A Single Lens

An Autoethnographic Exploration of Support Work with People Labelled with an Intellectual Disability.

By

Johnathan Bevan

A Thesis submitted to the Faculty of Graduate Studies of The University of Manitoba in partial fulfilment of the requirements of the degree of

Master of Arts

Department of Disability Studies

Faculty of Graduate Studies

University of Manitoba

Winnipeg, Manitoba

Abstract

I have been working as a professional support for people labelled with intellectual disabilities for many years. While there has been research done about support work from multiple perspectives, it is my impression that the lived experience of being a support worker for adults labelled with an intellectual disability is largely missing from the literature. Utilizing an autoethnographic methodology, I provide the perspective of a direct support professional through a disability studies lens. In this writing, I will contextualize the role of the support worker within contemporary society. This includes historical framing, policy and theory influencing the field, as well as the dilemmas inherent in supporting a marginalized population. Through engaging in a reflexive examination of my professional experience, I will provide a picture for the reader of the complexities involved in trying to enact meaningful supports for people labelled with intellectual disabilities. I identify the priorities support workers should focus on to generate best practices and examine the aspects of the work that are under their direct control. All this is done in the hope that we can create a more inclusive society for all people.

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Chapter 1: Introduction

There is not a single person that lives without any supports in their lives. Each of us, at some point in our lives, has needed someone to teach us, help us, prevent us from making mistakes. We each have skills specific to our own person. A blend of abilities that make us unique. An extrovert can be admired for their easy social grace. An introvert could gain respect for their calm and repose. We all exist on a spectrum. Our individual quirks and foibles endearing us to some and repelling others. This interdependence can manifest in many different ways depending on the nature of the relationship and the goals of each person (Gerpott et al., 2018). Were my computer to stop working as I write this sentence; I would be unable to deploy any technical skills other than banging it with my hand. I have known people in my life whose natural academic abilities make my own seem embarrassingly meager. The idea that we all need supports in our lives would seem unusual to no one.

When the need of support reaches a certain degree, we tend to change our minds about the value of the person needing that support. If a person needs supports in almost every aspect of their lives, they are afforded little value within contemporary society. For many people labelled with an intellectual disability to live full lives, supports are necessary. Much like everyone else, people labelled with an intellectual disability exist on a wide spectrum of abilities. They have certain areas where they excel, and others where they may need support for the duration of their lives. These areas are largely dictated by the nature of the impairment they live with. Impairments related to a label of intellectual disability have a wide array of type and degree. How these impairments manifest will dictate the level and type of support they need to live a full life. A full life as they define it, not the people who support them.

During the second half of the 20th century and into the present, there has been a great deal of thought and effort put into improving the lived experience of people labelled with an intellectual disability. Influential ideas such as normalization (Wolfensberger & Tullman, 1982) have sought to bring labelled individuals away from the margins and into the mainstream. The chief effort among these has been the process of deinstitutionalization. This is the process through which people were moved from large congregate care settings to smaller scale living situations similar in number to a typical home. The potential of this unfinished project to improve the lives of labelled people is immeasurable.

Within this new living scenario, the people responsible for facilitating the day to day lived experience of those who are living in supported situations are the frontline support staff. Depending on the level of support needed, the frontline line staff could be directly facilitating every intimate aspect of a person's life. Despite this pivotal role in the lives of people labelled with an intellectual disability, these support staff are often under resourced, under paid and over worked. Even when specialized training is provided by their employers, it is still difficult to integrate the knowledge into the workplace (Dubé, 2012). There are high levels of burnout related to interactions with the supported individuals and organizational challenges within the support agencies staff work for (Mutkins et al., 2011).

To illustrate the complexity involved in support work, we can look at the example of choice-making. There is ample evidence supporting choice making as a key indicator of higher quality of life for labelled individuals (Chichevska-Jovanova & Kostikj-Ivanovikj, 2016; Pallisera et al., 2020). The ability of support staff to facilitate choice making is often hampered by various factors involved in the periphery of the lives of people labelled as intellectually disabled. Adults who have been labelled as intellectually disabled living outside of large

institutions often reside in group homes with other people who have a similar label. The needs of each of these individuals can be quite disparate. It is left to the frontline staff to determine how these needs can best be met.

It is a typical situation for a staff to work in a group home supporting 4 individuals with 2 or 3 support staff on any one shift. This situation creates multiple barriers for the staff to support choice making of the individuals they are supporting. Mealtimes must consider the tastes of 4 different people. Some of these people may have special diets due to physiological conditions such as PKU or Celiac disease. After a meal, staff must assist the people they are supporting in making a choice of what they want to do with their time that day. If there is any disagreement between the people, then the staff must make another compromise to ensure that some meaningful activity is done during their shift. Staff must also engage in constant risk assessment for the activities that the individuals want to participate in. Trying to develop a plan that can come close to respecting the desires of everyone whose home the staff is working in is a complicated effort.

The expectation that a staff will be able to provide adequate choice in a person's life given the complexities of the living space of the people they support is a tall order. Yet this is the expectation of the job. This complexity is compounded by the reality that there is little, or no training focused on concepts such as facilitating choice making in this environment. When adequate training is paired with increased staffing it has been shown to increase engagement of the people being supported (Stancliffe et al., 2011). Choice making is just one example of a myriad of elements that make up the day-to-day existence of a person's life. I do not illustrate this complexity to exonerate staff of their responsibilities. Rather I am attempting to demonstrate

to the reader that the job of being a support in the life of a person labelled with an intellectual disability is difficult to do well.

It is also common for support staff in front-line positions to be working two or more jobs in the support field or related fields. This is due to most frontline positions not paying a living wage. This leads to staff having to work with little or no sleep as they transition from one workplace to another. They also must keep straight the various policies and practices of the different support agencies they are employed by.

Disability support work has not been professionalized. A survey of job advertisements online reveals a line of work that is largely underpaid, requires no specialized training, and emphasizes availability over the workers ability to do the job well (*Direct Support Professional - No Experience Required*, n.d.; *Direct Support Worker - Part Time Weekends | Current Opportunities*, n.d.; "Home Services – Casual Direct Support Workers 1," n.d.; *Quadrant Self Service*, n.d.). One of the advertisements surveyed prominently declares, "no experience required". It has also been my personal experience that people entering the field in the current climate are not viewing their work as a career, but rather a means to an end. Staff are not encouraged to be analytical about their work. They are generally encouraged to be present and ensure that nothing bad happens. They are encumbered by rigorous medication procedures, chore checklists, and shift documentation. Each of these taking precious minutes away from the time they should be providing supports to the people they work with.

The results of these various challenges to the support worker affect the outcomes of the people they are supporting. Many people labelled with an intellectual disability have their entire lives mediated by support staff. If these staff are not being challenged to examine their work critically, the result will be a wealth of wasted potential. This lost potential is a predicable result

of a society that does not value a person once they have been labelled with an intellectual disability (Schwartz, 2011). Once a person has been categorized in this way, they are set apart and then require action to repatriate them to a state of normalcy. The label itself is extremely stigmatizing, aside from any impairment the person may experience (Keith & Keith, 2013, pp. 10–16). This is the struggle that disability activists have been engaged in for the last half century or more. The expectation that they should desire to belong in the fictive category of normal has been forced on them from multiple interests.

Activists in the disability community disavowed the concept of this fictive normalcy. Within the segregated settings set aside for them they found kinship and began to organize to fight for a more inclusive society. They sledgehammered inaccessible curbs and began to undertake political actions (Patterson, 2012). They developed new frameworks for understanding disability such and the medical and social models (Michael Oliver, 2012). It can not be argued that this battle has been won. We do not live in an equitable society and old conceptualizations of disability as a personal tragedy stubbornly persist. When a person has the label of intellectual disability placed on them, their entire life will be altered. Not because of the label itself, but because of society's reaction to that label.

Imagine a life where all your formative experiences are wiped away. Your first kiss or getting drunk for the first time. Having a best friend or having the wrong friends and getting into trouble. Imagine if the people in your life saw you fail and did not think to help you learn and grow, but rather assumed this failure was an essential aspect of your being. You are never left alone, never allowed to wonder or explore. You never had the opportunity to make large mistakes and learn from them. You are expected to be compliant, quiet, and well behaved. If you are not, the people around you see no problem in physically restraining you or giving you

sedative medications to bring you into compliance. No attempt is made to understand the motivations of your actions. If your motivation is understood but it does not fit within other's plans for you, then you must either get in line or continue in constant conflict.

Do you want to drink pop everyday? Many do, but you cannot. Do you want to go for a walk in the park on your own to think things over, or just explore? This is an activity many enjoy, but it is not for you. From the time you are young all these decisions were deemed too complicated or dangerous for you to make. Depending where or when you were born you may have been taken from everything you knew and placed in a building with many other people who were said to be like you. If you were lucky you saw your parents on weekends. Most likely they would slowly fade from your life. This fading being a symptom of professional advice to forget about you or a complicated reaction to watching you suffer in a place no person should be made to suffer. Your siblings would not be told about you. Medical professionals would instruct your parents to have other babies and forget about you.

In your adult life, perhaps you would be *allowed* to live in the community with the rest of society. When this happens, your potential neighbours might hold meetings about whether you should be allowed to move into your house. You would have no say about who or how many people you lived with. Your home would be filled with a steady rotation of staff. These people are charged with your care. Depending on the quality of the staff and how well they know you, your life can be extremely different. You may or may not have a say in any of the following life events: what you have for meals, what time you go to bed, what you do in your spare time, who you get to socialize with, how much time you can spend alone, what kind of emotions you can have, or what clothes you will wear on any given day.

If you are a person who has been labelled with an intellectual disability, many or all these realities would be visited upon you. Your reality is likely one that no one else in society would tolerate. The further a person deviates from what is conceived of as normal, the more their agency is diminished. For these people, every transgression made against other's expectations will contribute to the label they have been given.

This is not to say that people who have been labeled with an intellectual disability experience life as a tragedy. They experience life like anyone else. Making the best of the situation they have been put in. Some people experience life as tragedy regardless of their circumstances. Some experience life as a blessing regardless of their circumstances. In my experience, the same is true of people who have been labelled with an intellectual disability.

The experiences described above are not universal, however, being labelled with an intellectual disability will likely result in your agency being significantly reduced. Sometimes this reduction will be based in fear of what you might do. Other times it will be based in fear of what others might do to you. Accounts of the abusive situations labelled people endure are plentiful . It is also likely that the accounts we do have are only the tip of the iceberg in terms of the number of stories that exist. Having the label of intellectual disability placed on you sets your life's course in motion. Very few can transcend the mold set out for people with this label.

Contextualizing intellectual disability in contemporary society is an extremely complicated affair. Current practices relating to intellectual disability have their root at the core of our social being. Our ideas of the value of the individual inform how we assign value to the people we meet in our lives. For many people, value is based on what you contribute to the collective. Contributions are not measured blindly though. Certain categories of contribution hold greater value than others. At the heart of many of the things we value is a certain kind of

intellect. These are people like artists, entertainers, businesspeople, technical innovators, and intellectuals; all capable of generating and conventionally articulating new ways of interpreting and interacting with our environments. These intellectual qualities are greatly appreciated. If you do not possess these intellectual gifts, then hard work will suffice. If you work hard and contribute to the machinery of the modern economy, you will be rewarded.

People who fulfill roles that are valued work together to contribute to the overall economy. Where do the people who are unable to fill these roles go? They need to be dealt with; we cannot just let them not contribute. For these people we have the social services. Composed of well-meaning, hard-working members of society; the social services can innovate an endless series of programs to help these outliers find their place in our modern society. This is where most people labelled with intellectual disabilities reside. They are placed at the margins, protected by the umbrella of services devised for their benefit by social service agencies. These agencies do their work very well. They keep people safe, for the most part. They do enough to be able to say that the people in their care are living lives of meaning. The result of this arrangement though is sustained segregation. People labelled with an intellectual disability are still viewed as an unfortunate accident. They are not seen as valuable members of our society. It seems that society has generally agreed (begrudgingly at times) that they are worthy of caring for. It is unclear if doing any more than maintaining life is needed though.

In this autoethnographic writing I will seek to poke around the edges of our current status quo. I will explore my own professional experience, seeking the points of pressure where we can open our minds to new possibilities for the lived experiences of people placed in our care. I will be acknowledging the very real restraints of funding and convention throughout. My purpose though is to seek out what a front-line support worker can do to expand the possibilities of the

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lived experiences of people labelled with intellectual disabilities who live within systems of support.

1.1: Key Terms

I will not simply be providing definitions for each term within this section. I will be attempting to contextualize each term within the purpose of the greater writing. In doing this I hope to shift the emphasis away from the classical definitions of each term and provide a way to understand the various terms as they act in the lives of people who have been labelled with an intellectual disability.

i.   **Intellectual Disability**

For the purposes of this thesis, I will not delve too deeply into medical classifications related to intellectual disability. There are many resources a reader can turn to for medical definitions. Readers can visit the site for the American Association on Intellectual and Developmental Disabilities (https://www.aaidd.org/intellectual-disability/definition) to learn a functional definition of intellectual disability. These definitions do little for a support worker in the way of helping to provide supports to people. They also provide little context for the lived experience of people who have been labelled with them as an aspect of their being.

It is my impression that the medical categories that have typically been placed on people often serve to further impair their ability to exist as an equal in society. Support staff should be aware of the increased medical risks associated with various diagnoses (i.e. heart conditions associated with Down Syndrome). They should not however fashion themselves as medical professionals whose sole purpose is safeguarding physical health. I will therefore be focusing on intellectual disability more as a socially constructed entity.

Dissecting the individual attributes that lead to a person being labelled as intellectually disabled from the inter-relational consequences of having that label placed upon you is a complicated proposition. What is true is that there is a spectrum of cognitive abilities. This is inevitable given the great variation among humans. There is a biological reality that motivates the diagnosis of intellectual disability. To diminish this reality is a rejection of the lived reality of people. In disability studies scholarship this distinction would be between impairment and being disabled (Morgan, 1992; Oliver, 2012). There has been some argument surrounding the impairment/disability dichotomy, which will be examined later in this writing. Many of the barriers experienced by people labelled with an intellectual disability are causally socially constructed. Attributes perceived as personal attributes are brought about by the person's participation in the social matrix (Diaz-Leon, 2015).

How we conceive of intellectual disability is pressingly relevant to the support worker. If it is understood as largely an individual circumstance whose manifestation is inevitable, then there is little work to do. The support worker need only adopt a custodial stance and ensure that the person is safe from harm and able to have their basic needs met. If we shift our understanding to include the ways that society acts upon the labelled individual and creates an oppressive reality, we can begin to modify the supports we provide to remove barriers to inclusion and equality of opportunity.

It should be noted that there are two instances in this text where the words are blacked out. I did not want to include the terms used in these direct quotes but wanted to preserve the integrity of the quote. These blacked out words should be interpreted as meaning people labelled with an intellectual disability.

ii. Support Worker

Support workers are the professional staff who are charged with the support of people labelled as intellectually disabled. This support usually has an emphasis on supporting inclusion with family, social networks and in the greater community (Hewitt & Larson, 2007). The Province of Manitoba describes this work as encompassing the following (*Families | Province of Manitoba*, n.d.):

- provide day-to-day direct support to individuals.

- provide opportunities for the individual to learn new skills in a variety of areas.

- assist the individual to achieve their personal goals.

- assist the individual to contribute to and participate in the community.

- assist the individual to develop relationships with others.

The most in-depth training program for support workers in the province of Manitoba describes the skills you will learn in their program as follows (*Disability and Community Support - Overview :: Red River College Program & Course Catalogue*, n.d.):

As a student, you will learn how to assist persons with disabilities to plan and achieve their personal goals and maintain their health and well-being. You will understand how to promote the development of inclusive communities and display competent, responsible, and professional behaviour and attitudes. You will also have an opportunity to experience a variety of community settings through your fieldwork, or practicum, which makes up about one quarter of the program.

Job advertisements for support worker positions often include terms such as support, inclusion, encouraging, administering, assisting, role model, and administration. For most

positions, the required education is a high school diploma. Though some advertisements state that grade 10 is sufficient. Many agencies prefer some training such as that provided by Red River College, but this is not a requirement of any front-line position that I have been able to identify.

As a reader can identify in the language used, the essence of the work done by support workers is vague and open to interpretation. The kind of support required varies greatly depending on the person receiving supports. What is asked of a front-line support worker will vary depending on the supervision team they are working with. The emphasis chosen by the management team will significantly affect the environment that a support worker is engaged in as well as the quality of supports provided to the person receiving them.

The fluid reality of support work gives rise to a series of issues for the worker. An individual will have ideas about how best to do their job. However, if these ideas conflict with priorities of management there will be tension. Due to factors such as challenging behaviour, inter-personal conflict, and structural issues relating to staffing and supervision, support staff tend to experience high stress levels and have a high rate of workplace staffing turnover (Mutkins et al., 2011).

These realities directly impact the quality of support provided to the people receiving it and affect the perception of this work in the greater community. There is an expectation that support staff fill a complex role with little or no training outside of that provided by coworkers on the job. This can often result in a disconnect between the stated values of organizations and the lived reality of the supports provided on the front-line.

iii.   The Social Model of Disability

The fundamental concept of the social model of disability is that people are not disabled by their impairments but by the structural barriers placed before them by the societies they live in (Oliver, 2013). One of the easiest examples that make this idea clear is that of curb cuts. Without these simple structural adaptations navigating city landscapes becomes nearly impossible for wheelchair users. This concept extends beyond the built environment though. The barriers affecting people with impairments are as much conceptual as they are physical. When applying the social model to the lives of people labelled as intellectually disabled the complexities become difficult to analyze.

To remove the barriers placed before labelled individuals would require a fundamental restructuring of the value we place on cognition in our society. It would require every level of our society to adjust their conception of what makes a person valuable. The myth of the autonomous individual, independent, and contributing to the economy, must be examined to make room for those who are not able to perform traditional roles within this system. The cognitive impairments experienced by many people may prevent them from fulfilling these traditional roles, but it does not mean that they are lacking value as human beings.

In applying the social model, I will be examining the role support staff play in disabling the individuals they work with, the societal systems that perpetuate the marginalization of people labelled with an intellectual disability, and the methods that can be implemented to promote growth towards full inclusion. I will be examining the role of implicit ideologies such as ableism and individualism that reinforce the idea of disability as a tragedy (Oliver, 2012). I will be utilizing the social model as a tool for exploring the systems of oppression that act on the lives of people labelled with an intellectual disability (Mike Oliver, 2013).

A key element of the social model is a distinction between being disabled and impairment. An impairment is regarded as the functional limitation resulting from, in the case of this writing, a functional cognitive impairment. These impairments are not accounted for within the construction of the physical, social, and economic systems that they exist within (Tregaskis, 2002). As a result of this, parallel systems have been devised that do account for these impairments but enact exclusion in direct and indirect fashions. The most well known of these are the institutions that were built with increasing frequency throughout the industrial revolution. Through a social model critique, I will examine how we can de-institutionalize practice and enact models of support that promote inclusion.

