

**Challenging Categories: An Ethnography of Young Adults with Down
Syndrome in a Community in Ontario**

By

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**A thesis submitted to the Faculty of Graduate and Postdoctoral
Affairs in partial fulfillment of the requirements
for the degree of**

Master of Arts

in

Anthropology

Carleton University

Ottawa, Ontario

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Abstract

This thesis explores the impact that being categorized into a specific category of disability has on the lives of a group of young adults with Down syndrome in Ontario. It is an ethnography of young adults who attend a community-based day program and the staff and guardians with whom they regularly relate. It also tracks the influence categories of intellectual disability have had historically, and currently have, on the lives of individuals with Down syndrome. It shows the ways in which the participants are complicatedly resisting a disabled, Down syndrome identity, and the ways in which the program is both complicit in and in resistance to the limitations imposed on these individuals. This thesis ultimately points to the ways in which social perceptions, power relations, and widely held understandings of Down syndrome largely determine the opportunities and experiences of people categorized as having Down syndrome.

Acknowledgements

While there are many individuals who have supported me as I have completed this thesis, I first and foremost need to thank my older sister, Gemma. She has been both the inspiration and driving force of this thesis. She is my biggest cheerleader and best friend. She is an intelligent, witty, proud, optimistic, compassionate, and motivated person, and witnessing the successes and barriers she experiences as a young woman with Down syndrome has been the primary motivation for this project. She supports me unconditionally and I love her dearly.

I owe a great deal of gratitude to my supervisors, Alexis Shotwell and Jen Pylypa. Without their support, knowledge, insights, and expertise this thesis would not have been possible. I feel very lucky to have had a committee made up of female academics whose approach I both respect and admire.

I would like to thank the program for hosting me. Additionally, thank you to the participants at the program for sharing their days with me, and the participants' guardians for making time to meet with me. The work the program is doing is both unique and incredibly important.

Finally, I would like to thank my parents for supporting me unconditionally throughout this process. Particularly, my mother, Janie, who has spent countless editing papers and being my emotional support throughout my academic degrees.

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Chapter 1: Introduction

When I began fieldwork at a day program that facilitates employment and integrated, daily lives for young adults with Down syndrome, I planned to explore the ways in which the young adults conceptualized themselves as well as their knowledges, skills, and capabilities. However, after spending two months at the program gathering data and sitting down to write about my findings, I found that my goal changed. While I still focus on the experiences of the young adults I worked with in this thesis, my priority is to show the ways in which their daily lives are shaped by their categorization as individuals with Down syndrome. I still aim to explore their self-conceptions within or outside of a Down syndrome identity and the ways in which that imposed identity shapes and is shaped by their lived reality. However, my experience with the program and its clients also led me to explore the ways in which their medical positioning, social positioning, and the specific positioning within the community and the program all come together to create a particular experience of what being categorized as having Down syndrome looks like for individuals.

In this thesis, I will track the social relations, assumptions and implications tied to their identity, and the power relations that further contribute towards their lived experiences. I aim to do these things as a means of understanding what exactly being a young adult with Down syndrome means for these individuals. I will discuss the major actors and actions that contribute towards the meaning of having Down syndrome for my participants.

I chose to focus on young adults with Down syndrome for a number of reasons. First, my older sister by 16 months is a young adult with Down syndrome. She attends

the day program where I did my research, but was not a participant in the project, although she is mentioned occasionally within this thesis. As a result of growing up with her, the implications of her categorization and the barriers she experiences have always been sources of frustration for me. Experiencing her intelligence, wit, complexity, and passion have been positive, central aspect of my life. She is the biggest source of my desire to do this research.

Second, individuals with Down syndrome are often left out of disability activism and research. They are a significant portion of the population of people with intellectual disabilities, but they are often either the source of biological research or ignored in favour of autism research. Additionally, while their presence in the media and general recognisability results in the majority of people recognizing the disability, the general public are often ill-informed and unaware of their lived realities. I frequently have people tell me they “don’t know much about Down syndrome,” and react with surprise when they find out that the participants of this project work, read, and are learning to cook.

Third, individuals with Down syndrome occupy a unique category. Their disability has been biologized and medicalized through the identification of trisomy 21. Their disability is associated with both physical characteristics and intellectual capacity. They are targeted for pre-natal abortions, but are also widely represented as universally cheerful, happy individuals. They also have a variety of experiences. Individuals with Down syndrome have varying cognitive capabilities and different individuals may be sub-categorized as high or low functioning. Their social skills, interests, talents, motor skills, and clarity of speech vary. They also have varying experiences of health: some of

them may have heart defects, lung problems, sleep apnea, or childhood leukemia, while others may have no health issues.

Their category, then, is complicated. However, trisomy 21 and the physical indicators of the syndrome solidify and stabilize their abnormal categorization and assign their membership to the category. That they have the same chromosome-based syndrome that has been named “Down syndrome” is not contested, but what having this syndrome means for their lives, experiences, and identities, and what it should mean, is certainly contested by this thesis.

In order to do this, I think it is important to first define how I understand the ontology of Down syndrome. I understand the category of Down syndrome as varied and unstable. By this, I mean that I acknowledge that there is a dominant understanding of Down syndrome which has been shaped by centuries of historical factors that contributed towards the creation of the category. This dominant understanding is held as relatively stable by the culturally prevailing ideologies of the biomedical system, the Canadian education system, and general Canadian culture. I argue that there are power relations involved in the conception of the category of Down syndrome that have shaped and continue to shape the experience of the syndrome for those who are diagnosed. Once applied, the category works to both enable and disable those with the syndrome. I contend that the diagnosis of an individual with Down syndrome places a set of inherent assumptions, expectations, and limitations on the individual. These significantly influence the individual's social and cultural positioning, resource access, and self-conceptions.

I take up Bowker and Star's (1999) social categorization theory in which they explain that the enforcing and spread of categories and standards involves negotiations of force; that is, apparently universal categories are the "result of negotiations, organizational processes, and conflict" (1999:44). So, while there is a dominant understanding of the ontology of Down syndrome, this is the case because it has been constructed and held as stable by these dominant forces, and so the ontology can be understood as much more varied and unstable than it is presented by the medical and education systems. There is no one universal experience of Down syndrome and it does not mean one universal thing. By this I mean that while having Down syndrome may currently mean experiencing certain learning difficulties within the dominant education system, experiencing particular co-morbidities of health, and being born with an extra twenty-first chromosome, for those who have the syndrome it may also mean excessive disciplining, atypical limitations, frustration and unnecessary barriers within a social reality and disabling society that creates obstacles for them, or a variety of other things. This thesis attempts to track the meaning of having Down syndrome for a group of young adults based on their understandings, the understandings imposed upon them by the program they attend, and the hegemonic understandings held by Canadian society.

That a dominant understanding of the category exists and is held as the universal, stable understanding of the ontology is important. If medical, educational, and political professionals are all in the powerful position to determine how these categories are understood and used, then the desires, experiences, and social contributions of individuals with Down syndrome can easily be erased and ignored. I am curious about the impact that this cultural positioning has on these individuals and their ability to effectively

undermine their social position and reduced humanity, and their rights to social space, life, and flourishing.

Background to the Research

I intend to use Bowker and Star's theories about social categories in *Sorting Things Out: Classification and its Consequences* (1999) as a means of thinking about the creation of categories like Down syndrome and the work that these categories do. Bowker and Star are interested in the invisibility of categories. They believe it is important to explore how categories are both made and kept invisible, and how invisibility of categories impacts or allows for the ordering of human interaction. They emphasize the importance of looking at how it is that wide-scale classification decisions have been made. They also argue that categorization carries with it a particular ethical agenda, in that each standard and category "valorizes some point of view and silences another," (Bowker and Star 1999:4) and that as categorization is an ethical choice, it is necessarily also dangerous (Bowker and Star 1999:5). They acknowledge that since classification systems do not work for everyone, it is important to understand how "standard narratives which appear universal have been constructed," (Bowker and Star 1999:41) which is one of the major aims of my thesis. They explain that "negotiations, organizational processes, and conflict" (Bowker and Star 1999:44) all contribute towards the construction of categories that appear to be universal. They point out that while information infrastructures are largely invisible, they are never invisible for everyone, and can instead act as barriers for some (Bowker and Star 1999:33-34). Within the decision process of creating classifications come choices of what is made visible, given that there are both advantages and disadvantages to being visible in a given system, and to what degree

(Bowker and Star 1999:44). Bowker and Star point out the politics in the design of classification systems, but they also allude to the inherent power in the creation of categories and standards.

Bowker and Star call attention to the importance of doing ethnographies and historical studies of classification systems in use (1999:323). They explain that classification systems which are embedded into working infrastructures are at risk of being black boxed making them both potent and invisible (Bowker and Star 1999:325). They argue that the individual's life trajectory is “twisted and torqued” (Bowker and Star 1999:324) by classification. This idea of torque is explained by them as the experience of the system breaking down and not functioning for the individual. It is important, then, to explore how classification systems are built, changed, stabilized, embedded, and made universal, while also uncovering how they act on and shape the experience of the individual being classified. Understanding how the category of Down syndrome was created, shaped, and changed over time is one of the primary goals of my literature review.

Ian Hacking (1995) also offers a useful means of thinking about classification through his ideas about looping effects in the chapter “The Looping Effects of Human Kinds.” He begins by explaining that the human kinds he is using to think with are the systems of classification of kinds of humans. He argues that these human kinds are loaded with values; they have intrinsic moral value which separates them from the normal, making conceptions of normalcy crucial to the creation of deviant kinds (Hacking 1995:367, 371). Human kinds become inherently descriptive and evaluative through their creation in contrast with normalcy, in that the kind “differs from the usual”

just by being a kind, and so “differs from what is right” (Hacking 1995:372). Kinds, then, have typically been classes of deviants (Hacking 1995:367). They are either something people want or do not want to be based on their inherent moral value, and so they are often medicalized as a means of stripping them of their moral value (Hacking 1995:367). This moral value separates human kinds from natural kinds.

The human kind the individual is placed within “affects the field of possible intentional actions,” (Hacking 1995:368) and enables people to redescribe their past to fit their current human kind classification (Hacking 1995:368). So, for Hacking, the act of classifying people “works on people, changes them, and can even change their past” (Hacking 1995:369). This understanding of classification builds towards Hacking's explanation of the looping effect. This is a dynamic process in which classification creates behaviour changes which creates feedback causing the classifications to be modified and reformed, creating changes in the kind's behaviours again (Hacking 1995:370). Hacking emphasizes that even when kinds are biologized, for example understood as genetically-based, they are not immune to looping. When the cause of kinds is re-understood, a reorganization of kinds may occur. This re-sorting is called “wandering,” and is something Down syndrome as a human kind has experienced a great deal. Hacking allows for a theoretical conceptualization of the ways in which the category of Down syndrome has been defined as abnormal, and so became a human kind, has been wandering throughout history, and has experienced looping through the changing scientific knowledge claimed on it and through new theories inducing “changes in self-conception and in behaviour of the people classified” (Hacking 1995:370).

In her book *Animacies* (2012), Mel Chen offers a means of thinking through the implications and work of categories and standards. She explores the concept of animacy which she uses to interrogate “how the fragile division between animate and inanimate – this beyond human and animal – is relentlessly produced and policed and maps important political consequences of that distinction” (Chen 2012:2). Through thinking with animacy, Chen is taking up ideas about liveliness and scales of being alive, and so relies on an assumed animacy hierarchy which is implicitly invoked through language and classifications. This animacy hierarchy can be basically understood as placing humans at the top as the most animate, followed by animals, insects, then plants, rocks, and objects. However, Chen argues that these categories are less static than this hierarchy assumes. Chen's discussion of animacy becomes particularly provoking when she uses it to talk about bodies with disabilities and their perceived animacy. She argues that unproductivity through impairment is enough for another human to view a human with a disability as dead, through “denial of disabled existence, emotional life, sexuality, or subjectivity” (Chen 2012:210).

