A Qualitative, Participatory Exploration of Belonging: Experiences & Conceptualizations through the Perspectives of Adults with Intellectual and Developmental Disabilities

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Abstract

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Experiences of belonging are a basic human need (Baumeister & Leary, 1995), and the accessibility of belonging might look different for individuals labeled with Intellectual and Developmental Disabilities (IDD) due to historic and ongoing exclusion. This qualitative, participatory study explored how adults with intellectual and developmental disabilities defined belonging, reflected on experiences of belonging, and co-constructed a conceptualization of belonging together. With a focus on presumptions of competence (Biklen & Burke, 2006), and epistemic agency (Taylor, 2018), this project includes individuals with lived experiences as opposed to proxy voices. Through a Disability Studies lens, the findings of this study (1) document co-researchers experiences of belonging, (2) describe belonging through five key components as illustrated in a co-constructed visual, and (3) document the alignment and power of participatory methods in centering the lived

experiences of individuals with IDD in research. The project also suggests implications for schools, families, communities, and researchers.

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Chapter 1: Introduction

In this study I attempt to build further understanding of experiences of belonging from the stories and experiences of adults labeled/with intellectual and developmental disabilities (IDD[1]). The phrase "labeled/with" is intentional language used to denote the way in which labels are ascribed to individuals by professionals who note a deficit in intellectual and adaptive functioning. The word 'labeled' is added to this phrase to denote the power dynamics present in the assigning of labels, and the '/with' denotes others who identify with/connect and self-ascribe this label/identity. Ashley Taylor uses this language to describe the socially situated nature of the label (Taylor, 2018). Belonging is a long identified human need, which has been explored across disciplines (including sociology, education, psychology, etc.). In conceptualizing this project, I am thinking about the Othering and Belonging Institute's definition which says belonging is: "having a meaningful voice and the opportunity to participate in the design of political, social, and cultural structures that shape one's life — the right to both contribute and make demands upon society and political institutions" (Othering and Belonging Institute, 2023). This definition highlights agency, opportunity, and reciprocity. But I'm holding space to co-create and understand how the project participants define belonging. Experiences of belonging, and the accessibility of belonging might look different for individuals labeled with IDD due to historic and ongoing exclusion both within and beyond school contexts. Half of students labeled/with ID or multiple disabilities are included in classrooms with their nondisabled peers for less than 40% of their school day (Agran et al., 2020). Belonging, thereby, must be understood through the stories, voices, and experiences of those with IDD. This includes, for example, the places, systems, and qualities of relationships which foster a sense of belonging, as well as the emotions

[1] The AAIDD defines ID as "a condition characterized by significant limitations in both intellectual functioning and adaptive behavior." (AAIDD, 2023).

surrounding and reflections on these experiences. In this chapter I will (1) share an anecdote of belonging, (2) describe extant literature on the human need for belonging, (3) name the relationship between oppressive systems and the accessibility of belonging, (4) differentiate inclusion from belonging, (5) highlight the gaps in current belonging literature necessitating a participatory approach and (5) introduce the project.

An Anecdote of Belonging

My professional interests are largely guided by the relationship I have with my older sister, Brittney. A true introduction to this project, and the rationale for this work must include a personal and familial reflection of belonging. Brittney has Down Syndrome. This diagnosis comes with many assumptions and promptly led to early intervention and later a referral to special education services. Due to my mom's advocacy, my sister was able to attend our neighborhood schools throughout her K-12 years. Despite inclusion within our school community, and an incredibly supportive elementary special education teacher, my clearest, early memory of my sister experiencing belonging was not until the summer before she started high school.

One early summer morning, my parents, sisters, brother, and I pulled into a parking lot about fifteen minutes from our home. The summers prior we soaked up time together swimming, roasting marshmallows over bonfires, and carrying out our own renditions of the summer Olympics on the grass outside my grandpa's cabin. This summer was different because Brittney received an invitation to a camp that involved being away for a week. I had been gone for a week before, so had my younger, non-disabled sister, but my parents never really had to wonder if an invitation to summer camp was open to me. This wasn't the same for Brittney. A label of IDD came with a lot of assumptions, which caused our family hesitation around how welcoming or open invitations really were. This hesitation was reinforced many times.

We hopped out of the car and several other high schoolers approached my sister sharing excitement and enthusiasm for the week ahead. I know my parents were nervous at this drop off, and I heard that echoed from other parents as they pulled out luggage and supplies for their high school children (all labeled/with various disabilities). I remember Brittney looking out from inside the bus with a big smile on her face as she lifted her hand up into the windowpane and waved goodbye to us. We loaded back into the car. I held some curiosity and wonder for what would unfold for Brittney when the bus pulled away from the parking lot. Maybe it was my age that allowed my wonder to be hopeful, but now I can reflect back and empathize with the more nervous-wonder my parents held.

I do not remember what all unfolded for me the week Brittney was away, but I have a pretty vivid memory of returning to the same parking lot a week later and getting a gigantic hug from my big sister. She had a bright new t-shirt on and was surrounded by a few of the friends she made while away. In this project, I argue belonging is subjective, and something identified and defined by an individual themselves. While Brittney didn't get off the bus and say, "I belong here," her smile told me that. The way she continued to tell stories and looked forward to her next gathering with this group of friends told me she felt belonging. A few weeks after camp Brittney invited us to join her for a video night with this new community. Together we watched one photo after the next surface, each of which spoke to the commitments and beliefs of the camp that everyone should have the opportunity to try new exciting things and build community. Brittney went parasailing, she climbed a rock wall, she connected with other youth her age from all over the country. She was beaming. Still today, she is connected and involved in leadership with this organization.

A few years later when I started high school, Brittney invited me to one of this group's Friday night hang outs. I have clear emotional memories of the peace I felt in this community. I

think my peace came primarily from seeing my sister get to be all of who she is, and as a result be accepted, encouraged, and wanted. This story speaks to a few key aspects of belonging: freedom to be oneself, agency in choosing friends, reciprocal friendships (away from family members, or paid support staff), and longevity (many of these people have now been close friends of hers for nearly 20 years). This story is also one of the few times I have seen that type of smile on my sister's face. Although I had been away to camp before, my opportunities to find chosen community that allowed me to be myself were far more frequent than those my sister had access to because of her disability label. I had choices and options and did not typically have to question if I would be openly received. Unfortunately, community organizations, school spaces, sports teams, even neighbors, sometimes hold some hesitation, reservation, or fear in extending these same opportunities to someone with a disability label.

Belonging and the Need for Belonging

> *"Belonging is not just about membership, rights, and duties . . . Nor can it be reduced to identities and identifications, which are about individual and collective narratives of self and other, presentation and labeling, myths of origin and destiny. Belonging is a deep emotional need of people."* - *Yuval-Davis (2004, p. 215)*

At the most basic level, belonging is a human need (Baumeister & Leary, 1995). Across contexts, cultures, and lifespans, individuals have an innate need for belonging (Leary & Kelly, 2009). Maslow (1943) was one of the first to name this critical need of humans. In making this claim he moved away from foundational behaviorist ideas around the limited number of and simplistic nature of human needs (i.e., food, water, shelter). Belonging has been conceptualized and defined through the "belongingness hypothesis". This hypothesis, described by Baumeister and Leary, says humans "have a pervasive drive to form and maintain at least a minimum quantity of lasting, positive, and significant interpersonal relationships" (Baumeister & Leary, 1995, p. 497). There are two criteria in meeting this drive. First, ongoing and frequent

interactions with a minimum number of people. Next, the interactions must happen consistently over time and work towards the well-being of both individuals. To summarize, the hypothesis says belonging requires frequent interactions between the same people, as opposed to intermittent/inconsistent interaction(s) with a number of different people. Through these types of interactions humans create interpersonal bonds. According to Baumeister and Leary, interpersonal bonds can lead to a sense of belonging.

Belonging is a dynamic process, not something simply measured and achieved, but an ever-changing construct (Yuval-Davis, 2006). Currently, the idea of belonging shows up in many disciplines. A focus on belonging is rationalized by the benefits of belonging in student performance (e.g., motivation and achievement literature), towards mental health, in behavior, and in identity development and formation. Despite this, there is a notable gap in the experiences or feelings of belonging through the lived experiences of individuals labeled/with IDD. This is especially important considering the historic othering and marginalization of this population, both in everyday contexts (like schools), and more broadly through the process of science and knowledge generation (Shogren, 2023).

Marginalization and Accessibility of Belonging

> *"Belonging connotes something fundamental about how groups are structurally positioned within society as well as how they are perceived and regarded. How are they positioned in the collective narrative?" (Powell, 2019).*

Much of the existing literature on belonging recognizes the subjective element of belonging (Mahar et al., 2013; Brown, 2015). Meeting the emotional need and personal motivation to belong looks different for every individual. It is something that is experienced within and measured by an individual, not objectively measurable by an outsider. Oppressive systems and interactions, like ableism and racism, restrict access to belonging for individuals with marginalized identities. Individuals with disabilities are one group who have been and

continue to be marginalized both in our schools (Carter & Biggs, 2021) and communities and in research (Fulton et al., 2021). Ableism on both systemic and individual levels creates barriers to opportunities and experiences of belonging. Here, I draw on TL Lewis' working definition of ableism: "A system of assigning value to people's bodies and minds based on societally constructed ideas of normalcy, productivity, desirability, intelligence, excellence, and fitness. These constructed ideas are deeply rooted in eugenics, anti-Blackness, misogyny, colonialism, imperialism, and capitalism. This systemic oppression that leads to people and society determining people's value based on their culture, age, language, appearance, religion, birth or living place, "health/wellness", and/or their ability to satisfactorily re/produce, "excel" and "behave." You do not have to be disabled to experience ableism" (Lewis, 2022, n.p.).

The Difference Between Inclusion and Belonging

"Belonging is not about joining something. It is about co-creating the thing that you're joining and in order to co-create you need power." (Powell, 2019).

When access to belonging is recognized as variable and something informed by our identities and the ways in which systems marginalize certain groups of people, the difference between measures of inclusion and understanding of belonging becomes clear. One way inclusion differs from belonging is that belonging asks questions about power. McBride notes that belonging asks the question "who gets to decide?" or who gets to choose and inform? (Lopez, 2021). Another way the difference between inclusion and belonging has been described is: belonging focuses on the internal, the response to schooling by the individual student themselves; and the term inclusion focuses on the external, and describes policies and decisions put in place within schools (usually by adults) to bring students together for learning experiences (Berryman & Eley, 2019, p. 989). This concept can be generalized outside of educational

contexts as well. Inclusion provides basic access; belonging asks what does an individual need to access meaningful relationships and opportunities.

To be included within a space or group there is often a social pressure or expectation to fit in. Consciously or unconsciously people change their behavior and their ways of being to be accepted or to exist in a space (Pearson & Rose, 2021). Systems of power influence an individual's agency to socialize in ways of their choosing. Conceptualizations of disability throughout research derived from a medical model of disability are focused on fixing, on resolving, and pulling one closer to this idea of "normal" (Pearson & Rose, 2021). These beliefs and arguments are rooted in ableism, one system of power which constricts agency. The systemic and individual influences of ableism reify normalcy. Within special education contexts, one clear example of this is the (external and/or internal) expectation of individuals to adhere to ableist norms (Ferri & Bacon, 2011). For example, students with autism are asked to alter their behavior (to mask or pass) in order that they may fit into a general education classroom or resemble the 'normative' student (Pearson & Rose, 2021; Taylor, 2018). By "'normative' student" I draw on Baglieri et al.'s critique of normal, and their discussion of normalcy as a construct; socially, culturally and contextually defined (Baglieri et al., 2011).

In many contexts or situations, it is not safe for an individual to fully be who they are within a specific context or space. This extends beyond labels of disability. Individuals of various marginalized or historically oppressed groups face negotiation of identity and constructions of normalcy, and the oppressive expectations for being included. For instance, autistic individuals may deliberately or subconsciously mask (use certain strategies or behaviors to protect themselves from systems and stigma) (Chapman et al., 2022). Masking is one-way individuals navigate oppressive expectations to be included or fit in. As Dr. Brené Brown notes, "Fitting in is one of the greatest barriers to belonging. Fitting in is about assessing a situation and

becoming who you need to be in order to be accepted. Belonging, on the other hand, doesn't require us to change who we are; it requires us to be who we are" (2015, p. 145). True belonging, as argued here by Dr. Brown, allows someone to be (and safely be) all of who they are rather than change themself to fit within the norm and be included.

Belonging in Extant Literature

Extant literature explores belonging as: (1) significant in identity formation (Faircloth, 2009; Groves et al., 2018; Raver et al., 2018), (2) connected to behavior (Battistich & Hom, 1997), (3) important for motivation and achievement (Goodenow, 1993; Leary & Kelly, 2009), and (4) as significant in mental health (Arslan et al., 2022; Shochet et al., 2011). There is more limited research focusing on the connection of belonging and individuals with marginalized or multiply marginalized identities, including individuals with disabilities. This is not surprising given the systematic exclusion of individuals with IDD in knowledge generation and scientific processes (Shogren, 2023; Taylor & McDonough, 2021). Just as learners labeled with IDD are often denied full inclusion in educational spaces, they are restricted from engaging in knowledge generation. An IDD label, in and of itself, often leads to individuals with IDD to be denied epistemic competence (Taylor & McDonough, 2021, p. 28), even in knowledge generation about their own experiences.

While the benefits and importance of inclusion have been documented for individuals with IDD, there is a substantial gap in attention to belonging. This is significant as a right to access or inclusion alone does not equate to belonging or meaningful membership of all students (Hall, 2010; Power, 2013, p. 68; Strnadová& Walmsley, 2018). There are two specific gaps in the literature which this project attends to: (1) specificity and clarity on what belonging means and how it's defined by individuals labeled/with IDD, and (2) exploration of experiences and feelings of belonging through the voices and lived experiences of individuals with IDD. There is

prevalent literature, throughout special education, based on proxy perspectives of individuals labeled with/IDD. I use the term "proxy" or "proxies" to represent the various individuals who speak about and for individuals with IDD. These individuals include but are not limited to parents, caregivers, other family members, teachers, professionals- anyone besides the individual themselves. Taylor (2018) might argue that the questioned credibility and trustworthiness of individuals with IDD might lead to seeking out proxy accounts (Taylor, 2018, p. 9). These perspectives, specifically parent perspectives, have been used to begin to understand belonging for individuals with IDD (Carter et al., 2016). As a result, the lack of engagement and inclusion of individuals labeled/with IDD in research often goes unquestioned (Taylor, 2018), and thus there is limited understanding of belonging from those with direct lived experiences. A focus on belonging necessitates the engagement of firsthand perspectives and experiences on what it means to belong both due to its subjective nature, and as a result of the systemic, continued exclusion and marginalization of individuals labeled/with IDD (Taylor, 2018).

Purpose Statement

This project builds on extant literature on belonging, and seeks to inform and expand special education literature, by addressing gaps specifically as they relate to the experiences of individuals labeled/with IDD. This project responds to the call made by Taylor and McDonough (2018) asking educators to recognize the responsibility they have to "safeguard [...] epistemic potential" of their students and recognize that they do not yet know the full potential of their students (Taylor & McDonough, 2021, p. 35). In this work I extended this call beyond traditional educational contexts, and also attended to the untapped potential of individuals with IDD in research contexts. This project aligns with Shogren's (2023) call to co-develop and co-lead "the process of science" that impacts the lives of those engaged (Shogren, 2023, p. 174). Within the bounds of a dissertation, we offer an example of participatory methodology with individuals with

IDD. The goal of the project was to move beyond the inclusion of individuals with disabilities in research and center the voices of those with lived experiences throughout the research process from conceptualization through analysis.

Research Questions

The questions which guided this project include:

(1) *How do individuals labeled with intellectual and developmental disabilities describe their feelings or experiences of belonging?*

(2) *How can we understand the spaces, relationships, and systems that foster a sense of belonging for individuals with intellectual and developmental disabilities?*

(3) *How do individuals labeled/with intellectual and developmental disabilities take up participatory methods to engage in research and disrupt ableist assumptions, power dynamics, and roles?*

Guiding this work is the conceptualization of disability and understanding of power through a Disability Studies (DS) lens (Oliver, 2013). Through a DS perspective, further understanding of the experiences of belonging for individuals labeled/with IDD, holds the power to inform systems and bring change to inequitable spaces. These ideas will be explored more deeply in Chapters two and three, along with the extant literature on belonging (including the intersection of belonging and IDD), and a review of participatory methodologies with individuals with IDD.

Chapter 2: Review of Relevant Literature

In this chapter, I address: (1) How conceptualizations and experiences of belonging have been explored by individuals labeled/with IDD in research, and, (2) how research might be reimagined to center and learn through firsthand accounts of belonging for individuals labeled/with IDD who have been systematically excluded and marginalized. To explore these topics, I draw on several bodies of literature from the fields of psychology, sociology, social work, and education. First, I will examine the systemic exclusion of individuals labeled with IDD within schools, community, and research contexts. Next, I will evaluate the ways in which this exclusion shows up in extant literature on belonging. Finally, I will name the urgency and importance of centering the values and voices of individuals with IDD in research on belonging.

Systemic Exclusion of Individuals Labeled/with IDD

Individuals with IDD labels have been and continue to be excluded on various levels (individual, system and cultural) (Baglieri & Lalvani 2019). In the following sections I describe: (1) the history of exclusion of individuals labeled/with IDD and its relationship to normalcy, (2) what ableism and systemic exclusion looks like in schools and communities, and (3) how ableism and exclusion of individuals with IDD unfolds in research contexts.

History of Exclusion and Construct of Normalcy

The exclusion of individuals labeled/with IDD results from the historic and ongoing inferior status ascribed as a result of their disability. These rationalizations and beliefs towards different opportunities and access for individuals labeled/with IDD are often rooted in the construct of normalcy, specifically deviance from the norm (Davis, 2013). Normalcy is used to reference what people should be able to do and how they should go about it; any deviation from this expected or assumed way of being is grounds for marginalization (Baglieri & Lalvani, 2019). Linguistically there is a connection between the appearance of the word

norm/normal/normalcy and the word ideal. Davis (2017) writes about how when the concept of ideal is contextualized in statistics (knowing it's unattainable), the concept of average surfaces as a way of understanding "normal." This is when *ideal* begins to be conflated with *average* (Davis, 2013). The normal curve allows clear indication of distance from normal, and these differences become deviations (Baglieri & Lalvani, 2019). Through an ableist lens, this concept of normal creates understandable grounds for othering and marginalizes "deviant" individuals or groups of individuals.

While legal safeguards have furthered the rights of individuals labeled with disabilities, they do not fully address discrimination and continued exclusion as a result of not being perceived as "normal". It was not until 1975 that students with disabilities were afforded the right to public education. In 1990, the ADA (Americans with Disabilities Act) was passed which addresses inequality/discrimination in employment, public services, and accommodations (Americans with Disabilities Act, 1990). Certain finite rights are secured through this law, but ADA alone does not create protection from exclusion. Similarly, in 1975, the Individuals with Disabilities Education Act (IDEA) provided the legal right for an education. Despite this legislation, individuals with disabilities still experienced exclusionary educational practices (separate schools, self-contained spaces, etc.). Behind the development and implementation of legislation are deep beliefs about who is worthy, whose life is valuable, and who deserves access.

These beliefs are deeply ingrained not only in individuals, but in the paternalistic structures and systems in which we are all embedded. The result is not only a long history of exclusion but restricted agency for individuals labeled/with Intellectual and Developmental Disabilities (Goodley, 2014). Practices like sterilization, eugenics, segregation, restraint, objectification, etc., have all been "under the guise of necessary and benevolent paternalism" (McDonough & Taylor, 2021, p. 197). These same structures restrict access and agency in

schools and limit access to knowledge and learning which further exclude adults with IDD and impact their agency to take up political or epistemic roles.

Systemic Exclusion and Ableism in Schools and Communities

As previously mentioned, there are legal requirements towards access and inclusion of individuals with IDD both within schools and other public spaces (see IDEA and ADA). These laws are intended to combat the result of longstanding discrimination. In schools, inclusion is mandated through IDEA and embedded in the clause that schools must offer and support educational placements for students identified with disabilities in their Least Restrictive Environment[2] (LRE) (IDEIA, 2004). Through IDEIA, inclusion (in terms of placement) has become a metric for equity in schools. Inclusive placements (i.e., students with disabilities being placed in a classroom with their same-age peers as opposed to a separate/contained setting) have been documented in research literature to benefit students with disabilities academically, socially, and in communication development (Agran et al., 2020). When environments are inclusive, students without disabilities also demonstrate better academic and social outcomes (Cole et al., 2004; Hehir et al., 2016). Instruction in general education when compared to segregated spaces provides: increased access to curriculum and instruction, heightened engagement, improved academic and social outcomes, and access to peer supports (Agran et al., 2020; Giangreco, 2020). Despite this, students with IDD continue to be placed in self-contained, segregated classrooms for the majority of their school day (Agran et al., 2020). Argan and colleagues (2020) provide several reasons for this, including: perceptions of competence, stratification based on economic/demographic status, biases, teacher preparation and experiences, capacity, and limited access or awareness of current research (Argan et al., 2020, p.

[2] Least Restrictive Environment says that students receiving special education services should be educated alongside their general education peers to the greatest extent possible.

6). These reasons for segregation for school-age students with IDD, can be extended to community and employment contexts (Carter, 2021). Further, the epistemic disempowerment experienced throughout schooling teaches individuals with IDD not "to regard themselves as future citizens" (Taylor, 2018).

Just like legal mandates driving educational possibilities, ADA created the legal protection for individuals with disabilities to access and engage in public services and employment. Similarly, current legal measures provide basic rights but do not address the oppressive systems and beliefs which underlie segregation. With the Olmstead decision, in 1999, the deinstitutionalization movement began with a shift to community-based placements and services for individuals with disabilities. Almost 25 years later, individuals with IDD continue to desire more genuine social inclusion in their communities (Merrells et al., 2019). While social inclusion within community contexts has largely been studied through the perspectives of family members and service providers, Merrells et al. (2019), highlight the importance of understanding community social inclusion through the unique experiences of individuals with disabilities themselves. A primary theme that surfaced in their interviews with individuals with disabilities was feelings of being outcast, segregated, and excluded within their communities. Participants in this work also described exclusion from paid work and other opportunities in which they desire access (Merrells et al., 2017). If paid work was available for individuals in the study, it was often a short term experience. This trial-based mindset is also seen in educational settings (Biklen & Burke, 2006). Adults with IDD also described difficulty finding and engaging in reciprocal friendships (Merrells et al., 2017), which may be connected to the ways in which ableist presumptions of competence have restricted opportunities to peers and social networks over time. These findings highlight that in community contexts, ableism persists on individual, cultural, and systemic levels (Baglieri & Lalvani, 2019).

Systemic Exclusion and Ableism in Research and Knowledge Generation

Systemic exclusion of individuals labeled/with IDD results from ableist systems and assumptions about competence (Baglieri & Lalvani, 2019). This is evident in K-12 schooling experiences and in community settings. Thus, it may not be surprising that individuals with IDD are also commonly excluded from engagement in research. Taylor (2018) describes this through a framework of epistemic injustice: "a cyclical relationship between social exclusions and epistemic exclusions" (p. 4). As a result of segregation and exclusion of individuals with IDD, the absence of the voices and direct perspectives of those within knowledge generation and research contexts goes unquestioned. Most often issues that are relevant to the lives of individuals with IDD are explored in collaboration with parents, caregivers, service providers, and educators who are often typically non-disabled and serve as proxies for disabled people.

