

Dream/hope/love/create/act (and back):
A collaboration in the dis/ability field

by

Jessica Sahlstrom
B.A., University of Victoria, 2011

A Thesis Submitted in Partial Fulfillment
of the Requirements for the Degree of

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Supervisory Committee

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Jessica Sahlstrom
B.A., University of Victoria, 2011

Supervisory Committee

Dr. Sandrina de Finney, School of Child and Youth Care, University of Victoria
Supervisor

Dr. Michael Prince, Faculty of Human and Social Development, University of Victoria
Departmental Member

Abstract

Dream/Hope/Love/Create/Act (and back) is a collaborative arts-based research project on the experiences that support workers have with enacting support, care and education practices in the disability support and education field. Five support workers were interviewed using arts-based and collaborative methods. Conversations focused on the disciplining power that policies, systems and structures have over the support practices provided to young people labeled with an intellectual disability. Questions were formulated on support worker experiences with enacting care, behaviour support, and curriculum. The following four issues were central to the inquiry: child development and the pressure for language acquisition; issues of consent in everyday practice and clinical spaces; the creation and enactment of behaviour plans; and disability labels and the diagnosis process. The in-depth, unstructured arts-based individual and group conversations were collaboratively designed with research participants, and topics of care, support and professional ethics were intentionally politicized. Conversations took place during the creation of poetry, painting and collage to grapple with practitioners' own power in shaping the worlds of young people. By way of experimenting with diffractive approaches to analysis, assemblages of poetry, art and theory were created as thresholds for entry into the larger thesis assemblage. Transcripts and art were analyzed while thinking with various theoretical threads from critical disability studies, feminism, queer theory, critical race theory and social justice, with the purpose of blurring and resisting harmful and normative support practices. This study shows that support workers are honouring the bodies and communications of resistance of the young people with disabilities they support. This study also shows support workers as deeply self-reflexive as they engage in critical practices in resistance to ableism.

Dream/Hope/Love/Create/Act (and back) has implications for informing research, training and education that grow support work practices to become increasingly consensual and designed with and for young people with a variety of disability labels.

Key Words: arts-based methods; feminist disability studies; politicized care ethics; support work; children and youth

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Territorial Acknowledgment

I acknowledge that the work of this thesis took place on the traditional territories of the Coast Salish Peoples, primarily on the territory of the Lkwungen (Songhees and WSÁNEĆ Nations), as well as on the territories of the Cowichan and Squamish nations. By way of locating myself, I am an uninvited white-settler living on the traditional territories of the Songhees and Esquimalt Nations. I acknowledge my white-settler privilege, and my accountability to that privilege in the face of ongoing acts of colonization of our land, our school systems, social and health care services and legal systems. I acknowledge that this thesis was created inside an academic institution that privileges colonial systems of creating and sharing knowledge, as well as teaching and evaluating student progress; and the long history of Indigenous resilience and action against such administrations. I am humbled and honoured for the privilege to complete this work on these territories.

Gratitudes

I want to thank Sandrina de Finney for her dedication to my process. I am so grateful for the difficult and thoughtful questions that helped me navigate complicated theories, and for her continued belief in my ability to complete this project, despite my many moments of uncertainty. Thank you, Sandrina, for always reminding me of the importance of this work. I am so honoured to have grown this thesis from and through your teachings.

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I want to thank my friends and family for their encouragement and love, for opening their homes to me when I needed to be and write alone, but not alone. For feeding me; for letting me walk their dogs; water their plants; share teas and treats. I was especially thankful when, in different ways, they helped me come to terms with much needed breaks from the process and helped me return to the process. These were difficult life lesson years, and all the love kept me going.

Thank you Pkols, the cedar tree at Francis King, Hemma Community Acupuncture, and poetry.

Dedication

The work of Dream/Hope/Love/Create/Act (and back) is dedicated to JR.

Prologue: The Responsibility to Stories

“Take Will Roger’s story, for instance. It’s yours. Do with it what you will. Make it the topic of a discussion group at a scholarly conference. Put it on the Web. Forget it. But don’t say in the years to come that you would have lived your life differently if only you had heard this story. You’ve heard it now.”
(Thomas King, 2003, p. 60)

Each time I read Thomas King’s (2003) *The Truth About Stories*, I find myself learning something new about the power of stories in shaping our worlds. Still yet, I wonder if I truly understand their power; or am acutely aware, which makes me uncertain if I want the responsibility of telling stories, especially retelling other people’s tellings. I feel stories, their weight, their humour, their harm, their love, their hope; it is a great privilege, gift and responsibility to receive the stories of others. At the beginning of King’s (2003) book, he references Leslie Silko’s *Ceremony* as a way of explaining both the evil of the world and the power of stories to produce and/or disrupt that evil. In King’s (2003) summary, it was Witch people who brought evil into the world. In Silko’s story, according to King (2003), Witch people from all over got together to see who could come up with the scariest thing:

Until finally there was only one Witch left. No one knew where this Witch came from or if the Witch was male or female. And all this Witch had was a story. Unfortunately, the story this Witch told was an awful thing full of fear and slaughter, disease and blood. A story of murderous mischief. And when the telling was done, the other Witches quickly agreed that this Witch had won the prize. “Okay, you win,” they said. “[B]ut what you said just now—it isn’t funny. It doesn’t sound so good. We are doing okay without it...take that story back. Call it back.” (Silko, 1977, as cited in King, 2003, p. 9-10).

As King (2003) explains, the Witch could not call this story back. Using *Ceremony* as an example, he presents a warning “to be careful with the stories you tell. And you have to watch out for the stories that you are told” (p. 10).

In addition to being responsible to and for the stories we tell and hear, we also need to be responsible to silence. Silence is something that can at times be used productively, and as language and silence are culturally produced and interpreted, silence might mean different things to different groups of people. However, when you are silent about a harm you have witnessed, you become complicit in that violence. Furthermore, intentional, productive, thoughtful silence is different from the act of being silenced from telling your story. As explained by Lorde (1984):

For when we have been socialized to respect fear more than our own needs for language and definition, and while we wait in silence for the final luxury of fearlessness, the weight of that silence will choke us (p. 44).

In this thesis, I have grappled with my role in speaking to the stories and silences shared by research participants. Our conversations, which focused on their experiences with children and youth whose mode of expression and communication is primarily non-verbal, were dynamic. I could take their gifted stories in a multiplicity of directions, and I worked on retelling them with honour to their spirit. I therefore acknowledge that my retelling is just one way among many.

This thesis can be viewed as a contribution to the stories that “try to set the world straight” (King, 2003, p. 60), one that works on being brave enough to do so despite my uncertainty of retelling stories. It is constructed with data offerings from research participants, and with theory, literature and poetry from a diversity of communities who also might have been driven to set the world straight; refusing to be silenced by forces such as ableism, colonization, heteropatriarchy, racism and sexism. I am grateful for the knowledge they produced before me,

for without their stories, without their courage, their willingness to reclaim what was either stolen or denied or used to oppress, this thesis-story could not be formed, not like this, not with this language.

As a white-settler, able-bodied, neurotypical, cisgender-woman, heterosexual, middle-class person who is able to access higher education, I acknowledge how this location can enable me to slip into a position of “not-seeing,” with less to lose, materially, by staying silent and complicit in violence. I am also aware of the history of white academics and feminists diluting and appropriating theories to the benefit of their careers. As Tuck and Yang (2012) point out, “settler scholars swap out prior civil and human rights based terms, seemingly to signal both an awareness of the significance of Indigenous and decolonizing theorizations of schooling and educational research, and to include Indigenous peoples on the list of considerations” (p. 2), and this is an example of how we settlers might move ourselves to innocence. To expand on this example, in disability studies, scholars will often appropriate terms like decolonization and assimilation without mentioning land, race or culture, to describe either the incorporation of people with disabilities into the normate “center” or their rejection and institutionalization. Additionally, much of the field of disability studies has been created off the body of work of queer and racialized activists and academics, drawing on experiences of the poor and working-class, without associated scholars being poor or working class (Piepzna-Samarasinha, 2018). Disability studies already has a word to describe the erasure and silencing of people with disabilities—ableism—and it intersects and interacts with colonialism, racism, sexism, homophobia and classism, but it is not those things. With these histories in mind, I have difficulty telling research stories entrenched in ideas of ownership that suggest these are not my stories to tell. Yet, if I do not lean into that discomfort and tell these stories, speak to injustice

when I hear and see and sense it, I am not honouring my own voice, and those of the research participants; the stories I received were gifts and sharing them is now my responsibility.

The participants shared with me their perspectives on issues of practice, power and consent that they observe in their work experiences in clinical, educational and community spaces, discussing issues of disability diagnosis, treatment, therapy and education. As I worked with the many stories that flowed into my thesis to create my version of many intersecting stories, I tried to honour my responsibility to those stories, and to tell them with respect and humility. I will now move into my thesis, starting with a first offering to carry throughout the journey of this document:

I'll say it when someone is like, 'well, do you know how dangerous it is to have a child swinging big blocks around trying to hit people? And I'll be like, 'yeah, but behaviour is a form of communication, so I wonder what he's trying to tell us?' (P, research participant).

Language Choices

Throughout my thesis I primarily use people-first language, in line with People First BC. People-first is a movement within the cognitive disability/intellectual disability community that emphasizes self-advocacy, freedom, choice, respect, dignity and inclusion in response to dehumanizing and paternalistic practices (People First BC, see <http://www.bcpeoplefirst.com/>). For example, I say "person with a disability", or "people with intellectual disability labels" as oppose to "intellectually/cognitively disabled-person." I will also say, "person who uses primarily non-verbal expressions." I make such a language choice because of my experience working in communities with people with cognitive and intellectual disabilities who have taught me to do so. This does not mean all people in this community use people-first language; this is

also not to deny its problematics. Similarly, there is a strong movement of people identifying as “disabled person,” for much of the same reasons outlined by the people-first movement, reclaiming identity-signification and labels from able-oppressors. In critical disability studies, scholars typically use and identify with disability-first language. A point of tension in my thesis, therefore, is that my language choice conflicts with the language found in the theory that informs my theoretical framework.

There is a vast history of people with intellectual disabilities having their personhood denied and being silenced from self-definition and from defining their own care-terms and needs. According to Goodley (2014), using the person-first signifier seems to align with values such as autonomy, choice and independence, which all require a highly socially productive and flexible person who has access to an income earned through the capitalist labour economy. Goodley (2014) highlights that very few can achieve the necessary “ideal of personhood” to participate in capitalist economies, exercise full choice, and independence (p. 32). Goodley (2014) alludes to the important contribution of the people-first movement, while at the same time suggesting that such a language choice aligns with neoliberal capitalist ideologies. Such ideologies, according to Goodley (2014), perpetuate ableism, and have constructed those with intellectual disabilities as outside productivity, economies and citizenship. Self-advocates in the people-first movement are perhaps reclaiming self-definition and responding to the history of people with disabilities being “discarded by society” (Goodley, 2014, p. 34). However, people-first language does not question or call attention to the ways that ableism blocks us from celebrating values like interdependence and disability pride.

I have been taught to use people-first language by many of the young people I have worked with as a support worker; work experiences that flow into this thesis but are not

explicitly talked about. The choice of how to identify and how to use labels in ways that resist ableism, while also honouring one's right to self-definition, can be a difficult, deeply political tension to navigate and sit with; self-identification is further complicated by people's diverse, fluid, and intersecting social locations. These terms are loaded, flawed, and deeply situated in historical and socio-cultural contexts. Choosing either "identity first" or "people first" as the only two possible ways a person might language their disability also limits a person to the English and Western/Global North framings of disability. For example, Indigenous communities might not use the term "disability" at all. Therefore, I acknowledge that this explanation of my language choices does not represent the entire conversation; my choice in language remains an unresolved tension for me in my work, and I remain always open to considering challenges and options as they are proposed by the incredibly diverse disability activist communities.

The Shape of My Study

Over the last decade, I have been working as a support worker for children, youth and adults with complex intellectual disability diagnoses in the context of groups homes, community inclusion programs and private in-home respite. Many of the people I have worked with also carry multiple other diagnostic labels, including psychiatric and behavioural. The people I have worked with primarily or exclusively use gestural communication to express their needs, and some use even subtler forms of communication. It is inside this non-verbal world where I am required to provide personal care such as baths and assistance with dental hygiene, companionship, and other tasks associated with "support work."

My study took shape around problematics that are at play in how support work is conceptualized and enacted in the day to day. I focused my questioning around support work with children and youth who use primarily non-verbal communication to convey their possible

needs and desires. This expanded to include issues of education and pedagogy. As such, one of the guiding purposes of this thesis was to invite support workers and other professionals in the broad disability support field to imagine a different way of supporting young people whose language is primarily comprised of behaviours, facial expressions and other forms of non-verbal communication. These children might have “non-verbal” disability designations, be labeled as “developmentally delayed” or have an intellectual disability designation. They also might be “un-labeled,” or going through the disability diagnosis process. I used various methods—art, conversation, poetry—to question, blur, complicate, resist and create a collaborative and activist-informed arts-based research study with support workers and other child and youth professionals, guided by hope and action.

Another purpose of this study was to talk about the medical model’s influence on disability support work, which is underwritten by the larger dynamics of neoliberalism, capitalism and biopolitics. These dynamics might create barriers that prevent support workers, and other people in this field, from supporting an ideology of belonging. The medical model focuses purely on the “biological reality” of someone with a disability, ignoring the person’s environment and culture, while also discounting the historical, social and spiritual aspects of health (Wendell, 1996, p. 35). Neoliberalist ideology encourages and supports self-reliant subjects, constructing citizens as individually responsible for their own wellbeing and success, and for overcoming barriers and limitations, thus creating a myth that a neoliberal culture is an equal-opportunity culture (Goodley, 2014; McRuer, 2006). Capitalism is an economic system dependent on individual citizens’ ability to participate in the production of capital. In a capitalist culture, greater value is placed on subjects who can sustain capitalism, subsequently celebrating individuals able (or willing) to work increased hours (McRuer, 2006). A capitalist neoliberalist

subject occupies a stable, autonomous and independent subject position, one that can exist unchanged across time and between environments. Biopolitical discourses in dis/ability studies show how policy and compulsory able-bodiedness work together to strengthen the hegemonic “normal” center, affirming ability as the typical and normal subject position, rendering a disabled world unimaginable and undesirable (Goodley, 2014).

My study unpacks how support workers and other professionals who work with young people practice inside capitalist, colonialist and medicalized structures. My study questions how our current social order and context of practice [**read ableist**] strives to be accommodating, adaptive, inclusive, but ideologically and materially unchanged (Develin & Pothier, 2006; Goodley, 2014). The research participants and I considered the ways that institutional cultures of schools, as an example, do not appear to build critical evaluations into their curriculum expectations. Without a critical evaluation, the ableist assumptions or ideologies implanted into policies and structures remain unchallenged. The complacency of this work is demonstrated by simply attaching ramps to buildings and inserting a “special needs” place in the classroom to create inclusion. These physical changes of space are needed, but more conversations and action are also needed around designing curriculum and recreation through a disability lens at the onset. A similar argument might be made regarding race, class and gender minorities. The BC Ministry of Education does have various frameworks with the intention of accounting for diversity in education. One such framework is Universal Design in Learning (UDL). UDL acknowledges the diversity of learning styles, and BC curriculum is expected to be created through this lens. However, I am curious to know how and if UDL, in practice, accounts for non-verbal learners and neurodiversity, and not with the expectation that they will unlearn (so to speak) their neurodiversity. The curriculum expectations surrounding communication in BC’s schools is a

much larger conversation, and not one that is fully addressed in my research and thesis, where I focus primarily on the support work practices. However, compulsory able-bodiedness, like compulsory heteronormativity, the naturalization of whiteness and the assumption that class is transcended by choice and free-will, appears embedded into virtually every aspect of practice, discourse and policy. As such, this research project used a feminist intersectional critical disability theory framework (see for example Clare, 2017; Erevelles, 2011; Garland-Thomson, 2004; Goodley, 2014; Piepzna-Samarsinha, 2018) to unsettle the primacy of compulsory able-bodiedness as a practice framework.

When we work with individuals with disabilities, we are often taught to approach our support from a “rights” perspective: the right to choose, the right to dignity of risk, the right to full and effective participation, but rarely, if ever, have I been directed by a mentor, or supervisor, to ask the question “what is their world?” (Blyth, Chapman, & Stronach, 2016, p. 293). Using collaborative dialogue and arts-based approaches, I wanted to bring this question to the forefront of my study by exploring how support workers engage with, and possibly disrupt, rights-based inclusion and expectations of compulsory able-bodiedness and of verbal communication. To do so, I facilitated conversations with five front-line workers around issues of (non) consensual support in existing approaches to behaviour management and language acquisition, among other themes relevant to development and disability. We spoke to potential harmful approaches to support work, and produced art through primarily painting, poetry and collage as a way of countering oppressive structures and moving through our reflexive analysis.

I acknowledge that everything I produce is in process and not necessarily “new,” that my perspective can always be more nuanced, more critical, more radical, more loving and better cited. Despite these limitations, the perspectives and experiences shared by participants are an

important contribution to understanding support work from a critical, non-ableist standpoint, as they build on disrupting the hegemony of biomedical approaches to disability. The participants gifted me with their time, energy, love, analysis, creativity and so much more. I believe that sharing our experiences collectively and having very difficult and sometimes uncomfortable conversations is valuable work. My study created space for deep critical reflective work, and I was and am honoured and humbled to facilitate, gather, and share the contributions and gifts provided by the participants.

Research Participants

Up until recently, young people who use alternative communication were completely absent in disability research. Teachman, McDonough, Macarthur & Gibson (2017) argue that this is likely because researchers could not imagine their participation. In response to this gap, researchers are presently questioning how to show up responsibly and effectively in their work, calling to question definitions of inclusion as they create disability research methods (Blyth et al., 2016; Castrodale, 2017; Goodley & Moore, 2008; Teachman et al., 2017). However, disability researchers are also arguing for research by people with disabilities, contesting the stigma that surrounds who conducts research, and who gets researched (J. St. Pierre, 2012). This gap in research is present across the social services, and especially salient in disenfranchised communities, where the perspectives of those in perceived positions of expertise are privileged over those with first-hand experience. I subsequently acknowledge that front-line service providers are not the most important, or only voice, to contribute to perspectives on front-line service delivery. Nonetheless, support workers have often been left out of the many fields and arenas where disability research takes place. For this reason, my study participates in growing such a voice in research. While my participants included members of marginalized communities,

such as queer, racialized and “crip” identified folks, none identified having an intellectual disability; participants did identify as having psychiatric labels, chronic illness and different mental health labels.

Many feminist researchers are interested in studying with and for so-called “vulnerable” populations—populations whose experiences and ontologies have been silenced, or made invisible, by settler-patriarchal and ableist views of the world (Hesse-Biber & Piatelli, 2007). Some feminist researchers choose to “study up” and work with privileged populations (Hesse-Biber & Piatelli, 2007 p. 149). I chose to study-with support workers [**not up or down, but perhaps sideways and alongside as a fellow support worker**]. For my study, I invited front-line service workers who provide services to children and youth with non-verbal disability designations to participate in group conversations and one-on-one interviews. The people involved in my study had experience in behaviour intervention, counselling, Early Childhood Education (ECE), and support work in group homes, community inclusion programs, and overnight respite centers. The services we collectively provided differ between work environments and age-groups, anywhere from personal care and medication administration, to social and emotional education, to companionship, to facilitating access to community, to providing direct intervention on behaviours associated with one’s disability label. I understand that support workers, and other direct service providers, hold power-over the immediate choices of the people they serve, and at the same time are often constrained and managed by decision-makers in larger institutions: Community Living British Columbia (CLBC), the Ministry for Children and Family Development (MCFD), medical practitioners, their supervisors and directors, among others. However, too often as support workers we might construct our roles as outside the capacity to cause harm, constructing policy makers as perhaps out of touch with the

present needs of service recipients. And by this, I mean to say we risk erasing the many ways we—in positions of power, occupying greater privilege—might also participate in ableist practices or instances of ableism. Being a support worker in the disability field does not remove our responsibility to address and be accountable to our own instances of ableism. In these moments, we miss the nuance as we become incorporated into agendas that at times cause harm, and at other times offer genuine service and healing. As people who deliver the services, I believe there is great value in critically reflecting on the strengths of our work, as well as the places we might need to collectively grow, or shift our practice.

Some of this reflective work can be seen in the Chapters 3 & 4. However, I also encourage readers to visit the website created for the purpose of sharing the participants art-work and educational resources with the broader community. The website can be accessed by using the following link: [DreamHopeLoveCreateAct](#) (and back).

Chapter 1. Theory Stories

This chapter will engage with conversations around disability, inclusion and language as they exist inside and outside the academy (in poetry) (in practice). I begin with an explanation of the purpose of my study, as well as the theoretical orientation that informs the framing of my topic, methodology and analysis. I will then move into a broader discussion of the concepts and key issues in service delivery that my study explores. The concepts I amplify relate to issues such as consent, communication, behaviour intervention and classroom processes in relation to children who use primarily non-verbal forms of communication. I use key concepts of consent, care, power, language and difference to anchor my analysis, and work with the way they have been done and undone over decades. My conceptual explanation of my study draws on an interdisciplinary framework that includes critical disability theory, critical race theory, queer theory, intersectionality and feminist theory.

Unpacking Supportive, Educational and Care Practices

My study engaged with several issues related to the provision of services to “non-verbal” young people. First, research questions engaged with the pressure for language acquisition—such as what does it mean to be off the developmental map in language (Burman, 2008; Varga, 2011, p. 141)? Second, the questions engaged with issues of consent in the context of every-day practice. Third, the were questions brought to bear on the process of “labelling,” questioning the metrics involved in acquiring a diagnostic label, and the labelling process as a method of access to services and funding. Fourth, the questions critically engaged with behaviour plans. Behaviour plans are a set of instructions for front-line service workers to understand what the client is trying to communicate via their behaviour. In theory, the behaviour plan is meant for the client;

however, in practice its use in such a way may not be so clear. Currently, behaviour plans are developed by (primarily) a behavioural consultant who gathers information from front-line services providers. From this information, the consultant determines why the behaviour exists, asking the question, what does this behaviour provide the client with? Following this question, the consultant provides a plan to support front-line service workers in attending to the behaviour with the goal of replacing it with a positive (desired) behaviour or eliminating the behaviour all together. These topics interact with one another and are not distinct. To work with these topics, I will plug-into a range of interdisciplinary theoretical concepts.

Conceptual and Theoretical Nodes

For well over a decade, researchers and writers have been addressing the medical model's influence over the construction of treatment plans, which inform how service providers go on to address the needs of people with disabilities. The medical model has been scrutinized for its singular approach to disability, which Susan Wendell (1996) argues "has both cognitive and social authority to describe our bodies to ourselves and to others" (p. 117). Critical theory scholars have also identified and deconstructed the ableist attitudes in the education and health care system (Garland-Thomson, 2004; Goodley, 2014; Shakespeare, 2006; Titchkosky, 2003). Critical disability scholars are demonstrating how disability and ability are interdependent and mutually constituted constructs, engaged in a complex political and social relationship, each one informing the other, and usually in a hierarchical relationship (Garland-Thomson, 2004; Goodley, 2014; McRuer, 2006).

Goodley (2014), in the preface to his book *Dis/Ability Studies: Theorizing Disablism and Ableism*, explains that moving the researcher gaze away from individuals and toward ableist-disablist relationships in institutional cultures, such as schools and supportive living

environments, might create space for an ideological, anti-ableist, shift. According to Goodley (2014), when you understand disability through the purview of its opposite (ability), you perpetuate an able-bodied norm, and this is in reference to binary logic. Instead, drawing upon Ramlow (2006), Goodley (2014) creates a more nuanced conversation about dis/ability—“connecting across fields of difference”—where compulsory able-bodiedness and individualism are made visible and then decentered (p. 37). The following concepts frame the issues my study raises, as I strive to contribute to an ideological and systemic shift toward connecting across our differences in resistance of ableism (Goodley, 2014).

Power

My conceptualization of power is currently informed by feminist theorists who deconstruct power as a pervasive, productive force that is embedded in social, economic and political formations (Barad, 2007; Butler, 1993; Bordo, 1993; Jackson, 2013; Spivak, 1992/1996). Foucault (1982) explains how power can be wielded in harmful ways, what he refers to as “diseases of power” (p. 779). Foucault (1982) argues that the diseases of power, his examples being Stalinism and fascism, (and I might add Trumpism in our present political climate), enable domination and control of subjects who have become objectified (p. 779). The construction of subjects in such a way is an effect of power (Jackson, 2013). However, Foucault also spoke of power as a productive force inside relations of power, and I understand that power is circulatory, is everywhere, and is not necessarily weighted by constructions of “good” and “bad” but rather exceeds these (Jackson, 2013). Drawing on Foucault’s theorizing of power as productive, Jackson (2013) explains how “power relations are made of various points of instability that produce multiple sites and modes of resistance” (p. 840). Jackson (2013) is interested in these modes of resistance, and how people can transform themselves inside relations

of power. When a child or youth has a non-verbal designation, their site of resistance to power might be displayed as “behaviours” attached to their “label.” As an example, the curriculum children learn, and the design of classrooms, make learning “norms” seem compulsory. Yet, many children of diverse abilities, genders, sexualities, classes and racialized backgrounds actively resist these compulsory “norms.” These moments offer potential to reshape and reimagine approaches to care and education and offer “an opportunity for a subversive resignification of the norm” (Barad, 2007, p. 214). Moments of client / participant / resident / patient / parent / student / support staff resistance offers transformative potential to rethink and reshape the way that we engage in support practices inside relations of power. Such resignification of our practice is central to my collaborative, arts-based methodology, as I consider how we work inside our intra-actions with power and agency.

Agency and Intra-Action

As Foucault theorizes, subjects are not “determined by relations of power” (Barad, 2007, p. 213), but through instabilities, resistances and struggles inside intra-actions (Barad, 2007; Jackson, 2013). Barad (2007) asks, how are “such resistances possible?” (p. 213). She sees the question of cause—causality—central to the question of agency, decentering the linear notion that cause leads to effect (that a subject will act on an object to create an effect; the subject occupying power and agency, the object a passive recipient). To explicate causality and agency, Barad (2007) draws on Judith Butler’s theorization of the materialization and performativity of the body. Butler (1990) argues that the subject does not occupy “some stable existence prior to the cultural field it negotiates,” as power relations do not operate in a “unilateral” way where action leads to effect (as cited in Barad, 2007, p. 213). Butler (1990) also explains how bodies have been constructed as passive objects inscribed with cultural meaning, asserting instead that

bodies themselves are constructed, and their materialization and agency is a thing that is always in the process of becoming. As such, agency, inside relations of power, is made possible through repetition, through the materialization and performativity of the body (Barad, 2007). Through this framing, agency is not something possessed, but rather an enactment (Barad, 2007). In the context of support practices, agency is enacted through relationships with other human and non-human subjects. In this way, and according to Barad (2007), “agency is a matter of intra-acting...not something that someone or something has” (p. 214). Barad (2007) defines an intra-action (as opposed to an interaction) as follows:

The neologism “intra-action” *signifies the mutual constitution of entangled agencies.*

That is, in contrast to the usual “interaction,” which assumes that there are separate individual agencies that precede their interaction, the notion of intra-action recognizes that distinct agencies do not precede, but rather emerge through, their intra-action ([author’s emphasis], p. 33).

Understanding agency through Barad’s (2007) conceptualization disrupts the idea that agency is something that one can give or take by destabilizing the autonomy of all actors involved in the relationship (human and non-human).

