respect; in response to this question Jamie Daniel responded: “Oh in some, in some cases some of the staff that I’ve had to deal with were not very kind in some sense and other times they were good. Depends on the staff working, really” (Focus Group 1). In addition to noting that some staff were not very kind, he referred to how these are staff that he’s “had to deal with.” This speaks to the power dynamic inherent to interacting with support staff; these unkind staff are a fact of Jamie Daniel’s life that he has to manage, as he does not have direct control or choice over which staff he needs to interact with. This issue was also raised by Grim Reaper during the second focus group:

> Jessica: Are you able to request a certain staff?
>
> Grim Reaper: No. I tried. My manager told me I need to learn to get along with everyone.
>
> Jessica: But everyone has different personalities.
>
> Grim Reaper: No, exactly, that's basically what I told her. So, there's days like… there's certain days that I just stay locked up in my room. It's easier than putting up with people.

Here, Grim Reaper described both a lack of control over the staff that are assigned to him, and how this impacted him; he limited his own activities on certain days in order to avoid staff that he disliked. Grim Reaper's preferences for certain staff were also dismissed, as he was told that he needed to learn how to get along with all staff, implying that Grim Reaper was the source of the issue. This demonstrates a failure to recognize the reasons why people receiving support have preferences regarding their support workers. Jewel also discussed how she had experienced variance in staff quality:

> I don't know exactly how many staff here, but the only staff that can support me are working here… there's three, but one kind of doesn't work here very much. And that is because they couldn't treat me with respect. They didn't respect my scent allergy, my medical… They… there's other things I'm not going to get into but they…they didn't… I didn't feel treated

> as a human being and that’s why I don’t want… but they don’t see in their eyes that they did anything wrong for me to not want any support from them. So, they see it as favourites even though I see it as you couldn’t respect me, my property, my medical, and you made fun of my disability, so I don’t want anything to do with you (Jewel, Focus Group 2).

It was clear that the negative treatment she had received from some support workers weighed heavily on her. Some of these experiences were so negative that she did not feel comfortable elaborating on them during the focus groups. Like Grim Reaper, Jewel’s account reveals problematic responses to her attempts to assert control over which staff she receives support from. Her preferences were discounted as playing “favourites” rather than recognizing why she or others might have valid reasons for having preferences about support staff. Jewel also identified her negative experiences with support as dehumanizing and disrespectful, and it is notable that there are very few staff that she said she felt comfortable with.

While these descriptions of staff variance present situations where the participants did not want support from certain individuals, participants also talked about how they felt that some staff brushed them off, telling them that they did not have time to help them. While there was recognition that this could be caused by factors outside of the staffs’ control, such as being short-staffed or very busy, participants also reported that they felt that some staff simply did not want to help them:

> But other times it’s just like they just brush me off and only support me when they feel like they have time to support me. It also depends on their time too. Sometimes there are times when they’re busy and really overworked, and other times they just like they’re not busy and they just don’t want to work with me (Jamie Daniel, Focus Group 1).

Jamie Daniel seems to suggest that he understands these brush-offs as relating to him personally, and he connected being brushed off to feeling disrespected:

> Well, one of the things I feel that staff disrespect me with is when I need to get something done and they say they have no time, or they’re short staffed or something, and they just completely brush me off! That’s why I feel disrespected when they don’t really help me out when I need it, you know? (Focus Group 1).

This sense of disrespect appears to come from Jamie Daniel’s perception that his needs were being neglected; he emphasized that these times when he asked for help were times that he needed it. He seems to suggest that rather than working with him to find a solution, or find a time when they can help him, staff told him that they did not have time to help and ignored his needs. In his individual interview, Superman also indicated that he was frustrated by staff telling him that they did not have time to help him (Individual Interview 1):

> Student Investigator: Do you ever find that staff are not as helpful?
>
> Superman: Sometimes I do.
>
> Student Investigator: So, how come they’re sometimes not as helpful?

Superman: Ugh. When they tell me that they don't have time to do stuff.

After Superman expressed his frustration with being told that staff did not have time to do things, the support staff present in the interview jumped in to suggest that this was because Superman's schedule and the support staffs' schedule did not always sync up and this was the primary reason why Superman was told that staff did not have time to help him with his preferred activities. The support staff invited Superman to correct them if they were wrong, and Superman did not object to what they were saying. This exchange suggests tensions between the wishes of people receiving support and the available resources, something that Jamie Daniel mentioned as well when he alluded to staff being very busy and overworked.

Jewel and Jessica also addressed this issue, of being dismissed or brushed off when asking for help. While Jessica's account of this was second-hand, she reported that: "I've worked with a client that said their previous staff just dismissed them whenever they asked for help" (Focus Group 2). Jewel followed Jessica, saying she "totally agreed with that", and later (in focus group three) elaborated on her own experiences of being brushed off when asking for support. Jewel spoke of her frustrations with trying to receive help; she explained that staff sometimes refuse to help her if they perceive her as not needing it.

> So, I asked the staff for help, and I don't ask for help unless I need it. And I called over and they were telling me how to do it over the phone when I'm a visual learner, I need someone to actually show me how… and they

> didn’t come over and I said, ‘so you assume you’re an expert on what I need help with and don’t need help with.’ And they’re like ‘pretty much’ (Focus Group 3).

Jewel articulates that in these situations staff are making decisions about what she does or does not need help with, situating themselves as the “expert on what I need help with and don’t need help with”, this reflects a further issue, of staff making assumptions regarding (in)capability, which I will expand upon shortly.

Finally, Grim Reaper described a final element of staff variability: disengagement. Speaking on the laid-back work conditions of the disability support job: “Certain people are there for a paycheque and others are there because they genuinely care… because if you…in this line of work, this place you can honestly, they can get away with sitting on a phone all day if they really wanted to” (Grim Reaper, Focus Group 1). Here, Grim Reaper is suggesting that there is a divide between staff that are invested in the work that they are doing on a personal level, who “genuinely care”, and those whom he understands to have no interest in performing the supportive aspects of the role, instead wanting an easy paycheque.

In summary, almost every participant noted that there was a high level of variability in the quality of support that they received from staff, and that being brushed off (for whatever reason) when support was needed was a significant issue. Participants identified different reasons for feeling that staff were unequal in providing support, including unkindness, disrespect, and disengagement. They also highlighted how they were unable to control which staff they need to interact with, and how their attempts to exert control were rejected by managers within their organizations. The action of being brushed off is a particularly notable issue because it was identified as one of the ways that staff can be disrespectful, and because it seems that brushing off requests is a common, possibly automatic response from certain staff. While some organizational factors, such as being overworked, or conflicting schedules, were identified as reasons why participants might be brushed off, it was also attributed to staff not wanting to help, or staff deciding that participants did not actually need help. Finally, some staff were perceived as disengaged, and uninterested in providing support.

Sub-theme b) Assumptions of (in)capability

While I have shared Jewel's experience, where staff made the assumption that she was able to do things independently, the opposite, where the support staff appeared to start from an assumption of participants as being incapable, was also a prominent sub-theme related to unhelpful support. This was also a very emotional issue for participants. Jamie Daniel, Jessica, and Jewel especially expressed anger and frustration about the ways that people made assumptions about what they could or could not do.

Assumptions of incapability were identified as a concern almost immediately when the first focus group started and was revisited a number of times throughout all three focus groups. In the first focus group, when I asked about what participants liked about the programs they enjoyed, or did not like about the programs that they did not enjoy, Jessica spoke generally of her lived experiences of being disabled: “I will say when it comes to being disabled and you know, overall, I personally really don’t like it when people either treat me like a child, or assume what I can or cannot do” (Jessica, Focus Group 1). Here, Jessica was speaking of being infantilized and of assumptions being made about her capabilities, two concepts that are closely related but distinct from each other. In many cases when people are assumed to be incapable, they receive infantilizing treatment as a result, something that will be explored further throughout this section and my discussion.

As soon as Jessica mentioned how others made assumptions about her, Jamie Daniel responded that he knew how that felt because he’d experienced the same thing. A few minutes later, while describing his experience receiving swimming lessons, Jamie Daniel said of support staff: “They more just assumed what I was capable of and then just went with that. I didn’t like that very much” (Jamie Daniel, Focus Group1). This speaks to staff feeling that they are experts who do not need to learn from the people they are supporting about what they need. Grim Reaper also spoke on this issue. When asked if staff were supportive, Grim Reaper said: “I feel like people, when they’re trying to support you… I feel like when they try though, they think they know what’s best for you and not who you are” (Focus Group 1). Here, it is suggested by participants that rather than getting to know recipients of support, support staff adopt a patronizing approach. This approach, where “staff know what’s best for you”, reflects an assumption that those being supported do not, or cannot, know what is best for themselves. This demonstrates a support dynamic where staff are understood to be experts and knowledge-holders, discrediting participants' own knowledge about what they need.