Anne Fadiman's ethnography *The Spirit Catches You and You Fall Down* (2012) offers a useful example of impairment being enough to cause a disabled human to be viewed as dead. Lia, the sick Hmong child living in California, who is at the centre of the ethnography, has an extreme seizure which leaves her brain severely compromised, and on the verge of death. In spite of this, her parents bring her home from the hospital, care for her, and she continues to live, grow, eat soft food, cry, and be the favourite child of the family until she dies as an adult, although she has lost the ability to communicate, see, move, and shows no sign of conscious thought. Given this, the American medical staff

who dealt with Lia's seizure disorder for 4 years refer to the final seizure as "'Lia's demise,' or 'what may have killed Lia,' or 'the reason Lia died'," even though they know that she is not dead (Fadiman 2012:256). Despite the fact that Lia is alive, and her parents and social workers view her as living, her "vegetative state" makes her seem inanimate enough for the medical community to consider her dead (Fadiman 2012:257).

Most usefully, I think, Chen argues that people with disabilities, particularly through their medicalization, occupy a "rather strict container and a subhuman locus on animacy hierarchies" (2012:212). So, people with disabilities are placed beneath non-disabled people on an animacy scale, allowing them to be dehumanized and acted on as inhuman subjects (Chen 2012:212). The categories people with disabilities are placed in take up and convey the de-subjectified, dehumanized, and objectified position, allowing the categories to adopt pejorative, negative associations, to be used as dehumanizing insults to non-disabled subjects, or differently disabled subjects. This then creates a hierarchy of disabilities based on perceived animacy at which the "vegetable" who lacks mental capabilities is at the bottom and understood as least animate, and is conceived as an abject subject, a position on the animacy scale to be avoided and feared (Chen 2012:40).

Chen argues for the political and social importance of these categories. In taking up the use of vegetable to describe people with a loss of mental capabilities, she explains that the term informs what "proper humanity resembles – nonvegetables – and, further, that humans *could* in some way become vegetables" (2012: 41). She continues that the term describes what a discredited human is like: vegetables, which are not quite at the bottom of the animacy scale, as they are not stones in that they nourish through

consumption (Chen 2012:41). Through the use of the term vegetable to refer to particular humans we are also informed about how vegetables should be understood: “vegetables cannot think; they are passive; they merely survive; they are dependent, not freestanding plants, but partaking of plants' nutrients” (Chen 2012:41). So, through medical professionals’ and the larger public framing of a human as a vegetable, rather than a “severely disabled” human, particular politics and legal consequences are able to happen. Professionals in powerful fields like medicine are able to position lives as inanimate, and so inhuman, and in that, act upon them in particular ways (Chen 2012:42).

Chen uses this case to explain that, “language users use animacy hierarchies to manipulate, affirm, and shift the ontologies that matter the world” (2012: 42). Language, and by extension categories, then, have important implications for the individuals to whom they are applied. Through politicians, doctors, and other powerful actors invoking animacy hierarchies through comparisons to plants or animals, or through understandings of animacy as rooted in the brain and in capabilities of conceptual thought, or through connections between productivity and levels of animacy, the categories used to group people with disabilities take up and reinforce the animacy hierarchy. This places individuals with disabilities in subhuman positions, dehumanizing and de-livening them, which has important, dangerous political and life-based implications for them. As Chen asserts, “if animacy gradations have linguistic consequences and linguistic consequences are always also political ones, then animacy gradations are inextricably political” (2012:55). How these categories are created, used, and understood, then, is crucially important to explore and make visible.

Finally, Ladelle McWhorter offers a means of thinking about the political and social implications and larger moves being made when new categories of people are created, means of managing them are established, myths are positioned as facts, and abnormality is attacked. Through her book *Racism and Sexual Oppression in Anglo-America: A Genealogy* (2009), she tracks a genealogy of modern racism, showing how the term ‘race’ changed from meaning one’s “heritage or tradition” to meaning one’s “visible corporeality,” that is, their physical appearance and “biological inevitability” (McWhorter 2009:63). Within her genealogy, McWhorter takes up Foucault to show how knowledge about something can be developed, can influence cultural conceptions, and can be used to create new classes of deviants and types of abnormality (McWhorter 2009:176-184). Through this, she shows how ontologies such as race can significantly change meaning and be used as a politics of power to create and re-determine the meaning and use of human categories. She explains that a genealogy of race, or intellectual disability, not only accounts for “the emergence of things,” but also “destabilizes the very things it accounts for by showing how contingent they actually are” (McWhorter 2009:52). Tracing a genealogy of these seemingly stable categories and norms “robs them of the basis for the claim to be natural, simply ‘given’, or universal,” and in that exposes the “networks of power that invest and deploy” these norms (McWhorter 2009:51).

She links the political and social attacks against African Americans during the 19th and 20th century with attacks against the civil rights of people with disabilities and LGBT people during the same periods. She shows how management of those categorized as feeble-minded in the early twentieth century interacted with white supremacy,

scientific racism, and campaigns against sexuality in America at the same time (McWhorter 2009: 167). She explains that attacks on the feeble-minded would have also been attacks on African Americans, and that while different “disciplinary schemes” were established for “inferior whites” and “inferior races,” the containment, monitoring, and aggressive management characteristic of these schemes impacted both groups significantly (McWhorter 2009:167). She refers to campaigns against the feeble-minded as “intellectual segregation” and links these to the general campaign against deviant and excessive sexuality that was developed for, and publicly understood as for, the benefit of white supremacy (McWhorter 2009:164, 168).

Present Context

While I intend to outline the historical creation of the ontology of Down syndrome, the historical experiences of this population, and the current experiences of torque they are coming up against in a subsequent chapter, I think it is useful to briefly outline some of the core issues and experiences concerning these individuals currently. By setting up the present situation experienced by many young adults with Down syndrome, including the many instances of torque and friction they may come up against, I will be able to establish the social context in which my fieldwork took place, and the reasons why exploring this populations’ experiences is crucial.

A significant barrier and experience of torque for individuals with intellectual disabilities in Ontario is the ways in which they are managed and treated by the Ontario Ministry of Education and the Catholic and public school systems. Parent groups have advocated for the mainstreaming of these individuals, and as a result they often have access to both segregated and included education. However, due to their categorization

within the system, they are prevented from accessing the full benefits of completing secondary school. People with Down syndrome are generally rendered ineligible for a high school diploma. As a result, although they have technically completed secondary school, and generally spend between five and six years as secondary school students, they are not afforded the typical grades or signifier of completion that an average secondary school student is awarded. The consequence of this is that they are at a further disadvantage from the inherent disadvantages they experience through the stigma and assumptions that accompany their visible disability when attempting to prove their capabilities to a future employer.

That the education system does not set up a young adult with an intellectual disability well for work is crucial, as finding a meaningful job is particularly difficult for adults with intellectual disabilities (Maguire 2009:113). Sarah Maguire argues in her article “Getting into Employment” that despite “task force after task force, initiative after initiative, policy after policy, people with intellectual disabilities are still finding it hard to get a job” (2009:114). She explains that the historical separation of people with intellectual disabilities into long stay hospital wards, separate activities, and segregated schooling have created a lack of understanding about the contributions young adults with intellectual disabilities can make and about their “capabilities and aspirations” (Maguire 2009:115). In this context employment is not a solution, but rather a “vital factor in building a healthy community,” in that excluding people with intellectual disabilities from the opportunity to work prevents them from fully participating in society (Maguire 2009:115). So, Maguire explains, supporting people in working can “contribute significantly to fostering social cohesion and involving people in their communities”

(Maguire 2009:115). Work, then, is directly connected to feelings of inclusion within the community for young adults with intellectual disabilities, as well as being connected to community awareness of the skills and abilities of these young adults, making the accessibility of employment and increasing awareness about the successes of paid employment of adults with intellectual disabilities crucial to the lives of these individuals (Maguire 2009:118).

However, it is important to note that while inclusion in work is central to community inclusion for this population, the central reason for this prioritization of work for inclusion is that these individuals are living in a capitalist society which requires an individual be quantifiably productive in order to be attributed social and individual value. Critical disability scholars such as Deborah Stone argue that the category of disability was created to function to excuse those with disabilities from the labour market, whether these individuals wish to be excused or not (1984:73). Stone argues that disability became a “*formal administrative category* that determines the rights and privileges of a large number of people,” where specific classifications such as “legal blindness,” position the individual experience of disability into an objective category which legitimizes the individual’s claim for social aid and work exemption (Stone 1984:27). Stone identifies that the problem with disability as a category is that there is no set validating device, no certain knowledge obtainable on the individual, that can ascertain their belonging to the category, as disability is not universally the same and as some physical and intellectual disabilities can be falsified causing the category to be “based on a perceived need to detect deception” (Stone 1984:23). Stone importantly concludes that there are several key factors that have made the category of disability inflexible, or, in other words, stable.

First, as programs and legislation for managing the disabled mature, pressure develops to make the categories of disability used less vague and more precise (Stone 1984:189).

Second, standards of disability work through legal presumptions about entire categories of people, and once these legal presumptions are made they are difficult to undo (Stone 1984:189). Third, once individuals are “categorized as disabled, they become socialized to that role” (Stone 1984:189). Fourth, once “both the medical profession and state bureaucracies” label a condition as disabling, the public is educated to “believe the condition is actually disabling” (Stone 1984:190).

Instances of torque can be identified within this capitalist category of disability. Although its function to justify the removal of people with disabilities from the workplace previously prevented people with disabilities from losing the supports of their community when they were unable to work through giving them justified access to welfare, now their removal from the workplace is a point of segregation and oppression for the same population. As a result, programs like the site of my research argue for the skillfulness and capabilities of people with intellectual disabilities. They argue for the right of this population to have their labour exploited and their productivity recognized, as a means of facilitating their inclusion in their community and the public’s perception of them as useful, fully animate citizens. This results in people with intellectual disabilities paying the program in order to eventually be paid.

Leanne Dowse argues that within the neoliberal risk framework, the preclusion of this population from economic citizenship causes technologies of citizenship to be used towards this population to allow them to manage risk, in the form of a “range of normalising, therapeutic and training measures designed to empower them, enhance their

self-esteem, [and] optimise their skills and entrepreneurship” (2009:577) . This creates problems, including an issue with the technique of ‘empowerment,’ where those with disabilities see this technique as “the promise of resistance [from interventions] through enabling the expression and valuing of the unique ways in which they inhabit their social context,” (Dowse 2009:577) while, care professionals understand empowerment in terms of individual responsibility and greater control, focusing on skills and resource access which services can facilitate (Dowse 2009:578). Dowse explains that this has caused a shift from “the notion of an emancipated self” achieved through political and cultural movements to the “virtuous, disciplined and responsible autonomy of the neo-liberal citizenry,” and so empowerment has become a power relationship which “holds the ambivalent promises of both freedom and constraint” (2009:578). So, individuals with intellectual disabilities are still seen as being able to access citizenship only through service and power relationships, and normalizing techniques that discipline them into the economic, risk-taking agent, without the liberated participation and independent choice and rights they desire.

My research program represents one of these service and power relationships, which attempts to allow this population independent choice and rights. They attempt to reduce the service and power relationships, and argue for much more independent choice, autonomy over labour type, and individual rights. However, disciplining the participants into the economic, risk-taking agent is still a component of this and the participants are still in a service relationship with the program. While for the program this structure represents the easiest means of accessing citizenship rights and inclusion for this

population, subsequent chapters will show that “freedom and constraint” are both complicatedly experienced by the participants.

While the education system and employment mark two interconnected moments of torque, looping, and degenerating animacy for contemporary individuals with Down syndrome, genetics and the medical system coupled with social understandings of Down syndrome create many additional important instances of the nightmare texture of torque for these individuals. These instances of torque include court cases over a doctor allowing the birth of a child with Down syndrome without insisting on prenatal testing or intervention; debates about prenatal testing and therapeutic abortions for babies in utero with Down syndrome, and the resulting widespread abortions once the trisomy is detected (Siebers 2010:186; Wright 2011:160-162). Since many children with Down syndrome are born with congenital heart defects and lung problems, other debates ensue about the possibility of withholding lifesaving treatments after birth, and these become part of the debate over their life worth (Siebers 2010:186; Wright 2011:162-163). Currently, then, people with Down syndrome are positioned as living lives that are largely preventable. This is reinforced through their having been defined as a kind, the identification through genetics of their kind as being chromosomally rooted, and their positioning as living dangerous, threatening, or unnecessary lives through a history of ableism, institutionalization, and hereditary concern. Disability groups argue that this practice is a form of “silent eugenics” (Wright 2011:147). This medically approved devaluation of their lives coupled with discrimination against this population in the education system and employment sector means that people with Down syndrome are

being forced to attempt to prove their capabilities in a society that believes they need not exist.

