Craft-based Interviews: Intervening in Intellectual Ableism Through Research-Creation

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Abstract

Lived experiences of people with intellectual and developmental disabilities (IDD) have been relegated to the margins of the humanities and social sciences research, even in the field of critical disability studies. The limits of existing research methods, which privilege written and spoken forms of communication, and the ableism entrenched in academic infrastructures, I argue, have been instrumental to this marginalization. In an attempt to disrupt these hierarchies, this thesis proposes a new research method called "craft-based interviews" as a way to do research, not *on* or *about*, but *with* intellectually disabled people through the process of creating together and communicating by other means than only words. "Craft-based interviews", in the way I theorize it, is a process-based method that can open up new channels of communicating in ways that counter and resist intellectual ableism in research practices and its privileging of the linguistic. Mobilizing the experimental ethos of research-creation, "craft-based interviews" affords a critical intervention, not only in enabling the participation of people with IDD in research, but in reckoning with ontological questions of knowledge, research and power. Through a detailed thematic analysis of the craft-based interviews I conducted with two people with IDD, and a discourse analysis of the correspondences I had with my own institution's ethics board, I explore the new possibilities that "craft-based interviews" can open up, and also interrogate the institutional barriers to conducting research *with* people with IDD in the humanities and social sciences.

Acknowledgements

While my name may have the copyright to this thesis, there is no such thing as singular authorship. To the kin and colleagues who wrote this with me. Thank you.

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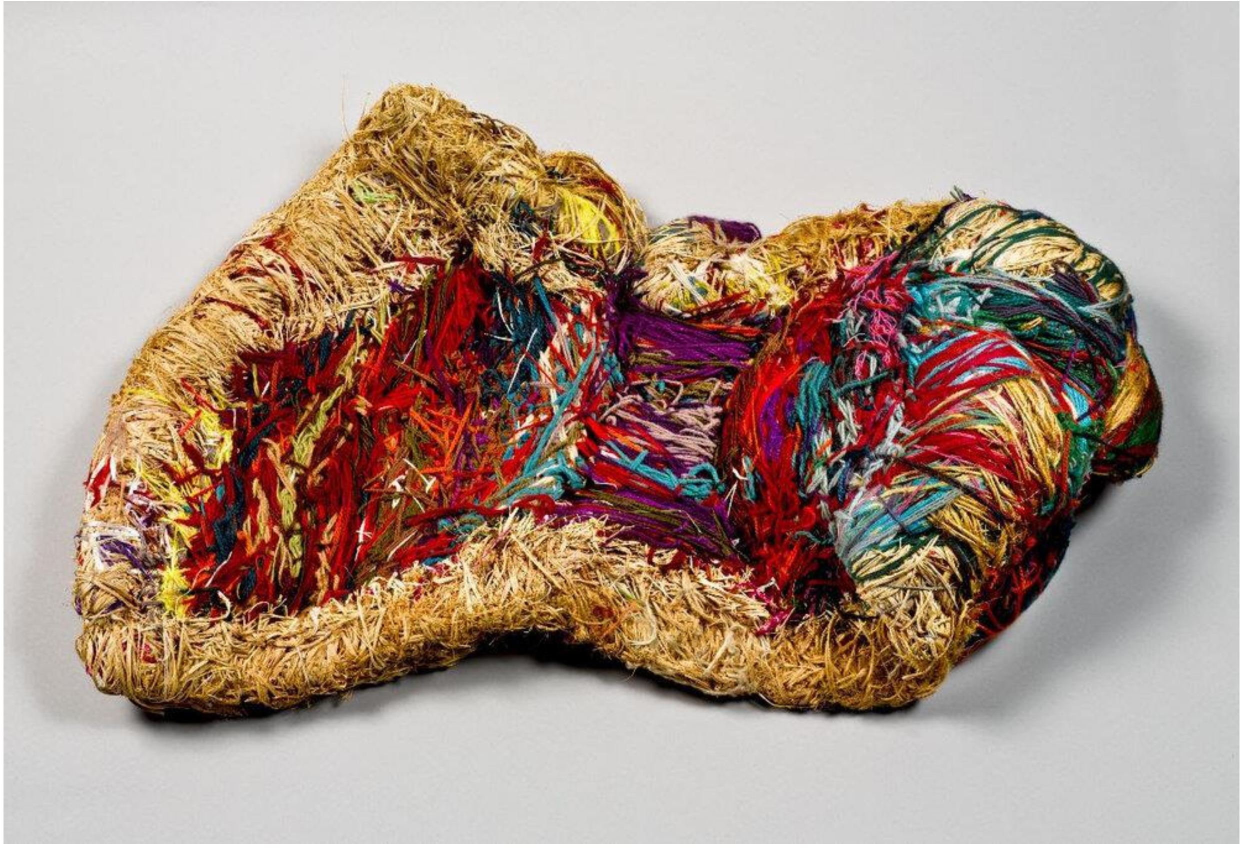

Figure 1: Judith Scott (1943–2005), Untitled; 1988–1989, Yarn and twine with unknown armature, 8×36×25 inches, Gift of Creative Growth Art Center, 2002, Photo by Gavin Ashworth (retrieved from: https://creativegrowth.org/news/virtual-insights-judith-scott-afam)

The enigmatic thread bound sculpture pictured here captures the unique style that fiber artist Judith Scott (b.1943- 2005) developed during the 18 years of her active career. Scott did not begin her career until forty-three, when she joined Creative Growth (CG) Art Centre, an organization that supports creative practices for those with developmental disabilities by providing them with a professional studio environment (CG, 2021). Prior to beginning her art practice, Scott was isolated in institutions for most of her life, a common experience for someone like Scott, who had Down syndrome, was deaf, and nonverbal.

Let me take a moment to describe what we are looking at (fig. 1): The rounded polygon-shaped sculpture is bound entirely by string. Golden twine lines the boarders of the piece, which as it concaves to the centre, is starkly contrasted with an assemblage of jewel toned yarn, including eggplant purple, cyan blue, and garnet red. Scott's work is often compared to cocoons or nests due to their intricate combinations of fibers and found objects. Their striking design led her to become one of Creative Growth's most prolific alumni. Despite her success as an artist, most of the writing on Scott emphasizes her disability, crucially undermining her work as an artist (Fraser 2010). Tom di Maria, the director of Creative Growth at the time, is quoted as saying that when Scott discovered fiber art she was finally "learning how to speak" (Joe, 2013). However, it was less that Scott was learning to speak as opposed to finally having the opportunity to utilize a conducive communication outlet for her way of speaking to be perceived as speech. And this is exactly what I want to explore in this research-creation-led thesis: how can creative practice provide people with IDD with other venues of communication than linguistic ones?

I begin with an introduction to Judith Scott because her work and life signifies the unattended artistic and communicative potentials that intellectually and developmentally disabled[1] individuals possess. The many barriers to recognition—in producing artwork and being perceived as producing *valid* work or even just being recognized as communicative and creative subjects in their own right—that disabled people are confronted with pose a range of questions about the nature of communication and artistic opportunity. In this thesis, I will explore some of these

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[1] Intellectual and developmental disabilities (IDD) is an incredibly vast (and vague) category. I use the term 'IDD' as outlined by the American Association on Intellectual and Developmental Disabilities (AAIDD), which characterizes disability by limitations in intellectual functioning, developmental and/or adaptive behavior, which impacts many everyday social and practical skills (AAIDD, 2021). Because much of the literature that I am in conversation focuses on cognitive disability, I use the term 'cognitive disabilities' as an umbrella term encompassing a range of conditions from IDD, Autism Spectrum Disorder (ASD), acquired cognitive disabilities such as dementia and brain injury as well as psychiatric disabilities and mental health conditions (Kittay & Carlson 2010; Fraser 2018). IDD is also sometimes theorized as a subcategory of mental disability in literature, so I use this terms in reference to scholarship too (Price, 2011). I interchange between the term 'IDD', intellectual disability, and specific conditions such as ASD or Down syndrome when applicable. In my framework, IDD is not monolithically characterized by a threshold such as an Intelligence Quotient (IQ) or an extra chromosome, but understood by the intricate biological, social and political factors that impact the state of functioning in society (Harris 2010, 58). I recognize that there are no essentialized definitions as the evolution of terminology is reflective of the various social and cultural environments from which a term is generated. Lived experience of disability often exceeds the limits of the category and the capacities of language, both of which attempt to arrest experience into a static moment, a definable term with sufficient and necessary conditions. But as many disabled people themselves know, this is not how disability works, subject as it is to the flows of experience unfolding into time.

questions by proposing a novel methodology based on research-creation. In what I call, "craft-based interviews," I work with two participants with IDD to create textile collage self-portraits, evaluating how this methodology complicates knowledge production in academia.

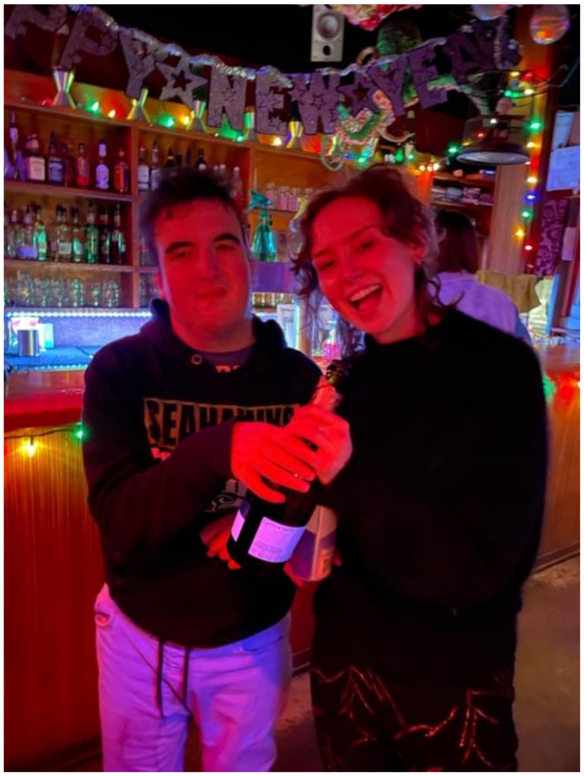

Figure 2. Gus (left) and Jessie (right) clutch a bottle of champagne and smile at the camera. They are bathed in the red hue of dim bar lighting; a "Happy New Year" sign strung above their heads.

Recognition of my Social Positionality

My understanding of disability has a twofold origination where it is at once produced through a range of lived experience and simultaneously through the ways that I place and understand this experience in scholarship.[2] My lived experience perhaps begins with my younger brother, Gus, who has an intellectual disability. This is an image (fig.2) of my brother and I this past New Year's Eve, which we spent hanging out in an empty restaurant that my friend worked at. Gus is charming, hilarious, stubborn (it runs in the family) and has a better memory recall than most people I know. Yet, because he is not "normal," people routinely make assumptions about his ability and agency. I joke that this sometimes works in his favour, like earlier that same New Year's Eve at a dinner with friends when the waiter just assumed that Gus wouldn't pay his own bill and delivered both checks to me. Or when we were in a long customs line at JFK airport after

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[2] There is no singular definition for disability within academia because multiple definitions exist depending on how one defines impairment, ability, and normativity. The fluidity of definitions takes into consideration the way disability manifests in relation to specific socio-political conditions of a given time (Davis; Erevelles 2011; Garland-Thompson 2011; Kafer 2013; Price While policy-oriented scholarship often promotes the use of person-first language to place the emphasis on the individual, many disability justice scholars and self-advocates use identity-first language to emphasize that disability is a fundamental part of their identity, and that this is empowering. To account for this in my research, when discussing disability, I interchange between writing *person with a disability* and *disabled person*. In doing this, I adopt the position of Tanya Titchkosky, who argues that the aim of analyzing language about disability should not be to mandate terms but rather "to examine what our current articulations of disability are saying in the here and now" (2011 cit. In Price 9). My ethos with language is to try to operate as agency centered as possible by tailoring my language to the specific identity and scenarios that emerge. My golden rule is that if I am unsure on what language to use, I just ask.

a red eye flight from Vancouver and the security guard moved us to the front because "he just didn't look ok," despite Gus saying "I'm fine" as he watched the luggage carousels spit out suitcases on the other side of the glass (a favourite experience of his). While these are eyeroll moments that I've learned to find humour in, they reflect the reality that many people, some of whom could as well be disabled themselves, are uncomfortable, assumptive and prejudicial of intellectual disability, revealing how deep ableism lies in the society.

Having an intellectually disabled brother is not the only relationship that informs my work, nor does this relationship entitle me to a knowledge base of disability. My generalized anxiety disorder, obsessive compulsive tendencies and panic attacks that at times impede my "social functioning," also provide me insight. And like many other disabled people, disability touches my life in many ways, and through many relationships. Rather than rattle off a list of the disabilities, mental health and addiction issues that have emerged at various times among my kin, I will sum it up in an assemblage of words: a mastectomy, McDonalds, inhalers, panic attacks, ass wiping, cuticle biting, suicide, the AIM Lab, genetic testing, "just getting it," special Olympics, hospital visits, sllllooooww walks, lots and lots of laughter.

That being said, my experience of disability and the way that I theorize it is an extremely privileged one due to my position as a white middle-class settler who is cognitively abled. Long before my brother was born, both of my parents worked in disability, my mum as a social worker and my dad as a professor, so I had two parents who understood intellectual disability, had access to the tools to "fight the system," and navigate the bureaucracy of funding and services. My family are native English-speakers, we have Canadian and British citizenship, and my parents are homeowners, which are just a few of the factors that produce my very privileged experience of disability, ableism and academia. Coming from this positionality, I recognize that I am another white person taking up space in the field, who risks reproducing #disabilitystudiestoowhite as well as being another cognitively abled scholar in the field. I strive to centre the voices of others, of intellectually disabled people and BIPOC scholars in my work and am open to the criticism and continuous learning that positioning myself as such requires.

Outline of the thesis

In the following chapters, I draw from critical disability studies, research-creation and sensory studies literature to investigate craft-based interviews as a method for understanding experiences of IDD and its place in academia. In Chapter 1, I present an overview of each of the fields that I am drawing from and contributing to. In Chapter 2, I foreground and elaborate on the methodology. Chapter 3 is a discourse analysis of the correspondence between the university ethics board and I, an interesting exploration in academic ableism. Finally, in Chapter 4 I present the findings that emerged from the craft-based interviews, evaluating the efficacy of the method.

Chapter 1: Literature Review

In this chapter I give an overview of the scholarship that my research is engaging with. I begin with a brief discussion of relevant concepts and definitions before contextualizing the rather peripheralized location of intellectual and developmental disability within critical disability studies (CDS). After introducing the concepts of “academic ableism” and “situated knowledge”, I conclude the chapter by approaching intellectual disability from the framework of research-creation, which is imperative to my research design, yet underutilized in the context of research on intellectual and developmental disabilities.

Mapping the Locations of Intellectual and Developmental Disability in Critical Disability Studies

There are many barriers to bringing the experience of intellectual and developmental disability to the academic conversation, a large one being that to engage in academic conversations one needs to be “rhetorically able” (Price, 2011). To begin with, I don’t know if my brother would identify himself as intellectually disabled. (In fact, if I asked him “how do you identify?” he’d probably say, “as a man.”) He’s not going to write an academic essay on whether he prefers person first language. I have no doubt that with the right support he could write an essay, but he’d pick a topic that is more interesting to him. In brief, my brother is unlikely to be the “rhetorically able” subject that academic disability studies and much of disability activism assumes.

Within the humanities, the field of critical disability studies has been instrumental to and applauded for bringing disabled people to the center by emphasizing the self-representation of people with disabilities (Bérubé 2010, 358). While this centering is absolutely valuable and politically important, it also has left out those whose self-representation does not take a form accepted within academia (e.g., publishable, conference-able, citable, arguable etc.). As articulative skills and rhetorical abilities of people with disabilities (whom are oftentimes physically disabled) have been foregrounded and celebrated, people with IDD were relegated to the margins of the field. As Kulick and Rydström note, the empirical material that most often gets examined in research focuses on “cultural artifacts” and representation by individuals with disabilities who are articulate

(2015, 15-16). Those who communicate outside of means accepted in academia and artistic circles, and/or lack the positionality to join these circles become indirectly excluded from being the subjects of disability activism and scholarship (Kulick and Rydström 2015). Each of these factors offer opportunities for IDD to fall through the cracks.