1.2: Key Groups/Organizations

There are several important groups that have been working towards the inclusion of all people in society. While I have many opinions about what would work best, or be best for the people I have supported, I do not feel that I occupy a special place where my ideas are better than everyone else's. My ideas must exist in dialogue with other's who have spent more time than me contemplating the place of people labelled with intellectual disabilities in society. I will spend some time here outlining what it is these groups have established as the norms that should be worked towards by everyone in society. Throughout out my writing I will refer to these groups as a reference point in my analysis.

i.   **People First of Canada**

People First of Canada was incorporated on April 6th, 1991, but has it's roots in activism reaching back to the early 1970's. They are a self-advocacy organization founded and run by people labelled with intellectual disabilities. Whenever possible in this writing I will privilege

the perspectives and priorities outlined by this group on their website,

www.peoplefirstofcanada.ca.

Their priorities can be located on their website (*People First of Canada*, n.d.) as well as in documents such as 'The Right Way' (People First of Canada, Canadian Association for Community Living, 2010). Given that they are a self-advocacy organization, I feel that their perspective must be given primacy when constructing any kind of argument related to intellectual disability. It is their voices that have been systemically disregarded, and so must now be given primacy when contemplating their lived experience. The stated priorities of the organization are as follows: the right to live in community, inclusive education, work and employment, legal capacity, income and supports, and the United Nations Convention on the Rights of Persons with Disabilities.

If it can be accepted that the definition of these priorities is malleable and able to be adjusted to suit different individuals, then I would feel comfortable accepting these as guidelines for further effort in contemplating models of support. The major difficulty I have with much of the advocacy related to intellectual disability is that there often seems to be a certain kind of person the advocacy is for.

Take for example the idea of work and employment. While this seems self evident to the advocate, it is not a possibility for everyone to take part in this aspect of life under traditional definitions. If 'work and employment' can be defined as being meaningfully engaged in a fully inclusive environment, then I would accept employment as a reasonable goal. If it is to have a traditional job where task completion is compensated with money then I would say that this goal is rooted in an ableist, capitalist framework that is exclusionary of people who are unable to fulfill this relationship. There are many people I have supported who have no appreciation of

money and what it represents. They also have no appreciation of completing tasks that are not causally linked to a tangible result. While it is likely possible that many of these people could be trained to complete a task and receive a tangible reward for doing so, this act would be so antithetical to all the other efforts being pursued for labelled people that the action would be fundamentally flawed.

Similar recontextualizing is required in areas such as inclusive education. Efforts at inclusion in schools are underfunded and chronically mismanaged. The result being that parents and children often resent the presence of labelled individuals in the classroom. This further stigmatizes labelled individuals, serving to justify the continuation of isolationist models. Children in schools are accustomed to witnessing people with labels of all varieties be excluded and disciplined regularly. It is no wonder that these children grow to perceive these people as the other and support the idea of their continued exclusion. For me to be comfortable with the idea of inclusive education I would need to see the system change to fit the people it is meant to educate. Currently, resources are funneled towards assisting children fit into existing systems. Systems that barely serve the children they were designed for, let alone the children who do not conform neatly to ideas of normalcy.

I stress my view on these stated goals to emphasize the reality that we cannot simply hope to accommodate our way towards inclusivity. There needs to be significant analysis of the systems we live inside of. This analysis needs to be followed by substantial reformation of these systems to foster inclusive models that account for the needs of all people. The UNCRPD is a document designed to cover the needs of all disabled people. While this is laudable and a necessary effort, the needs of disabled individuals vary greatly depending on the person and the specific impairment(s) that comprise their person.

ii. United Nations Convention on the Rights of Persons with Disabilities

I will also draw upon the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), as identified in *People First's* stated goals. Again, with the emphasis being placed on a generous interpretation of the rights identified within the convention. I will be emphasizing how these rights can be enacted in the lives of people labelled with an intellectual disability. Specifically, how front-line supports can begin to enact these rights in the absence of governmental, legal, or specific actions taken by social service agencies.

Chapter 2: Who am I Writing About?

2.1: First, Myself

I am writing about myself. I have been working as a professional support for people labelled with an intellectual disability since 2000. I will be spending time dissecting various experiences I feel are emblematic of aspects of support work. I will be attempting to critically examine my role in the lives of the people I have supported and develop an understanding of how my actions have affected the lives of the people I have supported. I will also be examining these personal experiences as symptoms of the support industry in general. There have been many conceptual developments over the course of my career. These developments have not translated to a significant change in the lives of the people I have supported. I will seek to identify the areas where focused attention would reap a significant benefit for the people being supported.

I feel it is important to state here that while I am critically examining support work, I am not being critical of support workers in general. Support staff exist with the same spectrum of quality that exists in any other profession. For the most part, support staff are well meaning people who are doing their best under difficult circumstances. There are rare exceptions of people who are malicious actors within the support profession, but these people are outliers. The issues in the support industry are largely systemic. Vestiges of institutional thinking permeate the ethic of support in a fashion that makes the institutional aspects of the industry invisible to those within it. I can best demonstrate this reality with a story.

A colleague of mine was assisting someone moving out of a large institution into a community home. When meeting with the institutional staff who had been working with this

person, that staff said to my colleague, "I just hope (person) has as good a life in the community as we have provided for them here."

For those in the community living movement, this statement will likely seem laughable. The staff at the institution was sincere in their sentiment though. They perceived the life lived by the person they were supporting to be a good one. No doubt the institutional staff sincerely cared for the wellbeing of the person moving into the community. The institutional staff would have a difficult time doing their job if they did not tell themselves that they were providing a meaningful life for the person they were supporting.

Even more recently, I have heard it said of a large institution still operating in Manitoba that, "It is not the same as it used to be." This is meant to imply that living in a large congregate care setting is no longer a fraught existence. This statement further demonstrates the gap in ideology between community and institutional living supporters. It is difficult for people to understand the distinction between bad or misguided staff and the fact that institutional supports are fundamentally flawed. This is instructive for those people working towards more progressive supports as it will inform the strategies used to shift people's perspective. The same is usually true of those working in the community as well. Most people think they are doing good work. The reality of practice though is that segregation is still widely practiced; just less so than when people lived in the total isolation of the large institution. When you work with someone for a long time you begin to perceive yourself (and are often perceived) as more than staff.

It is an unavoidable reality that support work is intimate and will give rise to close relationships between the staff and the person being supported. In my opinion, attempts to deny this reality diminish the humanity of both the professional and the person being supported. It is important to remember the nature of the work a support staff does with a labelled person.

Especially for people whose cognitive difference is more pronounced. In this case the support staff is intertwined with every aspect of the person's life. Meals, every aspect of hygiene, visits with family and friends, cleaning, recreation, advocacy, medical visits. Every aspect of a person's life is facilitated by a professional support. This is often the same person over a period of years. To tell either person involved in this relationship that it should always be clinical, and professional is to demand the impossible. Intimacy develops with proximity of this kind. Whether this intimacy develops in a healthy and emancipatory fashion is the important question, and one that I will attempt to define over the course of this writing.

2.2: The People Being Supported

Attached to this professional self, I am writing about the individuals I have supported. I must speak of them. It is them I have worked to support. I will not be focused on them in my analysis of my professional life except where our specific interactions illustrate an aspect of support I am attempting to define and discuss. I must clearly define the population I worked with for the reader to understand who it is I am advocating for.

In seeking the language to describe the people I have supported I am hard pressed to find the right words. It is difficult to speak of them in a way that makes it clear what makes them a distinct population from others. The available language is most often a language of deficit. I refuse to use this language (even for context) as it will only serve to perpetuate conceptualizations that are diminishing and allow those who I have worked with to be dismissed. The way we do research and the language we use, in part, create the world in which we live (Oliver, 2012). For this reason, great care must be taken in what words are used to reference a population of people. The difference, largely, is in cognition. This difference often manifests in behaviour; the way that they interact with the rest of society. There are many resources that

attempt to define the people I have worked with from a medical model perspective. I hope I will be forgiven for neglecting to use these easy, readily accessible cultural signposts to aid in my identification.

What I am not doing is speaking to intellectual disability as a category. I am in no way attempting to create a framework for every person who has been labelled as intellectually disabled. The population I am writing about, and who I have spent most of my time working with, are labelled individuals who are unable to be effective self-advocates. This is not to say that they do not self-advocate, but rather that they would have a great amount of difficulty being understood by those who do not know them. This difficulty does not arise from a variant such as slurred speech or a lack of verbal language. It is based in a framework of understanding that is fundamentally different from most of their fellow citizens.

This difference can be based in the very real impairments they live with that make traditional learning and comprehension difficult. It can be the result of sensory and information processing differences that make completing the activities of daily living a complicated and fraught task that requires supports. These differences are also likely a result of a life lived at the margins of society. In special classrooms, institutions, segregated day services, and suboptimal community living arrangements that deprive them of their right to live, experience, succeed, and fail in the same way most of us take for granted.

The way they move through the world is suggestive of a cognitive framework that is vastly different from my own in many ways. It should be noted that in many ways they are quite like me though. Many of them seem to process sensory information differently than I do. Reacting to sensory stimuli in a variety of ways that would seem strange to many unfamiliar with this population. There is often a lack of inhibition when it comes to social settings, or conversely,

a strong aversion to social settings. The cadence and quality of their movements is often different enough from the general population to draw in the eye in a public space. Their bodies carry the stories of a life lived as *the other*. Surgical scars, involuntary movements, compulsive actions, prolonged or avoided eye contact, loud voices, no voices. In some cases, they have distinctive facial or body features that mark them as different. Their wants and needs manifest in the immediate. Whether this immediacy has been conditioned or is innate I could only speculate. I have only worked to support adults and thus the root of many of their idiosyncrasies are not immediately apparent.

Even in writing these descriptions I have the sense that they are wholly inadequate. It does give a sense of how the existence of the people I have supported appears to those who do not know them. It does not give a sense of lived experience from their perspective though. It also does not give a clear sense of what it is like to spend time with them for years. The differences fade, and our shared humanity becomes more apparent.

This is what is important to focus on as we move forward in our relationship. This is what should be focused on when developing philosophies of support and policy. To begin with the person as an individual is what matters, not their membership in a group. Chunking identities together can only result in the status quo being maintained. Taking the time to look past the difference and seeing what is shared is our only way forward. This does not mean that we should seek to normalize and bring everyone into the fold of meaningful lives as they are defined currently. It means we need to appreciate that everyone has a different way of being, and that these ways have as much value as any other way. This is the role support work can play in the lives of those who require it.

As a result of the many factors at play in the lives of these people, another fundamental aspect of their existence is powerlessness (McConkey, 2009). This is one of the fundamental aspects of life with a label of intellectual disability. The detrimental effects of this powerlessness can not be understated. Where some labelled people have been able to carve out small enclaves of agency such as *People First*, the people I am writing in relation to still exist with little ability to change or improve their life circumstances. They are still at the mercy of well-meaning people getting it right when attempting to advocate for their futures. They can be placed at the mercy of indifferent, incompetent, or malevolent staff and social services with little recourse.

Due to the impairments of the population of people I am writing about, my perspectives could read as being limiting for people labelled with an intellectual disability. I accept that criticism. It may well be that I do not have big enough dreams for the people I have supported. The population of people that I have spent most of my professional career supporting are extremely limited as they relate to society in general. We speak of inclusion, but in practice this usually manifests as integration. We want people to emulate and embrace our values, rather than to allow them to create and define their own spaces.

Even those in self-advocacy movements such as *People First*, can only speak for those who can self-advocate. The population of people whose cognitive variations are more pronounced than the members of People First (i.e., those who would not be able to accept or reject membership in People First) require an advocacy all their own. In the same way that People First needed to differentiate itself from advocates of other disability communities. Through my perspective as a long-time support of this population I hope to begin the gestation of a new means of advocacy for those within the circles of support for these individuals.

The perspectives of direct support professionals and how they conceive of their occupation are not often represented in research. When they are represented, they are filtered through the needs of the people conducting the research and their specific subject. This research does not necessarily give a fair representation of the individual's view of their work. There are many nuances to the profession that are not easily tracked by quantitative data. The day to day of support work is comprised of thousands of small moments. These moments interact with each other to form the substance of the work. By extension, they also form the substance of the lives of the people supported. If an individual being supported has their lives moderated by professional supports 24 hours a day, the role of these moments can not be underestimated. Therefore, the support worker's role needs philosophical investigation and contemplation.

Chapter 3: Methodology

It can be difficult to engage the population of people I have worked with in research. It is a complex situation that must bear many considerations. Ethically it is complicated because there is no way to receive consent from them individually. Morally it is difficult because even if you can receive consent from a substitute decision maker, the person is still not able to give informed consent to their participation in the project. There is also the historical context to consider. Immoral and unethical practices have been repeatedly visited upon people labelled with an intellectual disability in the name of scientific research. I must consider how I am able to include the people I have worked to support in a fashion that leaves their dignity fully intact while still engaging with the complex nature of their place in society.

Here I hope the method of autoethnography will serve to provide a method in which I am able to discuss my professional life while still respecting the dignity and privacy of the people I have supported. I will be utilizing a self-reflexive autoethnographic approach. This will enable me to critically examine the practices that I have been a part of in my professional life. I am seeking to identify methods of support that have led to success in the lives of the people I have supported and identify practices that contribute to their ongoing disablement. I will also seek to provide some context for the reader to understand the environment these supports are being enacted within.

I will be seeking to utilize the inward gaze of autoethnography as a catalyst to identify emancipatory frameworks of practice in relation to the people I have supported. It is essentially a professional auto-ethnography I am writing (Denshire, 2014). I will be reflecting on myself, the people I support, the agencies I have worked for and have interacted with, and the greater

systems that encircle all of us. All of this with the express purpose of changing the lived experience for the people I have supported.

It is impossible for me to do any research relating to intellectual disability that is not in some way autoethnographic. I have spent nearly half my life working as a direct support professional. This extended period of intimate interactions has coloured my thinking and feelings about intellectual disability and the people who have been labelled with it. Various groups have attempted to 'professionalize' support work, and manufacture distance between the support staff and the person being supported. Proximity is stronger than rhetoric however, and human nature will tend to win the day. If you spend many hours, days, and years with another human being it is inevitable that you will form a genuine relationship with them, be it positive or negative. It will not be a coexistence devoid of feelings. It exists between a position as a clinical operator, responsible for the well being of the person you are supporting and an intimate actor who is interwoven into all aspects of a person's life.

While I am a paid support, I am not a neutral actor. For better or worse I interact with the individuals I have supported as I would any other human being in the same situation. To say I am biased would be a minimal descriptor. It is the understanding of the existence of this bias that led early writers to develop the auto-ethnographic methodology in the first place. I am situating my writing within an awareness of this bias. I will be attempting to examine the position of both myself, and support workers in general, in relation to the people we are supporting.

All sharing of knowledge is problematic, in that it is firmly rooted in the perspectives of the sharer. The socially constructed reality the writer shares from informs all aspects of their words. So, we must actively 'problematize' authority from the outset, to see it in its true form (Alvesson & Sköldberg, 2017). Having said that, I do have a great deal of knowledge and come

from an informed perspective. The result of this experience should not manifest as authority though. If anything, my position should be worthy of consideration. If it is spoken with an authoritative voice it is because I think that I am right. It does not follow that I am right. It does not even follow that there is a 'right' to be found in many situations. It is more likely that there is a shifting scale of more, or less correct ways to proceed in any given situations.

> 'The research process constitutes a (re)construction of the social reality in which researchers both interact with the agents researched and, actively interpreting, continually create images for themselves and for other: images which selectively highlight certain claims as to how conditions and processes – experiences, situations, relations – can be understood, thus suppressing alternative interpretations.' (Alvesson & Sköldberg, 2017;12)

It should be noted that I have no identified disability. I will not be able to fully conceive of the barriers present in the lives of disabled people or those labelled with a disability. My perspective is informed by many years spent working as a support for individuals labelled with an intellectual disability. I feel that I have gained some wisdom in these years and that it is worth discussing the evolution of my professional practice over this time. My position of being both inside and outside places me at a strong position for a reflexive/reflective inquiry into my role in the lives of the people I have supported. Narrating my professional and personal experiences will enable me to examine the effects of my role in the lives of the people I have supported. It will also allow the reader to critically engage with my experiences and form their own impressions of what the implications are. I hope that my writing, 'furnishes opportunities for understanding rather than establishes 'truths'' (Alvesson & Sköldberg, 2017, p.11). I perceive myself as having made the best decisions I could have with the information I had at the time. This, of course does not mean that I made good decisions.

In many ways I am an ideal researcher in that I was not aware I was doing research. It was not until I was 15 years into my career that it occurred to me to pursue a master's degree.

Two more before I took my first class. I was engaged in my career, dealing with day-to-day concerns. I was ignorant of the greater implications of my actions. The narrative in the field of support work is that we do important work that is underappreciated. This is often enough to sooth one's activist tendencies. It is true that the work is important. Given the devalued place people labelled with an intellectual disability occupy, many of them would not be able to have any interaction with society were it not for support in their lives.

The reflexive aspect of this paper will examine how I came to make the decisions I made. It will also examine how the systems I operate within influence the decisions I make. I will be critically examining how the society I grew up in shaped my perceptions of the work I chose to undertake. There is a problem of objectivity in this as well. Society has done little to ensure the inclusion of people labelled with and intellectual disability. This means that it has been the support industry I am a part of which has shaped much of my views. This creates in me a bias towards perceiving what we do as inherently good. Throughout my work on my master's degree, I have come to see the flaws of the system I am a part of. This tension places me in an uneasy position. I know the work I have done is good, and that the work I have done is deeply flawed.

There are so many considerations to account for when considering the lived experience of people labelled with an intellectual disability, it is unlikely that I will be able to account for all of them. It is one decision to say that one should always respect the autonomy of the individual and allow them freedom to express their agency. It is another decision to say that one should do this even if it means risking loss of employment for the support staff. If we apply a lens of always doing the right thing to different professions/areas of life we can see the unlikely reality that people will sacrifice their own security for an abstract ideal such as agency.

Success can be a difficult term in relation to people labelled with intellectual disabilities. There can be tension present between what others may define as success for an individual and what the individual themselves may perceive as success. For my purposes, in this thesis I will be defining success, as best I can, through the frame of the people I have supported. An individual's success can manifest in many ways. I will spend time defining it individually later in the thesis as individual situations are examined and thought through.

It is my impression that many of the people I have supported do not experience their lives as a tragedy. While an outsider to their lives may look upon them with pity, the individual themselves is quite often is able to find contentment in situations others perceive as intolerable. This does not relieve the responsibility of the supports in their lives to develop an improved lived experience. Especially around issues of personal agency and self-determination. I identify this characteristic merely to place the people I have supported and those like them outside the role of victims.