While there are many other instances of torque that people with Down syndrome experience while living and attempting to thrive in Canada, the final point of torque I will explore, which is universally experienced by this population and so crucial to understand, is their experiences of early aging. While in 1929 people with Down syndrome had a life expectancy of 9 years, by 1989 their life expectancy was 57 years, and currently 44 percent of the population will reach the age of 60 and 14 percent will live until 68 (Berney 2009:32). This means that the majority of people with Down syndrome are now living to experience old age, to the extent that those over 50 have increased 200 percent in the past 20 years. Complicatedly, because they experience signs of premature aging, they experience old age much younger. A key component of this early aging is early onset Alzheimer dementia, occurring 30 years earlier than normal, which includes seizures, personality change, and depression amongst its symptoms (Berney 2009:35-36). However, the impact of dementia for this population depends on the individual's "previous level of independence and the person's circumstances – domestic home or institution" (Berney 2009:34).

The results of this are that people with Down syndrome are dealing with new experiences of aging to a larger degree than has previously been seen, but because they are also experiencing independence and stimulating, full lives to a degree that has been previously unavailable, the particular experiences of aging for this population is ambiguous and unpredictable. The physical exercise, mental stimulation, and social lives of the individuals at the program where I conducted fieldwork is largely unprecedented,

and so their particular experience of aging could potentially be much smoother and their longevity longer than currently reported.

Regardless, the experience of aging is more complicated for this population. Symptoms of early onset Alzheimer's are less likely to be detected and they are "encountering issues that include work, marriage, sexual relationships, and parenthood" which were not experienced by past generations who did not reach adulthood or were kept away from society (McGuire and Chicoine 2006:32). Additionally, their dependency on the close relatives and friends they lose with age is often greater than normal (McGuire and Chicoine 2006:32). They require very particular supports as they age and occupy the complicated space of a senior intellectually disabled adult, supports that are both social and health-based and which are largely difficult to find, as they extend beyond typical senior care, which is often lacking for a typical senior, and beyond the current supports offered by the program. However, the alternative is membership in workshop and centre-based programs which offer support to adults with a variety of needs and concerns, but are less able to offer the full, integrated lives, stimulation, or individualized support that my fieldwork program offers. There are no ideal options then, and because of the uncertainty of their aging, anticipating and creating the ideal context for aging is difficult.

Project Description

The research took place at a small day program in a semi-urban community in Ontario, Canada, and its surrounding sites. The program I used for my fieldwork is a fee for service charity program, which requires participants to pay a fee for the days they attend. The various sites of the program include: the home-base, which is a small, house-

style building where literacy programs, lunches, and some training programs occur; the work places, which vary from local restaurants to local clothing stores; the local transit buses, which are used by some participants and which the program uses to do transit training; a community gym where participants work out; and the neighbouring church where some participants volunteer. The program accepts young adults with intellectual disabilities who are capable of daily self-care and who want to work after they have completed high school. It was created after two parents recognized that their daughters would not be able to access the full lives they desired within the options available to them after secondary school. Their fear for their daughters' futures caused them to build a new program with their daughters and their daughters' peers in mind. The program is focused on being a community included organization, rather than a centre-based program that is segregated from the wider community. They describe their focus as a program as to provide work and other opportunities which are relevant and inclusive for this population in normal job and community settings.

I chose this program as the focus of my research because they attempt to advocate for and negotiate a less restricting understanding of Down syndrome through advocating for the participants' ability to work, contribute to their communities, and be integrated into their society. They argue for a fuller social role for young adults with intellectual disabilities, believe they have the right to have their capabilities recognized, and believe they should have access to full citizenship rights. They understand that additional supports are required for this population to work successfully and have full lives, and have developed a program which focuses on offering those supports. They offer more independence, self-determination, and options than the majority of programs available for

this population. They also prioritize community inclusion and the integration of this population into existing community resources, rather than community segregation. As a result, they are a relatively progressive program.

This thesis crucially stems from an understanding of the lives of people with Down syndrome as being valuable, positive, and not inherently risky or in need of prevention. While Rayna Rapp speaks about pregnant women who receive positive amniocentesis results as “moral pioneers” in that they individually must decide if a fetus with Down syndrome would have a life worth living, I begin with the assumption that the lives of these individuals are important and capable of being rich and well-lived lives (2000:3). The morality of their lives, then, is not rooted in the questions of prenatal testing, that is in their worth and prevent-ability, but in their rights to live full, varied lives as independent, assisted adults whose unique capabilities and desires are recognized, understood, and responded to.

The book *Mental Wellness in Adults with Down Syndrome* outlines the importance of “meaningful participation in community life” for the mental health of individuals with Down syndrome (McGuire and Chicoine 2006:4). They explain that participation in the community “promotes a sense of wellbeing, boosts self-esteem, and helps a person develop and improve social skills,” and that “physical activity, social events, travel, learning new ideas, and opportunities to interact with other people while doing these activities can all be beneficial. So too is employment in a job that the *person with Down syndrome* finds interesting and fulfilling” (McGuire and Chicoine 2006:4). Facilitating community inclusion and belonging, meaningful employment, then, should

positively influence the self-conceptions and perceptions of young adults with Down syndrome.

Methods

This research is an ethnographic study, the data collection for which included a combination of a literature review, semi-structured interviews, unstructured interviews, and participant observation. Ethnographic methods were essential for this project as they allowed for the lived experiences and voices of the young adults with Down syndrome to be prioritized and for these individuals to express their perspectives and opinions through my research. This is crucial, as young adults with intellectual disabilities are frequently spoken of, and for, when they are included in disability activism and research. While my research engages with individuals without Down syndrome who advocate for and work with these individuals, its primary aim is to give a full depiction of how these young adults conceptualize themselves, and of their lived reality.

I did participant observation which primarily engaged with seven young adults with Down syndrome at the program. The participants included three women and four men in their twenties. The participant observation involved attending the program base every day and spending my days with one or more of these seven individuals. I watched and talked individually with six of them at their various workplaces. I also watched five of them do various volunteer work for the local United church from which they access the space for the program base. I observed all of them as they took cooking classes every Friday, participated in a Ready to Work course, and did literacy work, all in small, rotating groups. I also observed and participated when they went to the gym, which they all attended several times a week, according to their individual schedules.

The unstructured interviews I did also primarily engaged the young adults with Down syndrome. These unstructured interviews took the form of casual conversation during the day as I engaged in participant observation. I had a list of questions I used as starting points for conversations, and would ask them about their days at the program, experiences as employees and program participants, and about their desires for the future. I would often engage them in these conversations when we commuted to their work placements together or when we were working out together at the gym, as these were instances in which we were alone together and so able to engage in one-on-one conversation without it distracting them from their tasks. I would repeat questions on different days if the participant was struggling with them and always gave them the option to return to a question on a different day or opt not to answer one. I did my best to ask questions of participants when they were engaged in a related task, for example asking about the gym while at the gym. I would also reword questions to make them easier when necessary, for example giving a list of possible answers if they were struggling to grasp the meaning of the question; in instances where I did this, I have noted this when I reference them in this thesis.

While some of the limited research that has been published which incorporates the voices of individuals with Down Syndrome focuses on reproducing an extended narrative in the voice of one or two key participants (Artkinson, Cooper, and Ferris 2004; Spencer and Walmsley 2006), I took the approach of using unstructured interviews due to the different nature and goals of my research. The information provided by the participants was transcribed by me, and when possible I quote the participants when talking about their opinions or desires. While I would have liked to have presented information in ways

that exclusively prioritize the opinions and experiences of the young adults I worked with, as the methods above successfully do, there were several barriers that prevented me from successfully doing so. First, my participant observation was conducted with seven participants rather than just one or two, which meant that I spent less time with each individual, but also meant that I did not overwhelm any one individual. Second, certain participants had an easier time understanding the questions I asked than others, and so were able to give me much more detailed answers. Third, the participants all have a tendency to focus on the positive, and so speaking to discrimination, frustrations, barriers, or difficulties they experience was rare, and asking directly about those things had the potential to upset them, which I wished to avoid. Fourth, I was limited when asking participants to discuss their identity, as identity and related concepts are abstract and so difficult to grasp and speak to for my population.

I conducted one semi-structured interview with the two founding directors of the program, Ellen and Janet. The interview took just over two hours to complete. The interview asked questions about the program's goals, the influence the program has had on its participants, the role the program has in the community, and the reactions community members and employers have had to the participants with Down syndrome. I asked them about the formation of the program five years ago, the future of the program, and limitations of the program. I asked about their perceptions of the participants, their choice to focus on employment as a goal for the participants, and their personal experiences as mothers of two of the participants. I use a significant amount of data from this interview in the subsequent chapters, because Ellen and Janet were able to speak to me from a number of perspectives as both parents and founding directors of the program,

and they were able to speak to the experiences of all seven of the participants with Down syndrome I worked with, as they know each of them personally and know each of their histories as well.

I also conducted semi-structured interviews with the parents of the participants with Down syndrome. I was able to conduct individual interviews with five parents other than the founding directors. Two of them were fathers and three were mothers of young adults with Down syndrome at the program. One was the mother of a program participant who did not take part in my research, while the rest were all parents of participants that took part in my research. One of the fathers was the husband of one of the founding directors, and the other father was the husband of another mother I interviewed, allowing me to get both parents' perspectives in both these cases. The interviews were each between thirty minutes and an hour in length. The interviews with parents asked questions about the experiences of their adult children with Down syndrome and the young adult's self-perception, community inclusion, and development since finishing secondary school. They allowed me to access information about the impact that the program has had on the participants' personal conceptions and feelings of inclusion, the skills that the young adult with Down syndrome has, and the standards they see the general public having for young adults with Down syndrome. I also asked about the parents' expectations and desires for their children's future.

While I did talk with the three employees at the program during my days spent there, and briefly with some of the employers, and I use some information from these conversations in the subsequent chapters, I did not conduct formal interviews with the employers or employees.

Chapter 2: “To Classify is Human”: The Categorization of Individuals with Down Syndrome

This chapter examines the work the category “Down syndrome” does in enabling and disabling those with the syndrome. Although the classification system of intellectual disability and the category of Down syndrome are currently understood as relatively fixed, the category has been manipulated, assigned varying standards, and reconceptualized by powerful actors throughout a long history. The categories people are assigned to and their changing implications transform the lives of the people placed within them. The category also influences their self-conceptions and life experiences, as well as their ability to effectively undermine their positioning, reduced animacy, and reduced humanity, and to claim their rights to social space, life, and flourishing. So, tracking the changing ways in which people with Down syndrome have been categorized, conceptualized, and managed is crucial to understanding their current cultural positioning, subjectivities, opportunities, and experiences. The lives of individuals with Down syndrome have been shaped by the development of a number of industrial and capitalist institutions, and so their experiences are manipulated and determined by intersecting discourses developed and held as stable by a variety of powerful actors. For the purpose of the work of this thesis, I focus on the ways in which social discourses and the social positioning of this population, the development and changes in standards of intelligence, and the creations of educational institutions and discourses have all transformed and shaped their lives throughout history.

It is the points of major change in the conceptualization of the term that are important to unpack as these are points of instability, where actors are redefining the

understanding of the term and are determining the boundaries and implications of the life of someone who is placed within the category at that particular time and place. It is through exposing significant points of change that we can understand the ways in which individuals with Down syndrome's life quality, opportunities for flourishing, and rights have been dependent upon the changing understandings of their category by larger society throughout history. That the autonomy, humanity and animacy positioning, and resource access of individuals with Down syndrome are all shaped by their categorization, means that their subjectivities are shaped by these categories as well. As the current medicalized, genetically-based, standardized understanding of Down syndrome has been solidified and the particular individuals it encompasses have been negotiated, their position within this category has continued to determine their access to resources, income, and educational experiences, as well as society's expectations of them.