Taylor and McDonough provide important framing around the lack of inclusion of individuals with IDD in research. They cite a lack of believed epistemic agency (2021), and push Biklen and Burke's presumption of competence (2006) and Donnellan's "criterion of the least dangerous assumption" (Donnellan, 1984) to presume epistemic competence. Ableist assumptions about individuals with IDD create barriers to inclusion in research. Two of these include: (a) presumed incompetence simply as a result of an ID label, and (b) an assumption that knowledge or generation capacity is connected to normative communication modes (i.e., individuals with an ID label or who are non-speaking are incapable of reasoning/engaging in the research process). Taylor (2018) describes epistemic disempowerment (p. 2) as occurring throughout the lives of individuals labeled with IDD (e.g., condescending comments, legal guardianship), and highlights the way this injustice exists within research contexts. Individuals are denied credibility in connection to an identity, and/or in connection with their communicative repertoire/approach (Taylor, 2018, p. 9). Epistemic competence is denied when ways of being,

communication, or behaviors differ from the "norm" and the use of some communication modes better lend themselves to one being deemed epistemically competent. To this end, the exclusion of individuals with IDD in research becomes justified.

In response to this systemic exclusion and the implications of educational research, Taylor calls for researchers to address the absence of these perspectives. Taylor notes, "by including people labeled with intellectual disabilities as active participants in educational research, researchers can together correct schooling practices that fail to prepare people with intellectual disabilities to experience themselves as knowers and be regarded as epistemic agents" (Taylor, 2018, p. 4). This call is echoed by Shogren (2023) who highlights the direct relationship between knowledge generation and practice and policy. In the coming section, I will highlight the ways in which perspectives of individuals with IDD have been excluded from literature specific to belonging.

Belonging Literature and the Systemic Exclusion of Individuals Labeled/with IDD

In the following section I (1) describe belonging broadly and address the accessibility of belonging to highlight the importance of understanding belonging through the lived experiences of those with marginalized and multiply marginalized identities, and (2) discuss the presence of proxy voice in special education literature.

Unpacking the Accessibility of Belonging

If belonging is an essential human need and a part of physiological functioning (Baumeister & Leary, 1995), then clarity on what it means to belong is critical in understanding how one accesses feelings of belonging. Baumeister and Leary (1995) connect the need to belong to a human desire for power, approval, and intimacy. As discussed in the previous section, access to power has been historically and systemically limited for individuals with disabilities and other marginalized groups. The belongingness hypothesis says interpersonal

bonds are created through ongoing and frequent interactions with a minimum number of people, and the interactions must be consistent and work towards the well-being of both individuals. These two elements of belonging are shaped by power dynamics, restricting the agency of individuals experiencing oppression. Ongoing and frequent interactions require accessibility and inclusivity of spaces and communities. Consistent and reciprocal relationships are impacted by ableist beliefs. Often non-disabled individuals engage in one-way relationships, or 'helping' type relationships with individuals with IDD (Carter et al., 2008; Rossetti & Keenan, 2018), which impacts the quality of friendship (Rossetti & Keenan, 2018). This may contribute to research that highlights that up to 40% of students receiving special education services (with a label of ID or multiple disabilities) shared no time with friends outside of school; and only an average of 10% of these students have frequent interactions with friends outside of school (Wagner et al., 2004). Despite these findings, there is research documenting the ways in which individuals with extensive support needs develop quality friendships (Josol et al., 2022; Rossetti & Keenan, 2018).

Friendships are central to belonging. According to Baumesiter and Leary, the need to belong is "a strong desire to form and maintain enduring interpersonal attachments" (Baumeister & Leary, 1995, p. 522). Feelings of belonging are not just about being a part of a group and sharing similar identity/identities, but about having interpersonal relationships and connections within that group (Easterbrook & Vignoles, 2013). Dr. Brené Brown talks about belonging as something to be reached and achieved both within oneself and within a greater community or group. This individual human need requires connection and a degree of mutuality. According to Dr. Brown, true belonging "is the spiritual practice of believing in and belonging to yourself so deeply that you can share your most authentic self with the world and find sacredness in both being a part of something and standing alone in the wilderness" (Brown, 2017, p. 40). In this

light, when an individual is freely their most authentic self, belonging is accessible as a result of building interconnectedness and interdependence. But, as noted previously, the freedom to be oneself is often suppressed by larger systems outside the control of an individual. A need for change is often implicitly and explicitly communicated to students whose ways of being fall outside ableist conceptions of normalcy; thus, limiting the accessibility of belonging.

Presence of Proxy Voice in Literature on Belonging and IDD

Brown's conceptualization of true belonging, specifically being one's most authentic self, affords this argument rationale for centering the stories and perspectives of individuals rather than proxies. The presence of proxy voice in research on the experiences of individuals with IDD is not surprising given the history of systemic exclusion previously described. There is a gap in special education literature, and more broadly inclusive education and belonging literature on the inclusion of first-hand accounts compared with proxy voices. The majority of published work on belonging (and many other topics) in the special education and inclusive education literature includes synthesis of the voices and perspectives of proxies, in place of the firsthand accounts, or lived experiences of individuals with IDD or extensive support needs (Dee-Price et al., 2021; McDonald et al. al., 2021). Some studies include disabled voices, but there is ambiguity around involvement based on vague recruitment and data collection procedures reported (Fulton et al., 2021). When researchers and educators fail to center the voices of those whom they seek to include, they "[impede] the development of more accurate understandings of our social world and educational institutions" (Taylor, 2018, p. 5). When researchers and educators center outside voices, it often centers normative goals or ableist perspectives, which is concerning given the direct implications and advocacy resulting from their findings.

Belonging in Educational Contexts

An individual's experience in school often extends to their experience in society; and

experiences of belonging for individuals with IDD across contexts might inform inclusive education, therefore it is important to highlight the way belonging has been understood and motivated in school settings. Belonging in school contexts has been defined by "the extent to which students feel personally accepted, respected, included, and supported by others in the school social environment" (Goodenow, 1993, p. 25) and has largely been conducted without specific focus on the experiences of students with disabilities (Carter & Biggs, 2021; Strnadová et al., 2018). This is concerning given the fact that students with disabilities have a history of being excluded and segregated in schools (Agran et al., 2020). School belonging shows up in four key conversations in literature: (1) in connection to achievement, (2) in relationship to mental health, (3) in conversation on behavior, and (4) in identity development (Faircloth, 2009; Slaten et al., 2016, p. 4). I will explore each of these areas in the following sections.

School Belonging to Inform Motivation and Achievement

In the early literature on belonging, authors tie feelings or a sense of belonging to motivation and achievement. They cite Maslow in this argument, specifically his claim that the need for belonging comes before a desire to gain/build knowledge (Goodenow, 1993). Belonging, within the context of schools, is subjective. It is held, felt, and assessed by the individual student. Class climate or some broader or more objective measure is not the same, and research findings suggest that it is the subjective feelings named by the individual which are those that impact motivation (Goodenow, 1993). Belonging, thereby, should be understood through the perspectives and accounts of individuals, rather than through generalizations or system-wide solutions. These early conceptualizations of school belonging as subjective, reaffirm the need to attend to experiences of belonging for individuals labeled/with IDD who have often been positioned as less than in educational contexts.

School belonging and connection to mental health

Next, the literature talks about belonging in schools as it connects with well-being and mental health. In this research, researchers most commonly highlight the potential harm correlated with lack of belonging. For instance, individuals who do not have a sense of school belonging may experience negative affective symptoms, including symptoms of anxiety and depression (Arslan et al., 2022; Shochet et al., 2011). Experiences of victimization are connected with diminished well-being and decreased sense of school belonging (Holt & Espelage, 2003). The relationship between mental health and school belonging has been documented bidirectionally. As such, mental health has also been documented as a barrier to experiencing school belonging (i.e., depression may contribute to low experiences of belonging at school), and lack of school belonging has been documented as a contributor to depression and other mental health diagnoses (Newman et al., 2007; Shochet et al., 2011; Slaten et al., 2016).

Belonging in the school context is explored in the literature as a protective factor for student mental health (Arslan et al., 2022). A few studies have looked at the interplay of bullying (as a form of victimization) and a sense of belonging (Arslan et al., 2022; Holt, 2003). A positive correlation has been documented with a sense of school belonging and victimization and/or psychological symptoms (Holt, 2003, p. 88). Belonging in this context is a protective factor for mental health in the school context. Belonging is also a factor in building resilience (McDonald, 2021).

School Belonging and Identity

Finally, there is research on the intersection of belonging and identity formation. Faircloth's assessment of belonging ties into Dr. Brené Brown's more layered definition of belonging in highlighting the centrality of identity development. Identity formation happens across an individual's lifetime, but adolescence has been documented as a unique time for the building of identities (Faircloth, 2009). Not only is adolescence a critical time period for identity

development, but identity formation is influenced by the context (e.g., the people, the environment, etc.). Thus, the school context becomes critical to an individual's experience or sense of belonging. One's identity development is "fluid," and ever-changing "by the affordances and constraints of one's context(s)" (Faircloth, 2009, p. 326). Faircloth names identity development and the process of self-understanding as critical aspects of belonging. Educators hold a unique power in their ability to create opportunities for belonging including relationship building and creating learning opportunities which connect students to their current self-exploration and identity formation (Groves et al., 2018). Despite these findings, there is minimal belonging research which intersects with disability identity and community.

Themes of Belonging for Individuals Labeled/with IDD

Belonging moves the "concept of social inclusion beyond narrow understandings and identifies it as not simply the promotion of the increased presence of marginali[z]ed persons" but the *valuing* of people with disabilities or individuals marginalized by other identities (Power, 2013, p. 68). When explored in relation to the experiences of individuals with IDD, a focus on belonging affords understanding of the perspectives and experiences of individuals with IDD, as opposed to a simplistic understanding of presence in a physical space. Strnadová and Walmsley note that there is strength in attending to belonging as "it encourages a focus on the individual, and what matters to him or her, rather than imposing solutions" (Strnadová & Walmsley, 2018, p. 1100). In an educational context, belonging moves beyond issues of placement and calls for educational systems to create and foster environments which value all learners, including those with disabilities, so that individual students can take up meaningful roles and build relationships.

The limited literature about belonging for people with intellectual and developmental disabilities is problematic considering the history of exclusion for this population (Carter & Biggs, 2021; Fulton et al., 2021). Much of the existing literature on belonging for individuals

with IDD has been led by Carter and colleagues. Carter, like others, recognizes a need to move beyond inclusion in pursuing equitable learning spaces for students with disabilities (2021). Arguably, students with disabilities in inclusive settings are still not afforded the same opportunity to experience belonging as their non-disabled peers. Presence within a general education space does not address the inequitable and oppressive systems at play. In their work, Carter and his colleagues developed a framework surfacing ten dimensions describing belonging across contexts which posits: "belonging is experienced when people are present, invited, welcomed, known, accepted, supported, heard, befriended, needed, and loved" (Carter, 2021, p. 16). These dimensions are drawn from Carter's own research, literature reviews, and his work with people with IDD and their families. Several of the dimensions introduced in Carter's work surface as themes in findings across studies about the experiences of belonging for children and adults with IDD. The dimensions of being present, being befriended, and being accepted resonated across the explored studies. I highlight references or overlap to the other components/dimensions of belonging in Table 1.

Table 1:
Presence of Carter's dimensions of belonging across other reviewed literature centering disabled voices

Carter's Dimensions (2021):	Strnadová & Walmsley, 2018	Hammel et al., 2008	Gur & Bina, 2022	Foley et al., 2012	Morrsion et al., 2019
Belonging	*Belonging*	*Participation*	*Belonging*	*Belonging/Wellbeing*	*Belonging*
Present	Chosen Places	Choice and agency	Safe space	Having things to do	
Invited					
Welcomed		Access		Included in schooling opportunities	"Discriminatory Attitudes" p. 15
Known	Reciprocal Relationships	Reciprocal Relationships	Social Interactions		
Accepted	Disability Identity	Membership	Accepted	Resilience	Feeling in and out p. 13
Supported	Adult identity	Reciprocal Support			
Heard	Chosen Places	Agency	Respected		
Befriended	Reciprocal Relationships	Connection		Good friends	
Needed	Community	Responsibility	Valued		
Loved					Dating/emotional relationships
Other dimensions:			Shared experiences	Home/family Self-acceptance	Disability spaces

Aspects of Belonging

Presence

According to Carter the dimension of presence highlights that spaces are significant, and "location matters" (Carter, 2021, p. 16). Within a place, it is the repeated coming together, often through routines or scheduled activities which is critical in understanding the experience of belonging (Carter, 2021). The concept in other literature represents both the *choice* and right to be in a space (Gur & Bina, 2022; Hammel et al., 2008; Strnadová & Walmsley, 2018). Belonging is tied to places of an individual's choosing rather than a place chosen or forced upon them (Strnadová & Walmsley, 2018). This theme resonated across the conversations I shared with the women in my prior work (Allred, 2022). Choice, or the idea of agency, is highlighted by Hammel who describes this choice as twofold including: *when* to be present, and choice in *how* one engages (Hammel et al., 2008). While the physical place is relevant to belonging, the social environment or the knowing of people within the place is just as important when considering experiences of belonging (Gur & Bina, 2022). Carter also highlights the interplay between spatial aspects of belonging and the routines connected to places which foster opportunities for relationship building (Carter et al., 2016). In summary, presence (or the right to inclusion) is part of belonging, but choice in choosing how/when one accesses the space is equally significant.

Reciprocity

The concept of reciprocity surfaces across disciplines in discussion of belonging. Research specific to understanding intellectual and developmental disability is one place in the literature where the intertwining of reciprocity and belonging is documented. According to Carter's ten dimensions, reciprocity seems to resonate most closely to his dimensions of "to be befriended", and "to be known" (2021, p. 24). The idea of befriending focuses on relationships in which both parties are needed, wanted, and cared for. Carter highlights the importance in

considering the opportunities for these relationships outside of family or professional support staff. This resurfaces the importance of choice. Access and opportunity for inclusion is therefore a critical basis for belonging, creating opportunities for shared enjoyable experiences (Carter, 2021, p. 25). Several research studies highlight the voices of disabled participants naming reciprocal relationships as central to their experiences of belonging (Foley et al., 2012; Hammel et al., 2008; Strnadová & Walmsley, 2018). Fulton summarizes reciprocity as a theme across several reviewed studies, specifically naming the give and take (both giving and receiving) in a relationship even if that is not necessarily equal (Fulton et al., 2021, p. 1018). The notion of reciprocity connects to presumption of competence and recognizing the social needs of people with IDD.

Acceptance and Respect

The third dimension of Carter's conceptualization of belonging which showed up consistently across the literature was "to be accepted" (Carter, 2016, p. 21). In his words: "the affirmation that you are accepted as you are - without condition or caveat - is central to belonging" (p. 22); which gets at the idea of an authentic self-named as a critical part of true belonging by Dr. Brené Brown. Without naming ableism, Carter talks about the need to change attitudes to move from inclusion to acceptance (and belonging). According to Carter, these discriminatory mindsets are broken down through relationships, and information sharing, or awareness campaigns/curriculums are not adequate in fostering belonging. The dimension "to be accepted" shows up as a theme in other literature on belonging as well (Foley et al., 2012; Gur & Bina, 2022; Hammel et al., 2008; Strnadová & Walmsley, 2018). In focus groups with adults (20-60 years old) with IDD, acceptance surfaces in the context of communities. Specifically, participants homed in on self-advocacy groups as being one of the only places they felt they were accepted and therefore belonged (Strnadová & Walmsley, 2018). In Hammel's work, disabled

participants push back on the notion of acceptance, calling for more: “It’s not that they accept me or not, I want to be respected... I prefer to have respect versus acceptance” (Hammel et al., 2008, p. 1454). These are important findings because it is through work such as this, that directly engages with listening to adults with disabilities, that we learn inclusion in normative spaces may not be what facilitates acceptance and belonging to the highest degree; this nuance is missing from Carter’s description of acceptance as a dimension of belonging.

Carter’s descriptive account of the components of belonging serves as a helpful framework for understanding the many ways belonging may be impacted or show up for individuals with IDD. While historically Carter’s work has been rooted in parent, proxy, and some first-hand accounts of people with disabilities, these ten dimensions are his synthesis based on a variety of proxy perspectives. The surfacing of these dimensions in work engaged directly with adults with disabilities (e.g., Foley et al., 2012; Gur & Bina, 2022; Hammel et al., 2008; Morrison et al., 2019; and Strnadová & Walmsley, 2018) strengthens the argument for these dimensions in an understanding of belonging. These firsthand perspectives highlight an understanding of belonging that involves reciprocal relationships, the importance or reciprocity and acceptance, of being an active and valued community member, and of having agency or choice in presence.

Belonging and Identity

Finally, participants surfaced the concept of belonging in conversations about identity: as an independent adult, and identity with their disability label (Strnadová, 2018). This echoes back to the notion of duality, discussed in reference to Dr. Brene Brown’s and Mahar’s works, in understanding belonging both as self-acceptance, and being a part of something/with people who respect and value you (Brown, 2017; Mahar, 2013). One way this has been documented in the literature is in research exploring “self-advocacy” groups or other disability affinity spaces.

Many reasons exist for explaining disability affinity spaces as contributing or creating a sense of belonging. One of these being the ability to understand one-self and develop or change or cling to one's self-concept in a new way (Beart et al., 2004). In thinking specifically about one particular self-advocacy group, Frawley and Bigby explore the idea of a common goal or advocacy/action focused work as a contributor to feelings of belonging within a group of people all labeled with intellectual/developmental disabilities. Thus, the self-advocacy space provided social connection, ongoing relationships, and time spent doing important work together fighting for the rights of people with disabilities (Frawley & Bigby, 2015). In both these ways, through self-concept and/or identity formation, and also through community-building with people with similar identities and experiences, self-advocacy or affinity spaces for people with disabilities become an important place in literature for understanding the experience and development of belonging.

Addressing the Specific Focus on Perspectives and Experiences of Individuals Labeled/with IDD

The need to belong is not unique to individuals labeled/with IDD compared with their non-disabled peers; but there are reasons to attend to the specific experiences and conceptualizations of belonging by individuals labeled/with IDD. These reasons include: (1) a reimagining towards more than inclusion/presence; (2) IDD labels are connected with other intersecting experiences of marginalization (e.g., segregated spaces, mental health disorders, etc.); and (3) the experiences of individuals with IDD have long been understood through proxy voice and the centering of lived experiences allows us to attend to additional dimensions of belonging (i.e., disability identity).

First, extant literature on belonging and IDD argue for a focus on belonging as an intentional move beyond integration and inclusion, citing the desire of individuals with IDD to

experience belonging (Carter & Biggs, 2021). Carter includes a visual representation (see Figure 2.1 in Carter, 2021) showing with small circles the trajectory of exclusion to belonging. Showing the placement of students with disabilities in a classroom space across various education models (including exclusion, segregation, integration, inclusion, and belonging). When the focus remains on inclusion in a place (both within and beyond educational contexts), the weight of learning, being, and accessing that space is left up to the individual (Jorgenson, 2007; Nelson, 2021). This responsibility or burden connects to learners' experiences of belonging, or lack thereof. Thus, a focus on belonging calls attention to the personal experiences and connections of individuals within a community or space (Carter, 2016; Hall, 2010).

Next, a specific focus on belonging for individuals with IDD allows an exploration of the ways in which an IDD label is connected to the previously discussed history of systemic exclusion, as well as an increased prevalence of mental health diagnoses. Diagnostic overshadowing is a term which describes the interference between ableist beliefs about the competence of individuals with IDD or extensive needs and the possibility of mental health symptoms or diagnoses. As a result of diagnostic overshadowing, individuals with an IDD label often do not get access to mental health services and supports (Tucker et al., 2021). For example, certain behaviors, when engaged in by individuals with IDD labels, are often attributed to the disability itself and not a possible symptom of a mental health diagnosis like anxiety.

In compounding ways, the basic human needs of individuals with IDD go unrecognized. In overlooking other diagnoses and in failing to provide mental health supports and services, our communities are implicitly communicating their believed value of the lives of those with IDD. Additionally, the misattribution of behaviors often leads to segregation of individuals with IDD and subsequent limited opportunities for belonging (Tucker et al., 2021). Mental health needs must be considered when thinking about the accessibility of belonging; similarly, the prevalence

of anxiety, depression, mood disorders, etc. within the IDD community (Munir, 2016) speak to the urgency in cultivating communities and spaces of belonging.

Finally, a focus on belonging through the perspectives of those with IDD is critical as much of extant literature has been written through the voices and thoughts of proxies (Hammel et al., 2008). Individuals with IDD hold important knowledge that is largely unaccounted for in academic literature (McDonald, 2021). Additionally, experiences of belonging for individuals labeled/with disabilities are impacted by their interactions with non-disabled individuals (Morrison, 2019). By shifting the focus of the literature to center the perspectives of individuals, in place of proxy perspectives, new levels of understanding about belonging may surface, including (but not limited to): (a) how belonging is defined and conceptualized by individuals with IDD, (b) how/if disability identity or affinity spaces might contribute to belonging, and (c) if individuals with IDD are experiencing belonging in the ways that matter most to them (Carter, 2021).

One specific limitation of proxy accounts of belonging is ableist assumptions about what belonging is, and what spaces or norms should be considered when reflecting on belonging. For example, Mueller and participants explored the ways in which self-contained special education spaces were safe spaces in students' educational journeys (2019). Morrison's participants also shared feelings of safety and understanding in disability affinity spaces in their reflections on belonging (Morrison, 2019). In summary Morrison found that discussion on belonging can open up important conversations about disability: "Disability spaces can give people opportunities to identify common experiences, learn new ways of talking about and understanding disability, and share useful information that helped in navigating the experience of disability" (Morrsion, 2019, pg. 19). These spaces were not uniformly reflected as spaces of belonging for participants, and agency around participation in these spaces remains critical.

Conclusion

Conceptualizations and experiences of belonging have been explored in connection with individuals with IDD. The majority of this research, like other work focused on IDD, is rooted in perspectives of parents, caregivers, teachers, or other service providers. There is only a small body of research that explores belonging for individuals with IDD through their own accounts. Carter and colleagues have established ten dimensions of belonging and many of these dimensions have surfaced across findings of research focused on firsthand perspectives. Continued research is needed to understand how individuals with IDD define belonging, how and if they are experiencing belonging in ways that feel meaningful, if their conceptualizations resonate with existing dimensions (Carter, 2016), and to connect disability identity and community to accounts of belonging. Research should be reimagined to address the systematic exclusion and marginalization of individuals labeled/with ID in school, community, and research contexts. In the next chapter I describe my dissertation project which centers the firsthand accounts of belonging for four adults with IDD and documents the way they take up participatory methodology.

Chapter 3: Methodology

Background

In thinking about the usefulness of qualitative research in understanding the experiences of individuals labeled/with disabilities from a Disability Studies lens, I was interested in exploring the following questions: *How can the traditional, dominant, or normed, ways of research be shifted? In what ways is research useful for people with disabilities?* (Barton, 2005). These types of questions are closely aligned with qualitative inquiry, specifically the purposes of understanding and interrogation (Bhattacharya, 2017) and disrupting the traditional focus on individuals marginalized by "dominant sociopolitical hierarchies" (Lauterbach et al., 2022, p. 183). However, even qualitative methods can perpetuate traditional power dynamics and ableist views if not taken up in critical ways.