Due to this privileging of normative communicative abilities and self-articulation in disability scholarship, the bulk of the work constituting the foundation of the field is theorized around physical disability, where little systemic attention has been afforded to questions of cognitive disability (Bérubé 2010; Puar 2017; McKearney & Zoanni 2018; Fraser 2018). Stuart Murray refers to this as the "slippage" of disability in scholarship, whereby the general use of the term "disability" refers to physical disability (2008). Even though cognitive disabilities have been given more attention as the field has progressed, they still exist in the margins of disability studies research in specific, and the humanities research in general (Murray 2008; Bérubé 2010; Fraser 2018; McKearney & Zoanni 2018; Woodfield & Freedman 2021). It should be noted that this shortcoming refers to all cognitive disability, not just IDD[3], which as a category of cognitive disability is most often relegated to medical and policy related fields as opposed to studying the social realities, everyday embodiments and cultural representation of IDD (Fraser, xii). The systemic erasure of cognitive disabilities, specifically IDD, has led several scholars to question whether the theoretical groundwork produced in the field of critical disability studies, which is largely based on physical disability, is *actually transferrable* to work centering IDD at all (Carlson 2011; Kittay 2011; Kulick & Rydström 2015; Fraser 2018; McKearney & Zoanni 2018). Staying with this question, I will now review major theories and models within the field and discuss how they may relate (or fail to do so) to IDD.

The Social and the Medical Models of Disability

One of the most well-known models of the field is the social model of disability, which is defined in binary opposition to the medical model. Historically, terms such as "defective," "deviant," and

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[3] While IDD is often conceptualized under the umbrella of cognitive disability, I make the distinction here to emphasize the unique cultural embodiments of IDD that result from its lifelong or enduring manifestation. I argue that this differs from other cognitive disabilities that are acquired throughout the lifecourse such as dementia or brain injury.

"sick" have been used to justify discrimination against people whose bodies, minds, desires, and practices differ from the unmarked norm. This, according to the coiners of the two binary models, reflects the medical model of disability, which emphasizes individual impairment as the root cause of any disadvantages experienced (UPIAS 1976; Oliver 1984).[4] The term 'medical model' is interchangeable with the term 'individual model' because they both place disability in the impairments of the individual bodymind (Oliver, 1984).[5] The medical model assumes that there is a certain standard, rooted in eugenics, from which disabled people deviate and medical interventions should be used to rectify normality. The common framework used to diagnose intellectual and developmental disability, where developmental bell curves, genetic difference and IQ are used as criteria (Harris 2010) can be understood as the manifestations of the medical model.

Contrary to the medical model, the social model of disability rejects the notion of impairment and situates disability in the social processes and built environments that constrict an individual's ability to move through life.[6] In the UK, from where the model originated, its primary purpose was to re-orient the way that social workers should approach the needs of disabled people. But over time, the concept of the social model has become a new way of conceptualizing disability as a social phenomenon – a revelation that shifted the onus from the disabled individual to a disabling society. Crucially, it turned into a catalyst for disability activism at large. But while the concept has brought in many benefits, including key systemic policy and infrastructural change, and it certainly has been central to the emergence of disability scholarship and activism, it also has been critiqued for its exclusion of IDD and other cognitive disabilities (Bérubé 2010; Price 2011; Carlson 2011; Kittay 2011; Kulick and Rydström 2015; Fraser 2018). Joining this rank of scholars, I now lay out how the social model comes to leave out IDD in different ways.

First, the concept overgeneralizes disability, failing to account for the complexities of individual differences. By positioning the disabled body as something that can dematerialize in an ideal

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[4] Impairment defined as: "Any loss or abnormality of psychological, physiological, or anatomical structure or function (WHO cit. In Shaw 1996)

[5] Disability studies scholar Margaret Price proposes the term "bodymind" to address academic rhetoric that overly emphasizes the physical body and underemphasizes the mind (2015). While the two are often conceptualized as separate entities, bodymind signifies the ways that the body and mind influence and entangle one another (Price 2015).

[6] Mike Oliver officially coined the social model in 1983 to articulate the ways that individuals are oppressed by the disabling barriers in society rather than their individual impairments (Oliver 1983). The concept sparked debate and has been discoursed, debated, and critiqued at length (Oliver 2013; Shakespeare 2017).

environment, the social model erases the heterogenous embodiments of impairment, some of which might persist in accessible environments (Garland-Thompson 2011; Kafer 2013; McRuer 2016). As many scholars have noted, as a biological function, cognitive impairment will not altogether dematerialize in the ideal social conditions, unminding the social model's ethos that disability is a social construction (Bérubé 2010; McKearney & Zoanni 2018). While many of the socio-political barriers related to cognitive impairment can dematerialize to a degree with proper funding and vast changes in social attitudes/understandings of disability (for example social isolation), cognitive impairment cannot be viewed entirely as a social construction.

Second by emphasizing the social creation of disability, the social model undermines the material realities of impairment, some of which involve pain and other unpleasant experiences such as brain fog and co-morbid health issues that people with IDD might live with daily (Crow 1996; Goodley 2001; Price 2015). In fact, all impairment—including physical (see Crow 1996) —has been systemically neglected in the social model of disability (Fraser 2018, 5). Due to this emphasis on disability as related to physical and social barriers, the followers of the social model have inadvertently homogenized disability through the prioritization of the physical body (Fraser 2018, 37).

Third, the social model, alongside rights-based discourses, excludes IDD through its overemphasis on autonomy and independence as the ultimate ideal. This is highly impractical for those who, like my brother, will always need daily assistance. As Eve Feder Kittay argues, we ought to acknowledge our lived interdependence, whereby what it is to be human is to undergo fluctuations in our dependency throughout our life (2011). Considered this way, dependency is revealed as an integral feature of human experience, including the very experiences of disability, and importantly IDD.

Political-Relational Model of Disability

Of course, much has happened since the invention of the social model and the field of CDS has taken many turns and new directions. Earlier limited models have been replaced by intersectional, disability justice frameworks and more nuanced conceptualizations of disability as an evertransforming category, fluid identity, and multiplicity of embodiments. However, despite these developments, IDD still exists within the margins of the field. Some scholars attribute the marginality to the continued emphasis on physical disability (Shildrick 2009; Goodley 2013; Fraser 2018). For example, in her critique of the term "body" to theorize about disability in general, Margaret Price proposes the term "bodymind" to assert that "mental disability matters, that it is an important category of analysis" (2015, 2). Similarly, Allison Kafer highlights the avoidance of cognitive impairment by the wider field and utilizes the phrase "able-bodiedness/able-mindedness" throughout her book *Feminist, Queer, Crip* (2013 15, 20). Further, Kafer proposes a political-relational model of disability (P-R model), where disability is *political* because it rejects the validity of predefined categories and *relational* because it is embedded in social processes and cultures (2013). While both the social and medical model are critiqued for assuming that "disabled" and "nondisabled" are closed and self-evident categories, a political understanding of disability instead explores the creation and entanglement of such categories (10).

Unlike the social model, which fails to capture the complexity of IDD and the entanglement of impairment, social positioning and relationality, the P-R model can be applied to IDD in a way that recognizes the fluid experiences of disability in relation to one's positionality while also accounting for the material reality of impairment within the construction. While this is a model that I have used to shape my understanding of disability, I still question whether it can fully be applied to IDD, because it hardly addresses the alternative ways of knowing that emerge with IDD, and how the knowledge base of IDD complicates what is known as the field of disability studies.

Problematizations of Ableism and Intersectional Approaches

In recent work, scholars have turned their attention from the disabled to the abled body, problematizing the unmarked bodymind of ableism instead. Among those are, Fiona Kumari Campbell who identifies the collective consciousness of ablebodiedness as the *abled imaginary* where an "unacknowledged imagined shared community of able-bodied/minded people [is] held together by a common ableist homosocial world view that asserts the preferability and compulsoriness of the norms of ableism" (2009, 4). While ableism is difficult to define, it broadly refers to the corporeal standard of bodyminds that equates ablebodiedness to normalcy (Campbell

2001; 2009; Leigh & Brown 2020). Said otherwise, the cultural contract that prescribes normativity is bound by an ethos of ableism. Similarly, Robert McGruer's theory of compulsory ablebodiedness examines how unmarked heterosexual and ablebodied identities intertwine to produce an insidious construction of normativity (2006).[7] In questioning how disability is constructed in tandem with the construction of what is "normal," such approaches have the potential to make room for the knowledges and ways of being that emerge with IDD.

Other scholars took these arguments further by amplifying the emphasis of the intersectional aspects of disability, and by bringing a much-needed emphasis on the deliberate production of impairment by structural inequalities and violence, particularly in the Global South. Using disability to justify the policing and marginalization of certain bodyminds is discussed at length by Nirmala Erevelles in an interdisciplinary framework of historical materialism and transnational capitalism (2011). Erevelles places disability as the enduring central sphere of oppression utilized to negotiate and reproduce social difference among intersections of race, gender, class, and sexuality (20). The production of marginalization situates categories of difference in a "dialectical relationship to the economic/social relations produced within the historical context of transnational capitalism" (6).[8] Disability relates not just to the identity politics that interact to produce difference but to how identity emerges through the material complexities of power structures and individual experience. In a similar vein, Jasbir Puar posits a powerful intersectional critique of "the normative (white, male, middleclass, physically impaired) subjects that have historically dominated the field" of disability studies (2017, xix). Asserting the limits of neoliberalist, eurocentric disability studies, Puar instead identifies disability as assemblages of capacity and debility "modulated across historical time, geopolitical space, institutional mandates and discursive regimes" (p.xiv).

By drawing attention to impairment as well as highlighting the sociopolitical forces that have and continue to exist across different geospatial realities, an intersectional framework of disability has potential to accommodate the questions of IDD that previous theories of disability have neglected.

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[7] This manifests in examples such as the fact that the World Health Organization listed gender identity disorder as a mental disorder until 2018.

[8] Highlighting the role of transnational capitalism invites a deeper discussion of how capitalist "productivity" is deeply intertwined with disability, class and eugenics but is out of the scope of this thesis.

[9] In their effort to decolonize disability studies (and not only trying to "expand it,"), the intersectional frameworks proposed by Erevelles and Puar can prove fruitful for questions of IDD, particularly because they attune to the complexities of identity. Instead of retrofitting IDD into theories of disability built upon a eurocentric and neoliberal framework, an intersectional framework can account for the subject for which an identity within a category of disability or ability is not conducive nor relevant to their reality (for example, due to cognitive impairment, social or geospatial location). Because "the conditions that make disability… are already ones of entrenched economic, racial, political, and social disenfranchisement," (Puar 2017, 16) focusing on structural violence and inequalities allows for a conceptualization of IDD that doesn't separate IDD from other categories of difference.

The Issue of Language

The enduring relationship between language, communication and personhood precedes the further exclusion of IDD from the canon of disability scholarship. Language is the dominant medium of communication and while it is not the only way that we communicate, capacity for linguistic expression is a key marker in determining citizenship and personhood, and without it, one's capacity is perceived as diminished (Baggs 2005; Price 2011; Dolmage 2017; Carlson 2021; Woodfield & Freedman 2021, 177). According to the logic of ableism, if one lacks the ability to be received as a valid communicator, one loses their agency (Price 2015; Woodfield & Freedman 2021). An inability to communicate is often equated to the inability to think (Woodfield & Freedman 2021, 177). Taking this further, as Puar argues, language as communication has been reduced to the realm of human capacity for thought and cognition, when in actuality language exists as multiple domains, extending to many forms of communication within and across species (2017, 26). By interrogating the place of language as a political platform, we can interrogate, as

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[9] Specifically, by interrogating the material realities of cognitive impairment within an assemblage of sociopolitical difference changes "the way we interrogate disability as a site of questions: first, because it arguably changes how we approach the definition, limitations, and potential benefits of inclusion in neoliberal frameworks; and second, because it problematizes existing pathways to intersectional coalition building in both the academic and political realms" (Fraser 2018, 7). This echoes the ethos promoted by Licia Carlson (2011), which claims paying attention to the specificities of intellectual disability not only entangles current conceptualizations of disability, but also challenges the broader discourse about the role and purpose of academia as an institution.

Puar suggests, what language *is* in order to destabilize privileged modes of communication and representation (27).

The privileging of normative communicative capacities has, no matter how inadvertently, been reproduced in disability studies. As elaborated by some activists and scholars, there is a significant lack of consideration of people less rhetorically abled in disability studies (Bérubé 2010; Kulick and Rydström 2015; McKearney & Zoanni 2018). But, as beautifully articulated and strongly asserted by Mel Baggs as a non-verbal autistic man in their 2005 Youtube video "In My Language," language and communication can be *many* things, and take so many other forms than what first comes to mind. As Ginsburg puts it, Baggs video is an example of user-centred digital media that "enable[s] people with disabilities to engage in a first-person discussion of their world and experiences" (2012, 102) in their own language. Artistic work such as *In My Language,* as McKearney & Zoanni also write, exemplify alternative forms of cognition and perception, not only as a platform to express their own embodied experiences, but to challenge core ontological beliefs of how we proliferate knowledge in the world (2018, 10).

I now move on to further exploring the entanglement of knowledge, disability, and rhetorical ability in the place where that entanglement happens most explicitly, and where legitimized forms of knowledge are created (in the white, western, colonial context). That is, the academy.

Academic Ableism

Recently, one of my friends told me that her undergraduate degree dragged on much longer than expected because she was transferred out of her media studies program into an interdisciplinary degree at the end of her third year. This was the 'accommodation' that she was offered for not being able to pass the single compulsory computer science course that the program required. She tried to pass the course twice, but because she has a learning disability that impedes her ability to recognize patterns, it was unrealistic for her to complete the course in the timeframe of an academic semester. Ironically, I am currently an MA student in media studies and have never stepped foot in a coding classroom.

Academic ableism is a term used to convey how "academia powerfully mandates able-bodiedness and able-mindedness" (Dolmage 2017, 7). In his book on the term, Jay Dolmage articulates how disability is constructed as the inverse of higher education due to the compulsory able-bodiedness and able-mindedness that is embedded into the structural processes and environment of academia (3). The inflexibility that my friend was met with in terms of the computer science course is an example of how academic ableism operates. The message reads: if you can't do the work on the terms of academe, then you do not belong in the academe. As Tobin Siebers frames it, ableism in academia maintains the question of who should and shouldn't be in school, from who should be taught, who should teach, and, as my research demonstrates, who is researchable (2011, xxii).

As Dolmage, Price and others trace, practices of exclusion are a pillar of the higher education system that privileges not just intellectual ability but "higher" intellectual ability. Exclusion can be explicit and easily identifiable, such as when disabled or so-called difficult students are segregated to separate spaces or transferred to different programs. But there are cases in which exclusion can be less apparent, emerging through the accumulation of implicit barriers and scenarios that reproduce compulsory able-bodymindness. Instances of such cases can be found in what Margaret Prices calls *kairotic space*, by which she names "the less formal, often unnoticed, areas of academe where knowledge is produced and power is exchanged" (2011, 60). Some examples are the impromptu discussions prompted by a Q and A period, the departmental lunch, and the Zoom breakout room. Kairotic space highlights implicit ways that "compulsory able-bodiedness" (McGruer 2016) and able-mindedness are reinforced. Kairotic spaces reinforce an abled imaginary that dictates who can and who cannot be part of academia. Mobilizing the concept of kairotic space is useful to understand the ways that IDD is marginalized not only in the formal structures of the academy, but also in the social processes that often go unnoticed.

Returning to the relationship between language and communication, literacy is a main factor in the exclusion of IDD in the academy, as it is the foundation of how knowledge is exchanged in academia. Scholar such as Dolmage and Price argue that the exclusion of those less rhetorically abled within academia perpetuates a form of structural ableism in the academia (Price 2015; Dolmage 2017). Referencing Judith Butler, Tanya Titchkosky theorizes disability in academia as a *justifiable absence,* where the barriers that keep disability salient are not recognized as barriers so much as outside of the imagined possible (2011, 78-80). In other words, disability is abject to the *abled imaginary* of higher education, prescribed and maintained through the conditions of academic ableism. As literacy is a fundamental pathway to access (including but not limited to entrance criteria) and engage (via scholarly discourse) in academia, it is not surprising that IDD is perceived as a "justifiable absence" (Titchkosky, 2011) within not only the institutions of higher education but also disability studies.