Since powerful actors determine how this category is understood and used, the desires, experiences, and social contributions of these individuals are often ignored and erased from their histories. As a result, this chapter aims to articulate the varying lived experiences of these individuals as they were forced into formalized subjected identities. A significant aim of this chapter is to take up Bowker and Star's ideas about social categories to explore the often invisible categories that have historically been applied to this population. I aim to expose the ways in which these categories were created and formalized, attached intentional implications which are now held as intrinsic to the identity, and how they work very intentionally to order human interaction and create barriers to those they are applied to. It also aims to expose instances of torque that these seemingly natural categories create.

I use Hacking's looping theory and Chen's ideas about animacy as a means of accessing and articulating the influence of these categories and their implications on the lived experiences of the young adults to whom they are applied. Hacking's looping effect is a dynamic process in which classification creates behaviour changes which changes the classifications, changing the behaviours again. I am able to articulate some of the identity implications of the categories, through discussing the impact that the categories may have on identity through looping. Additionally, Chen's animacy theories offer a means of thinking about the implications of being forced to occupy an explicitly subjected category. Through Chen's understandings of animacy hierarchies, the means by which these hierarchies are invoked through language and classifications, and the reduced humanity and animacy assigned to categories of disability can be better articulated. She emphasizes that professionals are able to position the lives that occupy disability categories as inanimate and through that justifiably act on them and control their lives. Chen's means of thinking about animacy hierarchies offers a useful language for discussing the ways in which disability categories work to transform the lives they are applied to.

I use David Wright's book *Downs: The History of a Disability* (2011) for the majority of the historical categorization tracking and unpacking I do in this chapter. Wright's goal in the text is to give a detailed and accurate history of Down syndrome, the people with the syndrome, and the major individuals who have influenced their history. His text provides a rich, detailed history of a group of people who throughout history have largely been erased and ignored, making it useful for the work of this chapter.

I begin with the section “Social Role” where I discuss the social roles occupied by people with intellectual disabilities historically. In this section I track the development of social categories of disability, and the use of these categories to increasingly formalize the segregation of individuals with intellectual disabilities and establish the social negation of their rights and inclusion. I also discuss historical changes in the twentieth and twenty-first centuries that have resulted in increased rights and social inclusion for this population. Next, in the section “Intelligence,” I discuss the establishment of intelligence as a measurable, quantifiable human characteristic. In this section I discuss the establishment of standards and tests of intelligence as a means of formalizing that lack of intellectual capability is a valid reason for a category of abnormality. I also show how the creation of the IQ test conflated intelligence with development and maturity and allowed for perceived intellectual abnormality to be officially measured and, in that, solidified. Finally, in the section “Education,” I discuss the various means of educating this population. I establish that intellectually disabled individuals were only believed to be educable during and after the Enlightenment. I discuss the means by which they were treated, educated, and experimented on throughout their post-Enlightenment history, and in that establish that education has been a source of torque for this population for centuries. I use this history to discuss their current experiences within the education system, suggesting that they are still not accessing appropriate interventions currently.

Ultimately, I aim to show that the categories individuals with Down syndrome have occupied have shaped their lives historically, that these historical circumstances and beliefs have determined the current dominant understanding of Down syndrome, and that their continued social positioning as an abnormal “other” continues to negatively impact

their lives, rights, and possibilities for flourishing. I aim to do this as a means of establishing the current context the participants of my research are living in, the reasons for their and the program's categorical resistance, and the dominant discourses and barriers that are influencing their lives as a means of contextualizing the findings of my fieldwork.

Social Role

Currently, people with intellectual disabilities are increasingly being included in society's institutions in Canada and their general communities. While this change in their social role seems relatively modern, this is only because a long history of changes in society's conceptualization of this population and their value, their deserved treatment, necessary management, and general humanity all contributed to their eventual removal from society. In the beginning of their traceable, recorded history, individuals with intellectual disabilities were largely included in their communities and cared for. It was only when ownership over property and inheritance became of a large enough concern that these individuals began to be managed through laws, identified through tests and standards, and increasingly rigidly categorized. These moves all eventually led to their institutionalization and complete segregation from society.

The term "idiot" was the first known term, or formal category, applied to people with, or perceived as having (as would have been the case with mute or hearing impaired individuals), an intellectual disability (Wright 2011:22). While at the same time categories like "natural fool" and "innocent" were in use, the implications and distinctions between the categories were not significant as they were used interchangeably (Wright 2011:19). Consequently, this discussion will lump these terms

into the category and concept of idiocy. So, while individuals with Down syndrome are currently understood as occupying an exclusive category of disability, historically they have also been sorted into and impacted by much more general, less rigid categories that included individuals who would later be categorically divided into separate disability categories.

Although a very general category, idiocy carried a specific understanding and application. In the “Prerogativa Regis”, a thirteenth century English court document, the terms natural fool and lunatic were first identified and defined (Wright 2011:19). Idiocy, or being a natural fool, stupid, innocent, or natural, was distinct from lunacy, and associated terms like mad, distracted, and crazy, in that idiocy was a permanent condition, while lunacy could be temporary (Wright 2011:19). Categorizing someone as a natural fool allowed the Crown to possess that individual's property, which then went to their heir after death, and the funds from the land were used by the Crown to provide for the individual (Wright 2011:19-20). These categories were created to make certain that the ‘appropriate’ individual had stewardship over property. One of the category of idiocy’s first uses, then, was as an administrative category, with social and torque implications for the individuals it was being used to administer.

The category was also originally used by the sovereign for reasons of protection of property and care of these individuals. In 1637, intellectual disability first became an explicit concern of the sovereign through William Harvey. Harvey, a well-known physician, petitioned the English Court of Wards and Liveries for “the determination of mental incompetence of his sister's son,” so that he could claim guardianship over the orphaned boy. The petition framed William Fowke, Harvey's nephew, as an “Ideot,” and

through it Harvey formalized the act of adjusting families and relationships when a kin is “not mentally capable of managing their own affairs” (Wright 2011:17).

The lack of a formal, distinct category for people with Down syndrome makes it impossible to know if William Fowke had the syndrome; however, there is proof that the syndrome existed by 1637 as a 16th century painting, “The Adoration of the Christ Child, circa 1515,” has been identified as having an angel, and possibly a shepherd, with the facial features characteristic of the syndrome, placing the syndrome's existence at least a hundred years before Harvey's petition (Neri and Tiziano 2005:17). This is important, as the existence of individuals with Down syndrome predating the establishment of the formal category of idiocy gives verification to the fact that the history of idiocy is central to the current experiences of individuals with Down syndrome. The social category of idiocy can be understood as encompassing individuals with Down syndrome at the time, and so the history of the term is the history of Down syndrome as well. The experiences of people with Down syndrome are intertwined with and reflected in the histories of individuals categorized as idiots, and not just influenced by them. So, when individuals with Down syndrome are currently being influenced by the pejorative use of terms like idiot, continue to be denied access to a full social role and rights, and are lumped into and influenced by general categories of intellectual disability, these experiences can be understood as directly connected to their long history within the increasingly negative, general category of idiocy.

These categories also had implicit moral implications for the individuals. Henry-de-Bracton argued in the thirteenth century document “On the Laws and Customs of England,” that idiots should be excused from criminal prosecution because they could not

distinguish right from wrong, and so did not have the ability to judge actions or their consequences (Wright 2011:21-22). This was reaffirmed in the “History of the Pleas of the Crown” by Sir Matthew Hale, which was published in 1736, and describes the acquittal of a fool for the crime of stealing a cup (Wright 2011:22). The category of idiot, then, worked as a means of administrating these individuals and their property, but also functioned to protect them. The category of idiocy legally positioned particular individuals as permanently less capable, less intelligent, and dependent. It officially located them into the position of the undesirable, abject other. As Wright explains, in absolving people with intellectual disabilities of crimes, “commentators universally agreed that their bodily and mental conditions were punishment enough – what they called, rather poetically, the ‘misfortune of fate’” (2011:23).

While these petitions and juries describe the categorization and management of people with intellectual disabilities with some property, they do not speak to the experience and management of impoverished individuals with intellectual disabilities. These individuals were largely managed by the poor laws, where the state required the parishes in England to provide relief for their poor. Individuals with intellectual disabilities appeared on welfare rolls, were placed in the trust of workhouses and houses of correction, and were dependent on the financial situation of the parish and changing circumstances of their families for care and support (Wright 2011:24-25). Their categorization as idiots gave them inconsistent access to care through clothing donations, payments, or “boarding out,” where kin and non-kin were paid to care for them (Wright 2011:25). It made their dependency official and placed the responsibility on the parish for their survival and care.

They, then, became socially acceptable dependents and networks of care were created to support them. These networks were not yet the official, segregated institutions that would eventually manage the care of this population. Rather, they were allowed access to informal networks such as the parishes that allowed them to continue to live and survive in their communities, or they were placed in more formal networks like the workhouse that were not created for their care, but took them in with the poor.

Generally, then, people with intellectual disabilities were not conceptualized within reduced humanity positions or formally, universally segregated from their societies. However, their classification was still created to reduce their rights, access to their property and independence, and generally formalize their initial social oppression. While standards to determine who could be labelled an idiot were increasingly developed during this time, the purpose of these categories was officially to legally protect and control this population and to activate existing networks of care to facilitate their survival. Hardening the boundaries of idiocy prevented individuals who did not require these protections from claiming membership in the category, which justified allowing for the continued existence of these protections. However, while the creation and hardening of these categories were a means of administrating and controlling this population, essentially of ordering human interaction, and so these categories worked for those who created them, they unintentionally created instances of torque for those they were applied to. Although these categories functioned in both positive and negative ways during this time, they crucially positioned these individuals in a category of otherness that previously was not articulated through clear categories and standards. Through this othering, these categories also articulated and established intellectual disability as abnormal. By

establishing these new types of human kinds, these categories set in motion the eventual segregation of this population into formal institutions and the increasing devaluation of their lives.

The Enlightenment movement contributed significantly to the repositioning of people with intellectual disabilities from a socially managed population to an institutionalized, segregated, and collectively intervened upon group of people. The success of some of the treatments and interventions on individuals with disabilities, which are discussed in the “Education” section below, resulted in the further management and medicalization of all individuals with disabilities. The focus by some of the intellectuals of the Enlightenment on education and improvement of people with disabilities and the resulting development of medical discourses on the treatment and training of children categorized as idiots resulted in the creation of the first asylums and institutions.

Institutions for idiots, which were created during the first few decades of the 1800s, became spaces where some educational and rehabilitation efforts were imposed on this population. Once institutionalized, the social role of individuals with intellectual disabilities became eroded, as they were no longer viewed as valid members of society. John Langdon Down became the superintendent of one of these institutions, Earlswood Asylum, in 1858 (Wright 2011:55). Down agreed with the creation of asylums like Earlswood, which was a separate asylum for idiots from those for people with mental illness. He also took this argument for categorization and segregation a step further by arguing that idiot children should be classified and separated based on their level of intelligence so that they could access the “amusement and occupation suited to their

various capacities” (Wright 2011:58). In arguing for this separate treatment, Down was contributing to a Victorian tendency extolling the benefits of classification, and the resulting specialized knowledge and treatments (Wright 2011:58).

Based on this desire to categorize and offer appropriate interventions, Down categorized the idiots in his asylum based on racialized groups, using phrenology and the racial theory of his time. He created a distinct category for people with Down syndrome, “Mongolism,” making them into a human kind, and allowing their collective experiences as a categorized group of individuals to be more accurately tracked and separated from similarly classified individuals from this point onwards (Wright 2011:10). This identification of people with Down syndrome as a distinct group did not prevent the rest of their history from being influenced by and combined with the general history of people with intellectual disabilities, as they were still part of the general category of idiots or individuals with intellectual disabilities. However, it did allow them to have a distinctly traceable history from this point onward, as their categorization as a subgroup of idiots was assigned distinct characteristics, features, and origins and causes.