Chapter 4: Where e come from: How Personal and Collective Histories Prime us for how we Interact in the Present

4.1 My Early Experience with Disability

When I reflect on my own history with disability, I would usually consider myself a total outsider. I have not experienced disability in my own body, aside from some injuries that impaired my movement for a brief time. These do not provide a strong base to build an understanding upon. I have had a relatively advantaged life, free of the barriers experienced by many people in society. There is one thing though. A detail of my life that I generally do not consider to be influential but upon reflection seems to have formed much of my framework though which I understand life.

My father was a type 1 diabetic. He was diagnosed at the age of 8 years old. This is a common enough chronic illness. It is not as stigmatized as type 2 diabetes which is often seen as being caused by the individual with the illness. For me, it introduced the reality of death and dying into my life. This possibility was present from the time I was born. My father would regularly have what we called 'attacks'. These were sugar level drops in his blood. When they occurred, he would shake and sweat uncontrollably, he would be unresponsive, he was totally impaired; incapable of caring for himself in any fashion. If some one did not intervene on his behalf, he would be dead in short order. I have seen so many of these attacks I cannot begin to guess the number. This included times, from a fairly young age, when it was just me and him at home and I needed to coax a Coke into him to bring his sugar levels up.

I remember feeling shame and resentment related to my father's illness. When neighbourhood boys would discuss whose dad could beat up the other's, I inevitably defended my dad's combat abilities. This was just a brave front though. Privately, I was thinking that they

were probably right, their dad could beat up my dad. We want our parents to be invincible. This was never a reality for me though. In the case of my dad, there was an ever-present vulnerability that defined much of what we were able to do growing up. The times I was the only other person home when one of his attacks started and I had to get sugar into him, I resented having to do it. I resented having to tend to what I perceived as a weakness in my father.

The presence of my dad's diabetes germinated an understanding of the vulnerability we all face in our lives. As I grew older, I came to understand that this was an acquired illness. My father had not always had to inject himself with insulin to stay alive. I also became aware that insulin was not always available and that there was a time where my dad would have been dead long before I ever had a chance to live. Even though his chronic illness was difficult to manage, and his life was perpetually under threat, my dad did not stop living his life. He was highly active in multiple activities. He did not allow diabetes to limit the options of what he wanted to do with his time. Sometimes this uncompromising stance put others in danger, such as the multiple car accidents that occurred because he had an attack while driving. Other times it caused embarrassment on his behalf, such as when he would have an attack in a public space and had to rely on strangers to protect his health. For better or worse, he persisted though.

4.2 Institutions and Intellectual Disability

To form an understanding of where we currently are in the field of support work, we must first examine where we have come from. If we do not spend time examining our personal and societal histories relating to intellectual disability, we will not be able to form a complete picture of where we are. Perhaps more importantly we will not be able to form a picture of where we need to go.

There is a long, inglorious history related to how society has dealt with intellectual

disability. I choose the words 'dealt with' specifically to evoke the nature of the relationship.

Prior to the industrial revolution and the mass migration of people into the cities from the

countryside, little is known of the fates of people labelled with an intellectual disability. When

many people began to congregate in cities, solutions needed to be found to deal with the people

who could not participate in the industrial machinery fueling urbanization. Among the people

seen as problematic were those perceived as having an intellectual disability. An emphasis on

defectology (Wehmeyer & Craig, 2013) prevailed, wherein the emphasis was placed on what a

person could not do. This resulted in the mass incarceration of people labelled as intellectually

disabled. There are many histories that have been written about the phenomenon of institutions

and how they established themselves in western societies. Licia Carlson (2010;23) summarized a

large swath of the progression well:

> The period from 1850 to 1880 is generally considered of optimistic institution building,
> with the aim of "making the deviant undeviant." From 1880 to 1900 there was growing
> pessimism, a shift to custodialism, to "sheltering the deviant from society", and from
> 1900 to 1920 there was an attempt to "protect society from deviancy," and the view of
> *people labelled with intellectual disabilities (my words)* as a menace. However, this
> history includes elements that persisted throughout.

The stories which have survived with the residents of these institutions paint a picture of

an intolerable life of abuse, neglect, and grossly under resourced services. The legacy of

institutions and what they represent in the framing and treatment of intellectual disability

permeates the current life circumstances of people labelled as intellectually disabled. The

mindset of institutions has never fully dissipated in our culture. The otherness affixed to labelled

individuals is still very much intact and defines much of their lives.

The trauma that lives in many of the people who resided in institutions is a significant

legacy of these places. I have seen this legacy in the people I have worked with. Some of the

people I have supported consume meals as quickly as they can to avoid having them stolen. This habit is typical of people who lived in large institutions. One woman I supported, after moving into the community, would disrobe at the end of the day and stand in the doorway of her bedroom with her clothes in her hands, waiting to have the staff take them from her. Her residential staff noted that this was the common practice at the institution this woman lived in. It would make laundry collection easier for the staff of the institution. This is the way of an institution. The degradation of the individual to support the function of the entity. A series of indignities both large and small that erode the humanity of the individual they claim to support.

In Manitoba, one of the most outspoken opponents to the continued operation of institutions is David Weremy. Weremy was a resident at the Manitoba Developmental Centre (MDC) and has been a vocal advocate for having it closed. A documentary featuring Weremy, *The Freedom Tour,* is widely used to raise awareness of the realities of living in an institution. In 2018 a class action lawsuit was filed against the Province of Manitoba. Weremy is named as the defendant in the statement of claim (Rosenfeld & Alfieri, 2018). Within this legal document are details of life at MDC as they were perceived by Weremy. In both the documentary and the statement of claim Weremy provides an account of the various abuses he suffered while residing at MDC. These included physical and sexual abuse by fellow residents, punitive measures (meant to correct behaviour perceived as negative) enacted by the staff, a lack of privacy and dignity, as well as being confined to locked wards; much like a prison.

To add insult to the injury inflicted on him, the province of Manitoba has refuted any claim in the lawsuit that is not based in time and date facts about MDC and the times Weremy came and left the institution (Ladyka & Koch, 2019). For the claims Weremy made regarding the injustices he lived through while residing at MDC, the province has employed the phrase, "and

puts Weremy to strict proof thereof". Similar denials were made by the Province of Ontario during a class action lawsuit filed against it after closing the Huronia Regional Centre.

Stories from families of suspected abuses that occurred inside institutions are also commonplace. Colleen Orrick, whose brother was institutionalized, suspected abuse had occurred in a bathroom at the institution where he lived. He had suddenly developed a strong aversion to using the bathroom. He refused to use it and went in his clothes instead. This despite never having an issue with using the bathroom previously. Years later after her brother had passed away a doctor inquired with her about evidence of sexual abuse that they had seen while examining her brother's body post-mortem (Burghardt et al., 2017).

In my experience this is often how these stories survive, especially for those who do not have the capacity to tell their own stories in a typical fashion. Families suspect something; they know that their child or sibling has changed. They are never able to get answers though. I have had many conversations with family members who were told that living in an institution was the best thing for their child. They then watched helplessly as the people they love unravel before their eyes. I hesitate to judge any parent who felt it necessary to place their child in one of these institutions. The implicit and explicit pressures placed on families to commit their children to these places was great. There was also little, or no community/political support provided to them that would support them in keeping their children at home.

A wall of silence surrounds institutions. To this day they keep their secrets close. The abuses recounted by Weremy are not uncommon in the stories that have escaped the institutional network that existed across Canada. Over-population, understaffing, and the absolute power of staff created a perfect storm for abuses to occur. In 1959, after visiting the Huronia Regional Centre (an institution in Orillia, Ontario), the journalist Pierre Burton wrote an article describing

the institution as he perceived it. The article was written as a warning to the public of the dire state of the buildings and living conditions. He described the crumbling infrastructure, lack of fire proofing and overcrowded dormitories where the residents slept. While the article does use questionable characterizations of the residents of Huronia, it is written as a warning to the general public of the imminent disaster waiting to occur at Huronia (Burton, 2013). Burton addressed over crowding and dilapidated buildings as his primary concern after a brief visit to the institution.

A 2009 class action lawsuit filed against the Province of Ontario cited the Walter B. Williston Report from 1973, which identified a series of flaws with Huronia's operation. These included: understaffing, overcrowding, patient labour necessary for operation of the institution, and dangerous conditions in the facilities (Baert & Poltak, 2009). These functional issues existed on top of the systemic abuse and neglect indicated by the residents named in both lawsuits. Despite repeated warnings from external witnesses, it took until 2009 to close the doors at Huronia. MDC remains open to this day.

The people who lived (and still live) at MDC and other places like it committed no crimes. The mechanism utilized to enact their incarceration was the claim that they were deficient and that the staff at MDC and other institutions like it would be able to fix them. This is a classic medical model conceptualization of disability. The medical model claims there is something wrong with the individual. It claims that this wrong can be fixed with the right intervention. This conceptualization does not allow for diversity and refuses to see the value of human beings who do not fall within the parameters of what they have deemed to be normal. The claims made by the large institutions upon their opening, that they could educate, train, and

generally provide a higher level of care for their residents were quickly abandoned. This may be indicative of several realities not directly addressed in their initial conceptualization.

It is likely that the language of training and education was used as a veneer for more fundamental motivations. One such motivation would be eugenics. Claudia Malacrida's excellent body of work related to The Michener Centre in Alberta, Canada, clearly outlines the eugenic motivations of that institution (Malacrida, 2005, 2015). Forced sterilizations were not uncommon at Michener, an effort to prevent the genetics of the those seen as unfit from continuing. Malacrida argues that the residents of the institution were devalued and seen as less than human (Malacrida, 2012). While she is writing about one specific space, this idea was common amongst all institutions. People labelled as intellectually disabled are still not seen as equal and worthy or capable of living a full life.

4.3 Closing Institutions is not the End of Isolation.

Despite the large institutions like Huronia having closed in Ontario this does not mean that their legacy has dissipated. The people who lived there are now in communities around the province, "carrying the legacy of institutional oppression, and have little opportunity to share their experiences." (Rossiter & Clarkson, 2013, p. 27) There is also the issue of a lack of willingness to change the conception of what constitutes acceptable living conditions. During the COVID 19 outbreak in the spring and summer of 2020 a story surfaced regarding a mass walkout of staff from *Participation House* in Markham, Ontario. The residence houses 42 adults labelled with various disabilities (CBC news, 2020). The outbreak resulted in the deaths of 4 of the 42 residents as well as 53 cases of staff testing positive for the virus (*COVID-19 Response / Participation House*, n.d., p. 19). While the COVID-19 pandemic did challenge many sectors of society, congregate care facilities (in particular, care homes for seniors) were hit especially hard.

This situation clearly demonstrates that the lessons gleaned from places like Huronia have yet to be universally integrated into the practices of social service agencies. The congregate setting was not the only factor contributing to this situation, but it is a significant one. If these people were living in lower capacity residences the outbreak would not have been so significant. The staffing crisis would also have been reduced as not as many people would have been interacting and spreading the virus.

Institutions such as Huronia and MDC are the manifestation of a prevalent aspect of the lives of labelled individuals. Isolation and exclusion are almost universal aspects of life with a label of an intellectual disability. It has been my experience this is a defining factor in the lives of labelled people. Prior to and during mass institutionalization this exclusion was physical and explicit. The remote locations of the properties and practice of discouraging families from visiting residents were external manifestations of the internal prejudices held by many in society. The closing of institutions does not guarantee inclusion though. In a review of self-advocate narratives it was found that the language around feelings of isolation and exclusion remained largely consistent across pre and post institutional narratives (Johannes et al., 2017). This finding reinforces the self-advocate assertion that an institution is not a building, it is an idea that can be practiced anywhere.

There have been efforts made by organizations such as People First and a collection of local Community Living organizations to establish a place for people labelled as intellectually disabled within the structure of our society. While there has been significant progress since the beginning of deinstitutionalization, there is still much work to do. Simply placing people physically in the community is not sufficient to ensure inclusion. In Canada there is no longer an overt emphasis on eugenics, but there remains a paternalistic attitude towards people labelled

with an intellectual disability. This stance results in the significantly reduced agency of labelled people (Ditchman et al., 2016). Within the agencies specialized to support labelled individuals it has been found that institutional priorities will often take precedence over the autonomy of the labelled people being supported (Petner-Arrey & Copeland, 2015). This can be due to both staff perceptions of risk as well of the stated priorities of the agency itself. This passive, and sometimes active, theft of individual agency was a defining attribute of institutions. It remains a reality for many people labelled with an intellectual disability.

Despite the huge improvement of community living arrangements relative to institutional models, their remains an ongoing lack of agency that defines the lives of people labelled with intellectual disabilities. In Manitoba, people who live under the umbrella of Community Living disAbility Services are often placed in living situations with 3 or 4 people living in one house. These people often attend day services that are based in a congregate model that has people of similar cognitive abilities attending to achieve a variety of goals. Except in extreme cases, these residences and day programs are staffed at below a 1:1 ratio. The people who utilize the services usually require complex and nuanced supports. These support models often group individuals based on categories and degree of impairment. This allows the supporting agencies to provide services tailored to suit the needs of these groups. Inherent in this model of supports is segregation. While these homes and day services are located within community settings, they still engender a state of exclusion by their very design.

4.4 Why do People Always Need to be Fixed?

As people move out of institutions and into community settings it has become apparent that the thinking which gave rise to institutions has not entirely disappeared. No matter how a service is designed it always seems to result in less than stellar results for the people using that

service. There still exists an idea of intellectual disability and the people labelled with it that seeped out of the institutions and into community settings. It is an idea of defect. That the people must be the ones to change to fit the expectations of the world around them.

The UNCRPD established the right of the individual to autonomy. It also establishes that people with disabilities should be respected and acknowledged as a manifestation of human diversity (Dickey, 2006). This has been far from the practice historically. It is also not common practice currently, despite declarations to the contrary.

There was a push for training at the dawn of the institutional era. The thinking was that people labelled as intellectually disabled could find their place in the modern economy. As I stated earlier, this is not possible for many people. Those who could be trained would do much better to enter a profession of their choice and learn on the job, in manner that suited their abilities. We seem to be incapable of accepting people as they are and helping them build the necessary skills to succeed. Many employers, social services, and even families want people to arrive ready to fit into the established systems. There is little effort to adjust systems to suit a diversity of needs.

Of course, when necessity pressures us, we do manage to find accommodations. Historically, once people were institutionalized, they were put to work in whatever capacity they were capable of to assist in the running of the institution. Many of the more independent residents functioned as free labour. They would complete many tasks necessary for the expanding complexes to function. Their staff were able to see the abilities of the residents because of their own inability to function without them.

This perspective did not survive the process of deinstitutionalization. A somewhat absurd situation emerged where people lost their freedom to contribute as they gained their freedom to live and exist in larger society. When applying the social model to questions surrounding intellectual disability, we must look at each situation as the sum of the histories that contributed to its manifestation. As I alluded to in the opening of this writing, intellectual disability is not simply a manifestation of the individual's capacity to reason and act within the systems of society. It is the product of a parallel social system enacted the moment a diagnosis is given and perpetuated upon the individual for the remainder of their life.

Another example of our inability to accept people as they are, is the interventions enacted on labelled children and adults to change their behaviours. This is a controversial subject with strong opinions on both sides. On the beneficial side, this practice has the potential to adapt a person's behaviour to suit current social practices. This has the potential to allow a labeled person to operate within societal norms, creating more opportunities for them. Conversely, it negates the person's uniqueness. Behavioural adaptive practices are usually designed to normalize a person's external presentations to make then more palatable to others in society. This is in obvious contradiction to the assertions stated earlier in the UNCRDP.

A clear example of this is the behaviourist methodology utilized by psychologists for neurodiverse children who have been labelled with autism. There are many videos and articles praising the results of these methods. The videos depict children crying and screaming while trainers have them complete meaningless tasks for rewards. These interventions are often targeted at diminishing behaviours such as stimming. Stimming is the practice used by many people to self-regulate. It can involve flapping hands, fidgeting with objects, vocal/physical ticks, or any other action which allows the person to regulate how they are feeling. The practitioners of

these behaviourist methods are aware of the controversy surrounding this method, but the normalization achieved is seen as so positive that they can overlook the objections of neurodiverse self-advocates to these practices. Historically, this practice could involve reward or punishment, but contemporary practice involves a reward-based system for children when they demonstrate compliance to authority.

These results, while seemingly significant do not result in a significantly better lived experience for the individual or a reduction in carer burden over longer timelines. It seems that unless we are willing to persistently apply behaviourists methods across a lifetime then the targeted behaviours will resurface (Hassiotis et al., 2012; P. C. Oliver et al., 2005). The idea that it is the individual that needs to change to make the rest of society comfortable is a typical example of a medical model framework being applied to impairments. In this case it is an active repression of coping methods used by neurodiverse individuals. These coping methods seem distracting or annoying to neurotypical people. Extinguishing these behaviours is seen a way to facilitate greater inclusion for the individual. We tend to reject other forms of discrimination like this. In certain contexts, expressive behaviours are even praised. Why then, do we feel the need to eliminate the various behaviours expressed by individuals simply because the have the label of disability?

This raises the question of inclusion vs integration. If a behaviour is not causing harm to the individual or others, why do we need it to be extinguished? Because it makes us uncomfortable? Because we do not understand it? We do not seek to include people who diverge from normal. We seek to change them enough that they can integrate, unnoticed, into mainstream activities. People labelled with an intellectual disability are expected to integrate into the current systems in operation. In schools they are tolerated to the extent they can participate in

a typical classroom environment. In workplaces, they are tolerated to the extent they can perform existing roles within a given workplace. If they are not able to directly participate in these environments, they may be tolerated if they are friendly and grateful. In some instances, they will not be tolerated no matter their efforts.

When labelled people meet this intolerance, they move into the parallel systems discussed earlier. Integrated to the extent that they are no longer completely segregated from the rest of society. These efforts fall far short of inclusion. I am of two minds about this. On the one hand these parallel systems can provide people with a modicum of safety. There are many who would exploit a labelled person's vulnerabilities if they were in a more inclusive setting. Keeping in mind the specific manifestation of cognitive impairment I outlined earlier, there is a high degree of risk for exploitation. The other side of this is, with greatly diminished risk comes greatly diminished opportunity. These parallel systems protect mainstream society as much as the people they are designed to serve. If people are kept to the periphery then society will find no need to question its treatment of them. The main question I have about the work I have done is whether the fact that I have done it has contributed to the continued disablement of the people I work with. If these systems did not exist, would we collectively be forced to make room for those who currently exist within them?

When we default to the expectation that people need to change themselves to fit into our current systems it is a statement of perceived value. The statement we are making is that a person is not good enough unless they are able to behave and think like the rest of us. We fixate on the individual's inability to adapt to our norms. They are measured by the things that they can not do rather than the abilities they do possess. This deficit model would later be addressed by the theorists who developed the social model of disability. Defectology is rooted in the medical

model of disability. A framework of understanding that sees the individual as flawed and in need of rehabilitation. The medical model does not see the ways the systems surrounding the individual work to manufacture disability where it need not exist.