What is important to highlight is that while concepts such as kairotic spaces or academic ableism are extremely powerful, they again are generated by and for those who are already in a position of academe. In disability theory, those who are conceptualizing such issues of access and exclusion are those who are already part of the academy, who have a level of rhetorical ability to arrive on academia's doorstep, recognize and theorize the ableism occurring. Less discussed are the questions of access as related to the cognitive disabilities that impede one from even entering these conversations within academia, the disabilities that impact literacy and verbal communication (Fraser 2018; Carlson 2021). And it is these issues of access that my research grapples with on a foundational level, leading me to ask: how do we develop methods and practices that centre the embodiments, communication modes and lived realities of people with IDD?

To reiterate, methodology for studying cognitive disability is lacking in the humanities in general (Fraser 2018, 5), and in CDS in particular. As Kathleen Sitter and Alison Grittner note, most research privileges speaking and writing methods in understanding lived experiences which inherently creates participation barriers for many disabled people who lack rhetorical ability (2021). Because of this, research about IDD is most often relegated to medical disciplines whereby the inclusion of IDD is limited to passive participation, stripping the dimension of embodiment in the research process (Goeke & Kubanski 2012). While many scholars have explored the "problematic" of disability, where the "severely cognitively disabled" subject is used as a disembodied tool for philosophical reasoning, the first-person embodied perspectives of IDD are excluded because we have yet to explore sufficient methodology to complete this research (Carlson 2011, 12; Fraser 2018; Carlson 2021, 74).

Situated Knowledge

The Feminist Science and Technology Studies framework of *situated knowledges,* coined by Donna Haraway, addresses the way that some people are more privileged ("better situated") to produce knowledge than others (1988). Knowledge is deeply intertwined with the structures of domination, oppression, and privilege that exist within our social relations and identities. As such there is no objective knowledge, rather all knowledge is, in Haraway's wording, "only partial" (583), reflecting the social organization of the conditions in which it has been produced. Allowing us to bring situated knowledges in an intersectional context, Patricia Hill Collins highlights the necessity of cultivating new knowledge based on the embodied experience of oppressed people (1990, 221). As opposed to translating Afrocentric feminist epistemology into a Eurocentric masculinist framework of objective knowledges, Collins highlights that situated knowledge as embodied experience is no less rigorous than abstract thought but much more accountable to the community from which it stems (1990).

In the context of my own research situated knowledge means recognizing not only the limitations of my singular perspective, but also interrogating the methodological tools that I use to gather knowledge and the impact that this has on my findings. The absence of embodied and agency-centered research specifically by and with people with intellectual disabilities is a key example of a knowledge base that is limitedly and able-mindedly situated. Speculatively, this is due in part to the social locations of disability as well as the foundational design of traditional research, within institution settings that maintain current structures of power.[10] Interlocking a Black feminist perspective with Haraway and bringing that into disability studies, it can be argued that an embodied knowledge base of IDD has been poorly subjugated by a dominant culture of ableism. Research that relies on speaking and writing, as Sitter and Grittner note, creates barriers to accessing the knowledge base of intellectual disability (2021). The need emerges to identify research methods that acknowledge the limitation of lingual knowledge.

I now turn the field of research-creation, which, I argue, has the potential to offer pertinent insight into research-methods that harness knowledge outside of the logocentric realm of research.

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[10] Research is a discursive device that reflects institutional power relations, this impacts the content of knowledge produced as discussed by Haraway (1988). Research also maintains some knowledge as subjugated, which maintains the specific flow of power (Foucault 1980; Bacci 2018).

Research-creation

Speech is taken as a sign of rationality in Western culture, and as such it is also taken as a direct indicator of the speaker's mental capacities (Howes & Classen 2014, 68). This privileging of spoken language echoes the integral role of language in clarifying one's citizenship and personhood as discussed by Price (2011) and Dolmage (2017) and other disability studies scholars. But meaning-making, communication and knowledge creation, as disabled artists such as Judith Scott and Mel Baggs manifest, occurs through many forms. The absence of multi-sensory and non-linguistic means of knowledge creation in academia is a manifestation of the hierarchy of senses, where hearing and speech have a strong association with intellect, due to their heavy hand in communication (Howes & Classen 2014, 1-4). And this is one of the barriers that I, through my use of research-creation, seek to address in this thesis: the absence of knowledge considered valid that falls outside of traditional scholarly realms.

The Social Sciences and Humanities Research Council of Canada (SSHRC) defines research-creation as "an approach to research that combines creative and academic research practices and supports the development of knowledge and innovation through artistic expression, scholarly investigation, and experimentation" (SSHRC 2012). But as research-creation increasingly establishes itself in Canadian graduate programs, conversations have shifted from what research-creation *is* to what research-creation *does* to our understanding of scholarship and knowledge (Manning 2016: Leavy 2017; Loveless 2019; Loveless 2020). For example, in their seminal article Chapman & Sawchuk argue that "the possibilities provided by the various artistic media that can be deployed for (2012, 14). This is echoed by Patricia Leavy, who discusses the ways of knowing in arts-based research as evoking critical conversations about social scientific knowledge (2017, 11). Erin Manning also emphasizes the "extra-linguistic" forms of knowledge that are generated from research-creation as a method that untangles questions which cannot be answered through normative modes of inquiry (2016, 133). Expanding research-creation into queer theory, Natalie Loveless explores the borders of research and passion as a practice of polydisciplinamory, where research-creation allows for a collaboration of multiple disciplines, methodological toolkits and frameworks of knowledge to open up the playing field of disciplinary knowledge production to its polymorphous potential (2019, 70).

Each of these scholars articulate a way that research-creation reckons with ontological questions of knowledge, research and power. In this thesis, I extend this literature on research-creation by putting it in the context of IDD. In so doing, I explore not just how IDD complicates the epistemology of contemporary disability studies but also what methods we can develop in order to challenge how the field theorizes disability. I argue that the experimental ethos and openness to emergent knowledge that research-creation affords can be aligned with the goal of exploring the limits of traditional humanities research (those that hinge on verbal/written methods of communication) in the context of disability.

That being said, it should be noted that research-creation is not immune to ableist undertones. Even when there are different mediums of communication involved in the creation, linguistic ability and/ or an appearance of ablemindedness is often necessary to be considered valid in these mediums.[11] As Tobin Siebers notes in *Disability Aesthetics*, to be taken seriously as an artist – or a research-creator, we may add– one needs to be able to explain the work (2010, 19). This is substantiated by the work of Judith Scott, who even in the artist book on her life was met with the condescending question: "Is it plausible to imagine an artist of stature emerging in the context of massively impaired intellectual development?" (MacGregor, 1999). In the absence of a possibility that people with IDD can be articulate artists in their own right, creative practices are often positioned as therapeutic activities for IDD participants, who are seen as lacking the rationality necessary to be creative (Siebers 2010, 19).[12]

There is some recent work to suggest an emergent and thriving relationship between disability and research-creation in Canada. However, the work that centres intellectual and developmental disabilities with this emerging body of work is considerably small. One example is 2021 special

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[11] Of course, there are exceptions such as the mad artist or the savant, even still these exist as one-dimensional characters

[12] I experienced this countless times informally over the course of this thesis. When explaining the premise of my craft-based interviews, people would often respond along the lines of "oh cool is that like art therapy?" or "I have a friend who taught special needs art." The first association is not position disabled participants as artists but as 'receivers' of therapy or training.

issue of the Canadian Journal of Disability Studies (CJDS) titled *Challenging Ableism and Audism Through the Arts*, based on the Vibe symposium hosted at Concordia. Of the three references to IDD included in the issue, is a presentation of a script by Michael Nimbley, that he co-created with his "creative ally," (Nimbley & Bourgeois 2021, 316) Catherine Bourgeois, during his artist residency with the Montreal theatre group Joe Jack & John.[13] Another article in the issue highlights the need for the disability art world to be more accessible to people with intellectual and developmental disabilities, corroborating that there is still a large gap in research-creation that centres IDD, yet there is no dedicated course of action (Bridger, Erlikh and Yi 2021, 18). In a different issue of CJDS, Lindsay Eales connects research-creation and Maddness in the performative autoethnography "Loose Leaf" (2016). The series bends rhetorical normativity to engage with embodied experiences of Maddness through Mad performance, offering a strong example of mental disability and research-creation emerging in disability studies literature (58). But there has yet to be a substantial exploration of work at the intersection of research-creation and IDD, which is precisely what my research seeks to address.

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[13] As explained in the article, the goal of these residencies is to experiment with interdependent creative models and practices that promote the emergence of artists with intellectual disabilities into the Montreal theater scene (Nimbley & Bourgeois 2021, 316)

Ch 2. Methodology

In this research, I employ research-creation, but I employ it in a specific way that merges the interview process with the co-creation of textiles to help horizontalize power dynamics (between the researcher and the interviewee) and unsettle the privileging of the spoken language in research with people with IDD. I name this particular mobilization of research-creation as "craft-based interviews", by which, I mean the weaving of interviewing and textile-based creating in process-based research. I introduce craft-based interviews as a novel method to critical disability studies, research-creation and communication studies in ways that can counter and resist intellectual ableism. In the following, I explain how I developed this new research method by tracing its steps from its beginning to the end.

Craft-based interviews

Seeking to entangle the interview process and research-creation, I combined semi-structured interviews with textile creation, a medium I work frequently with, into a series of craft-based interviews. I began the process by asking the following question:

1. How do traditional interview methods assume an unmarked, normative subject?

2. How can research-creation intervene in these traditions and provide alternative paths that are conducive to various embodiments of intellectual and developmental disability?

3. How can craft-based interviews transform and subvert the traditional interview process where the objective often times to is to learn about experiences of disability?

In an attempt to seek answer to these questions, I then took my cue from what Arseli Dokumaci calls "disability as method" (2018). Disability as method highlights the creative knowledge that emerges from embodiments of disability while also critically examining the naturalized hierarchies of our built environment (2018). Disability as method meant that my thesis methodology shall bend to match my participants (including their situated knowledges and access needs), not the other way around (2018). Thus, while I designed an initial structure for the craft-based interviews with my own embodied experience of disability in mind, everything was flexible enough to be refined alongside each recruited participant and their experiences of disability.

As mentioned, the design of craft-based interviews was based on the combination of a semi-structured interview format with the act of creating and sewing together with each participant. This combination began as, what Chapman and Sawchuk call, “research-from-creation” (2012) because the act of creating enabled an understanding of how textiles might epistemologically impact research about the embodied experiences of disability, as well as redefine the structures of power embedded in the interview process. This again aligns with a “goal of understanding different dynamics” and the development of new methods of knowledge production that Chapman and Sawchuk identify as integral to “research-from creation” (2012, 15-18). My research then flowed into “creation as research,” where research is “more or less the end goal in this instance, although the “results” produced also include the creative production that is entailed, as both a tracing-out and culminating expression of the research process.” (19).

Craft-based interviews are situated in conjunction with the canon of participatory action research (PAR), where participants are not passive subjects, but active collaborators involved throughout the research process (Whyte 1991, 19-20). This joint process of knowledge-production leads to increased insights and empowerment of all parties and enables the active engagement of marginalized people within the research process (Bergold & Thomas 2012, Kramer-Roy 2015, 1207). In the context of intellectual disability, there is a notable lack of research in both participatory research and research-creation, as most is conducted as research about the people in question and their problems, rather than with these people (See Goeke & Kubanski 2012; Bergold & Thomas 2012, 20). In the conceptualization of craft-based interviews, I draw from Patricia Leavy’s concept of the A/R/Tographical, integrating the role of Artist, Researcher, and Teacher into an interview space that merges knowing, making and doing (Leavy 2015, 4). In both of the craft-based interviews I conducted, participants were in control of their own creations, schedules and textile methods and I made it clear that we were collaborators on this project.

Why Textiles?

I employ textiles as the main method of creation because they are a medium that I have been working with for a few years. They are appropriate for this interview style because they can accommodate a range of skill levels and offer many avenues of engagement. The communicative power of textiles, both historically and sociologically, has been discussed at length by Sonja Andrews, highlighting that textiles have an enduring relationship to meaning-making (2008). Textiles engage multiple senses, often carry semantic meaning, and can be easily manipulated in a variety of ways. I utilize textile collage[14] because it offers a structure that is accessible, flexible to a variety of skill levels and appropriate for length of the interviews. Kathleen Vaughan employs textile collage as a methodology of experimental orientation due to the ability that the interplay of materials has to create connections that form the basis of discussion and learning (2005, 40). Textiles can bring a positive impact to research by "unlocking" memories from tactical or associative experiences as shown by the textile mapping research-creation work of Elise Olmedo, who explores the sensory and emotional contexts of space among working-class women in Marrakech (2018, 266).

Despite successful textile-driven research-creation, however, there has been little to no attention to textiles at the intersection of intellectual disability and research-creation, and this lack is exactly what I aim to address with my conceptualization of craft-based interviews.

Recruitment

I advertised for potential participants by using a small online flyer distributed over email to several English-speaking disability organizations in Montreal. It was also distributed by email to the Concordia's Access in the Making Lab Core Members, who passed it on to their networks. Three individuals expressed interest in participating, of those three participants, two completed the interview series; one was unable to participate due to logistical issues.

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[14] Textile collage is an open ended term that refers to the bringing together of multiple textile and fibre elements into a single piece of work

Structure

The craft-based interviews were predicated by one initial meeting of 1.5 hours, before a total of 4 hours of creating/ interviewing divided into a series of sessions that suited the participant. For Ariel, this was two, two-hour sessions and for Armen this was one, four-hour session. Each participant was invited to attend a final session of 1.5 hours on June 6th to collaboratively analyze the final textile collages however, Armen was unable to attend. All interviews were approved by the ethics board to take place either at my supervisor Dr. Dokumaci's Office in the Communication and Journalism Building at Loyola Concordia University Campus or at the Textile and Material Cluster in the EV building at Concordia Downtown Campus.

In an initial meeting with each participant, I first conducted a one-on-one semi-structured interview to get to know the participant and plan the following craft-based sessions. I first provided a general explanation of the research, asked each participant to tell me about themselves, and answered any questions they had. This was supplemented by the introduction of various textile materials, which participants were invited to use. All participants were shown the same material and asked about their preferences for the actual textile collage. The two initial meetings took place between February and April 2022. Then we moved onto the craft-based interview process.

The main object of the craft-based interviews was to have the participant make a textile collage that functions as a textile self-portrait in some way. All participants had access to the same equipment to create their textile collage (sewing machine, embroidery hoop, needle and thread, fabric glue and the use of a Brother embroidery machine). But the materials differed based on participant preference from the initial interview that predicated the craft-based sessions (see fig. 3). For example, Ariel requested black fabric, so I made sure that his kit featured a variety of black fabric whereas Armen preferred natural fibres, so I made sure those were included. I kept the initial outline of the craft portion very stark because I wanted to collaborate with each participant and ensure that their access needs and artistic preferences were met. In the process, I followed tips from Price's ethnographic interviews with mentally disabled scholars to refine a methodology that is developed in collaboration with participants (2011, 210). I thought of the interviews as spaces of negotiations and improvisations led by each participant.

Conducting my research in a way that was conducive to disability required many ethics amendments, and I was met with an unexpectedly long ethics approval process. I decided to include this process a factor of analysis because it exposed “the habitus of ableism” (Dokumaci 2018) embedded within academia. I began archiving all of the back-and-forth emails with the ethics board as well as the personal communication between my supervisor and I on the issue.