The devaluation of the lives of individuals with intellectual disabilities coupled with an increasing association of this population with immorality would eventually lead to both positive and negative eugenics being imposed upon these individuals. Positive eugenics focused on encouraging the production of desirable offspring through encouraging individuals with desirable traits to procreate, and negative eugenics focused on controlling the reproduction of those categorized as feeble-minded, often through sterilization. Through eugenic discourses individuals with intellectual disabilities became repositioned as dangers to society, and so preventing their births and stopping their lives

became a necessity for the greater social good. Their social role became conceptualized as both in opposition to the lives of those not categorized as idiots and as essentially non-existent as they were removed from society en mass (Wright 2011:85-86; Simmons 1982:52). Of those targeted by eugenics, “Mongoloid idiots” were particularly targeted for negative eugenics interventions given that their 'origin' had been linked to tainted heredity (Wright 2011:86). Their relatively absent social role would continue until the 1960s, when Bengt Nirje and American President John F. Kennedy would both push for deinstitutionalization for intellectually disabled individuals.

Bengt Nirje was a Swedish doctor who first developed the normalization principle, which had a huge influence on the experiences and lives of individuals with intellectual disabilities. Nirje’s experiences of horrible conditions in refugee camps following the Budapest revolt in Hungary influenced his position in establishing homes for children with cerebral palsy when he returned to Sweden (Wright 2011:131- 132). After Nirje became an influential Ombudsman for the Swedish Association for the Mentally Retarded, he played a central role in a 1967 law which gave people with intellectual disabilities rights to services in the community, which was one of the first of these acts in the world. During this time, Nirje developed the normalization principle which “sought to eliminate special schools and residential facilities” and integrate people with disabilities into the mainstream based on the “least restrictive alternative” (Wright 2011:132). This principle, Nirje explained, would not “make the subnormal normal' but will make life conditions of the mentally subnormal normal as far as possible bearing in mind the degree of handicap, his competence and maturity, as well as the need for training activities and availability of services” (Wright 2011:132). This was taken up by

the German-American academic Dr. Wolf Wolfensberger in America, where John F. Kennedy was president, and in Toronto, Ontario where Wolfensberger was a visiting scholar at the National Institute on Mental Retardation in the early 1970s (Wright 2011:149).

Kennedy's presidency brought considerable political attention to issues surrounding intellectual disability, due to the Kennedy family's experiences with intellectual disability through the president's intellectually disabled younger sister. He passed legislation making intellectual disability a federal health policy issue for the first time in America and was interested in "developing non-institutional, socially integrative practices to care for the mentally disabled" (Wright 2011:133-134). He took the stance that "care outside the institutions was... our greatest hope for a major victory over mental retardation" (Wright 2011:133-134). Kennedy's brother, Robert Kennedy, was a major figure in exposing the awful conditions in institutions, and exposures over the next decade brought the reality of the horrible institutional conditions into the public's awareness and led to the Civil Rights of Institutionalized Persons Act of 1980, which "authorized the Attorney General to seek relief for persons confined in public institutions where conditions exist that deprive residents of their constitutional rights" and, "formalized group homes as the preferred alternative to the large state institutional model" (Wright 2011:135-137). In Canada, advocacy for individuals with intellectual disabilities was beginning through parents of individuals with intellectual disabilities. They started what is now called the Canadian Association for Community Living over fifty years ago. The goals of this movement were focused on "closing institutions,

providing appropriate supports for people to live in communities and ensuring inclusive education and supported decision making” (Stienstra 2012:11).

While the Kennedys were arguably the most powerful figures influencing disability policy in America in the late 20th century, there were many advocacy based groups already pushing for deinstitutionalization before Robert Kennedy was touring institutions. An important example of this was the lengthy court battle undertaken by parents and advocate groups against the Staten Island Willowbrook institution in the 1970s. Willowbrook was a very large institution where the staff conducted numerous unethical and horrible medical experimentations on the residents, including purposefully infecting children with intellectual disabilities with hepatitis (Goode 2006:1637). While conditions were awful at Willowbrook, they are characteristic of many institutions in America at this time (Goode 2006:1637). By the 1970s, parents who had children at Willowbrook, particularly the Parents Benevolent Association, began to protest the conditions, and they were soon joined by professional staff employed at the institution (Goode 2006:1637). After the conditions at the institutions were broadcast by Geraldo Rivera, a television reporter for the ABC network, they were joined by various other concerned groups and together they filed a lawsuit in federal court over the inhumane living conditions (Goode 2006:1637-1638). This lawsuit resulted in the signing of the Willowbrook Consent Decree in 1975 which outlined the conditions that would have to be met at the institution for everyone there until their death (Goode 2006:1638) This decree was “one of the most significant events in the civil rights movements by and for people with developmental disabilities” (Goode 2006:1638). Lawyers for the plaintiffs who were “individuals and organizations representing the interests of the more than 5,000

residents who lived at Willowbrook at the time,” and lawyers for New York State also worked out over several years a detailed agreement for the closing Willowbrook (Goode 2006:1638).

It is also important to note that while parents, activist groups, and key powerful figures contributed significantly to deinstitutionalization and arguing for the rights of individuals with intellectual and other disabilities, people with intellectual disabilities were self-advocates as well. These individuals may not have gained any historical prestige, but they certainly existed. For example, Dorothy Atkinson recorded the oral histories of Gloria Ferris and Mabel Cooper, both of which are women with intellectual disabilities who became advocates during their lives. Gloria Ferris became an official advocate for a woman named Muriel, who was unable to communicate her needs herself (2006:14-16). She first advocated for Muriel while the two of them were living in long stay wards in a hospital and then continued to advocate for her throughout her life after both had left the hospital. Mabel Cooper learned to assert herself after being disciplined to be very passive while living in a long stay hospital ward. She joined People First and eventually became the chair of the London, England branch (Atkinson, Ferris, and Cooper 2006:17-19). Ray Loomis and Tom Houlihan are also examples; they were young men with intellectual disabilities who Williams asserts were pioneers of self-advocacy in America (2006:37). Williams argues that their stories prove that it was “people with learning difficulties themselves who began the self-advocacy movement” (2006:37). They helped start the advocacy movement by helping found a group called “Project Two”

for recipients of ENCOR¹ and lived historically important lives that are left out of historical accounts (Williams 2006:38).

As deinstitutionalization slowly occurred, group homes became the dominant model of living arrangement, as they acted as a compromise between the segregated institutions and the ideals of the normalized conditions envisioned by Nirje and Wolfensberger, and parents and advocates of this population (Wright 2011:139). While Nirje, Wolfensberger, the Kennedys, and advocates argued for community inclusion, the communities in which group homes were placed often responded negatively to them and fought against locating the homes in their areas. The public conceptualized individuals with Down syndrome as dangerous and as posing a threat to their children (Wright 2011:140). Through the introduction of these group homes, the social role of people with Down syndrome changed again. They were re-entered into their communities for the first time in over 200 years. They were still viewed as dangerous by some members of those communities and they were still segregated from the community in these group homes. However, through their integration back in these spaces, their communities would be forced to acknowledge they exist and learn to relate with them, encouraging a slow change to the social perceptions of these individuals and to the resources they were able to access.

Normalization would have a largely positive effect on individuals with Down syndrome. Their animacy positioning would be improved as they were being recognized as deserving the same qualities of life as their non-disabled peers. Through Kennedy, Nirje, and Wolfensberger, amongst others, recognizing the civil rights of people with

¹ ENCOR was a pioneer service founded by parents and professionals in Omaha, Nebraska which aimed to bring back all the people with intellectual disabilities in an institution 100 miles away from Omaha (Williams 2006:37).

intellectual disabilities, that those with intellectual disabilities are deserving of certain standards of life that institutions were not providing, and that these individuals deserve to be a part of communities, individuals with intellectual disabilities were effectively being moved up the animacy scale. Exposés of institutions shocking the public and instigating changes depended upon empathy and the ability of law-makers and the public to view people with intellectual disabilities as equally human.

Hacking's concept of looping is useful for describing how normalization and deinstitutionalization would impact the individuals who occupy the Down syndrome category. He explains that "to create new ways of classifying people is also to change how we can think of ourselves, to change our sense of self-worth, even how we remember our own past. This in turn generates a looping effect, because people of the kind behave differently and so are different. That is to say the kind changes" (Hacking 1995:369). Based on Hacking's analysis of looping, the behaviours of people with Down syndrome would change after deinstitutionalization to match the more human positions they were finally being afforded. They would be able to develop the capabilities to live independently now that they were being re-categorized as capable through placement in more animate categories, removed from the autonomy-restricting institutions, and in new positions as community members. Access to mainstream education would also impact their development and intellectual capabilities, changing the expectations of their kind. Through the increased recognition of their autonomy and humanity, the possibility of becoming knowers about their own kind and of a collective desire to resist their sub-human position and resource-restricted lives becomes more feasible. However, barriers in the school system, medical system, social conceptions, and access to the rights they have

been recognized as deserving, still prevent them from having equal rights through their category or from leaving the sub-human animacy position behind.

The civil rights of people with intellectual disabilities had another important moment with the Americans with Disabilities Act (ADA) in 1990 in the United States. The ADA was created after The Civil Rights Act of 1964, which prohibited discrimination on the basis of race, color, religion, or national origin, and led to people with disabilities pushing to add disability to the grounds of discrimination prohibited by the act (Burgdorf 2006:93). While bills periodically came to Congress to have this added, they were unsuccessful. In 1973 the Rehabilitation Act was adopted with a provision which prohibited discrimination on the basis of "handicap" in programs or activities that receive federal funding (Burgdorf 2006:94). However, disability rights groups continued to push for full anti-disability discrimination legislation, and after several small steps towards producing a "comprehensive federal statute that would prohibit discrimination based on disability," (Burgdorf 2006:94) the Americans with Disabilities Act was approved by the House and the Senate in mid-July 1990. The ADA defines disability fairly progressively, including people who both "have a record of" and are "regarded as" having an impairment:

The term "disability" means, with respect to an individual
life (A) a physical or mental impairment that substantially limits one or more major activities of such individual;
(B) a record of such an impairment; or
(C) being regarded as having such an impairment. (United States Department of Justice and Civil Rights Division 2009:7)

Although the definition of disability used in the ADA is fairly broad and is not limited to medically diagnosed experiences of disability, A.J. Withers, a Toronto-based disability

activist, notes that the act does “nothing to address systemic barriers... and the actual number of people who successfully pursue litigation is quite small” (2012:111).

In Canada, there is no federal disability legislation, however in 1982 the Canadian Charter of Rights and Freedoms was established. The Charter includes disability under the section titled “Equality Rights”:

Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.
(Government of Canada 1982:Section 15)

Additionally, each province in Canada has its own human rights code (Withers 2012:111). Ontario has disability-specific legislation, the “Ontarians with Disabilities Act,” which will be replaced with the ADA-like “Accessibility for Ontarians with Disabilities Act” in 2025 (Withers 2012:111). However, Withers argues that both are “essentially useless” because “the government has refused to enact the section making it an offence to break this law” (Withers 2012:112).

While the Charter was formed in 1982, in Canada activism for disability rights began in the 1970s, if not earlier, with significant awareness and policy changes beginning in the 1980s (Stienstra 2012:9; Prince 2009:xii). In the 1970s, groups like the Council of Canadians with Disabilities formed in response to the unwillingness of groups like the March of Dimes and Easter Seals to have at least half of their board members be people with disabilities (Stienstra 2012:10). This resulted in self-advocacy groups being formed in Ontario and the prairies, and then at national level, which pushed for representation by people with disabilities in policy creation and advocacy forums (Stienstra 2012:10). In 1980, the Rehabilitation International conference took place in Winnipeg which is “widely recognized” as the beginning of “the international movement

of disabled people and a turning point for global disability rights” (Stienstra 2012:10). During Rehabilitation International, the delegates who attended condemned the institution system, resulting in the creation of the Independent Living movement in Canada, which sparked the creation of Independent Living centres across Canada (Stienstra 2012:11). While Independent Living supports people with a variety of disabilities, the intellectual disability movement in Canada has an even longer history, as the Canadian Association for Community Living was formed in the 1950s, and focuses on the Community Living model and deinstitutionalization (Stienstra 2012:11).