This emphasis on deficit ignores human potential and relegates those who are unable to adapt to contemporary life to the margins, often forcibly. It does not seek to understand or value the perceptions of people who have been assigned a diagnosis. It embraces the lived experience of the professional helpers as objectively good. It then assesses all other lived experience relative to this falsely objective standard. It is within this paradigm that people labelled with an intellectual disability are made to exist.

Given this social disablement, it is not surprising that we might see anti-social behaviour. These are often referred to in the literature as "challenging behaviours". There is a wealth of research into challenging behaviours that manifest in labelled people. A variety of interventions are suggested for people based on the perceived problem they are facing. It can be tempting to accept these various interventions as a support. They present a solution to the complexities introduced into a person's life when they have behaviours that create distance between themselves and others in society.

If we adopt a human rights approach rather than a medical model approach though, other opportunities may present themselves. Many of the current interventions for these behaviours focus on controlling the behaviour itself. There is little effort made to relieve the root of the behaviour. I believe this is demonstrative of a perception of inevitability relating to these behaviours manifesting. Professional helpers do not see the behaviours as a reasonable reaction to a person's environment and lived experience. The behaviours are believed to be a manifestation of their labelled disability. They are understood to be inevitable. It is often the case

that these behaviours are causally related to events in a person's life though. They are , in fact, not an inevitable manifestation of a label of intellectual disability.

A human rights approach provides a different perspective than the medical model. If we have respect for the inherent dignity of a person, as is stated in the UNCRPD, then it is incumbent upon us to search for interventions to these behaviours that respect the person's right to self-determine. This is not to say that medications and therapies meant to address "challenging behaviour" will never have a place. It is simply to say that we must thoroughly exhaust all other options before going towards them. This process is not easy and relies on intuitions and trial and error interventions to remove causal factors in a person's life. In my experience, not restricting a person's right to self-determine often alleviates a great deal of the behaviours staff perceive as challenging.

4.5 Other Factors Contributing to Disablement

Further to these medical diminutions of labelled people, there have been robust debates in philosophical circles regarding the worth or personhood of people with intellectual disabilities. These arguments are based in abstract mental experiments that people in philosophical circles are quite fond of. They lose all power when confronted with reality though. It has been shown in numerable cases that the subjective experience of people labelled with intellectual disabilities diverges significantly from the objective indicators used to measure their quality of life. The best measure with which one can assess quality of life is not the experience itself but one's capacity to have experience. A person's access to expanding their realm of experience is also relevant (Reinders, 2014).

This expansion of experience is what is often missing in institutional lives. Alongside the rampant abuses, monotony is a feature often described by former residents of large institutions as a defining feature of institutional living. This monotony would be made significantly worse the more pronounced one's disability was. If a person is unable to move themselves and unable to express that they would like to be moved, it is likely that they would spend their entire time left in the same position. The only reprieve being when they had to have their undergarments changed or be put to bed. This is a great disservice for people who are unable to effectively advocate for themselves. Exercising autonomy and psychological emancipation are key elements identified by positive psychologists to general happiness (Leontiev, 2006).

The question remains whether people labelled with an intellectual disability have greater ability to access a variety of experiences. Relative to life inside of an institution, this has improved since community living became the norm. There are many who can access a wide range of experiences. For those who can not advocate for themselves in any traditional sense though, experiences can remain limited and repetitive. They have also largely remained segregated. For example, it is common practice for support agencies to hold agency dances. The intent of these events is to allow an opportunity for socialization for the people they support. The simple question of why the people they support do not go to non-segregated social environments is not addressed. The dances are a typical example of misplaced efforts on the part of social services. They want the people they support to have social opportunities. The statement these dances make though is that they should only be socializing with other people labelled with intellectual disabilities.

Having people labelled with intellectual disabilities present in other social settings, such as a night club, pose a risk. There is a risk of negative social interactions. There is a risk the

person may come to some harm in these settings. This is the same risk all of us faced as we defined our social environments. Support staff can still be present if needed. I used to take one of the men I supported to a country bar close to his house from time to time. He would have a blast, dancing and having a drink. It was also my experience that he had only positive interactions with the other patrons at the bar. The experience was positive for everyone involved. Looking back, I only wish we had done this more often. There was a small amount of risk involved, but that is what made it fun for the person I was supporting.

We must begin with the assumption that a person is able to go anywhere and do anything. From that point we should adjust supports to ensure that the people we are working with have every opportunity they can. Only once the opportunity has been tried can we evaluate whether they have enjoyed it and it is worth pursuing further. It is profoundly disabling to never try new things. People labelled with an intellectual disability must be afforded the chance to fail. Until we have increased people's exposure to risk, we will never be sure of what they are capable. They will also not see themselves as capable if they are repeatedly prevented from taking risk, and therefore prevented from succeeding and growing.

Another area that needs careful consideration regarding people labelled with an intellectual disability is intersectionality. When disability labels intersect with other factors that are disabling, such as poverty, the troubles that arise from medical models of support are exasperated. In the fall of 2019, I had a conversation with a staff from a major institution that was engaged in behaviour analysis plans for children living in remote communities. This initiative was an aspect of Jordan's Principle (Canada, 2017). Jordan's Principle seeks to equalize services between remote indigenous communities and urban centres by ensuring that services are offered where the children need them, when they need them. The implementation of

this principle has been deeply flawed and required further legal orders to bring the government of Canada into compliance with the spirit of the order. That is the subject of a different thesis.

This staff described the absurd situation of going into a home of a neurodivergent child with a nine-page plan for behavioural analysis and intervention to be implemented with the child. He sat with the mother of the child to get to know her and explain the plan to her. He discovered that she was the single mother of six with no other supports she could access within the community. He also discovered that she seldom had enough money to feed her family. He was faced with the question of where in this woman's reality does a nine-page behavioural intervention plan fit? This is a symptom of the medical model, which is unable to see the barriers between individuals and their ideal of normalization. The medical model is unable to consider whether normalization is even preferable to making room for diversity in the population. It also is demonstrative of the absurdity of the tasks support workers can face when they go to work. An almost laughable lack of understanding on the part of social service agencies as to what the people they are supporting need.

4.6 What Schools Teach Kids About Intellectual Disability.

I attended a junior high on the west side of the city of Winnipeg. We were an 'inclusive' school in the sense that people labelled with intellectual disabilities were in the same building as us. Infrequently these students would be in the classroom with us, a novelty and distraction to our daily routine. I have few memories of these students from this time. One person would attend my homeroom occasionally, he liked football. He would tell us this any time we thought to ask about his favorite sport. "Football!" he would shout out, as we all encouraged him.

Another girl would ride through the hallways on her specialized bicycle repeating the syllable "MO!" as she wheeled down the halls with the help of her support staff. I remember her name because I went to school with her from grade seven through to the end of high school. One more; a boy my age who had the uncanny ability to remember your birthday after having told him only once. He could remember this after a span of years with little difficulty, and even tell you which day of the week you were born on. These peers, and many others, were present in the schools I attended from the time I entered junior high until I graduated high school.

They were seen in the lunchrooms, hallways, assemblies, and occasionally a classroom. In many ways they were phantoms though. Both present and not. Included physically, but not integrated into the culture. This relationship formed my first conceptions of people labelled as intellectually disabled and where they belonged in society. Novel skills, such as those of people with savant abilities, serve to distract and amaze. Self-assured enthusiastic exclamations were tolerated and perhaps seen as a path to being accepted by peer groups, within a particular social context. These individuals were never truly included though. Never left to their own devices or encouraged to attend regular classes with their peers. We did not have flexible curriculums that allowed for their presence and participation. Recently I met a group of people who attended my high school that were now being supported by the agency I work for. They attended in the same years I did, but I never saw them. I had no idea any of them attended the school.

This is old inclusion. An inclusion that did not allow for meaningful participation. This is the system I interacted with all through my school years. In many ways it is the system that we all exist within to this day. Segregated classrooms still exist and function. Inclusive classrooms are underfunded, and teachers are not sufficiently trained or resourced to develop inclusive delivery of the mandated curriculum.

The school system sets the tone for the rest of society. What is modelled there will find its way into the systems in the greater society. The models that exist in schools reflect the values of society. Children learn by modeling. If we keep labelling practices that segregate as inclusive, then that is what these children will practice when they leave the school system and begin their lives in broader society. It would be better to name the practice for what it is so that at we have an understanding that we have a long way to go.

What does inclusion mean? There are many ways to label an action as inclusive without making a real attempt at adapting the system to allow full participation. We can allow for inclusion if the individual can participate in the existing model. The work I did for15 years is a good example of this distinction. I worked for a day service. A place where people labelled with intellectual disabilities come to spend their weekdays. It is meant to mimic the routines of the rest of society. We are in the community, along side other businesses. We go out into the community everyday to try a wide variety of activities. This is one form of inclusion. A way for all involved to look at the lives of people labelled with an intellectual disability and say to themselves, "Well that's not so bad is it?".

They are correct. It is not too bad. People are content for the most part. They can try and experience many things they would have no access to in a setting further removed from society. Most of the staff I worked with care deeply for people we support. They worked hard to provide them with a meaningful life. I made a concerted effort to develop relationships with the people who attend that service that allow them agency and dignity. It is still segregated though. Separate, and isolated from the happenings of society. A parallel system meant to occupy, not include. It has cost society little in the way of adaptation to allow the current system to persist.

Labelling something as inclusive without meaningfully adapting it only serves to further disable the people meant to be included. Adapting the thing to suit people labelled as intellectually disabled and only including them is also disabling. Anything that deepens the divide between mainstream society and those pushed to the margins is an act of disablement. This is true no matter the intentions. People have the right to access all the aspects of life that we all enjoy. The reality is that they are not currently able to access many aspects of life. Be it at school, in the workforce, or recreational activities, people continue to be excluded.

This is the state of life that persists for many people labelled with an intellectual disability. For them, inclusion is only possible if they can fulfill a need of the established systems in society. Barring that ability, they must move in parallel systems. These systems account for the uniqueness of the people they support in many ways but are unable to further the normalization of their presence in society in a substantial way. If it is feasible to feel satisfied with the current systems, we will not be inclined to change them.

In my junior high there was an assembly to observe Remembrance Day. We had all gathered in the main theatre of the school and were waiting for the event to begin. As 'The Last Post' was played on the trumpet, the girl who biked through the hallways began vocalizing repeatedly. "MO!... MO!... MO!". Sniggers of laughter erupted through the crowd, quickly suppressed by stern stares from teachers and a well practiced reverence for this moment, trained into us from our earlier school years. We all tried to pretend that she was not vocalizing for a brief time. We held onto what was normal for as long as we were collectively able. As the moment of silence that follows the playing of 'The Last Post' began though, the vocalizations became too much to tolerate. Her support staff wheeled her out of the theatre, presumably back to the classroom occupied by the labelled people at the school.

This event encapsulates for me the collective attitude of our society towards people labelled with an intellectual disability. We are happy to tolerate their presence so long as they are not disruptive of our patterns of normalcy. The tittering of an assembly of preteens constituted her removal from a communal event so that the event could retain its reverent atmosphere. It is important to honour our veterans and contemplate what they sacrificed their lives and health for. Is that more important than making room for everyone in our communal actions?

I have had many experiences around the sometimes-awkward behaviours of people labelled with an intellectual disability. Anytime I am in a place where the normative practices are being transcended by a labelled person, I get a feeling in my gut I have always associated with acute embarrassment. Flushed, awkward, I just want the discomfort to end and for *normal* to recommence with shy smiles of acknowledgment. To be able to slink away and go to a place where the person I am with is not being stared at. Where people are not annoyed at having their own *normal* disrupted. Then I think, why not? Why not stay and sit in this discomfort? Why is it that I have this feeling in me? Is it so bad that this person I am with is vocalizing in a movie theatre? Is the dialogue in a contemporary movie so complex that if a single word is missed attentions will unravel and the whole plot become incomprehensible? There is an expectation that if the person I am supporting is making disruptive noises in a theatre, I will attempt to guide them out or ask them to be quiet so the others who want silence can have it.

This issue is different if a person is just talking and in full control of the noises they are making. In many cases though, the people I have supported are not in control (for a variety of reasons) of the noises they are making. Their various vocalizations are a part of who they are. A manifestation of their being. There is the possibility that the person could and perhaps should learn to follow these social conventions. This possibility is entirely based on their ability to

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comprehend the situation they are in and their ability to control their expressed behaviours. Possessing these capabilities should not be the condition of a person's presence in society.

So much of what we find acceptable in our daily interactions is solely based on convention. Where can we be loud? How close should we stand to a friend, co-worker, or stranger? Who can we speak to unsolicited? The answers to many of these questions are largely based on who you are, or more precisely, how you present to others.

I am reminded of a funny situation. There is a man I have been working with for many years. He presents as an older white male. You would not suppose just from looking at him that he had been labelled as intellectually disabled. When a new staff starts, before they have been introduced to everyone, they usually think he is a staff member. Based on conventions, this makes his behaviour seem very strange and usually is considered rude. He seemingly refuses to open the door for a person arriving for the first time at the building. He does not say 'hi' when a person passing through for the first time says 'hello'. When these people come to understand that he is one of people that we support at the day service it is usually a source of amusement.

He is not being rude in his behaviour; he is simply following his own conventions. These have been established during a life under the care of various social services. He can be very interactive when you know him, but he is likely weary of strangers. When a new person arrives in his life he does not know if they will be around in 6 months. He does not know if they respect his point of view and will be responsive to his needs. In the context of his life, it is reasonable that he should hesitate to open himself to a new person. The risk is too great.

Chapter 5: Where We are Now: The State of Supports for People Labelled with an Intellectual Disability

5.1: The Systems of Support

It is often mentioned in the more progressive circles of support providers and certainly within advocacy organizations that a building does not define an institution. The physical space of a supported living situation does not mean that it will not be operating in an institutional manner (Lyle T. Romer & Pamela Walker, 2014). For those that are capable of supported living in their own homes the possibilities of choice and dignity are greatly increased. For the people I have supported though, who will always require intensive supports, their ability to make choices is still largely dependent on the attitudes of the staff working with them.

Contemporary supports for people labelled with an intellectual disability are a complex web of well-meaning bureaucratic institutions set up to help them live their lives. Whether or not they do this well is a matter of some debate. In Manitoba, the government funds and regulates the care of all adults who have been labelled with an intellectual disability under the umbrella department *Community Living disABILITY Services* (CLdS). The relevant legislation that governs the lives of people labelled as being intellectually disabled is the *Vulnerable Persons Act* (VPA). According to the act a vulnerable person, "means an adult living with a *label of intellectual disability (my words)* who is in need of assistance to meet his or her basic needs with regard to personal care or management of his or her property." (Justice, n.d.). To be covered under the VPA you must have been diagnosed as having an intellectual disability prior to turning 18 years old. The VPA, like most legislation is a web of complex legalese, but is most commonly understood through its five guiding principles (*Families | Province of Manitoba*, n.d.)

1. Vulnerable persons are presumed to have the capacity to make decisions affecting themselves, unless demonstrated otherwise.
2. Vulnerable persons should be encouraged to make their own decisions.
3. The vulnerable person's support network should be encouraged to assist the vulnerable person in making decisions so as to enhance his or her independence and self-determination.
4. Assistance with decision making should be provided in a manner which respects the privacy and dignity of the person and should be the least restrictive and lease intrusive form of assistance that is appropriate in the circumstances.
5. Substitute decision making should be invoked only as a last resort when a vulnerable person needs decisions to be made and is unable to make these decisions by himself or herself or with the involvement of members of his or her support network.

There are three key areas of the act. Support services, which address the living and vocational aspects of a person's life. Protection from abuse and neglect, which both mandates a person's right not to be abused, but also mandates that suspected abuse must be reported by third parties. Substitute decision making, where a person can have decisions made for them if they are incapable of making these decisions (*Families | Province of Manitoba*, n.d.).

Under the VPA a person can be appointed a substitute decision maker (SDM), "if the person is not able to understand information that is relevant to making a decision concerning his or her own health care, or his or her own physical, emotional, psychological, residential, educational, vocational or social needs, or similar needs, or is not able to appreciate the reasonably foreseeable consequences of a decision or lack of a decision." or if, "a person is incapable of managing property if the person is not able to understand information that is relevant to making a decision in the management of his or her property, or is not able to appreciate the reasonably foreseeable consequences of a decision or lack of a decision." (Justice, n.d.). If a person does not have an appropriate person in their life to act as an SDM they will be assigned a Public Trustee to act as their SDM.

SDMs have the potential to execute a great deal of control over a person's life. The wording in the VPA is such that it is open to interpretation and personal bias. SDMs make decisions about how a person's money is spent, what kind of medical care they receive, even if they can take part in recreational activities when a waiver is required. In an ideal world this power would be enacted in the least restrictive way possible. In our world, it is enacted in a fashion that tends towards mitigating risk.

These governmental systems act as oversight for agencies that provide services for people labelled with an intellectual disability. These agencies provide a variety of services meant to enrich the lives of labelled persons. They operate under service purchase agreements with the province. They operate at arms-length, with the government only becoming involved in operations when things are going wrong. This has usually been in the case of systemic fraud.

Well known cases of fraud have occurred in Manitoba such as that concerning the for-profit agency Hydra House which was found to be using public funds to pay exorbitant executive salaries, lease or purchase luxury vehicles for it executives, maintain a property in Florida, as well as multiple other misuses of public sector funds (Manitoba, 2004). A more recent case of misuse of funds involved a not-for-profit agency called *STEPS Resources Community Support Services.* The Executive Director and Chief Executive Officer were found to have purchased an 'operating system' for not-for-profit agencies with funds provided by the province. This operating system was one they had developed themselves and was purchased by them, from them, for use by the agency. Developing an operating system for a not-for-profit would generally be considered the job of the Executive Director. Yet this agency was leasing this system from the person who they were paying a salary to do that very job. This was being done at an inflated leasing rate. The province subsequently removed funding from the agency following an auditor's

report into its operations (Frew, 2020). In both instances the supports these agencies were providing were taken over by other large agencies already operating in Winnipeg.

This kind of fraud is often perceived as a harm to the government who is providing the funds. It is however much more harmful to the people who are supposed to be receiving supports. The millions of dollars wasted in these two cases could have been used to better the living circumstances of the people supported by the agencies in meaningful ways. The province will not miss a few million dollars.

Most services offered by these agencies generally fall under either residential or vocational categories. Residential services seem self-explanatory. Everyone needs a place to live, these agencies oversee the spaces where this occurs. Agencies buy or rent housing and operate it to the presumed benefit of the people they are contracted to support. There are several models of residential supports.

One that is common and likely assumed to be the general model of support by the public is that of shift staffed housing. This arrangement is when a home has one or more staff on shift 24 hours a day. The level of staffing will depend on the level of need of the people who live there. Within the shift staffed model there are several options for staffing arrangements depending on the level of independence a person is capable of exercising. Some people are always required to have a staff with them. There are even line-of-sight orders that require a person to be within view of a staff while in the community. These would likely be due to a person posing a risk to themselves or others in the public. Like many things related to intellectual disability, there is room for interpretation within this model. Some supports tend towards more restrictive supports, while others tend towards fostering greater independence. Most agencies

espouse the value of independence, but it has been my experience that the front-line staff largely dictate the level of independence available to the people they work with.