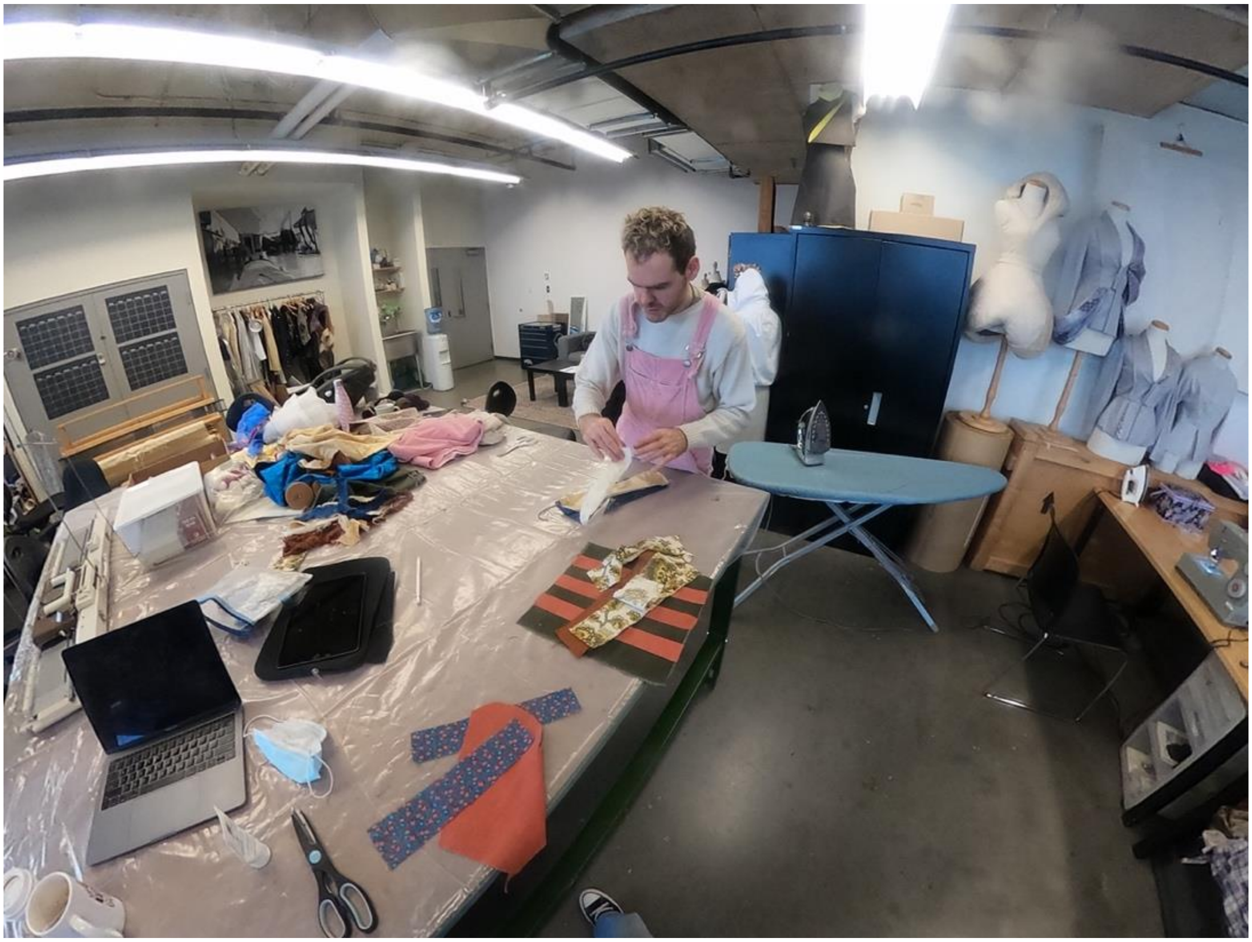

Figure 3. A fisheye lens photo of the craft-based interview table. On the corner of the table there is an array of different coloured fabric. An ironing board behind him, Armen stands at the center of the table working on his collage. A green and pink stripped square of the collage and various other strips of fabric are strewn in the forefront. Photo by the researcher.

Chapter 3. Ethics: A Saga

This research was initially designed to be completed at the Concordia University Loyola campus, however the location ended up being more inaccessible to participants than I anticipated. This resulted in multiple ethics amendments. While Loyola was a suitable location for Ariel because it is easily accessible by car and his mum was driving him, Armen preferred the downtown campus because he was familiar with the location and, compared to Loyola, it is much easily accessed by the metro, which he rides independently. [15] Thus, I submitted an amendment request to add the Textile and Materiality Cluster Space in the E.V building at the downtown Concordia campus on February 10th, 2022 and received approval on February 14th.

I recruited a third participant, but we were unable to complete the research in a way that fit the participant's access needs and obtained ethics approval. Neither Concordia campus locations were suitable, and after emailing and zooming with the participant and their mum, we determined that completing the craft-based sessions at the participants home was the best option. I informed the third participant that I would first have to obtain approval from the university to change the location. Given the ease and efficiency of my last ethics amendment (3 days), I did not think that this would be an issue.

As the correspondence between myself and the ethics board progressed, I realized that gaining approval to do research at the participants home was much more difficult and took much longer than I anticipated. At first, I assumed that this was due to my learning curve and errors as first-time researcher. It became increasingly clear that the difficulty I was encountering was in part the result of ableism. After 14 emails exchanged between myself and the ethics board, during which I had to follow up twice, submit two additional amendment requests and also justify my request for an additional review of the initial amendment request on two separate occasions, the University Human Research Ethics Committee (UHREC) denied my final amendment request on May 16th, 2022. I was not able to honor the request of my third participant to carry this research at his home, which was the location that was most accessible to him as an intellectually disabled person. I shall

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[15] Located in the suburbs, the Loyola campus requires transferring from the Metro to bus.

note that I received interest from additional potential participants that I could have moved forward with. However, I did not think that a logistics issue such as location justified excluding the third participant. I felt that if I excluded a participant based on the inability to come to campus, I would be reenforcing and legitimizing the barrier to come to campus, which has, as documented by Dolmage (2017) and others (Price 2011), historically excluded disabled people from accessing higher education.

Upon much frustration, and disappointment, both on mine and the participant's side, I have decided, in consultation with my supervisor, to problematize this denial by UHREC and turn it into a research problem in and of itself.[16] The questions that I ask in this chapter are as follows: How do university ethics boards deal with research in the humanities involving intellectually and developmentally disabled (IDD) participants? Which abilities are presumed within the construction of an appropriate research participant? And how do these assumptions impact which bodyminds are included in research and which ones are not?

To better understand how intellectual and developmentally disabled participants are treated as not "proper" research participants, I will conduct a discourse analysis of the amendment request that I pursued between March 15th and May 16th with countless exchanges between myself, the ethics board and my supervisor. In so doing, I seek to shed light on ableist bias in academic ethics procedures and provide insight into the specific needs and accommodations that are better suited to people with IDD in research settings. Insofar as the underlying principles of ethics boards are to ensure equitable treatment and avoid malpractice, we as researchers ought to be aware of how different procedures are better suited to different participants. We need to ask ourselves, as I also do in the following chapter, at what point does the prevention of risks become ableist and infantilizing?

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[16] The correspondence analyzed in this chapter occurred through my official Concordia email address, which as stated in Concordia's *Policy on Email Management*, are not private and can be accessed and made public. Furthermore, there was no privacy disclaimer included in the emails that I received from UHREC. Based on these grounds, I believe that the chain of correspondences in this discourse analysis constitute as publicly accessible materials.

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Initial Correspondence

Since one participant was only able to meet me at his home, on March 15th, 2022, I submitted an amendment request to the ethics board to include “at Participants' home (upon request)” to the approved locations for the craft-based interviews. After not hearing anything from the board for 20 days, and in the meantime, having to assure my participant who was getting antsy about meeting, I followed up on my request and was assured that it was still with the reviewer, and that they were experiencing a high volume of requests. Given both the concern of my participant, and the increasing pressure of the deadline (August) by which I had to submit my completed thesis, my supervisor followed up on April 5th to inquire about the delay. A day after, we received a response from the ethics board. Included in it was a variety of justifications for the denial that I found suspiciously contradictory, underestimating the agency of disabled people while overestimating their vulnerability and helplessness. The response read:

> The assessment provided is based on the expertise of a reviewer who works extensively with this kind of population.
>
> The concern about going to the participants’ homes to do the interview has to do with ‘boundaries’ (rapport between researcher and participant) and the fact that it would put the participant in a ‘more’ difficult position to discontinue/withdraw from the study should they wish to do so (after the researcher goes to the ‘trouble’ of going to their home to do the interview). It is not necessary for this study- interviewing can take place on Zoom or by telephone. There are also additional safety issues with COVID – and is the researcher ‘qualified’ to attend to any behavioral issues that may come up with a change in routine or someone else’s presence in the home (i.e., aggressive behavior? Inappropriate behavior?). While very unlikely to happen, these are issues reported sometimes by social workers and so on. Also, the only individuals who ever ‘visit’ the participants homes are usually social workers/community nurses who support and provide reports on their well-being and advocate for their needs and this might create a situation where the participant perceives that the researcher can do more for them even though they are reminded that it is a study that they are participating in and that they can discontinue from – should they wish to do so.

My amendment request had been denied, citing that it was not necessary to go to the participants home for this research as the craft-based interviews could be completed on Zoom. We had no option but to try the zoom option that was endorsed by the ethics board and I had to submit yet another an amendment request in order to be able to do so.

Since ableism can literally be hidden between the lines, I would now like to examine the UHREC's response in closer detail. Beginning with the opening justification, I want to explore what the board might mean when they say that their response is based on an expert with "this kind of population".

First, the use of the vague signifier "this kind of population" to refer to potential participants homogenizes intellectual and developmental disability, assuming that it is a self-evident category – a presumption unanimously critiqued by many disability studies scholars (Erevelles 2012; Kafer 2013; Martino & Schormans 2018). This signifier is used by the UHREC to justify their responses, grounded in the assumption "these types of people" require extraordinary treatment based on the "nature" of their disability. This bias can be read as a clear example of disablism, which is defined as "a set of assumptions (conscious or unconscious) and practices that promote the differential or unequal treatment of people because of actual or presumed disabilities" (Campbell 2009, 4). Treating IDD as a single or self-evident characteristic echoes reductive understandings of disability and goes against the foundations of the field of critical disability studies which considers disability as a set of fluid and heterogenous experiences, embodiments and identities.

Researchers in the social sciences have written about similar experiences with obtaining approval for ethics boards, where the evaluation process is impeded by outdated or medicalized understandings of disability (Mietola et al 2017; Martino & Schormans 2018). Furthermore, accounting for the situated and embodied knowledges that inform our experiences of IDD can be difficult to convey because, as Reetta Mietola, Sonja Miettinen & Simo Vehmas, so aptly put: "these ethical debates are often informed by personal experience, anecdotal evidence, or by mere gut feelings" (2017, 264). From my personal experience, I feel that I have built considerable relationships with intellectually disabled people, which have motivated me to do this research in the first place so that I, together with people with IDD, can look for ways to foreground their ability to assert agency. But how do you tell this to an institutional body which does not account for the interpersonal, and often unmeasurable, knowledge of disability that emerges from lived experience? Can an ethics board responsibly evaluate humanities-based research on IDD while adhering to a different construction of disability altogether? And who is responsible for initiating university ethics boards into disability politics, and educate them about alternative understandings of IDD?

With this in mind, I turn to the first concern that the UHREC expresses about ‘boundaries.’ The concern here is that a participant may feel uncomfortable voicing their wish to withdraw if the researcher is at their home. But one can ask: How can being interviewed at home “put the participant in a ‘more’ difficult position to discontinue/withdraw from the study” than when they are to be interviewed at the university campus? From an able-bodied person’s perspective perhaps travelling to a novel environment is not considered to be a burdensome factor. But from a disabled person’s perspective, being interviewed at home can eliminate any unnecessary and potential arduous or inaccessible transit to and from the campus. In fact, during the times of COVID pandemic, many disabled people voiced their concerns about going to campus (Hamraie & Acton, 2022).

Further, if one cannot travel independently, which was the case with my third participant, then doing the interview at home eliminates the logistical coordination of planning a ride. It also mitigates the risk of getting ‘stuck’ at campus in the case that the participant wished to withdraw but had to wait on a ride. Again, being at home eliminates the need to be in an entirely novel environment, which in the case of an IDD, where individuals often thrive on routine or may have specific sensory impairments, could add additional stressors. Given all these considerations, all of which I have conveyed to UHREC in my responses to their conditions, why is the participants’ request not taken into consideration in the decision by the ethics board? If one explicitly asks to be interviewed at home, why is it assumed that this would put them in a more difficult situation to discontinue than if they were obliged to travel to campus?

The UHREC is concerned about the impact of boundaries “after the researcher goes to the ‘trouble’ of going to their home to do the interview.” I question what is meant by the word trouble here, and why does their trouble to get to campus not have the same impact on their decision to withdraw? Undeniably, there are at very least equally variable factors for potential discomfort in both scenarios, given the precarity of public transit in Montreal and the fact that many people with IDD don’t travel independently. Additionally, why should the presumed ‘trouble’ attributed to me by the committee in having to relocate the interview to their home impact the participant’s decision? As a matter of fact, as a researcher, I do not feel like I am being troubled, but rather, I experience the inverse sentiment: I am thankful for their willingness to participate in my research and would prefer that they be as little inconvenienced as possible. And if this would mean that I should be troubled to go to them, then I would happily do so. Why is my wish to respect a participant’s request, and eliminate participant inconvenience because they are doing me a favor being disregarded as a possibility by UHREC?

Moving on in the response, the UHREC’s next concern is about behavior, illustrated by their question: is “the researcher ‘qualified’ to attend to any behavioral issues that may come up with a change in routine or someone else’s presence in the home (i.e., aggressive behavior? Inappropriate behavior?).” As a young femme researcher there is always a risk going into a participant’s home whether the research involves a disabled participant or not. Would the committee express the same concerns about an able minded participant? I ask you, the reader, what is the likelihood that my presence in your home after we had discussed and arranged an interview, would cause you to act in such a way described by UHREC? The stereotype here is that people with IDD are much more likely to be dangerous, aggressive and/or sexually deviant. As noted by many scholars in critical disability studies, the idea that people with IDD are dangerous has been used for decades to justify not only their exclusion from participating in society, but also their institutionalization, sterilization, and eradication (Kafer 2013; Kulick & Rydström 2015; Snyder & Mitchell 2015).

Contradictorily enough, while worrying about ‘inappropriate behavior’ reproduces the ableist rhetoric of a dangerous disabled person, the assumption that undercuts the entire response overemphasizes the participant’s vulnerability and assumes that participants with IDD ‘lack’ the ability to assert their agency and express their needs. According to these assumptions, the disabled participant is both the aggressor (the perpetuator of violence), and the infant (who is vulnerable and incapable of protecting itself at the same time). While seeming contradictory at first sight, both assumptions are firmly grounded in ableism, reproducing its effects in different ways.

Again, ableism clearly undergirds the UHREC’S final query that even when reminded of the study, it “might create a situation where the participant perceives that the researcher can do more for them” because the only people who ever visit the participant at home are “social workers/ community nurses. First, this statement presents an incredibly limited picture of intellectual disability by assuming the average participant is only visited by “social workers/ community nurses”. Meaning, people with IDD are not worth visiting by others. They are *unvisitable*. This to the degree that the sole people who visit them can only be medical professionals. Second, this statement paints the picture of the participant being quite helpless, unaware of boundaries and unable to act on their wishes. I thus want to ask: insofar as university ethics boards are responsible for protecting participants, at what point do protective attitudes become infantilizing and ableist? And crucially, how complicit is the UHREC in the exclusion of people with IDD from the research in the Humanities and Social Sciences by failing to consider the agency of their agency?

Next Correspondence

On April 8th, after consulting with my supervisor to help draft a response, I addressed my concerns to the ethics board and requested another amendment review to be done *but with* a different reviewer. Meaning, not with the reviewer who was presented as working “extensively with this kind of population”.

In my request, I first made it clear that given my participant's own access needs (participant specifically asked to be interviewed at home rather than come to the campus), visiting them at their home *is* the most accessible option and that I wanted to honor my participant needs and respect their agency. I felt uncomfortable pressuring them to come to campus after it was made explicit that this was unsuitable. I addressed that there is no evidence to suggest that the ability to withdraw exists to a higher degree in a university setting or that previous participants who had taken the trouble to come to the university campus were not put in a “less” difficult position to discontinue than a new participant who requests for me to visit them at their home. I furthermore addressed the problems arising from online, and the contradictions perpetuated by the UHREC. Let me explain this contradiction.