The year 1981 marked an important year for policy changes around disability in Canada. The year was the United Nations International Year of Disabled Persons, sparking Parliament to create a committee to look at the experiences of Canadians with disabilities, resulting in the *Obstacles* report which made recommendations for removing disability-related obstacles (Stienstra 2012:13). Many provinces responded by creating advisory councils on the situations of people with disabilities (Stienstra 2012:14). Ontario has notably never implemented this type of council, although Ontario does have the Minister of Community and Social Services who is responsible for disability issues and a connected disability office (Prince 2009:166). In 1992, a social services review was conducted of municipal, provincial, and federal services in Canada to see how well disability rights had been implemented since the Canadian Charter came into effect, the results of which were not positive (Stienstra 2012:13). In 1998, the ministers of social services at the provincial, territorial, and federal level, with the exception of Quebec, adopted the document *In Unison: A Canadian Approach to Disability Issues*, which expressed a new approach to disability in Canada with the vision that “persons with

disabilities ought to participate as full citizens in all aspects of Canadian society” (Prince 2009:172). The document identifies actions in the areas of disability supports, employment, and income security, and stakeholders in the ministers’ communities were asked to review a draft of the document, importantly allowing government and community stakeholders to work together (Prince 2009:172). The approach taken by *In Unison* was crucial because it prioritized the inclusion of people with disabilities in the creation of the document, and within that utilized the approach to disability policy advocated for in the disability movement (Stienstra 2012:16).

In Ontario, the last three large government institutions for people with intellectual disabilities closed in 2009 (Hickey 2012:590). These final closures were the end of a decade-long battle by disability advocates for the closure of segregating institutions (Hickey 2012:590). The government of Ontario began the deinstitutionalization process in 1977 with a plan to increase community living for people with intellectual disabilities (Hickey 2012:599). The first five institutions were closed by 1986, and the other fourteen were gradually closed over the next twenty-three years (Hickey 2012:599). A large contributor towards this change was the replacement of the Developmental Services Act, established by the Ontario government in 1990, with the Services and Supports to Promote the Social Inclusion of People with Developmental Disabilities Act in 2008 (Hickey 2012:599). This new social inclusion act removed the authority of the Minister of Community and Social Services to operate institutions (Community Living Ontario n.d.). With each closure, people with intellectual disabilities were placed in community-based homes.

Ontario also has the Ontario Disability Support Program (ODSP). This has a much larger impact on the lives of individuals with disabilities, although the income support provided is a minimal amount (Withers 2012:111). It also has a much more restricted definition of disability which requires medical documentation of the disability, and so enforces the medicalization of disability (Withers 2012:112). Withers notes, based on the definitions used by the ODSP and similar programs, that when being disabled has benefits, such as access to money or accommodations, the definitions of disability are “rewritten” to restrict access to benefits to as few people as possible (2012:112). However, when it comes to ineffective legislation, the definitions are broad to reach “as many voters as possible” (Withers 2012:112). So while the legislation in both Canada and America suggests an intention to positively influence the social role of people with disabilities through increasing their access to society and decreasing the possibilities of discrimination, the reality is that the legislation intentionally suggests this possibility, but very rarely results in meaningful changes. So while the adoption of the ADA, the inclusion of people with disabilities in the Canadian Charter of Rights and Freedoms, and the Ontarians with Disabilities Act all suggest huge gains in the disability civil rights movement, the reality is that people with disabilities still face significant discrimination, exclusion from the programs created to benefit them, limited assistance, and many barriers to full civil rights.

The normalization movement, fight for the civil rights of people with disabilities, and deinstitutionalization have led to parent groups advocating for the mainstreaming of individuals with Down syndrome. The education system is one of the major focuses of this mainstreaming work, where parent-led organizations fought against segregation

based on educational testing and medical classification, and argued for inclusion of people with Down syndrome in regular schools and for integration of them in regular classes (Wright 2011:150). Eventually, over time, this began to happen, as I discuss in the “Education” section below.

Currently, the Canadian Down Syndrome Society has a campaign which continues the efforts of the normalization movement. Their “See the Ability” campaign uses billboards with images of people with Down syndrome. The campaign has been running since 2012 and features a 2012 billboard, featuring Nick, and a 2013 billboard, featuring Maxwell. Both of these are still being displayed in Canada and were up in Ottawa and Toronto around the time of my research. They can be seen in figures 1.1 and 1.2.

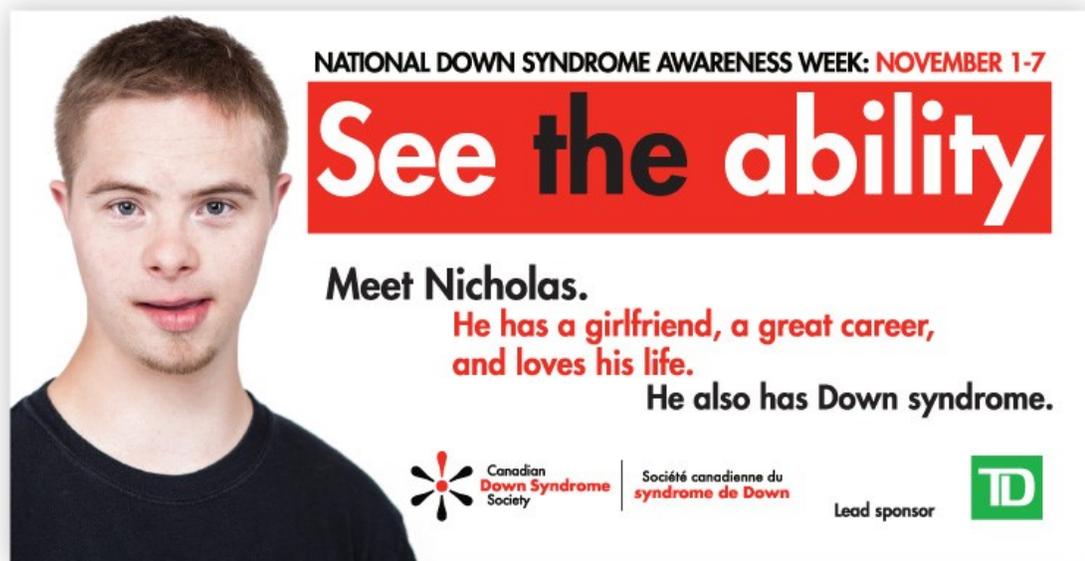


Figure 1.1 (Canadian Down Syndrome Society n.d.a)



Figure 1.2 (Canadian Down Syndrome Society n.d.b)

Both billboards attempt to normalize people with Down syndrome. They articulate very normal things and implore the viewer to see these abilities rather than the disability, even if having a girlfriend or being a best friend are not particularly skillful acts. They encourage viewers to view people with Down syndrome as normal parts of their social world and community, as living similar lives to their own, and as people worth building friendships with, employing, and rethinking. They suggest a normal social role can and should be occupied by this population.

The program where I did my research takes this normalization and mainstreaming a step further by advocating for the full inclusion of individuals with intellectual disabilities that are able to work in the workforce. It exists in a context where there are no programs which fully support individuals with intellectual disabilities in the workplace. The main program options for this population are a local L'Arche community, where people with intellectual disabilities live with people who do not have intellectual disabilities in integrated, but separate communities; services accessed through Community Living which supports people with intellectual disabilities in finding and

keeping employment, but with less support than the program offers; and centre-based programs. The program is advocating for normalization in the field of work, and arguing that with the right supports, accessing work and the further community inclusion that accompanies it, is possible. While the program is restricted to people with intellectual disabilities, its aim is to be as integrated in the community as possible.

The history I have traced in this section shows how the social role of people with intellectual disabilities has changed based on conceptions of this population, methods of managing this population, social discourses, advocate activism, and legislation. The height of the abusive treatment of this population through institutionalization and negative eugenics combined with movements for civil rights and social change, led to the eventual legal battles and legislative changes that have led to the current social role of people with Down syndrome. This current role is one where inclusion in the education system and community-living situations is largely established and expected. However, it is also one where employment is implicitly deemed unnecessary for this population, where their social presence is largely conceptualized in terms of novelty and charity, and where they are still generally removed from society through segregated, workshop-based programs after secondary school. Rather than accessing the full rights of an average adult, they are often socially positioned as child-like dependents in need of care rather than autonomy and assistance. Additionally, their positioning as living dangerous, negative, and burdensome lives still has a significant influence on their social positioning, as is proven through the general expectation that fetuses with Down syndrome be aborted when detected through prenatal testing. Accessing healthy sexuality, relevant employment, full social lives, and community-inclusion is still a struggle for this

population, and their long history of dehumanization, neglect, abuse, and social removal still influences society's general conceptions and expectations of them. While they have been reintroduced into the community, they have not been given full access to an adult social role, which the program where I did my fieldwork recognizes, and seeks to change.

Intelligence

Just as the social role of the category we now know as Down syndrome has a complex history, so too does the notion of intelligence, and its standards and measurements, as a means of categorizing and othering intellectually disabled individuals. Idiocy again serves as a key term for understanding this establishment of measurable intellect, as standards of intelligence were intrinsic to formalizing and assigning the category. The root of the category of idiocy's creation was based on an understanding of those to whom it was applied as having below average intelligence, requiring support and management, and needing exemptions from typical rules and laws. As the category became formalized, standards were developed for determining who would be officially categorized as an idiot. These standards were central to establishing the legitimacy and permanency of a category of abnormal, disabled other based on intellect. Taking up Bowker and Star (1999), exposing these standards is central to showing the ethical and dangerous decisions that were made in creating the category of intellectual disability, in determining what would be made visible through the categorization, and who would experience the barriers and torque that the categorization creates. The majority of standards created focused on tests of intelligence and further established that perceived intelligence and capabilities would determine who would occupy the abnormal category.

In 1590, Henry Swinburne, a British lawyer, gave a specific summary of the definition of an idiot in his “A Brief Treatise of Testaments and Last Wills,” in which an idiot was defined as of lawful age yet witless to the point of not being able to count to twenty, tell his age, or know his father. Tests of competence, then, were clearly outlined as part of the determination of idiocy (Wright 2011:21). In defining the category of idiocy, Swinburne also clearly defined the standards required to apply the category to an individual. By establishing these initial standards for these categories, Swinburne made the first known contribution to the stability and validity of the category, by suggesting exactly who could and would occupy the category of idiot socially and administratively. Swinburne’s tests of competence clearly defined level of intelligence as a clear indicator of idiocy. While Swinburne was defining the category in his well-known document at the end of the 16th century, the first formal use of the term idiot was not until fifty years later.

By the 18th century the process of deciding who would be categorized as an idiot became more formalized through public enquiries under the Crown called Inquisitions, in which local officials formed juries of “respectable men” to determine, based on evidence presented, the categorization of individuals (Wright 2011:23). Whether they were an idiot or lunatic, how long they had been one, the degree of impairment, and whether there were heirs was all determined by these juries (Wright 2011:23). In order to access the protection and guardianship of the category, then, the individual had to accept, or more likely be assigned through competence tests, testimony, and family petitions, the reduced subjectivity that the category implied.

These more formal tests further validated the category, its connection to intelligence, and the implications of being assigned to the category of “the idiot.” The

competency tests formalized through the Inquisitions also solidified the understanding of a bodily, corporal nature of intellectual disability, as physical appearance and health were introduced as an aspect of the diagnosis decision. The “size of their heads, deformities, or enlargement in their features, and vacuousness in their expressions,” were means of judging an individual’s status as an idiot, suggesting a conflation between physical disability and intellectual competency (Andrews 2002:70). The category of idiocy, then, mapped intellectual capacity onto physical characteristics, by allowing head size and the ‘punishment of their bodies’ to be used as aspects of their categorization.

Through the identification of the physical alongside the intellectual by intellectual men, physical disability could be read as a marker of reduced intellectual capacity, allowing both categories to be co-produced and to inform each other. The incorporation of physical markers of disability into the category of idiocy would result in the individual with a physical disability being read as less intelligent, and adopting the implications of the idiocy category. At the same time, the individual with an intellectual disability may be able to pass as fully capable until formally categorized, but then would be understood as less physically capable due to their intellectual disability. This conflation of the physical and intellectual would allow for phrenology and other future means of categorizing and developing standards that root the intellectual in the measurably physical.