As a result of being labeled with their disability, individuals with a disability are often not provided with the opportunity to engage in civic engagement through research (Taylor, 2018). Even research looking to gain an insider perspective has largely excluded people with disabilities (Lester & Nusbaum, 2021, p. 5). There is a recent trend towards engaging in inclusive research with individuals with IDD. Bigby and colleagues report through their 2013 literature review that there are three ways of doing inclusive research: (1) individuals with IDD give advice, (2) individuals with IDD direct and control research, and (3) individuals with IDD work with people without IDD in different roles towards collective research (p. 3). Participatory research methods are one tool for inclusive research that aim to disrupt ableism and support epistemic agency specifically as it exists in research (Stack & McDonald, 2014; Stevenson, 2014). Further, participatory methodologies may improve research quality by forming partnerships, creating accessible spaces and opportunities, increasing validity of research, and creating a sense of mutual trust (Stack & McDonald, 2018; St. John et. al., 2018). Thus, I designed a participatory

study (most closely aligned with Bigby's collaborative approach to inclusive research- listed as number 3 above) to increase understanding of belonging through the conceptualizations and experiences of individuals labeled/with IDD.

Data was generated through a variety of tools and modes, which were selected by participants. Some of the potential data generation tools I proposed included: interviews (Nicolaidis et al., 2019; Bhattacharya, 2017; Lester & Nausbaum, 2021), focus groups (Agan et al., 2008; Trevisan, 2021), photo sharing (Collier, 1954; Harper, 2023; Woolrych, 2004), maps (Annamma, 2016; Futch & Fine, 2013; Powell, 2010), and collective analysis (Frankena et al., 2018; Rix et al., 2020). Data generation occurred beginning in the summer of 2023 after IRB approval and recruitment and concluding in January 2024 with co-analysis. Following the direction of Vega-Cordova et al. (2020), I fully mapped out the various phases of the research project to understand the way in which each phase included collaborative activities (See Vega-Cordova et al., 2020, p. 321), while holding space for the priorities of participatory methodologies. The design sought to disrupt traditional methodologies which do not see individuals with IDD as active contributors or agents to research, but often as "objects of research and theory" (Taylor, 2018). To do this I engaged with participants as co-researchers. The participatory design, and embedded agency and flexibility within participatory design created a framework for decentralizing researcher power and goals, and instead made space for the recognition and execution of participant values, priorities, and choices.

Theoretical and Conceptual Framework

The theoretical framework guiding the project is drawn from the field of Disability Studies. Situated within the lens of Disability Studies (DS), the conceptual framework consists of an (inclusive) social understanding of disability, presumptions of competence, epistemic agency, and conceptualizations of belonging.

Theoretical Framing

Disability Studies. A Disability Studies framing provided me with the opportunity to reckon with the problematic approaches used to explore disability (Oliver, 1992). Emerging from rights-based advocacy, Disability Studies moves away from medical framing of disability and conceptualizes disabilities through social barriers and contexts (Boxall, 2018). Disability Studies is interdisciplinary, and moves away from a focus on intervention, which limits understanding of the social and political nature of disability (Linton, 1998b). Disability Studies addresses several key dimensions which are critical to the framing of this project: a social construction of disability, focus on the lived experiences of individuals with disability, and recognition of the importance of access and agency.

Kafer's political/relational model of disability notes that disability is not solved through medical intervention or changing towards "normal," but through political and social change (Kafer, 2013, p. 6), which creates space for reimagining (p. 9). Siebers pushes for a model of disability which recognizes the interplay between agency and environmental access/restrictions (Siebers, 2019, p. 40). Both of these models aim to understand the social imposition of disability and resulting experiences of oppression (to some degree). Disability Studies honors the importance of acknowledging disability as critical to analysis and furthering knowledge (Linton, 1998b, p. 120). Boxall's inclusive social model of disability emphasizes the importance of including individuals in the process of theorizing their own identities and lived experiences (2018, p. 205). A Disability Studies lens is a critical part in approaching qualitative work which seeks to center the lived experiences, and knowledge production of individuals labeled/with IDD.

Understanding of Disability. The shift from the medical account of disability towards a social model was an impactful political move and it also created space for considering the value of knowledge obtained through lived experience (Connor et al., 2014, p. 20; Kerschbaum &

Price, 2017). The social model of disability places the deficit within the accessibility of society and calls for societal changes to allow people with disabilities greater access to contribute and engage. The social model situates disability as a social construct, and because disability is not located within an individual, society has a responsibility for the outcomes and experience of all its members (Oliver, 1983; 2013). Further, Siebers names the importance of understanding the social model as an epistemological model. This requires individuals being described by the model as crucial and required participants in building and sharing knowledge (2019, p. 42). In other words, authentic use of social model framing of disability requires the centering of lived experiences.

This model restricts (and contradicts) an understanding of disability in which professionals or others deemed experts (without lived experiences) prescribe interventions to mediate disability. Instead, support must be considered through a social-ecological view of disability which acknowledges the evolving and ongoing support needs of individuals rooted in their own desires and contexts (Jones & Gallus, p. 6). These supports are ultimately understood through the experiences and perspectives of those labeled with disabilities. Boxell (2018) proposes a vision for an inclusive social model "which develops and expands multiple and diverse ways of understanding social oppressions, while at the same time diverting attention away from perceived individual deficits. Integral to the inclusive social model is a commitment to using inclusive means (people discussing and theorizing their own experiences) to develop inclusive understandings, which are as accessible as possible to as many people as possible" (p. 205-206). This vision guided my conceptualization and methodological decisions for the study.

Conceptual Framework and Theoretical Alignment with Conceptualizations of Disability

Within a Disability Studies lens, several key concepts informed the framework for this inquiry which explored belonging and intellectual and developmental disabilities. Key

conceptual ideas included: presumptions of competence, the problematic prevalence of proxy voice, political membership, and epistemic agency. Each of these ideas will be explored individually but it is the intersection of these ideas under the umbrella of Disability Studies which provides the necessary structure and framing for this project. Additionally, two previously conceptualized frameworks of belonging will be shared to highlight the ways this project sought to build on and expand prior understandings of belonging.

Presumptions of Competence. Presuming competence is critical to understanding belonging and how it's conceptualized and experienced by individuals with IDD. Presumptions of competence are rooted in Disability Studies in Education literature (Connor, 2019). Biklen and Burke described this idea in 2006, citing communication differences (specifically expressive communication difficulties) as a primary reason for educators to dismiss students or assume incompetence (Biklen & Burke, 2006). They claim that educators use verbal communication as a measure or prerequisite consideration to cognition or competence. This idea is rooted in a vignette which returns to a time when Biklen was watching Burke engage and communicate in a preschool setting. Jamie Burke, at the time communicated via facilitated communication. The authors describe schools as the site of initial labeling, and how various labels come to signify incompetence and become a barrier to inclusive instruction and contexts. The authors call for (1) a commitment to inclusive education, (2) educators to hold curiosity and understand how a learner experiences their environment, (3) educators to seek ways to allow an individual to speak for themself, and (4) recognition that normal is a social construct. Each of these ideas guided the conceptual framing of this project, but I held close to the second (holding curiosity for the learner's experience) and the third (allow an individual to speak for and share themselves) in the study. Since conceptualization of 'presumption of competence' (this idea of an outsider knowing or assessing competence based on specific observable skills/behaviors), outsider assumptions

about people with disabilities have grown. Assuming incompetence, an ableist tendency both within and beyond educational settings, leads to restricted access and opportunity for individuals labeled with IDD.

While communication modality served as the initial indicator of these presumptions or assumptions, evaluating competence moves beyond communication, which is documented by the continuance of this labeling when communication differences do not stand in the way of engagement (Taylor, 2018). Even when individuals are communicating in preferred/normative ways, educators continue to make assumptions about their competence. Within school settings in particular, these researchers found educators wanting students to demonstrate certain skills/behavior or more overarching 'competence' before gaining access to educational experiences and places. Educators who chose not to presume competence invoke an absence of opportunities for their students (Kliewer et al., 2006). Outside of schools, these experiences are mirrored in ableist perceptions of normativity and competence which influence the spaces and opportunities in which individuals with IDD are granted access.

Biklen and Burke argue for the significance in "admit[ting] that one cannot know another's thinking unless the other can reveal it" (Biklen & Burke, 2006, p. 167). In their work, they state the presumption of competence is not something to be proved or located but instead it's "a stance, an outlook, a framework for educational engagement" (Biklen & Burke, 2006, p. 168). This framing is critical both within educational spaces and beyond. The responsibility is not on an individual labeled with a disability to demonstrate competence, but the burden lies on the educator/community member/researchers, etc. to figure out how to make learning or other opportunities accessible (Biklen, 2020).

Students with IDD often rely on a teacher's belief in their competence ("as capable sense-makers") and their right to curricular access in order to access the same educational opportunities

available to their non-disabled peers (Kliewer et al., 2004, p. 387). This reliance continues beyond school boundaries in the way community members, employers, and family members' beliefs about competence influence the agency of individuals labeled with IDD. When others presume competence and ensure accessibility, individuals with IDD have the opportunity to demonstrate or enact agency (Biklen & Burke, 2006). Further, Biklen says that even if an individual has a history of not performing in anticipated or expected (normative) ways, this does not excuse a person who presumes competence from believing an individual will at another time demonstrate complex thought or understanding (Biklen & Burke, 2006). Fabricated conceptions of normalcy must not inhibit presumptions of competence.

Proxy Voice. Biklen and Burke highlight that educators and researchers have often and continue to fail to presume competence (2006). Not presuming competence leads to defaulting to proxy voices to gain information about the lives, desires, and priorities of people with IDD. This becomes especially true in research contexts, especially when priorities of the medical model of disability are centered. One danger of the medical model is the value judgment made on disabled people and their lives. Within a medical model understanding, disability is considered a part of an individual, and contextual understandings (whether social, historical, etc.) are not considered or necessary. This thread of 'normal' or 'normalization' is central through the early history of special education research, which rationalizes the focus on intervention work to address any recognized deviations from the norm (Baglieri & Shapiro, 2017, p. 18-19). Put in other words, one "feature of medicalization is the exaltation of the role of the doctor or professional in matters of diagnosis and treatment" (Baglieri, 2017, p. 20). This statement indicates a desire to center and prioritize the voices, goals, and opinions of professionals, as opposed to the voices of those with lived experience or direct impact. As a result, the voices of individuals labeled with IDD are

commonly replaced by proxy voice, and first-hand accounts or direct lived experiences are largely absent from academic literature (Kim et al., 2020; Powers, 2017).

Studies on belonging have often enrolled parents, caregivers, educators, or other proxies as the primary participants (e.g., Carter et al, 2016). While this group of participants has allowed for further understanding and perspectives on belonging, excluding the voices of individuals with disabilities in research on their own experiences reifies the ableist idea that only certain voices can be valued or trusted (Taylor, 2018). This is problematic and is a reflection of broader stigma and assumptions of disability (Baglieri et al., 2011). When researchers and educators fail to center the voices of those whom they seek to include, they "[impede] the development of more accurate understandings of our social world and educational institutions" (Taylor, 2018, p. 5). When researchers and educators center outside voices, danger lies in the implications and advocacy from their work, as it often centers normative goals or ableist perspectives.

When researchers instead presume competence of individuals with disabilities, the lived experiences and voices of disabled people can contribute to knowledge generation and subsequent policy and practice implications. While proxy perspectives can be helpful in considering supports and environments, if they are the sole story, they may misrepresent or restrict the full understanding and knowledge of lived experiences. The risk in centering and valuing proxy voice over firsthand perspectives is the devaluing of the knowledge and voices of individuals with disabilities, hindered understanding of our social world, and continued educational and societal inequities for disabled individuals. If researchers claim to hold a DS lens, their subsequent inquiry and engagement should be built on the belief of presumed competence and inherent value in all voices (Biklen & Burke, 2006).

Political Membership. The political membership of disabled people is situated amidst histories of oppression and power dynamics. Disability has remained the "uninterrogated marker

of inferiority" and throughout history citizenship debates have been used to justify the exclusion of other minoritized individuals (Taylor, 2015, p. 84). Citizenship has been defined and created through the voices and perspectives of non-disabled, white, men, based on their beliefs of inadequacies and social hierarchies (Baynton, 2013). As a result, much of what it looks like to be a "good" citizen is shaped by these paternalist norms and priorities. For example, capitalist values of efficiency and productivity often push individuals with intellectual disabilities outside of normative conceptualizations of political membership (Linton, 1998). Further this capitalist, and paternalist value of independence is quick to call out individuals with disabilities as not "good" or productive, discounting the reality that we are all interdependent beings (Taylor, 2015). Despite this, individuals with intellectual and developmental disabilities are actively engaged in civic practices. Taylor (2015) names several examples including: "self-advocacy networks, within regional and national government structures, within schools, institutions, and/or care-homes, even within workplaces, artistic fora, through play, or through intimate relations of care" (p. 188-189). These demonstrations of political agency push back on normative views of civic engagement.

Epistemic Agency. Finally, the idea of epistemic agency is a central construct in exploring intellectual and developmental disability and belonging through a DS lens. Epistemic agency in this conversation can be described as an individual's "ability to produce, convey, or use knowledge" (Catala, 2020, p. 756). Ableist assumptions create a belief that individuals labeled with IDD are not in a position to contribute or produce knowledge in educational research. This may be due to lack of experience and personal connection, and/or a lack of firsthand experience (Taylor, 2018). Wherever these assumptions are rooted, they have deeply impacted the literature base and limit our understanding of first-person accounts and insights on experiences of belonging.

DS (and DSE) scholars recognize these literature gaps, and signify they are rooted in more than just assumptions about ability, but also in assumptions about value and worthiness (Baglieri et al., 2011; Boxall, 2018; Connor, 2019). DSE scholars also speak to the intentionality in excluding disabled voices from research and recognize the deep impact this exclusion has not only on research but policy and advocacy. Connor asks, "What knowledge is of most worth? Who decides? Who benefits?" (2019, p. 11). According to Baglieri "the issue of voice- that is, who is allowed or not allowed to tell their stories- figures prominently into how DSE approaches questions about research and inquiry" (2011, p. 273).

Taylor highlights these exclusions as a framework of epistemic injustice, which shows "a cyclical relationship between social exclusions and epistemic exclusions" (Taylor, 2018, p. 4). The concept of epistemic injustice, as defined by Fricker, is injustice in a person's ability to be viewed as a knower (Fricker, 2007). As a result of their disability, individuals with a disability are often forbidden the opportunity of partaking in civic engagement through research. Social power is held by non-disabled people in determining who can contribute or who counts as a knowledge contributor (Taylor, 2018, p. 2). Thus, there is a significant level of control and intentionality in whose voice is included or sought out in knowledge production. Further, inherent assumptions or beliefs about the cognitive nature of individuals with disabilities draws many systems and researchers towards proxies to explore matters related to the individuals labeled with disabilities instead of disabled people themselves. This injustice creates not only diminished status as an epistemic agent in connection to social context, but also limits civic and educational opportunities (Taylor, 2018, p. 3). In this study, epistemic agency speaks to the value and worth recognized in the stories and knowledge contributions of individuals labeled with intellectual and developmental disabilities. This framework values the lived experiences of individuals with IDD over the agendas and interventions of professionals (e.g., within the field of

special education). DS scholars also situate this idea, of valuing lived experiences and embodied knowledge, as central (Linton, 1998).

Belonging Situated within these Beliefs

Next, I will explore two conceptualizations of belonging through the lens of DS and the aforementioned concepts (i.e., presumptions of competence, proxy voice, political membership, and epistemic agency) guiding this project.

Renwick's Conceptualization of Belonging. This framework of belonging affords the proposed work attention to the difference between inclusion and belonging and provides an avenue for thinking about one of the reasons centering first person accounts is significant. In tradition with their theoretical approach of grounded theory, Renwick and colleagues have developed a theory through which other researchers and individuals can frame their thinking about youth experiences of belonging. The categories informing a sense of belonging within their framework include interacting with similar people, negotiating meaningful roles in the community, engaging in social relations, and finding a good fit (aligning with the norms and expectations of a space/group) (Renwick et al., 2019, p. 952). Renwick's framework for belonging is a "departure from many westernized notions of inclusion that often equate inclusion to participation in socially normative activities" (Renwick et al., 2019, p. 961). This perspective posits that individuals can fit within the normalized view of social inclusion but may do so in "ways that may undermine genuine belonging" (Renwick et al., 2019, p. 966). In other words, Renwick argues inclusion does not always equate belonging and the categories identified in their work may provide more accurate understandings of an individual's sense of belonging in a space. This framework is an important part of this project's conceptual framework as it is built through firsthand accounts.

Allen et al.'s Conceptualization of Belonging. Allen and colleagues (2021), scholars from the field of psychology, provide another conceptualization of belonging. Their conceptualization (See: Figure 1 in Allen et al., 2021, p. 92) is significant as it pulls from across disciplines to summarize and frame what factors play into a sense of belonging. These authors call into their framing the significance and critical impact systems of oppression have on the various opportunities, motivation, perception, and competencies of individuals to fulfill a sense of belonging. Further these authors speak to the way in which a sense of belonging is dynamic and the four components of (1) competencies, (2) opportunities, (3) perceptions, and (4) motivations continuously inform, restrict, and create possibility for each other (Allen et al., 2021). These four components are situated and informed by "social, cultural, environmental, and temporal contexts and experiences" (p. 92). This conceptualization of belonging aligns more closely with the critical lens I take up in framing this project, specifically in recognizing the way in which systems inform, and limit possibilities; and also, in recognition of various perspectives and interpretations on what it feels like to belong.

Positionality

As a family member to an adult labeled with IDD, a former special education teacher, and as a student at a university special education department, I am reflective of the ways I am embedded in and continue to participate in ableist and oppressive systems and structures. As a previous special education teacher, I worked within a segregated, self-contained classroom space. While I was in this role I had a part in perpetuating segregated education for students with intellectual disabilities. Despite this, I used the agency I had within this program to advocate for my students' rights and access to more expansive educational opportunities. I also recognize the power I hold as a student in a higher education institution, specifically in terms of my agency and power in exploring research agendas which may impact policy and practice. In this study, I

aimed to use participatory methods to disrupt the power dynamic which exists both in my role in higher education and as a non-disabled individual.

Next, as a non-disabled, white, heterosexual woman, I am aware of the advantages I have been afforded in my own personal and educational journey. I recognize the responsibility I hold as someone given these affordances to work to deconstruct the power hierarchies in the systems in which I find myself. I also recognize the intersection of these identities creates a particular perspective and lens which I carried through the research process and into analysis. Throughout the project, I paid close attention and considered the way in which my positionality impacts my own understandings and participant experiences from project conception through analysis and in the implications drawn from this project.

My own positionality, identities, and experiences have informed my design of this project. I recognize my own responsibility in disrupting normed special education research on/about people with disabilities. Over the past several years I have engaged in learning about how special education is laden in capitalist motivations and ableist dispositions. I recognize my own interests may be served as a family member, advocate, and support person for someone with IDD; and in recognition of these interests and biases I am committed to being critical of my own assumptions and am committed to unpacking the ways I have been and am still engaged in ableist systems. I am committed to decentering preconceived goals of this project through my commitment to participatory methodology. Entering this project, I understood that a participatory approach may shift my initial goals and ideas as I developed a better understanding of the needs and desires of the individuals involved, who were my partners in this project. I leveraged several approaches to engage in such reflexivity including reflective memoing, ongoing member checks, and critical reviews from friends or paid consultants (Saldaña, 2013). I also believe our shared connection (though my own is not first-hand but instead a familial connection) provided a space

for rich conversation and a willingness to be reflective, open, and honest about their own experiences.

Research Design

The following section describes the methodology of the project, including the research questions, context and participants, data generation tools, and data analysis process.

Methodology

Participatory Methodology. In 1995, Cocks and Cockram named participatory research as a means by which to "deliver meaningful services to people with disabilities" (1995, p. 25). Participatory research sits on many assumptions: society creates groups of oppressed individuals, knowledge generation is connected to emancipation, people have the agency and ability to solve their own problems, empowerment comes through collective action and researchers have a role in liberation (Cocks & Cockram, 1995, p. 31). This approach disrupts traditional power dynamics in research, giving leadership and control to individuals with disabilities (Bigby et al., 2014). Participatory research believes people are capable of sharing, creating, and acting on knowledge and as a result involves engaging people as co-researchers in participation and action (Sitter & Grittner, 2021). This was my goal in this proposed work.

Contextual Fit of Participatory Methods. There are several reasons participatory methodology is a fitting approach to explore the experiences of people with IDD and belonging. First, it's a tool for understanding first-hand or lived experiences of marginalized individuals (Sitter & Grittner, 2021). Next, participatory methodologies closely align with the values and goals of a DSE theoretical lens. For example, DSE supports research and action which presumes competence of people labeled with disabilities (Connor, 2019, p. 11). This methodology disrupts the power dynamic between researchers and people with disabilities (St. John et al., 2018). Additionally participatory methods are a tool for disrupting previous traditional research with

people with disabilities and may improve research quality by forming partnerships, creating accessible spaces and opportunities, increasing validity of research, and creating a sense of mutual trust (Stack & McDonald, 2018; St. John et. al., 2018).

Participatory Methods with Individuals with Disabilities. Characteristics of participatory research with people with disabilities involves surfacing relevant phenomena (a research problem) and then partnering with disabled people to collectively explore and address the research problem together (Chappell, 2000; Cocks & Cockram, 1995). Participatory methods are built on five central assumptions: (1) oppression creates oppressed groups which requires systemic change; (2) "knowledge generation" and application are central to emancipation of the oppressed; (3) people are able to "work towards solutions to their own problems;" (4) "knowledge generation, education, [and] collective action" are connected to the "empowerment of oppressed people; and (5) researchers should be actively involved in the work of liberation (Cocks & Cockram, 1995, p. 31). These assumptions are relevant to the proposed project and several of them are directly addressed in this work, including recognition for systemic change based on prior research and inquiry work; knowledge generation to better inform change which aligns with the goals of people with disabilities; and creating solutions or steps forward in collaboration with and directed by individuals with disabilities.

The research methodology selected holds significant power. Research methodologies hold the power to communicate belonging both within the context of the research itself and belonging in the process of knowledge generation more broadly. A chosen research approach, and the research environment holds power "to change the relationships of people with developmental disabilities to the system of knowledge production and the actors therein and to authentically and fully say 'you belong,' we must change practice as usual" (McDonald, 2021, p. 101). Participatory methods align with the Disability Studies lens of this work by focusing on the

lived experiences and recognition of the social construction and implications of disability. Participatory methods also honor presumptions of competence, a move away from proxy voice, and center and highlight the epistemic agency of individuals with IDD.

Research Questions

I engaged in qualitative and participatory methodology to develop understanding of how individuals labeled with intellectual and developmental disabilities understand and experience belonging. The design sought to disrupt traditional methodologies which do not see individuals with IDD as active contributors or agents of research, but often as "objects of research and theory" (Taylor, 2018). The participatory design and embedded agency and flexibility within participatory design created a framework for decentralizing researcher power and goals, and instead made space for the recognition and execution of participant values, priorities, and choices. This participatory project aimed to increase understanding of the ways in which adults with IDD have historically or currently experience belonging. Participants shared the way they make meaning of their experiences of belonging through interviews, art, and document analysis. The project also sought to increase understanding of how the participants engaged in meaning-making as individuals and within the context of a small group.