In my original (very first) ethics application, which I submitted in October 2021, I had included an option for the craft-based interviews to allow for Zoom participation if interviews cannot take place in person due to Covid. During the review process, the committee expressed concerns about the Zoom craft-based interview, stating that: "[t]he UHREC feels that doing these types of interviews via Zoom with the participants for this project may not be feasible and would require you to conduct them in person" (Personal Communication, October 19th, 2021). Back then, they explicitly asked that I remove the Zoom option due to feasibility. Now however, the amendment reviewer is saying that the interviews could as well be completed on Zoom. I pointed out this contradiction to the committee in my response and it was not acknowledged by them in any additional responses. For transparency, before moving on to the next correspondence, I include my full response to the UHREC:

> In addition to this amendment request, I would still like to request another amendment that will allow me to include the option to visit participants at home. For this second amendment request, you can find my responses to the reviewer's response below:
>
> 1. As I stated in my original application, this research was designed in a way to allow for zoom participation in the event that interviews cannot take place in person. However, UHREC's response (Dated October 19, 2021) Condition 7 stated the following:
>
> "SPF, Section 7e (Research Participants): Craft-based interviews will be taking place via Zoom if they cannot be done in person. The UHREC feels that doing these types of interviews via Zoom with the participants for this project may not be feasible and would require you to conduct them in person."
>
> Upon this recommendation, I removed the Zoom-based interviews. Now, the reviewer is asking me to do the interviews over zoom on the grounds that this research "Is not necessary for this study- interviewing can take place on Zoom"
>
> The reviewer's response is clearly in contradiction with the response given by UHREC previously. As the designer of this research, I agree with UHREC's above-quoted feeling that "doing these types of interviews via Zoom with the participants for this project may not be feasible and would require you to conduct them in person." Importantly, given my participant's disability and their own access needs (participant specifically asked to be interviewed at home rather than come to the campus), visiting them at their home is the most accessible option.
>
> 2. The reviewer states that: "The concern about going to the participants' homes to do the interview has to do with 'boundaries' (rapport between researcher and participant) and the fact that it would put the participant in a 'more' difficult position to discontinue/withdraw from the study should they wish to do so (after the researcher goes to the 'trouble' of going to their home to do the interview)."
>
> During the recruitment phase of my research, I talk to all my participants (either on phone or zoom) explaining my research in full detail, answering their questions and addressing any of their concerns. During that phase, I will make sure to emphasize that they can discontinue/ withdraw anytime, even if I am visiting them at their home.

> Furthermore, the issue of boundaries that the reviewer mentions exist to the same degree (if not more) in a university setting, where this interview was originally supposed to take place (in accordance with the UHREC approved protocol). The fact that other participants of the same research have taken the trouble to come to the university campus did not put them in a "less" difficult position to discontinue than this new participant who requests for me to visit them at their home.
>
> 3. The reviewer states that: "There are also additional safety issues with COVID"
>
> The researcher is triple vaccinated and will be wearing a Kn95 mask at all times as will the participant. The researcher will be abiding by the government guidelines.
>
> As in the way that this research has been originally approved by URHEC (where the participants are supposed to come to the university setting), the participants are at more risk of exposure to COVID than me visiting them at their home.
>
> 4. The reviewer asks: "is the researcher 'qualified' to attend to any behavioral issues that may come up with a change in routine or someone else's presence in the home (i.e., aggressive behavior? Inappropriate behavior?).
>
> Yes, the researcher is qualified. As stated in my original application. I have 10 plus years of experience working as a support worker for individuals with intellectual and behavioural disabilities. As well I have a brother with an intellectual disability that I regularly provide care for.
>
> 5. The reviewer states that: "Also, the only individuals who ever 'visit' the participants homes are usually social workers/community nurses who support and provide reports on their well-being and advocate for their needs and this might create a situation where the participant perceives that the researcher can do more for them even though they are reminded that it is a study that they are participating in and that they can discontinue from – should they wish to do so."
>
> In the fields of critical disability studies and anthropology of disability, there are many researchers (including my own supervisor who is the Canada Research Chair in Critical Disability Studies) who visit their disabled participants at their homes. In fact, my supervisors' doctoral and postdoctoral research projects included visiting her variously disabled participants at their homes.
>
> With these answers, I still ask for this second amendment which would allow me visit my participants at their home, should they prefer. Further, given this reviewer's contradictions with UHREC's previous response, and given my research situatedness in critical disability studies and disability justice (rather than a medicalized approach) I would like to ask for another reviewer to assess my amendment request.

My goal with my response to the UHREC was to a) highlight the contradiction within their justification, and b) address the committee's concerns and provide solutions that were grounded in critical disability studies scholarship and highlight the agency of participants. By doing so, I hoped to provide enough evidence to the board to reconsider my request so that I could complete the research at the participants home.

In Limbo with the Participant

On April 11th at 9:13AM, I received confirmation of receipt of my amendment request, after three more emails exchanged that morning to clarify the paperwork, I received ethics approval to complete the craft-based interviews over Zoom. I was assured that my amendment request for at home interviews was still pending. My participant and I went ahead with trying things out online.

But it turned out that Zoom was an unsuitable option with my third participant, as I expected based on our experience with the preliminary introduction via Zoom. While the participant and I did earnestly try to complete the craft-based interviews online, it was not conducive to the participant. The session was confusing to navigate online, especially as the participant had no previous experience in textile craft. Missing the materiality of being together, the Zoom option did not work because co-creating could not be pursued when mediated through a screen.

But what was most striking during our Zoom meeting was not what happened or what did not happen, but my participant's expectations about what would happen. During the session the participant asked twice, "When are you going to come to my house?". I was unable to give him a definitive answer due to the ambiguity of the situation of having to wait for the ethics board to respond. How could I explain to him that I was in a limbo and that my university's ethics board was essentially considering him too vulnerable to have me at his home?

Next Correspondence

On April 14th at 4:52PM I received a response from the UHREC, where I was again assured that "those with expertise working with this type of population" were involved in the decision-making. Their response reads as follows:

> Members of the committee, including those with expertise working with this type of population, have reviewed the request to go to participants' homes for the activities. Normally, it is not customary in this kind of research paradigm to go into the homes of individuals with intellectual and developmental disabilities to ensure participation in a research project. They are usually invited in the very spaces that the research is actually taking place. The HREC's view on this is not an arbitrary decision that diminishes empowering the participant or amplifying their voices.
>
> With this in mind, here are a couple of options you can move forward with:

1) Zoom – You already have Zoom activities approved through an amendment request, so you can choose to continue doing it this way if you prefer.

2) If there is difficulty for participants in getting to campus on their own, you can arrange for transport adapté (adapted transportation). It was not clear as to what kind of difficulty there was in accessing campus, so depending on what that difficulty is, then this is an option that can be considered. Alternatively, researchers in this field also pay for taxis (sometimes through grants) to bring participants to the research space.

3) Going to the participants' home: If this option is the best-suited option because for some reason, options 1 and 2 are not suitable for a particular participant, then you may do so only if you are accompanied by your faculty supervisor. To address issues of safety and boundaries by doing data collection in the participants' personal space, that is their home, your faculty supervisor will need to accompany you to make sure that there is no misunderstanding about both your role as the researcher and the right of the participant, for example, to discontinue, should they wish to so.

As I did with the last response for the UHREC, I will now dissect the ableist discourse embedded within this response. The first point made by the committee, (which again includes those who have "expertise working with this type of population,") states that "it is not customary in this kind of research paradigm to go into the homes of individuals with intellectual and developmental disabilities." However, I must ask: how is this statement validated, and who validates it? In fact, this statement explicitly contradicts *the International Handbook for Applied Research on Intellectual Disability*. The handbook addresses that because many people with IDD's cannot travel independently "it is important that the venue for the interview is easily accessible to the interviewee. Ideally, the interviewer should travel to the interviewee's day-time or residential setting" (Perry 2004, 118). Crucially, there is also existing research in critical disability studies and anthropology of disability, where researchers have visited cognitively disabled participants at home, such as ethnographic interviews on personhood and disability in Uganda (Zoanni 2018), on domestic communities in England (Randell & Cumella 2009) as well as doing fieldwork in group homes on positive life experiences and intellectual disability (Mietola et al 2015).[17]

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[17] While research in these examples primarily took place in group home environments versus independent of the state, I consider it akin to living with family or interdependently, especially given the push for community living in the disability justice movement.

But I am less concerned with challenging the validity of this statement than interrogating what is meant but the use of "customary" as a justification. What is meant by the statement that research in the participants home is not "customary"? What is deemed customary, and who defines it? What kinds of research subjects does this "customary" assume? If the most accessible option for the participant is, in fact, against the customs, then what counts as customary needs to be interrogated and treated as a barrier to participation itself. Meaning what is customary needs to be interrogated as a form of exclusion and a manifestation of both ableism and disablism. It not only assumes a set of standards which reinforce the able-bodymind (ableism) but also contributes to the erasure of participants who cannot meet customary standards (disablism).

As noted by many contemporary scholars working at the intersection of cognitive disability and humanities, we are entering unchartered territory where typical research methods, both within disability studies and the political and medical fields in which cognitive disability is historically relegated to, cannot adequately address embodied research that centers IDD (Fraser 2018; Friedner 2018; McKearney & Zoanni 2018; Grittner & Sitter 2021). As such, a reliance of what is customary on the part of the ethics board, not only risks further reinforcing the lack of research at the intersection of the humanities and IDD but it also prevents new research aiming to address this lack from emerging in the first place. Imagine, what if my two other participants had also requested to be interviewed at their homes? What would then have happened to my research?

Looking in closer detail, the options that the UHREC provide possess underlying assumptions of able-bodyminded privilege. Zoom is suggested again as Option 1, despite the fact that I had already explained why it was an unsuitable option for the participant that I was trying to visit at home and pointed out how it was contradictory to the UHRECs initial review. (To remind, while I had an additional participant interested, the purpose of pursuing this ethics amendment was so that a participant did not have to be excluded due to issues of research design). The continued pressure to use Zoom can be interpreted as a suggestion to find a participant who could complete the interviews over Zoom (or who could come to the campus), rendering those who cannot as ineligible.

Similarly, Option 2 constructs the issue as one of transportation that is reasonably overcome by arranging a ride. Does this suggest that participants who are unable or don't feel comfortable leaving home are unsuitable for research? By trying to find ways for the participant to bend to meet the research, as opposed to considering the needs of the participant when providing solutions, the UHREC exemplifies an attitude that a participant *should* be able to come to campus. While these transportation options might be suitable for some, to assume that these could not be equally as burdensome again reflects an able-bodymind privilege. If being unable to conform to these options renders a participant as a "justifiable absence," [18] (Titchkosky 2012) then how many perspectives are erased from research?

Finally, the last option reflects an assumption that my supervisor is able-bodied and free to accompany me as my research needs require. The questions that come to mind are: Is it within the normal duty of a supervisor to be able to attend four hours of interviews on such short notice? Is this level of intense supervision truly necessary for an interview primarily focused on crafting? We are not dealing with traumatic or sensitive topics here. And even then – in the case that such topics may arise, is the level of concern justified? The lengths at which I would need to be supervised (and for the situation to be surveilled) to complete this research at the participants home reflects an assumption that the participant is *severely* vulnerable and needs constant surveillance to be protected.

To be clear, I am not the first one to problematize ethics board reactions to participants with IDD. Infantilizing and overly protective attitudes among ethics committees as a factor has been identified by several scholars conducting research on IDD who have aptly noted that this promotes the exclusion of adults with IDD from research opportunities (Dalton & McVilly 2004; McDonald & Kidney 2012; Mietola et al 2017; Martino & Schormans 2018). As such, several strategies have been developed by the International Association for the Scientific Study of Intellectual Disabilities (IASSID) to promote and provide guidance for the development and execution of research involving IDD that mitigates risk while ensuring respect for personal autonomy (Dalton & McVilly 2004). In an effort to explain this position to the committee, I shared excerpts from the IASSID

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[18] Titchkosky theorizes disability in academia as a *justifiable absence,* where the barriers that keep disability salient are not recognized as barriers so much as outside of the realm of possibilities (2011, 78-80

with the ethics committee, along with a request for an additional review in my reply. My request, which I sent on May 3rd 2022 (again after consulting with my supervisor) read:

> In my previous amendment request, I did not make it clear that the parent of the participant will be at home during the time that the research would take place. I want to emphasize this point.
>
> Option 1:
>
> Zoom is only an acceptable option for participants who have prior sewing/craft skills and who can independently create the textile collage. Otherwise, it is not appropriate.
>
> Option 2:
>
> I do not feel comfortable asking my participant to take a taxi to meet me or transport adapté for several reasons.
>
> 1) The participant and their parent, whom they live with, have explicitly requested to complete the research at home. I believe that the participant feels more comfortable at home and perhaps having his mum close by, not involved, but there if additional support is needed. After my last ethics response, I re-asked the participant if they would like to explore options for completing the research on campus and their response was a definitive "no". The first fundamental ethical principle asserted by both the International Association for the Scientific Study of Intellectual Disabilities (IASSID) and the Council for International Organizations of Medical Sciences (CIOMS) is: "respect for persons, including their autonomy and right to self-determination" (2004). In line with this principle and standing with disability justice movement, I respect the participant's agency and I trust that the participant is making the best choice for them. Offering a taxi or transport adapté will equal to taking a decision on behalf of the participant and impose it on him while he clearly requested this to be done differently.
>
> 2) As many people with intellectual disabilities thrive on routine and familiarity, there is a greater possibility of ending up in an overwhelming situation on campus as it is a new, unfamiliar environment. This is very unlikely, but more likely to occur than in an environment in which they are already comfortable, and additional support is close by.
>
> 3) Transport adapté is consistently unreliable and late, an issue that I come across frequently in my current research position with the La Société québécoise de la déficience intellectuelle (SQDI). This presents another opportunity to end up in an unfamiliar situation or possibly be on campus longer than anticipated. Furthermore, same day modifications to Transport Adapté reservations are only permitted for medical appointments and returning from a court of justice, so the participant will have less control around leaving campus, impacting their ability to withdraw or causing more distress.
>
> 4) Logistically, this option will require a greater timeline and expense, neither of which I have the resources for as a Master's student who has restricted financial resources, and is on a strict deadline to complete her research by August.
>
> 5) This option does not address the issue of added Covid risk, from taking public transit or a taxi, and then being on a college campus.
>
> Option 3:

> To even pursue this option, I would need to ask the participant if they are comfortable with having another person in their home and if there would be space for us three to social distance effectively. I also need to consider the access needs and schedule of my supervisor as not all supervisors are able-bodied and available upon request to join their supervisee's research.
>
> As stated, the parent of my participant will be present throughout the duration of my visit. The presence of the parent would fulfill the third-party role sought by UHREC.
>
> My request for amendment is not so much an issue of transportation as it is about respecting my participant's decision-making power and agency and accommodating his access needs. As stated in the IASSID recommendations "That ethics committees/institutional review boards recognize the expertise of people with intellectual disabilities, their families and advocates and, wherever possible, consult with and involve people with intellectual disabilities, their families and advocates in their deliberations" (Dalton & McVilly, 2004, p. 61).

In my previous requests I did not make it clear that the participant lived with their mother, who would be at home during the time that the research would take place. While I should not need to emphasize the presence of a parent when the research is concerning a fully consenting adult, I did so in the hopes that maybe it would ease the committees concerns about boundaries. My goal with this correspondence was to clarify my research and address that the solutions provided by the UHREC were not conducive to the realities of IDD. For example, anyone who has used Transport Adapté or knows someone who has will know how unreliable and often anxiety provoking this service can be. In referring to the IASSID, I hoped that the UHREC would reconsider my amendment request taking it into account the access needs of the participant.

Next Correspondence

On May 16th, 2022, I received a final response from the committee:

> Your email was forwarded to the committee and your responses were taken into consideration by those with expertise in working with this type of population. Please note that the committee reviewed the responses but are insisting you pick amongst the proposed solutions. As such, the amendment request for this particular change (apart from the Zoom option, which was approved) has not been approved.

Dismayed and frustrated, I didn't respond to this further as my window for completing the research in time for an August graduation was closing. In consultation with my supervisor, I decided to proceed with analyzing the interviews from the two completed participants; and (rather than taking

UHREC's denial as a defeat) to turn the entire process into a research issue in and of itself, which has led to the writing of this chapter.

Who Can Be Researched?

To reflect back again on the process, the problematization of my engagement with UHREC crucially points at the fact that the most privileged participants have the easiest access to attending research, either because they have the most independence, privilege, or heightened access to a network of support. They are the "proper" research subjects that ethics boards want us to research, the ones that can meet predefined standards for "normal" research. They are not research subjects who call into question these standards of normativity, who require ethics amendments to make participation feasible, or those who complicate the ontology behind "the capacity for consent."

My third participant who was unable to participate – according to this ableist logic of exclusion – would be considered the one with the highest need for support. Importantly (though I have not thus far mentioned), he was also the only person of color who expressed interested. Given the historical exclusion of multiply marginalized people from the fabric of social life, I don't think that any of these are a coincidence, highlighting how research design and the findings that emerge are deeply intertwined with race, class, gender, and how an intersectional approach, as adopted by Erevelles, Puar and others, is fundamental to critical disability studies research. Not only does this lead to a reproduction of existing hierarches within research, but it again, promotes the erasure of research participants that are deemed as 'too risky' because of their inability to conform to safe standards and customs of research as legitimized by the academy.