The development and popularization of the IQ test in the 1900s had a significant impact on the categorization of people with intellectual disabilities as well as their concrete positioning as less-intelligent, less-capable, disabled individuals. The development of this test stemmed from a problem noted by educational psychologists in

the early 1900s of inconsistent and conflicting medical categories and systems of classification for the individuals being placed in institutions (Zenderland 1998:90). In response to this problem, they sought to develop standards of classification through tests of intelligence. These tests first required a standardized understanding of “normal,” against which abnormal intelligence could be judged (Zenderland 1998:89). Alfred Binet undertook this kind of standardizing work in France, by systematizing “the assessment of mental ability based on simple tasks commonly performed by specific age groups” (Wright 2011:94). Binet used children in Parisian schools to produce a scale of age-based normal cognitive abilities, linking age with intellectual understanding. His tests compared intellectual capability only, rather than conflating physical and mental disability which had remained common up until this point (Wright 2011:94-95, Zenderland 1998:95).

Through these tests, Binet was able to establish a standard of classification which could then be used by professionals outside the psychological profession. In creating tests for use in institutions, Binet’s new approach to classification involved:

Arranging a series of simple tasks and questions according to their degree of difficulty, as experienced by normal children ages three, five, nine, and eleven. The simplest involved following a lit match with one's eyes, the most difficult answering abstract questions. Other test items contained in this scale asked children to identify objects, to make rhymes, to compose sentences, or to compare lines of different lengths... he recorded the number of tasks or questions completed satisfactorily. (Zenderland 1998:96)

Binet used these tests to create category standards for the classification of idiots, in that, “institutional patients labeled idiots... did not seem able to go beyond the sixth of his thirty tests, while those labeled imbeciles rarely got beyond the fifteenth” (Zenderland 1998:97). He also used the test to create norms for children of different age groups, against which a child's mental age could be determined (Zenderland 1998:97). Binet's

scale eventually became the Stanford-Binet scale and allowed doctors to rank individuals based on mental age in the form of IQ, where a normal child ranked at 100, a mentally deficient child ranked below 70, and in Lionel Penrose's The Biology of Mental Defect an individual with Down syndrome ranked between 20 and 25 (Wright 2011:95-96). Wright explains that through the IQ test, “individuals with Mongolism had their intelligence ranked by numerical equivalents, thereby enhancing the scientific justification for their diagnosis, education, and segregation,” and the test provided the means for the ranking of intellectual disability from “low through moderate, to severe” (Wright 2011:96). Binet had intended the test to be used for education; however, Henry Goddard, an American psychologist, and other eugenicists coopted the test to “identify and segregate the unfit” (Wright 2011:95).

This test would and still does have an interesting looping effect for the category of Down syndrome. The use of the IQ tests by physicians to position individuals with Down syndrome's intelligence and capabilities in terms of age, allows them to be conceptualized as halting learning and development at that point. The result of this would be that they were and are largely unexpected to excel beyond the intellectual capacity expected of their ‘developmental age,’ which would likely impact the education and treatment they receive. Thus, they would be unlikely to have access to the resources and intellectual challenges that would allow them to excel, causing a looping effect of their only being mentally and intellectually developed to whichever IQ score they received, rather than potentially developing further. The looping effect here would be similar to that of Hacking's “inaccessible kind,” in that it would be more likely to impact the behaviours of the larger human unit around the kind, than the kind itself (1995:374). It would cause the

human unit to have minimal expectations of the kind and offer them minimal resources as a result. However, I want to be careful here; I am not suggesting that people with Down syndrome cannot understand how they are classified and so cannot create self-conscious feedback, as Hacking argues of the autistic child, as my fieldwork proves they can and do, only that their management was so restricted and contingent on their dependence, that behavioural looping seems more likely to be occurring in the larger human unit at this point than with the actions of the individual.

Additionally, while developmental age and IQ are still in use and applied to people with Down syndrome, they are flawed concepts that do not allow for the nuanced, complicated maturity and intelligence that they actually experience. The IQ tests created a very strict definition of what counts as intelligence, pre-setting the type of intelligence that will be counted within the infrastructure of the test. That the IQ test gained popularity in the fields that intervene in the lives of individuals with Down syndrome is important, as it continues to be used as a means of quantifying their intelligence as below average and asserting their reduced animacy and humanity. The IQ test also positioned individuals with intellectual disabilities as perpetually children, in that their low IQ is conflated with a permanently mentally young state of development. This allows physicians, caregivers, and others who interact with these individuals to treat them as if they are children, which, according to Hacking, would result in their accepting their childish position and changing their behaviour accordingly. The IQ test, then, created a conception of them as undeserving of the full rights and autonomy of an adult, which is rooted and solidified in their child-based mental age. If they are not adults, but when adult aged are still equivalent to children, then they are less fully animate than their

'normal' counterparts. The IQ test also created a new conception of normalcy, that is not only determinable based on success at basic mental tests and consensus, but which has been standardized, and in that is measurable. So, an individual with Down syndrome is a human kind whose abnormality can both be measured and hierarchized, and in that their position as an abnormal human kind becomes much more static. The quantifiable nature of the Down syndrome human kind that the IQ test creates makes the resistance of the kind that the participants in my research undertake a difficult task. The measurable nature of their abnormality allows their placement in the subjected kind to be assigned cultural validity. This validity, which is based on the assumed validity and popularity of the IQ test itself, means that in order to effectively resist the kind they must prove the implications of the test invalid.

The history of measurable intelligence as a means of assigning disability shows how a lack of a particular type of idealized intelligence became a means of creating a category of subjected others. It shows how proofs of unintelligence were used to formalize the disempowered position of the intellectually disabled individual. It exposes the ways in which standards were created to justify the abnormal category. It shows how the view of the powerful men who established these standards of intelligence were prioritized and valorized in these instances, and the views and opinions of those being categorized were silenced. The creation of official tests of intelligence including the IQ test established that only a limited means of expressing knowledge would be accepted as proof of intelligence. The IQ tests also solidified the dehumanized position of people with intellectual disabilities by suggesting that they are permanently child-like, and so are

never capable of full adult development and are never requiring of the full social role, rights, or possibilities of adulthood.

Education

The changing understanding of the intelligence and capabilities of people categorized as idiots had an impact on the educational efforts that were imposed on them and accessible by them historically. While standards of intellect were just a means of ordering humans and establishing their belonging to the category of idiocy at first, eventually the understanding of intelligence as educable resulted in attempts at “improving” individuals with intellectual disabilities. The reasons for and goals of these educational efforts have changed significantly from the Enlightenment, when they first became the focus of educational efforts, to the present day. These educational efforts, however, and their categorization within them, have consistently been a source of torque for this population.

The Enlightenment movement in the mid-17th – 18th century had a notable impact on the understanding of idiots and their education. John Locke's contribution to Enlightenment thought had particular implications for the understanding of intellectual disability. First, Locke used people categorized as idiots to undermine Descartes' argument that individuals are born with innate logical ideas, and to argue that humans' ideas and mind are shaped by their experiences in the world. For Locke, idiots were “unable to perceive, compare, distinguish, or to abstract concepts and ideas,” moreover, for Locke, “idiots could not draw conclusions from their sensory perceptions, which... placed them on par with 'beasts' and the 'non-human'” (Wright 2011:30). Locke, then, invoked an animacy hierarchy in 1690, using cognitive understanding to place those with

intellectual disabilities as subhuman, and as such implicitly less animate. While for Locke idiots were just a means of proving a point and so he never conceptualized a full theory of idiocy, his writings allowed for a “new philosophy of the mind” which claimed “minds – any minds – could be improved given the right environment of sensory stimulant... all individuals were capable of some intellectual improvement,” and has had a significant impact on contemporary education and understandings of disability (Wright 2011:32).

Aspects of the Enlightenment movement premised that human behaviour, like the natural world, had laws that could be understood and environments that could be manipulated. From this came an understanding of humans as improvable through investigation and education (Wright 2011:32). This resulted in medical practitioners using children with disabilities as test cases, as “quasi-experimental subjects of a more general enlightenment project,” to understand the underlying laws of human disease and disability. The premise was that if people understood to be incurable, like idiots, were able to improve their skills and “life status” through education and scientific study, they would be proof of the effectiveness of the Enlightenment project (Wright 2011:33). The Enlightenment project, then, had a fairly fluid understanding of the category of idiocy. Of particular note was the case of The Wild Boy of Aveyon, a young mute boy brought to Jean Marc Gaspard Itard when the latter was a young physician, who had been “captured running wild in the woods,” and deemed an incurable idiot. Itard wanted to “elevate the boy from savagery to civilization,” an allusion to problematic understandings of people with disabilities as representative of an earlier stage of human evolution which becomes of particular importance later in history. Itard failed to fully resocialize the boy, but did teach him to identify letters and understand simple words (Wright 2011:35).

These types of experiments were a positive part of the beginning of education efforts for people with intellectual disabilities, and accessibility aids for others with disabilities, but they were also sources of torque and they solidified the understanding that the idiocy category implied that those categorized are something less than human to be developed and improved upon. When researchers used idiots as test cases their lives and minds were assumed to be malleable, unnatural, and treatable. As people with intellectual disabilities they were subhuman, underdeveloped beings, who could potentially be improved through medicine and experimental techniques which would bring them to higher states of cognition and abilities of communication, and therefore to higher states of humanity and animacy. While the understanding of their intelligence as malleable resulted in problematic experiments, it also allowed for the category of idiocy to be destabilized through their understanding of it as potentially non-permanent.

The educational experiments of the Enlightenment movement influenced the treatment of idiots as institutions became the dominant means of managing this population. Down was a proponent of using institutions to rehabilitate and improve the condition of idiots. As a result, when Down established the category of the “Mongoloid idiot,” he argued that rehabilitation was a possibility for this group, through tongue exercises, for example, as a means of them reaching “normalcy”, or rather, something closer to humanity (Neri and Tiziano 2005:16). However, these interventions were still based on an assumption that “Mongols” were unnatural and needed help accessing full humanity. While Down’s categorization of people with intellectual disabilities was problematic and only accurate in the grouping of people with Down syndrome as a distinct group, it allowed for particular interventions to be developed that applied

distinctly to those with Down syndrome. These included the rehabilitation efforts like those used by Down, but also education efforts following from physician Edouard Séguin. Of particular note, was Tredgold's textbook *Mental Deficiency* which outlined the possibility of literacy for these individuals and outlined some of his “experimental concoctions” for their treatment (Wright 2011:74-76). The use of institutions as places of potential tailored education and rehabilitation would be overshadowed, however, by the eugenics movement’s taking up of this population in both positive and negative eugenics efforts.

The normalization movement and parental advocacy resulted in individuals with Down syndrome becoming included in the school system in the form of segregated schools, eventually segregated classrooms in general schools, and in some cases currently integrated into the general classroom. Even so, individuals with Down syndrome still experience problems with the education system’s approach to their perceived intelligence and capabilities. Even with the categorization and individual education plans developed to provide students with Down syndrome and other intellectual disabilities with an education experience similar to their non-disabled peers, torque is still experienced by these individuals in schools.

In Ontario, the Ministry of Education categorizes students based on their learning potential within the education system, and those that are outside of the norm are placed in categories of “exceptionalities” (Ontario Ministry of Education 2001:A20). These exceptionalities include the categories of having a learning disability, having an intellectual disability, or having a developmental disability, and often encompass students with Down syndrome (Ontario Ministry of Education: 2001:A16-A20). Those who are

identified as having an intellectual disability (a learning disorder) or as having a developmental disability (a severe learning disorder) are ineligible to receive a diploma after completing secondary school if they access “alternative” (Ontario Ministry of Education 1999:58) curriculum which is not eligible for credit. Since a minimum of 30 credits are required to earn a diploma, these students are rendered ineligible (Ontario Ministry of Education 2001:A21). They instead get a certificate of accomplishment from the principal when they leave secondary school, often after being there for six years (Ontario Ministry of Education 2001:62). However, there are some individuals with Down syndrome who have successfully taken secondary school courses without significant enough mortifications to render their curriculum "alternative," and so have been able to earn the credits required to complete secondary school and earned a diploma. It is also important to note that some individuals with Down syndrome take university classes. The case of Jaffer v. York University is an important example of this, as Ashif Jaffer sued York University in Ontario for failing to accommodate him appropriately resulting in his failing to complete his first year (CanLII 2009).