The ‘Other’ and Difference

Power—as embedded in discursive formations, policies, institutions and relational practices—can be used to maintain a cultural hegemony, constructing certain subjects as objects of power (Spivak, 1992/1996). This maintains a subject/object dichotomy that produces ‘Othering’ practices. In the context of feminist theory, Simone de Beauvoir used the concept of Other to describe the relationship between men and women, men being the subject and woman as Other (Wendell, 1996). As explained by Wendell (1996):

When we make people ‘Other,’ we group them together as the objects of our experience instead of regarding them as subject of experience with whom we might identify, and we see them primarily as symbolic of something else—usually, but not always, something we reject and fear and project onto them (p. 60).

Wendell (1996) goes on to explain that this process of objectifying people, and reducing them to (often) abject symbols, is sustained by imbalances in power. Through ‘Othering’ processes, the normal center is reinforced, and the abnormal/normal binary sustained (Wendell, 1996).

Erevelles (2011) traces the origins of creating certain bodies as deviant, or “Other,” to the Enlightenment period, where the European, bourgeois, heterosexual, male and healthy body was used as a standard of measurement against which other bodies were measured, defined and subjugated. Women’s bodies, as an example, were constructed as inherently inferior based on values attached to physical and bio-emotional differences. In later decades, with the increase use in colonial forms of measurement, so-called “observable biological facts” connected to race were used to institutionalize deviant bodies in efforts to eradicate difference and preserve the normal center (Erevelles, 2011, p. 30).

Feminist theorists (see, for example, Butler, 1993, and Haraway, 1989) have used the theory of difference as a disruptive force against processes of normalization (Erevelles, 2011). Instead of locating biological difference as a barrier, they have asserted that cultural and political systems of power produce uneven access to opportunity, and thus differences in access to wealth, education and other material privileges. Susan Wendell (1996) writes at length about difference, distinguishing difference from practices of ‘Othering’, stigmatization and oppression. She writes how difference is value-neutral, and that “...to those with a disability, their difference is not exotic, and it may be valued for itself, or for the different knowledge, perspective, and

experience of life it gives them” (p. 67). Erevelles (2011), however, argues that these theories are complicated for the disabled body, as the biological reality of living with a physical and/or intellectual limitation produces very real material barriers, and these operate with systemic and political systems of power, and identity intersections.

In 1991, feminist theorist Kimberlé Crenshaw developed the framework of intersectionality, which makes visible how race, sexuality, ability, class and gender, among other factors, continuously interact to amplify and sustain marginalized subject positions (Nash, 2009). Crenshaw (1991) wrote that “the problem with identity politics is not that it fails to transcend difference...but rather the opposite—that it frequently conflates or ignores intragroup difference” (p. 1243). When we fail to make visible and work from a place of intersectionality, important intragroup differences are erased. The result is programming that might fail to adequately acknowledge the ways that race, class, gender, ability and sex—among many other dynamics—interact to shape experiences. Since Crenshaw’s earliest works, intersectionality has maintained its usefulness and relevance as both an analytical frame, as well as a tool in praxis (Cho, Crenshaw and McCall, 2013). In feminist critical disability studies, an intersectional analysis of social formations of race, class, gender and ability make visible the biomedical and neoliberal structures that maintain the assumption that disability is something to identify, label and eradicate (Erevelles, 2002; Garland-Thomson, 2004; Wendell, 1996.). A feminist intersectional analysis does not stop at understanding the different potential “identities” or cultural influences that might inform a behaviour or create a need. Intersectionality as a tool for praxis also opens a dialogue about structural and systemic power and oppression, understanding that any marginalized subject position was created because difference threatens those with the most power (Cho et al., 2013). At the same time, difference is something we learn to see and it is an

operation of power to use difference divisively. When I create an environment where I think with capacity and I hold myself accountable when I am wrong, it is a political act of sharing power and space. This comes from both a reflexive political praxis, and one that requires intersectionality and a value of difference.

Crip Theory

Robert McRuer's (2006) book *Crip Theory* decentralizes compulsory ableist norms, using queer theory and other cultural studies traditions as foundations. Emerging in response to the erasure and invisibility of lesbian voices in feminist theory (Rich, 1980), Queer theory (see Butler, 1993; Roen, 2002; and Sedgwick, 1990) challenges sexual and gender identities as stable social constructs, questioning and disrupting the harmful homosexual/heterosexual male/female binaries. Queer theory makes visible how these binaries create deviant 'Other' bodies and sexualities. In this way, queer theorists argue that bodies outside cisgender and heterosexual are continually being disciplined to maintain heteronormativity through various mechanisms, such as media representations, social policy and Patriarchal **[controlled]** motherhood (Rich, 1990).

McRuer (2006) writes that crip theory, like other avenues of critical theory, "emerges from the cultural studies traditions that question the order of things, considering how and why it is constructed and naturalized; how it is embedded in complex economic, social, and cultural relations; and how it might be changed" (McRuer, 2006, p. 2). According to McRuer (2006), crip theory, and the theory of "compulsory able-bodiedness," which produces disability, are "interwoven with the system of compulsory heterosexuality that produces queerness" (p. 2). To "crip" something is to acknowledge that a disabled world might be desirable and possible; it is an action taken to resist compulsory ableism (Goodley, 2014; McRuer, 2006). As McRuer (2006)

further explains, the action of “cripping,” and the purpose of crip theory, is to nurture a collective ideological shift in consciousness as demonstrated by new ideas, relations, curriculum and infrastructure. Through a crip theory lens, categories of disable and able are fluid and coexist, transforming the question of “access” away from creating accommodations and toward incorporating diverse ways of knowing, doing and being (p. 71-72). According to McRuer (2006), crip and queer difference, under neoliberalist capitalism, becomes akin to a commodity, something to package, consume and celebrate. Both crip and queer theoretical orientations provide counter-hegemonic discourses on neoliberal capitalist systems that rely on sensationalized stories of overcoming and transcending queer and crip social identities. However, this action needs to be careful not to flatten the dynamic biological and material specificities of those living under the large umbrella of “disability.” The material implications of living with an intellectual disability under our current social structures is far different from the impacts of a chronic illness; all further complicated by the many intersecting social locations a person occupies.

As explained by Sherry (2013), evoking the concept “crip” without naming its historical connection to oppression, as connected to racism and classism, might detract from the economic reality of many people who are living with disabilities. Sherry (2013) views crip [**the re-claimed identity**] and criping [**the action**] as inherently problematic and critique its trendy use in primarily white disability studies academia. Sherry (2013) criticizes McRuer’s coming out as crip as mere performance in cultural theory, without potential to address structural and material inequity. As Sherry (2013) argues, the term cripple has been historically only traced to those with physical disabilities, and the singularity of “crip” politics and academia might alienate advocacy and activism from across the disability spectrum. In constructing his argument, he uses

examples of women leaving abusive relationships who have suffered head injuries, and those of the intellectual disability community who align with People First language (Sherry, 2013). His claim being that these groups would be offended, or alienated by the term, drawing from his experiences of working with these groups. However, I wonder if Sherry (2013) is somewhat under-claiming his own connection to academia and whiteness in his critique, while also using his front-line experience to construct himself outside the possibility of homogenizing these groups.

In contrast to Sherry (2013), Kafer (2013) sees *crip* as an expansive and portable term, with roots in social justice. She also acknowledges that *crip* can simultaneously be exclusionary of people who want cure for their impairments, or who do not align with the cultural movement. *Crip* and queer theory might create space for fluidity within (sometimes) hard-to-carry mental health and disability labels, at the same time as it disrupts and complicates the broad and fluid categories of sex, sexuality and gender. By bringing “*crip*” theory into my study, I am doing so in acknowledgement that promises of cure and of individual fulfillment and happiness as ultimate goals of life, which are fed by capitalism and neoliberalism, cause significant harm to bodies and minds that cannot be cured, and fail to hold space for the harder-to-carry (Clare, 2017; Kolářová, 2017). I evoke the “*crip*” used by Kolářová (2017), who explores the harm caused by the promise of cure. She uses “*crip*” as a “critical strategy [for] rupturing ideologies of cure, rehabilitation and overcoming, ideologies that inflict hurt and violence (not only) on *crips*” (p. 244). My study speaks to intellectual disability and neurodivergence, both of which have little space in the Western/Global North social imaginary as valid differences. This might be evidenced by the historical and present investment of government funding into short-term normalizing and stabilizing therapies, such as psychiatric services and speech language

therapists. In this spirit, I use a “crip” orientation as a resistance to normalizing practices that have taught me to treat away pain, trouble, difference and difficulty.

Crip theory occupies a place of controversy, contradiction and tension; for Kafer (2013), the point is to exist inside of those created tensions, busting the able/disabled binary (Kafer, 2013). I draw on crip theory in my study, grateful for its analytical frame and justice-oriented potential.

Dis/ability

“This desire to make people wince suggests an urge to shake things up, jolt people out of their everyday understandings of bodies and minds, normalcy and deviance” (Kafer, 2013, p. 15).

As previously discussed, I primarily use people-first language (person with a disability) in respect to the intellectual disability community who taught me to do so. However, I feel uncomfortable choosing a “right” label or frame inside the limitations of the English language; I acknowledge that the options are insufficient and all problematic in some way. The idea of trying to have one perfect universal label for a plethora of disability experiences homogenizes differences amongst differences. Moreover, “disability” is labeled differently between cultures, with terms not necessarily translatable. I do agree with Goodley (2014), McRuer (2006) and Kafer (2013) who see disability as (at times) a cultural category, at other times an entry-point for analysis, and as a thing that describes very real material, corporeal, and physical experiences. Puar (2017) describes disability “in relation to assemblages of capacity and debility, modulated across historical time, geopolitical space, institutional mandates, and discursive regimes” (p. xiv). Puar (2017) continues to explain the role of globalization in the construction of disability. From a human rights perspective, the expectation of accessibility is universalized, with mandates for inclusion and equality built into the United Nations Convention on the Rights of Persons with

Disability. However, as Puar (2017) argues, a person's disability in one part of the world might be entirely accommodated, but in another, the resources and infrastructure simply are not available. This is also true between different political jurisdictions and social and economic environments in Canada. In this way, a person can be further debilitated or capacitated depending on where they live in the world, and in the context of very different and highly stratified and inequitable global, economic and material realities (Puar, 2017).

Goodley (2014), who draws on Puar's (2010) work on debility, interrogates the power structures (ableism, sexism, racism, classism, neoliberalism) that shape access to resources. Goodley (2014), along with many other theorists, make visible the ever-expanding definition of disability, and therefore, those included in that naming. Goodley's work is also informed by McRuer's (2006) work on crip theory, through which we might begin to imagine both an abled and disabled world—that something about disability is even desirable. Desire can loosely be defined as a productive force that urges movement toward something more than a biological need (Erevelles, 2011; Sedgwick, 2003). According to Sedgwick (2003), our affective desires, which are different from our biological drives such as eating, are the ones that make us feel alive, such as music, poetry, joyful and abhorrent textures, love (Sedgwick, 2003). Affect “can be, and are, attached to things, people, ideas, sensations, relations, activities, ambitions, institutions, and any other number of things including other affects” (Sedgwick, 2003, p. 19). Desire is therefore not something fixed, but rather in constant evolution (Erevelles, 2011). Using the language of “desire” might offer opportunity to re-frame experiences with disability away from a capitalist framing, which creates limitation and lack, forces that might prevent proliferation. Disability disrupts desire at the level of one's worldview, the desires we perhaps did not realize were desires, the ones informed by naturalized ideals such as feelings of independence. In doing so,

disability, as it enters a “desiring machine” (Deleuze and Guattari, 1983, as cited in Erevelles, 2011, p. 50-51), produces new ways to desire being human, in relationship with other humans, technology and non-human species (Erevelles, 2011). I believe the point is not to focus on individual bodies, or desiring a disabled body, but rather a disabled and abled world—an ontological shift in the way we think, and the way we achieve affect and need.

Goodley (2014) warns, a caution originally published by McRuer (2006), “one should be mindful, however, that any discourse could be ‘appropriated, commodified, and made to serve the dominant interest’” (p. 175). As such, conversations around re-imagining and desiring a disabled world cannot be divorced from the sociohistorical shaping of capitalism and neoliberalism, systems which benefit some more than others. These are systems that create and sustain race, class, gender and ability disparities, and continue to cause physical harm to children (Clare, 1999; Inclusion BC, 2018). An example of such harm includes how the mythical able norm grants teams of doctors the right to measure and observe children with cerebral palsy for the purposes of education (Clare, 1999). Clare (1999) refers to this as a neo-freak show, discussing children’s peculiarities and differences as if they were not in the room, creating a spectacle of their bodies. Moreover, and as recently discussed by the Inclusion BC (2017) report “Stop Hurting Kids II,” children with disabilities and behavioural difficulties continue to be secluded from their peers. Parents surveyed for this report expressed that the use of restraints in BC’s public schools persist despite releasing a similar report in 2015 (Inclusion BC, 2017).

Piepzna-Samarasinha (2018) and Puar (2017) both point out, disability comes with very difficult and challenging days; no amount of reimagining or desiring a disabled world will make disability less difficult on those days, and in contexts of persistent structural inequity.

Accessible Care

A central focus of my study is the way that front-line support workers understand, enact and problematize their role in providing “care” to young people with disabilities in group homes and educational environments. According to Kelly (2013), care in disability studies can represent the “failure of medical cure and neoliberal progress; it is a deep compassion and empathy; a highly intimate relationship; an institutionalized approach to disability; a transnational supply and demand of feminized labor; [and] a dependency on state-funded programs” (p. 790).

Piepzna-Samarasinha (2018) points out that in western countries, people with disabilities have historically had two ways of accessing care: through government-funded programs and institutions, or through the family home. They explain that these “two forces” have “sometimes, well, often, come with abuse and lack of control” (p. 33). For example, under the guise of “care,” people with disabilities have experienced forced sterilization, sexual abuse, physical abuse, restraint, neglect and other methods of dehumanization (Clare, 1999; Kelly, 2013; Piepzna-Samarasinha, 2018).

Kelly (2013) begins her conceptualization of “accessible” care by describing the complicated and at times violent relationship that the field of disability has with “care.” Kelly (2013) explains that the potential for “daily practices of ‘care’ to veer into pain and oppression is high” (p. 786), ranging from instances of abuse, to the constant change in caregivers and support workers. Kelly (2013) challenges the “binary” of “carer of” and “cared for” (p. 787) to highlight the importance of centering the person one supports as the person describing what care is to be received, how and when. Kelly’s (2013) analysis also makes visible the blurred and deeply gendered boundaries of caring, in order to decenter its attachment as a purely altruistic function, or as a purely process-oriented action to create access to ones needs.

Piepzna-Samarasinha (2018) speaks to issues of care centered on those inside the disability community. They write of the capacity for people with disabilities to care for one another and highlight the gendered nature of this work. As they explain, trans and femme women, and often those who are also chronically ill/disabled, often fill the gap of independent living models and paid supports. As a result, much of care work has been heteronormalized and gendered, and thus deeply devalued, depoliticized, undertheorized and often constructed as private work. Piepzna-Samarasinha (2018) provides numerous examples of the way that people with disabilities can define their own care within their own communities, thus reclaiming care from dominant institutional models, which have largely been informed by ableist and colonialist agendas of institutionalization, erasure and cure. In bringing an explicitly politicized lens to my analysis of support work, I call into question the tensions inherent in the process of “care.”

I extend Piepzna-Samarasinha (2018) and Kelly (2013) analysis of care to support practices with young people, and to environments where young people have been constructed as occupying and enacting little agency and self-determination; where their agency—their sites of resistance—are silenced in unequal distributions of power relations. For example, if support practices are to be provided where the recipient directs the care, how does this compete with expectations of smooth, organized classroom processes? How does this interact with the strict bathing and eating schedules sometimes found in care facilities and group home living structures? I also call into question the social and cultural expectations of “care,” and of having clear professional boundaries, while also challenging our assumed expertise over the behaviours, needs and body-minds of young people.

Working Against the Harm of Normalizing Body-Minds

Eli Clare (2017) uses the term “body-mind” in his book *Brilliant Imperfections: Grappling with Cure*. He does so “in order to recognize both the inextricable relationships between our bodies and our minds and the ways in which the ideology of cure operates as if the two are distinct” (Clare, 2017, p. xvi). I use the term “body-mind” in resistance to the pervasiveness of white Western medicine and cure, while not discounting its value. According to Clare (2017), “curing” the body, or temporarily fixing and correcting impairments, is a focal point of Western medicine. In this system, bodies and minds become separated and fragmented. Western cure also promises a return to a body that was lost or was never had. For young people with disabilities, that extends to their entire body-minds; “cure” ideologies underline the impetus to make a child as non-disabled as possible, while preventing future disabilities, and this gets woven into capitalism and neoliberalism. A child’s body is divided between specialists, who focus on corrective equipment, medicine, speech, movement; there is a specialist for each body part who is professionally trained in medically informed cure and prevention practices. The bio-medical lens prevails even when the care provided is family- and patient-centered. As Clare (2017) stresses, the promise of cure and prevention found in the unquestionable support of normalizing therapies might render the nuances and benefits of disability invisible (Clare, 2017).

In addition to unpacking therapeutic and Western medical practices, my study also speaks to recreational programming, and policies that shape educational, health and mental health interventions that support workers apply to their practice. Some of these are formerly taught in practice-focused educational disciplines such as social work and child and youth care; however, others appear to be formed and created by support workers as they learn with and from the person they support. In some participant examples, perceived intellectual disability showed

unexpectedly in their work environments. I wanted to engage with various examples of how disability appears to be constructed as an experience restricted to medical spaces and special education rooms during childhood. According to research participants, disability education or nurturing an expectation to think with both ability and disability, is not yet part of the standard for education for those who work with children and youth. At the time of writing, the School of Child and Youth Care and the School of Social Work at the University of Victoria each offer one course with a special focus on disability. Early Childhood Educators have the option of specializing in disability, or not. Yet, regardless of whether one is trained in special education, or disability, children and youth with disabilities exist in all areas of practice, including counselling, recreational programming, family services, outdoor education, and schools. For those who choose to make disability their field of practice, advanced training options are limited to one of the many therapeutic fields dedicated to “curing” or correcting disability. Fields such as special education, behaviour intervention, and speech pathology, in different ways, might inform a child’s own view of their disability as always negative, as something to hide and/or unlearn.

More grimly, Garland-Thomson (2017) might critique some of the methods of practice as informed by a “eugenic logic,” which—and speaking from a solely disability perspective—she defines as “modernity’s sustained commitment to eliminating disability from the human condition” (p. 53). Though Garland-Thompson (2017) was discussing eugenics in terms of disability, the eugenics movement did not just seek to erase differently abled bodies by forced sterilization; this treatment was enforced on black and brown bodies, queer bodies and poor bodies—essentially any human who was deemed “unfit” for parenthood. “New” eugenics and compulsory able-bodiedness, as drivers of ableism, flatten the nuanced experiences of dis/ability, both the gifts and the struggle. Such a flattening provides virtually zero space for disability to

exist in childhood. This is seen through developmental milestones. It is also seen through the emphasis on early-Autism diagnosis, so that treatment can begin as early as possible. Similarly, eugenic logic, as a tool of ableism, naturalizes the choice to use equipment such as leg braces and walking sticks to correct the growth of a child's body without questioning whether their purpose is necessary, or desired, or comfortable. As such, eugenic logic primarily directs the onus of change at the bodies and minds of children, not their environments, and even less so their adult professional workers. The naturalization of eugenic logic blinds child professionals and support workers from dismantling the oppressive myth of the ideal colonial child (Varga, 2011). In "new" eugenics, which many in the disability community view as an extension of the old eugenics, prenatal genetic testing is being marketed as protecting children's rights to be born without a disability (Ekberg, 2007). In addition to pre-natal screening, new eugenic practices, such as gene therapy and bioengineering, provide future parents the option of removing genes from embryos that might lead to serious illness or disability (Ekberg, 2007). Gene therapy tells me the story of unwanted children, and thus reveals what body-minds are seen to have social value, purpose and currency. Furthermore, they reveal a gross misunderstanding of what lives are worthy to live a life.

With (new) eugenic narratives seemingly foregrounding much of our work, how might we assist children in developing a sense of disability pride? This question is particularly important given that "cure" and/or "overcoming" disability is one of the central features of the work I and the participants in my study engage in, as we are tasked with facilitating inclusion into often inherently exclusionary spaces. Disability perhaps needs first to be constructed as "not normal" and devalued for a person to internalize shame. The school system, as an example, participates in this construction by encouraging a child to participate in speech therapy at the

smallest hint of speech difficulties in English-language acquisition. I do not want to critique speech language therapy, or any of the therapies designed to support, cure and/or correct and/or lessen the effects of disability, without also holding true that they are important to, and have supported, many people. I struggle with my support work roles with the mandates, objectives and policies that uphold harmful structures (even the most inclusive programming and policies), while holding space for the fact that many of the people I support express a yearning to be “normal” and “cured,” and to access these services. On the one hand, it is an important ethical commitment to honour people’s choices to access services of their choosing, in a way that works for their needs. On the other hand, I understand how unequal access to power mitigates choice, and alternative options of support are often not funded, or presented as options. My study therefore exists in a place of tension and contradiction.

Kafer (2013) uses the idea of “compulsory nostalgia” to unpack the desire to be “normal.” According to Kafer (2013) compulsory nostalgia is embedded in biomedical approaches to disability (p. 43), which assume that disability is something no one would ever want. This is evidenced by the often-posed question, “but if you had a choice, wouldn’t you prefer to be non-disabled?” (Kafer, 2013, p. 44). The disabled body and mind, under biomedical cure, are always being pieced together to pass as able-bodied and neurotypical, and ableism naturalizes this work (Puar, 2017). Kafer (2013) discusses the need to imagine disabled futures because “disabled people are continually being written out of the future” (p. 46) and, I would add, suppressed and silenced in the present through medication, restraint and a hyper-focus on normalizing therapies, as discussed by Clare (1999; 2017) and Puar (2017). Body-mind differences, while packed with experiences of pain and struggle, also provide a new way of understanding oneself in the world (Kafer, 2013; Wendell, 1996). Creating intentional spaces

that nurture differences might “generate new possibilities for intellectual connections and activist coalitions” (Kafer, 2013, p. 131), and trouble our current approach to inclusion and belonging.

Troubling Inclusion

“Overall, the design and position of most of the disability doll accessories in the catalogue and website further reveal how disability is included only at the margins and often in explicit connection to medicine, healing, and whiteness” (Schalk, 2016, p. 45, critiquing American Girl dolls and their accessories).

“Inclusive education can only hope to break the inherent paradox through supporting the radical vision that disability is in fact desirable” (Goodley, 2014, p. 166).

“Instead of these various strategies for culturally rehabilitating disabled people’s experiences into recognizable normativities, curricular cripistemologies cultivate ways of realizing failure as an appropriate response to the finite goals of inclusionism” (Mitchell, Snyder & Ware, 2014, p. 298).

Scholars in critical race theory and disability studies have critiqued inclusionism as a national project to incorporate racialized, sexed and disabled ‘Others’ into the goal of reproducing the nation (Ahmed, 2012; Erevelles, 2002; Mitchell et al., 2014). From this perspective, inclusionism becomes a tool to naturalize the agenda of capitalism and neoliberalism, thus ensuring capitalist neoliberalist subjects available for the national economic project. Bodies-minds that are unable to reciprocate care or participate economically are devalued for their inability to achieve productive citizenship (Erevelles, 2001; Mitchell et al., 2014). Erevelles (2002) shows how inclusion, when aligned with the production of autonomous and competent future citizens, falls short when faced with children with severe brain damage and intellectual disabilities. She goes on to explain how these children become “forgotten” citizens, as the very concepts of “autonomous” and “competent” locate “persons with cognitive/severe disabilities outside the margins of “active citizenship” (Erevelles, 2002, p. 6). Erevelles (2002) argues that this positions children with severe disabilities as “(ir) rational and (non) autonomous—qualities that are then equated with non-competence, non-status, and ultimately

non-citizenship” (p. 6-7). Goodley (2014) describes this as the formation of “abandoned citizens.” According to Goodley (2014), an abandoned citizen “relates to the way in which citizens are abandoned and cast off if they fail to meet the neoliberal imperative” (p. 31). It seems to me that the environment that feels “safe” is also an environment with an objective to discipline, to produce, or find “normality,” or normal subjects. We diagnose, label and treat the so-called problem of unruly children. If that fails? The child becomes an “abandoned citizen,” failing to meet the expectations of a neoliberal ableist mandate (Goodley, 2014).

Mitchell et al. (2014) explain that inclusion in public school systems involves making disabled bodies as non-disabled as possible in efforts to fit the disabled ‘Other’ inside an already-existing educational model. According to Mitchell et al. (2014), the purpose of special education classes and therapies is to “make estranged bodies better fit normative expectations” (p. 298). These practices extend to the family system as well. For example, for a family with a child with severe disability diagnoses, often nurses and other caregiver supports are built into the family structure by necessity, providing skilled nursing care that parents cannot always offer. Furthermore, the children themselves cannot live up to expectations of “independence” and “autonomy,” as even their bodies might require continuous intervention to stay alive. Therefore, the myth of autonomy and the nuclear family structure cannot be sustained. In this way, the family home becomes a crip and queer space as it resists nuclear family structures and incorporates support workers and nurses into family structure. Though not explicitly discussed, some of the issues raised in this study might apply to the home environment as well.

Inclusion, as a national project, is also yoked to Western medicine and cure (Goodley, 2014). The biomedical model, in its attachment to cure, has at times been a force that naturalizes disability as a temporary and/or treatable phenomena; the authority of the medical model enables

the naturalization of this temporality and/or erasure (Clare, 1999; Wendell, 1996). Absent from this discourse are those with permanent, life-long conditions such as cerebral palsy, auto-immune diseases, traumatic brain injuries, intellectual disabilities and neurodivergent folks for whom a biomedical cure does not exist; for whom a cure might not be wanted or necessary, for whom in many cases continuing to seek a cure is a complete rejection of disability as a valid difference in body-mind (De Schauwer, Putte, & Davies, 2017; Clare, 2017; Kafer 2013). Absent from inclusion rhetoric are the landmines one must traverse through daily living, the extra time needed to complete tasks, the poverty one lives in when subsisting on Persons With Disability (PWD) income assistance. Absent is the way that neoliberalism and capitalism, along with white supremacy and ableism (and many other disciplining forces) govern who can be included, and silence and render invisible those who are materially and physically constructed outside normative boundaries.

Literature suggests that the issue with inclusion is not a definitional issue, but an issue with how it is put to work (Clare, 1996; Erevelles, 2002; Goodley, 2014; Kafer, 2013). For Goodley (2014), drawing on Braidotti (2006), Erevelles (2011) and McRuer (2006), the assumptions with inclusion as it pertains to young people going through the education system are that (i) they want to be included and (ii) disability as an experience is undesirable. The piece about desire is important to note, for if children are always taught to relate with their disability as something 'Other', how might they know to desire anything else? De Schauwer, van Hove, Mortier and Loots (2009), in their qualitative study with young people going through the inclusive education system in Brussels, wrote that children with disabilities want to be involved in the same activities as their peers, but are frustrated with the extra work and energy required to participate at the same level. Their study made visible that, in the context of Brussels, children

with disabilities navigate and reinvent the single path toward inclusion; and expressed their frustration in doing so. Critical disability studies scholars might complicate De Schauwer's et al. (2009) representation of children's desire for inclusion, drawing on theories of compulsory able-bodiedness (Erevelles, 2011; Goodley, 2014; Kafer 2013), which discipline those with disabilities to overcome their body's design, force ones' body to participate at someone else's impossible standards. Audre Lorde (1984) might critique the desire for inclusion as symbolic of "a mythical norm," explaining that "those of us who stand outside that power often identify one way in which we are different, as we assume that to be the primary cause of all oppression" (p. 116). Bodies become the focus of oppression and the site for discipline, and structural and systemic forces produce how disability is lived, and what it means to be included.