Bringing together Disability Studies, presumption of competence, and epistemic agency provides a lens to understand participatory methods as a needed avenue for gaining knowledge and understanding of belonging for individuals labeled with intellectual and developmental disabilities. This project was built on my understanding and work from a pilot project (Allred, 2022). Methodologically, I centered the sharing of stories to emphasize the value of individuals with IDD as epistemic agents (Taylor, 2018). I intentionally engaged directly with adults with IDD, as opposed to using family voices or other proxies as the primary voice/participant and gathered information and stories from them about past and current experiences in and outside of

the educational settings where they have felt belonging. Additionally, together we engaged in analysis about our shared work and experiences.

My research questions for this work were:

(1) How do individuals labeled with intellectual and developmental disabilities describe their feelings or experiences of belonging?

(2) What can we understand about the spaces, relationships, and systems that foster a sense of belonging for individuals with intellectual and developmental disabilities?

(3) How do individuals labeled/with intellectual and developmental disabilities take up participatory methods to engage in research and disrupt ableist assumptions, power dynamics, and roles?

Context and Participants

This project was not defined by specific contextual boundaries, rather, participants were recruited who identified with an intellectual and/or developmental disability, and together we explored the contexts in which they have or do experience belonging. I recruited four participants to engage in this process with me. I began recruitment by sharing a brief description of the proposed work and a recruitment flyer with organizations and individuals with IDD I was already connected with (see Appendix C). Recruitment materials were shared with organizations and individuals in both Minnesota and Washington. Further, three individuals were previously involved in a small pilot project with me around this work and I reconnected with them to see if any of these individuals would like to be involved in co-creating this work with me. Two previously involved individuals wanted to continue this work and engaged in early planning.

To be included in the study, participants had to meet the following Inclusion criteria: (1) be 18 years or older, (2) have an intellectual and/or developmental disability label, and (3) have access to a phone, computer or other device to connect with myself and other participants. After

confirming alignment with the defined qualification criteria, I reached out to further describe the project, answer any questions, and set up a time to review the consent process with the individual. During this initial consent process, I took care to understand the presence of formal guardianships/conservatorships. Consent from guardians was gained as needed.

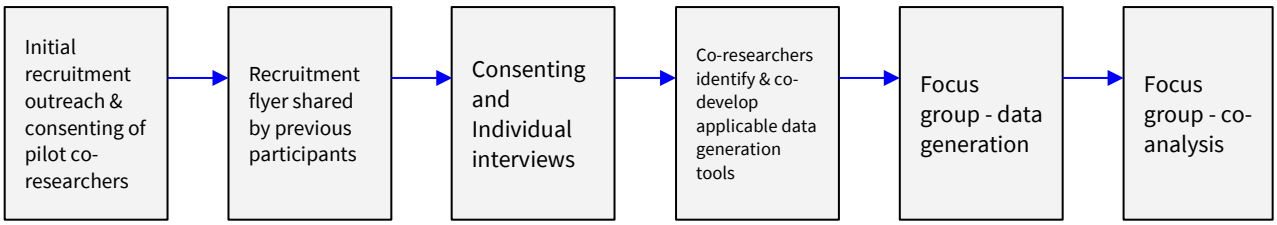
Data Generation

I initially connected with the participants from my 2019 pilot project to gauge their interest in getting involved with this more in-depth process, and to see if they were interested in helping to co-design and prepare data collection tools and processes. Two of these participants were interested and consented to participate and be a part of the planning and recruitment process. Together we drafted interview protocols and thought through meaningful ways to engage in shared group activities.

After eligible participants went through the formal consent process, they were involved in creating and engaging in a variety of data generation activities. Data generation tools included: interviews, small group discussions, photo-elicitation, artifact sharing, and creation of a visual representation. Within the tradition of participatory work, I provided an overview of the data generation tools which we might potentially use and shared sample protocols. However, I committed to recognizing and holding space for co-creation of these experiences and recognized that they would evolve once we began our shared work. I also held a commitment to ensure co-researchers preferences in data generation were honored, and regardless of their choices continued to include them in the full duration of the research process. The visual below demonstrates the ways in which a traditional dissertation timeline was informed by participants engaged in participatory methodology. The primary data collection method for the project was interviews. A variety of other data collection tools were discussed with co-researchers, and co-researchers selected the methods they were most interested in using to share a fuller picture of

their stories (Bhattacharya, 2017). A few of the possible additional data collection methods included photo elicitation and artifact sharing, mapping and art creation, and small group discussions.

Figure 1: Data Generation Process



Interviews. Each participant engaged in semi-structured open-ended interviews during the data collection portion of this project (Bhattacharya, 2017, p. 127). First, co-researchers engaged in an initial interview which lasted approximately thirty to sixty minutes and was sometimes broken up into multiple sessions depending on the needs and preferences of the participant. Prior to engaging in the initial interview, I connected with individual participants to ask about accessibility and access needs to help co-create spaces where stories and knowledge can be shared. Accessibility decisions and accommodations created by other participatory research served as a resource for me as I offered a scope of possibilities for what our conversations or engagement could look like (i.e., Nicolaidis et al., 2019) and considered the way COVID-19 had increased awareness to possibilities for more accessible experiences (Ahlers et al., 2021). Initial conversations and sessions were used to inquire and observe communication preferences, which are hugely important in creating opportunities for full participation and accessible research spaces (Powers, 2017). Interviews occurred over Zoom or by phone depending on the preferences and location of participants. The interviews were audio recorded with participant permission and Zoom interviews video were recorded if the participant provided permission. Recordings were collected to create transcriptions of each of the sessions.

A sample initial interview protocol is included in Appendix B. This is a sample, and the initial interview conversations were developed, modified, and updated with individual co-researchers as the study unfolded (see individual protocols in Appendix C). In addition to developing and selecting questions, this group focused on accessibility considerations necessary for centering disability (e.g., for example, but not limited to, live captioning, spotlighting on Zoom, additional accommodations, etc.) (Kerschbaum & Price, 2017). Common research practice exerts expectation and assumption of spoken language, and places reliance on "conceptualizations of a normative bodymind" (Lester & Nausbaum, 2021, p. 5). The interview also explored individual participants' experiences of belonging across experiences, places, and relationships. I created a few questions prior to each interview to create some structure for the first interview conversation. These included, "what does it feel like to belong?" and "who makes you feel belonging, and what do they do which makes you feel this way?" At the close of this first interview, we brainstormed together ways in which the participants might share additional stories or qualities of belonging or how they wanted to proceed in our work. Ideas generated by participants included further one on one conversations, photo sharing, artifacts, asking new questions, or a small group discussion.

The next step varied for each co-researcher. Depending on individual preference, this second interview held space for participants to expand on the stories and content from the first interview with the use of photo or artifact elicitation, and/or mapping or visual creation (these tools are described in further detail in the following section). This second interview was semi-structured and lasted approximately thirty to sixty minutes. Questions like "what was happening in this picture which made you feel belonging?" or "how often do you go to this place?" (see Appendix B) guided the elicitation process to further triangulate the data captured in the first interview. At the end of this interview or the next step, participants helped co-create and imagine

a small group discussion space for continued sharing. Co-researchers helped envision this space and were given an opportunity to opt in or out of the group portion of data collection depending on their preferences and availability. I intentionally did not list an observation as a possible next step in place of this interview conversation. I believe the narrative was best explored through the direction and lead of the individuals with IDD, as opposed to me showing up at a place or event and trying to create my own account or representation of the place or relationship the participant has already described. I also did not want to unintentionally shift the dynamics of a space the participants described feeling belonging. Thus, narratives, photos, artistic representations, and conversations were the primary data sources contributing to my understanding of belonging. Table 2 includes a summary of the various forms of data generation each co-researcher chose to engage in during our process. Some chose to engage in a second semi-structured open-ended interview.

Table 2.

Data Generation Tools by Co-Researcher

Data Collection Tool:	**Coral**	**Esme**	**Betty**	**Dory**
2021 Project Data	Yes	Yes	-	-
Individual Interviews	2	3	3	1
Documents/ Artifacts	-	Yes	-	Yes
Maps/Visual Representations	Yes	-	Yes	-
Photo Sharing	Yes	Yes	-	-
Small Group Discussions	3	0	3	3

Documents and Artifacts. Within the small group discussion space, documents were introduced and collectively discussed and analyzed. Documents were used to provide further understanding and support other data sources. In this project, the documents and artifacts supported shared understanding of the interview data (Bhattacharya, 2017). Documents (i.e., creative representations, visual representations, and photos) were used as one part of data collection to increase accessibility, to add detail or nuance to participants accounts of belonging, and to triangulate data collected during interviews, document analysis, and small group discussions (Sitter & Grittner, 2017). Further, documents provided more expansive options for input and responding (Ahlers et al., 2021).

Maps or Visual Representations. Following the initial interview, mapping was one possibility for participants to further engage and share their stories. Mapping involves creating a visual representation based on one's own experience(s) over time and space; this provides researchers a tool for gaining a better understanding of an individual's story or a particular phenomenon (Futch & Fine, 2013). Educational journey maps are one tool for understanding the intersections between individual identities and experiences and political experiences or forces within educational settings (Annamma, 2016; Powell, 2010). Maps have also been used as a tool to bridge differences (e.g., language) in interviews (Futch & Fine, 2013). In this project, maps served as one possible tool and activity for participants to engage in reflection, and to share their experience(s) with belonging. One example instruction or prompt said: "write or draw about the places and experiences where you felt a sense of belonging." One co-researcher wanted to interact with this prompt as is the others worked tangentially to create a visual representation of belonging together which did not conform to typical mapping practice. Audio recordings of co-researchers' explanations of their maps or other visuals were collected when participants consented and shared their interpretations during an interview or small group discussion.

Photo Sharing. Photo elicitation is a methodological tool often used to supplement qualitative interviews, originating in anthropology literature (Collier, 1957). It involves using one or many photos to evoke further information or conversation during a research interview (Meo, 2010). Photo sharing has been named a tool within participatory methodology and has been explored in special education research (e.g., Kaplan et al., 2008). Photovoice or photo sharing allows individuals to select and share a photo and add their own words, allowing them control in the way they are "represented" by research (Woolrych, 2004, p. 14). One benefit of photo elicitation is the potential to create space for report building and allow researchers a new viewpoint into a participant's social world (Harper, 2023). Thus, photo elicitation was offered as a form of engagement in both the first and second interviews and within the focus group space. An example prompt used with photo elicitation in the project was, "share with us a picture of something that reminds you of feeling like you belonged."

According to Kaplan and colleagues, photo elicitation is a tool which can move individuals from participant roles to co-researcher roles. Kaplan calls this tool photo voice and follows Woolrych in using photos as a tool for shifting control to individuals with disabilities and away from the researcher (Kaplan et al., 2008; Woolrych, 2004). Photo sharing is one data collection tool which created more accessible interview experiences for participants during my previous project (Allred, 2021), as it provided visual information to support and extend the stories shared through narrative form in the interviews. Participants used pictures to support initiating storytelling or to further my understanding of their experiences and descriptions. Photo sharing was a part of document and artifact data collection in this project as a way to increase accessibility, provide an alternative means of expression, and evoke further story-sharing in interviews and focus group contexts.

Small Group Discussions. The final part of data collection was a group space created for co-researchers to convene to share knowledge (both emotional and experiential) and generate understanding of their shared and/or differing stories and experiences of belonging in learning contexts and beyond. In proposing a group setting, I was cognizant that they are often inaccessible spaces, specifically for individuals with communication disabilities (Ahlers et al., 2021; Trevisan, 2021). Despite this, Agan and colleagues have documented focus groups as a helpful tool for participants when the content is rooted in both emotion and experience (Agan et al., 2008). Stories of belonging are full of emotion and experience. Thus, I worked with co-researchers to create a space which accounted for accessibility needs and allowed co-researchers to engage in ways they choose.

The small group was optional; each session lasted approximately 45 to 60 minutes beginning with time to make introductions, get to know one another, and begin building trust. There were three group sessions. The group time was filled with questions, activities, and interactions created and put forth by the co-researchers. The agenda (activities and conversation) making up each group session was co-constructed with co-researchers, but an example protocol is provided in Appendix B based on the small group collaboration we engaged in during the pilot project (Allred, 2022). Amendments, suggestions, and/or revamping of the group session protocol occurred during individual interviews and was adjusted collaboratively at the start of the group session. The small group discussion sessions were guided by participant interest, a desire to elaborate or share more (through verbal communication, with photos, or through art), or wonderings about what others have shared. Esme, one of the co-researchers, chose not to participate in the small group. She shared a preference for continuing to share in a one-on-one context with no specific reason, but maybe because of her desire to keep the conversation focused on a particular experience of hers.

Data Analysis

This project sought to extend the ways in which participants with IDD have typically been involved in the analysis process of research by continuing participatory methodologies into analysis. Data analysis for this project had two main parts: (1) co-constructed analysis on data around conceptualizations and experiences of belonging, and (2) secondary analysis on the ways in which participants demonstrated agency during the research process. The goal of the first part of analysis was to collaboratively synthesize our work together on belonging to co-create a resource or tool for participants to disseminate in meaningful ways. The goal of the second part of analysis was to document the ways in which participatory research methodologies are possible and the extent to which individuals labeled with IDD take up their roles as collaborators and co-researchers from development through analysis. Many participatory projects provide limited details about the ways in which participants (with IDD) have been involved in analysis, and because I sought to honor the epistemic agency of the individuals I worked alongside, it made sense to engage in co-constructed analysis

Part 1: Co-constructed Analysis. Analysis was an ongoing process and together we used ongoing sensemaking to inform our next steps in data collection and our time together. Including participants in the analysis process is central to the theoretical and conceptual framing of this work which views individuals with IDD as active contributors or agents to research, rather than as "objects of research and theory" (Taylor, 2018). The sensemaking and analysis of participants was central to this project; how co-researchers wanted to engage in analysis and their own interests and curiosities guided our shared analysis space. Group analysis included debriefing one another's stories, drawing connections or highlighting differences, and exploring further wonderings about belonging together. Based on co-researchers consent and willingness to share their stories and ideas, analysis included review of: summaries and central ideas from

individual interviews, document/art/photo review, and small group summaries. Member checks (Brantlinger et al., 2005) were used as the foundation for all data used in data analysis. Summaries were constructed collaboratively with participants involved in each part of the project. For example, individual interviews were jointly summarized for themes and understandings and the group collaboratively reviewed these ideas or representations once they had been member checked by the relevant participant. Together, following the desires of the group (and the lead of one co-researcher), we engaged in an arts-based activity to document and share our co-constructed analysis of the cycle of belonging. This took the form of a co-constructed visual of the cycle of belonging, which matched co-researchers' desires for representation along with the most salient themes from our shared time. In order to capture Esme's insights and values in our analysis, I routinely took summaries from our small groups back to her, along with the drafted visual, to describe the groups thinking as well as to get her ideas on updates or iterations. The final co-constructed visual was created and agreed upon by each of the co-researchers on Zoom's collaborative whiteboard feature. Findings from this primary analysis are found in Chapter 5: Shared Conceptualization of Belonging.

Part 2: Analysis of Engagement of Individuals with IDD in Participatory Methodologies. In addition to the group analysis, I took ongoing analytic memos throughout this project, documenting the ways I observed participants engaging as epistemic agents and various dynamics which surfaced during our participatory process. The memos were recorded in a digital table after interactions with co-researchers (both formal data collection sessions, and phone calls/email correspondence with co-researchers as well as their support staff/caregivers). The memos included the date of the correspondence, the purpose/context of the correspondence, and reflective notes about our discussions as well as my analytic noticings. These memos guided my secondary analysis and directed me to certain individual and group conversations as I explored

these various themes and ideas. I first used open coding to review the data to describe and understand the presence of patterns and themes (Miles et al., 2017), and I was guided by my conceptual and theoretical frameworks in this process. The coding tree from the first round of coding was developed primarily from the conceptual and theoretical frameworks. After completing this initial round of coding initial patterns and themes from the initial coding process, along with the patterns and themes noted across analytic memos, were used to further develop the coding tree for a second round of coding (Miles et al., 2017). Transcripts of sessions, session summaries, and analytic memos were reviewed to map on relevant codes and compile moments representative of patterns and themes. This process is summarized through the coding tree which guided my analysis of the participatory process (See Appendix D). Next, I will share one example of this coding process and how patterns and higher-level codes were developed over the two rounds. For example, *presumption of competence*, a Round 1 code, was coded in an early memo where I reflected on a phone conversation with a parent about the ability of their adult child to engage in this work. Another Round 1 code was *participation across research phases,* an example of this was from a one-on-one interview conversation where Coral shared a story about getting invited to go out to dinner with friends from her apartment building. Through my analytic memos after this session, I highlighted the continued, perceived inequity of power, the session feeling like more question-and-answer type dynamic; which Coral had selected in configuring our agenda; but I noted feeling restricted in my understanding of her interests and curiosities in the inquiry process. During the next interview when creating our agenda, Coral selected to create her own questions for the group about belonging. This moment from the second interview was coded during Round 2, under the theme of *co-researchers taking up power in the participatory process through initiation*. This highlights the difference in the more traditional role of participant in research, and the enacted expansive participation of a co-

researcher in the research process. The results of coding these patterns and themes are discussed in Chapter 6: Methodological Findings.

Chapter 4: Individual Stories

Before exploring the findings of our shared work (Chapter 5), our co-constructions of belonging, I will introduce each of the four co-researchers involved in this work. The honoring of their individual backgrounds, stories, strengths, and participation preferences are necessary context for understanding how we co-constructed belonging in our shared space. In introducing each co-researcher, I will share information learned about them through our shared conversations and in their accounts of belonging and community. While each of the participants joined the project based on identifying as someone with an intellectual and developmental disability, specific disability labels are not something we spent time unpacking or exploring and hence will be left out of the participant descriptions. If disability labels would have been surfaced by participants, or been something they wanted to explore together, I would have included discussion of it in the findings. Instead, I honor participants' agency to decide if disclosing their disability to a conversation feels relevant, important, or something they want to do. Oftentimes individuals with IDDs have visible physical features which do not allow them the choice in disclosure; here there is a possibility to allow choice in making this known. Instead, I will introduce participants as they described themselves to me and as they showed up in our sessions. First, I will first introduce the two participants who were a part of the pilot group, and who supported initial conceptualizations of this project: Coral and Esme. Next, I will introduce Betty and Dory, who joined this work after the pilot phase and also engaged in co-constructing our sessions and findings.

Coral

Coral is in her 30s and is sociable, silly, and deeply caring about her work and relationships. “I love my job,” Coral shared, “and I’m proud when I’m getting paid.” Coral currently works at a daycare center as an assistant in the classrooms. Prior to this job, and during the early part of our project, she was employed at a local grocery store where she had long-standing connections with

other employees and community members. She enjoyed this work because of its social nature. She shared her experiences running into friends from high school that she knew from classes, and from sports: “I like to see people I know from [local] High School […] I was a cheerleader in high school.” In response to Coral I asked, “Do you see other cheerleaders from high school when you are at work?” and she responded, “Yeah sometimes, and oh! I saw my cheerleading coach.” The interconnectedness of her community connected with the idea of being known and being recognized. The importance of reciprocal relationships was something we explored together. Coral also shifted living arrangements during the duration of our project. Specifically, she transitioned from living in an individual apartment in a complex filled with adults with various disabilities, to living in a group home in a nearby suburb. These changes, both in work and living, sparked many of Coral’s topic interests in our shared group space.

In Chapter 5, I will continue to unpack the group’s exploration of belonging in the context of our living situations, but for Coral, she shared individually that being able to walk to community spaces (e.g., movie theaters, restaurants) is really important and enjoyable to her. Throughout our conversations I also learned of Coral’s involvement in Special Olympic sports, Christian-community spaces (specific to people with disabilities), and travels to see family. Coral also shared with me a love for cooking and “looking up new recipes online,” going out to restaurants and being active in her community, listening to music (especially at concerts), and going out on dates with her boyfriend.

In terms of support needs, Coral mentioned the idea of safety: “I need a [support person] with me [...] I just want to be safe with the stove.” She recognized in recounting certain stories or in sharing about her hobbies and interests that there are certain spaces or moments where she is supposed to have staff with her or supporting her. An example of this was in cooking and trying out new recipes. Aside from this idea of safety, support needs were not something Coral surfaced in our

conversations. However, as I engaged in our interactions, I knew through conversations with her mom that some of the shifts in her life (i.e., living spaces) were the result of ongoing difficulty in coordinating support and staff to meet these needs identified by her family.

Coral's Engagement in the Research Process

Coral began exploring belonging in this space during a pilot project for this work in Winter 2022. Coral and two other women engaged in both individual and shared spaces to share stories, wondering, and sensemaking about their understandings and experiences of belonging. In this space Coral shared a lot about the idea of invitations and others initiating her inclusion to activities and in relationships. At the start of planning for this work, I reconnected with Coral, and she shared enthusiasm about continued engagement. In our first meeting, Coral expressed interest in helping to plan and reconsider the structure of conversations and activities we had engaged in last time as we thought about inviting new people into our conversation. A part of this was her identifying questions she wanted to explore, including: "Do you feel like you belong where you live?" and "Do you feel like you belong when you are doing activities that make you happy?" The timing of our new shared space aligned with many changes in her individual life circumstances (e.g., job and home), which created curiosity about how others experienced these changes in various areas of their life. Coral engaged as she was available throughout the group sessions. At the end of our sessions Coral expressed an interest in continuing this work through writing about belonging.

Coral's Definition and Exploration of Belonging

In our initial conversations Coral said, "belonging is like making music." We talked about the magic of being in spaces where everyone knows the same words and enjoys dancing together. She shared additional example moments of belonging such as cooking a recipe with support staff, listening and dancing to music at a concert, and described experiences at her workplace. I asked Coral what it felt like when she was in these positions of belonging and she said, "I'm feeling loved."

Coral talked about the happiness she feels in moments of belonging. In an early conversation she juxtaposes the happiness she feels in sharing a meal with others, to the sadness she felt when her grandma passed away, “it was really sad [...] then, I was grieving.” In Coral’s stories and explanations, belonging seemed to be something experienced in moments when things aligned and when there is a shared interest, enjoyed with someone she has a relationship with, and in some places more consistently like working in the grocery store. An important reflection was that it was fluid; it is not something she felt like she achieved and accomplished but requires ongoing social negotiation to be in spaces doing activities with people she loves. This was evident as Coral talked about being able to choose social engagements and activities in the apartment complex, which seemed to be in contrast to the email conversations I had with support staff in the group home about a weekly “outing” they had planned for the house residents.

Esme

Esme is in her 40s and lives in a quiet suburb in a group home near her family. She works in a grocery store chain as a shelf stocker and sometimes on the front end of the store. Throughout our conversations Esme shared that what she enjoyed most about work was seeing people she knew when she was bagging or up at the front end of the store. She shared that she had worked with many of the same employees for a long period of time but did not explicitly share that such longevity contributed to increased feelings of belonging or membership in that space. Esme shared her enjoyment of coffee shops, going shopping, and traveling. She is a beautiful storyteller and has a knack for describing her emotional experiences both in the past and in the retelling.