Jewel's experience discussed during the previous sub-theme, where she was brushed off when asking for help because staff decided that she did not need it, has many similarities to what Jamie Daniel and Grim Reaper said; staff made assumptions about what she was capable of, and felt they knew what was best for her. This is reflected in what Jewel said: "you assume you're an expert on what I need help with and don't need help with". While Jewel's experience was the only case I observed where participants referred to staff assuming they were able to do things more independently than they actually were, it demonstrates a similar issue. It suggests that participants' own knowledge as to what help was needed or wanted was discounted and dismissed. Instead, staff believed they knew better than the people they are being paid to support regarding their own needs.

Speaking more on her experiences of being infantilized, Jessica spoke about how she felt the visible aspects of her disability contributed to the assumptions that people made about her and the infantilizing treatment she receives as a result:

> Also, I don't know if anyone else experiences this, but I use a cane and a wheelchair and I look much younger than I am. A lot of people tend to

> baby talk when they speak to me, and that's extremely aggravating… It pisses me off so much, excuse my language…just because I'm walking differently doesn't mean that I'm a baby (Focus Group 1).

Baby talk is understood by Jessica as an infantilizing behaviour that reflects assumptions about what people are able to understand; when one uses baby talk, they are assuming that the person they are speaking to would not otherwise be able to understand them. Jamie Daniel sympathized strongly with Jessica's frustration adding: "All during my childhood, I've always been talked down to. And I've always had issues in my childhood because I've always been, I've always been a feisty fucker" (Focus Group 1). Both Jessica and Jamie Daniel emphasized how aggravating condescension and baby talk were, highlighting how important it was to them that staff did not infantilize them.

This issue, of being talked down to, was revisited during Focus Group 3. We were editing one of the infographics, "DO NOT treat disabled youth, teenagers or adults like babies or children," when Jessica suggested that we should add a point about not talking down to people. Jewel strongly agreed with this:

> I know a lot about liver disease and I was… the doctor was trying to tell me something that I knew wasn't true, and so I went to my pain doctor and told him and he goes 'oh, he was just talking down to you because he didn't know you knew as much about liver disease as you do' and I literally had the words 'don't talk down to people' 'cause he said 'oh he was just

> talking down to you because he didn't know that you knew' (Focus Group 3).

Jessica elaborated on this, adding that the dynamic is like: "I'm able-bodied, you're disabled, so you're dumb." (Focus Group 3).

In addition to discussing the assumptions that were made about them, participants also described how these assumptions impacted their lives. Jessica pointed out that: "…it's so demeaning to assume what we're capable of". This language, of being demeaned, is significant. It reflects a sense of being devalued or treated as lesser. Jessica also discussed how being assumed to be incapable can be harmful because it can lead to self-doubt. She spoke of this several times, particularly in the context of education: "Everyone made me think I was stupid because they put me in the lowest classes, and I was getting As. Then I go to college, and I started getting As, and I'm like 'wow, I'm actually not dumb'" (Focus Group 3). While these experiences that Jessica was referring to occurred outside of the boundaries of a disability support relationship, they demonstrate a critical harm that can occur when people are told that they are not capable, as theorized through the theoretical framework of epistemic injustice. The relationship between this subtheme, assumptions of (in)capability, and epistemic injustice will be explored further during the discussion section.

In summary, participants were greatly troubled by the assumptions that were made about them. Participants shared that they felt that staff made assumptions about what they were capable of and acted like they knew what was best for them. This suggests a dynamic where staff are understood to be experts, privileging their knowledge over those being supported. Participants reported that being talked down to was especially aggravating. Talking down to people reflects infantilizing assumptions about what people are able to understand, and it was very important to participants that they not be infantilized. Jessica also discussed how she felt people often infantilized her because of her visible disabilities. She also described how constantly being assumed to be incapable is demeaning and can create self-doubt about one's capabilities.

Sub-theme c) Directing or doing for participants can lead to neglect of opportunities for skill development towards independence.

The final subtheme describing how help could be unhelpful involved discussion around how directing people or providing too much support could lead to neglect of opportunities for skill development, making things more difficult in the long run. Jessica returned to this idea a number of times during Focus Group 1 emphasizing both how skill development had been important in her own life, and how she worked to help people find ways of doing things that work for them. This was first brought up in the context of staff making assumptions about what people can or cannot do; after Jamie Daniel suggested that staff should get to know what people are capable of instead of making assumptions, Jessica said that: "And also if I could add, for disabled people if you just do things for us, we're not gonna become self-sufficient when we're older, we're always going to be dependent" (Focus Group 1). Jessica expressed this idea, that support workers doing things for people could lead to dependence, which Jamie Daniel agreed could lead to long-term negative consequences:

> I would say according to what she [Jessica] was saying that, if, if people don't learn how to do stuff, they'll always be dependent on staff or whatever. They'll never be good in the long run in life, you know? So, if anything it's better to learn while you can while you're still young and then you can use that life skill later on (Focus Group 1).

Upon learning that Grim Reaper and Jamie Daniel were often directed by staff about what they needed to do in their daily lives, Jessica became very passionate about pushing back on this, arguing that: "…if you are telling someone to do this and do that there's no freedom or autonomy. How are people supposed to learn life skills if all you are doing is directing them?". She connected this to her perception that disabled people are often treated like children, adding "teaching them rather than directing them is so important. Yeah, I feel like people treat disabled people like children."

While this idea, that directing or doing things for people was infantilizing and could create long-term dependence, appeared less frequently in my data, I thought it synergized well with the other two subthemes to create a portrait of unhelpful help. Tying these subthemes together, my first subtheme, that help was of variable quality, suggests that not all staff provide equal quality of support. Some reasons why staff were reported to be unhelpful included disengagement, disrespect, and overwork. Participants described how they were unable to exert control over who they received help from, as their concerns regarding staff were dismissed and they were treated as though they were the problem for not getting along with them. Participants also reported that they often felt brushed off by staff when they asked for help and were unable to receive the help they needed when they needed it. My second subtheme, assumptions of (in)capability, proposes that staff often make assumptions about what people need and what is best for them. These assumptions can be observed through they ways people are talked down to or otherwise infantilized. Finally, this third subtheme suggests that staff sometimes direct or do things for the people they are supporting rather than teaching them, leading to less independence in the long run. Staff failing to teach people how to do things that they could otherwise learn connects strongly to assumptions of incapability; people are assumed to be incapable of learning, which leads to them never being taught. This failure to teach then leads to a lack of skills, producing incapability. These three elements of unhelpful help correlate strongly to the theoretical concepts of epistemic injustice, ableism, and disablism, which I will expand upon in my discussion chapter.

Theme Two: Practices participants wanted to see from support staff.

Sub-theme a) Respect for boundaries

The importance of respect for personal boundaries was something that came up in several different ways throughout the focus groups and interviews. Different participants expressed this need in different ways, but the importance of respecting boundaries was touched on by almost every participant.

In his interviews, Superman stressed the importance of personal boundaries around his living space. He talked about how his sisters' lack of respect for his boundaries would cause him to come into conflict with his sisters. It was clear that these conflicts were very upsetting for Superman, as he also talked about how much he appreciated when staff would provide emotional support when dealing with these conflicts. Rather than entering his space without permission, Superman greatly appreciated that staff would enter his living space on his terms instead:

Superman: I always kept my bedroom door closed 'cause my bedroom was off limits.

Support Staff: That's good.

Superman: I didn't like it when my sisters went in my bedroom.

Student Investigator: So, are you saying that staff show respect by not going in your space when the door is closed even though sometimes your sisters don't respect that?

Superman: I like it when [social service organization] respect that, Danny.

Support staff: Personal space, right [Superman]?

Superman: Yes.

Support staff: We understand. I think a big thing [Superman], that you care about is allowing staff to come into your apartment or your room, right?

Superman: Yes.

Support staff: You know it's completely up to you always.

Superman: Yes.

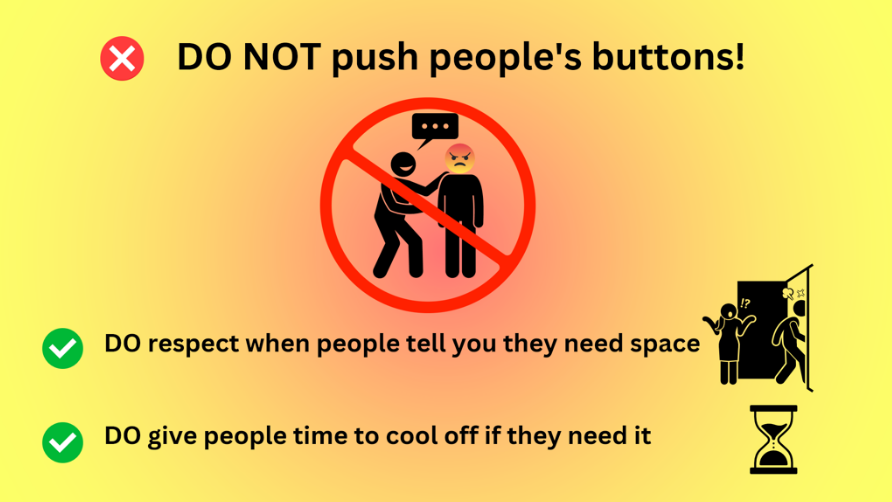
Here, Superman is emphasizing the importance of being able to make choices about who is allowed in his living space. When his sisters enter his living space against his wishes, they are denying him the ability to exercise control. The support staff proposes, and Superman agrees, that it is important that choices about who is allowed in his room are made on his terms. Thus, staff showing respect for this boundary was very important to Superman.