Simplican and Leader (2015) write about the need to move social inclusion to its radical edges, critiquing the assumption that inclusion means belonging to dominant groups. They also write about the way inclusion is measured based on (seemingly) arbitrary numbers. For example, they discuss how researchers use the Index of Community Involvement to identify how "included" someone is in their neighbourhood and community spaces. As Simplican and Leader (2015) stress, "these are "thin" indicators because they tell us about the quantity of interactions but fail to tell us how individuals interpret their significance" (p. 721). Additionally, these indicators are Western-centric and fail to consider cultural differences. The practice of quantifying and measuring inclusion uses colonial and patriarchal methods of assessment, which fail to raise the voices of those that school systems are seeking to include. This practice, therefore, uses a language and a value system that is historically oppressive and 'Othering,' and also fails to create space for the voices of insider cultures. The standard of inclusion becomes a measurement, rather than a means to restructure the culture of schools and communities (Kelly,

2013). I see this as non-listening and non-consensual inclusion; something disguised as material and concrete, yet largely tokenistic and removed from its affective and social justice origins (Ahmed, 2012; Kelly, 2013). As an example, Kelly (2013) writes how “accessibility,” which is an inclusion tool, has become a bureaucratic check mark, rather than a moral and ethical drive. Inclusion gets taken away from the disenfranchised community and becomes owned as a publicity tool by the institutions that oppress and disenfranchise the group they seek to “include” (Ahmed, 2012; Kelly, 2013).

This sort of inclusion, guided by an equal-rights or human rights framework (Ahmed, 2012; Erevelles 2002) at times fails to address the structures that create disability, as well as the effects of that disability (Erevelles, 2002). Undergirding these sentiments is the harmful assumption that everyone has equal privileges, rights, needs and access. Blyth et al. (2016), in their Badiou-inspired essay on inclusion, write:

More needs to be said about the belonging/including dimension in particular. It suggests that “inclusion” is a concept that starts from the outside and seeks to redress a deficit in engagement: to bring something “in” that was previously “out.” “Belonging,” on the other hand, is more like an analogous “family” relationship—you have to start on the inside” (p. 298).

Indeed, the inclusion rhetoric propagated by school districts and policy that informs community support services ominously echoes the inclusion and accommodation rhetoric used to include young girls in the same education as boys, or Indigenous students into a mainstream system, without considering the need to alter the curriculum, or challenge academic institutions (Parisi, 2002, p. 577).

Diagnoses, Funding and Access to the Center

A diagnostic label, which might go on to inform support, is not necessarily a problem. However, when used as a basis for exclusion or when packed with stigma, a label becomes problematic. As Blyth et al. (2016) ask, “does every label instigate a kind of accumulative politics that eventually corrupts its good intentions?” (p. 294). As support workers, we are involved in enacting medical plans informed by labels and medical diagnoses. We are also responsible for documenting how a young person’s funding is being used, and how young people are progressing through their social and developmental goals. As support workers and, I would add, educators and school-based counsellors, our work is often informed by young people’s care plans, behaviour plans and other diagnosis and behaviour management documents. A young person with disabilities will often have multiple support workers (or caregivers, respite workers, and educational assistants). As such, their plan is used to direct all their support workers to work with them in the same way, despite differences in our support practices, and differences in our relationship to the young person. As example, they dictate how to speak to the young person; how to both avoid behavioural issues (say, for example, hitting and biting) by not using potential trigger words; and what steps to take to support the young person emotionally deescalate. They will also be accustomed to support developmental progress, such as how to support a young person with using their words to express their needs rather than gestures and emotions, which is particularly relevant for my study.

Behaviour plans are fixed in a moment of time; they are a linear and concrete set of instructions, and unless revisited and revised, are a static document. Typically, a behaviour plan would not necessarily shift depending on relational and environmental contexts. Furthermore, if a behaviour plan seeks to correct an undesired behaviour, I worry that they subjugate certain

forms of communication and might enable children with “problem” behaviour to be constructed as bad or deficient, instead of their behaviour being listened to and met with in place of deep and critical curiosity and respect. I think with Bordo (1993), who draws on Foucault and Derrida, and wonder, is a behaviour plan (a thing I have created and implemented in my work and have found extremely useful, while also problematic), a tool for enforcing specific socio-cultural and historical expectations on unruly bodies? Erevelles (2000) argues that “disabled students epitomize the unruly subject,” and in the context of education, the unruly subject is seen as “disrupting the disciplined control of schooling” (p. 34). In this way, the unruly subject occupies an agential force that disrupts the various disciplining powers that produce subjects fit for the normative center. In contrast to the stable subject position and the docile body, which is seen as inert and acted on by various normalizing political, cultural and social forces, the unruly body cannot be disciplined.

Diagnostic tools and labels are political, problematic and seemingly so necessary, which is why understanding how support workers engage with and around these labels is a huge piece of my study. Goodley (2014) says of labeling, “each side of the dis/ability divide either brings with it privileged or limited access to social, cultural and economic capital. Ability undergirds citizenship. Yet, a disability diagnosis gives access to support systems and welfare systems” (p. 167). Labels are packed with tension; to be labeled, or not labeled, under the DSM-V, is sometimes a choice, sometimes not. Often, children are labeled without their consent, without considering other factors such as variances in class, context and culture (Goodley 2014). It seems to me that instead of shifting our approach to education and support, where we might reimagine space, time and purpose through a dis/ability lens, we simply relegate unruly bodies to the margins, and then govern these margins with labels. Unless, perhaps, the person comes from

money, equipped with resources, time and love, and then they might have the luxury to transcend their label, use their label to gain access to services and support, or avoid the label altogether (Goodley, 2014). Without these factors, a child might be at an increased risk of experiencing harmful institutional care practices. Some of these include the use of restraints, not benefiting from additional community supports outside strict funding models and being removed from the family home either through a child protection order, or through perceived parental choice. Without access to funding, resources (and advocacy skills for both), a child is also at increased risk of removal from classroom processes, which disconnects them from their peers. In these situations, a child might be subjected to all forms of abuse, with the most pervasive form of abuse being neglect (see Inclusion BC's report "Stop Hurting Kids," 2015/2019). As children with disabilities move through the school system, some might not benefit from meaningful engagement, and might be subjected to behaviour programs that service to socially condition, rather than empower (Inclusion BC, 2019). Children might be at increased risk of being hyper-medicated, incorrectly diagnosed, and not given an opportunity to build community and a circle of belonging and connectedness (Clare, 1999; Clare, 2017; Inclusion BC, 2019). This, however, is not the story for everyone, and a child's access to wealth and resources informs the kind of care they might receive.

Enforcing and Policing a Single Language Expectation

i s t u,,,,,m b l e in this lan guage
i fa ll down in this lang ua GE
i am p & I & n = in this lang | uage.
my (mouth). heart. arms are losing muscle + in this l
a n g u a g e
my body does not \$ recognize the taste \$ of this –
language –.
i long

in this LANGUAGE.”

—e.n.g.l.i.s.h./for all of us who are held captive (Waheed, 2014, p. 177)

I introduce the topic of language from a critical race theory and social justice perspective, in acknowledgement that the trouble with the English language as a violent colonial tool, implicated in epistemic genocide, has already been deconstructed. I am not necessarily changing this conversation but building upon the work of critical race theorists. It is from Black poets like Nayyirah Waheed and Audre Lorde that I have learned of the ways English has been tooled to oppress, control and silence across continents, genders, classes, dis/abilities and races. Waheed’s poem reminds me that enforcing a singular language, based in a singular worldview, with an expected tone and syntax, can cause physical and emotional harm. All cultures and creatures have a language system, but the history of the English language, as well as the Spanish language, seems more loaded with stories of oppression than others (Puar, 2017). I think with this history, these words, as I join my thinking with critical disability studies, noting too that the disability to speak with verbal language is not a culturally specific phenomenon. However, the action to pathologize speech-language disabilities might be unique to cultures dominated by ideologies of cure as informed by Western medicine.

J. St. Pierre’s (2012) work is part of a growing movement that focuses on language acquisition and performance from a critical non-medicalized position . J. St. Pierre focusses on stuttering, deconstructing the expectations of syntactically and fluent spoken English (2018; 2015; 2012). From a disability perspective, “to perform normalized speech one must move according to a particular rhythm, analogous to dance, as the “correct” production of speech relies upon an intricate coordination of breathing, articulation, facial expression, bodily stance, and gesture” (J. St. Pierre, 2015, p. 50). According to J. St. Pierre (2012), current literature frames

challenges in language acquisition as an individual and highly medicalized problem, removing any sort of responsibility from the listener, and I would add contextual and environmental responsibilities. J. St. Pierre (2012) labels the limitations in language acquisition and stuttering as “broken speech,” based on the stutterer’s departure from the hearer’s expected rhythm, from intonation to sudden shifts in syntax. In their reframing of broken speech, J. St. Pierre (2012) acknowledges that the responsibility of broken speech is the responsibility of both the speaker and the hearer, and in this sense speech is relational. J. St. Pierre (2012) explains that intonation and syntax are not universal constructs, but change from culture to culture, and from context to context. Speech-therapy programs and assistive technology allow a person with verbal delays to participate socially and economically (J. St. Pierre, 2015). However, the communication is still something different from the expected, or assumed, or perhaps even desired, language ability, with a shift in tone, a broken piece of syntax, or a grammatical inconsistency. The speech might be slowed or deciphered through a machine. Subsequently, in efforts to eradicate what I might say is a constructed limitation with real-world implications, I wonder if a person’s communication ability is devalued, as they fail to achieve language proficiency; I consider these problems, as well, for children whose primary language is not English. For example, Indigenous languages are not presently considered for school credit, and therefore are not valued as formal language systems. Furthermore, I worry and wonder whether the focus on verbal language acquisition devalues embodied, gestural and behavioural communication. Burman (2008) and Garland-Thomson (2004) claim that we are choosing to privilege the able-bodied by discouraging forms of communication outside formal language.

The notion of “formal” language—that if it has not been coded and categorized, it does not qualify as language—is a contested concept. As explained by Baggs:

Like counters, stairs, and drinking fountains, language was built mostly by non-autistic people, with the obvious results, and my biggest frustration is this: the most important things about the way I perceive and interact with the world around me can only be expressed in terms that describe them as the absence of something important (para. 3).

Baggs (2010) continues to write of their language as something patterned and situated inside sensations, of sound, feeling and texture. As Baggs (2010) reflects on their own language acquisition, they explain how they worked with tone to understand words. Baggs (2010) does not consider the words they type and speak as constituting their language, but rather sees these as an “artifact of a shoddy translation” (para. 16). Baggs (2010) critique of language is important as we consider expectations of language acquisition and neurodiversity. Language and communication are diverse across the vast human spectrum, from different cultures, to different neural developmental pathways. However, young people with communication differences outside Euro-Western framings of development continue to have their communications suppressed by so-called development specialists.

Burman (2008) stresses that “language acquisition is taken to mark the graduation from infancy into early childhood... when infants develop into children who develop into adults, through universal steps moving from ‘babbling,’ to first words, to sentences” (p. 182). According to Burman (2008), learning language in this way suggests that language acquisition is a linear process, and is centered around verbal utterances. Develin and Pothier (2006) explain this in terms of a cost-benefit analysis: which children will give us the biggest return on our investment? Likely children with the ability to learn verbal language. But, as Develin and Pothier (2006) ask, “is this an appropriate way for us to value each other?” (p. 18). I do not mean to

argue that individuals sit down and rank children on how able-bodied they are in relation to their earning potential. However, children are most definitely ranked on their ability to measure-up to an idealized and constructed norm through IQ testing, psychometrics and speech assessments, among many other metrics (Burman, 2008; Mitchell et al., 2014; Simplican & Leader, 2015). As Burman (2008) cautions, “it is the normalisation of development that makes abnormality possible; and vice-versa—in the sense that the special education system has always deeply structured, rather than merely supplemented, the mainstream schooling system” (p. 21).

At some point, an observation is made, a concern created, a measurement and assessment undertaken, a label produced, which leads to a child’s removal from mainstream education, from the classroom, from the so-called normal center (Burman, 2008; Goodley, 2014). Do we simply accept these outcomes? Why do we want to maintain this system, anyway? I merge the issue of “the disabled speaker”, the speech pathologist’s role in supporting the child achieve syntactically cohesive language, with the support worker who chooses not to listen to behavioural communication with the expectation that the child will use their words.

I see a link between issues of power and consent with the way difference operates or gets operationalized when working with children and youth. In subsequent chapters, I will explore this in greater depth in relation to my study. I will unpack the use of psychometrics to measure disability and the way that curriculum and classroom processes, as well as behaviour modification, are enacted on the bodies of children drawing on the stories from practice I have collected over the course of my study. I will draw on conversations that I had with study participants regarding early childhood, behaviour intervention, and youth transitioning services. I will unpack the construction of children with “behaviours” as difficult monsters (Simplican, 2015), and will speak to the various ways that the participants in my study work against

normalizing practices, and/or participate in this practice with tension and with important questions about their roles and ethics. I will also discuss acts of resistance to these practices, and possibilities for other practices that were shared with me. In this way, my study works against normalizing practices, enacted inside power-over relationship dynamics, making moves toward intricate, interdisciplinary intra-actions, inside political and ethically complex relational practices.

Chapter 2. Gettin' Artsy with Political Purpose: Collaborative Arts-Based Feminist Praxis Methodology

For my study, I invited front-line service workers who provide services to children and youth with non-verbal disability designations to participate in arts-based group conversations and one-on-one interviews. As previously mentioned, the people involved in my study had experience in behaviour intervention, counselling, ECE, and support work in group homes, community inclusion programs, and overnight respite centers. During our conversation, we collaboratively discussed the ethics involved in working with young people with disabilities, and I asked participants to speak to their experiences with enacting front-line services.

When I think about the ethical and political complexities of support services for those with disabilities, I begin to imagine all these tiny inter- or intra-connected machines and assemblages. Philosophers and psychoanalysts Deleuze and Guattari (1987) have theorized how we might think differently about assemblages of ideas, forces, actions and bodies. I also find the concept useful to shift my own thinking away from seeing things like data, theory, and concepts as individual, compartmentalized entities, toward seeing them as intra-connected. They describe the way that an assemblage, on the one hand, appears as a “signifying totality,” problematically solidified into a subject position that becomes difficult to challenge, such as the categories of “disabled” and “victim,” but also the category of “inspirational” (p. 4). Deleuze and Guattari (1987) also explain that an assemblage can rupture problematic subjectivities and produce entirely new ways of organizing our bodies and relations. An assemblage, then, “is continually dismantling the organism, causing signifying particles, or pure intensities, to pass or circulate, and attributing to itself subjects that it leaves with nothing more than a name as the trace of

intensity” (p. 4). I understand this second part of their definition as describing the vital energy that passes through a series of things that come together to form a whole. An assemblage could be a distinct “object” or “objects,” with a clear subject(s), but from another perspective, an assemblage is also interconnected multiplicities and relationalities. By presenting their book as an assemblage, or like “a little machine” (p.4), Deleuze and Guattari (1987) provide a lens that can be applied to thinking about qualitative methodology as emergent, multiple and relational. I also see their description of an assemblage as a potentially valuable tool for critical disability praxis, as subjects might be more readily understood as fluid, contingent, and not fixed and solidified.

Throughout this chapter, I explain how I enacted methodology as a form of emergent, action-centered praxis, as part of my thesis-assemblage. To support my study’s topic focus and ethical commitments, I have created an interdisciplinary research methodology that is informed by disability, feminist and arts-based methods. I also draw on methodologies that have been informed by the work of Deleuze and Guattari, which have provided me with language to imagine differently, beyond dominant modes of doing, being and thinking (Jackson & Mazzei, 2013; MacLure, 2013; C. St. Pierre, 2013). I will first describe my method of writing, before moving into a description of my art and interview methods, followed by an overview of my theoretical and ethical orientation.

Crip Writing

McRuer’s (2006) analysis of academic writing, where he argues for the “desirability of a loss of composure,” informed my initial vision of re-presenting conversations, ideas, art and knowledge (p. 149). I worked and am working with the energy of theory and data by mixing different styles of writing and artwork. McRuer (2006) might argue that this is one way to “crip”

research, and I wish to also use diverse modes of expression to “crip” support practices. Crip writing is acknowledging that modes of expression do not need to be unidimensional, linear, or traditionally Eurocentric in their academic form. Rather, in a crippled academia, the text might be messy and disorganized. The academy would value the in-process writing as well as the tidy, linear and cohesive texts, and modes of expression outside written language. I have used McRuer’s ideas about crippling writing—losing composure and structure in some sections—by **[bolded & off-set text]** and tangents and art **[and some might say, this thesis is trying to be art]** research.

Procedural Ethics

My ethics combined procedural ethics, such as gaining approval from UVic’s Human Research Ethics Board and obtaining signed consent from the participants, as well as an on-going ethical commitment through a process of relational reflexivity. I grounded myself in my own social locations, and the experiences this social location limits me from truly knowing (Phelan & Kinsella, 2013). Consent forms were signed at the end of our first meeting, after participants had an opportunity to discuss what would be involved. I obtained verbal consent, as will be explained later, at each stage of the research. As best as possible, I strived to make it clear that participants could rescind their consent at any point prior to my final examination copy being submitted to my committee. Participants also understood that either me or other participants might use their art pieces and transcript for collage, and that their art might be added to and changed by others involved in the research. Such art would be difficult to return or remove from the research.

Inviting Participants

I initially contacted two community agencies to share my recruitment poster. Of these two agencies, one agreed to share my recruitment poster. Unfortunately, I did not attract any research participants from this connection. Subsequently, it was suggested to me that I reach out to my personal contacts. I amended my ethics and got approval to recruit from my personal contact list.

I sent a group email to people I knew in the community through various shared workspaces, including people I knew through friends who worked in the field. I also reached out to some with whom I have close friendships. I bcc'd all email addresses for confidentiality. From this email, four people expressed an interest to participate in my study, and a fifth participant volunteered because they knew of my research. To avoid possibility for coercion, I made it clear in my consent forms that should someone choose to withdraw, or not participate, their decision would not impact any current relationships. Likewise, I did not individually contact any of my personal contacts, thus removing some pressure to respond.

After I had five participants, I contacted each participant to further discuss the project's aims, methods and ethics. From these communications, I discerned that most participants were more interested in individual interviews, rather than group work. Based on this response, I planned individual interviews with participants, with an optional final group meeting for those wishing to connect with other participants.

Food & Gifts

I incorporated food into my research because I believe that food is a way of bringing people together. I also believe that no one should conduct or participate in an in-depth critical interview on an empty stomach, and I see it as an honour to feed people. One thing I did not

expect was that participants would bring food themselves and wanted to share their food with me. Each participant also received a hand-painted jar as a thank you. I filled these jars with different chocolates and teas that were preferences of the participants. One participant had a dog that I knew would be present during the interview, so I put a dog biscuit in the jar as well. These gestures were a way of honouring the time and effort the participants gifted me.

Questions

The following questions were the draft of questions I gave to the research participants, and were informed by my own practice experience, as well as my engagement with literature from critical disability studies and child development theory.

Stories from practice

1. *What kind of work do you do?*
2. *Without using any identifying details such as names, places or appearances, tell me about an experience working with a child/youth who communicates nonverbally...*
3. *Without using any identifying details, such as names, places and appearances, and if you have experience supporting children or youth attend medical appointments, what have you witnessed in medical spaces...*
4. *Without using any identifying details such as names, places and appearances, what aspects of your work do you enjoy? Frustrate you? Wish were different?*

Child development and the pressure for language acquisition

1. *What is communication?*
2. *What does language acquisition do?*
3. *What is language?*
4. *What are the pros and cons of current language acquisition plans and practices?*

Issues of consent in every-day practice, as well as in clinical spaces

1. *What does consent look like in a non-verbal context?*
2. *How can we trouble exclusive, language-focused means of accessing consent?*
3. *What are the ethical issues at play with non-verbal consent?*

The creation and enactment of behaviour plans

1. *Can we imagine something different?*
2. *Who are these plans designed for and who benefits most from these plans?*
3. *What are the pros and cons of these plans –what do they produce?*

Disability labels/the process of labelling

1. *What have we witnessed/experienced during the labelling process?*
2. *What do labels do?*
3. *How do we (re)act regarding a person's label?*
4. *What else might be possible?*

To engage participants in the process of creating the research questions, I asked the following:

1. *What stands out in this list for you?*
2. *What is this list missing?*
3. *How shall it be arranged?*
4. *Where shall we start?*

Ethics of Relationship Building

I received a mixed reaction from participants to my open-ended choice-driven approach to the research questions. I learned from my first meeting the value of collaborating and consenting right from the beginning on processes and structure. I provided the first participant with a list of questions a week in advance and discussed some research needs by email. However, there were some details that were not covered during our email exchange, which created a longer interview process than planned, as we stumbled toward a beginning. I learned from this experience that, to engage in a meaningful collaborative process, two meetings would be necessary.

The focus of the first meeting was to establish shared understanding and a sense of connection, explain the consent parameters, what the interview could look like, discuss concerns, decide on an approximate interview length. The first interview was also an opportunity for participants to choose the art medium(s) they would like to use during the interview. I made the choice not to record the initial meetings, as it was also an opening for the participants to consider

if participating in this research was indeed something they wished to do. As mentioned earlier, each participant received a print-out of the possible research themes, and optional research questions. This provided them with a chance to think about the personal, ethical, political or practice-focused issues they felt needed to be raised and discussed. A second purpose of this initial meeting was to develop a collaborative research relationship, where I became familiar with participant's environmental and/or food needs. Such actions apply a similar ethic used in disability research practices, where instead of research participants needing to fit inside a pre-determined set of rules and expectations, researchers educate themselves on participant needs, and work those needs into the design of their research methods (Castrodale, 2017; Teachman et al., 2017).

I asked these questions of comfort and need while also knowing that historically, more so for some groups of people than others, it has not always been easy, comfortable, or safe to disclose needs. By using methods informed by critical research methodologies, as well as a collaborative feminist praxis, I understand the necessity to move beyond simple accommodations and adaptations of the research space. To do so, I facilitated intentional conversations on what each person involved in the research needs and wants to happen. Not every "need" can be ascertained and accommodated prior to an interview, as us humans are fluid creatures. However, whenever possible, I tried to involve the participants in the design of the research, without requiring a disclosure, or a "coming out" of disability or mental health. I entered the space of research from a place of not knowing, even for those whom I knew quite well. I strived to challenge my need to set up "safe" spaces, and instead nurture "brave" space (in reference to Micky ScottBey Jones, 2017, as cited here <http://adriennemareebrown.net/2018/01/04/lets-be-brave/>), based on the suggestion of the first research participant who challenged me on my need

to set up “safety.” In disability research, space is a very important consideration “if we understand disability as contextual, changing, and mediated by socio-spatial-temporal knowledge–power relations” (Castrodale, 2017, p. 47). Castrodale (2017) acknowledges that space and context are so often not seen for the way they might shape the knowledge produced during an interview.

Time, like location and environmental needs, were also negotiated in our initial meeting and revisited and agreed on through the entire process. I checked-in on participants’ energy levels, and honoured and appreciated moments of silence as we processed the conversation through art. The conversations we had were emotional and critical, and required an enormous amount of energy, and I often checked in—“How are you for energy?”—taking a fluid and flexible approach to time (Kafer, 2013). Each participant had a different idea about how long they might like, and some participants wished to continue working on their art pieces after the interview was complete.

Art Methods

My interviews combined exploration of the research questions through discussion and art making. I applied an unstructured approach to art in my interviews, incorporating art as both an activity to do, as well as a medium to express ideas and feelings. I have many reasons for doing so, but one crucial reason is my ongoing decentering of verbal language—specifically, patriarchal and colonial forms of verbal language communication, forms of language that are difficult for many of us. I think of the ways that paint, drawing, and mixed-art methods can help fashion communication where language does not yet exist (Lorde, 1984). I used art as an invitation, and not as an expectation.

Several forms of art making as methods were used in addition to unstructured in-depth verbal interviews, as explained below. During the “paint” interviews I provided participants with raw canvas, paint, paint brushes and invited participants to use their own materials. The canvas was placed between me and the participant. The sole instruction the participants received was to begin painting when they felt inspired. I offered to engage in a parallel art making process as a way of accompanying the participant in their art making and exploration of the themes.

In one interview, we used pencil crayons on paper and “doodled” as we talked. I used paper to take notes, shaping my letters in ways that matched with the emotion the participant expressed. During moments where she vented her frustrations, I used block and angled letters; where she expressed a seeming joy, I used smooth-flowing letters. She filled almost an entire piece of paper with concentric multi-coloured hearts. Another participant requested to use driftwood, rocks and other materials found in nature that she could incorporate into her art. I gathered these materials from Pkols (Mount Douglas), which is on W̱SÁNEĆ territory, and from the Dallas Road Waterway, which is on the traditional territory of the Songhees and Esquimalt nations. We used these materials to create messages of hope and love, at times stopping to write a short phrase, word, or symbol on the material’s surface.

I took photographs of this art, and the participants were invited to keep their creations; however, the participants chose to leave most of the creations with me, except for one art piece. The exception was one participant who wished to submit her art for publication. All the art was gathered together to be used during our final research gathering.

Interviews and Art Sessions

Most participants engaged in an unstructured arts-based interview with me. For one participant, we began with one open-ended question. The interview took shape through my

probing and follow-up questions, and them using the paper of “suggested” questions as a visual guide by choice. One participant requested a semi-structured interview. For this participant’s chosen topic focus, I created a draft of research questions that I sent to her a week before our interview, and which we revisited together in our second meeting before the interview began. We agreed on a time allocation for the interview and went through the list of questions from beginning to end. This is a way of honouring that there is not one singular method for arts-based, conversational qualitative data collection, but rather different methods that work for different people. Despite my methods being collaborative, I acknowledged my role as moderator; it was my job to pay close attention to keep the focus on the interview topic, while also not interrupting the energetic flow.



Figure 1. One of the in-process art pieces that would later be revisited and discussed with the artist/participant during our collaborative analysis. This piece was worked on over two meetings.

Collaborative Analysis

Four of the participants expressed an interest in gathering for a final research meeting to make more art with the transcript and in-process art pieces. However, on the day of the

gathering, two of the four participants had to cancel, and I made the choice not to reschedule.

The purpose of the research gathering was to engage in a process of collaborative analysis with the intention of bringing a critical approach to a traditional content analysis (Berg & Lune, 2012). Traditional content analysis would follow several cycles of reading, coding, generating, collapsing and arranging key themes, comparing these emerging themes and creating sub themes, and identifying links and gaps within and among various data sources (Berg & Lune, 2012).

According to Berg and Lune (2012), content analysis finds points where participants agreed and disagreed, looking for “*consensus, dissensus, and resonance*”, and identifying “trends and patterns” ([author emphasis] Berg & Lune, 2012, p. 187-188). My data analysis method followed this procedure, but I also used threads of a collaborative conversation analysis, which Moss (2007) describes as “interrogating the interactional contexts within which researchers and the researched socially construct the phenomena under scrutiny” (p. 380). I revisited the data with participants in efforts to deconstruct our own perspectives, producing a less linear and researcher-driven process of reading, coding and reducing data into themes. As Hesse-Biber and Piatelli (2007) explain, “through collaborative inquiry and reflexive knowledge building, researchers can deconstruct hierarchical relationships and produce research that is useful and meaningful to participants and the larger society” (p. 148).