Throughout our conversations Esme spent the majority of our time talking about the feelings that surfaced when she felt belonging in a relationship many years ago: “It’s calm. It’s peaceful.” While she did not bring this up during our first call, once she shared about this relationship it was something she was very interested in describing to me. This felt really important both to Esme, and

to me, as I reflected on the common assumptions that people with disabilities don't have the same desires for romantic and/or intimate relationships. It was this relationship that Esme compared everything else too. This relationship served as a barometer of sorts, a tool of comparison, when I asked her if other experiences, relationships, or spaces fostered belonging for her. This tool or tactic of comparison was not unique to Esme's narratives and will be described further in Chapter 5.

In terms of her support needs, Esme did not share much. She occasionally shared about her staff supporting dinner preparation, and/or in providing transition out into the community. Occasionally I interacted with Esme's staff when we began with more structured scheduled calls, but this was not always fruitful, and we quickly shifted to Esme calling me when she wanted to talk. This may be part of the reason the group research context was not as appealing or as good of a fit for Esme, which I describe in this next section.

Esme's Engagement in the Research Process

Similarly to Coral, Esme began this project during the pilot project in Winter 2022. She expressed interest in continuing these conversations and explorations of belonging. Despite this, she shared early on during a conversation that she did not want to join group calls and would rather meet just the two of us. She did want to know what others were sharing and expressed openness to others hearing about her stories and interests. For example, she posed a question "do you feel like you belong in romantic relationships?" which she wanted to share with the group. My commitments to this work led me to honor this decision and continue to include Esme and her contributions to the group discussion and co-constructed understanding of belonging. This involved returning to Esme in a one-on-one context after each of our group calls to share back what we discussed together, what we created, and what we asked. During these one-on-one check-ins, I also gathered her feedback, wonderings, or differing opinions to bring to the following group setting to share with other group members. While this process is non-traditional in a research context, I believe it not only aligned

with the participatory framework I took up, but it validated Esme's sense of agency and validated her opinions and boundaries about her participation in the project.

Esme's Definition and Exploration of Belonging

In addition to "peaceful," Esme used a variety of words to describe belonging: "belonging is important," "it's respectful and kind," "it's unique," and "it's different." After surfacing her prior romantic relationship, she continued to return to this when comparing other types of relationships, spaces, or activities. This previous relationship served as a tangible touch stone for describing and characterizing whether the other parts of her life and other experiences mapped onto this feeling of belonging, she had previously experienced. As Esme shared such a clear experience with this concept of belonging, I began to wonder about how conceptions of belonging developed if someone had never been in a situation where they felt such strong feelings of belonging, which will be further explored in the Discussion section. Esme expressed the sadness and devastation she had with this relationship no longer being a part of her life; and with the realization that nothing compares to the feelings of respect and uniqueness she felt with her boyfriend and his family.

Betty

Betty is in her 20s and is currently working at her local grocery store. She has held this job for a few years and shares she enjoys it because it is so close to home. Previously, Betty had worked a few different types of jobs, but both required a much more complex and timelier commute. She has many hobbies and connections in her town, and she mentioned throughout our conversations that she enjoys the familiarity and sense of safety such connections provide: "Here, I feel very comfortable, comfortable and open and more alive. Because I can be by myself. And I can take the buses anywhere. And I don't have to wait for my mom and dad to pick me up." Betty enjoys many artistic activities, including painting and pottery, theater, and spending time with her dogs. During the data collection of our project, Betty was living in a home with her parents. Throughout our sessions,

Betty and her family were working to find a good match for a housemate and social companion who could move into a house with Betty. Shortly after we finished co-analysis, I got to visit Betty and meet her new companion/housemate and see her new home. Support needs for Betty came up a few times and these conversations always occurred before we had our routine check in around consent for video recording. Her support needs were usually in the form of allowing space, time, and attention to processing emotions, including both the delay in moving into her new house (due to a complex situation with an intended housemate), and grief around the death of her family dog and later the death of an important family friend. During both these instances Betty communicated very directly how she might need support in communication, in pauses in sessions, or in scheduling flexibility. Betty talked frequently about how much she enjoys her town, which is rural, but accessible with public transit. She uses the bus line to commute to the town center for work and other community activities. In conversation with her family during the time frame of this project, I heard them describe their need to wait to find a housemate before Betty could live in her new space. From this, I inferred that there may be some safety concerns, or a need for social company and relationship.

Betty's Engagement in the Research Process

Betty joined the group after the pilot stage of the project, in the Fall of 2023. She first met with me in a few informal calls to see if she was interested in the project and to talk through the process of ongoing consent. After she agreed to get started, we met one on one for an initial conversation about belonging. Betty expressed interest right away in describing belonging through art. I offered to share an activity we had done during the pilot, following the mapping process (Annamma, 2016) and she quickly shared that she wanted to do something different. During this time, Betty began leading our session and talking me through her process. She shared a desire to create a more accessible activity for participants to engage in, processing in real time with me that

"some people can't draw" or hold a utensil "of a certain thickness." She created a template for her cycle of belonging (see Figure 2), describing it as "an outline that's simple for understanding." The outline included sticker icon symbols representing the various parts of the cycle of belonging as it exists for her. She explained the reason for a simple outline, "that way if they do a lot of art, they don't have to ask somebody else questions all of the time to understand." She shared that we could bring this activity to the group by creating a template on a shared space where co-researchers could move pictures, draw depictions, and work together to make a cycle that fit each of their understandings of belonging. Later on in our group sessions, Betty helped to lead this activity and explained both her own work and how we could use this interactive tool together to create a visual representing a shared understanding of belonging. She also shared some interest in future dissemination or sharing of our work if groups were inclusive and open to her being present.

Betty's Definition and Exploration of Belonging

In our early conversations, Betty shared "Belonging means that when I find a space or when I find a group or when I feel safe that feels like to belonging to me." She also noted, "If you don't feel safe you may have bad dreams, you don't know what's next." In Betty's description, there was a quality of something being known and familiar, that continually surfaced throughout her stories of belonging. When I asked Betty to describe what it felt like when she feels belonging, she said, "I feel all of the feelings at once." Betty shared feeling belonging in places where she can be herself and where it feels safe to be herself. This shows up at home, at the local bookstore, and stores around that area make her feel "comfortable, open and more alive because I can take the bus anywhere and I don't have to wait for my mom and dad."

When I asked Betty about spaces of belonging in school she shared, "I liked school but I was always in the disability area and couldn't be with my other classmates." She went on to say, "When I was younger, I didn't feel belonging in school, because I got pulled out all of the time." Betty

reflected, “Why do I have to be pulled out when I want to stay and learn from the teacher?” She said she remembers this “not feel[ing] right,” she also explored frustration in recounting days when she was given the day off when standardized tests had happened. She reiterated that she needed school to learn and so it didn’t make sense to have days where she did nothing if other kids were doing something teachers thought she couldn’t do. In her recollections of her time at school, there was a contrast to the earlier description of belonging as places where she felt safe and somewhere where she could be herself, “I didn’t have a lot of friends because I wasn’t able to open up.”

Another part of explaining belonging for Betty was her understanding of others’ body language. She referred to this as a superpower, which she got when she was very young. She said with gusto that “it ruins everything for me.” In describing an example, she recounted an encounter with school staff: “they didn’t hit me or anything but their body language was that [...] he wanted to put me out because he saw I just wasn’t good enough for his ranking.” Next, she recounted a memory of being bullied in middle school where a boy pushed a desk into her, and another day pulled on her scarf. She quickly led into how this experience, on top of the low expectations of educators for her learning, made her feel like “just a piece of trash, or big garbage that needs to be demolished.” She added again that it wasn’t just kids that were bullying her, but adults as well. She could understand through their body language how they felt, “I can feel what they’re feeling, and this made me feel sad because I can’t be myself.” She went on to say, “Not everyone’s brain works like mine, but I stay in my ways to keep myself safe, because I don’t want to go through this 100 times.” Her brain tells her body and mind it can’t be its true self if it wants to be safe in school. Betty stated, “So sometimes I feel most comfortable and safe when no one else is around,” as this pressure of monitoring other feelings and thoughts can subside. Thus, this component of being herself is key to Betty feeling a sense of belonging.

In a later session, Betty created a visual to represent the cycle of belonging she'd been describing (Figure 2). Betty described, "This circle is like a cycle. It starts in one place (maybe the firework), moves around, and throughout the years it all starts again. It's like salmon when they go upriver, mate and lay eggs, they open and when they are big enough, they go out to the ocean, and when they are big enough, they swim back to where they belong. Sometimes it may go clockwise, sometimes like a triangle, and it could go [motions zig zags]." Betty described the symbol and moved from the question wondering bubble to the mouth that is talking and listening to people at school (headphones) and backpack. She expressed wondering if other people can feel like they are in your shoes. Betty described that when you feel that it leads to a firework, which represents a sense of belonging.

Figure 2.

Betty's Cycle of Belonging

Dory

Dory is in her 30s and joined us after the pilot stage of the project. She currently works as an assistant in a preschool and fills her free time with lots of social activities including theater, sports, and time with her friends. Dory lives in a large apartment complex where other adults with disabilities live. She shared, "I like it because I wanted more freedom". Dory described this freedom

as independence. The choice to request support as needed and make choices for herself on how she wants to spend her days. She shared in a group conversation how this living environment creates a feeling of belonging for her. When I asked her to describe to someone else what this independence looks like she shared, “well I get to choose when I want staff, which is mondays, and then other days there is no one coming in and out of my apartment. I’m on my own without someone telling me to do this or that, and I can come and go as much as I want to.” Before this explanation, Dory described an apartment where she lived where “I would have had to go to the staff apartment, check in with them. Tell them what, when I'm leaving and tell them when I'm back. It was like we had to do it day after day. It was like, *do we really have to do this when we're adults*?” To which another group member responded, “yeah, I’m an adult too.”

Dory’s Engagement in the Research Process

Dory began engaging in the Fall of 2023 as one of the additional participants after the pilot stage of the project. She continually provided suggestions on how to move forward together as a group. She wanted to be involved in both individual and group conversations (i.e., interviews and art sessions). Dory provided feedback and opinions on the structure of group calls, time for community building, size of the group (decisions on continuing recruitment), and next steps or ways to stay connected as a group. Throughout our conversations and time together, Dory encouraged other group members to share and was thoughtful about creating relationships which made this type of sharing possible. During our first full session together, Dory came to our call with a prepared speech. She had previously shared an interest in this. After sharing, Dory shared that she had not done much speech writing since her mother had passed away. Her mother used to help her with writing, editing, and practicing her speeches. Co-researchers were curious to hear Dory’s speech, and she shared it again with the group. This speech provided the basis for a lot of shared conversations, especially relating to participants’ experiences which did not foster belonging.

Dory's Definition and Exploration of Belonging

Dory entered our initial conversation with a prepared speech about her experiences of belonging, and *not* belonging in spaces and relationships throughout her schooling career through her young adult life:

> *When I was in high school, I really didn't feel a sense of belonging. Unfortunately, I was one of those individuals that was bullied a lot. Plus, I got left behind and excluded. Nobody wanted to hang out with me. After school or even the weekends. I've been slapped in the face. I've had spit balls put in my hair. And if you don't think that's bad if it gets worse. I've been called both retard and retarded. But now, I want to thank those bullies. They motivated me to become a public speaker. Sometimes all it takes is to hear someone's stories to stand against bullying. I believed something positive would happen over this And it did. I was selected to go to senior awards night. I was one of the 40 students that got the athletics Scholar Award. It was for students that did sports during their senior and junior year that managed to keep their GPA at 4.0, and that were positive role models to their teammates and classmates. That's my story of high school. But now I'm going to talk about work. Before I got my job at the early childhood center, I worked at a hair salon. It was definitely not a place of belonging. I mean, when I got to work, instead of "Good morning", I got yelled at for being early. I would hear gossiping and swearing all day long. One day, I was in the back room doing my job. And I heard gossiping. It was about me. They only said they hired me because they didn't want to do the job. And if you don't think that's bad it gets worse, one of the stylists called me the R word. I told the manager and she didn't care. She said "my money is more important than you". Even though I got treated badly. They're lucky. I still showed up to work and stayed positive and showed kindness. I prayed I would get out of the salon someday. A dream is a wish your heart makes when you're fast asleep. No matter if your heart is grieving. And if you keep believing a dream is a wish that will come true. My wish finally came true. I got an email from a work coordinator. And they said they were in need of a dishwasher for the [early childhood center at local church]. This was my dream job. I love what I do. Kids bring me joy. Especially when they come up for hugs. And when they say I love you [Dory]. It was the best therapy during the time my mom died. I'm accepted. I am loved for who I am. Plus, I'm included outside of work events. I feel so much love at my work. I love everyone I have met through the church and I cannot wait for more years to come. Thank you to everyone for accepting me and including me and for giving me rides home. It's been a blessing. I'm going to end on this note. When people tell me I can't do something because of my disability. It makes me try harder. Thank you.*

After her speech, Dory shared with me that "Belonging makes me think of another way of saying be inclusive. Everyone, especially those with disabilities, all deserve to be included. Because

oftentimes when it comes to school, we're often left behind or we're getting bullied." I asked Dory to describe to me what it felt and looked like to be included somewhere and still not belong, for example within the context of her work at the salon. She replied, "It was great that they tried to hire me, but I feel like they didn't really want me there. It felt like they just made me make a fool of myself." As Dory described in her speech, there was this lack of relational acceptance, or reciprocity in the salon work environment. She added, "It makes me feel accepted when someone wants to make you feel like you belong, because it makes you feel like you are included. And they're telling you that they want you here and they're happy to see you." Dory carried these understandings of belonging into our group context by directly sharing her speech and by centering the idea of belonging encompassing more than being included.

Individual Accounts

Holding space for these individual accounts is critical in understanding the depth of work co-researchers engaged in during our shared spaces. The conceptualizations they drew together during our group sessions were built on each of their individual histories, through negotiation of critical qualities of belonging. These individual accounts highlighted the wide range of engagement experiences of co-researchers and how they centered their strengths and interests in our group space. Further, while each of these individual accounts define belonging from an individual lens and provide examples of these experiences, the individual approach does not synthesize experiences in the same way the shared conceptualization does.

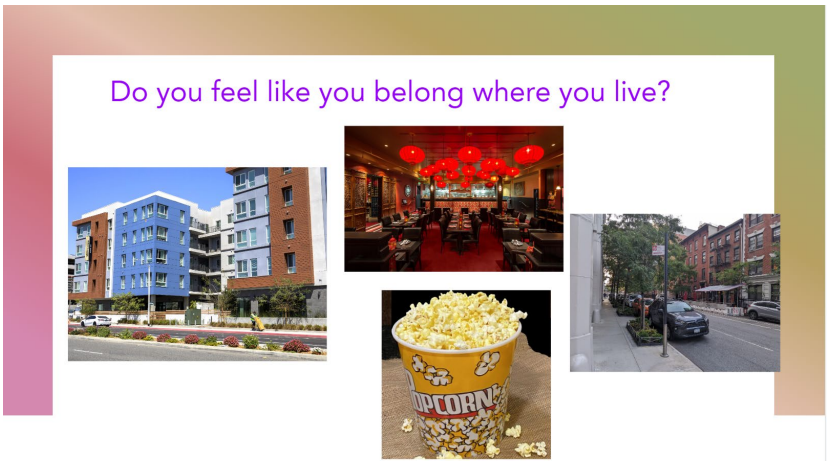
Chapter 5: Shared Conceptualizations of Belonging

Following individual sharing, co-researchers came together in group calls to explore their stories and reflections about belonging. Each person carried their own unique social histories, reflections of these social histories, and communicative repertoire and preferences into this shared space. These individual stories and ways of being informed the questions that surfaced, the modality of sharing, and the shared conceptualization of belonging that was developed. Co-researchers brought to these sessions curiosity about others' experiences (what might be similar and what might feel different) and their own interests that they sought to explore collaboratively. Together we created a space which met participating individuals' access needs, and facilitated their contribution in the process of collaboration, conceptualization, and co-creation.

Co-researchers shared this virtual space for three sessions which lasted about an hour each. Each session included check-ins, getting to know you questions, and time spent sharing about individual experiences of belonging. Some sessions included individual story sharing, co-researcher initiated question exploration, and reflective art activities. Co-researchers directed the agenda and focus of each session, which led us to co-create a visual by the end of our third session. Ongoing changes to individual accessibility led to us modifying the agenda at the start of each group to fit the group's needs on the day of each session. The shared conceptualization of belonging, Figure 6, was completed during our third group session, and is the culmination of both the individual and group discussions and reflecting we engaged in together. This visual represents the co-analysis product from our time together. In this chapter, I will first describe each of these five central components of belonging based on the definitions, examples and sensemaking shared by participants during our group sessions. Then, I will describe the co-analysis process which led to the co-creation of a visual at the end of our time together.

Figure 3.

"Do you feel like you belong where you live?"



Note. Co-Researcher slide posing Coral's question: "Do you feel like you belong where you live?"

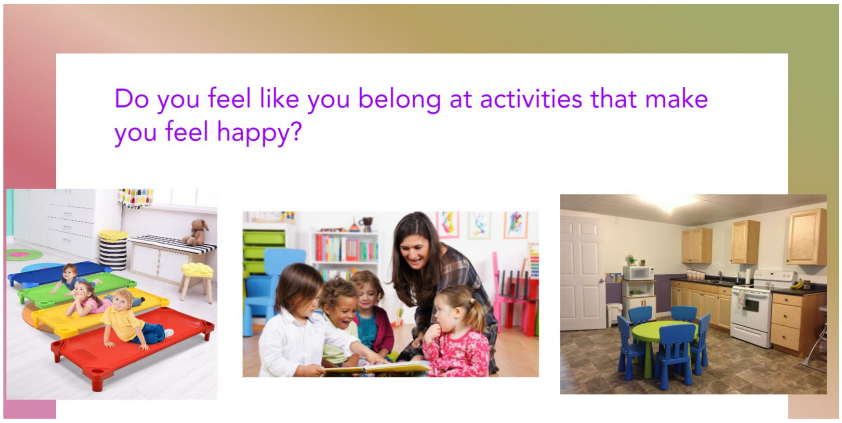
Exploration of Co-researcher Wonderings

During individual conversations I gave participants choices (i.e., Do you want me to ask a question, or do you have a story you want to share?) for how to structure our conversations. While each co-researcher began conversations in different ways, they each eventually asked me to pose a question. I had a variety of prepared questions and slides with visuals and typically asked participants which question they wanted to talk about (i.e., do you want to talk about the question 'what does belonging mean to you?' or 'are there places where you feel belonging?') and participants would select where they wanted to go in our conversation. In individual conversations this often led to participants asking their own questions (see Figure 3 and Figure 4). Coral created the two slides displayed in Figure 3 and Figure 4 with the questions "Do you feel like you belong where you live?" and "Do you feel like you belong at activities that make you feel happy?" to explore her curiosities with the larger group. Each of the photos on these slides was representative of a part of her own story that helped her to respond to this question. Esme wanted the group to discuss their experiences in romantic relationships and asked the group, "Do you feel like you belong with

your boyfriend or girlfriend?" Each of these questions were included on a list of possible meeting agenda activities and were explored by the group with the question writer posing and elaborating on their wondering.

Figure 4.

"Do you feel like you belong at activities that make you feel happy?"



Note. Co-researcher slide posing the question: "Do you feel like you belong at activities that make you feel happy?"

Variability in Participant Responses

The conversations that surfaced from these prompts included a lot of variability. During our sessions, co-researchers arrived at the idea that it really depends on what it feels like for them as an individual to belong and how/if their experience with the question reflected this. For instance, Dory and Betty both described living in spaces where they felt belonging, but their reasoning for this differed. Dory shared about feeling a sense of belonging in her current apartment, which she called "fully independent living," where she "choose[s] when [she] wants staff," and is given agency in the supports she receives. She also shared a piece of that belonging is that "[she] can come and go when [she] want[s] to," to the social activities she engages in. For Betty, she frequently described her family home and the location of her home as a site of belonging. She described the feeling of belonging as all of the feelings at once, and one place she named was her family's home "because I feel safe when I'm at my house. My parents' house. I can be myself when I'm back home." In asking

this question, Coral reflected on the very different experiences she's had in recent living situations and shared with group members how she values accessibility and social activity in her home, "I like to be able to walk to concerts, restaurants, or something." Both Dory and Betty described living in places where they had choice and agency in how they wanted to spend their time and in leaving their home to access social opportunities beyond their house/apartment. Esme reflected on this question by saying "no, not so much," indicating that she doesn't feel like she belongs with her roommates. I asked, "With other people you feel belonging which you described them as patient and calm, are your roommates patient and calm?" She responded, "no, that's different" highlighting how her housemates don't meet her need for belonging the way other relationships have. This same variability surfaced in responses to the other co-researcher questions, highlighting the many factors shaping belonging and the subjectivity and importance of seeking individual reflection and feedback on the nature of belonging in conversations about their own lives. This variability informed the multi-component conceptualization of belonging that the co-researchers developed.

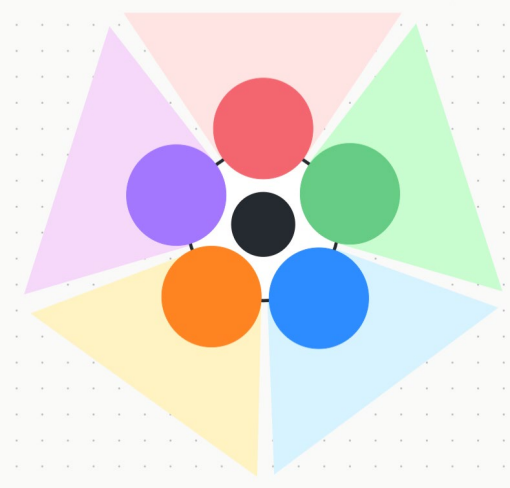
Co-created Visual of Belonging

The first group conversation led co-researchers to identify some similarities in their experiences of belonging and reflect on the definitions and examples everyone had shared. Using the zoom interactive whiteboard feature and Betty's leadership, the group co-created a visual to represent the core components of belonging and selected a variety of visuals to represent each area. Betty helped to identify a zoom diagram as a starting point for creating a co-constructed account of belonging. She knew she wanted to find something that could represent a cycle that included many components and described a diagram with many parts or sections in a circle. Together we found a sample diagram that met these requirements on zoom (see Figure 5). Next, Betty created several drawings and shapes to serve as starting points for her co-researchers who didn't want to draw or create but preferred to just drag and drop visuals. Before the first interactive session, Betty created

several digital drawings of symbols she thought might be useful and pulled several shapes into the interactive whiteboard space so that participants could easily slide, drag, or point out pictures they wanted included in the diagram.

Figure 5.

Initial template for interactive zoom whiteboard



.

Over the course of two hour-long sessions the group co-created a visual conceptualization of belonging (see Figure 6). This visual was also informed by Esme (who did not want to participate in group sessions), who provided feedback after each iteration about what she agreed with, how her stories fit in, and what we might change. In the following sections I will describe how co-researchers defined each of these sections, share some of the examples and stories that surfaced to represent each of these components of belonging, and describe examples of how co-researchers understood and thought about their interconnectedness.

Figure 6.