In this chapter, I examined the pivotal role that ethics boards have in shaping the 'researchable subject,' and the implications that this has for participants with IDD. The concerns and subsequent suggestions made by the UHREC manifest as academic ableism in the way that they construct the "proper" participant (Dolmage 2017). I conclude by asking: How do we both acknowledge that vulnerability is a real concern without undervaluing the autonomy and decision-making power of the participant? How do we conduct research that foregrounds the agency of participants with IDD while also accounting for varying degrees of vulnerability, and dependency among participants? Again, at what point does it cross the threshold from protective to inhibitive?

Approaching university ethics boards as a site of academic ableism, evokes more questions than answers, and I want to conclude by questioning not only who can be a ‘proper’ research subject and who cannot, but also what research becomes rendered absent due to barriers that prevent some research designs to exist.

Chapter 4: The Craft-Based Interviews

In this chapter, I revisit and analyze two craft-based interviews conducted during the Winter/Spring of 2022. First, I provide an overview of each participant and the work that was created before moving into an analysis of the craft-based interviews as a novel research methodology with people with intellectual and developmental disability.

Thematic content is divided into two sections: 1) Material Impacts of Co-Creation, and 2) Corporeal Experiences of Disability. The first section attunes to the impacts of co-creation on the material reality of the research as it emerged in three major themes: 1.1) The Affordances of Textiles, 1.2) Impact on Power Dynamics, and 1.3) Welcoming Silence. After laying out the specific impacts of the methodology, I flow into the second section, which focuses on the realities that emerged due to the craft-based interviews: 2.1) Navigating Social Relationships, 2.2) Infantilization, and 2.3) Hesitancy as a Byproduct of Infantilization.

The excerpts of the transcripts are written exactly as was said. They are not edited for grammar and include the um's, repeated words and thought processes as they unfolded in real time by the participants. Because the crux of this research hinges on rejecting compulsory able bodymindness, it felt contradictory to edit the transcripts for syntax and grammar. To some degree, each of these moments hinge on a material interaction afforded by the creation element, highlighting how method is equally revelatory as the content that emerges from it. Would I have made such revelations or developed such concrete examples within the traditional interview format? Would participants have been able to reach the same level of personal analysis through verbal self-reflexivity alone? How would the power dynamics have impacted the interviews without co-creation?

Introducing Participants

Armen

Armen was the first participant to email me, responding to my research flyer, which his boss had sent him. We met on February 17th at the Textile and Materiality Cluster space at the downtown Concordia campus. Located on the 10th floor, our initial interview overlooked the grey haze of mid-winter in Montreal. Contrasting the weather, Armen arrived wearing a beautiful blush jumpsuit which he had hand dyed and sewed. Before we met, I had struggled to understand if Armen qualified as a participant because he identified as having Autism Spectrum Disorder (ASD), which while overlapping with Intellectual and Developmental disabilities, is also considered a distinct category. But because ASD encompasses such a broad range of people from those who are able passing to those who are considered "profoundly disabled," it felt unproductive to eliminate Armen's participation based on a categorical distinction.[19]

During our initial interview, Armen taught me how to spin roving into yarn with a drop spindle that he brought. I was a slow learner, but he was a patient teacher, demonstrating how to twist and guide the roving through the spindle in great detail several times over. His long fingers curled over the raw wool, coaxing it into a uniform string of yarn. Once I got the motion, we sat and began the initial interview, where the goal was to get to know each other and develop a plan for the textile collage. He began to tell me about himself and why he was interested in the research. As we spun, I asked him about naming and which terms he preferred; he didn't have a strong preference for terminology saying that he uses autistic or neurodivergent or what could be defined as an "aspie".[20] After we had spun yarn for about an hour (Armen much more successfully than I), we agreed to meet in the same location the next month to complete the craft-based interview in one four-hour session because this suited his work schedule.

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[19] Indeed, disability rarely fits into need categories and this dilemma attests to the messiness that studying disability welcomes.

[20] An aspie is a colloquial term for someone with Asperger's Syndrome. The term is no longer diagnostically used, instead identified on the autism spectrum however, it is still used by individuals as a positive identity marker

Ariel

The second participant, Ariel, and I first met a few weeks later in the lobby of the Communication and Journalism building on Concordia's Loyola campus. We had met through his mother who received my flyer through an organization for adults with IDD. She accompanied us up to Dr. Dokumaci's office for the first part of the initial interview, where the two of them sat side by side in plastic office chairs across the desk from me. Ariel was enthusiastic from the get-go, eager for his mother to leave us so that we could begin the introductory interview. Once alone, I asked him to tell me about himself and without much prompting, he clearly articulated a snapshot of his life. In the process, Ariel introduced me to each member of his family, his work environment and his social life. As Ariel had not previously worked with textiles, we spent a large portion of the meeting introducing him to various fabrics, yarn, roving, as well as different embroidery, sewing and weaving techniques. After seeing a piece of embroidered text, he had a lightbulb moment and told me that he knew the direction for his collage: he wanted to create a black-on-black piece embroidered with the words "Friendship Revolution 3.0"[21] at the centre. By the end of our session, we had agreed to meet on two more Wednesdays, his only weekday off work, to complete the textile collage. Before we parted, he made sure that we exchanged email addresses so that he could email me about the project and so we could confirm when we were going to meet next.

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[21] Friendship Revolution is a project by the organization Friendship Circle focused on breaking down inclusion barriers (https://www.friendshipcircle.ca/revolution-3)

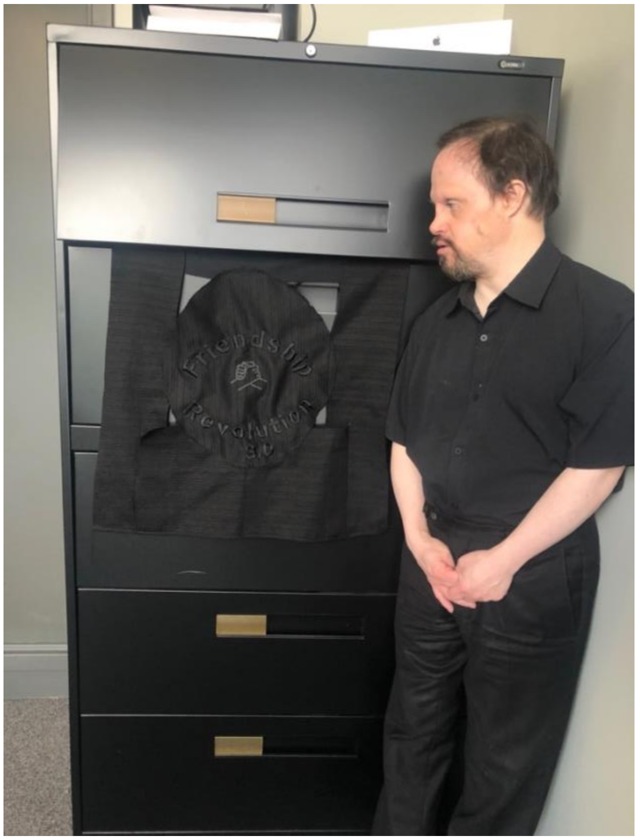

Figure 4 Ariel stands to the right looking at his completed textile collage. The piece is made of four thick strips of fabric sewn into a square, in the centre is a circular fabric patch with the words Friendship Revolution 3.0 and a line drawing of hands clasped together is embroidered in black and grey

Figure 5. Taking a wide legged stance, Armen holds is rectangular textile collage at an agle. The piece features three squares of contrasting stripes boardered by pink strips of velvet , the same material as his overalls

These are images of the collage that each participant created during our craft-based interviews. Despite having access to a range of materials, each participant chose only to incorporate fabric and sewing. Ariel’s (fig.1) piece is a reimagining of Friendship Revolution, which I came to know as a project that he is involved in that builds connections between disabled and non-disabled individuals. He decided to incorporate Friendship Revolution into his textile collage to build awareness about the organization and because he is passionate about it. He explained his ideas to me, and we worked together to bring them to fruition, chatting while we worked. While his design is based on the lettering, we worked from the outside in, first cutting and sewing the boarders, then constructing the middle, and finally designing the lettering together on Adobe Illustrator. The piece was stitched using a Brother Embroidery Machine, which I completed separately at the Textile & Materiality Cluster before our follow up session.

While Ariel stayed consistent with his vision from our first meeting, Armen (fig.2) did not conceptualize an idea beforehand, rather he focused on what emerged based on the materiality of fabric in the moment. Instead of using scissors, he began ripping long strips of fabric, creating thin straight lines which he sewed together with highly skilled precision, using no pins. He created three distinct squares before sewing them into the final format, almost the same logic that is applied to constructing a quilt. He preferred to work independently so I asked him questions while he ripped, ironed and constructed the piece. Because he was independent, I began sewing my own little pieces together so that I was not just idly observing, which felt strange and disembodied. Admittedly, I was quite nervous to step into the "researcher" role, so having something for both of us to do eased the conversation and I was surprised by how organically conversation flowed and the level of self-disclosing that we shared.

By mobilizing the method of craft-based interviews, I argue that the research-creation process allows us to foreground the creation element, thereby backgrounding the formal interview process to the point of (at times) almost forgetting about it. Engaging primarily in research-creation as a method of inquiry allows for different kinds of knowledge to emerge in ways that, as I shall explore in the following, might not have been possible through a traditional interview. With the openness and flexibility that the research-creation provided, each participant came to embody the space differently, free to choose how to approach the material, the interview, and the relationship with me (the researcher).[22] Crucially, research-creation allows for research to be performed through multiple and alternative forms of knowing (Chapman & Sawchuk, 2012; Manning 2016) and I will now address these knowledges by exploring the specific themes deduced from the interviews, starting with the affordances of textiles.

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[22] From this point on, instead of using the term researcher, I will just be referring to myself (Jessie).

1. Material Impacts of Co-Creation

1.1 Textiles as affordances

The traditional interview format prioritizes normative methods of communication based on verbal means, reinforcing the compulsory able bodymindedness of the researcher and the participant. In her research with physically disabled people, Dokumaci utilizes ‘disability as a method of research creation’ (Dokumaci 2016) to explore the micro-affordances of disability in the everyday. Furthering Dokumaci’s research, which focuses on physical disabilities and utilizes visual ethnography to capture the experiences that are otherwise rendered absent, I focus on people with IDD and employ the medium of textile craft as an affordance to attune to experiences of disability as they are unfolding in time and space. Craft-based interviews, I explore in the following, allow for knowledge to be formed not through intellectual abstractions about “what it means to be intellectually disabled,” but through the embodied experiences of disability that emerge through material engagement.

To begin, textiles mediated the interviews as a tool of relationality, prompting participants to share with me. This mediation occurred in two distinct ways: technically, more in the case of Armen who foregrounded tactility by choosing fabrics based on the feel and quality of materials, as well as semantically, more prominent with Ariel, where fabrics promoted memory association and evoked the sharing of previous experiences. The fact that two different interactions emerged through the mediation of textiles demonstrates the potentials of textiles to offer different ways of meaning-making, highlighting their flexibility as an intervention in interviews.

Semantic relationality to fabric emerged from the craft-based interviews with Ariel. He most often associated fabric and other materials with people or memories as opposed to the physical properties. In this next excerpt, negative memory associated with denim material was a large rationale as to not wanting to use it. I showed him a series of fabric swatches and Ariel immediately replied:

> I don’t want to use any of that [referring to denim fabric] because it reminds me of the incident.

I didn’t probe more and moved on to different fabrics as his expression flashed to one that was visibly uncomfortable. However, I decided to include this moment as a point of analysis because it shows the ability of textiles to trigger memories or semantic associations. This echoes previous research findings, where fabric increases the participants ability to recount personal experiences, by triggering sense-based memories (Olmedo 2018). Although Ariel chose to work on a mostly black collage, the presence of other materials and the rationale behind choosing certain fabrics over others proved incredibly useful for getting to know him, in a way that I don’t believe would have been possible in four hours of typical interviews.

At times, Ariel also chose fabric based on personal preference, such as wanting to use black because he liked the color, however semantic association was his main rationale for both fabric and design choice. In the following quote, he identifies multiple meanings and aspects of himself that emerge through his fabric collage. Seated in Dokumaci’s office in our final session (fig. 6), I asked him to describe his self-portrait. He said:

> It is black because it is one of my favorite colors and I also picked black because I get depressed sometimes and doing things like this helps me out of it…the circle is to represent the Friendship Circle [the organization responsible for Friendship Revolution].
>
> Jessie: Why did you decide to use friendship circle in your self-portrait?
>
> Ariel: well because they have been there for me for a long time, and they are a family organization…

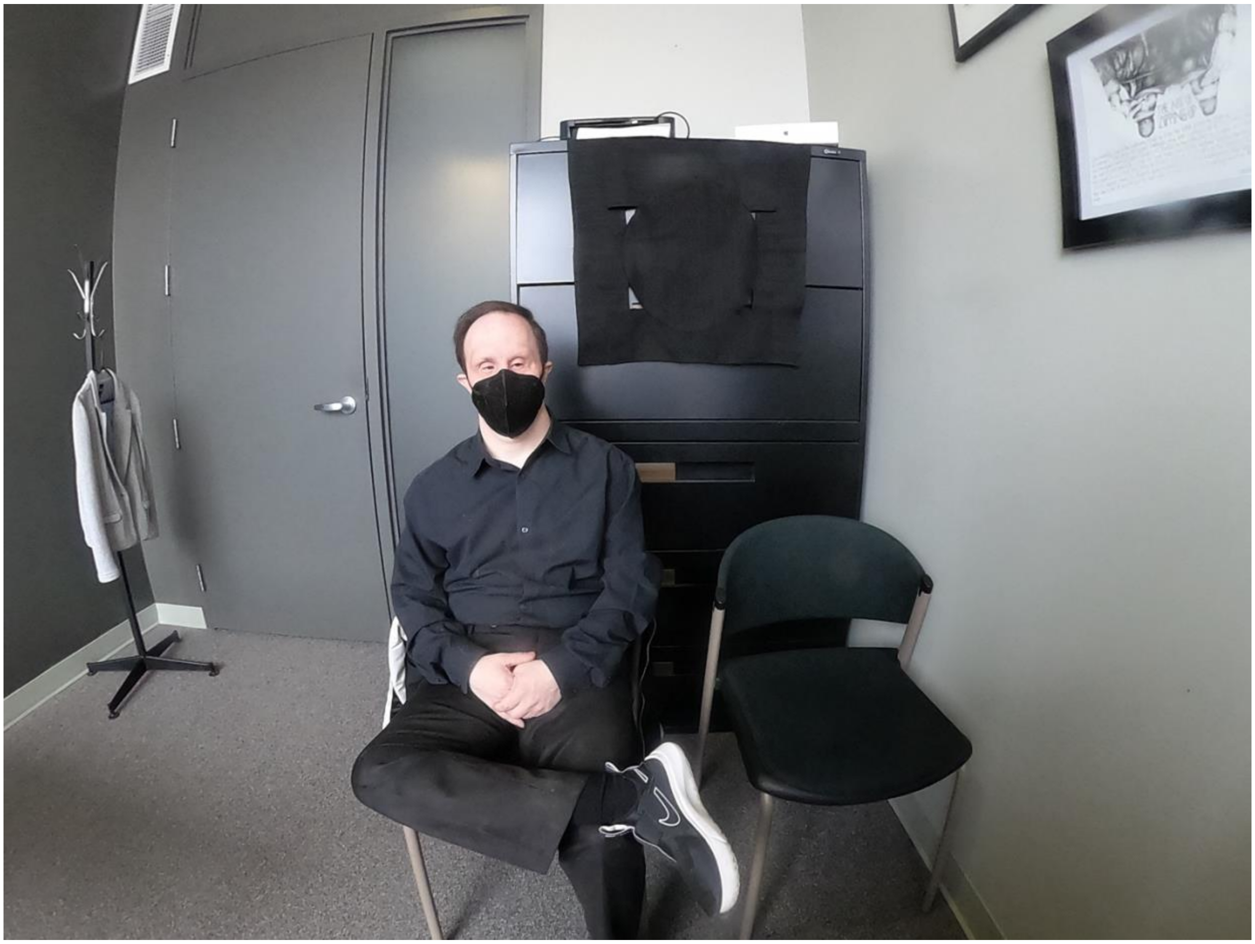

Figure 6. A photo of Ariel in our second craft-based interview smiling (under a mask) at the camera. He's wearing all black and his hands are crossed with an ankle resting on his knee, his collage (pre embroidery) is hung behind him.