In preparation for the group gathering, I emailed participants a portion of their transcript, and asked for their consent to share these pieces with the group. At the beginning of the gathering, I provided the two attending participants with selections from the transcript. We read through these transcripts, discussing what stood out for us, what the data stories made us feel, and what provoked politicized and ethical questions. We then shared additional stories from practice that were generated from our collective exploration of the data (art and interview

transcripts). We focused on similarities between the transcripts, and what stood out, and why it stood out. Our conversation was political and provided an opportunity to connect and learn from one another. From there, each of us created an art collage from the data stories, which focused on an aspect of the transcript. We cut pieces of transcript that resonated—me encouraging the two participants to use transcript text that stood out to them on an affective level out. The selected transcript was brought together with texts and images from magazines.

Collage can be defined as the bringing together of different mediums, from text to images to material objects, producing (sometimes) contestable spaces (Kilgard, 2009). Collage as a medium in research is one method that can embrace and create new conversations with dissonance (Kilgard, 2009). Collage is non-linear and layered art method, bringing together multiple divergent texts and mediums (Cosenza, 2014; Kilgard, 2009). As such, the method creates visual juxtapositions, which can be a powerful critical tool (Cosenza, 2014). I see the potential of art collage to resonate on an affective level as well as appealing to critical analysis. Collage aligns with my fluid approach to research and analysis and was helpful in enacting a diffractive analysis.

Barad (2007) explains that a diffractive methodology “is a critical practice of engagement, not a distance learning practice from afar” (p. 90). In this sense, a diffractive approach is an intra-active and entangled action between all matters in research; and a relational approach to engaging with data (Barad, 2007). Patty Lather (2016) describes this collaborative process as looking for patterns, rather than meanings. During this meeting, we did not focus on what data “meant,” as something solidified in the past tense, but rather, what data could create, or are creating, during our continued engagement with data and with each other. I made the decision to forgo recording this group meeting, as I wanted to engage in an informal process. I

explained to the two attending participants that they could take the transcripts and cut out phrases or words that resonated with them, and that they could follow their cord of creativity. I explained that they could piece together different transcripts to form a conversation or data poem or create something entirely different.

Some participants more than others expressed an interest for continued engagement, and I subsequently contacted these participants with data poems and pieces of writing, giving them an opportunity to share their thoughts. Most participants chose not to provide further analysis of the poems, and simply showed an appreciation for seeing the way their data evolved. One participant continued to provide ongoing thoughts and considerations, and this shaped the way I interacted with their data. For example, I would email a research poem, and they would ask me questions such as encouraging a different end point for the poem to produce a different affect. They would also share with me their feelings of the poem, and how it might relate to larger sociopolitical contexts. This informed whether I used a poem in the thesis or not, and where I placed the poem amongst transcripts and analysis. For this same participant, we had two other meetings to create data and research poems. This participant, who writes their own poetry, expressed an interest in learning about this process and participating in further data creation. The poetry from these two meetings have been shared on the website, and in the thesis.



Figure 2. The art gathering, where we turned my apartment into a messy artsy collaboration station.

Why Art?

At times, art is positioned as something “extra” to hard, rigorous data; a visual contribution to the real work—words transformed into numbers; numbers recalibrated into empirical truth statements, steeped in the logics of social-positivism (Barone & Eisner, 2012, p. 39). Arts-based researchers contest this perspective, explaining that visual art carries “a transformative power that can resist and dislodge stereotypical ways of thinking (Leavy, 2009, p. 219). If transformational change is the purpose of one’s research, as Leavy (2009) argues, words might not have the same power to effect that desired change [**what about fierce, reclaimed and poetic words? Signed words? Can words be visual art?**]. I question the purpose of art in research—is it an aesthetic pursuit, or does it require a participatory element, engaged with political acts (Bishop, 2012)? How might art research account for aesthetics (Barone & Eisner, 2012)? Barone and Eisner (2012) define the aesthetic vision of research as “a complex attention,” one which involves “tensions and harmonies,” colours, affect, and is also transformative (p. 37). Clover (2011) explains that often arts-based researchers have been criticized for using art as purely affective. Accordingly, the art in art research is simply “a self-

indulgent exercise for the privileged few,” and therefore, Clover (2011) argues that to be research, art must also contribute pedagogically and/or politically (p. 14).

As Barone and Eisner (2012) point out, “one important attribute of works of art, and arts-based research, can be their capacity for enhancing alternative meanings that adhere to social phenomena, thereby undercutting the authority of the master narrative” (p. 124). Art in research has been used to create accessibility and inclusion of diverse voices with children and youth (Tilleczek & Kinlock, 2013). Art has also been used as a political counter-hegemonic action with and for marginalized populations (Clover, 2011; Johnston, 2016). Arts-based methods have been used to provoke, collect and disseminate data in conjunction with verbal written analysis. At times, the verbal written analysis has consisted of what Pelias (2005) and other arts-based researchers call performative writing, in which the writing itself is a performance. For example, Mackenzie and Belliveau (2011) transformed research data into a script and created a performance from data collected over three years at a Montessori school in Vancouver, BC. This project aimed to show the potential that theatre has for community building in schools.

As art can sometimes swerve into being focused solely on aesthetics, as Clover (2011) suggests, it can also at times be tokenistic and simplistic, applied without thoughtfulness. Art methods are likewise bound by the same limitation as other research methods (Barone & Eisner, 2012). While it provides an alternate angle, it is still responsible for telling stories; and researchers are responsible and accountable to their work, for art methods do not exist outside interactions of power and privilege that shape all research. Keeping these important limitations in mind, I nonetheless see art as research as occupying a potential to invite critical questions, inspire creative thinking, affirm marginalized experiences, raise and amplify voices, among other

potentialities. For me, I used art as a language to amplify the (entangled)(messy)(half-baked) thoughts, feelings and potential actions embedded inside our research conversations.

Poetic Representation

“I was walking my dogs, admiring the autumn day, when an entire poem spoke itself into existence” (Richardson, 2017, p. 1).

Laurel Richardson’s lengthy tenure as a poetic researcher provides her with the privilege of broadcasting the way poets pick up poems, just like that, in the middle of the ordinary. I cannot begin this paragraph by telling you that language comes to me in the middle of a shower as I exfoliate the calluses on my feet. I need to explain how poetry is a craft I work with, as a tool, as an art and as a mode of research. Furthermore, I need more citations to back up this explanation. Using poetry as methods of data generation and analysis has the potential to make visible the in-between parts of communication and experience because of the rhythm it produces; the unmapped. I see this as a counter-hegemonic action—acknowledging an alternative mode of expressing research that counters the privileged form of communicating and disseminating knowledge (Harding, 2007).

I used poetry as method because of the way it attunes to our various “senses” by attending to both the materiality of language and the incorporeality of thought (MacLure, 2013). Our thoughts, through this framing, are not seen as solid; to be incorporeal is to be without material and bodily form. In this way, poetry lives between the constructive space of language and the incorporeal, affective and emotional space of our spirits. As explained by Lorde (1984), “where that language does not yet exist, it is our poetry which helps to fashion it” (p. 38). Poetry is an aesthetic and critical practice, according to Prendergast’s (2009) extensive review of poetry in research. I see poetry as having critical potential because it allows for a different kind of

language—it can rupture long-standing ideological conventions with a single phrase. I am interested in poetry as a transformative practice, as a different way to enter, or engage with, data, experiences and bodies. Prendergast (2009) questions whether anyone can be a poet—perhaps not anyone wants to be a poet, or identifies as a poet, but I believe that everyone can be a part of a poetic practice. As such, the poetic analysis and representations are in-process offerings; attempts to pull concepts and experiences out of their comfortable shapes. I used poetry as a method of analysis to raise “the hues and textures” of language (Glesne, 1997, p. 206). Glesne (1997) quoted Octavio Paz (1995) in her article on poetic inquiry:

‘What the poem shows us we do not see with our carnal eyes, but with the eyes of the spirit poetry lets us touch the impalpable.’ Through accessing the senses, poetry makes one pause, reflect, feel (p. 213).

Poetry creates sounds as letters crash together and those letters come alive in my body; I experience a rhythmic dance as my emotions move; I experience affect. Thinking of onomatopoeia... words can resonate in our bodies even if we don’t understand their use. From Glesne (1997), I leap into MacLure’s description of Deleuze’s philosophy of language: “This non-representing, un-representable, ‘wild’ element in language” (MacLure, 2013, p. 658). The use of poetry in research, what Glesne (1997) refers to as poetic transcription, might allow the researcher to move beyond coding and categorizing, tapping into the vitality of affect, approaching language from a place of “wonder.”

Plugging into “Wonder”

Of data analysis, MacLure (2013) explains that “while the coding and categorizing of data can reveal patterns of regularities, this is a retroactive, knowledge producing operation that makes things stand still, and the price of knowledge gained is stasis” (p. 662). I asked myself

before beginning this project, how can I/we make our analysis move? Show our conversations as emergent and ongoing? How can I/we enact an intention to create movement that unsettles the privileged way of knowing and being, movement that opens space for collaborative and art-inspired creation? McCoy (2012) writes about qualitative research that “some encounters might just be collisions—random & chance, but when encounters are lasting and they cohere, they are not just collisions. Forces are produced. Momentum. Counterforces” (p. 764). So I asked, how might we see and show the collisions of data... staring at us...alive?

Jackson and Mazzei (2013) explain that as one writes, or as one analyzes data, one plugs into various texts and mediums, and in this way, data analysis becomes an assemblage of thoughts and ideas. As these thoughts and ideas contact one another, data begin to move somewhere else, and their process of being is seen and communicated. The process of “plugging in” subsequently makes visible things that traditional coding and thematic analysis might not see (Jackson & Mazzei, 2013). St. Pierre (2013) discusses this fluid, entangled approach where data become seen as an assemblage, as both a something new, and a making visible.

I put plugging in to work, by plugging into wonder (MacLure, 2013). By doing so, I strived to create a non-linear in-process assemblage as a form of emergent, collaborative methodology. MacLure (2013) explains that wonder is different from outliers, for “wonder” starts with a sensation in the body. Such data that produce wonder stand out, and not necessarily because of their difference to other data, but because of their capacity for affect. She writes, “these moments confound the industrious, mechanical search for meanings, patterns, codes or themes; but at the same time they exert a fascination, and have the capacity to animate further thought” (p. 228). The data can be objects, sounds, poetry, paint and/or the words and sentences

spoken (MacLure, 2013); or the unspoken; or the break in conversational flow when a participant stops themselves mid-story to check-in with the researcher: *can I talk about this?*

Wonder happens when data inspire a curiosity in the researcher or create a sensation in the body, as if the energy of data are connected by an unbreakable thread between the material and the researcher (MacLure, 2013). I find this thread terrifying because, while it is connected to me and the data and the collaborators who produced these data, it also exists somewhere else, and that place of somewhere else has yet to be created. MacLure (2013) also says that wonder is not safe, or “an uncomplicatedly positive affect” (p. 229). Wonder, the thread of wonder, “is not entirely under our control,” stresses MacLure (2013), describing it with words like “horror” and “disgust” and “monstrosity.” She goes on to encourage researchers to avoid “mute surrender to the colonialist administrations of social science” (p. 228). In this way, wonder allows the researcher to politicize their work by asking difficult questions of the research data; it becomes more than simply sharing research findings.

Sometimes, some forms of quantitative researchers in the social sciences rely on binaries and other human-constructed sorting systems that have become so natural that their origin has been forgotten—or never taught, which is a way of ensuring a collective forgetting. At its most basic level, **[and I am keeping this basic on purpose because one should always be careful of critiquing something they know very little of]**, quantitative research looks toward numbers to inform an action, whether that action is the creation of a social or environmental policy or program, or a course of treatment for biological disease (St. Pierre, 2013). On the surface, this kind of research appears very tidy. Tidy things and spaces feel safe. Data get cleaned, outliers are removed or quantified, and wonder might get set aside. Quantitative research provides a human

person with numbers to assist in making an informed and rational choice. Its purpose is clearly identified at the very beginning.

St. Pierre (2013) writes that a positivist approach comes from the ontological positioning that the world can be known, at least in a small way, at least enough for us humans to “adjust our lives accordingly” (p. 225). In this way, we treat the circumstances of our world as natural, the circumstances being the organizational systems that provide a frame for our cultures, which we know cause some people greater harm than others. Instead of questioning whether these systems are continuing to serve our relationships to one another and with our environment, we question instead how we might better fit, and point to the ways we do not. We perhaps create a space for a necessary counter-culture, or bring an existing culture to the fore, but we do not change the structure and systems that inform culture, or injustice, or inequity (from intimate, familial culture right to structural and institutional cultures), and therefore perpetuate exclusion. By “we” I am referring to primarily white patriarchal settler-colonial culture. I include myself in the naming not just because I am a white-settler but because I live and work inside the systems created by this ontology. I often benefit from my privilege in ways that I may not fully see; sometimes I too forget to ask important politicized questions on why processes and procedures are done in a certain way. Drawing on Deleuze, who was inspired by Lewis Carol, St. Pierre (2013) writes that her purpose is not one of certainty; she, like Deleuze and Lewis Carol’s famous Alice, wonders about, and at times creates, worlds where we might live and think and do differently.

It is from this place of imagining that I approach methodology; it is from my ontological place of knowing what it feels like to be silenced or slowed by class and mental health and chronic illness and trauma and gender that I approach methodology. I approach my methodology not with a desire to capture the authentic researched moment, but rather to place different data,

people, and stories together, with raw, unrefined, in-process vulnerability to create something tangible and connected. The vital possibilities these new assemblages might produce have been described by Jackson and Mazzei (2013) and MacLure (2013). All heavily influenced by the work of post-structuralist theorists Deleuze and Guattari, their approach to research lives inside the assemblage threshold, in this in-between place of “wonder” (MacLure, 2013); a place where you can “plug in” (Jackson and Mazzei, 2013, p. 266) to theory, and into methodology, as you plug into data, as data plugs into theory, and into method, and into life.

Intersectional Feminist Praxis

In acknowledgement of feminism’s non-innocent history, such as its involvement in the eugenics and residential schools movements, I strive to bring an intersectional feminist praxis that is anti-colonial, anti-racist, and anti-ableist (Cho et al., 2013; Clare, 1999; hooks, 2003). The collaborative nature of my “feminist praxis” research was designed to unsettle the medical authority on supportive approaches for young folks with intellectual disabilities. I did so by bringing perspectives of front-line service workers to the forefront on issues of practice, power and consent that they observe in their encounters in clinical, educational and community spaces (spaces where diagnosis, treatment, therapies and education take place). My feminist approach is a critical framework for making visible that for centuries, (white) (able) (cis) men with money have controlled what stories have been told and how, thereby subjugating diverse ways of creating knowledge by valuing only knowledge considered to be “scientific” or empirical evidence (Harding, 2007; Hesse-Biber 1997; Lorde, 1984). In developing my collaborative arts-based methodology, I acknowledged that creative methodological interventions on their own cannot resolve deep-seated issues such as ableism. Nonetheless, I feel it is important to continue to press against oppressive systems, and this methodology is one such way.

There are many ways to counter ableism and the hegemony of positivist research, but I did so by using methods that consider and support community building, interdependence, and modes of knowledge production and sharing that go beyond empiricism. My approach was relational and required that I attune myself to the contexts, experiences and energy levels of the participants during the sessions. I focused on both process of the research as well as what the research might produce, growing the data assemblage and the website where the art we created is shared. As best as possible, with so much room to grow, I endeavoured to share ownership over the process, collaborating on research design and questions, but also sharing space of analysis with interested research participants who had the desire to participate in analysis and knowledge sharing (Kirby, Greaves & Reid, 2006).

Ethics, and Getting Uncomfortable

Through a reflexive process I tried to “deliberately increase the complexity of the research process” (Kirby et al., 2006, p. 39) by seeking to understand and question how my “positions and interests are imposed at all stages of the research process” (Kirby et al., p. 39). As such, I considered why I asked the questions I asked (and why I ignored other questions). As front-line practitioners, we are taught to treat the whole person as nested within their unique cultural, social and political environment, and build relationships inside varying ecological contexts. I brought that stance to my research by integrating a relational and sociopolitical ethics. Carolyn Ellis (2007) writes:

Relational ethics recognizes and values mutual respect, dignity, and connectedness between researcher and researched and between researchers and the communities in which they live and work (. . .) Relational ethics requires researchers to act from our

hearts and minds, to acknowledge our interpersonal bonds to others, and initiate and maintain conversations (as cited in Vandekinderen, Roets, & Hove, 2014, p. 298).

I endeavoured to attend to and nurture the relationships I engaged in during the research process, with an awareness and accountability to social, political and historical events that shape our different ontologies and epistemologies (Vandekinderen et al., 2014). This stance is congruent with conversations in disability where theorists and self-advocates encourage practitioners in the field to work with the whole person, not simply their disability (see organizations like People First, Inclusion BC and The Body is not an Apology). My ethics are interconnected with my whole self and I made conscientious and reflective moves throughout my study. I acknowledge that power operates in a circular nature between researcher and participants. I as researcher occupy a privileged location that enables me to determine how their stories are represented; sharing productive power in representing data stories is part of my critical praxis.

Given these ethical commitments, I was transparent about my intentions and ontological orientation, and kept my heart open to ideas that challenged me. I embraced the unknown with respect, and strove to create a “democratic partnership,” where all voices in the research process have equal weight, acknowledging the diverse ways people might tell their stories (Vandekinderen et al., 2014, p. 313). I believe fostering a democratic research partnership involves me acknowledging that I hold responsibility to the research participants and am responsible for facilitating a meaningful and respectful process. I am not absolved of the responsibility to my white-settler, cisgender, middle class and able privilege, and I was and am careful not to move myself to positions of innocence simply because my methodology is centered on uprooting oppressive systems. Moreover, as the author of the final thesis, as the person who materially benefits the most from this study, I remembered not to romanticize or

over-claim the collaborative research process. At the end, I still receive a degree that will give me power and privilege, which might afford me with opportunities that some people in my study might not equally access.

According to Denzin and Lincoln (2003), a researcher's perspective is attached to their particular social lens, the bio-psycho-social and historical factors that flow into a human experience. In addition to my social location, my social lens is also made of an unstoppable hope, love and care for the world. I exercise my political and critical voice, which attends to intonations, facial expressions, the temperature of the room, the things that are going on in the lives of the research participants that I don't know about (their social location and context), the history of humans, past, present and future, and also acts of colonization on this land and on all species. In this sense, my ontology acknowledges that everything is connected, everything is political, and everything has power (Jackson, 2013). I acknowledge that I cannot see or hear *all the things* in a researched moment, and perhaps sometimes my privilege allows me to ignore what I do not wish to process, or what lies outside of my ontological boundaries.

I believe that people are always more than how they present—we are packed with stories that inform our identities: respecting these untold stories, the unknown and unnamed, is a value I lead with in all my group interactions. It is not so much that I am above making assumptions about people based on their perceived identities in relation to class, race, gender and disability, among many other signifiers. I am not. I am however committed to checking my assumptions, receiving other people's feedback, and integrating these to change my future actions. I acknowledge that no matter how much I nurture inclusivity, I am still consistently and always operating inside broader socio-economic and political relations of power (Blyth et al., 2016; Jackson, 2013). I am reminded by other researchers who caution students against using the

language of “co-researchers,” as it can sometimes disguise the power imbalance that invariably exists. As Blyth et al. (2016) discuss,

As authors/subjects, we present ourselves as “ally,” “co-participant,” instigator of “self-advocacy,” “emancipator” while noting that “intellectually disabled people were (and are) marginalized in the main disability movement” [authors’ discussions and memos; see also Docherty, Blyth, Townson, & Chapman, 2010]. There’s an implicit but-not-by-us in that recognition. We confess here to a “fragile position,” whose “inclusivity” invites a certain amount of suspicion, especially toward a contradiction whose thought *includes*, but whose writing just as surely *excludes*” ([author’s emphasis] Blyth et al., 2016, p. 293).

Likewise, I do not think it is ethical to claim full “collaboration” or use the term “co-researcher” unless a study consists of “full collaboration,” and if this were the case, all collaborators would receive authorship of this study.

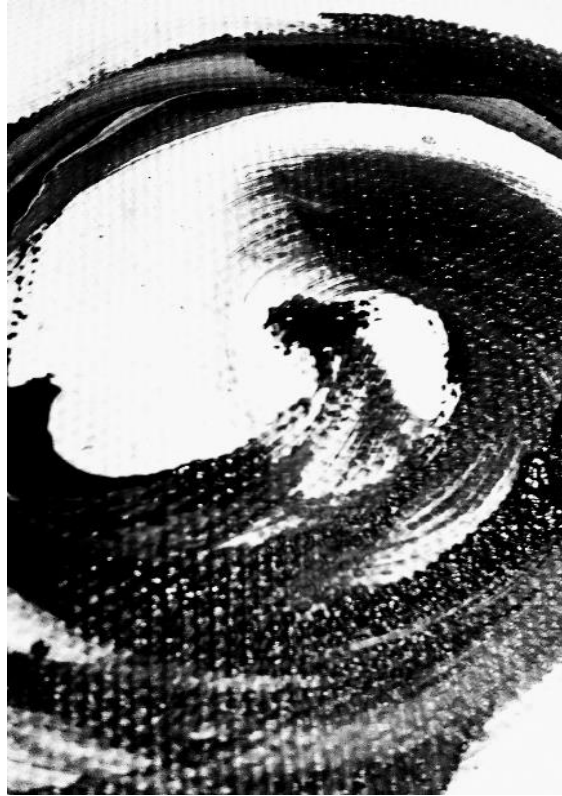
Additional Limitations

I made the choice to focus on experiences of support workers, in recognition that research has historically failed to research people with power and privilege, and critically questioning their power, privilege and responsibility (Hesse-Biber & Piatelli, 2007). As support workers, I think it is important to produce ethical work to reflect on our power and privilege, and I see this as a strength of my research. However, because my research does not involve service recipients, and cannot comment on how these services are received. There will always be a part of me that wished my study involved children and youth service recipients as well, and I see this as a gap in the knowledge my study produced.

I made the choice to approach the interview and analysis methods collaboratively, sharing responsibility and power in the research process. Using a collaborative research methodology has allowed me to use methods that fit the participant's needs, rather than trying to fit the research participants into an already determined set of research practices. For this reason, my methods had the opportunity to honour and value the varying ways people might tell their experiences. While choosing to create an emergent methodology allowed flexibility and creativity, it also created many divergent stories, and working with these stories at times felt nebulous. Furthermore, as my focus was on systemic issues, I have not focused on a single age category, or work environment, or type of service provision. As I jump from one service area to the next, from one context of practice to another, it might be difficult to follow the thread of the thesis story.

I initially imagined my research would provide more opportunity to collaborate and create more art, knowledge and action as a collective. I wanted to create a more sustainable group-process, where we discussed what we might like to do with the art, such as gifting the art to an organization, or creating a booklet that could be used by service providers. I abandoned this idea, as I abandoned my wish to engage in a participatory action research, because these goals clearly exceeded the scope of an MA study. Such research requires enormous energy, creativity and organization. It was and is difficult to acknowledge that I simply would not be able to complete research in this way. However, I am committed to creating community for support workers to grow our practice and taking action on ableism; these are threads that I will continue to pursue beyond the MA process.

Chapter 3. “You Need To Ride That Wave With Her”: Stories of “Wonder” and “Wondering” Inside Stories



You need to ride that wave with her.
 Because they designed the board for
 Bodies that bend, move, adapt;
 Make space inside the waves
 With their smooth transitions and subtle shifts
 lean in, lower down, switch—
 As if their bodies know something of water others don't;
 Her whole body crumbles down

I introduce this chapter with an image produced by SW, and a poem I constructed in response to the image. The first line and the last line of the above poem are verbatim quotes

provided by two different participants. The intention with this art-assemblage is to decenter the child as the problem, and to center the various social, political, environmental, and biomedical systems that form the context—“the water”—of a child’s life.

As explained in the previous chapter, I hosted arts-based conversations with support workers. The art media used were agreed upon before the interviews and participants elected to draw on paper and paint on materials collected from nature or on raw canvas. Artmaking sometimes occurred in the background of our conversations; at other times artmaking was the conversation, with parts of the interview recordings silent, except for the sound of brush strokes against the canvas or pencil scratches against paper. Our conversations were heavy and filled with passion; energetic art pauses felt both appropriate and necessary, as information and emotions were processed. During the final collective gathering, two attending participants and I used the method of collage to work with data. We brought together different visual images from magazines and joined these with selected examples from the transcribed interviews and our own artwork. I also spent time on my own going through transcripts, placing transcripts together alongside different images. I joined verbal data from different interviews together to show data in conversation, trying to amplify a commonality or a divergence or create something new. The above assemblage is an example of that work.

This chapter shows participant art, my own data poems, selections from transcripts, as well as a small amount of field notes that grapple with support and care work’s many tensions. I show my learning as I apply my emerging methodology to the process of gathering, reading, sitting with and communicating what was shared, as participants and I worked together inside our collective experiences with the tensions of support work practice. The tensions of support work practice, as discussed by Kelly (2013), acknowledge care work’s complex history and

multiple definitions, which also includes forms of oppression. Participants chose how to identify themselves in this thesis, and most elected to use their initials; one elected to remain anonymous, and another elected to use the name they publish under. I will credit the data poems created by Casey, the participant who wished to learn how to create data poems. The participants were invited to keep their original art, and consented to this art being scanned, photographed, used and played with in the creation of this thesis.

Thinking Inside an Assemblage

Jackson and Mazzei (2013) write that “an assemblage isn’t a thing—it is a *process* of making and unmaking the thing, a process of arranging, organizing, fitting together” (p. 262). They explain that a researcher can “plug into” these assemblages, which are made from data that are more than the participant’s voice, that attend to other things, moving away from the tidy themes that a research interview might produce, or call upon. Staying true to the original transcript, or data-art, is second to what research can produce, the product, the something new, as data across interviews encounter one another. By fitting together different data, the story changes, and expands. Jackson and Mazzei (2013) posit that this might “resist oversimplification” (p. 262). The concept of “plugging in,” which I introduced in the previous chapter, is a way to think differently with the various parts of an assemblage. As a researcher, I plug into theory as I think with art and data in efforts to create something new, be that an art product/object/assemblage, a previously unthought example, or a question I have yet to ask.

By creating a data assemblage, I am bringing together seemingly separate objects (transcript, data art, ideas, theory) to create artistic affects that intra-act with one another and researcher/viewer/reader. I view the seemingly stable and distinct assemblages as fluid and emergent, each its own entry point into the broader thesis assemblage. The thesis assemblage, as

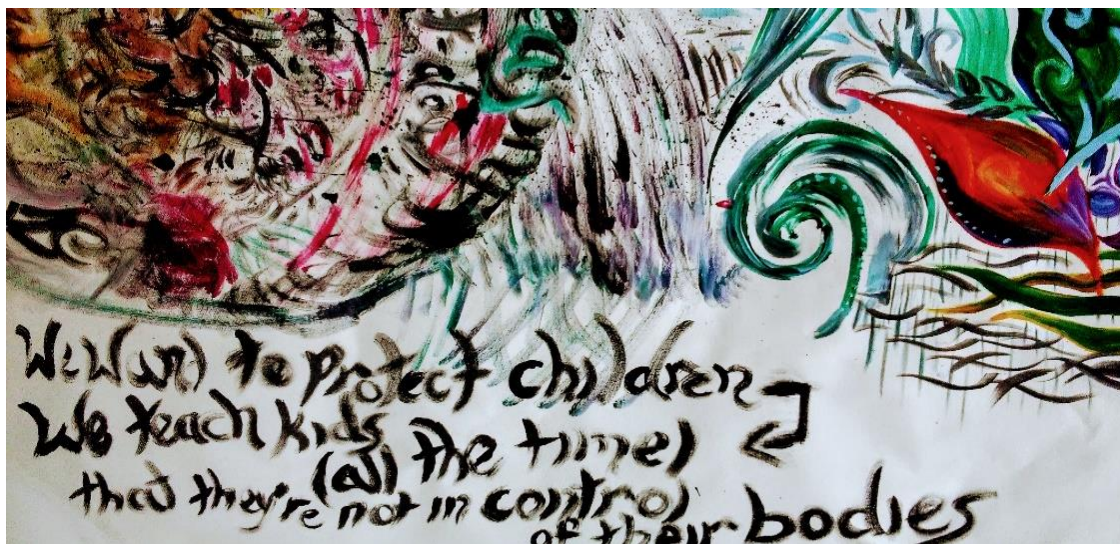
such, is not something pre-existing, but a machine that evolves as I—and others who might engage with the assemblage—plug into its various intensities, iterations, shapes, and points of entry. I call these data assemblages a “threshold,” and each threshold shows visual art, data poems, and theoretical and participant quotes in conversation, where the different affects interact. At times this might feel disorienting, as data poems mix with participants’ artwork and collages, with my representation of data through prose, with verbal intonations and exchanges, with affects of love, rage, care and hope. As such, the data inside the thresholds inspired a sense of “wonder,” were data that “glowed” (MacLure, 2013, p. 228; MacLure, 2010). MacLure (2010) uses glow to conceptualize the experience of working with small pieces of qualitative data in their “beginnings” (p.282)—perhaps before interviews have been transcribed, or after observations have been made. The concepts of glow and wonder are almost synonymous, according to MacLure (2013); and for data that glows, the mind begins to ask questions of that glow, and burst with connections to theory, other data, other glows and wonders (2010). I see this as part of the process of “plugging in.” I crafted these data with glow and wonder together as possible points of entry into the always-in-process thesis-assemblage, in efforts to experiment with diffractive entanglements (Barad, 2007; Lather, 2016).