Another form of boundary setting involved being able to walk away or otherwise disengage from emotionally intense situations. This was very important to Jewel and Grim Reaper especially, and they discussed how having these boundaries violated made them very angry. Jewel described a situation where she was frustrated with a phone conversation, but the staff kept calling her back even after she hung up:

"…yeah they kept calling back. They didn't take the hint and they kept calling back, and I threw my phone and lost some very valuable pictures" (Focus Group 2). Grim Reaper strongly agreed that being able to walk away was very important and influenced his relationship with staff:

> Well, I got some staff that are literally… that I'm close with 'cause they'll respect it and if you tell them 'I'm pissed off right now, you need to leave me alone', they'll leave you alone but there's certain people that will sit there and provoke you (Grim Reaper, Focus Group 2).

Grim Reaper proposed that there were two different kinds of staff; those who respected him when he told them he needed time to cool off, and those who do not allow him to establish this boundary. Grim Reaper said that he had a positive relationship with staff specifically because they listened to him when he told them that he needed time to cool off. Thus, having a positive relationship with staff was predicated on respect for his boundaries. We captured the importance of this principle in one of the infographics:



✗ **DO NOT push people's buttons!**

✓ **DO respect when people tell you they need space**

✓ **DO give people time to cool off if they need it**

Jewel also discussed the importance of respecting boundaries when getting to know new staff; because of her past traumatic experiences, it was very important for her to set the pace with new staff:

> I've been mistreated by one of the guy staff and he's not around anymore, but another guy staff came working here after him and I was afraid to get to know him, to let him in because of being hurt again. So when I first met them, I explained to them I had been hurt in the past. And I don't mean to

> come off as defensive and not let you help me and getting to know you when… but I have a wall up right now and I just… they need to let me get to know them at my own pace (Focus Group 2).

Thus, Jewel wanted staff to respect her need to get to know them at her pace, rather than staff imposing themselves and their help on her.

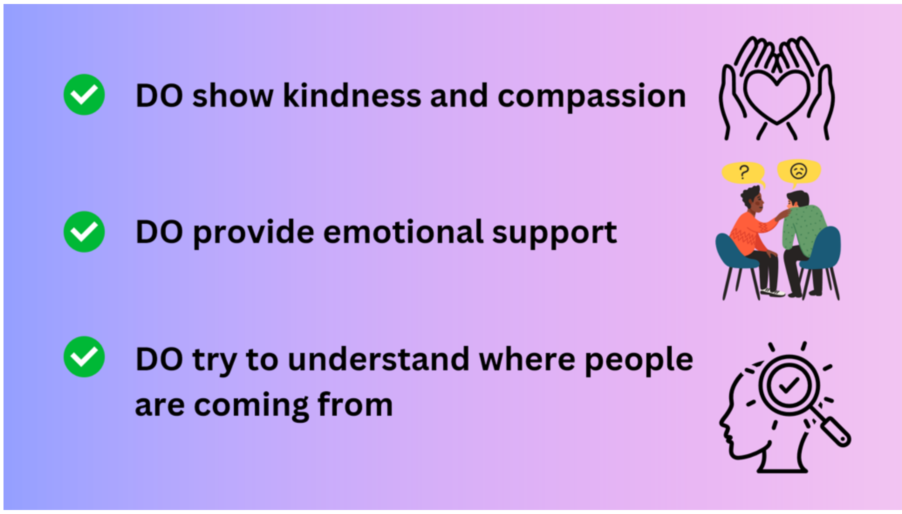
A final form of boundary-setting explored the ways boundaries around help should be established. This was first proposed during Focus Group 1 as an alternative to staff making assumptions about what support is needed: "So in supporting you, sure, they do some things, but I also think if they stop to ask you what you need help with and what you don't, it might work a little better" (Grim Reaper, Focus Group 1).

Jessica strongly agreed with Grim Reaper's point and Jamie Daniel added that: "I would like it if they would ask me what I need help with first… and what they could probably do better would be as far as they even ask what you are capable of and then they can show them what they're capable of and they can go from there" (Focus Group 1). This piece of advice given from Grim Reaper, Jessica, and Jamie Daniel, that staff should stop and ask about what people need help with before providing it, emphasizes the need to respect their knowledge about what they need.

While several different forms of boundaries were discussed throughout the focus groups and interviews, a key element that is shared between them is the importance of control; control over living space, control in emotionally intense situations, control over relationship building, and control over when help is received. Respect for these boundaries allows people to have control over these domains and others. Lack of respect for these boundaries, meanwhile, results in staff exerting power over the people they are supporting. Respect for boundaries also demonstrates respect for an individual’s self-knowledge regarding their needs, contrasting approaches that presume that staff know best. In doing so, staff resist perpetuating epistemic injustice and situating themselves as experts, which I will explore in greater depth through my discussion.

Sub-theme b) Kind and compassionate treatment

The need for kindness and compassion came up several times during the project and was captured in the following infographic:



✓ **DO show kindness and compassion**

✓ **DO provide emotional support**

✓ **DO try to understand where people are coming from**

When discussing staff that they liked, or what they wanted staff to do, participants often referred to how important it was that staff were compassionate and provided emotional support when they needed it. Superman especially touched on this sub-theme a number of times, stating that staff often support him by helping him feel better and comforting him (Individual Interview 1). He also said: “I like it when they [support staff] are being really, really, really kind and gentle” (Individual Interview 1).

Grim Reaper also described the importance of staff showing care for how he was doing emotionally: “I prefer maybe more like one of my boys [particular staff identified by Grim Reaper as preferred and trusted]. So, my boys will always make sure I’m okay if I need some help with something… but they are also the ones who believe in me and know I can do anything for myself” (Focus Group 1). Here, Grim Reaper emphasized the importance of staff making sure he was doing okay emotionally, but also that he wanted staff to believe that he was capable of doing things independently. This suggests a need for staff to not only be kind, but to also hold the people they are supporting in high regard, demonstrating respect for their capabilities. Finally, Jamie Daniel spoke of a therapist that he really liked:

> I actually have a one-to-one person that does therapy with me. And he’s funny and easy to get along with. And every single time we meet up he gets me a pop so that we can have something to drink while we talk, you know? … so he’s pretty nice. In fact, he’s very happy for my situation (Focus Group 1).

Jamie Daniel seemed to appreciate a number of things about this therapist. He liked that he was easy-going, and that he seemed invested in how he was doing;

rather than reacting neutrally to Jamie Daniel's successes, he celebrated them with him.

Thus, in addition to co-creating the infographic above, participants emphasized the importance of staff providing emotional support and showing compassion through emotional investment in how they were doing. By doing so, they demonstrated that they valued the people they work with on a personal level, a form of treatment that resists the degradation and dehumanization of those labelled/with intellectual disabilities encouraged by systemic ableism. Respect for capabilities, as touched on by Grim Reaper, also resists assumptions of incapability and its associated epistemic injustices, providing one example of how support staff can work towards epistemic justice instead. I will unpack these implications further through my discussion chapter.

Subtheme c) Recognition and respect for individuality

Finally, participants wanted to be recognized as individuals with individual needs, preferences, and personalities, represented in the following infographic:

✗ DO NOT put disabled people into a box!

✓ DO work with people to find ways of doing things that work for them

✓ DO get to know the person as a person, including their interests

✓ DO give people freedom to choose what to do

This was proposed as an alternative to making assumptions about what people were capable of based on their diagnoses, or without getting to know them first. Jamie Daniel spoke on what he wanted from new staff: “So let’s say there’s someone new, not just judge by appearance or the way they speak, but to ask and see what they need and then if they need more support then go from there kind of thing, you know?” (Jamie Daniel, Focus Group 1). Here, Jamie Daniel emphasized the importance of getting to know the person in order to learn about what they need rather than making assumptions based on what they look like or how they speak. Jessica spoke on the importance of getting to know people on a personal level:

> I would say it’s really important to build a rapport, so meaning building relationship, getting to know the person because yes, we’re disabled but

> we also have hobbies, we like different things. Don't put us into a box. Get to know us (Focus Group 1).