Another model of residential support is home sharing. This might be more commonly known as 'fostering', but there has been a move away from this idea in recent years to that of sharing a home. Ideally this model is enacted as described. People share a home with a person or family and can live their lives with appropriate supports from the home share provider. This is not always the case. Many people gravitate towards this arrangement for the monetary compensation rather than from a motivation of what is best for the person being supported. Like every other professional involved in a labelled person's life, there is no quality assurance.

The third common model of supported living is supported independent living. In this case the person will live in their own residence. They have staffing supports that will help them with various aspects of their lives as required. This model can also exist in a cluster model where an agency will own or lease an entire apartment block where people they support live independently. This allows for staffing to be available on-site 24 hours a day in case there is a need for them. People who live in this model are generally independent in most aspects of their lives. They require specific assistance in limited areas which is provided by the supporting agency.

Vocational or day services can cover a wide array of programs aimed at enriching the lives of labelled people in the province. Like residential services, there are a variety of programs offered to suit the needs of the individuals being supported.

Day programs, or day services can have several different manifestations. People with more pronounced cognitive impairments tend to be placed in leisure/recreational day programs

focused on developing social and life skills as well as going on a variety of community excursions aimed at promoting community inclusion and enriching personal experience. The focus of each program will vary depending on the needs of the individuals who attend. The people who attend each individual program tend to be placed based on their similarity to the people already in attendance. In this way a single program can offer more specialized supports for the people who attend.

For people who have less significant cognitive impairments day services can focus more on life skills needed to operate independently in society. They can provide work experience or social and financial literacy classes to help a person move towards greater independence. Within this model can exist a variety of services including sheltered workshops, social enterprises, and class-based programs.

There are also supported employment programs geared specifically towards helping labelled individuals find and keep work. These programs will work with the people they support and community workplaces to fill existing positions or create a position tailored to the individual based on their abilities. Other employment-based programs exist but operate in a segregated fashion. These programs are social enterprises and sheltered workshops. Both provide income to the people who attend them. Financial compensation is usually below minimum wage in these programs. They will often frame their services as preparing people for competitive employment.

These programs are meant to enrich the lives of the people attending them. Ideally, they would provide a certain number of skills and then the people who use their services would move on. The service providers are disincentivized from completing this process though as they are funded on a per diem model that means they will lose funding if they lose program participants.

Supports are susceptible to the inclinations of the staff overseeing them. The world views of staff, relating to intellectual disability, will influence the methods of support enacted. There is also a concern in any social service that it is self-perpetuating. When a staff's employment is dependent on the person they support needing that support, they will tend to resist moves towards that person's independence. Like many practices related to intellectual disability, this is not a conscious oppression. The staff who see the people they support as always needing them do not do this out of malice. They want to help, but they also *need* to help to ensure their future financial security. Regardless of intention, these models are still mostly segregated. They effectively support a person's existence within a parallel society.

When these systems are functioning, they are good at maintaining life. Each regulation imposed on the lives of supported individuals are rooted in well-meaning action. My colleagues and I go to work each day with good intentions. Systems do what they are designed to do though, regardless of their intention. The fact remains that the community living model currently in place has resulted in the continued segregation of people labelled with intellectual disabilities. Decades of work has resulted in little evolution in the lived experience of people labelled with intellectual disabilities beyond the initial gains won in the transition from institutions to community living. Unequivocally, community living is a marked improvement over institutionalization. Community living has manifested the potential for agency amongst the individuals being supported. In my experience though, this agency is dependent upon compliance of the person being supported. In congregate care settings, if an individual does not want to go along with the congregate plan, they are unable to participate.

This is not the individual's fault. If they do not feel like doing something, of course they should be allowed to refuse participation. Surely then, it is the staff's fault. They make the plans

and facilitate the people they support taking part in those plans. However, in an under resourced sector, it is hard to blame people doing the best they know how to. Staffing ratios dictate that planning needs to consider the needs of everyone they are supporting on any given shift. Unless you are staffed at a 1:1 ratio (which is exceedingly rare), this is near impossible. So, compliance is a necessity of effective support in the current system.

Here then is the culprit. Provincial governments set funding for supports, so it is their fault that people are not all staffed at a 1:1 ratio and able to do whatever they want with their time. Governments have limited resources though and are under constant pressure to cut taxes and reign in expenses. Perhaps it is no one's fault? We have inherited the systems of thinking that have manifested the current state of our society. These systems take little stock of the needs of people who are interdependent on others to life a full and meaningful life. In neo-liberal western thought, the autonomous individual is paramount; provided they can fend for themselves. The more an individual is dependent, the less value they have in our society.

The reality of the current situation for people labelled with an intellectual disability is that there is a lack of dignity in their lives. This is a product of systemic structures that do not value their lives as equal to those who can live their lives without the same level of supports. It is not abuse that is occurring, in the legal sense (though this still does happen with alarming frequency). It is a more subtle form of abuse that is present. It is what Sally Robinson has identified as emotional and psychological abuse (Robinson, 2013). In her research Robinson identifies a lack of respect for the dignity and humanity of people who have been labelled as a form of abuse that is present within the culture of support work.

Support workers are often hired with no experience or training. In many agencies training is confined to frontline supports training new staff as they start on the specifics of the job. This is

done on shift and left largely at the discretion of the more senior staff doing the training. This has potential to be a positive thing. If the senior staff has a positive view if the work, then this will be passed on to new staff. If the senior staff is exhausted and just doing their best to get through every shift, then this will also be passed on.

This is how I was trained in the early 2000's and for the most part, this is still the common practice. The result of this is that there is little time for contemplating the more abstract nuances of the job. The *why* of the work is focused on the practicalities of meal preparation, facility maintenance and medication delivery. While these things are important in most cases, the real *why* of the work needs to be focused on the long view of what we are doing. What are our ends as support professionals? If it is simply to maintain life, then we have failed to appreciate the gravitas of the work.

If we adopt this broad definition of abuse, then this is a reality that I have not only witnessed but also participated in. There are complexities in groups that make it difficult to manage all the needs and expectations of how their lives should be lived. Congregate settings are inherent in the funding structure of supports provided for people labelled with an intellectual disability. There are inevitable problems in these settings that cannot be addressed without significant reforms to how supports are provided. For those whose impairments prevent them from advocating for themselves there is not an opportunity to address the short comings of the supports that are provided to them. This results in people being forced to endure situations that most people would not tolerate.

Within the population of supported individuals, it is not uncommon for people to be violent to each other or to their staff. While staff can leave and seek employment elsewhere if they determine that the violence is too much for them to endure, this opportunity is not available

to the people being supported. Occasionally, if the violence is extreme enough, or presents an immediate danger to physical well-being, people's supports will change to accommodate their violent tendencies. This is difficult though as it can mean that the person is placed in a situation where they are living on their own, without any roommates. Funding bodies are not very keen on this setup as it is a huge cost to provide one-on-one staffing and maintain a residence for a single individual.

The hesitancy to place people in one-on-one staffing situations means that it is unlikely that people will be removed from violent situations unless it presents a significant danger to their physical well-being. I also suspect that violence between people being supported goes largely under-reported as it reflects poorly on the support provider. The result of these factors is people are systemically left in scenarios where they are experiencing violence on a regular basis as a matter of routine. The rates of victimization among adults labeled as intellectually disabled are alarmingly high (Codina et al., 2020). This is not to say that staff are not doing their best to prevent violent situations or other forms of victimization. It is merely to state that people are experiencing violence regularly. While this violence is often not to the degree that it would cause significant injury, it is beyond a level most in society would tolerate in their day-to-day peer interactions.

This interpersonal violence can manifest for a variety of reasons, each dependent on the lived experience of the individual. I use the example of violence because it is a behaviour that many of us would not tolerate in our daily lives. If I had a roommate in university that routinely slapped me on the head or kicked me in the shins, I likely would not stay in a living situation with them for long. There are many aspects of the support provided to labelled people less evident than interpersonal violence that would not be tolerated by most people. For example, the

diminished agency I spoke of earlier. We need to question why these elements of life are considered tolerable for some. How have we been able to normalize life circumstances that many of us would not tolerate?

5.2 How do We Enact Supports?

When considering our actions and methods as support workers we must look deeper than the behaviours of the people we support or the rules of the agencies we work for. We must take each individual as they arrive in our lives and puzzle out how best to support them. I will relate here a story that may demonstrate some of what I am referring to.

I am sitting with a person at a computer. They communicate using English but are often difficult to understand. It is apparent that they are upset and are in the process of an escalation that usually leads to violence. This violence can be directed at staff, their peers, or property. I have been working with them for less than a year but am already familiar with this pattern of behaviour. Through trial and error, I have learned how to redirect their attention away from the subjects that tend to lead to this violence in them. None of these strategies work today. The violence is inevitable.

As it begins, I instruct a co-worker to move everyone out of the area he and I occupy to prevent them being injured directly or accidentally. The person I am supporting directs their anger at me. I see this as a success as a support. If they are trying to hurt me, they are not trying to hurt others. I train in a grappling martial art for a hobby. I have a good understanding of how injuries are caused in situations of interpersonal violence. I am capable of not getting injured in this altercation more than my coworkers. More importantly, I know what will cause pain or

injury to the person I am supporting and am careful not to do anything during this situation that will cause him injury.

He repeatedly lunges at me, grabbing my clothes, trying to punch or bite me. I hold him off with open hands, not wanting to hurt him. Piece by piece he tears my shirt off as he gets a hold of it in successive attempts, I let him. Tearing my clothing has little chance of causing him injury and does me no harm whatsoever. When he is unable to harm me, he goes after furniture and appliances in the area he can break or throw at me. One by one I am removing these items and handing them to a colleague who is watching. I am in control of this situation, as much as I can be. I let him flip the couches, this also causes no harm. Eventually the environment is free of everything that can be thrown or broken. I have asked my colleague not to intervene as this will just lead to this person being physically restrained. Restraints greatly increase the risk of some one being injured. I do not want that.

They are yelling at me, telling me they want to kill me, calling me a "bitch". The person is telling me they want to go and kick one of their peers. If I had not intervened by physically preventing this person from doing what they wanted to do, they would have gone to one of their peers and kicked them repeatedly. I know they are capable of this; I have seen it before. I am keeping my voice low and calm. When they say they want to go and injure their peer I calmly tell them, "I am sorry, but I can not let you do that." The violence is then redirected at me. We begin again. This cycle of the direction of their violence moves between me, their peer, and property repeatedly. This goes on for about an hour.

As their anger dissipates and their energies wane, other emotions begin to surface. These are fear, remorse, and deep sadness. They say they are sorry to me repeatedly. They ask if the peer they were trying to target with the violence is ok. They sit on one of the couches they had

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recently flipped, and I sit with them rubbing their back. "I ripped your shirt?" they say. "Yes," I tell them, "but it's ok, I can get another shirt."

"I hit you?" they ask. "Yes, but it's ok," I tell them, "I am not hurt, and you are not hurt. Nobody got hurt, it will be ok." They are weeping openly; I am crying a little.

I have several scratch marks on my arms and hands, the furniture is perhaps a little worse for wear. They have no physical injuries that I can see and none of the other people I support are injured during this incident. Is this good support? I do not know.

Leaving this situation, I had the sense that I had earned this person's trust much more deeply than when I was simply a fun staff. They now know that I will not try to hurt them no matter what they try to do to me, or someone else. This is a deep and lasting trust that has helped extricate us from very tense situations. Is this trust justified though? It exists, but how can I possibly sit inside of this trust and continue to earn it. It is easy as a support staff to misuse the trust given you by the people you work with. To manipulate them to make your life easier. I see this all of time. I have done it myself. You catch yourself, suggesting doing a certain thing or to move in certain direction to suit your own needs. We are all human. We tend to avoid the more difficult road, even if it is the morally correct direction to move in.

This person's anger is still there, but I am often able to walk them away from it. The two of us have an understanding born of a prolonged violent situation. When this person is in a good mood, they are charming and gregarious. They have a robust sense of humour and are very caring and generous to everyone around them. I have seen them offer their favorite snacks freely to their peers. They often provide reassurance to peers or staff who express they are not feeling well or seem upset. I many ways they are someone who it is a joy to spend time with. The kind

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of person who makes me laugh when I think someone is willing to pay me to spend time with them.

From time to time they explode with anger though. This anger is unrelenting. I have never been able to identify its root. I have no doubt that it has its beginnings in some trauma from the past. This kind of anger often does. This person often expresses that they are mad with someone who has nothing to do with the workplace I am in. I have no effect on the impetus for their anger when this is the case. What are we to do with someone like this person? How do you support them? Is it fair to have other people compelled to spend time with someone who has done them violence? Is it fair to remove someone such as this person from the company of others because they are traumatized and do not have a means to resolve this trauma?

One option is to adjust their supports to minimize risk to others. They need to live somewhere but it does not have to be with other people. They need to do something with their days, but it does not need to be around people who will be subject to their violence. Removal is often the kneejerk reaction to situations like this. It is not an entirely unjustified reaction either. If my relative were subject to this kind of violence I would certainly be inclined to want them to not have to experience it anymore. It could be argued that this kind of reaction is what led to the closing of institutions in the first place. Families did not want their relatives to be exposed to the violence and neglect that characterized life inside of institutional walls.

If you had a co-worker or roommate who was violent towards you on an ongoing basis, how long would you tolerate it? Even if they were remorseful afterwards, would you want to subject yourself to further risk by remaining in an environment with them. Likely not. Removal of the violent actor would be the ideal course of action for the subjects of their violence. In a

population that is systemically traumatized such as people labelled as intellectually disabled though, there would be a great number of people that would need to be removed.

It is also true that the peer who this person wanted to hurt that day has themselves hurt peers and staff from time to time. Their mode of violence was a rather effective pinching technique. Maybe they should be isolated too? This point of view obviously goes no where productive. It is also not acceptable to allow people to exist in ongoing violent situations.

In the environment created by the systems of support currently being enacted, there is little recourse for anyone. The victim of violence must endure the presence of the person who hurt them because there is no other place for them to go. In my experience violence is often viewed as a matter of course for people labelled with intellectual disabilities. It is perceived as an inevitable part of their lives. Within the support industry, surviving violent incidents is often seen as a badge of honour. The stories of the things you have survived serve as a curriculum vitae for you credentials as a support worker. It is, after all, hard to tell the story of the time you went a whole day with everyone being content and peaceful and make a compelling narrative. Reactions are often understated in relation to what they would be if you heard about these situations occurring in any other context.

It is the responsibility of support staff to prevent this violence from occurring. A method that is commonly utilized by support staff is punishment. Often in the form of the removal of a favorite item or activity. Much like a child, an adult labelled with an intellectual disability will have ultimatums placed on them to ensure compliance. An unstructured conditioning program within which a person may lose their *privileges* because of what is deemed poor behaviour. You did this so no that, or if you do not do this there will be no that. Much like the problematic behaviourist methodology discussed earlier but less systematic and more confusing. This system

of punishment is not a method people are trained in. It is a result of people reverting to what they know and have experienced in situations of power imbalance. If you have the power to withhold and have a desired result you want to achieve, then why not utilize this power to get what you want? It is a relationship we see played out again and again in our society. It is in fact a result of the almost total lack of meaningful training that situations like this persist in support work.

5.3 What Does it Mean to be Meaningfully Engaged?

For five years I supervised a day service which is attended by 23 individuals. Every one of them has complex and nuanced needs that need to be met each day. This presents what I consider to be the impossible situation of trying to meet the needs of each of these individuals throughout each day. Not only do I and my colleagues need to address the needs of the people we support, but we also need to consider the demands of the funding body (The Province of Manitoba) as well others within the people's circle of support. Sometimes these interests align, and everyone can work together in a meaningful fashion towards supporting the person to capitalize on their potential. With so many interests to consider though, it is often the case that compromises need to be made to try and accommodate everyone's priorities.

The emphasis of the Provincial funders is often one of being busy. They do not want to look at a life plan (a document detailing the life activities of a person from the last year) and see that they have done nothing or next to nothing over the year. This focus has its roots in an honest concern that people who cannot advocate for themselves will be left to wither on the vine if people are not compelled to engage them in meaningful activities. This has led to a situation where we at the day service felt compelled to have a steady list of daily activities that everyone can participate in and to always be looking busy throughout each day.

This does not sound so terrible on the face of it. Individual choice is important though. This arrangement can set up a situation where the activities take precedent over individual choice to appease the expectations of funders.

This is indeed the situation I found myself in, where it became the expectation to run large, visibly busy activities in the program location throughout the day, regardless of the needs of the people I am supporting. I am of two minds about this. I do feel that great effort is often required to engage the people I support in activities. I also believe that there is great benefit to be had from this engagement. I do not however think that we are set up in a fashion that enables this to occur in a meaningful fashion. This is largely because there are so many individuals to account for in the planning of these activities. There are those who can engage in focused activity with no trouble and enjoy the process. For many though, sitting at a table and focusing on an activity for anything longer than a minute (or even just one minute) is near impossible. Does this mean that they are not meaningfully engaged?

The people who do not enjoy doing 'activities' as they are generally defined, receive far less formal program delivery than those who do. Day services for the population I work with are meant to replace gainful employment for the those who attend. Those who would be unable to be trained in a job still need a place in society to spend their time. We would attempt to provide a space where they can be themselves, feel safe, and be meaningfully engaged in the time they spend with us. This was not always possible, but I feel that we have done a fairly good job of creating a meaningful space with the resources we have. A long-time colleague of mine always says that we want to create a place the people we support want to come. That they have had so many difficult trials in their life that we do not want to add yet another. In many ways I agree with this.

Many of the people who attend the program where I worked lived in one of the two large institutions still in operation in Manitoba at some point in their lives. The horrors of these places have been well documented. The people I have worked with are extremely vulnerable due to their lack of ability to relate details of what has happened to them in their personal histories. Our priority was always to allow these people a safe place where they would not be judged for who they were. As a supervisor I emphasized to staff that they must engage with the people with empathy and understanding. With out this frame for our work we will be facing a constant fight against things we can not change.

When I was a frontline staff, I often became frustrated with feeling compelled to do group activities that generated no interest in me or the people I was meant to be supporting. The people I worked with in this time generally showed little interest in being engaged in this fashion. My solution was to disregard the direction I was receiving from my supervisors. I began to operate within the system of support as a single entity that was a component of the supports but not necessarily integrated. I did not make this explicit. I held the value that I need to be meaningfully engaged with the people we supported. I also took to heart the value of being person centred in the things I was doing. This meant that I could not really engage in large group activities. In my perception, it was not possible for me to be person centred and to be running large congregate activities.