Depression is not something that we had discussed before, so I was surprised by this response. However, Ariel's sharing this information (with relative ease) shows how textiles can hold multiple layers of meaning to be revealed on the participants' own terms (perhaps this is an instance of Ariel engaging in retroactive analysis of his own work, his fabric choices prompting him to reveal more about his personality.) His openness to sharing on one's own terms suggests that research-creation affords an agency-centered approach to analysis, whereby the participant is encouraged to make personal revelations, rather than the researcher abstracting understandings from a disembodied view. As shown in Ariel's rationale, the color of the fabric conveys both personal preference and deep emotionality, while the choice of shape (circle) and text (friendship revolution) semantically relates to an organization that is very close to Ariel, revealing another aspect about his life. Contrasting black, his favorite color, with being depressed while also connecting to the topic of Friendship Revolution suggests a connection between friendship and depression, to infer further perhaps an ambivalence about friendship or loneliness – a theme that I will return to shortly.

Armen was much more focused on the technical qualities of the material, such as the composition of the fabric, as opposed to personal associations he attached to them. He showed a strong preference for natural material and said that he picked fabric based on the way that he anticipated it would feel, avoiding synthetic material at all costs. Tactility played an interesting role, as while Armen made choices based on tactility, he often used sight to anticipate this as opposed to running his hands over the material. When asked about his rationale he replied:

> Definitely tried to go with the natural fabric. Everything here is I think cotton. Yes, everything here is cotton, so definitely natural, even the sewing thread is cotton.

As tactility and naturalness were the largest factors, I asked what came to mind when he interacted with the material and he replied:

> Armen: I guess when I touch things I often think of its composition, it's not very heartwarming memories, it's more technical stuff: composition, weave structure, color…where does the color come from? Is this printed with dye or is it printed with inks, which gives it a different texture on the surface. How easy is it to work with? That's usually the type of stuff I think of when I touch material.
>
> Jessie: That makes sense because you're an artisan.
>
> Armen: Like I look at this green and I think … this looks like the linen I bought to make these other overalls. I look at this brown, and it looks like the natural dye that I used, it's almost exactly the same shade, I look at this and I think this is a nice pattern I wish I could see the whole thing, it looks interesting, it looks very regal, a very particular French style maybe? I just think of little things like that.

Armen had a clear preference for the technical properties of the material, which he later related to semantic ideas. Through this we can see that the relationship between fabric and choice is a highly personal one, which reveals aspects of who that person is. In Armen's case, the technical preference, such as the choice to bring his own thread to avoid using polyester thread, reveals his meticulous attention to detail, high level of commitment to his craft and a strong aversion to synthetic material. The technical choices become a dimension of the interviews, revealing how active the craft and techniques utilized in any interview scenario – craft-based or traditional – shape the content of the research.

My method of craft-based interviewing, while unique, shares similarity with other techniques that subvert traditional interview styles, such as the wheeling method proposed by Laurence Parent (2016). In her mobility studies research on how physically disabled people navigate their neighborhoods, Parent utilizes wheeling as a method of interview. Highlighting the non-neutrality of mobility studies (which most often privileges walking), Parent also argues that the materiality of mobility aids plays an active role in shaping the content of the interviews. Drawing on Parent, I argue that the materials that make up the craft-based interview space were not inanimate objects but active agents of the method itself (2016). By circumventing the necessity to ask direct questions and enabling creative choice, more was revealed about the participant than perhaps rehearsed lines of questioning could provide. Armen was able to tell me about himself, without me asking what it was I wanted to know Bringing creation to the forefront, through the help of the materials and the space, enabled a more nuanced as well as agency-centered approach to interviewing. Crucially, this method allows for participants to engage in their own revelations and analysis. When I asked him how the self-portrait element factored into the creation of his collage he replied:

> Armen: Um I guess my controllingness comes in because of like how neat and tidy I try to make it look and um… but I also I like to think that I am an organically inclined person, but maybe I'm more gridded in my approach. Even though my aesthetic isn't very griddy my approach might be very gridded… so that might be the aspect that is representing me.

Armen's words above further show how creative technique itself is an element of self-portraiture. The associations are made by Armen about himself, revealed through his fabric choice and technique and how (in his mind) it corresponds with w ho he is. Like Ariel and his association with depression, the fabric becomes a proxy for self-revelation by giving participants the space to make their own connections. Armen decided to make the grid and only made the association to his controlling nature himself after we had completed. The fabric enabled this degree of self-recognition and enabled him to share it with me. Leaving space for participants to make their own associations demonstrates how textile collage can offer an agency-centered approach to embodied interviews. Furthermore, it multiplies the mediums by which participants are able to communicate with me. As opposed to expecting a participant to only tell me about themselves in words, such as in a traditional interview, including a tactile, and creative element allows for the opportunity of personal revelations to occur through the engagement of multiple senses.

The multitude of approaches that each participant took to complete their textile self-portrait highlights the multiple ways of meaning-making that textile craft offers. There is meaning-making through personal preference, such as only using natural fabric, and there is meaning-making through semantic associations, such as a fabric revealing a personal trait or a past event. There is also meaning-making through taking a specific approach and meaning-making through how each participant reacts to the materials present during the craft-based interviews. As revealed in these moments, foregrounding the "other materialities" present in an interview space can lead to a deeper engagement with the embodied practices as well as the multi-sensorial intricacies that are rendered absent in normative interview methods (Parent 2016). Attuning to the extra-lingual knowledge that emerges from interviews is crucial to ensuring a certain level of accuracy, as it circumvents a one-size-fits-all methodology that has traditionally excluded people with IDD. The multiple possibilities for meaning-making through the craft-based interviews highlight how textile collage offers different approaches conducive to varying embodiments of disability. This is not in the sense of essentializing one technique to neurodivergence and one to IDD but in the sense that creating together gives participants the agency to embody a research situation in different ways through the worldbuilding opportunities that textile craft affords.

This echoes a notion of Heideggerian *openings* that emerge from "being-in-the-world," the idea that we are inseparable from the relational engagement of our material reality, and the materials and inanimate objects that we encounter are not passive but are active agents in shaping reality (Heidegger 1992; Jensen 2016). Excusing my oversimplification of Heidegger, I apply the notion of *openings* to the world to the worldbuilding opportunities that research-creation affords. My craft-based interviews afford many *openings* for what and how participants share about their lived experience as well as the way that creation impacts the degree to which they self-discover through the exercise.

1.2 Impact on Power Dynamics

Foregrounding the creation and backgrounding the formal interview deeply impacted the relationship formed between each participant and I. While the power imbalance that exists between the researcher and the researched is impossible to fully eradicate in the context of academic research, creating together helps horizontalize the power dynamics embedded in the interview by emphasizing the element of co-creation. Departing from the traditional interview, where the interviewer is in control of questions to which the participant responds, relationality emerged more organically. As Parent notes in the wheeling interviews, when both the researcher and their participants are engaged in the same activity (which, in Parent's case, was wheeling together) the scope of knowledge shifts from exploring participants perspectives to the perspectives that emerge together (2016). Disrupting the traditional formalities of verbal interviews mitigated the power dynamics, providing more comfort to the participants and to myself. With Armen, whom I sensed more hesitancy self-disclosing, the questions that I had prepared didn't spark the same length of discussions as they did with Ariel. However, as we moved through the craft-based interview, the act of creating and working together led to a relationality between us which enabled a greater comfort. Speaking to this point, when I asked Armen what he thought of the format of the interview he responded:

> I think it was a nice... like I liked the discussions I've had with you, and I think that was most of the focal point for me rather than the actual making of this [referring to collage] and this helped facilitate that…Its usually what draws me to people, mutual interest in making and having something to spend time with someone definitely makes their company more enjoyable. Not to say I don't enjoy the company of other people with whom I behave differently. Two people who are engaging together with something creatively and tactile wise definitely help makes me comfortable and helps facilitate conversation and like getting to know each other or just any further getting to know each other and strengthening bonds…

The combination of creativity and tactility promoted relationality between us, or as Armen puts it "strengthen[ed] bonds".

The research environment of craft-making and the knowledge that emerged from it were deeply connected, where engaging the creative, the tactile and the talk and (as I will explore later on) the silences provide a space of comfort and being at ease. Patricia Leavy names this practice A/R/Tographical research, where creating together integrates the role of Artist, Researcher, and Teacher into a space that merges knowing, making and doing (Leavy 2017, 4). In our space of knowing, making and doing, Armen's ability to comfortably share his embodied experiences emerged in multiple ways. I learned about him through the direct connections he made to what he was *making* (e.g., his connection to the grid pattern as representing his controllingness), as well as all the rich conversations that were enabled through the comfort of *doing.* Given the power dynamics that prevail in research about people with IDD or ASD, and their historical reduction to mere subjects to be researched about, increasing their comfort to engage in agency-centered research can be considered among the anti-ableist offerings of craft-based interviews as a novel research methodology that I develop in this thesis.

While Armen expressed hesitancy to share and self-disclose, Ariel was the opposite. He had little hesitancy to share about himself, and at one point he even suggested that we film a formal interview so he could explain Friendship Revolution (which we did). I learned about him through the associations he made through his textile collage and through our interactions while creating (which I will discuss in greater detail in the themes section). Because Armen is a highly skilled textile artisan, the comfort that he expressed could be related to his familiarity with the craft. But, even in the case of Ariel, who had no previous experience, creating together impacted our relationship by implicating us as collaborators. This offering of co-creation again echoes Parent's finding in the wheeling interviews, whereby engaging in an act together (Parent wheeling, me creating) shifts from learning *about* the participant to learning about our embodied experiences together.

Radical Reciprocity

At the end of our session Armen and I were sitting around the table debriefing our session and he made a comment that struck me and encapsulates this theme. He said:

> You're not a researcher in a lab coat looking at me through a lens you're participating with me and sharing things with me.

While I am not autistic, I shared my experience as someone with high anxiety and my reckoning with identifying as neurodivergent which propelled our discussions. Sharing as much as you are asking of your participants is what Lisa Tillmann-Healy calls *radical reciprocity,* and is "a move from studying "them" to studying "us" (2003, 735). In her text *Mad at School,* Price cites radical reciprocity as a key element of disability studies' methodology because it encapsulates how the work needs to be carried out in consideration of the interdependency and care that disability kinship encompasses (2011, 210). Armen's comment reflects the embodied-ness required to do critical disability studies work in the way Price sees it. To be clear, I did not set out to employ radical reciprocity and share my life with participants, but in the process it felt impossible not to do so given the subject matter and the mutuality of engaging in the same act. Creating together with my interviewees, I was not able to distance myself from the interview process. Like Armen, I felt that the impetus to self-disclose was enabled by the act of creating together and through the divergence from a typical interview format where we both may have felt a social pressure to remain 'professional' and distant.

The act of creating together through textile work allowed each participant and I to feel comfortable sharing experiences of disability, which proves to be another benefit of the craft-based interviews that I propose as a novel methodology in critical disability studies research. For example, in the following exchange I kind of rambled on about myself which led to Armen sharing some really insightful feelings about navigating being an able-passing autistic adult. The conversation flowed as such:

> Armen: When I was diagnosed, I was also diagnosed with GAD and started seeing a therapist for the first time so a lot of changes in the brain with the pandemic in the background, so I guess it's been a big snowballing effect of changes and not only changes but also me coming to terms with certain things about me and accepting them and yeah.
>
> Jessie: That's very fair and I've been on and off anti-depressants, taking them irregularly, and during the pandemic I committed to taking them and coming to terms with a dependency on medication as ok not a personal weakness … and I find having friends who are also neurodivergent produces an intimacy or a feeling of them just getting in like my best friend is autistic and I find there is like an intimacy that I don't have with anyone else

> just like getting things about each other that like I sometimes feel with other people I need to mask certain behaviors and like//
>
> Armen: … fit in? Like worrying about their perception or assumed perception of you…I want to find intimacy with people but I'm afraid that if I say that I am [neurodivergent] in the back of the mind I'm like is that going to be a dealbreaker for them.

What Armen and I are both expressing is a fear of societal judgement and a simultaneous need for acceptance, a basic need that is nuanced in endlessly different ways depending on positionality. In this exchange, it is me who leads the conversation towards more intimate subject matter and Armen who then shares and expands upon my comment. The sharing on my part was unintentional (In fact, upon looking back I was surprised I said all of that to him). I have decided to include my portion of the transcript because in the ethos of radical reciprocity, it would have been unfair to publish Armen's self-disclosure without my own.

In attempting to horizontalize the power dynamic and be vulnerable with participants, I admit that I have run the risk of impeding boundaries. This risk can arguably be greater for participants with IDD or ASD who may already have difficulties discerning social dynamics (Perry 2004). The risks that participants may perceive us as closer than we are, or that I-the-researcher share something that makes them uncomfortable are inevitably embedded within an alternative research design such as this. But the solution is not to not take up the new research method that I am proposing on the basis that it involves risk. As researchers, we need to be cognizant of such risks. Craft-based interviews based on radical reciprocity requires our constant self-reflexivity along with 'checking in' with participants and finding ways to remind them of the contours of the social boundaries.

1.3 Leaving Room for Silence

27:21- 29:01; 30:21- 36:08; 58:15 – 1:03:36; 1:33:53- 1:34:15

These time markers are some of the many moments filled with silence during my craft-based interviews. In these moments, our attention was grabbed, not by words, but by other things, such as needles, pins, or scissors. In creating with your hands instead of relying on the volley of question and answering, breaks in conversation occurred organically. In these spaces of not speaking, both participants, and myself were allowed the fallow time to think, reflect, digest, and therefore have more opportunity for earnest sharing. In fact, when re-listening to my interviews, I noticed that silences were often followed by interesting revelations on the part of the participants and myself.

In traditional interviews, silences stand out as disruptive, as awkward pauses where researcher and participant hang in dead space. Silence often reinforces a power dynamic, where the researcher is waiting for response. The focus that cutting requires, a mouthful of pins, and the hum of the sewing machine were all spaces where silence was allowed to exist in my craft-based interviews with disabled participants. But I ask, how did silence itself become a material element that impacts the interview? I now move onto explore this question.

After our previous conversation on neurodivergence and social relationships, Armen and I fell into one of these logical lapses and became busy sewing. About eight minutes after he returned to the subject of connection with a sudden addition:

> Armen: And like trying to talk to people trying to like to interact with them or initiate contact I guess I do it in a different way that other people might find unusual. Sometimes cold...sometimes too forward
>
> Jessie: That's interesting cold too forward??
>
> Armen: Yeah I don't try to sugarcoat myself while talking to people and -I can but I don't usually like to– I like to approach things very directly because there's no point in beading around the bush…and um I don't know people might be put off by that so then I have I try to adapt but that doesn't come up very intuitively so that might also put them off some people might feel put off

Similarly, after a 32 second break to sew, Armen expanded on a previous thought:

> The best example I can give is every time I've sort of forced a social interaction on myself just so I could not be alone ...I don't want to be that wallflower person, so I forced myself to endure it.

Breaks such as these two instances allowed for participants to return to conversations on their own terms, increasing their agency. In fact, these breaks, and the ability to focus on the craft often led to incredibly insightful revelations that had to do with vulnerability or heavy conversations such as the ones above.

Referring to his sound piece 4' 33" (1952), whar artist John Cage calls "the absence of intended sounds," is treated as a positive and productive space (Weagel 2002, 259). Drawing on Cage, I consider the absence of words as a productive element of craft-based interviews with people with IDD. In this new methodology, silences are not treated as uncomfortable and lost moments; to the contrary, as inevitable moments which can be highly generative and evocative. They can help evoke additional revelation by opening space for memories and associations to flow from different elements of tactility. Moving to the content that emerged from the silence, Armen's insight echoed Ariel's previous point about depression and friendship. This encapsulated another key theme, a desire for friendships/intimacy, which I move onto explore in the second section of themes.