Jessica wanted staff to recognize individual characteristics of the people they were supporting such as their personalities, interests, and hobbies. Building on this, Jessica added: "Yeah, and that way when we do need support, we'll feel more comfortable asking for that support. Knowing that you're not gonna judge us because you've gotten to know me as a person is very important". This highlights the importance of relationships built on the recognition of people as individuals; otherwise, support and other aspects of the care relationship are based on what staff assume they know. Thus, participants wanted support staff to recognize their individual needs and strengths, getting to know them as individuals.

In summary, participants wanted support staff to respect their boundaries, show them kindness and compassion, and get to know them as individuals. There were a number of different ways that the participants emphasized the importance of boundaries: they wanted staff to respect their living spaces, allow them to walk away when upset, give them the power to set the pace when getting to know new staff, and determine what support they received. These different forms of boundary-setting share a common element: those being supported are able to take greater control over the support they receive when these boundaries are respected. Next, the participants described how they wanted support staff to be kind, compassionate, and provide emotional support in addition to practical supports. This was demonstrated through one of the co-created infographics and was also visible in the ways that participants spoke about staff that they liked; they emphasized how they wanted staff to show care for them on an emotional level. Finally, participants stressed how important it was that support staff get to know them as individuals with individual needs, strengths, and preferences. They demonstrated this through one of the infographics, but also spoke about how knowing them on this individual level allowed them to feel more comfortable receiving support and ensured that the support they received was the support that they wanted. Taken together, these approaches to providing support prioritize the needs and preferences of those being supported, resisting ableist assumptions, avoiding epistemic injustice, and providing alternatives to disabling treatment.

Discussion

When I developed this project, I came at it with the research question: “what do people labelled/with intellectual disability want support staff to know in order to facilitate more respectful, equitable, and consistent support relationships?” My two themes, which described the ways that support was unhelpful or harmful, and what participants wanted to see from support staff, speak to this question. In this section I will explore how my findings align with the existing literature and consider these findings through the lenses I outlined through my theoretical framework: critical approaches to disability and epistemic injustice.

My first theme, which described how participants felt that support was too often harmful, was broken down into three subthemes: a) variable treatment, b) assumptions of (in)capability, and c) directing or doing for participants leading to neglect of opportunities for skill development. My first subtheme, variable treatment, was one that was noted in some of the literature, particularly Weissman et al (2022) and Robinson et al., (2022). Weissman et al., (2022) identified variability of staff engagement with participants as a barrier to positive experiences in recreation programs, while Robinson et al., (2022) reported that they observed infantilizing and demeaning treatment from some support workers towards the people that they supported. Both of these critiques are ones that participants in this project made; staff disengagement and experiences of demeaning treatment were both specifically referenced by participants.

These experiences of demeaning and unkind treatment suggest that some staff may hold ableist attitudes and which are then reflected in the disablist ways they treat support recipients. Returning briefly to a description of ableism and disablism, ableism refers to an overarching system that constructs non-normative body-minds as less than fully human, while disablism refers to the assumptions and practices that promote unequal treatment of those with non-normative body-minds (Campbell, 2009). With that framework in mind, Jewel's quotation where she described how she "didn't feel treated as a human being" by some support staff is significant, as she identified the sense of dehumanization that was created by the way she was treated. Jewel said that she felt this way because she felt that the staff behaved very disrespectfully, drawing a connection between their disrespectful behaviour and a dehumanizing impact. Disrespect from staff can imply that staff perceive those labelled/with intellectual disabilities as unworthy of respect and inherently less than those without this label. Thus, the disrespectful treatment that Jewel and others described throughout this subtheme was disabling and reflected ableist attitudes, issues that will recur throughout this analysis.

Another issue visible through this sub-theme occurred when Grim Reaper and Jewel tried to exert control over which staff they interacted with. In response, they were treated as though they were the problem. This is problematic for three reasons. The first is that their testimonies that certain staff were unkind or difficult to deal with was discredited by staff; rather than taking their issues with staff seriously, they were told by staff that they needed to learn to get along with everyone. This suggests that they were experiencing testimonial injustice, where their accounts were not taken to be credible due to prejudices – arguably rooted in ableism - against them (Fricker, 2007). The second issue is that by framing recipients of support as the problem, the organization implicitly adopted a medicalizing lens; they located issues within service recipients and aimed to create change within them rather than looking for other solutions. Thirdly, by identifying service users as the problem and target of intervention, organizations failed recognize the need for change or take responsibility for the actions of staff. This was an issue that was noted by Robinson et al., (2022) as well; they found that the young people labelled/with intellectual disability participating in the study reported that when they made complaints they had very little impact, and they had limited potential to renegotiate when they found support dynamics to be unfavourable.

The final core issue that was raised when participants talked about variable treatment was how staff often brushed them off, sometimes seemingly automatically, when they asked for support. Participants identified a few possible reasons for this including staff feeling overworked, staff not wanting to help, or staff making the decision that the participants did not need help. Overwork in the disability services sector can be understood as a systemic issue. In the Canadian context specifically, research into the work conditions for disability support staff who are designated as personal support workers have identified them as part of a social class known as the precariat which refers to “a multitude of insecure people, living bits-and-pieces lives, in and out of short-term jobs, without a narrative of occupational development.” (Standing, 2011, as cited in Zagrodney & Saks, 2017, p. 32). These precarious work circumstances can be understood as a consequence of the structure of Canada’s neoliberal healthcare system and the undervaluing of the work that is performed through these roles (Zagrodney & Saks, 2017). This can be understood as also being rooted in ableism, as a result of a society that does not value or prioritize the needs of disabled people and consequently does not invest a lot of public resources into this sector (Friedman & VanPuymbrouck, 2019). Thus, issues of overwork are not the result of the individual worker or agency but are instead reflective of larger social forces, such as governmental funding decisions and underlying ableism (Friedman &

VanPuymbrouck, 2019; Zagrodney & Saks, 2017). The second issue, that of staff not wanting to help, was referred to in one of the papers I reviewed if only indirectly. In a constructivist grounded theory study around quality disability support, Topping (2022) identified staff wanting to help as an important factor determining the quality of support – thus implying that quality is negatively affected when staff do not want to help. Finally, Jewel described how staff denied her help when they perceived her as not needing it. This reflects a dynamic where staff exerted epistemic privilege over those who were being supported; staff knowledge about what they thought Jewel needed help with was considered more credible than Jewel's self-knowledge about what she needed help with (Carel and Kidd, 2014; Scully, 2018). This connects to my next sub-theme, assumptions of (in)capability, where I will discuss this in greater depth.

Next, I want to revisit an assertion that I made during my findings: that there is a connection between assumptions of (in)capability and infantilizing treatment. When staff make assumptions regarding someone's capabilities, they situate themselves as 'experts' regarding what the person they are supporting is capable of or needs help with. As Jewel put it, the staff assumed they were "an expert on what I need help with and don't need help with". As discussed previously, this demonstrates staff exerting epistemic privilege over the people they are supporting. This can also be understood to reflect paternalism, as staff are understood to both 'know more' (have a larger domain of knowledge) and 'know better' (their knowledge is considered more credible) than the individuals they are supporting (Scully, 2018). As Scully (2018) highlighted, disabled people are often assumed to have a “global epistemic incapacity” (p. 116), where impairments in one area are assumed to erase the capacity for knowledge in all others. This assumption, that a person’s impairments erase their capacity for knowledge, is based on prejudgements rooted in ableism, specifically that knowledge held by support staff is inherently more credible simply because they are not labelled/with intellectual disability (Scully, 2018).

The connection between assumptions of (in)capability, paternalism, and infantilizing treatment was most clearly articulated by participants when considering ways staff often spoke to them, ways of speaking which they understood to be infantilizing, such as baby talk or otherwise talking down to them. Such behaviour reflects an underlying belief that adults labelled/with intellectual disabilities are ‘eternal children’ (Mills & Lefrançois, 2018). When support staff or others do this, they are assuming that they need to change the way they talk in order for the person they are speaking to understand them. While it may sometimes be necessary to use plain language or otherwise adapt speech to meet others’ communication needs, it is clear that participants had experienced people speaking to them in ways that they found insulting: ways that, to participants, assumed they were unable to understand. Thus, infantilizing treatment emerged as a direct result of assumptions of intellectual incapability.