Because I was focusing on one person at a time in a congregate setting, I would most often be working with people with complicated behaviour that did not easily lend itself to working in a group setting. My colleagues and supervisors were happy that these people were being positively engaged. I was content because I was having meaningful connections with the people I was supporting. The people I was working with were happy because in the time I spent

with them they had a huge amount of agency in what we did. A favorite activity of a few people I supported is watching videos on YouTube. I have watched some specific videos more times than I can remember. Failed videos, music videos, and various comedy videos were repeated daily. We would often recite them afterwards to great comedic effect.

I found there was almost always a door you could walk through to find the best aspects of the other person. Whenever I would encounter a person who no staff wanted to spend time with, my curiosity was piqued. I would make tentative approaches to them. I would seek a way into the world they were experiencing and try to walk along side them there. I have repeated this process many times over the years. I always thought of my work as building bridges between me and the person I was supporting. Each interaction was a piece of that bridge. If it was built well then it lasts for years, and both parties can cross it whenever they need to interact with the other.

This was meaningful for me. It appeared to be meaningful to the people I was supporting. For a time, I was able to fill a need in their lives.

5.4 What Happens After?

I am quite confident that I was good at my job as a frontline support. I honestly engaged with the people I worked with. I tried to improve their lived experience in any way I thought of in that time. In the end though, I was making promises I could not keep. I am no longer in the lives of those people in anywhere near as intimate a fashion as I was when I worked with them directly. As often happens when someone is good at their job, I got promotions. I moved from the frontline into management. Eventually I moved to a different section of the agency where I work. I do feel that I was an important person in the life of the people I supported. This makes it all the worse that I am no longer in their lives.

This is an argument as old as disability activism. Staff are not friends. Very few spend time with the people they support outside of the hours they are being paid. Very few staff stay involved in people's lives past the end of their employment in their support network. This must be a consideration when engaging in support work. In the book *Deinstitutionalization and People with Intellectual Disabilities in and Out of Institutions,* Thomas F. Allen shares his story of living in institutions for sixty years. I was struck how he referred to staff in the institutions as his friends on several occasions. He had contacted these friends to help him move from one institution to another, in the hopes of a better existence (Johnson & Trausadottir, 2005). There is a tension in the relationship of a support staff and the person they are working with.

We are very clearly not their friends in any traditional understanding of the word. Yet, it is often true that a person's support staff will be their closest friend. It can be argued that if this is the case, that a support staff is not fully doing their job. In our society there is no clear way to establish natural relationships for people labelled with intellectual disabilities. This must be the orientation of our work though. It is easy to fall into the trap of friendship when you are engaged in support work. It feels like a natural state. You spend more time with the people you are supporting than you do your own friend circle. A support staff is intimately involved in many aspects of the lives of the people they are working with.

One summer in my first job in the field I was out for a walk with one of the men I supported. I had by this time grown close to him and enjoyed going with him for long walks through the neighbourhood he lived in. We would talk some and he would make a variety of observations about things as we passed by them. His favorite topics were girls and dogs. Both topics had the potential to end with us both laughing uncontrollably about the grossly inappropriate nature of his commentary. His ability to produce speech was impaired. He had a

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few words I readily understood, a series of gestures, and illustrative noises with which I was able to have a variety of conversations with him.

On one of these walks, he was adamantly directing me in a specific direction. We had never walked this way before, and I had no clue where we were headed or why. He used the one arm he had good control over to point me in the right direction. We meandered for quite a while until we arrived a row of housing that appeared to be accessibly designed. The doors were all ground entry, and the living spaces were all single stories. I had never seen the man I was supporting so adamant before and I was curious as to where he had led me.

We walked down the row until we arrived at a door. Here he gestured and verbalized adamantly that I should knock on this door. I had some hesitations; I had no idea where we were or who was behind this door. But on his insistence, I walked towards the door. I knocked and waited to see if anyone would answer. Sure enough, a man answered. He used a wheelchair and answered in a friendly and open manner. I asked him if he knew the man I had brought to his door, pointing back to the man I was supporting. He looked around me to where I had left the man I was supporting, at the end of the entry walk. He told me 'no', he did not know him. Then he said something that surprised me. He said we were welcome to come in anyway and spend some time.

This was a moment of tension for me. If this situation had occurred today, I would certainly have gone in and at least spent one afternoon sitting and hoping to find a natural connection for the man I was supporting. A person with a working knowledge of the social model of disability would have recognized this moment as a fortunate tool to deconstruct a barrier in this man's life. Knowing more about the social isolation that is prominent in the

disability community; this chance connection could have been just what both men needed to enrich their lives. I did not go in.

I immediately began to run risk assessments in my head about the issues that may arise from me going into this stranger's home. This was a completely foreign environment where I had no control. After learning that the two men did not know each other I decided to leave. From the moment he realized he did not know the person living behind that door the man I supported looked disappointed. I felt this disappointment in my gut. He was so sure, so energized by the possibility of his actions leading towards whatever connection he was anticipating. I can only imagine how he felt when his plan did not come to fruition.

In retrospect, it is obvious to me that I was ill equipped to deal with this situation correctly. Perhaps there was not a correct way to deal with the situation. I wish I could have facilitated a friendship for the man I worked with. I wish I had knowledge of the importance of these connections in people's lives and worked a little more to foster what could been a positive development in his life. I had been working in the field for less than a year though. I did not understand the things I feel keenly now. I also really enjoyed spending time with this man. I thought of him as a friend as much or more than I saw him as a professional relationship. I think this enriched the support I provided him, but it may have also caused me to lose sight of the fact that he rarely had unpaid people in his life. He would see one family member infrequently, but this was the extent of his unpaid social interaction. My self identification as this man's friend dulled the edge of my perception of the things that were missing from his life. This self-identification also motivated me to provide more comprehensive supports to the man and make attempts to enrich his life I may not have without my perspective being what it was.

This leads to the eventuality all too familiar to people living in supported situations, that I no longer see him. I am certainly not his friend now, if I ever was. I still care for him and know how he is doing through people I know who still see him regularly. In the end I was not the person he needed in his life. For the time I worked with him I hope I was a good support. I was not the thing that would stay in his life though. I was transient, as so many others have been. I know that house is fortunate in that there are two staff who were there before I started and are still there to this day. That speaks well for one aspect of the lives of the men who live there. The time it takes to know them has been maintained. I cannot speak to whether that knowledge has been applied in a fashion that is enabling. The missing thing could have been that man in the accessible housing complex. A friendship that would enable an enduring relationship with someone who was in his life simply for the pleasure of knowing him.

This situation happened in 2001. Things have changed somewhat, and social service philosophies have shifted to reflect the importance of agency in the lives of the people they support. I am still left feeling that there is not enough being done to foster this agency and allow it to grow and flourish in whatever direction seems natural for the person being supported. It takes time and education to develop a nuanced personal philosophy of support. It takes time to understand a person with impaired communication. To grasp what it is they may want or need to enjoy their lives.

Natural supports are unpaid people who are involved in the lives of supported individuals. If we examine our own lives though, who are the people we would consider 'natural supports'. Old friends from high school or university. Neighbours from when we grew up. People who shared our hobbies or interests as we moved through our lives. These are experiences that are vastly different for the people I have supported. For them, these connections

are fleeting at best. Perhaps if they have long term staff, they may be able to retain a friendship through the stored knowledge of that staff. When that staff leaves though, the likelihood of that friendship continuing greatly diminishes. If the person is unable to say, "I want to call Bob, here is his number", over time it is likely connections will be lost. I am left questioning whose interest the pursuit of natural supports is in. Is it yet another big idea that will only be achieved in half measure? It is almost comical to say 'we must have natural supports' in the context of the position labelled people have in our society today.

It was often asked of me in planning meetings if the person being discussed has made any connections with their peers at the day service. With very few exceptions I answer 'no'. Is this a grand failing on my part to facilitate connections between the people who attend that service? I suppose that is a possibility. It has always been the case that the people I have supported have sought connection with the staff in the building. This is not an ideal reality, but it is reality. Should I deny it? Put endless efforts into making people who are labelled as intellectually disabled become friends so that they can have natural support? Or should I accept the reality that they are more compelled to socialize with their staff and build a system around that. Given the inevitable staff turnover, this could be a recipe for disaster. What other option do I have? I refuse to not accept people's decisions about who and how they socialize with others. Further to that I have no idea how I would ever compel a person to be friends with another person they have not shown an affinity for.

The lack of natural supports in the lives of the people I have worked with are a symptom of multiple factors. The sustained use of segregated models of support impedes the forging of relationships outside of the intellectual disability community and its adjuncts. This begins in schools and continues throughout the life span of individuals labelled as intellectually disabled.

Unless someone can move from school into unsegregated settings, it is likely they will spend their adult life within the network of support systems. This is well intentioned in the sense that many of these people will need supports throughout their life span.

Initially it seems like a good idea to provide labelled people a safe space in which they can exist. We must accept that every year they spend in these segregated settings is another year they are not forming natural relationships with other people is society. It will be another year that people in wider society are not learning how to make relationships with people who see the world a little differently than themselves. Segregated settings amount to a compounding of lost opportunities. These opportunities can only be recovered if we allow for risk and desegregate all forms of support. To achieve this, we each need to open our lives to people labelled with intellectual disabilities and experiment with the ways their support needs can be met while integrated into the fabric of society.

Chapter 6: What is Within the Support Workers Control?

6.1: The Situation of the Support Worker

For the support worker on the front lines, it can often feel like there is no recourse to amend the practices of your workplace. History, social service agencies and inter-agency squabbles, government priorities, and supervisors all create constraints within which the support staff is ensnared. They must fit their own support work within these systems. I have often had conversations with the staff that I supervise addressing their frustration with their inability to move the dial in terms of the supports they are able to provide to the people we work with. This is a frustration I have on almost a daily basis. I work within an antiquated system that is not too far removed from the institutions they were formed in reaction to. This system serves to protect the people who come to us from the ravages of a society that cares little for their well-being.

I am not satisfied with this, nor are many of my colleagues. In the grand scheme we have little recourse as to the care that is provided for the people we are paid to support. We cannot force governments to fund higher staffing ratios so we can begin to enact true integration into the communities we exist within. We may have some input into our own agencies practices but are helpless when it comes to cooperating agency's practices. It is not within our power to shift the culture to respect and value the lives of the people we support.

What is left for us? Just ourselves. We have total domain over the perspective we approach our work with. This is where our real work is located. We must struggle to deinstitutionalize our thinking and open the door to new possibilities of support that will result in increased potential for the lives of everyone, including ourselves.

6.2: The First Step is Inside

I am sitting with a woman in a kitchen. She is petite with shoulder length hair. She says, "Drink". I repeat, "Drink". This has been going on for more than an hour at this point. This has been going on for weeks. I go through fits of losing my mind, being entertained, and just getting through it because it is my job. "Drink,"… "drink"… "Drink"… "drink". There is only me and one other staff who are willing to play this game with her. It is tedious and mind numbing, no two ways about it. When a staff is unable to keep their focus on her she immediately becomes upset and throws herself to the ground and bangs her head. It is easier to switch off between the two of us who are willing to plat the game. Once this woman becomes upset, it can be difficult to get her settled again.

Her face is directly in front of mine now, her nose no more than two inches away from my own. "Drink" she says, her eyes partly cross-eyed she is so close. I pause for longer, drawing out the moment, trying to find the game within her game. "…drink". She explodes in giggles and spins in a circle. She holds her hands in front of her face, her fingers twitching rhythmically.

At no point was this the thing I would chose to have been doing. It was exceedingly difficult to stay focused and provide the supports that this woman needed. I needed to reframe my point of reference for what was enjoyable about this job. It is true that when she brightened from time to time, I felt happy about having been able to facilitate this for her. I was exhausted by the process though.

This was an extreme situation but, in many ways, it encapsulates my perception of what support work should be. I conceive of support as a human right. This right to support supersedes my desire to not be bored. I am therefore compelled to provide the support that the person is expressing to me that they need. If I am to avoid job burnout, resentment, or loss of interest in

my work I need to perform a cognitive shift. I must move towards the person I am supporting and begin to discover the world through their eyes. In doing this I often find that the person begins to move towards you as well. They can meet you halfway and you can discover different aspects of their personality not apparent at first meeting.

Complex behaviours like this are a form of communication. This person was not trying bore me. This was not 'attention seeking' behaviour. It was the way in which this person was telling me, 'I need this right now, it is the thing that is helping me function'. Accepting this behaviour and not trying to correct or change it maintains the dignity of the person being supported (Friedman, 2020).

The person receiving supports has the right to express themselves in the way that feels natural to them. In the case of this person, the repetition of the word "coffee" was comforting. In some ways it was a request. We had a coffee for them, ready to be drank whenever they wanted it. They would occasionally sip a small amount and then return to the repetition. Their ability to choose to have coffee, however small the amount, was important to them. These interactions suggested to me that the word game regarding the coffee was even more important.

These games are not uncommon. Another person I supported would play a name game for however long you could bear to play it with them. He would call my name "Oh Jooooohnnnn". I would then have to repeat the same phase using his name. We would do this for an hour or more at a time. Another person I worked with had a script he would run through with me based on a series of YouTube videos we had watched together. As we were running through the script, they would correct me whenever I made a mistake in the order or phrasing of the words and actions.

I focus on this repetition because it is an element of the work that many people find difficult. There is beauty inside of these difficult elements of support work. If you make the decision to not be bored and begin to explore these interactions with a curious eye, there is much that can be learned.

You will be unable to do this work well if you cannot get control of your thoughts and actions. Self-awareness and an ability to perceive your own thought processes and how you are enacting different situations will greatly improve your ability to provide meaningful and effective supports (McConkey, 2009). If you are always reactionary to the behaviours and events you encounter in the workplace you will eventually whittle yourself down to a nub. There must be joy and growth within your practice if you are to persist. While this joy can come from the people you support (and often does) it should not be your primary source. This is not fair to the people you are supporting. They have their own struggles and pleasing you should not be one of them.

There are many stressors on support staff. Seeing violent behaviour or experiencing violence against your person are common experiences for support staff. These realities contribute decreased well being of support staff (Noone, 2013).

Earlier I described a situation where I had a prolonged physical altercation with someone I was supporting. It was a very emotional experience for me and exhausting both physically and mentally. When someone is trying to physically injure you, regardless of their ability to do so, your body starts to produce adrenaline. This affects your thinking as well as your physicality. I have seen support staff react to this with more force than was necessary to resolve the situation. Reacting or acting with minimal intervention is necessary to provide supports that cause the least harm possible.

This reality exists in every aspect of support work, not just instances of physical violence. Without a mindful approach you will revert to what you have always done. If it is your tendency to do things for people you feel are having difficulty, you will carry this into your support work. It may seem like you are helping the person. The reality is if a person never has to overcome challenges, they will not grow or learn new skills and will exist in a state of learned helplessness. Further to impeding their ability to reach their potential, learned helplessness leads to increased risk of depression (Reynolds & Miller, 1985).

When considering how to intervene in the lives of people being supported, we must always consider the repercussions of this support. This raises the question of social model considerations when enacting supports. In the case of the physical altercation I described, what are the social model considerations?

There are contributing factors that lead to that specific case, as well as many other less severe incidents with the same individual. The preceding factors are what must be parsed out when attempting to enact supports for people that tend to react violently to their life circumstances. Sometimes these preceding factors are not easy to identify though. Sometimes they are unavoidable. It is often the case that a violent reaction can be brought on by something as trivial as a person not being able to get a thing that they want. A typical response to this would be to say tough luck, you cannot always get what you want. When you are providing support though, this is not an option.

It is true that the person cannot always get what they want. This is true of everyone. However, if a person is focused on getting a particular thing, telling them "no" is rarely going to serve alleviate their wants. With most people, these reactions can be anticipated. It is then the responsibility of the support to put in place systems that take this anticipated response into

account and work to lessen its likelihood of occurring. Supports must provide a path towards any goal a person has set for themselves. It is not up to us to correct these goals or

The systems of support that surround a person are the factor that will disable or enable them. The frontline support staff is the first contact of these systems. They are the enactor of any strategy meant to enable a person's inclusion in society. As a frontline support, we must be vigilant of how we are enacting these supports. We must monitor ourselves to ensure we are providing supports focused on the wants and needs of the person being supported, not ourselves.

If you are unable to have some control over your thoughts and reactions to adverse situations your relationships with the people you are supporting will quickly degrade. Here techniques such as mindfulness will come to your aid. Mindfulness can seem mysterious to those unfamiliar with it, but it is quite simple. You must be aware of your thoughts. That is all. If you are caught in negative interpretations of the events that occur during a work shift and the same occurrences happen repeatedly over time, you will eventually solidify negative notions of your work and the people you are supporting. Being mindful of the stories you are telling about your work and the people you are supporting can greatly change how you perceive your work. One significant consequence of this is that your relationships to the people you support will begin to greatly improve. One study showed that training in mindfulness techniques greatly reduced the instances of physical restraints being used by support staff (Singh et al., 2009).

It has always been my practice when I enter a new work environment to see who is being ignored and see what I can do to get into the world that person is inhabiting. Often these ignored people have a history of violence towards staff. They have found a place where they are able to be happy enough being left alone. Staff have decided that it is better to leave them in their isolation rather than risk provoking a violent outburst. This leaves everyone without a strong

relationship when difficult situations inevitably manifest. The supported person has no path towards their supports to ask for help or express discomfort. The supports have no established relationship to help speak to the person when they are in a heightened state. Further to this crisis model, it is both a loss and an injustice that this person has been given up upon by the very people who were supposed to reach out to them.

This reality is largely a product of the stories that have been told and reinforced by previous supports. These stories are passed on to new staff who enter the person's life. I have seen time and again people interpret the behaviours of the people they support personally. They internalize the behaviour as an attack or rejection of them as a support. This is a story the impoverishes everyone involved.

What story should you be telling yourself? The first is that it is the right of the person you are supporting to have you provide the best possible support you are capable of. If you have and reinforce the notion that it is the person's right to have exceptional supports provided by you (not someone) then you will be much more likely to work past difficulty towards improving the person's life situation. This support should be defined by what the person demonstrates they need. It should not be defined by you or anyone else, regardless of intention.

6.3: It is Better to ask for Forgiveness than Permission.

I worked with a man for many years who was focused on getting his hands (or more accurately, his mouth) on food. He loved food. When he was enjoying a meal, he was audible in his enjoyment of it. He was strong, broad shouldered and exceedingly difficult to redirect if he was focused on getting a meal that was not his to have. There was one instance when a colleague of mine was at a grocery store in the bakery section picking up groceries for the service we worked at. A shopper approached him and asked him, "Should he be doing that?" My colleague

turned to discover our broad-shouldered friend with half of his body inside a display case eating donuts at an alarming rate. This should be sufficient to demonstrate his lack of reservations around eating food he probably should not.

Around lunch time, at the day service I worked at with this man, he was always on the lookout for a chance to eat someone else's lunch. This was a problem in that it is not acceptable for him to get other people's lunches. It was also a problem in that sometimes people have physical reactions to having food they are enjoying taken from them.