Visual Conceptualization of Belonging

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Be Yourself

The first of the five components of belonging that the co-researchers identified was the element co-researchers labeled “be yourself.” The images within this section are (1) a mouth, which Betty shared represents feeling safe to “talk about your feelings and be yourself;” (2) balloons floating into the sky, which Coral shared as representing the celebration and happiness that comes with getting to be yourself;” and (3) a layered star that Betty created, which highlights that belonging “feels unique” (Esme). An element of safety surfaced in this final component. Several co-researchers told stories or directly described the self-awareness and social awareness they carry and tap into to know what spaces they are safe to be themselves in. Dory talked about this component as being able to communicate what she feels and what she needs in different environments. Each of the four co-researchers talked about contexts where they feel they can be themselves. For Esme, this was in a relationship with an old boyfriend; with him and his family she felt she could be herself (e.g., “He

was happy to see me and I was calm"). For Betty, this was in familiar contexts like her family home, with family, with a few close adult friends, and in routine places in her neighborhood (e.g., "I like [pharmacy] on [local street name]. It makes me feel safe. I can be myself and be more alive. Because I can be by myself."). For Dory, she spoke not about trying to hide or needing to change herself, but not feeling belonging when she was not accepted in places or in relationships for being herself and asserting her wants and needs (e.g., at the salon she worked at). Rather, she felt belonging when family or others "support [her] goals in life." Finally, Coral added to this component by sharing when she feels comfortable to be herself, it's like a party with lots of balloons. When we were reviewing a draft of the belonging visual, she said "I want balloons." When we were reviewing the 'Be Yourself' section, she said it "feels like a party." While each of these individual perspectives differ, co-researchers' personalities inform the impact of finding spaces where they can be themselves. Most importantly, there was recognition that there are times, places, and people where they know they are safe to be themselves, especially in a conversation with Betty and Dory. Betty opened her explanation of belonging by saying, "when I find a space, or when I find a group, or when I feel safe, that feels like belonging to me." This reflection of safe spaces (referencing people and places) was ongoing throughout our conversations. This strong awareness is likely the result of contrasting experiences with bullying for showing up as they are.

Relationships

The next of the five components of belonging was relationships. This title was chosen to represent the wide variety of people that foster a sense of belonging for the co-researchers. Co-researchers started by talking about the types and categories of people who fostered belonging, and together we brainstormed a word that was inclusive of all the people described. For some, friendships were critical; for others, family and romantic relationships were important. Co-researchers described how it is difficult, rare, or unique, as described by Esme, to find and sustain

relationships which meet the characteristics necessary for belonging. Two of these characteristics included: (1) reciprocity and (2) cross-context or multiple settings. When I asked co-researchers to describe what they meant by relationships, Betty shared "it's about friendship and family," and Dory said, "my boundaries are being respected." This highlights the idea that there are both certain types of relationships which represent belonging, and certain qualities or values for these relationships.

Reciprocity. This aspect of reciprocity consistently showed up across co-researcher stories and reflections. Similar to the co-researchers' description of self-awareness, it was evident that co-researchers had experienced times where they saw through a situation where someone was present and engaged relationally for some purpose other than forming a connection and the relationship was not bidirectional. Betty added it's "important that they understand me, and a relationship means they know about me and don't take advantage of me." Dory described the relevance of reciprocity in several different contexts, but one of the clearest examples was her reflection on her time in the workplace. When she worked at the salon, as she shared in her speech included in Chapter 4, she not only felt like her colleagues were uninterested in connecting with her, but they stated very plainly that she was only hired to do the tasks they did not want to do. She offered this in juxtaposition to her experience at her current workplace where she frequently interacts with a variety of coworkers outside of the workday, whether that be for a meal out at a restaurant, or a colleague showing up at a theater event. Co-participants described how relationships only have potential to foster feelings of belonging when "someone wants to make you feel like you belong, because it makes you feel like you are included. And they're telling you that they want you here and they're happy to see you" (Dory).

For Esme, the tenet of reciprocity showed up through a romantic relationship. Throughout each of our conversations, she shared that this relationship was the most important part of how she understood belonging. Esme described feeling loved and wanted by someone else and sharing those

feelings towards them. In this case, Esme described how she has never experienced anything comparable to this sense of belonging. “It’s just not the same,” she shared many times as I asked her about other relationships in her life. In both Esme’s example and with other co-researchers, there is an understood sense of the mutuality of interest and support in relationships. Co-researchers emphasized how this is critical in fostering feelings of belonging.

Multiple contexts. Each of the individuals engaged in this process shared examples of belonging which included relationships that crossed multiple contexts. For example, a relationship was not usually described as fostering belonging if it was limited to just school, or just work, or only at a particular community organization. Instead, relationships that surfaced as those fostering belonging involved interactions across multiple settings. Betty described a relationship with someone from a local organization focused on individuals with IDD, but it was the interactions and relationship she maintained outside of this organization that she recognized as holding a quality of belonging. Dory described both work colleagues that she connected with as friends outside of work, and friends from summer school who became longtime friends who she continues to connect with now that school is over. Coral talked about a relationship she made with a volunteer at a local Christian organization, but it was the memories she had at concerts and out to meals with this person outside of organization events which surfaced as most important in the relationship. Co-researchers described how the natural extension of most relationships that exist for the purpose of relationship (and not employment, service, or exchange) happen across settings. This element of cross-context relationships is something that may indicate the depth of a specific relationship. Relationships existing across multiple settings was one theme of relationships that fostered belonging in this group.

Strengths/Confidence

The third area co-researchers identified as a key component of belonging began titled school and eventually evolved into strengths/confidence. After shared conversations, most of what co-

researchers were recalling from school were the opposite of their feelings of belonging. In Betty's initial creation (see Figure 2), a backpack served to represent a part of the cycle as to how/when she experienced belonging in school. While the backpack remained in the figure as a symbol of schools recognizing our strengths and gifts, the category represented being recognized for strengths and finding confidence across settings and relationships. Dory shared that school felt like a place of belonging when her strengths were recognized. In her first session Dory's speech highlighted how awards night at school brought her a sense of belonging. In a group session, when talking about any moments at school that created a sense of belonging, Dory shared with the group: "I was picked to go to senior awards night and got a medal for academics." This was the one moment throughout high school she remembered as feeling like she belonged, despite the instances of bullying she experienced and recounted. Esme did not reflect much on recognition for her strengths in school but shared about the confidence she felt in interactions with her boyfriend and his family. This confidence fed into her feelings of belonging in these relationships.

Coral described feeling confident at work and being recognized for her strengths in her current job placement- a school. Through her facial expression and tone, she shared the excitement and happiness she has for getting to do sign language during some of the activities at her job at the daycare. Her colleagues recognize her expansive communication repertoire as a strength and encourage her to sign in their classrooms. In this example Coral exudes confidence in her skills to sign, and the school seems to recognize this as a strength and incorporate it into her workday. Thus, the element of having your strengths and confidence recognized is deeply connected to the other theme co-researchers identified as part of belonging, being able to "be yourself." Co-researchers recognized this interconnectedness and hence described this as a cycle bouncing back and forth between these different areas to inform a sense of belonging.

When Coral shared her day care/school as a place of belonging, I knew this might cause

some tension for another co-researcher (Betty) who had communicated to me earlier that she doesn't feel comfortable with young kids. Despite Coral sharing this story and adding a photo of a classroom to our shared visual, Betty did not resist the inclusion of this photo on our shared visual. In this moment I wanted to be sure all opinions were represented, and in my analytic memo noted the way acquiescence might be at play. During this example, and others in our process, I decided to step in and prompt: "Coral says she feels belonging at her day care with young kids. Betty, do you feel like you belong with young kids or in schools?" This prompt was followed by a pause (of several seconds) before Betty replied, "no I don't like being with lots of little kids." I repeated back what I had heard Coral share, "Coral feels belonging at the day care because she likes working with kids and gets to use her strengths like sign language and art." Coral nodded. "And Betty you don't like being around little kids, and don't feel like you belong in that setting." Betty said "yes, that's right." Knowing the daycare visual was an important part of Coral's story, I waited to see how this might play out. Betty shared about how her work was also a place of belonging. At this time, we added the grocery bag photo which represented Betty's workplace, where the environment fostered belonging for her. This is one example of several moments of negotiation, where co-researchers often leaned towards silence or agreement but because of our previous conversations I had the opportunity to interject and ask if there was true agreement or if we could adjust our visual to better represent and account for all of our experiences and understandings.

Places

The fourth component of belonging identified by co-researchers is places. In defining this category, co-researchers continually drew connections back to the other components they identified. Two additional qualities of places were highlighted in the shared definition: (1) accessibility and (2) familiarity. During the discussion of places, co-researchers named specific places and shared stories about how/what made various places spaces of belonging. Like other areas of the diagram, places are

informed by one's ability to be themself, be in reciprocal relationships, lead with confidence and be recognized for one's strengths, and spaces where "it feels like a firework" of belonging. Three example places surfaced across co-researchers through our conversations: (1) the theater, (2) living spaces, and (3) neighborhoods or local communities.

In a shared group space, we revisited prior individual conversations to share stories with one another of places which have been the site of belonging. Dory shared in a get to know you session that she was gearing up for a busy couple of weeks of rehearsals for a play she had been cast in at her church. Betty, who also had shared with me her positive experiences with theater, asked Dory some more about the show and her role. After reflecting on this shared interest, Betty stated: "acting has a sense of belonging because everybody has a role to play." Dory agreed. I have never been a part of a play or acted in a theater, but I agreed that I feel like I belong when I'm in a place filling a dedicated role as a part of a larger team or group of people working towards a common purpose. Much of this conversation reflected other physical spaces (places of work, team sports, etc.) where individuals are designated to and fill a role and are appreciated. In our initial individual conversation, Dory named theaters as one place she feels belonging: "I think I thought of another one. It's every other year where [City name] Community Church puts on plays and that I definitely feel belonging because you're with each other so much practicing and practicing. And then you get to know each other more, and it just becomes a happy family." Dory added that her church theater community has an inclusive audition process. In response to my wondering about tryouts she said, "It is in two weeks, and for this group all you have to do is try out and you're in. And that's the way the director does it. I wish more theaters were like that." Anyone who is interested in auditioning is cast in a role, and a community (or family as Dory feels) is created.

Another popular topic of conversation when discussing places of belonging was living spaces. Three of the participants had recently lived in spaces where they felt they belonged. One

commonality in these conversations and stories was their reflection on accessibility. Coral led our discussion on living spaces as sites of belonging and asked the question: “Do you feel like you belong where you live?” She led with accessibility being a significant component for her. In sharing with the group she said, “I belong living in apartments.” During our one-on-one conversation where she decided to ask this question, she added several pictures to the slide to represent what belonging where she lived meant to her. Coral shared “there’s lots of sidewalks,” “restaurants,” and “it’s a big building.” Her preference and highlighting of “I belong living in apartments” is explained by her recent experiences (first) living in her own apartment in a building with other adults with disabilities and (next) living in a group home in a more remote suburb. Coral connected with Betty and Dory over this in our group space, as both Betty and Dory appreciated the freedom that an accessible living location provided to them. Dory frequently referencing how she can “come and go as I want,” and Betty sharing “I can take the bus wherever I want. I don’t have to wait for mom and dad.” When I took this question back to Esme, she shared that despite the move to a new group home (different house, same people), she continued to feel like she did not belong within that community. She highlighted the contrast of these relationships with the relationship she had with her boyfriend and his family, “it’s not the same,” she shared. In sum, being in a place which allows consistent, smooth access to places and people of one’s choosing is important in feeling belonging in a living space.

One final example of places of belonging for participants was what they described as familiar spaces. While co-researchers didn’t highlight familiarity as a tenet or critical component of belonging, many of the places where they experienced belonging were places, they had spent a lot of time at and returned to over and over. Esme shared visits to her favorite coffee shops. Betty spoke frequently about her hometown and the spaces she has frequented countless times: “I feel belong in a lot of places, but it's sometimes hard. It depends on the day, but mostly where I feel happy is when

I'm [in my hometown]. With people I know. Yeah. And familiar. Yeah, it just, it makes stress go away." Dory also talked about her childhood neighborhood and the sense of belonging she feels when she returns for visits to her neighborhood: "I would say I definitely feel belonged. When I see my dad on weekends. I definitely feel belonged in that neighborhood because everyone's just so friendly to each other and wants to include me as well at some of the holiday parties." This quality of familiarity seems critical in thinking about neighborhoods or home communities as places of belonging; this differs from what felt important to co-researchers about theater (clear role and community) and living spaces (accessibility to chosen people and places).

Feeling

The final component co-researchers described as central to belonging is the "unique" (Esme) feeling belonging creates. Betty talks about it as being something "you can feel in your whole body," and that it involves "being comfortable in your own shoes." In introducing the art activity and her own artistic representation she said, "with your heart when you feel a sense of belonging, it's a firework." A shared experience with the component of feeling belonging was the certainty or confidence of its presence that co-researchers described–the feeling is not subtle. Esme, for example, initially described the feeling of happiness and a sense of calm when she feels like she belongs, but in recounting other happy relationships or experiences she was quick to tell me "That's not the same." Although it was often difficult to label, co-researchers were confident in identifying this internal feeling as important to belonging. Like each of the other key areas in the shared conceptualization of belonging (be yourself, relationships, strengths/confidence, and places), co-researchers had unique experiences related to what it "feels" like to belong that were specific to their own personalities and stories. This does not devalue group synthesis, but instead highlights the importance of centering individual perspectives and opinions in decisions about their own lives.

Power of Co-developed Synthesis and Visual

Throughout the research process, co-researchers engaged as active members in the process of data generation and analysis. We regularly checked in on the typical steps or process of research and co-researchers initiated involvement at each step. The steps included: (1) ask a question, (2) find the people we want to talk with, (3) make a plan, (4) explore our ideas, (5) describe what we learned, and (6) share with the people we want to share with. Co-analysis was an intentional component of our relationship and time together. Co-researchers engaged in the analysis process to their desired extent and were actively involved in shaping our agendas and course of analysis. The co-created visual presented in this chapter was the culmination of shared conversations and sensemaking on participant experiences of and reflections on belonging and the curiosity they held for others' experiences throughout this process. The agentic nature of this participation stands in strong contrast to typical involvement of individuals with disability in research as the "objects of research" (Taylor, 2018). After this shared visual was reviewed by all of the co-researchers, we had a shared conversation about dissemination and what would come next. Each individual thought about where they wanted to share this work and had a different approach. A few of the ideas shared spoke towards accountability within disability communities and others towards practical outcomes and conversations (Barnes, 2002). Dory talked about sharing the visual in her social media spaces because she is active in many disability centered groups and often engages in advocacy through her posts. She also shared excitement about the possibility of presenting this together somewhere. Coral shared she would be excited about doing some more writing about what was shared and discussed together. Esme reflected on how and if she might be willing to use this as a tool to have conversations with her family about her desires and wish for a romantic relationship. Betty shared a desire with the group to combat ableism through activism, "Maybe share to people who doubt disabled people and say hey you might think it's bonkers that we exist but we are not the same, and we have our own minds. If you see this [referencing our visual]. The world might become a better

place for all disabled people." While I had originally envisioned a shared next step for dissemination, the very different, important responses shared by co-researchers highlighted the nature of this work and reflection on what collective, co-constructed dissemination looks like. Through these various avenues, participants are holding true to our shared analysis while using the visual as a tool to inform the spaces and relationships that feel most impactful for them in the present moment.

Chapter 6: Methodological Findings on the Power of Participatory Processes with Individuals with IDD

Throughout this shared exploration of belonging, co-researchers with IDD engaged in an inclusive, participatory research process. This approach resists ableist tendencies in traditional research methodologies (Bigby et al., 2014). This chapter will relay findings responding to the question: *How do individuals labeled/with intellectual and developmental disabilities take up participatory methods to engage in research and disrupt ableist assumptions, power dynamics, and roles?* The power of participatory methodology was evidenced throughout the research process from study conceptualization, to recruitment and consent, to data collection, and through analysis. The decision to engage in participatory methodology is a direct reflection of the commitments central to the theoretical and conceptual frameworks informing the study (e.g., Disability Studies [Oliver, 1992], Presumptions of Competence [Biklen & Burke, 2006], Epistemic Agency [Taylor, 2018]) and shaped the subsequent data generated and findings. As Shogren (2023) notes, "Participatory approaches have the potential to challenge the status quo as they require changes in the ableist approaches that dominate the generation of knowledge" (p. 173). In this project, participatory methodologies reinforced co-researchers' agency while disrupting traditional and ableist research approaches by (1) upholding a commitment to the presumption of competence to create space for knowledge sharing and generation, and (2) holding intentional space for flexibility and responsivity to create a more accessible research process. Throughout this process my initial commitments and awareness of my own positionality in the process fostered space to reinforce co-researchers' agency; but throughout the process it was co-researchers who supported one another's agency.

Presumption of Competence, Knowledge Sharing, and Co-generation

Framing this research through participatory methodology with a foundational presumption of competence led to intentionally creating a space for knowledge sharing and generation with adults

with IDD, who are often excluded from direct engagement in knowledge production. According to Biklen and Burke, communication differences are not a reason to dismiss an individual's competence (2006). Instead of drawing conclusions based on the way co-researchers presented in the research space, this commitment to the presumption of competence calls for curiosity and placed the onus on me to understand how each co-researcher experienced the environment. Individual sessions with each participant created space for me to intentionally hold this curiosity and spend time understanding the way in which each co-researcher experienced, communicated, and engaged in the research context. My curiosity in this context was part of my stance of presuming competence, but curiosity without action would have been inadequate. Next, I will share four examples of how a baseline presumption of competence created space for co-researchers to share their knowledge and co-generate a conceptualization of belonging. These included: (1) creating space for Dory to share a speech she wrote, (2) co-researchers engaging in inquiry initiation through developing questions, (3) Betty's attention to accessibility, and (4) our co-created visual of belonging. While describing each of these examples, I will highlight the strategies I employed to uphold my curiosity and commitment to the presumption of competence.

Dory's Speech

The first example of how I enacted a presumption of competence involved my first meeting with Dory. Dory and I first met over a zoom call to talk about her interest in getting involved in this project. During our meeting, Dory expressed interest in joining the research project and at the end of our meeting we talked through the nature of ongoing consent throughout our potential time together. This conversation was not recorded, but I shared with Dory some of the activities the group in the pilot project had engaged in (i.e., sharing stories, responding to questions, an art activity, and shared sensemaking). I emphasized that these were just ideas and what was most important for the project was following the ideas and interests of the co-researchers involved. Dory said that this all sounded

good and asked when we could meet again to start talking about belonging. About a week later we met again via zoom. After joining the call Dory told me she had written a speech that she wanted to share with me about belonging. Our consent conversation occurred after she shared this speech so that part of the conversation is not recorded, but she said she wanted to start by sharing her speech before talking through some of the questions about belonging that surfaced in our first call. She also asked that I record the speech so she could share it with her current employer. Her speech, which is shared in Dory's section of Chapter 4, included experiences of belonging from high school through her current job and social context. This speech highlighted so many of my own questions about her experiences of belonging (i.e., Where did she experience belonging? Who fostered that feeling for her? Was belonging more than being included?) without the need for direct prompts or my control or structure of the conversation.

As Dory finished her speech she read, "When people tell me I can't do something because of my disability. It makes me try harder." This line from Dory's speech seems directly relevant to the traditional approach to research in the field of IDD, which is often *on* versus *with* participants. Dory opened our time together by framing for me that a lack of presuming competence, and communication (direct or indirect) that her disability would be a limiting factor, would lead to her trying harder. While I was committed to presuming competence as I deepened my knowledge of and relationship with each of these individuals, I was honestly surprised with this first call with Dory. When she finished her speech I responded, "Oh this is so wonderful [Dory]. Thank you. This totally surprised me. I didn't know you were going to prepare that for today." In reflecting on this moment, I recognize how my own internalized ableism, despite taking up this framework and methodological approach, contributed to me feeling caught off guard by the beauty of Dory's initiation of our time together.

Co-researchers' Question Development

The second opportunity to highlight how a presumption of competence shaped the methods of the project involved providing opportunities for co-researchers to develop questions that guided data generation. The presumption of competence requires a stance of curiosity, as well as an expansive outlook. During our shared time together, I found myself drawing on the principles of Universal Design for Learning (UDL) (CAST, 2018). Participatory work with adults with IDD required me to reflect on my conscientiousness around multiple ways of representation, engagement, and expression. UDL aligns with participatory methodologies and the presumption of competence by positing that all learners, including those with complex needs, learn when learning opportunities are designed and facilitated in accessible ways. Just as UDL is a framework for providing more accessible experiences in school, these ideas can be extended to think about accessibility in other spaces of engagement. Drawing on the key tenets of UDL, participatory methods necessitate that co-researchers help think about representation as well as the content of our shared learning/sense-making. For some co-researchers, this started with choices. For example, during Coral's first session, after sitting in silence for some time (around 30 seconds), I asked, "do you have an idea about what we should do next or would you like me to offer a few choices?" Both Esme and Coral routinely asked for me to offer choices. During both of their first individual sessions, one of the choices I offered was to ask a different question. Esme and Coral were interested in writing their own questions about belonging to explore with the group in a later session. Through these examples UDL can be used to understand all researchers as learners and knowledge generators.

Coral crafted two questions to bring back to the group. These questions, first referenced in Chapter 5, were: "Do you feel like you belong where you live?" and "Do you feel like you belong at activities that make you feel happy?" In bringing these questions to the group, Coral suggested we add pictures to the slides. Together we spent time selecting photos for the slides which resonated with Coral's responses to these questions. The pictures served as visual cues she could use as she

asked the group this question and provided her own examples based on stories connected to these pictures. When choosing to ask her own question, Esme spent some time reflecting internally before she shared her question: “Do you feel like you belong with a boyfriend or girlfriend?” Without the presumption of competence, a more traditional approach to researching belonging with adult participants with IDD might have involved me having a structured set of questions to explore with co-researchers. Instead, the framework of presumption of competence created an opportunity for me to enact my belief that co-researchers would come with their own interests, questions, and ability to pull together their stories to create a question to investigate together with the other co-researchers. Further, my presumption of co-researchers’ competence supported my recognition that each of the co-researchers brought their own interests, values, and curiosities, and necessitated participatory methodologies to center and honor their individual desires and wonderings.

Betty’s Creativity and Thoughtful Considerations of Accessibility

The third example of how a presumption of competence shaped the project methods involved Betty’s suggestion that we integrate art during the sessions. During our second session, when I was meeting with Betty individually, she shared that she wanted to do art and asked about what we did in the pilot group. Before I pulled up the activity from the pilot group to show her, she started brainstorming about accessibility in art. She said, “I think if some people can’t draw, stickers, or they could have a certain way of doing things, because some people don’t have the same skills as ours.” I agreed and asked, “Do you have any other ideas along with stickers as to how we can make this accessible for others?” Betty said, “Well we could have like a template. [...] Like I mean just a simple shape and then they can go from there. Some people might want an outline. Because some people might have a hard time, so this helps get an understanding of what they can do.” I agreed and thanked her for her ideas and asked if she still wanted to know what we did before or if we should create something new. She still wanted to hear about what happened in the pilot group space, so I

described the journey mapping process and shared an example that was created. During my description of the journey mapping (Annamma, 2018), I emphasized "this is just an example," "I know how creative you are, so I don't want this to hold you back," to which Betty responded, "Also some people think I'm crazy but when my brain is super loud and full of dreams. It feels like my brain belongs to another planet, and another solar system." I acknowledged Betty's reflection and she promptly added, "My art style is like Picasso or like contemporary or abstract. It's just that's how my brain works…A lot of words, or lots of buildings and people doesn't.... I want to be connected to my art piece." In this reflection, Betty was disrupting the more structured activity I had previously engaged in, and helped to describe to me how her brain works and how other people might have similar experiences or needs for expansive activities. This conversation resulted in the creation of Figure 2 (e.g. Betty's initial cycle of belonging), and in the next session, Betty created the template and outline she envisioned to support other co-researchers' engagement in this activity. The belief that Betty had more to offer through her creative mind aligned with the participatory methodology and study commitments, and Betty's generation of an art activity resulted in the central visual we co-created during analysis.