In addition to discussing how assumptions regarding her capabilities were a part of her life, Jessica also described a few impacts that these assumptions had on her. First, she described these assumptions as “demeaning”, which reflects a sense of devaluation: these assumptions make her feel lesser than those who are not labelled/with intellectual disabilities. This aligns with Jewel’s experience of dehumanization, described in the first section, also pointing to a connection to ableism; degradation where disabled people are constructed as inherently lesser reflects ableist structures. Drawing on Campbell’s (2009) definition of disablism, which refers to the assumptions and practices that promote unequal treatment of those with non-normative body-minds, behaviour that emerges as a result of assumptions of (in)capability as described in this section are inherently disablist. Jessica also talked about how constantly being assumed to be incapable can create self-doubt. This reflects a secondary harm of epistemic injustice, the erosion of epistemic courage (Dohmen, 2014). Epistemic courage refers to one’s ability to feel confident in their knowledge even when it is challenged (Dohmen, 2014). When epistemic courage is eroded, it causes people to doubt whether they can trust their own knowledge, just as Jessica described. Thus, epistemic injustice is visible through this subtheme not just because of the ways that support staff assumed epistemic privilege over the people they were supporting, but also through the harms associated with this treatment.

The third subtheme, that directing or doing for participants can lead to a neglect of skill development, connects well to several pieces of the literature. First, I would like to highlight a connection to the study by Rapley (2004), which observed three main interactional styles group home support staff used:

babying/parenting, instruction-giving, and collaboration/pedagogy. Rapley described collaborative/pedagogical interactions as ones where residents were involved in decision making, staff spoke to residents more like equals, and suggestions were given rather than directions. This suggests that interactions where staff aim to teach rather than direct reflects a shift away from the more common ‘babying/parenting’, or interactions where recipients of support are inherently infantilized, towards a dynamic that respects them on equal footing. The importance of making suggestions rather than giving directions was also discussed by Antaki and Crompton (2015), who analyzed conversational practices that can promote personal agency for people labelled/with intellectual disabilities. They found that moving away from giving directions facilitates a power dynamic where those being supported are able to exercise personal agency; rather than staff telling them what to do with the paternalistic expectation that they obey, those being supported are able to make choices about how they would like to proceed. While my sub-theme revolves around skill-development rather than agency, the principles are similar. ‘Agency’ for Antaki and Crompton (2015) focused on the promotion of decision-making power as a form of independence and autonomy. Participants in this project, meanwhile, highlighted the importance of skill development as a facet of independence; participants expressed concern that suppressing opportunities to learn created dependence on staff that would not otherwise exist. This sub-theme also ties back to infantilization; Jessica directly connected the idea that “people treat disabled people like children" with staff doing things for the people they support rather than teaching them. Ultimately, a failure to teach reflects an assumption that those being supported would be unable to learn. This assumption then perpetuates a lack of knowledge about how to perform these skills.

My second theme focused on the practices that participants wanted to see from staff. I broke these practices down into three categories: a) respect for boundaries, b) kind and compassionate treatment and c) respect for individuality.

The first practice that participants wanted to see, respect for boundaries, was supported by some of the studies that I included in my literature review. First, Edwards et al., (2021) emphasized the importance of participants being allowed to choose which activities they engaged with and for how long. They discussed how participants had a much better time when they were allowed to take breaks when they wanted them. This reflects what participants in this study said, that it was important that they were allowed to walk away from things and take breaks, particularly when they were upset. I would also like to highlight a connection to a study by Finlay et al., (2008), which observed the interactional practices that support staff used while playing games with people labelled/with profound intellectual disability. In their paper, they described how staff were often persistent about engaging these individuals in these games, even when the individuals did not seem interested. Finlay et al., (2008) point out that staff often treated ambiguous participation or non-compliance as either temporary reluctance or a failure to understand. I saw a similar pattern at play in what Jewel and Grim Reaper discussed: how some staff refused to respect their boundaries and persistently engaged them when they needed time away. Finlay and colleagues (2008) described how staff persisted with trying to play games with group home residents and did not accept or recognize the ways the participants tried to communicate that they were not interested in participating. In both cases, staff engaged in persistent behaviour that neglected boundaries and denied the agency to choose whether to engage. Topping and colleagues (2022) also touched on the importance of respecting boundaries, as they noted that it was very important that staff understand support recipients as the experts rather than themselves. Respect for boundaries is significant from a theoretical standpoint because it reflects a power dynamic where those being supported are able to maintain a level of control. When staff respect boundaries, they are implicitly acknowledging and valuing the person's capacity to self-determine by recognizing that the person is the best judge of what they need. Self-determination for people labelled/with intellectual disability has been strongly connected to quality of life for those so labelled, both theoretically and empirically (Wehmeyer, 2020). This demonstrates respect for an individual's self-knowledge about their needs and avoids situating the staff as the expert, a dynamic that works towards epistemic justice. In contrast, when staff do not respect boundaries, they are using their epistemic privilege to impose what they think is appropriate on the people being supported. Secondly, in making these decisions for the people being supported rather than with them, staff are operating from a paternalistic and infantilizing approach. This is challenged through the recognition of and respect for the boundaries of the people being supported. Staff instead are working towards epistemic justice and avoiding infantilization.

Next, participants emphasized how they wanted staff to be kind, compassionate, and emotionally supportive. These traits were also emphasized by Patricia Seth, a self-advocate who was involved with the Huronia class action lawsuit when asked what needed to change about support: “You should be able to get emotional support and not have a worker who will just talk down to you, and boss you around” (Seth et al., 2015, p.65). It is notable that Seth directly contrasts an emotionally supportive dynamic with one where staff talk down to her and tell her what to do; as previously discussed, feeling talked down to was a significant issue for participants in this project as well. This suggests that emotional support and kind treatment are ways of behaving that specifically oppose support relationships where staff assume epistemic privilege over those they support.

Emotional support, in addition to be being valued by self-advocates like Seth, was found by researchers like Robinson and colleagues (2021) to be an important factor during their inquiry into positive aspects of support relationships. They found young people in support relationships wanted to feel that staff cared about them. They reported that the young people felt support staff cared about them when they provided emotional support, gave reassurance when needed, and demonstrated care regarding their wellbeing. These principles were echoed by participants in this project, particularly Superman, who greatly valued the reassurance and emotional support that staff provided to him. Additionally, Weissman and colleagues (2022) suggested that friendly interpersonal styles were important to quality recreation support and Topping and colleagues (2022) said it was important for support staff to treat support recipients like people. Overall, this sub-theme speaks to the importance of positive regard from support staff towards those being supported. Both Grim Reaper and Jamie Daniel spoke to how this was important to them; Grim Reaper described support staff that he could trust as having faith in him, and Jamie Daniel appreciated a staff member that celebrated his successes with him. The importance of positive regard for support recipients is supported by research into group homes reported to provide quality services; Bigby and colleagues (2014) found that a culture of positive regard for residents of group homes played a large role in determining which group homes were understood to provide quality service. Rather than regarding or treating support recipients as less than fully human, kind and compassionate treatment opposes disabling behaviours that reinforce ableist structures. When staff demonstrate respect for support recipients' capabilities, they are also resisting epistemic injustice. Rather than making pre-judgements that assume that the person's testimony cannot be trusted, staff are trusting in support recipients' capabilities instead. In doing so, staff are working towards epistemic justice, where those labelled/with intellectual disabilities are not discredited due to their identity category.

My final sub-theme, respect for individuality, aligns well with other studies investigating quality support relationships. Topping and colleagues (2022), especially promoted the importance of recognizing those receiving support as individuals with individual needs and preferences, as they identified this as the underlying factor determining support quality that all of others were dependent upon. Other studies, such as Gridley et al., 2014, emphasize the need for person-centred support, which similarly speaks to providing support that is tailored to the individual. Working in this way presents an alternative to basing support on assumptions. When support staff engage with individuals to learn more about them and find ways of working that are unique to them, they are allowing support to be built based on the individual's knowledge about what they need. They are also demonstrating that they value that individual, rather than considering those they support to be a homogenous group. Recognizing each individual's needs and strengths privileges their own knowledge about what they need, works towards epistemic justice, and resists dehumanization and infantilization of people labelled/with intellectual disabilities.

In summary, my two main themes, which reflected the ways that participants found support was harmful, and practices that they wanted to see in support, were deeply intertwined with issues of ableism and epistemic injustice. Many of the harmful practices shared by participants, reflected ableist worldviews that construct those labelled/with intellectual disability as lesser, particularly devaluing an understanding of people labelled/with intellectual disabilities as knowers. Staff often assume epistemic privilege over recipients of disability support and demonstrate testimonial injustice by discrediting their accounts. The assumptions that are made about support recipients, and the actions that support staff take in response to these assumptions are often infantilizing, reinforcing support dynamics where staff 'baby' or 'parent' those they are supporting. In contrast, the alternatives participants proposed, such as respect for boundaries, situate those being supported as experts on their own needs. This places those being supported on more even epistemological footing, better supporting epistemic justice. Care and compassion from support staff demonstrates resistance to the dehumanization encouraged by ableist structures. My final sub-theme, respect for individuality, was well represented in the literature and reflects an alternative to making assumptions regarding (in)capability. By working with individuals to learn about their individual needs and strengths rather than presuming, staff are working in a way that respects those they are supporting as knowers and works towards epistemic justice.