Patti Lather (2016) describes diffractive analysis as “an object pulled out of shape by its framings” and, equally important, “framings pulled out of shape by the object. This challenges who you think you are as a researcher in a way that holds promise for advancing the critical edge of practice” (p. 126). The diffractive process also disrupts the distinction between “data” and “data analyzer,” and thus creates a synergy between the two, rather than an analysis action that moves in one flat, static direction. As Mazzei (2014) explains, one way to create “productive emergences” involves reading data with theory (p. 742-43). For my data analysis, I wanted to

show the layers of stories participants shared with me, and I wanted to show their data alongside critical theory, as if the two are conversing with one another. I feel this connects data with theory and theory with data, as their aliveness becomes visible. I think with E. St. Pierre (2013), who explains that “words surely do matter, but they do not exist outside discourse and practice. They are laden with theory, values, history, culture, politics, and power” (p. 224-225). My engagement with the data here shows there are multiple potential patterns, inroads and entry-points and I make some of these visible through wondering with conversations-art-theory assemblages. I also strive to deepen my analysis away from generalizations, assumed similarities and easy, definitive motifs, to show data in relationship with broad and complex sociocultural, economic and political systems, in constant revolution. To me, this is how my methodology plugs into “wonder,” and how I practiced applying a diffractive analysis to my data assemblages, seeing differences as productive. It is my intention that the thresholds into the thesis assemblage that follow might, in a small way, act on Alison Kafer’s (2013) call for “critical maps of the practices and ideologies that effectively cast disabled people out of time and out of our futures” (p. 33). In this context, the thresholds work against and question the abled temporal systems and structures that eliminate children with disabilities from worldly futurities; as such, in part through dominant modes of research, they are systematically and structurally excluded from our created futures (Kafer, 2013).

(Un) Controlling Bodies

“You don’t have to take a special course in working with kids with exceptionalities, like it can just be something you know because its imbedded in what we do” -P



“Our [The early learning center where SW works] belief is that it’s like, in order to be able to learn, you have to be able to function, you have to be able to listen, you have to be able to communicate your needs and wants and um also once they do get into the school system there’s one teacher and like thirty kids or something, twenty-five, thirty kids. And so they have to be able to be good communicators with their peers as well, and like have some self-help skills and what not because they um, need them” (SW).

ECE—who can belong—Classrooms

*ECE—who can’t belong—neo-medical institutions/hospitals/abandoned citizens?
(field note, October 30, 2017)*

Threshold 1. The painting was created during my conversation with SW, with my scribbles and field notes on the left, and her flowers and foliage to the right.

In this section, I am bringing together stories that SW, LV and P shared on experiences with care and education in their work, and I conclude with a reflection Casey contributed on care and control. I recognize that “to care” and “to educate” are both broad actions, and ones that are received and enacted differently by different people, and ones that are influenced by environmental contexts, among other factors. In the painting featured in Threshold 1, I wrote on the canvas something that SW said: “we teach kids all the time that they are not in control of

their bodies,” and I think this might be particularly and differently true with children who are non-verbal and labelled with intellectual disability. SW also said that children “need” to obtain the same forms of social skills and communication in order to have their basic needs met, and I wonder if this “need” is associated with conditioning bodies for normative performance and obedience? From SWs perspective as an ECE, she must prepare children for primary school, with the knowledge that teachers cannot manage every unique difference. Here, this expectation is not set by SW, but by a hierarchy of educators; those with more authority than SW determine what a classroom will look like, and what children “need” to fit into that classroom. In this context, the teacher’s needs and tasks trump those of the children, and their individual support. I begin with SW reflecting on “circle time,” which P, in a separate interview, described as an opportunity for kids to “read a story and go over the schedule for the day.” In the following transcript sample, SW also explains her view on forcing children to sit in circle time:

I also don’t believe in forcing kids to do circles. Like if they’re interested that’s great, but I also really don’t like when teachers make them sit down, and sit still and sit cross legged and listen, because I just feel that’s not realistic. Especially at that age, for everyone’s learning styles. Like some children just physically cannot sit still and listen. Um, like if they’re sitting still, they’re not listening. And um, if they’re you know moving around then they may be listening. And then there’ll be other children that will be five years old and still just not interested at all in sitting down for circle time, which I feel like is fine as well. Because um, yeah, I don’t think anything is sinking in or they’re learning anything if they really don’t want to be there and if the whole time they’re just focusing on like, how do I get out of this? When’s it going to stop? [...] They [educators] make everyone sit for circle time. Yeah, and it’s kind of like a little bit painful for me to watch

like the little boy that's so active and just like fidget and like not pay attention. And the whole time they have to be reminded, like, stop making noises, sit still, stop bothering your friends, stop grabbing toys, stop poking people. And the whole time, it's silly to me, cause it's stressful for everyone, for the teachers, and it's just annoying trying to get a kid like that to try and sit still because, um, it's just a daily thing. They're not going to do it. And it's also really stressful for the kid because they end up usually acting out, maybe throw a tantrum. Or if they don't, if they're mild tempered, they might sit there, but again, they're not listening. They're still doing their whole thing, like they just like actually can't.

SW described the stress of forcing children to sit still, and that the purpose of circle time—receiving the daily schedule and listening to a story—might be lost, as children lose interest and focus. However, she also attributed a specific kind of loss of focus to “a kid like that,” which is perhaps suggestive to broader assumptions about certain children who demonstrate their lack of focus, as oppose to others whom might be “mild tempered.” However, SW places the responsibility on the educator to facilitate learning and seems to advocate for educators to become responsive and attentive. I join SW's story with LV's practicum experience at a group home for children. LV described this experience as taking place “very early on in [her] practice and experience.” She described the group home as a “behaviour program,” and that she now understands that many of the children were likely “coming from trauma,” but she only understood at the time that they had “behaviour designations.” She shared the following story:

He ended up in our care because his parents didn't know how to care for him. They weren't given the tools. He ended up in the treatment program and he had autism, and he was non-verbal, and also English was a second language in his household [...] but I think

that all of us were on the same page that the best thing for us to do was create a consistent safe environment. So that there was no unpredictability for this little guy. So that he would start to feel comfortable and safe enough to communicate with us how he wanted to. I remember me and another staff having to get him into the tub one day, like had to wrestle him into the tub because he, like he was so confused he didn't know what was up. [...] It was really uncomfortable because I'd never really had to do that before. And with somebody who wasn't able to tell us what we were doing wrong, or what the problem was.

In these two environmental contexts, LV and SW provide examples of situations when they facilitated an aspect of social skills education (SW) and personal care (LV). Both examples take place inside scheduled workdays of care attendants and educators, where one part of their job is to enact daily plans. Both stories describe stress and discomfort as care and educational practices are forced and enforced, and I wonder if these are examples of how curriculum and policy “acts as if the body does not exist” (Erevelles, 2011, p. 21). Likewise, this might be demonstrative of the tension between curricular and theoretical expectations and assumptions of body-minds as they interact with actual material body-minds. If it is true that “ableist values are imbedded into our ontological souls” (Goodley, 2014, p. 32), then it becomes difficult to challenge, unpack and change the way we support and educate children, and how we choose to show up in consensual ways with deep listening and ethical practice. Asking the question, what is the function of circle time, and what is the function of a bath might allow space to reconsider the potentially ableist body expectations that we as support workers are expected to enforce. As an example, P spoke of circle time as well, which she also calls carpet time:

If I know something is particularly challenging for a child to do, I'm not going to explicitly say, you have to do that. But like, is it impossible for them? Could we work toward some things that would make this more possible? Like I would be told, this kid never participates in circle time [...] I'm like, why? They're like, she hates it, it's sensory overload. So I'm like, but how does she get the visual schedule? [they say] Well, she goes over and looks at it after. I'm like, okay, does she have interest in joining the other kids? They're like, no. It's going to be really hard for her, and it's not a goal of ours. I'm like, interesting. So she has to sit in the manager's office, while they have carpet [circle] time, because she hates it. Can't we just change the way we do it so that everyone can be involved, but we get the same information out? It doesn't need to be this structured thing that's apparently sensory overload.

In P's story, she shares how she supported a child's inclusion in receiving the daily schedule. She did so by questioning the structure of "circle time" through engaging with the environment and the school schedule imperative. As practitioners, we often work in spaces that so obviously host many children with disabilities and whom may also be neurodivergent. Despite the diversity of young people, we provide care and education on able-body terms, and on a colonial and able-bodied time structure. P, SW and LV's exemplar stories show that sometimes educators continue to push this sort of care and education even when it causes stress and harm for all involved. When I bring these three stories together, I begin to see how disability and difference might not be considered when creating programs, or enacting care expectations.

Kafer (2013) encourages disability scholars to "look" for disability, and in doing so, to challenge the boundaries of normativity. Kafer (2013) asks, "where do we as disability scholars and activists, continue *not* to look? Where do we find disability, and where do we miss it?" (p.

149). I would like to add, where in practice might we see disability and difference and immediately un-see it, as if difference never showed and disrupted our routine and flow? It seems to me that disability, among other body-mind differences, continues to be experienced as a surprise. As explained by SW, sometimes educators might not adjust their actions and schedules accordingly. As I work to unthink the able/disabled and included/rejected binaries, I also begin to re-think the skills children need to function, and the multiplicity of ways those skills can be acquired. As P critiqued, there is a division between “special education” practice and regular-streamed children, and that begins early on by removing the child from circle time who experiences it as “sensory overload.”

So what does forgetting to think with disability, behaviour, or mobility difference, do to practice approaches? Especially as support workers/educators encounter things that are non-negotiable aspects of our work, such as providing a child with a bath? Casey made a comment during our conversation about support workers specific to those with diagnosed disabilities, and how we are “caught in a really interesting crux of needing people to be disabled [for funding reasons], but not needing them to be so much work.” They said that

control is at the locus of a lot of it. We want to control bad behaviours because they scare us. Things we don't understand really fucking scare us. And, at the heart of it, and I'm being really critical here, but I think at the heart of it is the desire to keep our clients safe. And to help, like help them live a fulfilling life, but we've already done this thing where we've removed them from purpose. And, I feel like we're moving away from putting people in institutions and seeing them as sub-human. But it's still holding, like there's still that attitude.

They shared that things shifted in the way they support their clients when they stopped “trying to make that person exist on the level that I wanted them to exist on.” Much of “care” work and education requires children, youth and adults with disabilities to overcome, transcend, and exist on a level that we care workers want them to exist on, according to these examples, but these expectations also operate inside complex political and social systems. As Puar (2017) explains, “service economies...are impelled into the production of these ‘objects of care’” (p. 80). Casey explains this as the need for disabled people to be disabled, but “to not be so much work.” Puar (2017) suggests that service providers are expected to produce care but are left with very little resources for themselves. The expectation for children to sit and listen, and the need to have a child take their bath at bath time, might emerge because human bodies have been expected to operate on a timeline that works for the employer, union expectations and service contracts, depending on the site where such work takes place (Puar, 2017). The more care that is completed efficiently, the more time will be made available for other people and other care routines; and this might not be compatible with the fluidity of real lives. I see this in the expectation to achieve a certain level of hygiene by a certain time (so the next bath can take place); and by disciplining children’s bodies to sit and appear focused.

The biopolitical dimensions of education, such as circle time, condition bodies to be docile and obedient, and this impacts different bodies differently. As Puar (2017) explains, “all bodies are being evaluated in relation to their success or failure in terms of health, wealth, progressive productivity, upward mobility, [and] capacity” (p. 15). I wonder if genuine inclusion requires a more critical look at debility and capacity under biopolitical and capitalist expectations of rehabilitation and cure. Inclusion, much like consent, might be an evolving, fluid, ongoing

action; one that involves listening to children’s communication, and where they are nested in a socioeconomic context, as much as it might involve environmental and structural changes.

The Re-Think, Re-Frame Resources

“How do you work with a kid on the spectrum? Like, how do you not? But there’s this assumption that it can’t—like there’s not capacity to learn about emotions” (P).



“Nonverbal consent is not, or maybe it should be the other way around...nonverbal consent...I feel like that... a lot of people who have verbal limitations or who are nonverbal totally, actually get thrown under the radar and things happen” (LV).

Threshold 2. I see the leaves, rock and bark shown in the above photograph as representative of the values we can bring to our work with children. These are just some examples of ones with the potential to disrupt some of the harmful, and sometime unhelpful, practice expectations that might create choices that go against consent, fueling assumptions about capacity that might have some children “thrown under the radar.”

Puar (2017) describes the matrix of “capacity,” “debility” and “disability” as “mutually reinforcing constellations” (p. xv). Does thinking with this constellation unsettle the status-quo, the expected rhythms of care and education environments? Thinking with “capacity” necessitates thinking with debility, as both capacity and debility—though “seeming opposites”—create “population aggregates” (p. 13), either you are capable, and therefore belong with the capable group, or you are not. However, using Puar’s framing, a child’s capacity to learn becomes a fluid and shifting ability when considered in the disability-capacity-debility matrix, across geopolitical contexts. Unfortunately, capacity is often applied in terms of “capacious” bodies (Puar, 2017)—

those that can be incorporated and included through equipment like assistive technology and normalizing therapies. As examples, the child who will sit still, whether they listen or not; the child who will be bathed on scheduled, whether they want the bath or not.

Curing the Unexpected Behaviours

*Sterilize care plan
Make small incision
Peel back thickened skin, open
(field note, October 15, 2017)*



“One of the best things about the company I work for was how emotionally involved many people were. And it gets messy, it totally gets messy, um, but it should. You shouldn’t be able to support people in a clinical clean way. I don’t believe in that. Um and as someone who has been in the medical system, who has been in facilities, like I have been detained in mental health facilities, like how damaging it is to be in a sterile environment where there isn’t flexibility, where there isn’t love, where there isn’t messiness” (Casey).

CURE: “Framing it as a kind of restoration reveals the most obvious and essential tenets. First, cure requires damage, locating the harm entirely in the individual body-minds, operating as if each person were their own ecosystem. Second, it grounds itself in an original state of being, relying on a belief that what existed before is superior to what exists currently. And finally, it seeks to return what is damaged to that former state of being.” (Clare, 2017, p. 15)

Threshold 3. Throwing ink and love at the “Clinical Clean Way” was created by me and VR. VR drew the heart image during our research conversation, and during our research gathering, I used her image and ink on canvas to create the art piece. Both the field note poem and this art piece were inspired by Casey, who reflected on and challenged the expectation to conduct care in a “clinical clean way.”

Applied behaviour analysis (ABA) therapy is an option available to children with an Autism Spectrum Disorder (ASD) diagnosis. ABA is often considered the most scientifically valid early-intervention therapy for children with an ASD diagnosis, but is not the only option, and does not exist without some critique (Weatherhead, 2017). As with most therapies for children with disabilities and neurodivergent children, ABA involves a team of support, including Speech Language Pathologists (SLPs), Occupational Therapists (OTs) and Behavioural Consultants, who collaborate to create a child's behaviour therapy plan. Behaviour Interventionists, as front-line service providers, enact the plan with the child. VR wanted to focus our conversation on behaviour intervention, using her experiences working with a young child diagnosed with ASD and delays in verbal communication. VR shared that she “never had to work with a child that was non-verbal [before]” and that “at the beginning it was hard to get like, any sort of reaction from him.” She then explained how she focused on relationship building. Describing herself as “a really patient person,” she explained that

for the longest time I would just sit near him, and like stare into space. And like, just be near him. You know? And eventually he started seeing me. I guess he just got used to having me around! And then say he got hurt, or whatever, or he started crying, so I'd be there.

She said at that point, she “started doing the therapy with him” because she had “his trust.” She explained that the purpose of her job “was two things, it was him using the visuals, he needed that for preschool, or not in preschool, but like elementary school, like kindergarten [...]” and “responding to social cues.” Her task was to expose the child she supported to the textures and sounds that triggered “hitting, biting, a lot of kicking” behaviours. Through this form of therapy, she reinforced positive behaviours and desired communication, and discouraged the child's non-

verbal gestural language. She described this therapy as really “hard” to provide, but also acknowledged that some children do require additional support to navigate their social and environmental worlds:

VR: I think I had like a brush. And I would put it on his hand. And it was just part of my goals. It was like, for him to be able to withstand different textures on his skin, but it would always like, terrify me cause I would see him like physically react to these things. And like, even just like, touching him lightly with the brush. It was like those bristle brushes? Like for babies. So it’s very soft. Like, I wouldn’t cause him physical pain. But like I guess...

Me: Like for a child with Autism it would...

VR: Right, so I would just like touch him with it, and like right away I would like, tense up. I could tell he was like about to explode. Like he just hated it. So I would try to do it when we were doing something else. Like we would have an iPad, like twice a day, twice in my sessions, I would allow him to watch a two-minute video. So during that time, I would try it, and see if he’d let me cause he’s concentrated on something else, and that seemed to work. And eventually it was okay, like there were days when he couldn’t do it. A lot of the times I was worried about just like, causing him to be, like, what’s it called? Just, unpleasant experiences for him. Even like, turning the light on, or flushing the toilet. He hated that. So like, even like changing his diaper, like the, adhesive, for the diaper, that sound would set him off, like washing his hands, the cold, it was like, too much. So it was like, everything pretty much.

Me: And it was your job to desensitize him to all those things by exposing him to all these things that were causing him harm?

VR: Yup.

I asked VR if she could imagine a different way to support children who have high sensitivities such as children with ASD, and she asked, “like in a way that doesn’t cause them physical pain?”

After thinking on the question, she shared the following:

Sensory is in everything. You know? And if you’re gonna be set off by touching a certain material, like it’s just important to learn to handle those things. So I dunno, I have no idea. This is what my OT told me to do, so that’s what I would do, right? And obviously I would look up ways, but all it would say is exposure, like you have to expose them and start with the stuff they can handle, to the stuff that they can’t [handle].

In VR’s telling, she speaks to her powerlessness to change the child’s plan—it is created by a collective of professionals, and at this time there are not many other funded therapeutic options for children with ASD. She also speaks to her power to work with this plan in collaboration with SLPs, structuring his therapy in environments that worked for the child:

[...] It was really hard to get him to do those things [ABA therapy] when other kids were around, because of the chaos, so I would have to try during lunch when he was by himself to do these things, which was good because he would get some therapy out of it, but then he would never get the social part out of it, cause he would just try to avoid everyone. It was just too much for him. So if he was healthy, and in a good mood, and everything was okay, he was able to go play with a child, and I would just step back and let him do his thing. But if I saw that he was starting to lose interest, or if he didn’t know how to react to something, then I would step in and say something like, “oh, your friend wants you to do this...why don’t you try this...” But it was very hard to do those things

when the environment was so stressful. I tried for him to have like his own little corner, so his mom bought him a tent, so I was like, oh, this is great! It's like a place that's dark, cause the light really bothers him. So we had the tent, so while I was there, cause I was only there for three hours in the morning, it was fine cause I would like keep all the other children away. When I was gone, none of the other teachers would do anything. It was really annoying!

VR's experience with this one program, with this one company, speaks to her difficulty to enact therapies in dynamic and uncontrollable workspaces, and how she needed to think beyond the actual 1:1 therapy, and consider other teachers, children, lights, and sounds.

Casey, who worked in a MCFD-regulated group home for youth with special needs designations, explained how certain behaviours used by a youth become constructed as "problematic behaviour." Casey provided an example of a youth who was considered "violent" and labeled as "oppositional." After changing the environment and making "staffing changes," the new staff learned "how to appeal to his needs and how to understand what his verbalizations were telling them." For example, "what sorts of breathing meant that he was having anxiety and was going to be more prone to an outburst." Casey continued to explain that "he went from being perceived as incredibly dangerous, had one on one workers, to living in community and doing [a] fucking amazing job." According to Casey:

This person was being painted as this monster, as unmanageable, and needed all these chemical interventions [pharmaceuticals], and that was not the truth. And every time they [acted out], I was like yeah, teach them how you speak. If this is the way you need to educate people about your language, bring the hammer down man.

Casey explained that their client's so-called violent and oppositional communication escalated the more he went unheard. In Casey's example, they viewed their client's "behaviours" as efforts to teach others how that person communicates. While Casey cannot speak on behalf of their client's experiences, their perspective and actions as a support worker move against the actions of others, others who might cast those with aggressive behaviours as deviant (Simplican & Leader, 2015). There are times when a person might have a dual diagnosis of mental health and intellectual disabilities, where anti-psychotic medications might be appropriate. However, the instinct to uniformly pathologize behaviors as biological and psychological before considering social, emotional and environmental discord, is very suggestive of the biomedical authority over people's lives. The pathologizing of behaviour impacts the type of care children, youth and adults with disabilities might receive, and is an example of how bodies become fragmented and worked-on instead of worked-with. As Casey said, "you shouldn't be able to support people in a clinical clean way" and behaviour plans keep things "small and manageable" because keeping things small and manageable is "controllable." They analyzed this as a flaw in the system, one rooted in a fear of difference: "we are so scared of death and infirmity that we lock our disabled and elderly away."

When I asked LV, who also worked in group homes and a program for youth with special needs, what she would like to see different in behaviour plans, she said:

I think more emphasis needs to be put on the individuals and not so much a clinical perspective...when you're working with humans the golden rule is everyone is different, but in behaviour plans they're treating everybody the same. And you know like, they need to be changed with the times, with the individual as they grow, too.

As I insert this quote from LV, as I think of her view of behaviour plans as “treating everybody the same,” I am compelled to ask, is that perhaps a subterranean purpose of behaviour plans? Not necessarily to treat everybody the same, as behaviour plans are individualized, but to create bodies that might unlearn their differences, make difference in communication more manageable, thus producing sameness in bodily performance. At times, a behaviour plan might be created, or a chemical intervention provided, prior to thinking about other factors that might be producing the concerning behaviour. As Goodley (2014) explains, the body is not outside “economy, culture, language and material practices” (p 84). Furthermore, “by attempting to erase the social context in which bodies become known seems to suggest that there is a body outside of culture and understanding” (Goodley, 2014, p.84). For Goodley (2014), there is a need to recognize both “materialities and materializations that constitute the disabled body” (p. 84). By materialization, Goodley (2014) is drawing on social material theory and is referring to capitalism’s effect on the social and cultural realities of people’s lives. In the context of disability studies, capitalism shapes access to labour markets and informs how bodies might be acted on through intervention, labelling and diagnosis. ABA and other forms of behavior intervention might be one way that disabled bodies are acted-on to create “biological citizenship,” which Goodley (2014) defines as “modern states” regulating “their citizens’ bodies by various practices and institutions, some medical, some quasi-medical” (p. 88). Body-minds move in sometimes confusing and destructive ways in order to communicate emotional dysregulation. Emotional dysregulation is typically used as an umbrella term to describe behaviours sometimes associated with very real mental health and psychiatric experiences, some of which are detailed in the various editions of the *Diagnostic and Statistics Manual (DSM)* (M. L. Johnson, 2015). One such example is self-harm behaviours, which M. L Johnson (2015) critiques as being treated with

almost too much celebration by queer theorists. She explains that such behaviours have been written on metaphorically as a disruptor to normativity, as an agentic act of resistance; but they neglect to discuss the pain, trauma, and/or material and physical consequences sometimes associated with such behaviours (M. L. Johnson, 2015). M. L. Johnson (2015) approaches emotional dysregulation from what she coins as a “feminist psychiatric disability studies” in her crip discussion of self-harm:

[I]nterpretation of cutting as feminist aesthetic, queer revolt, or postcolonial protest raises red flags because it empties the text of its disability content and erodes the self-cutting/borderline reader’s potential moment of recognition. Being erased within the margins of the dominant sexist, heterosexist, racist, and ableist cul-ture [*sic*] by another theorist working the margins produces a particularly sharp discomfort (p. 257).

I worry about the harm caused by the medicalizing and pathologizing dysregulation. Likewise, I am concerned with the seeming-dismissal of complicated behaviours too easily written off as an intellectual incapacity to regulate one’s emotions. This might result in people being silenced through medication or ignored because the trigger of such behaviours might be too difficult to understand. I also worry about behaviours only being viewed as a resistance to disciplining forces; or, as M. L. Johnson (2015) explains, being used for symbolism in queer theory’s “revolt” against normative body formations (p. 257). Such behaviour, for those who live outside verbal language, and who occupy an intellectual disability diagnosis, might trigger a risk of being over-medicated, or medicated incorrectly.

In an example of such behaviour being incorrectly assessed, one of LV’s clients had rotting teeth in her mouth and was being medicated for years. LV suggested that no one considered whether her “scratching her chest up” might be linked to physical pain. Furthermore,

this person's paperwork was out of date, and therefore the dentist could not extract a painful tooth because the necessary forms were not available for someone to consent on her behalf. It would seem that the group home collectively, in their silence, agreed that it was okay to medicate her behaviour, rather than critically investigate painful medical conditions. As LV says in Threshold 2: "a lot of people who have verbal limitations or who are nonverbal totally, actually get thrown under the radar and things happen."

I understand this as one way that ableism produces "smooth forms of personhood and smooth health; creates space fit for normative citizens," and in this production, expels disabled "Others" (Goodley, 2014, p. 21).

I understand what I need

But

You have to have a safety plan

Consent, boundaries, don't practice it

Be very pliable and obedient

Let someone into your personal space

We make ourselves stay very small.

Rotting teeth in her mouth

Who's the unethical one here?

Animals that are looking to survive

I dug deeper

She's in pain.

She said her name and thank you.

("Girlhood, disability and dental hygiene," Data poem, Casey)

The Child's File-Life



Threshold 4. Speaking in flowers.

“Speaking in flowers” was created during two research sessions. The leaves and heart-on-rock (which can be seen in Threshold 2) were created during a one on one interview where we discussed the ethics P builds into her work with children. The fish-bowl collage was constructed during a group meeting, where Casey cut pieces of transcript, images and words from magazines. After the collage was created, Casey and I debated whether to put the fish in the bowl. I questioned this choice because the fish would cover the pieces of transcript. The transcript they selected glowed with possibility for analysis and story-making. I asked, half-jokingly, whether the fish could be placed more to the side of the bowl. Casey clarified this would not work, explaining the story they were telling with this image: “The fish speaks in images [as symbolized by the flower bubbles], and floats by words it doesn’t understand. The fishbowl is a microcosm of institutionalized settings, being watched constantly, covered by words.” We acknowledged in this conversation that the kids, youth and adults we do and have worked with rarely (if ever)

have an opportunity to speak “their truth” without being written about, or spoken over, or analyzed. Although we cannot always know their communication, needs, desires, or how they are experiencing their “care,” we can bring a willingness to try and understand and listen; and so I joined the collage with the leaves and rock, which contain words from my conversation with P, such as “the willingness to show up over and over.”