Co-created Visual Representation of Belonging

The final example of the power of presuming competence inside participatory methodology is the co-generated understandings and findings that co-researchers developed together. The participatory approach led to an understanding of belonging directly from the perspective of those with lived experiences with IDD. As described throughout Chapter 5, after several sessions of shared group space, co-researchers (following Betty's lead) developed a visual representation of their experiences and conceptualization of belonging (see Figure 6). The presumption of competence allowed for power and control to shift away from my own assumptions about how the research should/could unfold, and instead center the questions, interests, and communication styles of each of

the co-researchers. Their conceptualization of belonging aligns with a reflection of Renwick's framework of belonging, where belonging is a "departure from many westernized notions of inclusion that often equate inclusion to participation in socially normative activities" (Renwick et al., 2019, p. 961). Specifically, co-researchers did not talk about inclusion into normative activities equating belonging. Rather, they talked about the importance of reciprocal relationships in these contexts, and spaces where they felt safe to be themselves as activities which fostered a feeling of belonging. Thus, continuing to center proxy voices about experiences of belonging for people with IDD likely would have brought about a very different process of sensemaking, analysis, and subsequent findings. This participatory process and the shared data generation and co-analysis was made possible by the ways in which co-researchers and myself engaged with and presumed one another's competence.

By presuming co-researcher competence throughout all study activities, traditional, ableist norms around communication (e.g., quick and delayed responses, emphasis on spoken language) were intentionally disrupted in this work. Wait time, both in one-on-one interactions and in our group space, was central to ensuring the knowledge of everyone was heard and considered. This required the patience and commitment of the entire co-researcher group. For example, at one point during the creation of the shared visual, Coral was asked about how/if the places section felt reflective of the stories she had shared. Coral did not respond quickly, and the group continued to wait for several more seconds, which gave her space to suggest that we add a few other pictures to better encapsulate the sum of her experiences. In this moment, silence and the lack of a spoken response was not interpreted as a lack of interest, desire to share, or competence; rather, together we worked to develop a range of modalities for sharing and responding to one another's stories and ideas. One tool in navigating silence was asking one another "do you want to keep thinking about this piece or should we move on?" In multiple moments Esme responded to this question with "I

want to stay here." This indicated that she did not have the words or means of representing or sharing another thought just yet but was continuing to process what we were focused on. The co-created, shared visual conceptualizing belonging (Figure 6), is a testament to the power of presuming competence of individuals with IDD, and engaging in participatory co-created data collection and analysis.

Accessibility, Flexibility, and Responsivity

Participatory methods innately allow for flexibility and responsivity to the goals, preferences, and interests of the individuals involved in the process. By definition, participatory methods necessitate that the decisions, adjustments, and structure of a project align with the desires of the group, rather than the researcher. While this flexibility and responsivity is not new in the context of this project, adding in a focus on accessibility supported heightened flexibility and responsivity to meet the needs of and allow for engagement of co-researchers with IDD, who often draw upon more expansive forms of communication and engagement. While participatory methodologies feel like the best option for disrupting ableist research tradition, the findings from this participatory project also hold possibilities for building more expansive quantitative and qualitative research with individuals with IDD. In this section I will highlight four individual examples of accessibility, flexibility, and responsivity with each co-researcher, and explicitly name the strategies co-researchers and I used to improve access for one another. These strategies ultimately led to building a stronger community within our shared spaces and more expansive data collection and analysis.

Esme's Interests in Engagement

Based on conversations with other co-researchers from the pilot project, in my initial envisioning of our time together, I originally imagined that we would all come together as a group after the individual conversations. However, as described in Chapter 4, Esme was not interested in joining the group and communicated in our first one on one conversation that she had an interest in

continuing to talk and engage about belonging but did not feel a desire to do that in a group space. This caught me off guard and required my commitment to flexibility and the honoring of co-researcher preferences. The following excerpt highlights Esme's preference for engagement:

> *B: "[Esme] do you want to keep working together?"*
> *Silence*
> *B: "Do you want to keep having these calls to tell stories of belonging?"*
> *E: "Yes, yeah."*
> *B: "Okay, we can do that. So, but you don't want to be with other people. Is that right?"*
> *Esme shakes her head*
> *B: "Okay. Um, I'm wondering if you can help me share your wonderings with the group, and I can share their thinking back with you."*
> *E: "No."*
> *B: "Okay. What do you think [...]"*
> *E: "No."*
> *B: I hear you. What part are you saying no to? That you don't want to meet with other people?*
> *E: "Yeah, yeah."*

After this exchange, I went on to tell Esme that I was not trying to encourage her to join the group, but I wanted to know if she wanted me to share her ideas with the group. After we clarified this, Esme was interested and drafted the question: "Do you feel like you belong with your boyfriend? Or girlfriend?" This exchange caused me to pause internally and reflect on how I could continue my commitment to my frameworks and the goal of participatory design. My decision to let go of my vision for what a participatory project needed to look like supported my communication with Esme and created an opportunity to find out what she desired for engagement and how I could honor her preferences through our conversations and time together. This was important to me, and my memos from after this call include reflections of how it felt critical for me to understand Esme and to honor her desires. This response felt in stark opposition to the emphasis on compliance and traditional engagement expectations often required of people with disabilities in schools and society (Baustien Siuty, 2019). In this sense, participatory methods hold the power to disrupt traditions of compliance and traditional power dynamics both inside and beyond research contexts. Further, this honoring of

Esme's preference towards one-on-one conversations and refusal of a group space created the opportunity for belonging in the research space for Esme.

Coral's Growth in Expressing Opinions

Accessibility, by definition, requires everyone to be able to engage in an opportunity or space. As previously noted, research contexts are often not accessible for all bodies and minds (Taylor, 2018). While this project and the work we engaged in together may not be accessible for everybody, collectively we worked hard to ensure all parts were accessible for the individual co-researchers involved in the project. Accessibility in participatory work requires flexibility and responsivity to ensure the perspectives, interests, and priorities of each co-researcher are known and incorporated. For Coral, one way this played out was in her expression of her own opinions and ideas. At the start of our time together, and throughout the pilot group engagement, Coral came across as very agreeable. During individual and group interactions, she quickly responded "yeah," nodded, and otherwise seemed to be communicating contentment with the ways in which our time together unfolded. In a one-on-one context, one strategy I took up when I recognized this pattern through my memoing was to provide open ended questions rather than offering a forced choice (i.e., a yes/no type response). This strategy seemed effective in encouraging and providing space for Coral to share more of her own stories and ideas. For instance, when I first talked to Coral about her feelings of belonging where she lived, she responded "yes, mhmm." In drawing on this strategy of open-ended questions I asked, "Can you share more about that?" to which Coral responded, "I love it." This pattern continued through the structured asking of open-ended questions and her responses grew from initial short utterances (often agreeable), to longer responses with more specific ideas or opinions. This conversation led to Coral's development of her own question about belonging in living contexts shared in Chapter 5 and displayed in Figure 3.

While this question asking strategy was one example of how my responsivity created space for more accessible engagement in our immediate conversation and the project more broadly, Coral's willingness or openness to expressing her opinions and priorities more readily increased throughout our time together. There are examples of this from the start of our group time, at the beginning of the project, through our shared analysis, as our time together came to a close. For example, when I asked the group about our size after our first meeting and asked if they wanted to find more people to converse with, Coral quickly responded, "it [group size] feels good," to which multiple group members agreed. This resulted in our decision to keep our group at five members. When Coral missed part of a session where co-analysis occurred, I brought back the updated visual to her and she quickly requested changes and additions to our shared visual and added her reflection on the importance of these shifts. This interaction highlighted the importance of individual stories in conceptualizing belonging. Without the confidence to share her opinion, the co-created visual would not have represented what was most important to Coral. This highlights the importance of accessibility, especially in participatory methods when power and control shifts to research participants who are positioned as co-researchers.

Dory's Considerations of Community

Throughout our time together Dory continuously reminded us all about the accessibility of community. She reflected on how the way in which she engaged and the way in which we structured our time together impacted the relationships that would be formed. Dory shared, "Small groups feel good," when reflecting on the thought of adding more people to our group. Both Betty and Coral later echoed this sentiment. When discussing Dory's interest in sharing her speech in the group setting, she said, "Yes and also, I like the idea of first an icebreaker question. Something like your favorite Netflix show or it could be anything." During this interaction I quickly recognized my own motivation and excitement for her to share her stories and build connections with the other co-

researchers, but Dory graciously reminded me that slowing down was important because we did not all know each other very well yet. When thinking about the possibility of engaging in some creative representations, Dory added, “I'd rather be doing it with each other because then we could just talk to each other.” Dory continued this priority of relationship building after we began our group sessions.

During our first scheduled group call, I got a message from Dory saying “Metro mobility is late again. I’m not going to be home on time.” Dory apologized and communicated frustration that she had a new driver who could not figure out how to pick her up consistently. She shared frustration that her request with vocational rehabilitation to have her Uber rides reimbursed due to this ongoing conflict was denied. Due to the scheduling constraints of the other co-researchers, we started on time instead of waiting to begin, which felt in conflict with the commitment to building community that was so important for Dory (and for me). When Dory eventually joined the session, she quickly apologized for being late and shared her excitement for meeting everyone. By the end of our last group call, Dory had reached out to me in advance to see if she could stay in touch with one of the group members when we had finished working together. This call reflects the commitment co-researchers had to this work and to their relationship with one another.

Betty’s Assertion of Access Needs and Preferences

The accessibility of our time together was deeply enhanced by co-researchers’ recommendations and adjustments, particularly Betty. Betty provided ongoing feedback to me throughout the process regarding how the process could be more accessible to her needs and desires, as well as ways to improve accessibility for the wide range of bodies and minds who might be a part of the work. Here, I will highlight three instances where Betty demonstrated the importance of flexibility and responsivity to ensure accessibility in our participatory process. First, Betty demonstrated this most clearly through the choices she made and communicated about the way she wanted to engage in our shared work. During our first one on one conversation, Betty shifted our

conversation at several points. In one example, Betty had been talking about not feeling belonging in schools. After validating those experiences and feelings, I asked, "[Betty] were there any spaces or times in school where you felt belonging?" Betty began responding by describing how in school "[she] was always in the disability area" and was constantly "getting pulled out." She also remembered "getting easy homework" and shared that it was "frustrating like can't I get tougher homework to strengthen my brain." She started reflecting on a reading program she was a part of and then stopped herself and said, "I'm going to go out of this question a little bit because this is kind of working for me to talk about." She pivoted to speak about her ability to read body language and how this helped her perceive power dynamics and others' opinions. Betty reflected back to me her decision to veer away from the question because the story she was telling was important.

During another call, Betty was silent for longer than had become typical of our rhythm of communicating so I said, "Do you want to keep this conversation going or do you want to move on?" This phrasing was intentional and a way of putting the power of the decision in the hands of Betty, rather than making assumptions based on her communication patterns or my assumption that she was finished sharing or done engaging. In this example, Betty replied, "We can move on." I frequently asked co-researchers some version of this question (Do you want to keep this conversation going or do you want to move on?), and most of the time co-researchers were not finished and often wanted to continue building on the thoughts, stories, and ideas we were exchanging. Processing time, especially in these sessions where we were co-creating and building off one another's ideas in real time, was an important component of accessibility.

Finally, Betty showed strength in her ability to communicate preferences around access to our group space. Initially, she expressed some hesitation about joining the group through a series of questions and wonderings about what it might be like. I assured her we could make a decision when it got closer and she said, "That's kind of what my brain is thinking. And I think that will make my

mom happy, too. But it's also what I feel like on that day. But I'd love to hear some of their stories." Here, she exposes some of the internal dialogue and tension she was experiencing around feeling hesitant about the group space and a desire to hear from the others. In a later conversation, I reminded Betty of what the group time might look like, and I also reiterated that she could choose not to join the group calls and I would keep meeting with her one on one if that was her preference. The participatory approach allowed me to offer this alternative and to continue to engage with Betty in the ways she desired.

Betty ended up choosing to engage in the group and we met beforehand to talk about ways to make the space feel safe and accessible for her. While co-researchers didn't name this theme of safety in the shared conceptualization, this idea of safety surfaced in several stories. One adjustment we made required flexibility from the other co-researchers. This involved pushing the date of our first group session to a later date. Betty and her mother had shared with me about a recent issue with a new roommate in Betty's apartment, which caused a lot of emotion and took a lot of energy from Betty. Betty was self-aware in recognizing that she did not have the social stamina to meet new people and engage in the group conversations while processing this other emotional event. In one of our group calls, when I recognized Betty retreating from our conversations I said, "Betty, I think you had something else to get to today, do you want to stay on the call a little longer or are you ready to be done?" To which she replied, "I'm going to be done for today." This moment demonstrates how the design supported (1) creating space for the whole group to allow Betty to attend to her own needs, (2) recognizing and responding to Betty's cues regarding her capacity to engage in the group space, and (3) flexibility on the group's part in recognizing we might not get through what we had hoped to during the session.

Our Experience with Participatory Methodology

Throughout our time together, both during individual and group conversations (community building and sharing), and in co-creating our analysis, co-researchers demonstrated the ways in which they used power in a research setting to share knowledge and build shared understandings of belonging. In answering this question: *How do individuals labeled/with intellectual and developmental disabilities take up participatory methods to engage in research and disrupt ableist assumptions, power dynamics, and roles?,* co-researchers conceptualized individually what they hoped for during our time together and clearly communicated how they wanted to engage and communicate their knowledge and ideas. Co-researchers provided ongoing opinions and feedback on the size of the group and considerations around recruitment. At the start of each conversation, we engaged in ongoing conversations about consent, where co-researchers communicated their willingness to engage in research and with one another and to be recorded. Co-researchers advocated for accessibility throughout data collection and analysis and in turn we were flexible and responsive to one another's needs and dynamics within the group and individual contexts. Thus, while my conceptual and theoretical frameworks were necessary guides in framing this work, they were simply the foundation upon which co-researchers created an accessible space for co-creating understanding of belonging.

Chapter 7: Discussion

The purpose of this study was twofold: (1) to extend the literature on experiences of belonging through firsthand accounts of individuals with IDD, and (2) to document engagement in participatory methods with individuals with IDD. This chapter includes a summary of the study, critical conclusions drawn from the data in Chapters 4-6, study limitations, and implications for practice and for research. This study is situated on the idea that belonging is critical: in identity formation (Faircloth, 2009; Groves et al., 2018; Raver et al., 2018), for motivation (Goodenow, 1993; Leary & Kelly, 2009), and in mental health (Arslan et al., 2022; Schochet et al., 2011). As a result of its subjective nature (Goodenow, 1993), belonging is best understood through firsthand accounts and experiences. As described in Chapter 2, the need to belong is not unique to individuals labeled/with IDD compared to their non-disabled peers, but there are reasons to attend to the specific experiences and conceptualizations of belonging by individuals labeled/with IDD. While the experiences of one individual with IDD does not speak for the experiences of all individuals with IDD, belonging is not equally accessible by all people, and ableist (and other oppressive) systems and interactions, may uniquely shape the accessibility of belonging for individuals with IDD. Additionally, individuals with disabilities, specifically intellectual and developmental disabilities, are often denied access to sharing their experiences and understandings directly through research (Shogren, 2023; McDonald et al., 2021). One assumption that guided this study is the assumption that proxy voices are inadequate in unpacking and conceptualizing belonging from the perspectives of adults with intellectual and developmental disabilities. Conceptualization of belonging through the lived experiences and reflections of individuals with IDD provides the most accurate understanding of how belonging is negotiated across spaces. Participatory methods aligned with the guiding frameworks of this study and created an avenue for collaborating with individuals labeled

with IDD to further understanding of belonging based on first-hand experiences elicited to bring change to the world (Sitter & Grittner, 2021, p. 37).

This participatory exploration of belonging examined the following research questions: (1) *How do individuals labeled with intellectual and developmental disabilities describe their feelings or experiences of belonging?* (2) *How can we understand the spaces, relationships, and systems that foster a sense of belonging for individuals with intellectual and developmental disabilities?* And (3) *How do individuals labeled/with intellectual and developmental disabilities take up participatory methods to engage in research and disrupt ableist assumptions, power dynamics, and roles?* The findings of this study contribute to the research in two areas by: (1) highlighting the experiences of belonging of four adults with IDD both individually and in a shared conceptualization; and (2) offering a methodological contribution, by exploring the importance and power of participatory methodologies with individuals with IDD.

Chapter 4 outlined the specific ways each co-researcher thought about belonging and highlighted the ways in which they individually navigated engagement within the process of research. Co-researchers shared that belonging is: “important” (Esme), “like making music” (Coral), “like a cycle” (Betty), and “kind of like being included “(Dory). Each participant emphasized certain feelings or qualities of belonging and pulled these ideas forward to our shared group space. Chapter 5 explored the sensemaking and conceptualization of belonging that occurred in the shared group space, which culminated with a co-created visual of co-researchers' understanding of the cycle of belonging. Finally, Chapter 6 documented findings of engagement and agency co-researchers employed in this project throughout the participatory process, highlighting the ways in which co-researchers reinforced the presumption of competence and pushed for accessibility throughout all stages of the research process. The findings of this project highlight the possibility and importance of documenting lived experiences of individuals with disabilities through their own accounts. Further,

these consistent patterns of engagement and self-determination throughout the research process indicate that participatory methods are likely to be generative with other groups of participants with IDD.

Situating Project Findings in Broader Literature

Across the study, the systemic exclusion of individuals with IDD and histories of interactions with ableist systems and relationships surfaced in co-researcher stories. Four major conclusions can be drawn from the findings of this project when situated in the literature: (1) co-researcher engagement throughout the research process further documents the necessity in shifting away from proxy voice, (2) co-researchers recognize and reflect upon the accessibility of belonging through comparing their own experiences, (3) co-researchers build on the current inclusion literature, and (4) our co-developed cycle of belonging visual extends existing conceptualizations of belonging documented in the literature.

The first contribution of this study is the centering of the stories of those with lived experiences as opposed to proxy voice. The history of systemic exclusion in research and in schools and communities lends to the centering of proxy voice in the understanding and building of knowledge about the lives, experiences, and perspectives of individuals with disabilities. Instead, throughout this process, co-researchers were individuals with IDD and intentional efforts were engaged to center their desires, both in research engagement and in their recounting of belonging. The theoretical framing of Disability Studies (Oliver, 1992; Linton, 1998) and the conceptual components of presumption of competence (Biklen & Burke, 2006), necessitated my focus on lived experiences over normative assumptions of competence in our work. These frameworks supported this contribution because they helped me commit to centering the desires, preferences, and stories of participants with IDD in our shared exploration of belonging.

One of the many outcomes in this project that resulted from focusing on lived experiences versus proxy perspectives, was co-researchers generating their own lines of inquiry within our project. For example, Coral asked two questions based on our initial discussion together that she brought to the group to explore together (see Figure 3 and Figure 4). She asked: “Do you feel like you belong where you live?” And “Do you feel like you belong at activities that make you happy?” In these questions, Coral is speaking asks questions which reflect on her recent experiences and major life changes. With Esme, much of our time together was on a previous romantic relationship. Through centering her as a co-researcher as opposed to a proxy account of her experiences of belonging, specific and unique insights closest to her truest experience were revealed. This relationship was important to her and served as a barometer for understanding the significance of other relationships. This internal, subjective (Goodenow, 1993) feeling of belonging can only be felt and understood by an individual themselves. While proxy voices may speak to externalized expressions or conversations about belonging, they are one layer removed from the firsthand experience.

Another complexity with proxy voice and the removal from firsthand experience that became significant throughout the project is the core tenet of belonging defined by our group in co-analysis: Be Yourself. This tenet would not have surfaced in the same way through proxy perspectives about these individuals' experiences. Dory, Esme, and Betty all named recognizing there were/are places where it is safe to be themselves and places where that was not well received or safe. This experience with ableism, and likely other systems of oppression, are experienced by these individuals as a result of their disabilities. While a proxy perspective could come close to describing or assuming which spaces feel safe or where they see the individual most acting like themselves, a proxy account will never be fully accurate or whole in understanding another’s experience. In this vein, our understanding of belonging is incomplete without individuals accounting for and reflecting

on their own stories and experiences. This project contributes the firsthand perspectives of four individuals with IDD and the exploration of their interests about belonging.

A second contribution of this study is the extension of the literature considering the accessibility of belonging. Throughout this study participants shared stories and reflected on prior experiences of belonging by discussing their agency to access belonging and by comparing prior experiences to differentiate relationships and spaces of belonging. The need to belong is connected to the human desire for power and intimacy (Baumeister & Leary, 1995). Access to power, among other things, is deeply connected to intersecting systems of oppression (Baglieri & Lalvani, 2019). Ableism is one of these systems. The frameworks guiding this project, including a social understanding of disability (Oliver, 1983), enhance the understanding of ableism. Throughout our time together in this study, co-researchers recounted moments of frustration, and resistance in accessing belonging or accessing spaces where they felt belonging would exist.

Co-researchers used comparison as a way of navigating the idea of the accessibility of belonging and describing inhibited agency. A few examples of this explored in the findings were Esme's comparison of relationships to her previous boyfriend; Dory's experiences in different work environments; Betty's experiences in school and relative feeling of safety; and Coral's different living environments. Esme described colleagues and other peers her age she was connected to but when I asked if they created feelings of belonging, she repeatedly said, "it's not the same" and referenced the way she felt when connected to a prior boyfriend and his family. A similar sentiment surfaced in Dory, Betty and Coral's stories. Throughout the process co-researchers used comparisons to describe how experiences or relationships resonated with other experiences of belonging or were different. This suggests that belonging is measurable by the individual experiencing it, and if belonging is more accessible to certain people depending on power and privilege, attention should be

focused not only on the social impact of not accessing belonging, but the mental health implications of the accessibility of belonging.

A third contribution of this project is the contribution to the critical inclusion literature, specifically the differentiation of inclusion from belonging. Carter and colleagues (2021) explored belonging for individuals with IDD and delineated the differences between exclusion, segregation, integration, inclusion, and belonging. Inclusion has long been advocated for in special education research as beneficial to learners, both disabled and non-disabled (Agran et al., 2014). This study aligns with Carter et al.'s call to consider belonging in the conversation of inclusion for individuals with IDD (2021) through our co-created visual (see Figure 6). The visual highlights the importance of being able to be oneself and feel safe in a space, having reciprocal relationships, being recognized for your strengths, having familiar and routine contact with a place, and a unique and peaceful feeling. Co-researchers noted that many of the identified components of belonging can be missing when someone is just physically included in a space.