Implications for Social Work Practice:

The process I used for my project, the themes I have explored through my data analysis, and the infographics that were produced all have implications for social work. My process involved knowledge co-production, which allowed this project to better communicate the insights that my population of interest, people labelled/with intellectual disabilities, held about what they wanted to see from support staff. Through the use of this method, participants in this project were able to share what they wanted staff to know more directly, rather than knowledge dissemination and production being understood as solely the purview of the academic researcher. This in itself, I think, is an important approach for social work to take, one that reflects one of social work’s core values: respect for the dignity and worth of all people (CASW, 2024).

In short, my findings, which demonstrated a number of harms that the participants experienced in disability support, and practices they wanted to see instead, emphasize the need for social workers to challenge their self-perception as experts and to critically examine their own assumptions about people labelled/with intellectual disabilities. The participants highlighted a number of ways that professionals who interact them often discredit their knowledge and infantilize them – and the ways that this is harmful. This is an important consideration for us, as social workers, as we are professionals with inherent epistemic privilege over those we support, especially if they are labelled/with intellectual disability. My findings highlight the epistemic injustice those labelled/with intellectual disability face, and as social workers aiming to promote social justice, we must work in ways that actively promote epistemic justice for those labelled/with intellectual disability.

Finally, the infographics produced through this project, presented in full as Appendix C provide a number of direct dos and do nots for all people providing support to individuals with disabilities, including social workers. I would like to highlight that at least one participant of this project was very excited by the final infographics, requesting a copy so that they could use them for their own advocacy efforts.

As of August 2024, I have had several opportunities to present these infographics. First, I presented them to a “Social Work and Disability” class at McMaster University in November 2023. Although I ended up presenting the infographics by myself, two participants of the project met with me to discuss insights they wanted to share with the class, even though they were unable to attend. Dr. Ann Fudge Schormans, the class professor, shared that several students reported on their end-of-term class evaluations that they found my presentation impactful, and that it had changed how they thought about working with people labelled/with intellectual disabilities.

Next, one of the participants in this project and I co-presented at the Ontario Association for Development Disabilities (OADD) conference in April of 2024. During this presentation we presented the infographics and described the project’s process. This session was very well-attended, and there was a high level of engagement from session attendees; we included a discussion portion asking the audience to consider how they might apply what the infographics had shared to their organizations, and the audience proposed a number of ideas.

Following this OADD presentation, six people from various organizations providing services to people labelled/with intellectual disabilities contacted me by email to request a copy of the infographics. One of these individuals indicated that they were sharing the infographics not just with their team, but with other agencies that they were affiliated with. Another organization requested that my co-presenter and I share the infographics and have a question-and-answer session at their organization's team meeting, which we did in July 2024. I also gave a presentation about this project's methods at the *Qualitatives* conference in June 2024, where I passed around printed copies of the infographics. While I was very excited by how interested people were in these infographics, prior to distributing them, I copyrighted them with attribution-noncommercial-noderivatives 4.0 creative commons license. This means that people are free to distribute the co-created infographics, as long as credit is provided, they are not modified, and they are not gaining from them commercially. Finally, my co-presenter and I will also be presenting at the upcoming Community Living Ontario conference in September 2024. Thus, there has been clear interest for these infographics and the insights that they share – this is encouraging, as it suggests both recognition of the need for client-driven, person-centred for ways of providing supports and an interest in learning how to do so. I intend to continue to find opportunities to share these infographics with organizations and individuals that are interested in them.

Limitations and Reflections:

While I described a few of my limitations relating to my methods within that chapter, there are a few additional limitations I would like to expand upon here. Firstly, while intersectionality is extremely important and one cannot universalize disability experiences, I was unable in this project to really engage with how various social locations might impact how disability support was experienced. It is unclear how a larger sample size more able to capture a larger variety of intersectional experiences would have impacted the co-created infographics. The infographics also do not convey particular nuances of varied social locations, instead relying on points that are implicitly assumed to be universal.

My project was also somewhat limited by the constraints of my Masters program. While I was conducting this project, I often wondered if it was fully appropriate to consider it an ‘inclusive research project’, as I often had to make unilateral decisions without sharing control over the project with an advisory group of self-advocates or otherwise consulting project participants. This shortcoming was ultimately a result of the compressed timescale of my program; since the intended timeline for completion is 12 months, it was not feasible for me to work with an advisory team to determine the initial direction of my research, nor was it feasible to break my project down further to allow for additional consultation with project participants. Thus, my project was unable to fully reflect the principles of inclusive research.

Finally, I would like to acknowledge that although I worked hard throughout this project to ensure that the infographics represented the participants’ views and opinions rather than my own, the outputs (thesis, infographics) of this project are reflective of my subjectivities as a researcher and editor. There are a number of ways that my perspectives and opinions shaped the project, from which questions I chose to ask during the focus groups, to the images that I chose when creating the draft infographics. Another researcher undergoing the same project with the same data could have made an entirely different set of infographics. My experiences as a disability support staff and social work graduate student also played a role in how I engaged with this project; due to my work experiences and educational background I have strong opinions about which staff practices I perceive to be problematic and/or widespread. I reject the notion that researchers do not impact data or how it is analyzed, especially in the format that I chose, the repeated focus group and individual interview with a creative output attached. As a participant in the conversations, even as a facilitator, my interactions played a role in how the conversations proceeded. Although I did not speak my opinions, they still influenced how I reacted to the conversation, even if only non-verbally. Furthermore, as an editor of the infographics, my thoughts necessarily influenced how the infographics were constructed. I would not consider my perspective or investment in this project a weakness, but rather something to acknowledge as a factor that influenced how it turned out.

Conclusion:

When I developed this project, I did so with the aim of co-creating a tool that would help improve disability support by communicating the knowledge that people labelled/with intellectual disabilities had about what they needed from support to workers providing that support workers – both those currently engaged in support work, and future workers (i.e., students enrolled in programs preparing them for work in this field). I felt this was an important goal for a number of reasons. My preparatory work of engaging in the literature made clear the reality of historical and contemporary practices of unhelpful and uncaring ‘support’ stemming from institutionalization which continue to be evident in current support practices. It demonstrated as well the ableist assumptions and resultant dynamics that devalue knowledge held by people labelled/with intellectual disabilities. This knowledge combined with my own experiences working within this field, demonstrated that there was a need to learn from people labelled/with intellectual disabilities about what they wanted support staff to know. My chosen research question, “What do people labelled/with intellectual disabilities want disability support staff to know to facilitate more equitable, respectful and consistent support relationships?”, reflected this goal, and guided my analysis of data generated through the focus groups and interviews. I found participants described both what they had found unhelpful or harmful about support and the practices that they wanted to see instead. While working to co-create the infographics, the participants were eager to share their knowledge and excited by the final outputs. I was glad to hear that several participants wanted to share the infographics for their own advocacy. The co-created infographics reflected a number of ideas that the participants had about how support practices could shift for the better, particularly through respect for boundaries, demonstrating more kindness and compassion, and respecting each person’s individuality. Through actioning these recommendations, support staff can avoid harmful support experiences such as those described by participants in this project. In addition to avoiding harm, working in these ways will ensure that recipients of support are consistently treated with respect and compassion.

It is also important to recognize that issues of ableism, disablism and epistemic injustice were highly visible in what the participants shared. The prevalence of these systemic forms of oppression in day-to-day disability support experiences demonstrates why change is needed on a larger scale than the individual worker or organization; these are systemic issues requiring significant shifts in how people labelled/with intellectual disability are understood by those without this label. This suggests that there is a need for social workers and other professionals to reflect on their roles and find ways to work in collaboration with people labelled/with intellectual disabilities rather than talking down to them or positioning themselves as the ‘experts’. Finding new and collaborative ways to work together is a must for ensuring that people receive the kind of support that they want in the ways that they want. Future research should use inclusive methods to learn more about what people labelled/with intellectual disability want from support using a larger, more diverse, sample of participants. While this project was able to create a series of infographics that spoke to the experiences of my small sample of participants, there is a strong need to continue learning from people labelled/with intellectual disabilities with a wide variety of lived experiences.

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Appendix A: Focus Group 1 Questions

1. Can you introduce yourself and tell us what you like to do for fun?

2. What kinds of recreation programs have you been in?
    a. Which programs did you enjoy the most?
        i. What did you like about them / what made these good programs?
    b. Which ones did you not like?
        i. What didn't you like about them / why were these ones not so good?

3. Were the staff in the programs supportive of you?
    a. If so, how did they support you? / What did they help you with?
    b. Did you find their support helpful?
        i. Can you tell me more about that? / How was it helpful?
        ii. Are there other kinds of support you would have also liked them to provide? c. If it was not helpful, why not?

        i. What did they do that was not helpful?
        ii. How could they have supported you better? / What would you have liked them to do?
    d. In your experiences of support / when staff were supporting did you feel like staff treated you with respect?

        i. If yes, what did they do that made you feel respected?
        ii. What are some things that make you feel disrespected by staff?
        iii. If not, why do you think they did not treat you with respect?
    e. How do you want staff to show that they respect you?