This man also had a compulsion to keep the floors clean and free of debris. This was not something that seemed to be within his ability to control. Some of the staff had decided that to keep him from trying to get other people's lunches they would dump a bucket of Lego when he was done his own lunch. This would keep him focused on the Lego while other people finished their lunches in peace. It meant that they would not have to physically intervene to prevent an altercation.

The problem with this scenario, which may not seem so bad on the surface, is that the Lego dumping obviously caused this man distress. Further to that, people started to use the Lego at other times in the day as a means of controlling this man's behaviour. In defense of the staff, this man was large and could be intimidating to deal with when he was in a bad mood. I was not pleased at all with how this situation was developing.

One of the major indicators of institutional thinking is when actions are taken in service of the system rather than the people that system is meant to support. In this case I perceived the Lego dumping as a typical example of institutional thinking. To avoid having to deal with this man's behaviour around food and do some difficult work, staff had decided to take the route of

exploiting a compulsive behaviour to make their jobs easier. This action is no different in spirit than the use of physical or chemical restraints. The person involved has no choice but to clean up the Lego, and the action of dumping it caused him distress. Yes, something needed to be done to prevent people's food from being stolen. In my opinion, exploiting a compulsive behaviour was not an acceptable option.

I approached two different supervisors to address my misgivings about the use of the Lego box to control behaviour. I expressed that I thought it was unethical to continue this practice. In both instances I was told that there was nothing else that could be done and that we needed to stop this person from stealing lunches. It was perceived as an acceptable cost to exploit this compulsive behaviour. It is not that my supervisors were bad people. They were not indifferent to the issue; they just did not see another way forward. If it were a year or two earlier in my career, I would have seen the situation the same way that they did. I had a plan, but it would take focused effort on my part and would rely solely on me to be successful. I informed my direct supervisor that I had a plan and got them to agree to let me try.

My first step was to disappear the Lego box. I packed it up and found a closet in the building that no one ever used, aside from storage. I unpacked the closet, placed the Lego box on a bottom shelf, out of view. I then filled the closet again, rendering the box invisible. My next step was developing a plan with my coworkers to allow me to work with this person at lunch time to prevent him from stealing other's food. This involved having him be the last person to get his lunch at our usual lunch time. He was willing to wait patiently for his lunch at his usual spot. It was only when he finished his own lunch that he sought to get other people's. This gave his peers a good head-start on finishing their own lunches before he was able to finish his.

My next step was to move around the program with him after he finished his lunch to prevent him from stealing other's food. I walked close to him and paid close attention to where his focus was directed. When he moved towards the food he wanted, I would be ready and redirect his attention to another area, or just simply be in the way so that he could not get to the food. I received more than one pinch for my efforts, but I have been pinched so many times that I barely register it anymore. It worked well. I was able to stop the Lego dumping (through subterfuge), and demonstrate that another method was possible, it just required a little more effort.

Within the system I was operating and my own awareness at the time this situation occurred, this is likely the best-case scenario. There are institutional elements to this story I have become more attuned to over the years. Why, for example, do we all eat at the same time? In many ways it makes the job of the staff easier. It makes planning the day easier as we can put lunch related activities inside of a one-hour block. It tends to look and feel like a chaotic situation where no one is really relaxing and enjoying their meal though. In a congregate setting such as a day service there are many compromises that need to be made to accommodate the system and keep the program running smoothly. These compromises are made at the sacrifice of individual preference.

There is currently no better option for the people supported by the kind of day services I have spent my time working in. As I stated before, the people we support are not accounted for in advocacy campaigns. There is no space for them in society that they could step into should the day service be shutdown. A great deal of work needs to be done in this regard if we are to create a more inclusive society for these people.

Given this, it is incumbent upon current supports to deinstitutionalize their practices where they can and as they perceive a practice to be disabling. We must constantly be seeking new ways to allow for individuals to be who they are, without judgement or seeking to fix them. It is not always apparent to people who have existed within our current systems of support that their practices are oppressive or disabling. We must allow for experimentation and new practices to be developed to displace these old models of support. The only way to do this is to let go of notions of sameness that persist within support circles and allow new ideas to percolate.

This situation with the Lego is a hyper-localized example of a practice that had become entrenched but needed to be changed. Removing the Lego box as a possibility made it possible for us, as supports, to question our practice. We can then revise as needed within this new system devoid of the Lego box. This would not have occurred if I had gone with the flow and let what was occurring continue just because it fulfilled a need and kept the peace. The support industry needs to examine its Lego boxes and determine which are disabling and which promote agency and dignity for the people they work with.

It is important to remember that, generally speaking, no one sees themselves as the bad guy. If you feel that the supervisor or agency you work for is holding back the people you support, there is likely a seemingly reasonable explanation for why they do things the way they do. It is also important to remember that it is quite easy for people to get stuck in their ways. When someone finds a system that has generally worked to protect vulnerable people from harm, the prospect of introducing risk into that system can be terrifying. Most people who work as supports care deeply for the individuals in their care. To put an aspect of their safety at risk for an intangible gain can seem like a fruitless effort to long time support staff.

These risks increase with each new person that encounters the person being supported. There is no way to fully mitigate risk when dealing with people. There is also no way to enrich the lives of people in supported situations without engaging new people in the circles of support that surround them.

In the immediate vicinity of the day service I supervised, there were several other day services within walking or driving distance. It occurred to me one day that perhaps this may be a fruitful path to travel to expand the social circles of the people that attend the place I worked. I had little luck facilitating relationships between the people who attended. I thought other day services who specialized in supporting people with different needs than the people in my day service may prove fruitful in developing relationships. When I addressed this possibility with others in my agency it was immediately rejected as being impossible. There was concern around staffing and how we may go about interacting with other agencies with different philosophies of support or different perspectives in how labelled people should be supported. I plead my case but lost in the end.

This is a typical situation of risk mitigation that arises in any number of scenarios. I had my own reservations about this idea. I have supported people who act out physically when frustrated, bored, or in discomfort. It is likely the other day services support similar individuals. How would we explain our motivations if someone was hurt during our collaboration? What if someone witnessed an interaction between a staff and the person being supported that was questionable, or morally unacceptable? What if someone witnessed our own staff doing this? There is an ocean of possibilities that could prove disastrous with this one small effort to improve the lives of the people we support.

Reflecting now I suppose I should have just gone ahead and reached out first, then explained myself later. Not in a major way that would have jeopardized my employment, just in a small fashion that would demonstrate the possibility of the cross pollination. This is one way we can move forward. Testing new ideas that shift away from more conservative supports and seeing what can be gained. We cannot do everything by committee. If there is a good idea out there that holds potential to actualize the ideals we have been espousing since the 1960s then surely, we must try. My idea of interacting with other day services is not unique. It is not the most brilliant solution to the complex issues facing people labelled with intellectual disabilities.

What would be more ideal is find an unsegregated setting to interact with. This would better serve the goal of dissolving the barriers between people living with supports and those who live more independently. Desegregating communities is a large undertaking though. Making a phone call to a group of like-minded people is a small step. It is a step that could lead to others as we build on potential successes. It is also a step that is well within the reach of a frontline staff with little more resources than their own personal efforts. As a frontline staff we must seek these little steps that are within our grasp. We must act when we see the potential to enrich the lives of the people we support. What other choice do we have?

6.4: Reframing Psychology and Intellectual Disability: Accepting the Past and Building the Future

When I returned from a year spent living abroad, I resumed my old job at the day service I had been working at for the previous 4 years. The service had moved to a different building while I was away and there were a few new people being supported there. One of them was a man who had previously lived in the Manitoba Developmental Centre and was now living in the community and attending this day service. For most of the day he would sit in a chair with his

back against one of the large windows that surround the front area of the facility. He would pull a table in front of him and pull it tightly against his chest. He would then sit with his elbows propped on the table and his hands held together, fingers interlaced, and full of visible tension.

If anyone, staff, or peer, walked close to him he would kick at them under the table to ward them off. If a staff persisted in attempting to interact with him, he would push out the table and then chase the staff around trying to hit and kick them until the staff made it clear that they would leave him alone.

Responding to behaviour like this can be an ethically complicated affair. We do not want to leave this man in isolation, though he is clearly expressing that this is what he wants. Is it fair to let someone isolate themselves from everyone? This is not typical behaviour for people. Nothing was ever officially decided in terms of how we would approach this person, but the general attitude of the staff in this day service was that he would benefit from having more positive interactions with us and we need to try and reach through his defensive barriers. His behaviour was expressing that he did not feel safe having people close to him. He would never allow anyone to be behind him and was always vigilantly monitoring his environment in what I assume was an effort to keep himself safe.

As we got to know him and his family better over the years, we came to understand more about his personal history and why he behaved in this way. When he moved into MDC, he was able to have a verbal conversation and speak in short sentences. At the time I knew him he verbalized open vowel sounds but could not speak fully recognizable words. His family believed this loss of language was due to trauma he experienced while living at MDC, and I do not disagree with this assessment. We also learned that he had suffered a traumatic injury after

moving into the community at the hands of one of his roommates. After this, his family insisted on his living alone.

Given this information, a picture starts to form that provides us with a window of understanding into the behaviour of this man. These symptoms could easily have been attributed to his being labelled as intellectual disabled. Had we not been in close and ongoing contact with his family we also would not have had the context for understanding this behaviour. A loss of family is a common occurrence for people who were institutionalized. When family goes, so does the history of individuals who are unable to tell their own stories. They can not tell us stories of how they are feeling, why they are doing what they do, or what they would like to do with their time.

This man's behaviour was in fact a reasonable reaction to repeated trauma. He was defending himself from what he was experiencing as a dangerous situation. It does not matter that he had never experienced violence in our specific environment, he had experienced in multiple environments. As far as he was concerned there was no place that was safe. There are two distinct stages of a relationship that are relevant here. Knowing and not knowing. Your relationship with the person being supported prior to knowing is not just between the two of you. It is between the labelled person, every support staff in their history (likely hundreds if they are adults), and you. Until you differentiate yourself from the pack you will be a representative of that pack. If the person's personal history is largely positive, then the work of building trust will be easy. If the person's history is full of neglect and abuse, then the support staff has a long road ahead.

It took us years of work to build trust with this man. First, we had to coax him out from behind his table. Not by telling him to come out, but by returning to him again and again and

offering him kindness. Letting him know in actions, not words, that we will not hurt him and do our best to ensure that he is not hurt. Then we must convince him to allow us into his personal space. Again, we must convince with our actions and effort over time. Let him develop an understanding that we will not give up on him. At the time he retired from the day service he would repeatedly call out to his favorite staff with his hands outreached. While doing this, he would be vocalizing and trying to form words that were difficult to understand. Within this speech he had a giant smile on his face and would be saying the only distinct word I had ever heard him say, 'Friend'.

It is often the framework of psychology and psychiatry to pathologize the individual. They will look for things to fix in the individual because this is how they are trained to perceive people. When we discuss intellectual disability though this is not an accurate perception of what they are experiencing. There may be a series of behaviours that are typical of labelled individuals. These are just as likely a symptom of being devalued members of society rather than a manifestation of something inherent in themselves. These behaviours are a manifestation of them having been labelled, and their subsequent treatment by their fellow citizens. The label of intellectual disability allows people around the labelled individual to feel justified in subjecting them to differential treatment. Differential treatment that is generally well intentioned but rooted in systemic ableism and an undermining of the value of individual perspectives.

A prime example of this is segregation. Regardless of how segregation manifests, it is always a symptom of the idea that the person who does not fit must be removed. When institutions were in fashion all manner of justifications were used to incarcerate people behind their walls. As this system entrenched itself it then became necessary to maintain numbers to remain solvent as an entity. The same is true of segregated classrooms, segregated adult

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activities, segregated residences. Rather than examine the systems we operate under in society; we simply remove the outliers and continue as if nothing was ever the matter.

Parallel situations are abundant. When an indigenous community decides that they do not want to sacrifice their land for economic development, policing agencies are moved in to forcibly enact the status quo of economic development. Rather than examine the economic models that demand the exponential growth of consumption and industrial development, we label these land defenders as extremists and persist in development, sewing the seeds of our own destruction.

It has been well documented that people labelled with an intellectual disability are at a much greater risk of suffering abuse (Crawford, n.d.; Lindsay et al., 2012; Robinson, 2013). Sexual, physical, and emotional abuse are common in this population of people. This is both horrifying and tragic. It is possible for me to accept the various behaviours I have witnessed without having a good understanding of their causes. I work from the assumption that a behaviour is not the result of an internal flaw. I always begin from the idea that they way the person is expressing themselves can be understood as a reasonable reaction to their life experiences.

Many of the difficult behaviours I have experienced from the people I support are likely a response to their personal histories. Given this, I can attempt to address the possible triggers of this behaviour in their environment. We must acknowledge the external disabling factors that act in people's lives to exclude them from opportunities. This requires a degree of taking responsibility for the supports you are enacting and adjusting them to suit the person. There is no single method that will work to provide everyone with the supports they require. This is helpful in forming a framework of understanding within which supports can build a new world of

possibilities for the people who we work with. This can be difficult, as the behaviour can feel very personal at times and staff may feel they are being personally attacked.

It has been my experience that if a person is exhibiting a behaviour that is destructive to themselves, others, or property they are attempting to communicate something. When people have barriers to expressing, the need to be understood takes over and they seek to draw attention to their problem in any way they can. When these behaviours manifest, I will often approach the person who is exhibiting them in a calm and supportive manner. I will inquire with them what is bothering them and ask if there is anything that I can do in that moment to help them feel better. I am making eye contact, providing any reassurance that the person is comfortable with receiving and waiting for whatever response they can give. The people I work with are not able to verbally respond to these inquiries. I am not expecting them to say, "I have a headache, can I please have a Tylenol." I do think that they need to feel that they are being heard. That someone is attempting to address their concerns.

As a supervisor, I will sometimes use thought experiments to help my staff see that the behaviour being exhibited is communication. Imagine that you have a headache. You are unable to address the discomfort on your own. You need someone to help you alleviate the pain you are experiencing. On the first day you may feel somewhat put off by the discomfort. As the days and weeks wear on though, you will become increasingly frustrated with this constant state of discomfort. How may weeks, days or hours do you think you could live within this experience before you lashed out in some fashion. The pain can be physical or psychological, we all have these experiences. Many of us can describe this pain to someone and they will provide a solution. People who have communications impairments rely on those who know them best to recognize

patterns and know how to alleviate discomfort as it arises. This is one of the fundamental functions a support staff must fulfill.

6.5: Knowledge of Trauma and its Effects

Trauma informed care (TIC) has been gaining momentum as a framework of understanding the behaviour of people in supported settings. Trauma can result from exposure to circumstances where people feel a loss of control, fear, inability to act, as well as a lack of love, and compassion (*Making Sense of Trauma*, n.d.). This framework of trauma is often the daily reality within which people labelled with intellectual disabilities must exist. They are seldom consulted about where they go during the day, who they live with, what they eat, or any number of other decisions people outside of care systems take for granted. It is my impression that without a fundamental understanding of trauma and how it affects the body, a support will be unable to provide effective supports to many people labeled with an intellectual disability.

There has been some success in developing methods to address trauma experienced by people labelled with an intellectual disability (Mevissen et al., 2011), but this does not extend to those who are not able to relate their trauma in any fashion. There needs to be some capacity to express what they are feeling in a therapeutic setting to begin to address the trauma event.

Karyn Harvey estimates that 90% of the behaviours she sees in her psychology practice are trauma-based responses (Harvey, 2012). She states that trauma is pervasive in the lives of people labelled with intellectual disabilities. These traumas are both historic and contemporary. Without knowledge and understanding we will continue to perpetuate these traumas going forward. Systems need to be constructed to minimize or eliminate trauma wherever possible. The simple reality is that no one capable of reading and understanding what I am writing would tolerate the daily reality currently experienced by labelled people. It follows then that it is

unconscionable that we impose this life on anyone. It is true that they are people in need of support. This does not mean that they should be accepting of whatever they get. They should be able to express a standard they are willing to tolerate, and this needs to be respected.

Over emphasis on the behaviour that manifests and attempting to mitigate it, results in perpetuating the trauma responses the individual is exhibiting and missing the root of the behaviour. There has been a behaviourist tendency within the field of support for labelled individuals that is stubbornly persistent. Behaviour modification strategies such as Applied Behaviour Analysis practiced with neurodivergent people present themselves as effective measures to *normalize* people. These 'therapies' can be extremely damaging to the person who is subjected to them. They are also a form of erasure that negates the value of the individual in service of making the rest of us more comfortable.

The responsibility for enacting a trauma informed system of support must begin with the people working most closely with the individuals who have experienced the trauma.

6.6: Shifting the Frame.

There are frameworks for understanding disability that could prove fruitful in re-visioning the place of people labelled with an intellectual disability within society. In Mark Nuttal's analysis of the idea of personhood in the Inuit fishing and hunting village of Kangersuatsiaq, he identifies a significant detail in their conceptualization of disability. It is that disability is perceived as a state of being, rather than a category of person (Nuttall, 1998). The implications of this framework cannot be understated. This shifts the labelled person from a fixed state to a fluid one that will allow, once again, for potentialities within their life choices. The people who would be labeled as intellectual disabled in this culture do what they are able and are given an equal share of the resources acquired by the community. In this fashion

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everyone can be an integrated member of the community, valued for what they are able to bring to the collective. This mirrors the inclusion by necessity seen in large institutions written of earlier.

Nuttal (1998) also identifies an interesting element of intellectual disability, in that the diagnosis also shifts the caregiver from parent to incompetent. Medical professionals will force into question all the instincts that the parent has relating to the rearing of their child .

These frameworks lead to a new model of support that could prove to be a powerful fulcrum for moving the support industry into its next manifestation. To view the people supported by us as being in a fixed state is not an acceptable perception to hold. As my understanding of the work I do develops, it has led me to one conclusion. The only goal of our work should be to render ourselves unnecessary. Even if this goal unlikely to be attained, it should be strived for in any area where opportunity presents itself.

If a person is unable to prepare an entire meal, then allow them to take part in any step they can. If they are unable to dress themselves, allow them whatever agency they can exercise to pick clothing or put part of it on. Any place where the person is disabled, enable them. It may take time, it could be frustrating for everyone involved, but the alternative is stagnation and loss of potential.

After man years working the field, it can all start to feel the same. Day after day we go to work. We do our best help the people we support have a good day. This stance places no expectation on the people we support though. This lack of expectation is extremely disrespectful. It may not seem so initially unless you look at the person being supported as a complete human, not a person with a label. If we perceived them as a complete person, we would have the same

expectations we do of anyone else. We might assume that they want to grow and learn and have new experiences. The rate at which they do these things may be different from others, but it does not mean they do not crave these things.

This is an area where I know I have fallen short in my work. Perhaps due to my work being in a larger group setting, I was always concerned with people having good days. I was afraid that if I pushed them a bit, they may become upset and lash out at myself or their peers. It always seemed better to maintain equilibrium. It seemed better to allow them to do the things they wanted and never expect anything more of them. I was good at drawing people out and forming connections. I was less aware of their needs to feel challenged, gain new skills, and have novel experiences.