The collage made me feel uncomfortable when I looked at the woman drinking and smoking while pregnant, evoking damaging stereotypes of the “bad” mother. I deliberately stayed with that discomfort, as I thought about the hyper-surveillance of mothers as bearers of future citizens. Mothers are often recipients of social moralizing and blame, experiencing extreme guilt and judgement if their child is born with a disability, in particular FAS; and they, perhaps more than other parent-types, are harmed by the continual pressure to have and raise healthy babies (Landsman, 2009). Historically, the surveillance of mothers has been hyper-applied to those marked by class and race (Boyd, 2007), and I would add disability as well. Boyd (2007) provides the example of Sunnyhill Hospital for Children in Vancouver, BC, which acted as a neo-natal withdrawal center in the 1990s. At that time, there were no harm-reduction services available for mothers with problematic substance during pregnancy (Boyd, 2007). This model separated babies from their mothers, and as explained by Boyd (2007), “[m]ost of their mothers were poor, on social assistance, and First Nations, even though First Nations women’s narcotic use rates were no higher than those of non-Aboriginal women” (p. 11). This adds another dimension to the white mother in the above collage; her whiteness allowing her to avoid similar scrutiny and surveillance. I weave the concept of the “bad” mother into the fishbowl and its institutional hyper-surveillance fishbowl world. I question, is the mother really on the outside of this oppression, looking in, or entangled in the assemblage as well?

In this section, I intentionally disrupted the institutionalized surveillance that impacts the child, and its entire support and family system. I did so by bringing the research participants' fierce hopes embedded in the words on the leaves, and the love emanating from the heart on the rock. To engage with these complexities, I wanted to diffract this collage through other selections from my conversation with the participants, as well as feminist and disability theory. In what follows, I provide participant examples on our conversations regarding labels, focusing on what they produce and how they create meaning. I then provide an example of the Individual Education Plan (IEP) process, before concluding with an example of the assessment and rating system used in one ABA program, which serves as a gatekeeper to accessing services. These are all examples of how "lives are reduced to case files" (Clare, 2017, p. 112) through processes of institutional surveillance. I will begin by providing an excerpt from two distinct conversations, one with Casey and one with SW, separated by asterisks.

Me: You've said a couple things that I want to hear more about, one you just said about funding, and how they didn't have a label yet, the other thing that you said that I thought was kind of interesting was you notice that people, once the child does have the label, um, that other educators are now more patient? What's that about? Or, what's that about for you?

SW: Um, well, personally like I am interested in working with children with special needs and I enjoy it and I feel like I'm a pretty patient person, and I also have a lot of patience for like aggressive behaviours and what not. And if a child doesn't have that label yet, and we are not sure where it's coming from then other educators, I mean, including myself, but um, it can get extremely frustrating and um. Like I have an example of a child I have right now in my class whom just started in September and she will bite

children, and she will shove them as well, and push them and be aggressive. And it's also kind of random when she's aggressive. Like for me, I feel like there might be something going on for her like cognitively. But...and I think that my coworkers are starting to see that more now, but the first month was just a lot of like...like...everyone was just very frustrated with her. And like if she would have come in with the diagnosis it would have been a different story, even if she didn't have a support worker. Cause we... and you know, it makes sense...you're expecting different behaviours if you have that label and if you have that understanding, you have that like, concrete, like oh, that's why you act like that. Instead of just being like, that was really mean! Like, it's not because they're coming from a place of, not being sensitive, but like, when a child has certain behaviours, it just looks very mean.

Casey: You look at the discourse that changes and an official discourse again, you know, we're talking verbal, non-verbal, but we're talking official and not official [diagnosis], and like, if you can relate to someone as a human-person...and...and...the core of that...and sort-of move past, okay, the diagnoses say this, the plan says this, the paper work says this, like, those are guidelines, parts of the puzzle, but really putting the focus in the person who is being supported. And never taking for granted that you know because people will change and people are learning constantly as well. And I think especially in the disability field, we have a tendency (whether conscious or unconscious) to relegate people to a static place. Okay, this is who you are, this is as far as you're going to go, this is what you do. And then we address things with like med changes, and new behaviour plans. But. It's rarely framed, in my experience, as (pause) this person has

learned a new skill, this person is fed-up with these workers, this person has reached their absolute limit with being told where to eat when they don't want to do it. They just have no patience left for this shit. They've just very much reached their human limits. And it's always framed as, within the spectrum of their diagnosis, and. And I shouldn't say always. Always and never are not good terms to use.

SW shares how a diagnosis positively impacts how ECEs work with a child, as they provide an explanation for otherwise (seemingly) unexplainable behaviours. Casey is questioning the ethical implications of working with someone solely by the assumptions of what a diagnosis might produce, framing all behaviours within the scope and limitations of their label and not as someone with "no patience left for this shit." SW says, "you're expecting different behaviours if you have that label and if you have that understanding, you have that like, concrete, like oh, that's why you act like that." However, Casey might suggest workers move past the (perhaps) rigidity of a diagnosis and care plan, and toward relating "to someone as a human-person." Goodley (2014), drawing on the research he completed with disability scholar Katherine Runswick-Cole, explains that "the lack of diagnosis could substantively deny families access to specialised health and social care; no label, no help. Furthermore, no label meant no explanatory framework to draw on to explain the world about one's child's unique difference" (p. 87). In an ECE environment, SW acknowledged the struggle inside an "8:1 ratio" when a child has a special need, but does not have a label, and therefore access to funding. As an example, she was hired as "a temporary 1:1 to try and work with him [child with suspected Autism]" and further explained that

even if he was listening, I still wasn't sure what was going on for him, so it was still tricky. And he didn't, like I said, he didn't have a diagnosis, so he didn't have funding, so I didn't actually work long enough with him to even get to that point.

Individual Education Plans (IEPs), care plans, support plans—all the plans and resources—are not formerly put in place until a child goes through their diagnosis process, which can be long and stressful on families (Goodley, 2014). At this point, the child's file-life begins. As P explained, "the information recorded during their [children's] school years follow them." P said that the documents in school files are "strong narratives that the kids don't get to write for themselves. Like they're stories we [educators, support workers, counsellors] tell." She explained that because of these file stories, "people write off people before they even start," and she included the child's family system, alluding to how the family system is also documented and watched. She explained that "we need to tell a story about that kid that's going to make people want to work with them." Despite these stories being told by other people, she explained that the reports often read as a "first person narrative:"

And there's stories before that child was even born. Like, what is their mother's prenatal history? I understand developmentally why those stories are in the reports. For those medicalized reasons. But then in these files, in these school files, you'll find that there's so many different kinds of reports. Like these first-person narratives. Like this kid is six. He did not write that report.

Similarly, in group homes, Casey asks:

like why is there no, in my company anyways, why is there no let's focus on the positive strengths for a good like three hours? Let's focus on their resilience, like, let's tell a story

about how much respect they deserve. And, and...what your place is as a support worker. Like, very little of our orientation process is focused on that.

At the end of the day
that child deserves
to be seen heard with fresh eyes.
Otherwise by the time
the child gets to high school
there will be files upon files
Assessments upon assessments
stories written about them
but never by them.
—For what purpose?

(Data poem)

In my work with youth labeled with an intellectual disability who are transitioning to adult services, I have read some of these “thick files,” which sometimes (but not always) follow youth to their adult services when transitioning from MCFD care. Inside these folders are doctors’ notes, assessments, report cards and birth records. I have been instructed to read these files prior to working with the client so that I am aware of their triggers and support needs. While this is important information to know, I at times worry that, as support workers, we build a relationship with a person’s file, rather than with the person. I worry, too, that a person becomes “relegated to a static place,” as Casey described. Files—case files—potentially have power, and this power can be used to undermine the person’s growth and agency, and might also ignore the different ways that people relate to one another. Files “transform people into diagnoses and ‘expert opinions’ ...thousands of stories vanish beneath their authority” (Clare, 2017, p. 112). These files provide the evidence for ongoing surveillance and, from a critical disability perspective, justify pharmaceutical restraint and practices of (neo)eugenics and other acts of violence (Clare, 2017; 1999; Ekberg, 2007). They are also a mechanism of disciplinary power,

which determines “who should be included from those who must be excluded or eliminated” (Puar, 2017, p. 21). It is through such disciplinary power of, for example, behavioural designations and academic assessments, that bodies that cannot be obedient are identified, thus reifying the deviant and unruly body (Erevelles, 2011; Puar, 2017; Wendell, 1996). At the same time, the contents of such files contain the determining information regarding funding, and how much funding will be received; which then outlines what care or therapy or recreational supports this funding is applied toward. Such services then go on to reaffirm the body as deviating from expectations of smooth ability and capacity. Goodley (2014) explains how this disciplinary practice used to create productive citizens lead some bodies to experience an increased amount of surveillance and scrutiny than others. The child with an intellectual disability label in an educational setting becomes acted-on, watched, their daily behaviours documented by others across their lifespan.

The IEP is one such example. An IEP is created for every child in British Columbia who has a disability designation. The purpose of an IEP is to gather parents, caregivers, educators and different medical professionals involved in the child’s care and education. These documents outline and track educational and behavioural goals for children and are updated once a year. Each IEP is tailored to the specific needs and goals of the child and is therefore sometimes helpful to support children to achieve inclusion in education.

The following is an excerpt from my conversation with P on IEPs:

Me: So how could we account for more of a child’s voice in um, even behaviour plans, and IEPs, and all the rest?

P: Well I think for me, I’ve never been involved in a child’s IEP meeting where the child was present.

Me: Really?

P: Never. And I have always thought it's because I work in an elementary setting. But um, in my other work, I'm doing practicum in a community-based setting. And I'm working with youth, so everyone is over the age of 13, and one of the things that I've been advocating for, I mean, these kids of mental health diagnoses, and have behaviours and mental health designations in the school system, is that these kids need to be involved in their IEP meetings with the support that they ask for. So if they want the school counsellor there, or they want their parents to support them, their mental health clinician to support them, in whatever way I think, and part of my job is to prepare that kid to be ready for that meeting, um but to have their voice there and present so that every body can have a better understanding. And to not just have them for part of the meeting, but if they're things we're going to be talking about, the challenges that we see, like I think the child deserves to be present if they're 13, 14, 15, I mean, they're obviously able to understand what people are saying. And, they might have a lot more insight than us just talking about them.

Me: And so, like for kids who don't communicate with verbal language, like don't sign, like their language is primarily—

P: Like could be using an app?

Me: Yeah, like could be using an app, or like using behavioural communication. And like, attending to facial expressions, things like that, it's very subtle communication. I can hear people saying in my head, well, they can't participate anyways.

P: Yep!

Me: But like, what would you say to someone if they said something like that to you?

P: So if they said to me, particularly if we were talking about an older kid, [cup breaks] did your cup just break?

Me: It's been loose for a while...but it's now part of the research [Laughter]

P: That's beautiful...[laughter] um, what would I say, I'd probably say something sassy, but if I had to be professional...what would I say?

Me: You can give both answers.

P: Um, I think that a lot of it comes down to the way we value communication. Just because somebody can't speak verbally, doesn't mean they can't communicate. Doesn't mean their opinions aren't valid just cause they can't have a conversation like you and I are having, it doesn't mean that they don't have the functionality that we have, it doesn't mean we have brilliant ideas, it just means that you have to be a little bit more creative. Right? In the way we are going to include them. And sometimes that requires thinking outside the box. And I think, often we do things, and I'm often told we just don't do things that way. Like, why have I never been to an IEP meeting where the child was present? I have asked, and I've been told we just don't do that. We just don't do that? So, why don't we? Right? Oh, just cause it's just not been done. Okay. So can we start? No, we're not gonna start. And I don't have the authority to say, yes, we are going to start. What I can do is really get a parent on board, but a lot of parents are exhausted and they're like, I don't care if my kid shows up or not, I have to take an hour off work for this IEP meeting. In the middle of the day. Right? So I mean, what we have done is had an IEP meeting, and then presented parts of the IEP to the child and asked them

questions, and asked them for feedback. But they haven't been involved in the actual meeting process. I find it's a really great practice to include kids. Like when I have a parent meeting I'll often times include the kids. It gives you a lot of information on what's going on for the child, I think it's because our goals are so specific in an IEP meeting. We're looking at what are the goals, what are the strategies for us to achieve our goals [...participant explains IEPs] So often we have meetings in October or November, after the child has been in the classroom for a month, a month and a half, maybe two months. The case manager is new, the teacher is new, the support workers can all be new, so the only people who know what's the what is the family. Right? And so oftentimes, things are kind of introductory, and they're mandatory only once a year...

Me: So it's a mandatory once a year introductory meeting?

P: And it can be, the family can request a second IEP meeting, and we have done those, but um, they look less like an IEP meeting, and more like an Integrated Case Management meeting. And we work in silos a lot. So getting people on the same page, so they can take an hour out of their schedule, to talk specifically about a child, can be really really hard too. But I think we can do a much better job at including kids in the process. I think we think we're protecting them.

Me: What do you think they're trying to protect the kids from?

P: I dunno, like, maybe other people's opinions, a lot of times those meetings turn into a bitch fest, over what's not going well, excuse my language, but really, it's a complaint. It's a place to deposit complaints.

Me: About what?

P: About the child in the classroom that's not working. About how far behind the child is on their goals, how they don't have social skills, it becomes very deficits based. And like, the IEPs I see are very deficits based. And I'm sure they're different in different places, but I find them to be reactive, not proactive, in terms of behaviour goals. Like a goal could be, a child will verbally learn to communicate their needs. And then it will have an example of when the child can't do that. And then it will have some kind of sub-goals, like, the child will use a card to show they're frustrated, so they can take a break. And then a couple of those, and then a whole bunch of strategies. [...] But like, nowhere in there are we setting up an environment, like, we're looking at being really reactive. We're thinking about when the child can't communicate, and what it looks like where they're throwing a tantrum, or whatever. Rather than thinking about how can we design a classroom where all forms of communication are honoured, and like, we're not just looking at verbal communication as our main goal. But like, do you know what I mean?

P, drawing on her value of “thinking with capacity,” is advocating to bring a creative, generative and collaborative lens to the IEP meetings in order to meaningfully involve children in their own educational plans. From P's perspective, the IEP process is at times a “bitch fest” about what is not working in the classroom with this child, at other times an “introductory” meeting for attendees, and always deficit focused. This process contrasts with IEP process guidelines. Indeed, the most recent Ministry of Education (2016) Special Education Services: A Manual of Policies, Procedures and Guidelines (the Guidelines) say the following:

Parents/guardians and students have the opportunity to be active participants in the process, to initiate discussions regarding the learning needs or request school-based access to support. They should feel welcome and encouraged to contribute throughout the

process, and are important partners in the development of the Individual Education Plan (IEP). As a rule, students should be included in all phases of the process unless they are unable or unwilling to participate (p. 12).

Despite the statement—“as a rule, students should be included in all phases of the process”—the ambiguous caveat of “unless they are unable” creates a problematic subjective loophole, where children who could potentially be included will not be included in the process. I wonder what might happen to assessments, IEP planning and behaviour plans if a child’s voice was truly centered and included in a way that worked for that child or youth’s needs, without having their participation become tokenistic. An example of such inclusive tokenism is when the child is in the room, but not engaged; when they are spoken about, but not in a meaningful way.

Genuinely involving children and their families in IEP planning might bring a necessary disruption to the IEP process, to that disciplinary power, and decentralize the power from the educators. The process might take more time, require an increased amount of resources, and not necessarily be smooth. I do not believe it would be impossible. As P explained, it would require creativity to reduce the child’s potential barriers to inclusion; however, if the overarching purpose of IEPs is educational inclusion, what accounts for the exclusion in the creation of the plan? From the outside looking in, it appears to work in cross-purposes.

In early childhood development, assessments typically focus on four domains of development: social and emotional, cognitive, fine and gross motor skills, and speech and language development. The purpose is to assess children as they move through the “ages and stages,” continuing to treat development as a linear progression, identifying what children are outside the normal, or expected, range (Burman, 2008). As explained by the two ECEs involved in this study, if they suspect difficulty in any of these domains, they can conduct an observational

assessment of a child, and use this to inform parents that their child is behind in their developmental progress. Additionally, after a child has a diagnosis, VR explained that to access their behaviour intervention program, the child must undergo an additional assessment to determine whether they would benefit from ABA therapy:

VR: Yeah, so it pretty much was a list of children that my supervisor would go visit who were interested in joining the program. My supervisor would go and have a meeting with the parents, and see the child, and she would take notes on the child's cognitive, social, emotional, like you know, that stuff, and write notes, and from that, the Ministry would send us forms that we would have to fill out, and we would have to rate the children from "one-to-five", I believe it was. So under cognitive it would say "the child is non-verbal" and we would rate that for how much he needs to be in the program. So "one" would be like he doesn't need to be in the program and "five" would be like yes, he does need to be in the program. So if there was a child who was non-verbal, versus a child who had no social skills, they would probably choose the non-verbal child.

Me: Interesting.

VR: Well, it was very biased. Cause it was five of us, and we would mark it however we wanted. Right? Like however we thought it would be fair for the child, you know? So, it was "one-to-five" and at the end we would just add all the numbers, and at the end, whoever had the highest score would be the child that would get in the program. And this is already judging it after someone already judged it themselves. So it's from a biased opinion already, you know, from somebody who met the child once. And I mean, they got information from the parents, but she would also write her own thoughts, and her own opinions. We would try to be objective about it, but I feel like you're always biased when

you see these things. So it was hard for me to take part in that. I didn't feel comfortable. Cause I'm like, how do I know? I've never met this child, we don't have any doctors, I don't know, assessments, that we can base our decisions on, it's based on what we think is best, but who are we to think what's best for this kid, right? I felt like we were doing the bare minimum to figure out what these children need, and I didn't like it, I didn't like being a part of it. I don't know who's making these things, or how they come up with it.

Me: Can you think of how these assessment tools might look that might be less bias? Like how would you like to see them?

VR: I don't know, I think I'd like something by actual professionals. In the medical field, maybe by OTs, by SLPs, and their teachers, you know, like, I mean, I think at the end of the day, we still have to make a decision, but it would be nice to base it on something more than one person's experience with a child for one day. Like even for an hour....like how much can you get to know a person from an hour?

Me: And even professionals, like they're expensive...how much time would they give?

VR: Yeah, but it would still be nice to have more than one person's opinion on a child. And what if the child wasn't feeling well that day? What if he was sick and he wasn't sharing as much cause he was cranky? Or what if he just didn't want to talk because he isn't comfortable with strangers? So you know, what about all those things? I felt like we were doing the bare minimum to figure out what these children need, and I didn't like it, I didn't like being a part of it.

VR described how she and five staff would rate the children "however we wanted to," and how the assessment criteria was largely based on a snapshot of a child's life over a one-hour

in-home visit. She explained, too, that every child applying to the behaviour intervention program is reduced to a number that does not consider contextual factors, such as the child's mood the day of assessment. Although VR describes this process as imbued with "bias," the seeming objectivity of reducing a child to a number, and then scaling children's abilities and disabilities against one another, produces a "truth" about the child. In this way, assessments can sometimes create truth-claims that supplant uncertainty with a veil of certainty. Just as how doctors use numbers to determine an objective bodily event, removed from context, these numbers allow the assessors to seemingly remove their "political and emotional investments" from ranking children's "deservedness" for funding (Kafer, 2013, p. 60). Assessments also narrow down a child's set of behaviours and abilities into a diagnosis and create claims about severity; the analysis of these claims are rooted in ableist assumptions on what sorts of abilities a human requires to belong. Subsequently, that diagnosis is then used to inform the curriculum children and youth will receive, and what additional supports might be provided. The assessment, as it follows the child, will also be used to determine their educational stream, and what funding and supports might be required to make them fit. As acknowledged, these assessments become part of a child's file story, or file-self. As such, these tools appear to form the parameter of the fish's bowl, seep into its water, silence its forms of speech, and seek to dilute difference as they pollute and constrain space.

In VR's explanation of the assessment process, she notes that a child with delays or difficulties with verbal language will be granted access to the program over a child who might require extra support with their social skills. I found this piece interesting—the separation of speech language skills from social skills. When explaining what support with speech language looks like, VR explained that "the OT told me don't give in until he tells you what he wants. He

has to learn how to communicate with you. And like, just looking or getting mad isn't good enough. Even pointing isn't good enough anymore." The act of denying a child's own language can be made innocent by the expectation placed on children to progress through their verbal language milestones; gestures, no matter how clear, are not enough. Furthermore, the naturalization of normative development obscures the violent act of normalizing children (Erevelles, 2011). Acts that [**from my outside lens looking-in, loaded with my theory on anti-oppressive feminist praxis**] appear like silencing are suddenly transformed as required for the benefit of the child's future. These actions might also pass as ethical because, as Puar (2017) explains, "bodies understood as disabled, in particular cognitively disabled, have often been cast as inert passive objects rather than human subjects" (p. 26). This is not surprising, as they have already been seemingly reduced to object-status through numbers and file stories; constructed outside language capacity and complex beingness. However, despite these empirical framings, the young people we work with remain complex persons with agency and vitality. As Puar (2017) argues, our human-centric (and I would add verbal-centric) relationship with language has prevented seeing language capacity as multiple, and thus might justify the erasure of communication differences. Such erasure and naturalization provide reason to not to listen to a child's gestural language because "it's not good enough," as the OT told VR.

The multiplicity of language exists whether professionals in the field choose to listen, or not. There are moments in practice where children resist the surveillance, activities and authority of adults and the various forms of disciplinary power enacted across various systems of education and care. When this happens, the bowl cracks, and it is in these moments that tools such as creativity, love and hope become so valuable, such as the ones waiting on the outside of the bowl in Threshold 4. And so maybe the rock and the leaves are not inside the bowl, but

outside, and maybe the fishbowl is inside a lake, and maybe once the glass is shattered, the fish will have the whole lake. That, too, comes with certain issues. Like predators, as an example. What is more important? Freedom or safety? As if either wholly exist in one space, versus another.

Transformative Hope



*This isn't the kind of hope that
 Silences the hard
 Seeks cure
 Erasure
 End-points and easy resolutions
 Instead of revolutions
 Found inside
 The unsafe spaces that harm—
 This is the hope used to disarm
 The sickle
 Seeking larynxes
 Slicing throats.*

(Field poem; October, 2017)

Chapter 4. “Who Are We To Think What’s Best For This Kid?”: Disability

Justice and Care With Consent

It gets messy, it totally gets messy. But it should.

I’ve forgotten about it (laughter)
You are constantly reminded

(laughter) We do the best we can.
Would you like a hug?
Well no, you need to eat something.
My body tells me I’m full.
It’s written down. This is solid,
You can trust it.

It can be a relief
to rely on language.

It’s really nice to forget what I’m
Talking about

(data poem, Casey)

After Casey created the above poem, I asked them questions about their process, and what this poem might mean to them. They explained that they chose sentences based on “what catches my eye” and that they’re “not even reading the full transcript—it’s just what stands out.” Their poem might speak to the potential for plans to remove responsiveness and responsibility away from the support worker through what Casey described as “documenting” and “by following plans and policy.” As a support worker, Casey emphasized “you don’t need to be responsive in the moment because you have a plan” and how “people aren’t cool with uncertainty.” Their poem speaks to both the helpfulness of a care or behaviour plan (reducing errors and creating consistency between support workers), and the problematics (that support workers create a relationship with the plan instead of the person). Care and behaviour plans, in

such a framing, also might produce a static relationship with a person, rather than emergent and fluid ways of relating. Plans are a perhaps necessary aspect of our work; but they, like the support workers, exercise power as they uphold authority. Support workers wield the authority and power of the plan, and therefore it matters how they choose to work with both the plan and the person. As such, the support worker, the plan and the client/student, as well as shifting contexts, are all in a complex, entangled relationship. This entangled relationship warrants a critical lens.

In this final chapter, I expand on the relationships and intra-actions between participants and policy, infrastructure, and clients/students. I use selections from our conversations on topics of consent and risk-taking, linking to literature to speak to the possible implications for training and practice of front-line workers. Implications from this project show how the normative status-quo can be questioned and even ruptured across the training, practice and evaluation of workers and front-line practice. Using social justice, feminist and critical disability theories, I diffract participant conversations to produce emergent implications for disability practice. As I do so, I hold the acknowledgement that I and we are not studying and speaking on behalf of the people we support, but rather are engaging specifically as front-line workers with the entangled ethics and relationships of our practice. When approaching research, advocacy and action from a place of “speaking for” a marginalized community, there is an inherent assumption that a community is not already engaged in such work. In the disability community, it also runs the risk of producing and reproducing paternalist power-over relationships. When speaking “with,” research and activism emerges from the voices, agency and perspectives of the community being researched. Throughout this thesis I have used critical disability studies and social justice writing by people with disabilities as an action of speaking with the ideas and perspectives of the

disability community; and I again restate the participants and myself are not neatly situated on one side or the other of the able/disable binary. For this chapter, I first situate why this thinking and doing matters inside a historical context, and then I draw on the writing of Piepzn-Samarasinha (2018) to discuss how institutionalized and neoliberal care practices are being reclaimed by “crip” and disabled communities. I then move into the participants’ perspectives on everyday consent with children, followed by a short piece on leveraging privilege in resistance to ableism. While I weave implications for future research and practice into all sections of this chapter, I make these claims more explicitly in my final section.

“Where There Isn’t Love”

A key finding of this project is that how plans are created, and how support workers choose to engage and work with plans, matter. Historically, care and behaviour plans have been delivered in ways that contribute to oppression, with a person’s life structured by sterile institutional environments and medicalized care practices (Clare, 1999; Clare 2017; Piepzn-Samarasinha, 2018). Extreme acts of violence took place inside these large institutions that housed the so-called “feeble-minded”, such as sexual abuse, forced sterilization, physical abuse and verbal abuse. In addition to these abuses, many people were denied connection to broader communities, and to practice or even know their culture (Clare, 1999; Clare 2017; Piepzn-Samarasinha, 2018). These stories share historical space with other people whose bodies and spirits experienced similar abuses, bodies outside the boundaries of white, able-bodied, sane, neurotypical, and middle-class normativity. Drawing on Barad, Nye (2017) explains how “the past is never closed” (Barad, 2010, p. 264 as cited in Nye, 2017), and that we cannot erase our histories. She explains how “this is both the promise and the peril of our entanglements” (Nye, 2017, p. 11). Institutional living is sometimes discussed as if it were neatly situated only in the

past. However, the violent history of institutionalization, under all its guises, is not a “spectre” that immaterially haunts us; it can be seen and felt in ongoing practices of management and normalization (Piepzna-Samarasinha, 2018, p. 39). Such ongoing histories are examples of what the fear of difference, what ableist, colonialist, classist, sexist and racist ideologies, can produce. Furthermore, institutionalized care persists in the form of long-term care facilities and prisons, which often also serve as pseudo-care facilities for people with disabilities. As Casey explained when discussing issues of funding and inclusion:

We put a price on these people, we say you can't contribute to society, so here's this. We've got to the point where we're like, yeah but, you are people, sooooo let's try and not treat you real bad [*exaggerated/sarcastic tone*]. And just still not recognized. And again, in children it's different, but in supporting adults, it's like, anything within, that's safe, that isn't going to offer harm to themselves or their communities, should be permissible but it's, they don't get to live, for the most part, and not all of them, not all of them, I'm talking like worst case scenarios, but like, don't get to live according to their truth and their desires. And what they would be doing. As someone who has been in the medical system, who has been in facilities, like I have been detained in mental health facilities, like how damaging it is to be in a sterile environment where there isn't flexibility, where there isn't love, where there isn't messiness. Um, so yeah.