4. What would you want someone who was new to supporting you to know?
    a. What would you want a new support staff to do while getting to know you?
    b. What would you not want a new support staff to do while getting to know you?

5. What would a 'perfect' recreation support person be like?
    a. What kind of things would they say?
    b. What kinds of things would they do?
    c. How would they make you feel?

6. Are there differences between this 'perfect' recreation support person and some of the recreation support people you've had in real life?
    a. Can you tell me more about that?
    b. What makes someone a 'perfect' support person? (Or a really good support person?)
    c. What changes would you want staff to make in order to be more like this 'perfect' support person?

7. Before we finish today, I want to summarize / wrap up what we've discussed today so far – [recap of questions and responses – ask for the feedback following recap of each question]
    a. What do you think of this summary? Is there anything you want to add?
    b. Here is my last question for today -which of these things do you think recreation support staff should be trained on?

Appendix B: Focus Group 2 Questions

1. I've created a summary of some of the key points we brought up last time, and I'm going to share my screen to show you.
   Share screen to show summary and read it out:
    a. Is there anything you think is missing from this summary that we talked about last time?
    b. Are there any words you would like to change?
    c. Are there any new ideas you would like to add?

2. I've found two different examples of infographics that explain the "dos and don'ts" of different topics.
   Share screen to show example 1:
    a. What do you think of this infographic?
    b. Is there anything you like about it?
    c. Is there anything you don't like about it?

   Share screen to show example 2:
    a. What do you think of this infographic?
    b. Is there anything you like about it?
    c. Is there anything you don't like about it?

   Show example 1 and example 2 next to each other:
    a. Do you like one of these more than the other?
    b. Are there parts of these you'd like to see in our resource?
    c. Is there anything different you would like to do to it?

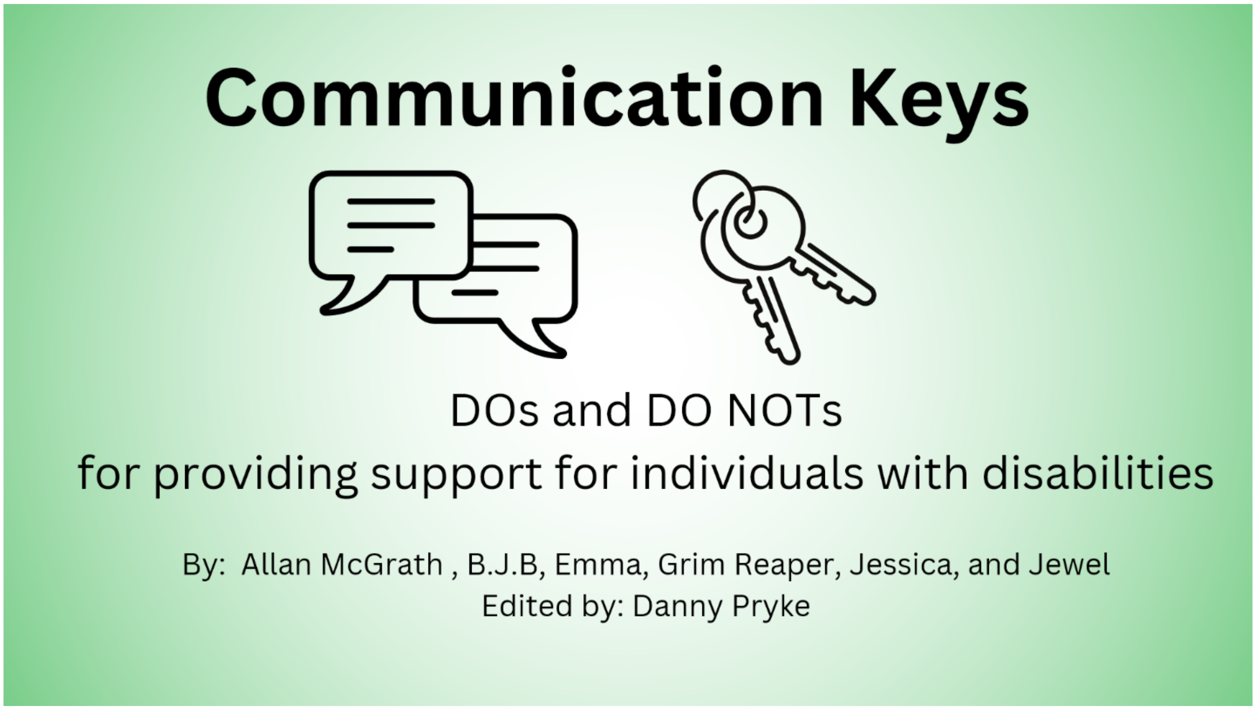
3. For this next section, I'm going to share a zoom whiteboard, and it's going to pop up for everyone. We're going to brainstorm some ideas about visuals and words you want included in the resource. If you're not sure how to use the whiteboard, I can either explain how to use it, or you can say your ideas out loud or in the chat if that's more comfortable.
    a. What kinds of images do you want to be included in the resource?
    b. What kinds of words do you want to be included in the resource?
    c. Do you have any ideas about how you want words and images to be combined?

4. These are some of the key ideas that I've heard from everyone:
   Summarize thoughts and suggestions provided
    a. Is there anything I've missed or that you would like to add?

5. My current plan is to take everyone’s ideas about what the resource should say and what it should look like and make some examples to bring to the next meeting, which you’ll give feedback on.
    a. Is there a different way of approaching this you want to try?
    b. Is there anything else you want me to keep in mind?

Appendix C: Communication Keys: DOs and DO NOTs for providing support for individuals with disabilities.

The following presents the infographics as jpeg images; the original document is a PowerPoint and each image is a separate slide



Communication Keys

DOs and DO NOTs
for providing support for individuals with disabilities

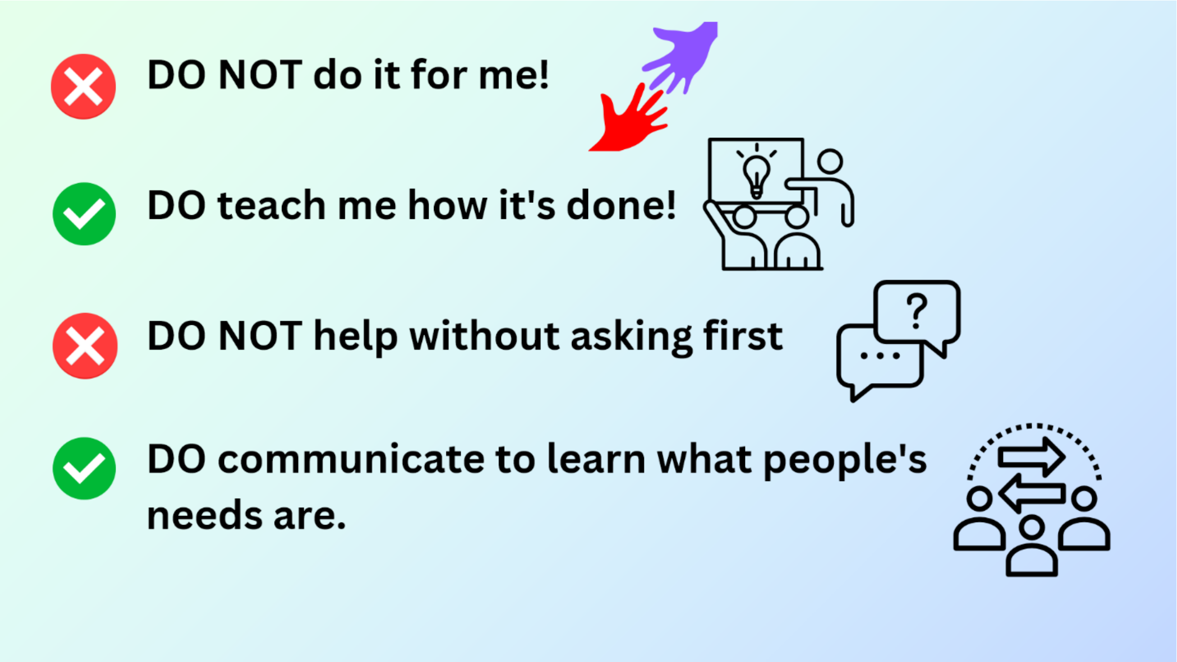
By: Allan McGrath , B.J.B, Emma, Grim Reaper, Jessica, and Jewel
Edited by: Danny Pryke

The Need for Balance in Support

"I feel like it's kind of like a seesaw where they either..."

HELP YOU TOO MUCH

OR NOT AT ALL



- ☒ DO NOT do it for me!
- ✓ DO teach me how it's done!
- ☒ DO NOT help without asking first
- ✓ DO communicate to learn what people's needs are.