When you are inside of the system this maintenance of calm feels right. Some objective analysis of this stance reveals how wrong it is. It has been my experience that after an extended period working in the same location (usually about 5 years), people begin to feel that their work is stagnating. They begin to lose interest and feel that their work is not progressing. I have seen this happen repeatedly. People move on to other work because they do not feel that they have made any difference. This seems to be a natural consequence of people labelled with intellectual disabilities being perceived as unchanging.

6.7: You only have you.

There are countless difficulties that arise within the work of being a support. Interpersonal violence, emotional violence, rejection, socially loaded actions that communicate disrespect. These behaviours seem to be designed to create space between the supported individual and the support. As these difficulties arise there is a choice to be made. There could be an argument made that we should react to these behaviours as we would for any other person.

After all, do we not want the people we are supporting to be socialized in a way that will allow them to integrate into society? The other side of that argument is to accept that these people have had life experiences where these behaviours are a reasonable reaction and defense mechanism to the injustices that have been visited upon them. Both perspectives have merit and can be accessed to form a meaningful and fruitful relationship with the person you are supporting.

In my own experience it has been the best practice to accept the behaviours that create space as a person's attempt to protect themselves from rejection. These behaviours can be addressed in an appropriate manner after trust has been established between you and the individual you are supporting.

It is best to build your support practice in a way that respects the person you are supporting and centres them in your support strategies. This will lead to a reciprocal relationship where you and the person you are supporting are able to grow and learn together. This strategy creates the potential for a enduring and fruitful relationship and joy in your work (Meer et al., 2018). Alternately, if you focus on controlling and supressing these behaviours it will only perpetuate them and cause you stress. It will also devalue the person you are supporting and keep them in the position of an oppressed person.

Regardless of everything else, you only have what you have. This can be added to over time and refined to be better implemented. Like the old saying goes though, wherever you go, there you are. There will be good days and bad days. You may have doubts about the meaning and quality of your work. They key is to remain curious and be honest about where you are at. If you or the person you are supporting have a bad day, that does not need to be repeated. You can express to the person you are supporting that you made a mistake, you were tired, or frustrated. You can let them know you will try and improve. When I have found myself getting frustrated or

upset in my work, I tell the person I am supporting what I am feeling. I tell them why I am feeling it. Assume that they are listening and understand.

6.8: Human Rights are the Foundation.

These suggestions for how the individual support worker can engage in their work are in service of one thing. The ability of people labelled with an intellectual disability to enjoy their human rights. Multiple frameworks exist that identify and support the right of people labelled with an intellectual disability. These include the UNCRDP, Manitoba's VPA, Canada's Charter of Rights and freedoms , and the United Nations Declaration of Universal Human Rights (UNDUHR) (*Universal Declaration of Human Rights*, 2015).

We must ensure that the rights identified by these documents are present in the lives of the individuals we support. When we do so, we will have been able to fulfill the bulk of our work. This is not a simple proposition though. For individuals who are unable to articulate their rights or understand the concept of rights generally, it is the support worker who must interpret how these rights will be applied to the lived experience of the people they are working with. This requires a great deal of analysis and interpretation of how a person can exercise a right. I will include a reminder here that I am not speaking of everyone who has been labelled with an intellectual disability. Many of these people are fully capable of understanding and enacting their rights. I am speaking here of those who can not, for various reasons, articulate or advocate for their rights in a typical fashion. For these people, self advocacy can look different.

Many of the people I have supported have developed communication methods such as physically directing staff to assist them with the thing they want. Other use vocalizations or other behaviours to express joy or dissatisfaction. This may not look like being a self-advocate, but it is. If we do not respect everyone's self-advocacy, we are compounding their disablement. If a

person needs to ask permission whenever they want a drink or a snack it diminishes their humanity. If they must wait and follow a schedule for eating , going to bed, or taking part in their community, it diminishes their humanity. When their humanity is diminished, it is easier to mistreat and oppress them because they are perceived as less than, not capable of making their own decisions.

This kind of control is so pervasive in the culture of support that it does not even seem to be visible to those who have spent time inside of it. When I have questioned staff on why they are restricting the rights of the people they are working with, the question seems so alien to them they are often unable to answer. It usually can be distilled down to the old trope of this is how it has always been done.

We are existing within systems that have changed the language, names, and places around supports, but have failed to inquire if the things we have been doing are of any value. As I stated earlier, these systems are reasonably adept at keeping people safe. Most people labelled with an intellectual disability who live in the community have their own bedroom to sleep in these days. What they can lack is any privacy in that bedroom. They lack agency over their lives and how they want to live them. Without this, they lack the dignity and respect that should be afforded to all people, regardless of impairments. It is not enough to simply say that people labelled as intellectually disabled have human rights, or that their rights need to be respected. This opens us to ableist interpretations of what it means to have and exercise rights.

We must instead interrogate each right as it can apply to the individual. We should inquire as to how they might understand and exercise their rights. We must work within their capacity to understand each right and how it can manifest in their life. This will not look the

same for each person. The way in which individuals will understand and enact their rights will be different.

Key to understanding the enactment of rights is that people are not being *abandoned to choice*. Being abandoned to choice means that a person is having everything they do framed as their choice. If person feels like sitting on the couch all day and drinking cola, then that is their choice. This assumes that that person has had a wide breadth of experiences to draw on to help them make this decision. David Schelly wrote about grappling with this dilemma (Schelly, 2008). He concluded that we must embrace a medical understanding of the person he was supporting to appreciate their differences. It has been my experience that medical framing of individual cognitions only serves to further stigmatize the people it is trying to define. There are some common characteristics between *some* people with similar medical labels. These characteristics affect each person in different ways though. Any step towards the essentializing of a person to a label is a step backwards. Fyson and Cromby articulate this well with the conclusion of their article examining choice, "human rights cannot be made effective unless and until more inclusive conceptions of personhood are accepted." (Fyson & Cromby, 2013)

The enactment of human rights in the lives of people labelled with intellectual disabilities is complicated and requires imagination. You can not simply take them to a voting booth to enact their right to participate in free and fair elections. When people cannot easily express how they want to exercise their rights, people who know them well must examine each right and how it can be meaningful in the lives of the people they support. These people can be staff, family, or self advocates who have similar life experiences to those we support. From the support workers perspective, we must always engage critically in this process. We cannot allow our own inclinations to influence how the person we support chooses to enact their rights. Our role is to

provide opportunity and context for the person and then allow the person to choose in the manner they are able.

Human rights form the foundation of a rich and rewarding life. They should not be neglected in the service of any distraction. Their enactment should always be practiced as they are defined and understood by the person being supported. For people who have had their rights restricted throughout their entire lives, this act in and of itself can prove revolutionary.

Chapter 7: Conclusion

As I have progressed in my career, I have transitioned out of frontline work and into management. In this role I have been a part of taking in new staff and orienting them to their role as a support worker. This is complicated as I have my own way of working and the strategies that I use are not always useful to other people. People walk through the doors of supported settings with the conceptions they have been raised with. These can be good, bad, or indifferent towards the people they are meant to support. It is not always apparent in the interview process how these people conceive of the place people labelled with an intellectual disability should hold in society.

It is my job as their supervisor to illustrate for them the potential of the people we are supporting. I can use words like dignity, but this is an ambiguous term. One that is not easily quantified in practice. It also can be trapped within an ableist ideology of what dignity looks like. I can say the staff needs to promote the human rights of the people they are supporting, but that is also confusing. Which rights am I referring to? Do they all need to be promoted all the time? To effectively advocate for the people I work to support, I must be specific. I must be present and providing guidance. I need to site specific examples for the staff I supervise and help them to see how to better provide supports. Better support strategies are often discovered in conversation. I do not hold all the answers. These supports should always be defined by what the person being supported defines as better. We must begin with the premise that we use the least restrictive practices possible. From here we can discover the potential of the people we are supporting.

We must always approach our work as a collaboration. The primary collaborator must always be the person being supported. They should be the ones who are dictating the actions taken in their life. Subsequent collaborations should be between the other people in the supported

person's life, professional or otherwise, focused on actualizing the priorities of the individual being supported. We must also prioritize the people being supported having as many non-paid supports present in their life as they want.

When I started working in my first support worker job, I had no idea this is what my future would be. Prior to starting that job, I did not even know that group homes existed. It has been a long journey of discovery for me. One where I have made many mistakes. It would not be an understatement to say that I did not have a hot clue what I was doing. It took a long time for me to understand the place I hold in the lives of the people I support. It also took a long time for me to see how to best do my job in a way that served the interests of the people I was supporting. I think I often fell into the trap of doing my job in a way that made it easier (in my perception) and fun for me and the people I was supporting. I do not think my working style diminished the quality of life of the people I worked with. It also did not set them up for long term success.

A few years ago, I was in the neighbourhood of the first group home I worked at. I thought it would be nice to drop in and see the men I had worked with. I wanted to catch up and see how their lives were going. I called and spoke to one of the staff I had worked with. They said that everyone was home, and that I was welcome to visit. I walked up to the house, it still looked exactly as it had when I worked there. In some ways it is a great example of community living and how it can be successful. I knocked on the door and went inside. I greeted the staff who I had spent many hours working with. We had been on multiple vacations together with the men we supported, and I knew her very well.

One of the men heard me enter and called out. He came out of his room visibly irate. He was yelling at me (in a good-natured way). Using his bliss symbol board, he began to grill me as to where I had been. Why I had not come to see him in the last many years. I, of course, had no

good answer to give him. There was no good reason to have not come by. I could have made the time if I had made it a priority. In the time since I had worked with him, I had started a new job and was busy forming relationships with those people. It is not that I had forgotten him, in fact I thought of him and the others in that home often. I was just busy. There was no natural way for me to remain in his life and maintain all the other things I was doing in my life.

This is the tension of support work. You want to be a meaningful presence in the lives of the people you are working with, but you must be careful of the way you are constructing that meaning. No matter how long a support staff stays within the support network of an individual there will come a time when that professional relationship ends. If it is not your intention to remain in a person's life past that end date, you must enact your supports bearing this in mind. There will always be a degree of intimacy, it is inherent in the nature of the work. You are more than just a support staff, but less than a dear friend or family member.

If I had known better, I could have enacted my supports in such a way that when I left that home it would have been knowing that they would all having enduring relationships that I had perhaps had a hand in building with them. I knew them all very well. I could have facilitated a friendship with the knowledge I had of them. Regardless of how friendly we are with the people we support; we are not their friends. The tragedy of this is that we are often the closet thing they have to friends. There is a tension in this that is not easily resolved within our society as it exists today. We have removed many of the precursors to forming friendship from the lives of people labelled with an intellectual disability.

If we are to progress, we must always bear in mind that we are paid to be in the lives of the people we support. This can never be an equal or reciprocal relationship. There will always be an imbalance here that can not be remedied.

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If support structures are not conscious and deliberate in their methods, then missed opportunities such as those I have discussed will continue to occur. This is not to say that life will be terrible for the people we are supporting. There will always be moments of joy.

I cannot imagine how much it hurts to have people continually come into your life and treat you like the most special person in the world only to have them leave after forming a strong bond with you. We must take the time needed to consider our role. We may not all come to the same conclusions, but the hazards of engaging in this work without considerable self-refection will only preserve the status quo. A status quo which is entirely insufficient.

The act of undertaking the process of acquiring a master's degree in disability studies has afforded me the time, and motivation to reflect upon the years I have spent as a professional support. It has allowed me to broaden my perspective of what is possible for the people I support. A social model lens has given me a tool to understand that it is highly likely that I have disabled the people I have worked with. This is true despite my best intentions. The conversations and literature I have imbibed while attaining my degree would benefit every person who occupies a supportive position in someone's life.

This period of learning and reflection is a luxury that is not always present for people who do this work. Especially those who do not aspire to supervisory positions. For most, you begin your work life and keep ploughing ahead, trying your best to follow the directives of the various interests at play. There is little time for critical reflection of how supports are enacted. Further to that, there is little encouragement to engage in critical examination of how supports are enacted at any level. There are also few resources to provide objective analysis to determine if the supports being enacted or sufficient or correctly focused.

The strategies I have outlined in chapter 6 of this writing are the ones that have worked for me. As I have stated though, what works for me does not always function in the same way for others. To summarize the fundamentals that have led me the strategies I have employed I would like to end this writing with a series of recommendations that would form a strong foundation for improving the quality of supports in people's lives.

7.1 Recommendations

i. Reflexivity:

I would recommend that we incorporate an element of reflexivity into our regular practice as professional supports. This can manifest in different ways, but it must be a regular and ongoing process for every level of a person's support circle. If you are a supervisor, take the time to question the decisions you have made, and the practices being enacted. Honestly consider in whose interest you have been acting. It is only by placing a critical lens on our work that we can improve our practices. The metric for this improvement must be the lived experience of the people we support.

A useful tool to begin the process of building a reflexive practice is Human Rights Committees. These committees can be comprised of staff, supported individuals, and external people with knowledge that would serve the committee. An excellent resource for starting a Human Rights Committee is the book *Human Rights Committees: From Compliance to Cultural Commitment* (Baker & Tabor, 2016). These committees exist to examine the supports being received by people. They can offer an objective analysis of how people are being supported. They can also act as a tool to educate members of a support network about the rights of the people they are supporting. For the people on the committee who been labelled with an

intellectual disability, they can serve as a tool of empowerment, where they can have a say in what supports are being enacted in their lives.

While a Human Rights committee is an ideal tool for reflexive practice, it is not the only possibility. At the level of the support worker, a staff can be reflexive on an ongoing basis simply by engaging in honest inquiry about why they do the things they do as a support. If it is common practice to administer medications in response to a behaviour, ask if it is the best thing for the person receiving the medication. If a person has a series of restrictions on what they can do with their time, question whether these restrictions are necessary. Staff must inquire as to whether there is a better way to address the concerns that the restrictions are attempting to mediate.

It is often the case that things are done in a certain way simply because they have always been done that way. If staff teams question the validity of the strategies of support in place, they will often find that a much less restrictive practice is possible.

The individual staff can start with just one restriction. Interrogate it thoroughly. Find a less restrictive practice and demonstrate its success. From here we can start to build a practice of emancipation that will influence the practices in the homes of the people being supported. We can also discover the places and practices that enable a rich and meaningful participation in society for all people who have been labelled with an intellectual disability.

ii.   The Person Defines What is Valuable.

Extending from developing a reflexive practice, supports must be vigilant in allowing the person being supported to define what is of value in their lives. We must seek to minimize the effect our own personal values have on the lived experience of the people we are supporting. If

we look at the practice of respecting human rights, a staff can infer from the actions of the individual being supported what rights are important to them. It is not always a straightforward process identifying what is of value to a person. It is also complicated finding ways to act on those values once they have been identified. If a person has had their agency limited throughout their lifespan, they may even have difficulty taking strides towards enacting their values.

It is incumbent upon supports to develop systems and practices that will honour any expression of value from the person being supported. The evaluation tool, Personal Outcome Measures (*Personal Outcome Measures | CQL*, n.d.), identifies many areas of a person's life where they can decide what they value in a given area. To take the common example of healthy living, within this tool it is up to the person receiving supports to define what good health is to them. They define their own concept of good health. Using this specific tool, it is then up to the supports to help this person in realizing their individualized definition of health. It should also be stated that that definition can change based on the person's own inclinations.

It is not for support staff to decide whether a person is eating too many chips or not getting enough exercise. The support staff's role is to try and provide enough information that the person is making an informed choice. After this the person should dictate the direction their life takes.

iii.   Power Resides with the People Being Supported.

It is easy to deceive ourselves into thinking that we know what is best for the person we are supporting. The more pronounced the impairments to communication, the easier the deception. The fundamental reality is that we do not know better. The more pronounced the communication impairment, the less we know. Supports must relinquish the notion that we are in charge. We must give away any power we think we hold to dictate the direction a person's life will take. It must be our constant task to seek out the places where the people we support can enact control

over their life's course. When we find these places, we should encourage them to take whatever control they are able to.

Again, this will look vastly different depending on the person involved. For some it may be having power over smaller choices, such what juice they want to drink. For others it could be facilitating their role as a self-advocate, allowing them to build a better future for themselves. The way this ceding of power manifests is almost irrelevant. What matters is that we acknowledge where the power should be and foster its growth. We are not caretakers. Our role is not to simply ensure that people are free from harm. Our role is to facilitate growth. To allow enough space and resources for the people we are supporting to fully actualize their potential.

Ideally a support staff should exist as a resource in a position of service to the person they are supporting. Depending on the person, this can require a great deal of careful observation and application of informed intuition. No matter how difficult the task, we must apply ourselves to it. Without this effort there will be no hope for change.

7.2 Final Thoughts

These recommendations, like the rest of this writing could easily exist as a living document. They can function as a strong set of fundamentals for a support staff to adhere to. Aside from the demands of handing in a thesis to receive a degree, the thoughts in this writing and the experiences that led me to them do not have a conclusion. Each week I spend working as a support for people labelled with an intellectual disability, I gain new insights into the complexities of the work. I form deeper understanding of the possibilities for the people I have worked to support. I also gain a keener insight into the barriers to inclusion that the people I support face.

The strategies I have discussed in this writing will not seem unfamiliar to people who worked the field of support long enough. Versions of these recommendations have been known in the culture for a long time. What is missing is the capacity to have new staff entering the field understand and enact the strategies that have been shown to be successful. I have encountered various elements of each recommendation in a variety of trainings I have taken over the years. The knowledge of what needs to be done is not the missing piece. We know what the problems are, and in a general sense, we know how to solve them. What we do not have is the strategies or the means to enact them in a meaningful way. So much of our time is spent managing the various minutiae of support that we can fall into the trap of losing sight of the purpose our work should hold.

To survive for a long time in the field you must be able to hold two realities in your mind simultaneously. The first reality is society as it currently exists, with its many faults. This reality is far less than ideal. For many it has created a lived experience that most of us in society would consider intolerable. The other reality is the ideal we wish to see manifest in the world. This reality has enacted emancipatory practices that provide people labelled with an intellectual disability the capacity to have agency over their lives and live as they see fit. Wholesale rejection of the first reality will result is exhaustion and end your dream of a better world before it has even begun. Losing sight of the second reality will result in settling for a status quo which is unacceptable.

You must not allow the challenges you will inevitably experience as you move through a career as a professional support to dampen your drive to improve the lived experience of the people you support. You must protect the spark of inspiration that drew you to this kind of work.

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Shield it from the winds of apathy and indifference. If enough of us begin to work together, we will be able to shift the culture in a more inclusive direction. These victories are not often won in grand gestures and sweeping change. They can be won with allowing someone to choose what they will have for dinner. They can be won by letting someone try something difficult, even if you think they will fail. I have met so many bold and passionate professionals, families, and people labelled with an intellectual disability in my career. Each one of these people engaged in deconstructing the barriers that were within their view. We must keep learning from each other, using our collective wisdom to shift the culture.

We must listen to the people we are working to support. They are the experts in what is needed in their lives, and they are showing us the way.

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