[Silence. Pausing, pausing.]

Casey points to the different kinds of living environments where a person with an intellectual disability label might live, depending on their age. They allude to a “worst-case scenario,” where people do not get to live “according to their truth and their desires,” and this perspective is both informed by personal experiences as well as experiences as a support worker.

Clare (2017) weaves past and present examples into a discussion of institutions, explaining how “this violence is made thinkable and doable through diagnosis” (p. 48). People living in institutions because of their intellectual disability label, or mental health label, continue to receive electric shock therapy and often live hyper-scheduled lives, spending much time in isolation (Clare, 2017). The violence—in its many guises—is “defended as treatment, not torture” (Clare, 2017, p. 48). Casey’s use of the word “we” has me thinking about who frames the reality of the folks receiving so-called care. Ableist and other oppressive structures have defined who people with disabilities are as a homogenized group, and then created spaces and treatments based on a largely bio-medical model of health care.

Some might argue that crip culture reclaims such care, as it proposes an ontology that embraces flexibility, situated engagement, and perhaps the messiness that Casey speaks to (Goodley, 2014; Kolářová, 2017; Piepzna-Samarasinha, 2018). Changing the language of care to a more emergent, politicized, non-normative framework might enable a relational, critical approach. Such an approach would meet human bodies at their fluid, shifting and contextual locations along the disability spectrum, in acknowledgement of their many identity intersections. Crip theory is one theoretical orientation that questions the production of normalcy, and critically engages with the values living inside daily practices of care. According to Goodley (2014), crip theory is a lived theory that “recasts what it means to be human” (p. 43):

Crip theory pulls us to one side and asks what do we desire of human beings? What are our children made to desire? What do we desire of our children? There is clear evidence that children are imbued with the neoliberal ambitions of parents, teachers and government. Enforcing normalcy through educational assessment is a form of systemic violence (Goodley, 2014, p. 40).

Working against the harm of systemic violence from normalizing care practices, Piepzna-Samarasinha (2018) uses a “crip” ontology in their book on disability justice, weaving disability justice into their framing of care work. They explain that “a Disability Justice framework understands that all bodies are unique and essential, that all bodies have strengths and needs that must be met. We know we are not powerful despite the complexities of our bodies, but because of them” (p. 21). While these cannot be homogenized, Piepzna-Samarasinha (2018) sees disability justice as part of the resistance to “all forms of oppression,” alluding to many histories of “cultural and spiritual resistance within a thousand underground paths” (p. 21). Their definitions of disability justice and care work are grown inside framings of collectivity / interdependence, and as such resist the high value placed on achieving independence. From this perspective, Piepzna-Samarasinha has created a book that can be used as a resource, providing tangible examples and tools to create collective care communities by people with disabilities.

One example Piepzna-Samarasinha (2018) provides that would be particularly useful for working with young people is that of “crip doulaship.” Crip doulaship is a practice that supports newly diagnosed folks coming into their “crip” identity, viewing such as a rite of passage, as a birth, not a death. They make visible the many people living with disabilities who are offering this care work to others, as bodies change, as one becomes crip. This shift in thinking switches disability from something that is sad, to something that is filled with complex community, and with an identity to claim with pride; not one removed from barriers, pain and grief, but one certainly imbued with love. The point is not to sensationalize crip as an essentialized subject location, or as a cool alt-living subculture *thing*, or much less to assume that “crip” is something that children with intellectual disabilities should or would want to claim. I use it here so that I and others might begin to think and work differently, from a place of teaching pride –a praxis

also taught by the works of Clare (1999) (2017), Kafer (2013), Goodley (2013), and Mia Mingus (see <https://leavingevidence.wordpress.com/>). I use this framework here as a disruptor to the way our body-minds have come to associate disability with struggle, sadness, isolation; something to fix, hide, control, unlearn, or eliminate from our human species altogether. Crip theory and disability justice have taught me that, among many things, crip culture can provide a vital lifeforce with community and love in the face of extreme invisibility and government programming and policies that allow people to live in poverty and unwellness, while telling them that this subsidy/funding/therapy is good enough.

As explained throughout this thesis, one barrier to the integration of a disability justice model is the continued denial of disability as a valid expression and variance of body-mind. Goodley (2014) suggests that the crip body, in its resistance to normalization, in its need for community and interdependence to stay alive, threatens the neoliberal and individualized achieving body-mind norm. By continually enforcing normality, and failing to create space to think with disability, a sense of belonging and pride might also be blocked. Through practices of neo-eugenics and the desire for the gifted child, no space is left in the social imaginary for dis/ability differences (Garland-Thomson, 2017; Goodley, 2014). How can there be love and messiness and deep consensual care when babies are already born with the expectations of a single body-mind shape (Landsman, 2009)? A shape that institutions and practices, through the authority of diagnostic labels, work to form a body into throughout one's life course.

I was just laughing.

She's so expressive

Am I like more receptive?

Fool-proof

Didn't have a diagnosis

Didn't have funding

It was a place to die

(Data Poem, Casey)

In my reading of Casey's data poem, they seem to check their privilege; the poem begins with the speaker "laughing," and it is unclear if the speaker is laughing at themselves, and their (perhaps) misplaced assumptions, or if they are laughing because the other actor in the poem "is so expressive." The poem moves more intentionally toward a self-reflexive stance, and the possible previous complacency and privilege of the speaker is now checked with a seemingly rhetorical question, "[a]m I more receptive? / fool-proof." These two lines have me thinking about how we as support workers might construct ourselves as knowing what might be going on at any given time with the people we support; furthermore, it appears to call to question where we are situated in the able/disable binary. When the speaker acknowledges—"Didn't have a diagnosis / Didn't have funding" followed by "it was a place to die," I return to my thinking of diagnoses and funding, the benefits of having a diagnosis—"if it is possible to name all the ways in which a diagnosis is useful" ([author's emphasis] Claire, 2017, p. 48)—and read Clare's (2017) questioning: "*Diagnosis is useful, but for whom and to what ends?*" ([author's emphasis] Clare, 2017, p. 48) with this data poem.

I think-with the material authority of a diagnosis and the medical/care/behaviour plan attached to such diagnosis, and how these inform and shape the course of a child's life; I think-with Clare (2017), who shows that enforcing normalcy might interfere with the creation of disability community and pride. I am provoked to ask—how can we do plans different? What action can we take as support workers and educators to show accountability to our privilege

inside dynamic and unstable power relations? What will we do to show responsiveness to the agency of the people we work with, while also working with ambiguity and uncertainty?

Centering Consent in Everyday Care

Non-written, non-verbal consent (from bureaucratic processes to day-to-day interactions) is not something widely discussed, and usually only in reference to issues of sexual violence and rape culture. However, care, education and child raising practices have normalized this idea that children cannot occupy agency over their bodies; that they do not know their needs; and this has been framed as a way we collectively uphold rape culture (M. Z. Johnson, 2016). Additionally, our present dominant practices sustain spoken language as the dominant mechanism by which intelligence, consent, needs and desire can be expressed and heard. Although subtleties in communication, in their uniqueness to culture and individual styles of expression, might be missed as we focus on verbalizations. Likewise, non-verbal “behavioural” communication might at times be overlooked as related only to one’s disability. As Casey explained in Chapter 3, sometimes a youth might have reached their “human limit,” their subtle communication—such as changes in breathing—ignored for too long, producing more visible behavioural communication, which gets constructed as deviant, and then subsequently pathologized. I believe we as support workers and educators have a responsibility to teach children that they get to control what happens to their bodies, and we can demonstrate this by attending to people’s subtle communications. Such intentional pedagogy and practice honours people as the experts of their needs, even when such needs are difficult to discern or understand.

SW explained how consent is “a tricky one because I think that sometimes it can take time to see if a child is consenting.” She provided the example of asking a child, “would you like a hug?” Though the child might nod their head, she at times sensed “that’s a clear no, you can

see it in their eyes.” From SW’s perspective, if a child communicates a version of yes, it is still experienced by her as ambiguous. SW further said, “and you can’t be like, well, they nodded their head! And like, give them a big hug anyways.” SW acknowledged, too, the difference between something like giving a hug, versus something such as eating:

And also at this age it’s difficult too because we send a few mixed messages. We teach them to listen to their bodies, and be independent, be honest with what your needs are and tell us what your needs are, but not all the time, because this is the time we eat [...] You teach them that people should listen to them when they say no, but then we also teach them, except when we say *this*.

As SW discusses, on the one hand she is trying to engage with consent in her practice, and by doing so, teach children consent. This collides with institutional policies, schedules and time constraints. In some ways, this contradiction seems to suggest that somewhere out there is a bad person who will not honour consent and that one day the child will be an adult and will need to know what “good” decisions to make. It begs the question, is it about teaching children to know their bodies, or know their bodily expectations as required by neoliberal capitalism? In this sense, all children are measured against the idealized “able child” that “controls their temper, eats responsibly and behaves appropriately to their parents” (Goodley, 2014, p. 88), and other authority figures who are also being disciplined to uphold such normativity. A child has choice and the option of consent, “except when we say this,” and perhaps only within normative boundaries, inside the disciplining structure of time.

If a child becomes disobedient, or unruly, refusing to eat at snack time or lunch time; if a child does not want to become toilet trained before preschool or kindergarten, their no, their body’s no, becomes something problematic. Sometimes, further investigation takes place to rule

out, or rule in, disability, either intellectual, neurological or behavioural. In terms of the already-labeled child, their communication might be constructed as a feature of their disability, and not their way of explaining that they do not want to eat, or they do not want to eat the food prepared for them, or a range of other possibilities that are preventing the child from engaging in snack and meal times. Such an example could be extended to bed time, bath time, play time, and so on. Children might require clear boundaries for health and safety reasons; the requirement to eat at a certain time despite what one is experiencing in their body is a way kids might learn that the schedule's/plan's needs are greater than their body's needs. The clock—by way of schedules—serve to reinforce that authority (Kafer, 2013); it becomes a necessity inside highly scheduled institutions that children learn to self-discipline and obey their adults.

On issues of non-verbal consent, P explained that “we don't teach kids consent in general,” going on to share her view on what we teach children:

We teach children very early on to be very pliable and obedient. And when they're not, we see it as a disturbance, so... even around the very most basic definition of consent, right? On let's say, physical touch, we expect children to allow us to physically touch them, physically move them, manipulate them, and there's a huge expectation that children owe affection to adults, right? And I think, and of course there's a whole gender analysis to that, and then if you add disability into the mix, if you add anything, it gets even more complicated, but I think as a practitioner, one of the things I like to focus on with kids is, what are your boundaries? Everyone has boundaries, how do you know what yours are, what do they look like, what do they feel like? With older kids we talk about porous boundaries and rigid boundaries, but with little kids we'll talk about, you know, when you let someone into your personal space, why, how do you know someone is safe,

how do you feel in your body. Those conversations are usually very verbal. You know, even if we add another medium like art or something, they are still very verbal. How do we start having those conversations when somebody doesn't communicate verbally?

Again, much like SW alluded to, P brings up the contradictory teachings received by children on issues of consent and choice. Children must meet the needs of institutions and become self-disciplining subjects; they are taught boundaries, and how to identify their boundaries, yet "we expect children to allow us to physically touch them, physically move them, manipulate them, and there's a huge expectation that children owe affection to adults." The school where P works offer curriculum that teach consent, while also teaching children to be "very pliable and obedient." Furthermore, she suggests that such curriculum, even when using a visual medium, is still centered on verbal-language. "How do we have conversations of consent when somebody doesn't communicate verbally?" P asks. In the research moment, this question was not resolved; as P indicates, also not one considered in curriculum development. Although there is no definitive answer to P's question, I do believe that it would be negligent to assume the impossibility of teaching consent, and this might require reimagining conversations as occurring beyond verbal language. The notion of agency might be applicable here, and as previously explained, is an enactment occurring through out intra-actions with the people we support, not something that someone has, or that is given (Barad, 2007). I recall Casey's previously discussed story about her client's nonverbal communication being silenced by staff, and how this led to aggressive behaviour: agency is always being enacted through our intra-actions, we just might not adequately pay attention, tune-in, listen. If it is true that agency occurs inside intra-actions, and that intra-actions occur continuously between more than simply constituted human subjects (Barad, 2007), perhaps conversations and education need to be reconceptualized away from

instruction passed on to unknowing objects of education; that, perhaps, something inside our bodies already knows when our boundaries have been crossed; our consent ignored. This issue warrants further research and discussion, and so too does the question of educating staff on consensual practices.

Joining disability justice with consent-based practices might mean co-creating care and behaviour plans, and honouring non-verbal (gestural, behavioural, bodily) and verbal communication instead of trying to get the supported person to “exist on the level” you “want them to exist on” (Casey). Such practice approaches might require support workers to enter the world of the person one supports when that person invites you into their world. It extends beyond inclusion, beyond belonging. And, as the participants explained, it requires getting comfortable with unpredictability, with making mistakes along the way. As Casey says, “you’re going to fuck up, but you have to try;” and, as VR demonstrated, you need to keep showing up and being there. In many ways, participants storied how they approach their work from a place of consent—what I also like to call deep listening. I heard examples of intentional disruptions and critical questioning, as participants explained some of the limitations of their work environments, and the limits of their power as primarily support staff.

Taking Up Risk

I want to reiterate in this section that my thesis is not attempting to give-voice to or speak on behalf of young people and their experiences. Rather, my focus is on the experiences of support workers and the little understood roles we occupy and responsibilities we carry; how we grapple with seemingly non-sensical policies and rules, stretching our limits, and taking on risk; how we push against authority, and at times step beyond our job expectations to fill service gaps. By intentionally politicizing our practice, I am showing how complex our work truly is, and how

critical lenses help us work through difficult choices; how we make the choice not to accept the status-quo even when the status-quo is all that is funded. I am bringing these crucial questionings to the forefront, for ourselves and for other workers in the field. What follows is an excerpt from my conversation with P on allyship, taking on risk, and leveraging privilege.

J: If we as like, neurotypical, able-bodied people in the field, like if we're doing this work ...how do we show up as like agents of change in some ways for the school system, or whatever environment we're working in, but not be blocking voices? And yeah, taking up that space? What does change look like in our work environments?

P: When I think about that, when I heard that, one of the first things that popped into my mind was framing yourself as an ongoing learner in the world of disability, atypicalities, exceptionalities—whatever you want to call it—but also what I think is necessary is a lot of the other work I do, is that when I think of being a settler, I think about being an accomplice, so, somebody who's willing to take up risk to make change. And who's willing to leverage my privilege to support folks who are just not as privileged as I am. And so it's more than like, allyship, more than just being educated, just wanting to do something, it's about materially, physically, intellectually, emotionally, taking up risk when it needs to happen and the school system is a prime example because there's a lot of risk involved with people with different opinions at the table, and we're talking about the next twelve years of your child's life. [...] We can all take 50 classes about inclusion and disability and we can all talk about everything we know about the medical community, about what different issues can do to the body and can do to the mind, but like, that doesn't mean anything unless—like none of that means anything—that's just knowledge you hold that you've learned from other people. Like the best teachers are the

families and children you're working with. And you can't come in and read a textbook on inclusion. You have to figure it out and make mistakes along the way. And lots of times it is trial and error. Like there's a lot of trial and error in my practice, but at least you're willing to try again. And try again.

P explained the process of leveraging one's privilege and being an accomplice as a lived, daily commitment of trying, and trying again. P also stresses the need to take up risk to achieve structural and systemic changes in the workplace and to counter policies and practices that benefit some more than others. By taking up risk and being an accomplice in the struggle for justice, a person might be risking something material—like one's job, as an example. The activist principle comes from the ethos that those with the most privilege have more access to wealth and other material benefits, and therefore more resources available to risk action. However, as discussed by de Finney, Dean, Loiselle, and Saraceno (2011), often those in a position of providing front-line service are stopped from disrupting potentially harmful practices by strict policies. As they explain:

No matter how dedicated or passionate about our work we might be, we often come face to face with the deeply embedded nature of these barriers, the difficulty of building strategic partnerships, a lack of knowledge, skills, resources, and supports to enact change, and backlash when we challenge the status quo. When this happens, our work is depoliticized and its potential for lasting social change is restricted (p. 373).

Participants spoke of the limiting structures and hierarchies in their work environments—as practicum students and as support staff. They also spoke of the way they worked against practice environments and policies that failed to think with the complexity of disability, and of how they took up risk to navigate accessibility barriers; likewise, as VR discussed, there was also a sense

of “I was just doing what I was told.” As P explains above, much of the work of inclusion is “trial and error;” and while this is true, it concerns me that a critical justice framework for practice is not presently centered in education; that disability practice is not centered in education, child and youth care, or social work as a critical practice lens. This is not to claim that critical perspectives are never included, or that there is not an opportunity to learn such a framework (see Boyd, 2007; and Robertson & Larson, 2016). However, increasing the opportunity to learn a critical language as an expectation of training and education might provide students with a foundation to understand and work against some of the oppressive systems they encounter in their work.

Keeping in mind VR’s rhetorical question that introduces this chapter—“who are we to think what’s best for this kid”—I was interested in the way participants took up risk and leveraged their privilege, despite this not being something imbedded in our training, education, or workplace policies. In this way, taking up risk is an example of participants rupturing the normative status quo. These actions are suggestive of the need to reinforce what these ruptures produce at every stage—from education, to training, to practice. As support workers, we do not need to accept oppression; and for us to act, we need to learn how to identify and name oppression.

Participants took up risk to work with the unique differences of the people supported when policy failed to include such differences. As an example, LV took on risk to honour the non-verbal, gestural consent of one person under their care who grew up in institutions, when a government agency would not:

Me: So what does it take to step into that place of like, being with her? Or like, even just like, what does it take to make the decision to do the hand-over-hand consent?

LV: The frustration by the system I think. I just got pushed too far for her not to have access to the things she deserves. And she has no family, she has no one else, that I just felt so strongly that this was what I needed to do, so that I made sure she knew that she was important and that she mattered. You know, cause she grew up in the institution, she's probably felt forgotten about her whole life. It was really important for me to let her know that I was going to do whatever it takes.

Me: Do you feel like you took a risk with that?

LV: A little bit. And you know, at the end of the day, I did it because there were two other staff there, and I was just like, I'm going to do this [...] The risk was (pause). I risked the staff being like, oh my god, NAME is out of line here. And risking that I could get in trouble from somebody. But I also knew that the outcome and what it was going to give her, was worth the risk.

As LV explained, she risked her job, but she also risked how her colleagues might perceive her; she therefore risked her relationships. This action—which could be discussed further in terms of ethics—is not to discount the smaller ways that support workers take up risk. Participants also discussed the ways they changed space, or created space, in opposition to most of the people they worked with. Such work is exemplified by the following image, and described in the conversation between LV and I:



Figure 3. A place to be different.

Me: I'm just looking at this art piece you're doing and we're talking about this place to be different, and it looks like this really protected space to just wiggle around and be crazy.

LV: It does kind of, doesn't it? [...] This is the weird nasty outside world, but this is a pocket of safety and understanding.

Me: And it takes a lot of work, hey? Like a lot of self-work. [...]

LV: Self-reflection and then also always checking yourself in the sense of, am I doing this for my own good, or am I doing this for someone else's good, you know?

LV's pocket of "safety and understanding" was similarly communicated in P's action to "build a nest" for children with complex educational needs, and in VR's action to create a quiet space for the child she supported with ABA therapy. The actions to create safety, or pockets and nests, are supported by the risk that participants take on to produce such spaces. Support workers involved in this study work with risk, with fear. Risks are not only taken in the resistance to policies; policies in themselves are a risk. Therefore, it could be argued that risking a young person's emotional health is less risky than disrupting smooth-flowing schedules.

Participants identified the need for an increase in education and training on critical disability practices, and for such an approach to be embedded in our practice approaches with all young people. They also emphasized the importance of learning on the job, which raises the importance of providing adequate resources, mentoring, and room to explore beyond prescriptive programming. They discussed the need to listen to and work with non-verbal communication in school-based support, but how this need is often also placed in opposition with the expectations and roles of teachers. This study has shown that institutional hierarchies can at times interfere

with providing support in ways that align, ethically, with the needs and perspectives of participants. Participants also identified how diagnostic labels are problematic, while at the same time, a vehicle toward access to services. Finally, they emphasized how we continually restructure our workspaces, as they are rarely designed to think about and work with disability. For instance, P explained that the school where she works has yet to implement “basic accessibility pieces,” such as accessible playgrounds. This contrasts with her experience in hospice, where “some kids had CP and stuff and would come regularly, while other kids had cancer. It was a huge vast variety of abilities, and families that came from different backgrounds and different communities.” She went on to explain that the facility was

a place to live comfortably because everything was so accessible. Like for people with a bunch of different abilities. You could move comfortably from space to space, and play on the playground, and play outside, and get through doorways, and get from one door to the other, like so easily because everything was made for that purpose. Like, in other parts of life, everything is made for people who walk, and people who talk.

P’s time working in hospice taught her how inclusion can be thoughtfully structured. This unique and important “alive and loving place” was created for children with very complex care needs. It was designed for the function of disability and chronic/terminal illness; and is also used as a break for the entire family system, while also offering educational, recreational and counselling services; in short, it is a space to be different. In some ways, we have moved away from institutions and toward inclusion, for example by creating “inclusive” classrooms. However curriculum and pedagogical practices and outcomes remain highly verbal-centric: the flow of the class and getting through the required educational material is too often prioritized over creating accessible and inclusive spaces. The example of genuine inclusion in an institutional setting that

P offered provides education to children who are sick or have complex physical and intellectual disabilities. This institution is subsequently removed from the so-called inclusive public-school institution. I wonder, in considering this example, as compared to inclusive schools, how this space was designed by thinking-with-disability supports. I imagine, what if all spaces were designed to think with disability differences; not in efforts to assimilate or flatten difference, but to grow-with difference. What if we approached our work and worlds thinking with difference and disability, as something that is inherent to our process, as non-negotiable, and an expectation. This would not be about generating perfect inclusion, but rather about creating disability spaces; it would be about intentionally complicating the world where our work takes place.

Future Research

A key focus of this work was to imagine a different way to practice support work with young people with a non-verbal label, and who also might have an intellectual disability. The purpose was to interrogate the different ways we show up in our work across the diverse settings in which support work occurs. It is important to restate that support workers are not homogenous; we also live across diverse social locations with intersecting forms of privilege and marginalization based on racialized, gendered, abled and classed norms. The perspectives of diverse participants in this study demonstrate the various ways workers might connect across our differences to create intentional spaces of belonging and change and justice-doing (Reynolds, 2012). Justice-doing, according to Reynolds (2012), extends beyond human rights. As she explains, “social justice includes all domains of social life. It is beyond the more narrow scope of human rights and justice systems, which primarily uphold laws” (p. 19). Justice-doing works in resistance to “dominator culture”, and is also a teaching offered by hooks (2003):

Dominator culture has tried to keep us all afraid, to make us choose safety instead of risk, sameness instead of diversity. Moving through that fear, finding out what connects us, revelling in our differences; this is the process that brings us closer, that gives us a world of shared values, of meaningful community (p. 197).

Given the depth of participants' complex negotiations of risk, advocacy and politicized practice, further conversations and research are needed to fully grapple with the enormous roles and responsibilities support workers occupy. This study calls out the complacency of some educational, therapeutic and medical practices that stratify and fragment body-minds; that acknowledge the need for consensual and inclusive practices but fail to consider and value non-verbal communication as valid. This work is suggestive of how certain aspects of humanity are made to matter more, creating normative development, adhering to strict hygiene expectations, and following schedules matters more than learning justice, dignity and diverse ways of being and connecting across differences. My study raises the work that the support workers engage in (which is outside their paid responsibilities) to disrupt such normalizing rules and practices. Building on the findings of this study, as I go forward, I will continue to challenge hierarchies of power, participate in justice-doings alongside the people I work with and other support workers (Reynolds, 2012). I will build on the growing body of work that centers politicized and critical practices in resistance to ableism.

Support workers—whether it is a formal job expectation—have a role in restructuring spaces to be different; and the participants of this study told me of the ways they restructure space as they embrace the “messy” and unexpected. Do we need to rebuild all our spaces to change the way we think, act, do? And if we address structural inclusion, does that also address ideological barriers to access, such as the need for children to be as able as possible? I remain

curious about our reach toward idealized and perfectly inclusive spaces: disability is a broad category, with a vast amount of intragroup differences and diversities. The young people we work with are by no means homogenous, and there is no single agreement in the disability community on what is needed. A multitude of perspectives and voices are required to shatter overly simplistic, singular solutions and responses. There remains much debate among disability rights groups, and the language used to define identity is varied. Bringing some of these debates into our care work will help us create multiple, responsive and accountable practices. Such vital nuances will continue to grow our support and care work away from assuming pre-ordained preferences and needs. It will also potentially take this work beyond what is presently imagined. At this time, inclusion remains synonymous with inclusion into one version of the many possible worlds we can collectively create. Future research in the context of British Columbia support work, funding and contexts might build on other research presented throughout this thesis that investigates what practices of curricular and structural inclusion are working well; and might also research the ethos behind inclusive practices, and ones not yet imagined. As P acknowledged, “there could be something really frickin’ bad-ass and I just haven’t encountered it yet.”

Consent was also acknowledged by the workers as a critical aspect of practice, for it acknowledges individual agency and centres a relational practice, where needs, people, bodies, relationships, environmental contexts and other forces are entangled with one another, continually shifting. As such, our work is constantly reconfigured and renegotiated. Inclusion, as mentioned earlier, is partial, emergent, ongoing work much like consent. Conducting engaged, collaborative research with service providers around issues of consent is important if we are to continue growing this action outside of bureaucratic and clinical spaces, and solely beyond the

context of intimate touch. What the participants did not say, and what I did not ask, was whether educational staff and support workers are offered the opportunity to attend consent and inclusion workshops and training. From my experience in group homes and inclusion programs as a support worker, consent was not (at that time) discussed, and it was also presumed that we all understood inclusion as a concept and action.

While my study deliberately focused only on the experiences of support workers, from what participants shared, young people with disabilities can and should be included in the decisions about their lives. Young people with disabilities who are navigating services like respite, ABA, occupational therapy, and special education, can and should be included in future research, policy development, and decisions that impact their care, plans and lives; just as young people need to and can be included in the IEP process. To do this important research, able-body and neurotypical researchers in disability studies might continue to ask how they can help and support what the disability research community, and disability communities more generally, are already working on achieving.

On what this might mean for conducting further research on these topics, I turn to the “nothing about us without us” disability movement. This is not to discount the importance of having support workers also represented in research, because they too have often been excluded from research on this topic, but future work on a similar topic should include the perspective of young people with intellectual disability diagnoses, who are experiencing or have experienced the special education and health care system. Even better, it should be led by young people with disabilities, in the process shattering what Teachman et al. (2017) consider to be method biases that see people with a non-verbal disability as incompetent research subjects. They argue that research methods need to change, since,

Communication impairment, rather than limiting a person's involvement in research, provides an opportunity to reconsider and expand the ways we think about talk in interviews and how social relations are formed in the dialogical relation that is all of our communication (Teachman et al., 2017, p. 8)

Researchers need to continue to shift how we come to understand language and communication, and their connection to intra-actions and agency outside strictly verbal terms. This was something that I strived to do in small ways by incorporative visual art, and by co-creating the research structures; however, I have much work to do to continue unlearning my verbal-centric approaches to research. For my methodology, I drew heavily on ideas from disability/crip, queer and racialized community advocates and activists (such as Clare, 1999, 2017; Lorde, 1984; Piepzna-Samarasinha, 2018), who do not necessarily identify as academics. My writing is nourished by their work. I believe their writing, words and art are very much needed as we work toward building less elitist collective access and consensual research and practice cultures, with one another and with our environment. Future research on similar topics might continue to build upon activist writings; echoing Piepzna-Samarasinha (2018), I also hope to see more publications on disability justice conversing with one another. While this study did not engage with issues of environmental justice, it is a topic that underwrites all others and one that urgently needs to be explored in relation to disability justice. There is much to learn, as we grow, as we work with the difficulties brought on by environmental degradation, continued colonization, and unrealistic body-mind expectations.