✗ DO NOT ignore me!

✗ DO NOT brush me off!

✓ DO pay attention to what people want to communicate

✓ DO find ways to communicate with non-speaking people

✓ DO recognize when people are doing well

✗ DO NOT put disabled people into a box!

✓ DO work with people to find ways of doing things that work for them

✓ DO get to know the person as a person, including their interests

✓ DO give people freedom to choose what to do

✓ DO build a rapport by getting to know the person at their pace

✗ DO NOT take it personally if people are guarded around you!

✓ DO have fun

✗ DO NOT take yourself too seriously

✗ DO NOT treat disabled youth, teenagers or adults like babies or children

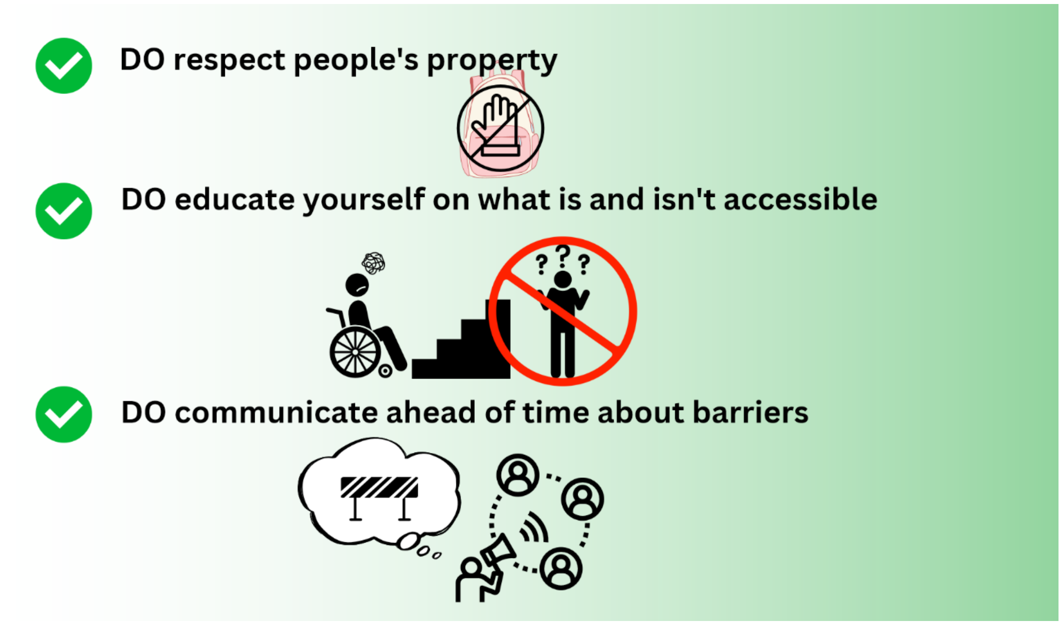
✓ DO avoid using baby talk

✗ DO NOT talk down to people

✓ DO show respect for people's needs

✓ DO communicate about stressful situations in advance, if possible

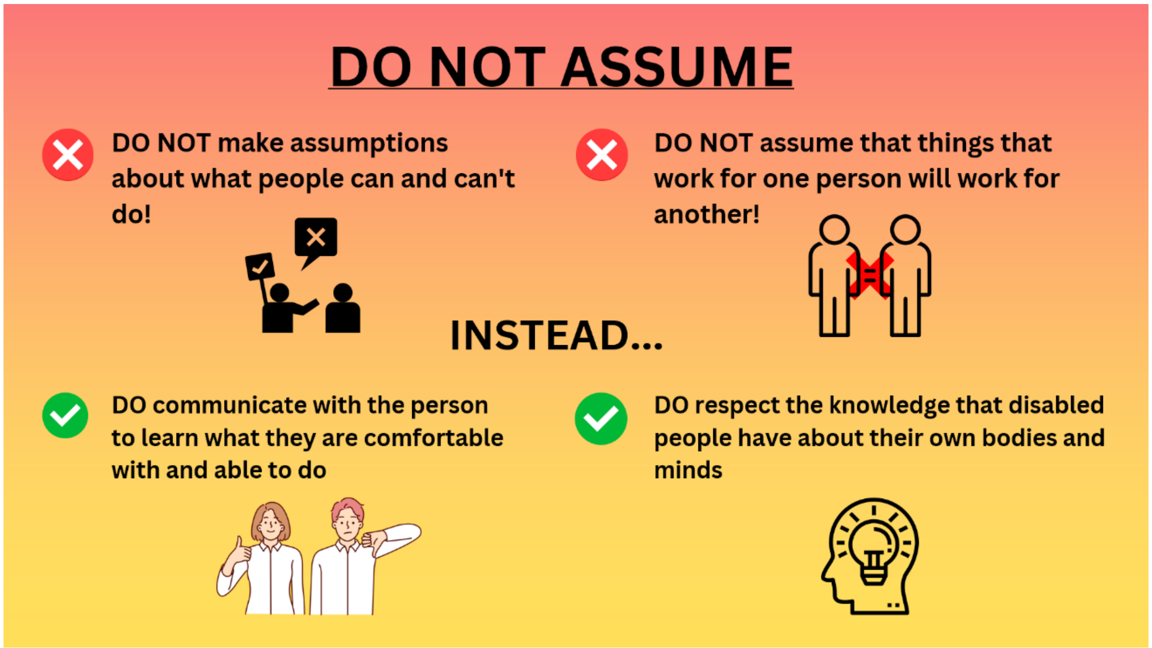
Example: warning someone with sensitive hearing before testing a fire alarm is a way of showing respect for their hearing sensitivity



✓ DO respect people's property

✓ DO educate yourself on what is and isn't accessible

✓ DO communicate ahead of time about barriers



DO NOT ASSUME

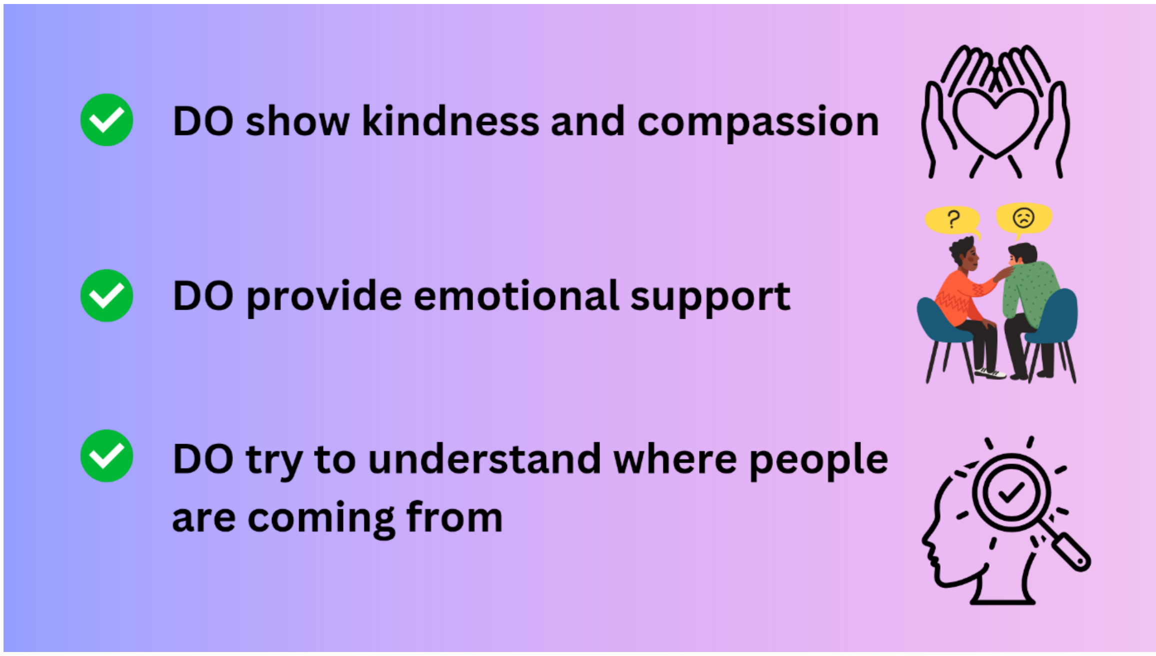
- ✗ DO NOT make assumptions about what people can and can't do!
- ✗ DO NOT assume that things that work for one person will work for another!

INSTEAD...

- ✓ DO communicate with the person to learn what they are comfortable with and able to do
- ✓ DO respect the knowledge that disabled people have about their own bodies and minds

✗ DO NOT push people's buttons!

- ✓ DO respect when people tell you they need space
- ✓ DO give people time to cool off if they need it



- ✓ **DO show kindness and compassion**
- ✓ **DO provide emotional support**
- ✓ **DO try to understand where people are coming from**