Much of Dory's sentiments through her storytelling align with Carter's idea that "inclusion provides the foundation for belonging" (Carter, 2021). Dory's experience being included in a workspace where she didn't feel a sense of belonging is a testament to this notion. Carter (2021a) notes that inclusion does not equate relationships, and this study and the co-constructed visual of belonging build on Carter's idea to suggest that not only does inclusion not equate meaningful relationships, but it doesn't negate ableism. In Dory's example, she was in relationship with her colleagues but their ableist beliefs and interactions were demeaning. These interactions supported the foundation of inclusion, but without the experience of belonging. Despite the clear difference between belonging and inclusion, very little special education literature addresses the need to belong for students with disabilities. This study contributes to the literature by highlighting examples of belonging, documenting the way individuals with IDD make sense of and express their experiences

of belonging, and offers a visual suggesting a cycle of belonging which builds on the foundation of inclusion.

A final contribution of this study was a conceptualization of belonging which builds off prior literature on belonging. Our findings and conceptualization of belonging (Figure 6) fit within and build upon existing theories and models including Renwick's conceptualization of belonging (2019), Allen and Colleagues' work on belonging (2021), and Carter's Ten Dimensions of Belonging (2016). Table 3 offers a comparison of these different models. Each of these models (see Table 3) is similar in some ways to the co-created visual our group created. Renwick's Conceptualization explores "finding a good fit" which involves negotiating norms and navigating expectations (2019), which resonates closely with the stories participants shared in relation to the Be Yourself category. Allen and Colleagues (2021) offer a model which considers larger systems and the way social and cultural systems impact all aspects of one's sense of belonging. Additionally, their model considers the true interconnectedness of these different components and the necessity to interact and have needs met in each of these areas to reach a sense of belonging. Finally, Carter's (2016) dimensions address some of the feelings co-researchers described in our project which described how they feel when they belong.

Table 3.

Comparison of Theories or Models of Belonging

Model of Belonging	Our Co-Created Cycle of Belonging	Renwick's Conceptualization of Belonging	Allen et al.	Carter's Ten Dimensions of Belonging
Tenets of Belonging	(1) Relationships (2) Strengths/ Confidence (3) Places (4) Feeling (5) Be Yourself	(1) Interacting with similar people (2) Negotiating meaningful roles in the community (3) Engaging in Social	(1) Competencies (2) Opportunities (3) Motivations (4) Perceptions All shaped by "social, cultural, environmental, and	(1) Present (2) Invited (3) Welcomed (4) Known (5) Accepted (6) Heard (7) Supported

	Relationships (4) Finding a good fit	temporal contexts & experiences"	(8) Befriended (9) Loved (10) Needed

Our model aligns with other pre-existing models about the importance of relationships. Allen and Colleagues (2021) name the environmental and temporal contexts which influence access to opportunities for relationships and Carter (2016) highlights befriending (and reciprocity) as central. Our conceptualization resonates with Renwick's (2019) by naming the need for meaningful roles, and our model talks about this as a recognition of strengths and the subsequent confidence that results from that. Our co-created conceptualization of belonging builds upon these three models of belonging by: (1) incorporating the tenet: be yourself, and (2) the idea that these components of belonging inform one another.

Looking Forward

In the next section I will describe the limitations of this study, the implications of our findings for practice and research, and offer direction and hold space for the potential of future research in this area.

Limitations

Despite the host of qualitative findings from this study, there are a few limitations which are important to explore. One limitation is related to the methodology. Participatory methods are intended to be envisioned and initiated with co-researchers from the beginning (Cocks & Cockram, 1995). This project was conceived as a part of my doctoral journey as my dissertation, and as a result, some of the initial process of participatory work "identification of a problem or issue," was done in isolation. (p. 31) I came to the work to search for participants with a hope and interest in focusing on belonging. My preconceived ideas limited or informed the full possibilities of a participatory framework. Despite this, as described, co-researchers engaged with me to inform the

structure of our time together, the content of focus, “generation of collective knowledge through the investigation of the problem” (p. 31), our analysis modality, and desires for dissemination.

Another limitation of the project was that the model was created by a group of white women, which lacked the depth possible from a more diverse group. The stories and experiences of the white women co-researchers informed our co-created cycle of belonging, and thereby it likely is not representative of individuals with other intersecting identities. As discussed, the accessibility of belonging is impacted by oppressive systems. Ableism does not operate alone, but instead intersects with racism and other systems of oppression (Annamma et al., 2018). While I had hoped to recruit a more diverse group of co-researchers, the four co-researchers who first got involved felt most comfortable engaging in the work if the group was kept small. In future work it would be essential to explore the model with a more diverse participant group. In this further work, theoretical frameworks with an intersectional lens could be taken up to situate more nuanced and expansive understanding of individuals with intersecting identities.

Implications

The findings from this project inform implications for special education, community contexts, and research. The implications for practice are derived from our co-analysis and the takeaways my co-researchers shared as most salient described in Figure 6.

Implications for Practice: Be yourself

Special education teachers and administrators should focus on building communities of belonging for all learners, including their learners labeled with intellectual and developmental disabilities. It is important that students with IDD are not only included in general education spaces, but centered in relationships and spaces which foster belonging. Specifically, co-researchers name the importance of being able to be themselves. This requires self-acceptance and safe spaces for identity development (Faircloth, 2009; Groves et al., 2018; Raver et al., 2018); meaning students

must be in spaces where they are not being reinforced to mask or comply with certain ways of being. Special educators, general educators, and administrators should be reflective of normative expectations within a space and work to ensure communities exist where students feel safe showing up as their full selves and communicating their true thoughts and experiences. This may mean rethinking behavioral expectations in classrooms, incorporating UDL to provide meaningful ways of engaging for a diverse group of students, and providing accessible avenues for communication. Educators should not require students to engage in specific normative ways or mask in specific ways to be invited into or included in a space.

Implications for Practice: A Feeling

In considering classroom climate, educators and administrators should move away from their own observations or more objective measures and take up a more expansive understanding of how students are feeling inside a classroom community. The findings of this project reinforce the belief that belonging is subjective (Goodenow, 1993) and is an internal *feeling*. Further, the findings of this project document the ability and competency of individuals with IDD to speak and represent their own experiences; thus, educators and administrators should center the voices and lived experiences of learners with IDD to understand if and how they feel belonging at school. While seeking input from families (advocates, professionals, etc.) is a critical part of the special education collaborative process (Flint & Jaggers, 2021, p. 254), educators should first seek understanding of the feelings held by the individual themselves.

Implications for Practice: Relationships

The findings of this study highlight the importance of *relationships* in a sense of belonging. Co-researchers shared stories and conversation around the importance of reciprocal relationships where they can be themselves and have their boundaries respected. In the context of education, professionals should work to build communities where disabled and non-disabled students are peers

and have opportunities to develop reciprocal, meaningful relationships. This includes moving past peer models and supports that flow from non-disabled students to disabled students. Models such as these reinforce one-way, non-reciprocal relationships and risk reinforcing ableist assumptions. In our discussions, co-researchers sometimes mentioned 'independence' but their descriptions often highlighted interdependence (Sins Invalid, 2019)- the knowledge that we are all better when we are meeting each other's needs through authentic relationships. Further, co-researchers elaborated on a need for a wide variety of relationships including familial, friendships, and romantic relationships. Educators, family members, and community organizers should honor and respect the need for individuals with IDD to meet the same relational needs they recognize for nondisabled individuals. This is one area families, educators, and support people have power in the accessibility of belonging for their student/loved one with IDD. Families, educators, and support providers should provide extensive opportunities to form relationships and be mindful of ways we may be restricting the agency of an individual to make choices regarding the people and types of relationships they would like access to. This includes prioritizing individual voice and self-determination in choosing relationships included but not limited to relationships with service providers, friendships, romantic relationships, and housemates or those one lives with.

Implications for Practice: Strengths/confidence

Co-researchers also emphasize the importance of having their *strengths* identified and being *confident* in the process of belonging, which has several implications for practice. Allen and Colleagues (2021) might describe this area as competencies. While that framing does not fully capture what co-researchers explored in this area, one shared idea is the recognition that when others recognize and appreciate your strengths, it builds confidence. For educators, this finding emphasizes the importance of asset-based pedagogies (Flint & Jaggers, 2021) and strengths-based views (Shogren et al., 2016) of students. It is not the responsibility of individuals with IDD to convince

anyone of their worthiness or to negotiate their right to be included in a space; instead, educators, families, and community members should work to ensure individuals with IDD are acknowledged for their strengths.

Implications for Practice: Places

Finally, co-researchers emphasized the finding of *place* as essential to a sense of belonging and focused on spaces which were familiar, accessible, and routinely available. One implication drawn from this finding for practitioners, community members, and families is to have intentional conversations about how and if places are accessible, both physically and otherwise, to disabled individuals. Specifically, I encourage individuals to think critically about the impact of being in an inaccessible space and not being given choice or power in choosing to leave or be somewhere different. Accessibility, like ableism, is impacted by multiple levels: individual, cultural, and institutional/systemic (Baglieri & Lalvani, 2019). Co-researchers described accessibility in traditional physical terms (e.g., the ability to get to a restaurant, or into an activity or workspace), as well as other dimensions of accessibility (e.g., accessing content or opportunities). An implication of this finding for educators, community members, and family members is to pursue accessible spaces and advocate for improved accessibility in places identified as important by the disabled individual.

Implications for Research

There are several implications for research that can be drawn from the findings of this project. The first is the importance of being thoughtful in differentiating when proxy voice is relevant, and when the most authentic and important narrative comes from the individual with IDD. Further, researchers should be intentional in calling out the limited nature of stories, opinions, and perspectives shared by proxies on behalf of an individual with IDD. This requires acknowledging the role they play in advocacy or in expanding understanding of family systems, but not allowing parent/professional/family voice to stand in for the accounts of the individual with lived experiences.

Ideally this project suggests centering the firsthand perspectives or lived experiences of individuals with IDD in research on their own experiences and opinions which will inform policy and practice. This necessitates engaging individuals with IDD in research from initial conceptualization through analysis and dissemination (Shogren, 2023). Researchers, especially those within academia, have power and authority to choose what they research, who they research with, and how they engage in the systems and structures of academia. Researchers working to advocate for individuals with IDD should establish partnerships with individuals with IDD to not only center their voices as the participants of research, but as true partners in understanding various lines of inquiry relevant to their lives.

Finally, a second implication for research from this project is the importance of accessibility and flexibility in including disabled individuals in research and as co-researchers. Shogren (2023) refers to this as: honoring everyone's right to access "the *process* of science" (p. 1). In this project co-researchers continually communicated not only what their own access needs were (e.g., plain language, visual representations, etc.), but their thinking about what would create a more accessible space for a wider variety of needs (e.g., creating an accessible template) and communicative repertoires. Despite my experience, it should not be the responsibility of individuals with IDD to initiate or advocate for access to a research space. Instead, following the recommendation of Sins Invalid, we should build in opportunities for everyone to share their access needs (2019, p. 21). Offering routine and proactive access checks and conversations creates ongoing space for feedback and planning to create research environments that have the potential to foster more meaningful and generative experiences. Ultimately, creating accessibility in research aligns with the findings of this research; specifically, participants desire to be allowed to use their voice, be themself, and be in places which are accessible.

Conclusion

Above all, my hope is that this study provides a rationale for the importance and possibility of participatory research with individuals with IDD; and further, that participatory methodologies be acknowledged as critical to the further reimagining of educational justice for individuals with disabilities. When my co-researchers and I talked together in our final session about who and how we wanted to share our collective insights about belonging, Betty stated that she wanted to: “share to people who doubt disabled people, and say hey you are thinking it is totally bonkers that we exist, but we are not the same and we have our own minds, and if you see this I think the world might become a better place for us.”

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Appendices

Appendix A: Consent Forms

PARTICIPANT CONSENT FORM

Spaces, Relationships and Experiences of Belonging for Individuals with Intellectual and Developmental Disabilities

Investigator: Bailey Allred, fagerlee@uw.edu, 952-594-0219

Faculty Advisor: Carly Roberts, carober1@uw.edu

Investigator's Statement

I am asking you to be in a research study that I am completing as part of my doctoral coursework at the University of Washington. The purpose of this consent form is to give you all the information you will need to help you decide whether or not to be in the study. Please read the form carefully. You may ask questions about the purpose of the research, what I would ask you to do, the possible risks and benefits, your rights as a volunteer, and anything else about the research or this form that is not clear. When all your questions have been answered, you can decide if you want to be in the study or not. This process is called "informed consent." I will give you a copy of this form for your records.

PURPOSE OF THE STUDY

The purpose of this study is to better understand and explore experiences of belonging as they're experienced by individuals with Intellectual and Developmental Disabilities.

PROCEDURES

If you choose to be in this study, I would like to meet with you and other individuals with Intellectual and Developmental Disabilities to learn about you, your story, and the spaces, relationships and experiences which have fostered a sense of belonging. We will work together to choose questions and activities which allow you to reflect on these experiences and explore matters that are significant and important for you. Together we will revisit what you have shared and ensure that your stories are recorded accurately. Our zoom sessions together may include sharing of stories, and opportunity to share through drawing, writing, or through photos. During the study we will engage in interview sessions together over zoom. The first session will be a semi-structured interview where we will spend time getting to know each other and talking through the study. This will take approximately 30 minutes to an hour. At our next session, which may last about 1 hour, we will share and explore experiences of belonging in a focus group. This may include conversation, writing, picture sharing, or drawing. You can choose which way you share your experiences. Some questions we may talk through: How do you describe belonging? What does it feel like to you? Are there people or places where you've experienced belonging? Finally, we will engage together to analyze the data including the documents and stories shared, together we will highlight the key stories and experiences.

With your permission, I would like to record the audio and video of our interview/conversations so that I can have an accurate record of our conversation. I will transcribe this recording without identifiable information and destroy the recording after the study is over. Only I will have access to the recording, which will be kept in a secure location. If you would like a copy of the transcript of the interview, I will gladly provide you with one.

RISKS, STRESS, OR DISCOMFORT

Some people feel that providing information for research is an invasion of privacy. I have addressed concerns for your privacy in the section below. Some people feel self-conscious when notes are taken or interviews are recorded. Additionally, if you'd rather engage in all individual interviews we can do that in place of the focus group to increase confidentiality. Some people might not like talking about personal stories or details with a researcher or a group of people. You will have a choice to share what you're comfortable sharing.

BENEFITS OF THE STUDY

You may not directly benefit from taking part in this research study. One benefit of this study is an opportunity to share stories and experiences of belonging, and hearing from others. These stories have the potential to impact education and other supports for students and individuals with Intellectual and Developmental Disabilities.

OTHER INFORMATION

Taking part in this study is voluntary. You may refuse to participate and you are free to withdraw from this study at any time without penalty or loss of benefits to which you are otherwise entitled. Information about you is confidential. I will assign you a pseudonym and code the study information. I will keep the link between your name and the pseudonym code in a separate, secured location until the study is complete. Then I will destroy the information linking your information to the pseudonym. If the results of this study are published or presented, I will not use your name, or any other identifying information.

I may want to re-contact you for future related studies. Please indicate below whether you give me permission to re-contact you. Giving me permission to re-contact you does not obligate you in any way.

If you have any questions about this research study, please contact Bailey Allred at the telephone number or email listed at the top of this form. If you have any questions about your rights as a research subject, please contact my doctoral advisor, who is overseeing this project: Dr. Carly Roberts, carober1@uw.edu, 206-221-7894.

_____

Signature of investigator Printed Name Date

Participant's statement

This study has been explained to me. I volunteer to take part in this research. I have had a chance to ask questions. If I have questions later on about the research, I can ask the investigator listed above. If I have questions about my rights as a research subject, I can contact one of the course instructors. If I have questions about my rights as a research subject, I can call the Human Subjects Division at (206) 543-0098 or call collect at (206) 221-5940. I will receive a copy of this consent form.

____ I give permission for this researcher to audio/video record my interview and collect the artifacts I generate during the study

____ I do NOT give my permission for the researcher to audio/video record my interview.

____ I give permission for the researcher to re-contact me to clarify information.

____ I do NOT give permission for the researcher to re-contact me to clarify information.

_____

Signature of participant Printed Name Date

_____

Signature of parent/guardian Printed Name Date

Copies to: Investigators' file
Participant

Appendix B: Sample Individual Interview

Sample Interview Protocol:

**This is a sample agenda capturing some of the framing and rationale I held for my work with co-researchers. This was just a draft, a series of ideas for a potential plan. The next appendix shows the individual agendas built from conversations with co-researchers about the plan of participation that made the most sense and was most meaningful for them as individuals - this sometimes included sharing answers to the questions I'm about to lay out, sometimes involved co-researchers own questions, the sharing pictures, creation of art or drawing pictures, etc. This is my disclaimer that these are simply prompts and stems for the sessions that I thought might be helpful in drawing out stories, and experiences – but this was just a starting point and I diverted from this in whatever way participants choose.*

Sample Individual Interviews: (Approximately 45 minutes)

Agenda:	Prompts & Scripting:	Rationale:
Introductions	Share who I am, why I'm interested in this work. Share some hobbies, communities which are important to me etc. Ask participant to share what they're comfortable sharing.	Hold space to build relationships, trust, and get to know one another before entering times of sharing stories about belonging.
Discussion of Norms	Hold space for naming what's important for us in this virtual space. -Pull up some sample norms and ask participant if there are any they want to hold onto during our session item in your space that reminds you of belonging?	Understand what is important to each participant. Cultivate within our individual session and carry forth these norms into the group interview.
Potential Prompts/Conversation Starters	-One thing I'm interested in is understanding what you think about belonging. - What do you think of when you hear the word belonging? - Are there certain emotions you feel or think about? - Are there certain places where you feel belonging? People? Activities?	To gain some understanding and collect data around individual conceptualizations of belonging before coming together as a group.

Brainstorming Group Session	- One thing I'm interested in exploring is what you wonder about belonging. - What questions do you have about belonging?	My goal is to open the space to participant engagement in question creation for group session.
Activity: Mapping	Next, we're going to do a mapping activity together. I'm going to ask you to continue thinking about belonging and the spaces, and people, and activities that come to mind when you think of belonging. By creating this map you'll have one tool to share with me and your peers to talk about your experiences of belonging. <u>Prompt:</u> Use a piece of paper and a writing utensil to draw or write about your memories and experiences of belonging. You can be creative and draw or just write out words or names that represent these moments. Here's some ideas about what you could include: "Places that are important to you that felt like spaces of belonging - maybe someone's house, maybe this was a place where you were learning-school, or a sports center, etc." "People who made you feel like you belonged." "Experiences, trips, or other days or short periods of time where you felt belonging." You might draw these on a timeline so we know how old you were or when these things happened or you can put all the memories together.	My goal is to collect a visual form of data- that participants can share with others during the small group session, or with other people in their life as a tool or prompt regarding experiences of belonging.

Sample Group Interview:(Approximately 45-60 minutes)

Agenda:	Prompts & Scripting:	Rationale:
Introductions	Introduce myself again and ask participants to introduce themselves to each other by sharing what is comfortable.	Hold space to build relationships, trust, and get to know one another before entering times of sharing stories about belonging.
Discussion of Norms	Hold space for naming what's important for us in this virtual space.	Be intentional about naming the ways we can create a welcome space for ourselves and each other.
Sharing out of questions, or desired use of time (artifacts, maps, etc)	Provide time to share out questions we brainstormed on belonging. "____ do you want to share some of the wonderings you had about belonging?"	My goal is to create a space where participants are driving the focus, and activities.
Sharing	Provide everyone that would like some time to share their thoughts on belonging. - We could create a word cloud with words associated with belonging - Individuals could share pictures or other items that represent belonging - Individuals might share out their maps and describe some of their thinking	Create a space where individuals can contribute and express in ways that are most meaningful to them. Hold space for participants to hear from and learn from one another.
Conclusion	Thank participants for their willingness to share with me and with each other. Ask about contact information and share. I'll be reaching out again soon to analyze or review what we did together. We can meet together to figure out what's more important and how we want to share with others.	Co-Design, and a goal of participants voices shaping and choosing what is shared out.

Appendix C: First Individual Interview Agendas

Co-Researcher 1:

Setting: Zoom – Co-Researcher accessing through computer

Interview Agenda Item:	Notes:
1. Catch-Up	- Not-recorded
2. Consent	- Start recording after permission
3. Agenda Development for today's session	
4. Review older conversations	- Co-researcher pulled up previous hard copy documents
5. Structured questions to share stories	
6. Planning for group session	- Interest in sharing own questions with group

Co-Researcher 2:

Setting: Zoom- Co-Researcher accessing through phone

Interview Agenda Item:	Notes:
1. Consent	Start recording after permission
2. Agenda Development for today's session	
3. Speech – Artifact Sharing	Not planned in advance; co-researcher request sharing this first during our time together
4. Debrief Speech	Co-researcher shared a few places she wanted to share this (in our group, with work team)

5. Relationship Building/ Catch-Up	
6. Structured photo-based questions about belonging	Co-researcher remembered this from previous project & wanted to do this again
7. Forward planning	Co-researcher shared agenda items for our next session (including preference for community building time)

Co-Researcher 3:

Setting: Co-Researcher accessing through video call by phone

Interview Agenda Item:	Notes:
1. Catch-up	Not-recorded
2. Consent	Start recording after permission through zoom
3. Agenda Development for today's session	
4. Review older conversations and catch up on changes	
5. Talk about people and belonging	
6. Schedule next time to connect	Shared permissions to bring back key ideas to group space in the future

Co-Researcher 4:

Setting: Zoom- Co-Researcher accessing through computer

Interview Agenda Item:	Notes:
1. Catch up and review interest in project	Not-recorded
2. Consent	Start recording after permission

3. Agenda Development for today's session	Created list of choices together
4. Structured conversations with pictures to guide story topics	Co-researcher pulled up previous hard copy documents
5. Shared conversation about next steps and interests	Hesitancy in joining group sessions. Decided one on one call would be the next best step

Appendix D: Coding Tree Outline

RQ 3 – Analysis of Participatory Methods Process

Research Question: *How do individuals labeled/with intellectual and developmental disabilities take up participatory methods to engage in research and disrupt ableist assumptions, power dynamics, and roles?*

I. Round 1 Codes: Conceptual and Theoretical Framing

Parent Code:	Child Codes:
Participation across research phases	(1) Recruitment (2) Consent (3) Data Collection (4) Analysis
Presumption of Competence	(1) In recruitment and data generation conversations (2) In response and processing time
Epistemic Agency	(1) Co-researchers assert their agency with others
Accessibility of Research Process	(1) Co-researchers utilizing non-traditional methods of participation (2) Data generated outside of spoken language

II. Round 2 Codes: Patterns & Themes

Parent Code:	Child Codes:
Co-Researcher Agency	(1) Support of one another (2) My support (3) With others in proximity

Co-Researcher take up power to initiate throughout the research process	(1) Co-researcher initiation of data generation (2) Co-researcher initiation of inquiry – question development
Co-Researchers push back to build accessibility	(1) Consider & wonder about others access needs (2) Reflect on how their own access needs impact the group more broadly
Co-Researchers priority to build community	(1) Requesting agenda space for getting to know one another (2) Inquiry about ongoing connection outside of formal activities
Expansive Communication & Participation	(1) Space and time for processing and responding (2) Movement away from emphasis on spoken language (3) Impact of progression through conversations/activities
Innate Flexibility & Responsivity	(1) Shifting from my own assumptions about the structure of the project (2) Honoring of dignity & choice