As I conclude this work, I continue to wonder about the conversations I had with participants—and the questions I did not ask. My methodology, which I wove together with different sources from art to theory, has an *almost but not quite* feel to me. Drawing on Deleuze

and Guattari, I experimented with diffractive, emergent, non-linear entanglements with words, affects, contexts, politics, bodies, art and ethics. The way these ideas have been put to work in multi-media research offered me a valuable theoretical framework for my collaborative arts-based methods and analysis. I am unsure whether I truly enacted a diffractive analysis, and whether I truly used “wonder” as MacLure (2013) conceptualized it; did I work with the difference in data to produce something new? Did I follow the thread of “wonder,” and the feelings of monstrosity to create a multitude that disrupt the solidification of ableism, and the authority of positivist research on disabilities? Or did my project resort to a content analysis using art methods? I strived to enact the process of “plugging in” as explained by Jackson and Mazzei (2013), reading different theories and data together a way to think through the various affective intensities of this project; as a way to diffract meaning, and produce (or make visible) critical support work practices. This process enabled me to ask questions of the data, rather than work with only themes and concepts, and I became affectively connected to the analysis process; this was not an objective undertaking, but a deeply political and personal project.

This project has provided me with vital learning, and the gifts of the participants—their art, critical interrogation of power dynamics in practice, and emotional labour—will continue to resonate with me as I continue this work. And while my practice and ethos have been enriched, I now have a responsibility to the stories that were gifted to me along this journey, and to the knowledge I have gained. I commit to growing this knowledge in collaboration with communities already engaged in vital justice work; to leveraging my privilege; to staying with my fear, and helping others do the same. I believe incorporating disability justice, consent and a “crip” ontology might assist in education and caring for children, youth and adults with intellectual disabilities “according to their truth and their desire” (Casey).

Throughout the writings of this thesis, I have been putting together a website (<https://onlineacademiccommunity.uvic.ca/dreamhopelovecreateact/>) as one concrete resource coming out of this study. The website shares participant artwork and data poems and provides a list of resources that support workers can access to continue growing their practice. Some of these resources are academic, but many are links to publications created by the disability / “crip” community; this is one action I am taking to grow our practice from a disability justice perspective. In addition to sharing the products of this through the website and in future workshops, presentations and publications, it is my hope that this work might inform resources and learning activities for front-line workers, particularly in post-secondary settings.

Conclusion

One of the implications of my study is that it makes visible which bodies are inscribed with value; how certain bodies are made “normal” and how those processes are naturalized. Butler (1993) explains how naming a “norm” is not where that norming stops but is “reiterated by various authorities and various intervals of time to reinforce or contest the naturalized effect” (p. xvii). Erevelles (2000) calls attention to the various ways that those with an intellectual disability resist the disciplining forces that naturalize ability—and continue to resist able-body/able-mind norms. This can be seen in the unruly body, a body that cannot be made able; that, by mere existence, destabilizes the authority of ableism and is simultaneously cast-out of our imagined futures (Goodley, 2014; Erevelles, 2000; Erevelles, 2002).

Ableism—in operation with the project of neoliberalism—leaves little room in our imagined futures for young people to grow-up with a disability, and with pride. I follow Erevelles (2011) question—which builds on McRuer’s (2006) question—“what might it mean to desire disability?” (p. 207)—to ask, “with what social conditions might we welcome the disability to come?” (p. 63). I also ask, what actions must we take, every day, to expect the disability that is already here as we map out crip futurities, working against the various mechanism that seek to erase disability from our futures (Kafer, 2013)? In doing so, we meet these young people inside their worlds with deep listening. Such a shift intentionally politicizes our work and worlds; is a justice-focused praxis, which is accountable to our own privilege and power, to the fluidity and instability of body-minds.

Barad (2007) defines agency not as something that one person has, but as an intra-action that occurs between all matters; this offers a relational and emergent conceptualization. I believe such an ontological shift in thinking about agency away from a hierarchical cause-and-effect

interaction that exists between only human-subjects provides new language for the complexities of our support work practice. In the disability field, this might be particularly useful as Barad's (2007) definition moves beyond thinking in strictly human-centric ontologies. As support workers, we work with a plethora of assistive equipment that facilitates communication, movement and eating. Furthermore, as the participants note, we rely heavily on documentation, and various care and behaviour plans. Understanding agency as an intra-action creates possibilities to disrupt the "support person" and "person being supported" dichotomy, understanding that we are in complex and entangled relationships. Agencies, as a series of forces made possible through the materialization and performativity of the body, continually change the ways we relate. By Barad's (2007) expansion of agency—as something also not necessarily fixed to present time—we need to continue to think-with the oppressive histories that materially haunt our present agencies, such as biomedical institutions and sanitariums, and how these histories are also entangled in the actions we take today.

Throughout this thesis, and informed by my intersectional feminist, decolonial and crip ethics, I made a commitment to disrupt issues related to ableism through everyday actions, which often involves taking up some degree of risk. Lykes and Coquillon (2007) explain that action researchers

seek solutions to everyday problems and—to a greater or lesser extent—to transform the social inequalities exposed through research by facilitating and engaging in specific actions that contribute to human well-being and a more just and equitable world (p. 298).

I aligned my study with this definition, but I have not claimed an action-based methodology. The action in my research came from the immeasurable way that differently talking, thinking, making and showing art in reflection on practice about disability might shift our approach to support

work. The action inside this thesis involves thinking deeply and with heart about the practice approaches that cause us harm, and that, as some participants discussed, we refuse to do anymore. Such doings reinforce us to continue acting in alignment with our ethics. The action of this study also comes from the power of working in solidarity with others across communities, disciplines and work environments; how we come to empower one another in anti-racist and anti-ableist practice. The action is also in the art objects we created, and the way they were shared with one another, and on the website associated with this thesis.

When I think of the everyday solutions that Lykes and Coquillon (2007) evoke, I question if I/we/us can solve ableism? Resolve ableism? Where would we even begin? Moreover, is it even ethical for me to organize a research action on ableism? What right do I have, what claim do I have, to challenge an ideology that I appear to benefit from as able-bodied and neurotypical? (Am I using my privilege, taking up space, appropriating, and blocking voices from a community I do not belong to?) These ethical questions never go away and have remained central to my methodology; as does the belief that, as people who work with children, we carry an added ethical responsibility to do this work with and for young people with intellectual disabilities; how we show up, and how we fail to show up, matters. Taking everyday actions against ableism, by “refusing” and “taking risk,” as P discusses, and building these practices into our work and ethos, might not solve ableism. However, it certainly has the potential to disrupt its pervasiveness as we work inside our intra-actions and collective agencies.

Social justice, art, feminist and critical disability theories and action were equally influencing factors in my methodological approach. I used a collaborative praxis methodology to keep myself and the participants “purposeful, hopeful, and dreaming” (Cahill, Cerecer, & Bradley, 2010, p. 407). I worked with a diffractive analysis in the way that Lather (2016)

describes, showing conversations, art, poetry and theory intra-acting with one another, and with me as researcher. I strived to pull objects and framings out of their comfortable or easy “shape” (p. 126). Through art, conversation and collaborative analysis, we questioned how as workers, we work inside these processes and practice expectations that might at times cause us harm. Furthermore, we created a space to amplify, expand on, share and honor those practices that are working, that are productive. We subsequently used artistic expression to challenge some of the ideologies that do not appear to serve young people with disabilities holistically, or with dignity, or with hope, or with love. Ideologies that inscribe bodies with oppressive meanings; and try to produce and reinforce stable subject positions; and impossible ideals of personhood. Subsequently, I am calling for us to shift our worldviews so we might continue to build on work—particularly the work of feminists such as Barad (2007), Butler (1990; 1993), and Kafer (2013)—that teach, write, and think-with the fluidity, materiality and complexity of bodies. Such complexities demand intra-active and emergent ways of relating and doing research.

I asked of myself at the beginning of this study, what would it look like to nurture a critical consciousness and use hope to foster a community that actively resists ableism and promotes dis/ability thinking? Paolo Freire’s work, and specifically his concept of “*concientización*,” or “critical consciousness,” is heavily cited by researchers engaged in praxis-based methodologies such as Participatory Action Research (PAR) (Lykes & Coquillon, 2007; hooks, 2003). bell hooks (2003) writes of the way educators can support students in unlearning dominator culture to create resistances against racism and colonialism. Hope and love are two such transformative forces. If we insert hope for change, in combination with love and compassion for where people are in their journey toward unlearning “diseases of power” (Foucault, 1982, p. 779), what hooks (2003) might call products of dominator culture, could we

resist how ableism, racism, colonialism, sexism and homophobia shape support work? Specifically, could such a transformative hope begin to create a consent-based and justice-centered support practice designed with the young people receiving our services? As hooks (2003) argues, we need to move beyond simply stating or naming a problem, because this can take away hope (p. xiv). For hooks (2003), hope is a concept with weight, an essential ingredient in transformative education and in positive, counter-hegemonic change processes. Drawing on the work of Paulo Freire and Mary Grey, she writes how “hopefulness empowers us to continue our work for justice even as the forces of injustice may gain greater power for a time” (p. xiv). I approach the intersections of ableism, racism, classism, colonialism and sexism with hope for something different; the abled-world is quite possibly, unconsciously, afraid of hope because hope breeds resistance, endurance. Hope makes people strong. It energizes our counterhegemonic systems, so that we no longer accept, ignore, or tolerate exclusionary and violent normalizing power practices. As I come to exist inside increasing limitations from my own chronic illness and mental health, I find myself seeing with increased clarity how systemic ableism operates. It is through this gap between my life and the expectations of ableism where I find a very real and tangible hope; my hope finds grit and community.

Great work is being done in front-line practice and I wished to grow and share those positive experiences, holding space for the multiple emotions that emerged as a result. Support workers are paid very little for the work that we do, and the participants in this study continue to show-up with such great love, compassion and ethics. I am so grateful that the participants in this study gifted even more of their time and love to participate in this study, and collectively work toward growing our practice toward a disability justice model.

Epilogue: Thesis Threshold

“For within living structures defined by profit by linear power, by institutional dehumanization, our feelings were not meant to survive. Kept around as unavoidable adjuncts or pleasant pastimes, feelings were expected to kneel to thought as women were expected to kneel to men. But woman have survived. As poets. And there are no new pains. We have felt them all already.

We have hidden that fact in the same place we have hidden our power. They surface in our dreams, and it is our dreams that point the way to freedom. Those dreams are made realizable through our poems that give us the strength and courage to see, to feel, to speak, and to dare”

(Lorde, 1984, p. 39)



Threshold 5. “Blah blah blah blah blah” created during research gathering.

“If collective access is revolutionary love without charity, how do we learn to love each other? How do we learn to do this love work of collective care that lifts us instead of abandons us, that grapples with all the deep ways in which care is complicated?”

(Piepzna-Samarasinha, 2018, p. 18)

DreamHopeLoveCreateAct (and back)

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Appendix A: Telephone Script

Hi [name of ED of organization], I am a graduate student in the department of Child and Youth Care at the University of Victoria. Do you have time to chat?

[if no]

I'm sorry to have bothered you-- Is there a better time I can reach you at?

[if yes]

I'm calling you today to ask if I can post recruitment posters at [name of organization] for a research study I am running at the University of Victoria, and also if I can post the same poster to your twitter and/or Facebook page? My research topic is related to working with children and youth who use non-verbal communication to express their needs and I believe some of your employees might be interested in getting involved. This study is not about your organization, but rather the broad disability field. If any of your employees choose to participate, they will not be asked to breach any workplace confidentiality

[if no]

Thank-you for your time!

[if yes]

Great! Thank-you so much...

[If unsure]

Answer their further questions....

Appendix B: Recruitment Poster

Dream/Hope/Love/Create/Act (and back)



To the (fabulous) support workers for kids and/or youth who use non-verbal communication:

Do you want to connect with other support workers in your field?

Do you want to talk about your experiences with consent with children and youth who use non-verbal communication?

Does participating in a collaborative arts-based research study with other support workers interest you?

Contact me for more information!

Jessica Sahlstrom

[email address]

This study is being conducted to partially fulfil the requirements of a Master's degree in Child and Youth Care through the University of Victoria.

Appendix C: Invitation to Participate

Dear _____,

You are receiving this letter because you expressed interest in participating in a research study on topics relevant to your work. During this collaborative study, we will discuss issues related to consensual practice with young people who use non-verbal communication to express their needs. Collaborative research means that you have choice in some, or all, aspects of the direction of this study. For this study, we as a group will collaborate on research questions, engage in conversations around these questions, and collaborate on an art project of some kind to express our discussions. You do not need any training, experience or skills in art.

The research study will take place between June-September/2017 at a time and location to be determined, but likely at the University of Victoria. This study will not ask you to breach any work-place confidentiality, nor ask you to disclose information about any of the clients you serve.

Participation in this study must be entirely voluntary and you are not committed to attend all group-meetings. You can choose to drop-in at your convenience, or attend every session. Moreover, you can make the choice to participate in an individual interview if group work does not work with your interests and schedule.

The purpose of this study is to create a community of support workers who share a passion in growing their practice and learning from one another. Central to this study is the question of if, and if so, how do support workers consider issues of every-day consent in their work. We will create an artistic representation of our findings to share with other support workers using a medium to be determined as a collective. Some examples include poetry, visual art, sketches and collage.

As this is a collaborative study, you will be asked what areas of consent are important to you, and will subsequently participate in creating research questions as a collective.

The questions we form might be around some of these issues:

1. Child development and the pressure for language acquisition
2. Issues of consent in every-day practice, as well as in clinical spaces
3. The creation and enactment of behaviour plans
4. Disability labels/the process of labelling

To participate in this study you must be over the age of 18 and have relevant experience in front-line work, with children and/or youth with a non-verbal disability diagnosis. Examples include working as a behaviour interventionist, support worker in a group home, or a respite worker. This study will not ask you to breach any work-place confidentiality, nor ask you to disclose information about any of the clients you serve.

As this study will likely take place at the University of Victoria, it is my hope that research sessions will take place on Sundays, as parking will be free for those who drive. I will provide snacks and hot beverages at every session, as well as bus transportation to and from UVic if needed.

If you are interested in participating, please let me know by email by __[DATE]__.

I am happy to answer any questions you might have, or if you would like to arrange an in-person meeting to gather more information before making your choice I would be happy to meet with you.

Looking forward to having you participate in this study!

Warm regards,

Jessica Sahlstrom

Email: [email address]

Phone: [phone number]

Appendix D: Participant Consent Form

Dream/Hope/Love/Act (and back):

An Arts-Based Collaboration in the Dis/Ability Field

You are invited to participate in a study entitled “Dream/Hope/Love/Act (and back): An arts-based collaboration in the dis/ability field” that is being conducted by Jessica Sahlstrom.

Jessica Sahlstrom is a graduate student in the department of Child and Youth Care at the University of Victoria and you may contact her if you have further questions by email: [email address].

As a graduate student, I am required to conduct research as part of the requirements for a degree in Child and Youth Care. It is being conducted under the supervision of Dr. Sandrina de Finney. You may contact my supervisor at [email] or [telephone number].

Purpose and Objectives

The purpose of my research is to create a community of support workers to collaboratively explore dis/ability and associated practices and policies, such as the process of diagnosing, labeling and managing a person’s disability. My research will explore issues of power and consent when working with children and youth who do not use verbal language to communicate their needs. I will bring topics related to behaviour management and language acquisition to all the participants at our first group meeting, where we will narrow down the research focus. You will have access to these topics in advance of our first meeting. A primary objective of my research is to create a collective research group where we critically engage with the scope of our practice—the systems and structures that construct the environments we work in—and then collaborate on an art-project as a group to share with the larger community. This is a collaborative project and topics will be determined and agreed upon as a group. The art you create during this research study will become part of the collective and will potentially be used during analysis and/or during dissemination of research results and/or included in my thesis.

Importance of this Research

This type of research is important because it provides a space for support workers to connect and grow our practice as a community. This research will also contribute to a growing body of work that is focused on support workers reflecting on their choices, as well as the policies and frameworks that inform and shape these choices.

Participant Selection

You are being asked to participate in this study because you have valuable front-line experience working with children and/or youth who use primarily non-verbal language to communicate. This experience has provided you with a unique insight into service delivery.

What is involved

The research takes place over three phases. If you consent to voluntarily participate in this research, your participation will include attending several group meetings where we use a combination of art and conversation to explore the questions we create as a group (see purpose and objectives). The first phase will be one or two group meetings where we engage in conversations about the work that we do. I will be audio-recording the conversations and taking notes. I will provide you with a summary and/or full transcript of our meeting(s). In the second phase, we will use our conversations to inspire different mediums of art, which will be determined both as a group and individually. Cartoons, drawings, paintings, and poetry, as well as other forms of art, are all possibilities. It is not a requirement that you have skills in any of these areas. All supplies will be provided by me. The third phase of the research will be sharing the content with the larger community. One option is to synthesize our artistic materials to form a zine and/or online resource. A zine is a small collaboratively created booklet, sometimes created to express grassroots knowledge and can use multiple mediums of expression. The zine will be distributed to workers who are new to the support worker field. You will have a choice whether or not to be involved in this final phase, and will not need to make that decision until the final phase. The time commitment varies, and you will be welcome to drop-in on sessions, or attend all sessions. Meetings will most likely take place on Sundays at UVic at one of the graduate student society's board rooms on a time to be determined. I will not be taking video recordings during our group meetings, but they will be audio-recorded and potentially photographed by me and/or other participants who volunteer to photograph our meetings. These photographs will be used as data and included in the dissemination of the results of the study.

Inconvenience and Potential Risks

Participation in this study may cause some inconvenience to you, including cutting into your personal time, potentially requiring you to travel to participate (depending on where you live), as well as require you to try something you may not have experienced before. Some people might feel uncomfortable at times if unfamiliar with group work, sharing/creating art, and/or being audio recorded.

There are some inconveniences involved in this study. For example, due to the time commitment I am asking, which will span over approximately two-three months, and the energy required for reflection on your work, it is possible that you might at times feel fatigued or overwhelmed with the process. Some of the topics might include discussing power imbalances and privilege, which can be challenging and uncomfortable. I will provide space for breaks during the group sessions. Hot beverages and food will also be provided. If you are ever feeling uncomfortable, or need to take a break during any of the meetings, you can take a break, or leave the group early, without consequence. You can also debrief with me outside of the research context, should you need or want to.

Benefits

This research has the potential to inform your practice by providing you with a space to reflect on your approaches to work, and the external/internal factors that affect your work, such as power imbalances. Moreover, you might have an opportunity increase your skill-set through collaborative work. This research also creates an opportunity to build community with other front-line workers.

This research might also benefit the larger community, as the knowledge we collaboratively create might be accessed by child and youth workers and others working in a service provision capacity. The

research has the potential to increase the state of knowledge, as very little research exists on the experiences of support workers in the context of support for people with non-verbal designations.

Compensation

To compensate you for any inconvenience related to your participation, food and beverages will be provided at all meetings. If you use the bus for transportation, I will provide you with bus tickets for travel to and from UVic. You will also receive a small gift as a thank-you for your time. If you consent to participate in this study, this form of compensation must not be coercive. It is unethical to provide undue compensation or inducements to research participants. If you would not participate if the compensation was not offered, then you should decline.

Voluntary Participation

Your participation in this research must be completely voluntary. If you do decide to participate, you have the right to withdraw at any time without any consequences or any explanation. If you do withdraw from the study, it may not be possible to omit your verbal contributions, as it is difficult to distinguish between voices during group meetings. However, you will have a choice at the time of withdrawing from the study to contribute your individual art, or omit your artistic contributions from the study. At this point, I will ask for you to sign the section on this form "Consent to continue using my contributions after point of withdrawal from the study." If I do not obtain your signature, I will not use your art.

On-going Consent

I will review with you the consent process at the beginning of each meeting and will ask for your verbal consent. This will be in the form of a yes/no response, hand raise or initial on a piece of paper. You will determine what works best for you.

Anonymity and Confidentiality

I will protect your confidentiality by giving you an opportunity to select a pseudonym to be used in lieu of your real name. I will refrain from attaching your name to the collaborative art that the group creates, unless you consent to use your name. Consent to be associated with the research by name will be obtained at the end of the study with you signing the final section of this consent form titled "**To be completed at the end of the study, or if you choose to withdraw from the study.**" I will not associate names or contact information with the data unless I receive your signed consent; without your consent, your pseudonym will appear on all forms of data.

I will protect your confidentiality by reminding participants not to discuss the specifics of our research outside the group. I will remind the participants at the beginning of each group session about confidentiality through a process of ongoing consent. Due to the nature of collaborative group work, I cannot protect your confidentiality between participants. All data associated with this study will be stored in a locked cabinet, which I am the sole person with access.

In addition to protecting your own confidentiality, this study will not ask you to breach any workplace confidentiality, or disclose personal information about the children and youth you serve in the context of your work.

Dissemination of Results

It is anticipated that the results of this study will be shared with others in the following ways: 1. On dspace, which is a publicly accessible University of Victoria database storing students MA theses and PhD dissertations, academic and community publications, including journal articles and newsletters; 2. if the group agrees, we might also create a zine, with an on-line resource, with our art to share with people in the disability field; and 3. The results might also be shared in presentations, at workshops, guest lectures, in print media and on social media, and on websites.

Disposal of Data

All data that is not published and/or incorporated into a zine, or used for presentations, workshops, and other media sources, will be shredded and/or deleted one year following the completion of my MA thesis.

Contacts

Individuals that may be contacted regarding this study include Jessica Sahlstrom ([telephone number]) and Dr. Sandrina de Finney ([telephone number]).

In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545 or ethics@uvic.ca).

Your signature below indicates that you understand the above conditions of participation in this study, that you have had the opportunity to have your questions answered by the researchers, and that you consent to participate in this research project. By signing this form you also consent to have your artistic contributions used during all phases of the research process.

Name of Participant

Signature

Date

To be completed at the end of the study, or if you choose to withdraw from the study:

I consent to be identified by name / credited in the results of the study: _____ (Participant to provide initials)

I consent to have my artistic contributions remain a part of the study despite my decision to withdraw my participation _____ (Participant to provide initials)

A copy of this consent will be left with you, and a copy will be taken by the researcher.

Appendix E: Research Topics

Upon the commencement of my study, the research participants and I will develop specific research topics and questions that might include, but are not limited to, the following:

1. Stories from practice
Possible questions: a. what kinds of work do you do? a. Tell me about an experience working with a child/youth who communicates nonverbally? b. If you have experience supporting children or youth attend medical appointments, what have you witnessed in these spaces? c. what aspects of your work do you enjoy? Frustrate you? Wish were different?
2. Child development and the pressure for language acquisition
Possible questions: b. What is communication? c. What does language acquisition do? d. What is language? e. What are the pros and cons of current language acquisition plans and practices?
3. Issues of consent in every-day practice, as well as in clinical spaces
Possible questions: a. What does consent look like in a non-verbal context? b. How can we trouble exclusive, language-focused means of accessing consent? c. What are the ethical issues at play with non verbal consent?
4. The creation and enactment of behaviour plans

[NOTE: Behaviour plans are a set of instructions for front-line service workers to understand what the client is trying to communicate via their behaviour. Currently, behaviour plans are developed by (primarily) a behavioural consultant who gathers information from front-line services providers. From this information, the consultant determines why the behaviour exists, asking the question, what does this behaviour provide the client with? Following this question, the consultant provides a plan to support front-line service workers in attending to the behaviour with the goal of replacing it with a positive (desired) behaviour, or eliminating the behaviour all together.]

Possible questions: a. Can we imagine something different? b. Who are these plans designed for and who benefits most from these plans? c. What are the pros and cons of these plans – what do they produce?

5. Disability labels/the process of labelling
Possible questions: a. What have we witnessed/experienced during the labelling process? b. What do labels do? c. How do we (re)act in regards to a person's label? d. What else might be possible?

Appendix F: Invitation to Participate for if there is a personal relationship

Dear _____,

You are receiving this letter because you expressed interest in participating in a research study on topics relevant to your work. During this collaborative study, we will discuss issues related to consensual practice with young people who use non-verbal communication to express their needs. Collaborative research means that you have choice in some, or all, aspects of the direction of this study. For this study, we as a group, will collaborate on research questions, engage in conversations around these questions, and collaborate on an art project of some kind to express our discussions. You do not need any training, experience or skills in art.

The research study will take place between June-September/2017 at a time and location to be determined, but likely at the University of Victoria. This study will not ask you to breach any work-place confidentiality, nor ask you to disclose information about any of the clients you serve.

Participation in this study must be entirely voluntary. **It is acknowledged that you may be involved in a personal relationship with the researcher. It is important that this relationship does not influence you to participate. If you would not participate if the relationship did not exist, then you should decline the invitation. Your decision will not influence the relationship.** You are not committed to attend all group-meetings. You can choose to drop-in at your convenience, or attend every session. Moreover, you can make the choice to participate in an individual interview if group work does not work with your interests and schedule.

The purpose of this study is to create a community of support workers who share a passion in growing their practice and learning from one another. Central to this study is the question of if, and if so, how do support workers consider issues of every-day consent in their work. We will create an artistic representation of our findings to share with other support workers using a medium to be determined as a collective. Some examples include poetry, visual art, sketches and collage.

As this is a collaborative study, you will be asked what areas of consent are important to you, and will subsequently participate in creating research questions as a collective.

The questions we form might be around some of these issues:

1. Child development and the pressure for language acquisition
2. Issues of consent in every-day practice, as well as in clinical spaces
3. The creation and enactment of behaviour plans
4. Disability labels/the process of labelling

To participate in this study you must be over the age of 18 and have relevant experience in front-line work, with children and/or youth with a non-verbal disability diagnosis. Examples include working as a behaviour interventionist, support worker in a group home, or a respite worker. This study will not ask you to breach any work-place confidentiality, nor ask you to disclose information about any of the clients you serve.

As this study will likely take place at the University of Victoria, it is my hope that research sessions will take place on Sundays, as parking will be free for those who drive. For individual interviews, I will accommodate your unique needs and conduct interviews at a location of your choice. I will provide snacks and hot beverages at every session, as well as bus transportation to and from UVic if needed.

If you are interested in participating, please let me know by email by __[DATE]__.

I am happy to answer any questions you might have, or if you would like to arrange an in-person meeting to gather more information before making your choice I would be happy to meet with you.

Looking forward to having you participate in this study!

Warm regards,

Jessica Sahlstrom

Email: [email address]

Phone: [phone number]

Appendix G: Email Recruitment to Personal Contacts

Dear support workers and respite workers,

I am conducting a research study that explores issues of everyday consent when working with children and youth who primarily use non-verbal communication. This research study is being conducted to fulfil my degree requirements to obtain a Master's degree in Child and Youth Care at the University of Victoria.

I have attached my recruitment poster for this study. If this is of interest to you and you think you might like to participate in an interview, or potentially participate in a research group, please email me for more information.

If you know of someone who might be interested in this study, please feel free to share this poster with them as well.

Also, as some of you might be involved in a personal relationship with me, the researcher, please know that your decision to participate must be entirely voluntary. Moreover, if you decide to disregard this email, your personal relationship will not be impacted 😊

Kind regards.