2. Corporeal Experiences of Disability

2.1 Navigating Social Relationships

Both participants revealed, in different ways, a level of dissatisfaction with social relationships, a longing for connection. From Armen's previous statements, I gather an anxiety about navigating social situations due to communicating differently, an anxiety shared by many autistic people (Greco 2022). As highlighted in many of our conversations, there was a longing for intimacy that was impeded by a dilemma: communicate differently and risk rejection, or mask one's disability and try to pass as abled and be disturbed with emotional distress and exhaustion. Navigating relationships was also a theme in Ariel's work, though revealed more through content of the textile collage as opposed to the conversations that arose. Friendship Revolution was the focus of the collage and Ariel spoke highly of the organization. He is currently participating in the organizations Walk for Friendship[23], which he called me to tell me about. On the website for the organization, he writes:

> I've been so fortunate to be a part of Friendship Circle where friendships are created with young people who have special needs. Together, we are creating an inclusive community that values each individual's uniqueness and contributions

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[23] The Walk 4 Friendship is on October 22nd, 2022. You can register for the event or donate here: https://www.walk4friendship.ca/

While he less explicitly states a dissatisfaction with his social relationships, there is an overemphasis on this one organization as a means of identity. Individuals with intellectual disabilities are not afforded the same opportunities for community participation and social relationships than those without disabilities (and I add those who are able passing or more independent), meaning that social organizations may take a larger role in one's life (Ditchman et al 2016, 36). This experience of dissatisfaction was further emphasized though his choice of black fabric, which as I previously discussed, was chosen both for personal preference and experiences of depression, suggesting an ambivalence towards friendship.

Ariel also put a higher emphasis on the relationality between researcher and participant as an outcome of the process. In our last session, as we were sitting outside eating Timbits and I asked him what he thought about his experience with the interview series he responded:

> Ariel: well. I learned how to use fabric, express my feelings through fabric, I got to learn how to sew, and I got to know you…lots of things.
>
> Jessie: what did you enjoy most?
>
> Ariel: well, getting to know you of course.

While this quote highlights the benefits that Ariel perceived out of this research, I was not expecting that getting to know me would be a factor in that. Ariel's comment manifests another instance of radical reciprocity, where the researcher shares with the participant to strengthen bonds and approach research in a more collective way (Tillman-Healy 2012). However, radical reciprocity, I must add, did not come without its own problems. In the process, issues with boundaries have emerged, such as Ariel thinking that we would be continuing to see each other every Wednesday and that this reciprocity was to continue beyond research.

Ariel's anticipation to continue, while bringing attention to the need for clear boundaries and the risk that accompanies mitigating a power dynamic, also further highlighted the need for friendship, which might not always be met in the lives of people with IDD. His eagerness to participate and enjoyment meeting me suggested that Ariel is perhaps not often in situations where he can develop relationships with new people. This could also be inferred by his eagerness to be involved with the research, something that was not even afforded to the third participant who, as I explored in Chapter 3, could not participate. All of these implicit and explicit barriers align with the lack of novel social situations that people with IDD's encounter due to systemic factors that inhibit full social participation.

2.2 Infantilization

In our first session, Ariel and I sat side by side hovering over a square of black fabric. We were planning the design of his piece, taking measurements, and marking the shapes out in chalk. The next step was to cut along the marked line, at which time we had this interaction:

> Jessie: Do you want to do the cutting or shall I?
>
> Ariel: The adult has to cut it.
>
> Jessie: Well, you're an adult too.
>
> Ariel: I know I know... It's just better you than me.

Ariel is 42 years old, yet, referred to me as the adult, implying that he was not an adult or at least not an adult who could cut fabric. Driven by the action of cutting, this moment highlighted an internalized infantilization that Ariel seemed to have. The historical and contemporary reality is that people with intellectual and developmental disabilities are often treated akin to children, and this moment suggested that this has happened to Ariel. The infantilization of adults with IDD's is a common yet incredibly harmful misconception that stems from the stereotype that they lack the ability to make informed choices (Ditchman et al. 2020, 39). Perhaps Ariel has been in too many previous situations where he was discouraged to cut and told that it was an "adult job," that could cause him harm. Paternalistic attitudes to autonomy are euphemized as a protective measure, fearing that the individual will put themselves or others in danger if given full autonomy (Wikler 2010, 184). While the risk of harm is a reality, I again ask (as I did in the previous chapter focusing on the ethics review process), at what point does it become infantilizing? At what point does the prevention of risk become the assertation of ableism and its deprivation of opportunities? The scissors issue is eerily similar to the issue with the ethics board, in both situations infantilizing people with IDD manifests as over assuming risks, resulting in a lack of opportunity to try.

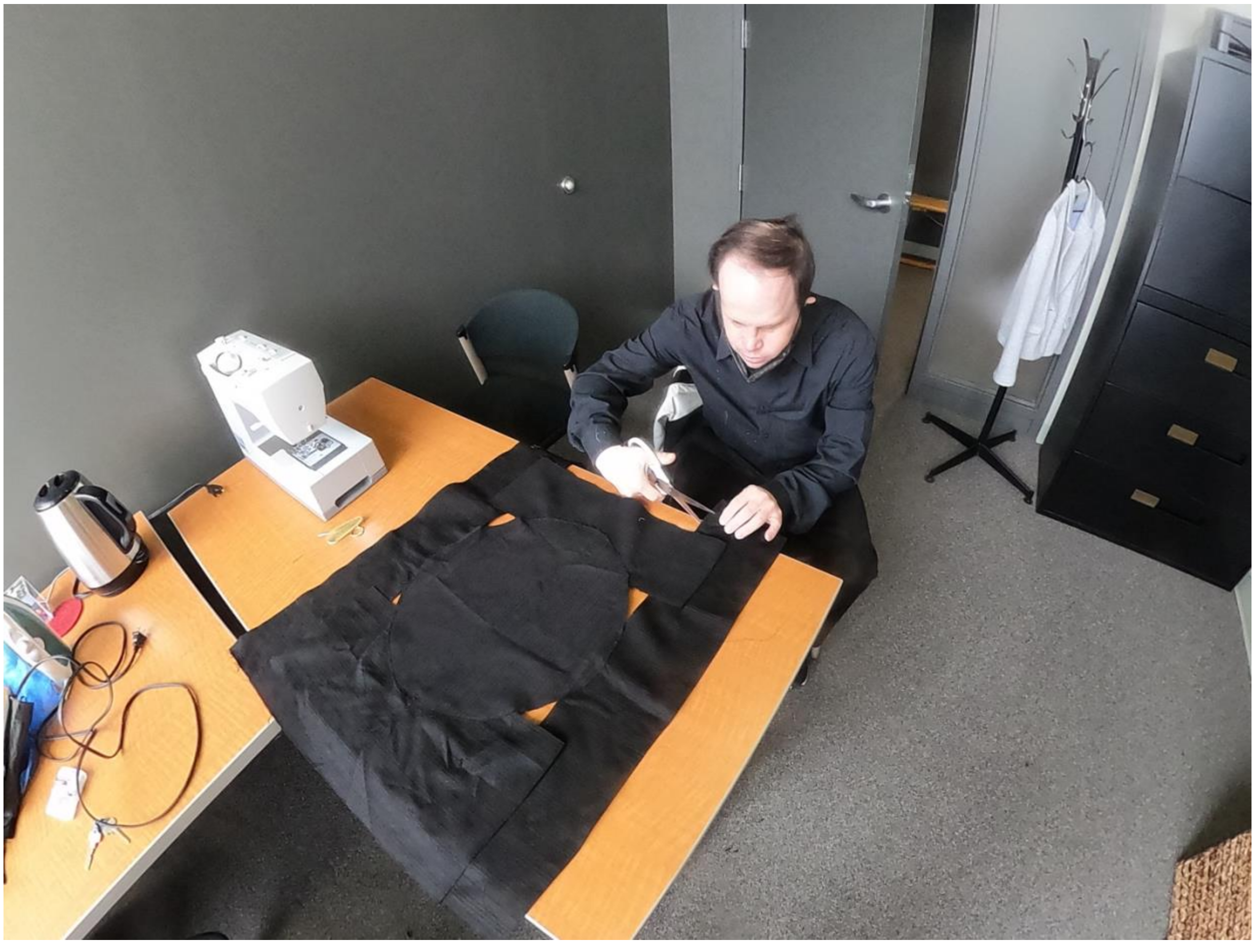

Figure 7: A wide angle photo of Ariel working on his collage in Dr. Dokumaci's office. He holds the fabric steady with his fingers. cutting leftover thread from the lower hem with scissors in his right hand.

I don't think that Ariel viewed himself as a child, as evident by comments such as discussing marriage, "because that's what you do at [his] age." Ariel's previous comment (about the scissors) and this one tells me that I would never have noticed Ariel's internalized infantilization (or the impacts of people with IDD being infantilized) if it were not for the shared craft experience. This highlights another way that co-creation is a method of knowledge production – one that is grounded in situated knowledges. By foregrounding "other materialities" (Jensen 2016), I was able to understand a deeply embodied dimension of disability which could have easily slipped my attention and remain concealed in normative interview methods. In other words, the research-creation aspect of the craft-based interviews I propose function in a way to attune to embodied beliefs or impacts that are not always apparent. Crucially, this interaction might have not materialized if I, too, infantilized Ariel, and did not even ask and give him the opportunity to cut. Again, this is another reason why, in the craft-based interviews with people with IDD, we (as the researchers) need to constantly remain self-reflexive of our own internalized ableism to not reproduce ableist social attitudes.

2.3 Hesitancy as a Symptom Infantilization

Despite no hesitancy to self-disclose, throughout our interview sessions Ariel kept repeating certain phrases that indicated his hyperawareness of pleasing the researcher and hesitancy to express his opinion about the direction of the textile collage. He repeated several times phrases as such:

> With you Jessie, I'm flexible.
> With you Jessie, I am up for anything.
> Remember I am open for anything.
> With you Jessie I am always easy going buddy.
> With you, I'm flexible.

The overemphasis on flexibility suggests a need to please and hesitancy to express opinion, adding another a dimension to the interview that would not have been revealed to the same degree without the craft component. This overemphasis suggests that Ariel does not have a high degree of comfort with decision-making, aligning with research showing that people with intellectual disabilities make far fewer choices compared to the general community (Stancliffe 2020). Such comments were not only reenforcing a power dynamic that I wished to mitigate but also disrupting the purpose of the collage, which was to be a self-portrait about the participant.

Given our previous interaction with the scissors, I was already attuned to the issue of infantilization as it manifests as hesitancy. Considering that autonomy and self-determination are often diminished for those with IDD, Ariel's hesitancy made sense. But as we progressed, engaging in the textile collage became an avenue to asserting agency via tactility. In situations where Ariel didn't want to make the decision (perhaps either because he didn't know or was nervous to), the action of creating became a way to circumvent this hesitance and allowed him to assert his agency. For example, in the following conversation when I was asking Ariel his preference on stitch type:

> Jessie: Would you like to stich it like…?
>
> Ariel: Its whatever you want jessie it doesn't matter
>
> .
>
> Jessie: Because what we can do is do the lines so they are invisible [shows him] or we can do it so visible [shows him].
>
> Ariel: Visible.
>
> Jessie: Ok, so like this [showing him the stitch].
>
> Ariel: Well not actually I was thinking like this [proceeds to take over and show me].

While Ariel initially said that it didn't matter, he, as these comments indicate, clearly had an idea in mind. In other words, it is not that he did not have any idea; rather he had an idea which he initially didn't share through verbal means, but he was able to do so (later on) through visual and tactile means. Though I cannot tell with certainty whether Ariel just didn't know how to verbalize what he wanted (and he physically needed to see the stiches to know what he wanted) or not, I can nonetheless speculate on how the process of engaging with and talking to each other through textiles enabled a venue for self-articulation. The opportunity to engage in direct action became a means for Ariel to express his agency, perhaps in ways that were unavailable to him through verbal communication. While this is a brief moment, it is telling and has significant implications for further uses of the craft-based methods, as it multiplies the avenues of communication, and allows for people with to IDD express their desires without having to use verbal means. Considering that people with IDD have historically been conditioned to an infantilized role (Ditchman et al. 2020), this particular offering of the craft-based interviews cannot be overemphasized.

Ariel also expressed a lot of hesitancy to try each activity independently, even though he picked up everything that he tried extremely quickly. Ariel was very cautious about learning to sew and nervous to do it alone, repeating several times "remember you have to guide me." Sitting beside me, Ariel first watched as I sewed and verbalized the steps. He then took over my seat and practiced straight stiches on scrap fabric as I guided his hands, his right foot carefully controlled the presser foot with precision. When it came time to begin sewing his actual collage, this interaction took place:

> Ariel: This one you really have to really really guide me because I don't want to go too fast but if you can tell me when to go and when to stop.
>
> Jessie: Of course. [begins sewing]
>
> Ariel: Should I slow?
>
> Jessie: No, you're doing awesome. [a few seconds later] You're great at this.
>
> Ariel: I know.

A byproduct of the infantilization that impedes self-determination is that adults with IDD are often not afforded the opportunity to take risks or develop autonomous skills (Ditchman et al 2016). Ariel's repeated hesitations suggest an unfamiliarity with risk, aligning with previous research findings. But while Ariel expressed hesitancy to try, he also expressed a great deal of agency in the situation by telling me exactly how he wanted to learn (e.g., you need to guide, tell me when to start and stop). These moments show a high level of self-awareness and attention to detail suggesting that the hesitancy is not grounded in his lack of proficiency, but is socially motivated, learned or internalized. By foregrounding the research-creation, craft-based interviews give participants room to exert their agency. Given the existing lack of agency so often and easily attributed to people with IDD's, the craft-based method's capacity to hold room for exerting their agency becomes extremely important. Throughout these exchanges, Ariel gradually expressed more agency, his hesitancy became less and less apparent the deeper we move into the craft-based creations. No doubt, this ease was also impacted by the growing comfort we had with each other as we moved through the research. But it was the process of creating together and talking through textiles that afforded the opportunity to increase agency among participants, diminishing hesitancy.

Conclusion

When beginning this thesis, I set out to explore the daily lives and perspectives of people with intellectual and developmental disabilities through my proposed methodology of craft-based interviews. Pairing an interview format with my love of textiles, this thesis was initially designed as a research-creation project, the focus being on what emerged from the co-creation of a final tapestry. As the project unfolded, I encountered many institutional barriers and the ways in which research might reinforce an able bodyminded subject. Writing about these barriers and contradictions (rather than preparing the research-creation outcome itself) became more urgent. Thus, I decided to turn to a written thesis to address the issues that have emerged along the way. I wanted to conceptualize the novel research method that I proposed both in ways to counter the intellectual ableism of traditional research methods and knowledge production and in ways to expose academic ableism prevalent in higher education institutions. I feel a little contradictory having written a thesis about research-creation where I myself, produced very little final creation, but I think it attests to the work and deconstruction that needs to be done to produce a research environment that enables the participation of subjects with intellectual and developmental disabilities.

Introducing craft-based interviews

The crux of this research is the exploration of a novel methodology for conducting research with intellectually and developmentally disabled individuals, which I have theorized as craft-based interviews. As demonstrated by the emergent themes discussed in the previous chapter, the craft-based interviews positively impacted the structure, relationality, and content of the interview process, enabling an understanding of embodied experiences of IDD that draws on many ways of meaning-making and communication. The action of research-creation was arguable more impactful than the products created in each interview, highlighting how “creation-as-research” (Chapman & Sawchuk 2012) allows for new knowledges to emerge that otherwise remain dormant. While the first category of findings, the Material Impacts of Co-Creation, highlights how the craft-based interviews function as a methodology, the second, Corporeal Experiences of Disability, shares some of the critical findings that emerged due to the methodology. Specifically, the social realities of disability, some of which were only uncovered due to the material reality of the interviews, proves a unique interaction that resulted from this research. This led me to again, question what research is rendered absent due to research design that reinforces a compulsory able bodymind?

Future Directions

As with much other research, I must admit that this research comes with its own limitations such as the small and heterogeneous sample size, and the limited time frame for this research. Both Armen and Ariel were fully verbal, so while we used other means of communication, we also used language throughout. How would the results have differed with someone completely non-verbal? Would there be the same level of efficacy with the craft-based interviews? There is also the need for craft-based interviews to be situated into a more substantial intersectional and decolonial framework. As Jasbir Puar notes the field of disability studies normalizes certain kinds of disabled bodyminds reinforcing a western idealized white disabled subject by isolating disability from issues of race, class, and colonization (2017, 67). Given this research's proximity to the academy, dominated by whiteness and productivity, and the privilege often needed to participate in research (e.g. the means to travel to campus), the framework of craft-based interviews risks reinforcing the idealized disabled subject (Puar 2017, 42). Aware of this, moving forward how can I mobilize disability justice scholarship and community collaborations to ensure that craft-based interviews can be a transformative methodology as opposed to one reinforcing existing norms?

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