All of the participants who took part in my fieldwork were ineligible to receive secondary school diplomas. So in their cases, even with all the categorization work and distinguishing of different syndromes and their characteristics, and arguments by Penrose and others about the varying abilities and mental capabilities, even nuanced intelligence, of people with Down syndrome, they are still being treated as part of an ambiguous group of people with intellectual disabilities. While finer-grained classificatory systems which better articulate and attempt to meet the capabilities and desires of people with Down syndrome would be a potential solution to the torque this population experiences, a

willingness to expand notions of intelligence and valid accomplishment would be required to effectively reduce this torque. This need for a more varied understanding of intelligence and independent accomplishment was clearly articulated by Jaffer's assertion that York University had a duty to accommodate him in his legal case (CanLII 2009).

Through placement in the categories of intellectual and developmental disabilities by the ministry, this group is rendered universally knowledgeable as they do not fit within the standards of knowledge created by the ministry and society. As this system works relatively well for most students, the standards remain largely unquestioned. However, the ways in which these categories possibly do not work for those with intellectual or developmental disabilities remains largely unknown to the general public. As the categories are working for the majority who have the cognitive functioning, knowledges, and skills required for success in this system, in this case measured by diploma attainment, and as the skills and knowledges of these individuals are considered less valuable, to which this system contributes, the fact that these categories and standards are not working for students with Down syndrome remains unchecked and so the problematic categories that enforce this remain invisible.

This experience of the system breaking down for these individuals is what Bowker and Star (1999) identify as torque. They experience torque when they wish to attend a school; they may not be able to attend the school assigned to their residential area, as it may not have the necessary resources in place or it may not be willing to adapt the curriculum for the student. This is more often true of elementary schools, but even secondary schools vary in terms of the quality of their special education programming, and so an individual may have to make a choice between being in the same school as

their siblings or being in a different school which has the appropriate resources. The system is not set up in a way that allows for their success, and so although they gain knowledge, literacy skills, work experience, social skills, and often take part in elective courses, they do not receive anything that acknowledges these gains, as they do not fit within the category of a student who can graduate.

Although they receive a certificate of accomplishment at the end of their school career, it is administered by the school and school board rather than the ministry, and they receive nothing that acknowledges their individual skills or advances during the typically six years they attend school (Ontario Ministry of Education 1999:62). This creates further torque for them in society, as by being categorized as intellectually disabled they are almost entirely excluded from further education. By being denied any recognition for their secondary school accomplishments, they are unable to prove that they have individual, useful skills for the labour market. This categorization of them as individuals with intellectual disabilities within the school system is essentially a categorization of them as knowledgeless and skill-less and unable to meet the standards required for full participation in society. Although fulfilling the normalcy movement in terms of inclusion, the system fails to actually meet their needs or provide them with the means of entering their communities after secondary school, and so their social role outside of secondary school is crucially being shaped as well.

Through the Ontario Ministry of Education sorting these individuals into these strict categories of disability, they can define the purpose of the education system for this group as inherently different from its purpose for the rest of the population. According to

the Ministry's Special Education guide, the specific standards applied to the categories of intellectual "exceptionalities" used by the ministry are:

Mild Intellectual Disability

A learning disorder characterized by:

- a) an ability to profit educationally within a regular class with the aid of considerable curriculum modification and supportive service;
- b) an inability to profit educationally within a regular class because of slow intellectual development;
- c) a potential for academic learning, independent social adjustment, and economic self-support.

Developmental Disability

A severe learning disorder characterized by:

- a) an inability to profit from a special education program for students with mild intellectual disabilities because of slow intellectual development;
- b) an ability to profit from a special education program that is designed to accommodate slow intellectual development;
- c) a limited potential for academic learning, independent social adjustment, and economic self-support. (Ontario Ministry of Education 2001:A20)

Through the standards set by these definitions, they can define the limitations and expectations of all individuals with intellectual or developmental disabilities. While Identification, Placement and Review Committees exist to sort individuals into these categories (Ontario Ministry of Education 2001:A16), my fieldwork interviews with the program directors suggested many individuals with Down syndrome are sorted into the category of disability that assumes they will not be capable of paid employment and "social adjustment". This perpetuates an understanding of people with Down syndrome as having limited potential within the school system and after, which the program is proving is not necessarily the case. While Individual Education Plans are developed for each individual (Ontario Ministry of Education 2001:A16), suggesting the potential for education tailored to their needs, assumptions about their potential and a lack of support

prevents the education system from benefitting many of them in meaningful, individualized ways.

The school system, then, creates a looping effect in that the positioning of people with Down syndrome as knowledgeable prevents them from accessing proof of their acquired knowledges, furthering their positioning outside of the secondary school system as knowledgeable. It determines and negates their potential social role. Additionally, through the ministry treating all people with intellectual disabilities who are unable to take part in a regular classroom independently as a uniform whole, people with Down syndrome not only become ambiguously rather than distinctly categorized, but the resources they have access to during and after secondary school become indistinct and untailored to their particular needs, a reversal of the moves made by specialists like Edouard Seguin, John Langdon Down, and Lionel Penrose.

The history of the education of individuals with intellectual disabilities that I have traced in this section has shown that while accessing education is a largely positive resource for this population, the systems through which they have accessed education have historically been and continue to be sources of torque. The education system's positioning of these individuals as uniformly intellectually or developmentally disabled, allows their animacy to be more easily denied. If they are knowledgeable through their lack of the distinguished proof of knowledge usually accessed through the system, then they are inherently less animate, as human animacy through Chen can be seen as dependent upon an independent, rational cognition that is denied them due to their positioning as intellectually and developmentally disabled in the education system. If they cannot independently access the particular abstract, structured knowledge of the

school system, then they cannot be considered educated or knowledgeable humans. This continues the knowledge hierarchies of the IQ test.

Conclusion

This chapter has discussed the varying social roles of individuals with Down syndrome, the changing conceptualization of their intelligence, and the various means by which they have been conceptualized and acted upon through educational and rehabilitation initiatives throughout history. It is clear that the seemingly stable aspects of the Down syndrome categorization have actually been very ambiguous and shiftable throughout history. As a result, their lives have been transformed over and over again, as they occupied various animacy positions and experienced loopings based on their social position, intelligence position, and manipulation through education. The instability of the category over its history suggests that its present conceptualization and the influence it has on their lived experiences and material realities are susceptible to change as well. Through the work of people with Down syndrome and their advocates, the category which classifies them can be seen to be in the process of another wandering and reconceptualization.

While the existence of people with Down syndrome seems to be threatened by an increase in therapeutic abortions and their widespread social acceptability, there are factors that contribute to a continued presence of individuals with Down syndrome in Western society for the time being. These factors include an increase in the average childbearing age of mothers, that religious and cultural reasons cause some women not to have prenatal screening, and the success of infant cardiac interventions for children with Down syndrome resulting in more individuals with Down syndrome living to be adults,

and the greater longevity this population is experiencing (Wright 2011:183-184).

Individuals with Down syndrome will continue, then, to occupy an important social space. The combination of the cultural positioning of them as living lives not worth living combined with community inclusion efforts and organizations advocating specifically for people with Down syndrome and pushing for their rights and place within society, causes the category of Down syndrome to embody “seemingly contradictory impulses to both integrate and eradicate... [symbolizing] the awkward space occupied by many common disabilities... as societies grapple with profound and conflicting social, ethical, and scientific imperatives” (Wright 2011:186).

The category, then, continues to determine their standard of life, access to tailored education, prospects of inhabiting a fulfilling career, social position, income bracket, stigma, and social relations. It informs their prospects of flourishing as human beings, rather than subhuman subjects. However, I think it is important to note that while I have been speaking in terms of categories shaping experiences, and influencing social and self-conceptions, I have spoken very little about the experiences of people with Down syndrome from their own point of view. Their relative erasure from history, positioning outside of society, and limited access to appropriate education and literacy means their point of view is largely absent from any accounts that include them. What I want to suggest, though, is that although their categories act upon them, they are not necessarily merely passive recipients of looping effects and the systems that work against them. Instead, they actively conceptualize themselves in terms that subvert arguments about the value of their lives and their rightful positions in their communities, as the following chapters will show. Additionally, while those who work with them have a broader idea of

Down syndrome and their capabilities, these allies both assist in expanding understandings of Down syndrome and impose existing limitations onto them. Their self-conceptions and the work these self-conceptions do engaging with and simultaneously undermining their categorization and reduced animacy, are, then, important to explore.

Chapter 3: Complicating Down Syndrome: Resisting, Rejecting, and Disciplining the Category

My fieldwork began with a meeting with the founding directors of the program, Ellen and Janet. The intent of the meeting was to establish the final details around my presence at the program, including the frequency with which I would be there, the aspects of the program I would be allowed to be present at, and whom I would be working with. As founding directors and as parents of two of the participants, Ellen and Janet asked me about the nature of the questions I would be asking the participants. They requested that I not talk about or ask questions about Down syndrome directly. This was something that I had not expected when I was developing my research approach and planning my entrance into the field. They explained to me that talking about Down syndrome makes both their daughters visibly upset. Ellen's daughter Jennifer, she explained, knows she has Down syndrome, but does not like the term. Janet's daughter Carolyn expresses in frustration that she just wants to live a normal life when Janet attempts to talk with her about Down syndrome. They then told me that they were not sure which of the other participants would be comfortable or uncomfortable talking about Down syndrome, and so I better not broach the topic.

This request surprised me. Based on my experiences with my sister I have never censored myself when talking about Down syndrome. I expected that the young adults I would be working with would identify as having Down syndrome to some degree, regardless if they fully conceptualized Down syndrome in terms the medical system would agree with. Finding out that some of them strongly reject the identity led to a series of questions on my part including, "What negative associations do these

individuals have with the term Down syndrome?”, “Where do these negative associations stem from?”, and, “From their perspective, what does a negative, Down syndrome life look like versus a positive, normal life?” Not being able to ask the participants about their thoughts, feelings, and opinions around being a young adult with Down syndrome meant that I would not be able to answer these questions by talking to them directly. I would have to use guardian interviews and observations. However, because one of the participants was present when I described my project to an employer who asked about it, I was able to gauge whether or not he would be comfortable answering some questions about Down syndrome, and ask him some direct questions about it.

After asking guardians, and one participant, about how their son or daughter, or they, think and feel about Down syndrome, I found that the participants have four relationships with the term Down syndrome and the act of identifying with their disability: they reject the category completely, they disassociate from the category, they redefine the category, or they accept the category. I argue that in all but the final relationship with the term, the participants are actively resisting the medical and social category of Down syndrome and the implications it imposes on their lives. Even in the fourth relationship I have identified, I found that acceptance does not necessarily negate resistance. Through a negotiation of the term and what having Down syndrome means for the participants in the program, whether that be in terms of how it impacts their lives or if it impacts their lives at all, they are deciding for themselves the implications of being a young adult with a cognitive disability and the limitations they will accept. In doing so, they are able to complicate the assumed meaning of Down syndrome and the assumed

limitations that are treated as inherent to a Down syndrome identity by allowing for the possibility of having experiences that are outside of those limitations.

The participants' resistance and at times rejection of the category is actually quite logical as the category of Down syndrome is a less stable category than it is generally perceived to be. Down syndrome is complex in that as a medical category it impacts the individual's physical experience – how they move through the world, how their body develops, and their physical appearance, but it also impacts how they think, process, express and experience emotions, and learn. It is not a stable, uniform category, although it is often treated as though it is. While there are somewhat stable aspects of Down syndrome and it is perhaps fair to acknowledge that certain things like driving independently or working as an accountant are unrealistic goals for most these individuals, the degree to which an individual experiences each of these impacts varies from individual to individual. The reality of Down syndrome is varied and is designated by a cluster of experiences, material realities, and social relations, as I will demonstrate through my unpacking of the participants' relationship with the category below. It is impacted and shaped by the structures and expectations imposed on it, but it is also influenced and shaped by the experiences and expectations of those who occupy the category. As a result, Down syndrome as a cognitive and intellectual disability is not a stable, universal experience. Rather, it is varied and complicated. There are many realities and experiences of Down syndrome, and the participants' rejection of the category allows for an understanding of Down syndrome as outside of the assumptions and limitations held as stable and universal. So, even in the very rooted aspects of the syndrome that allowed for the medical and social category to be clearly defined by John Langdon Down

and eventually stabilized through medical discourse, there is still variety, inconsistency, and space for destabilization. Given the category's instability, the variety of relationships the participants have to the category, including the perhaps seemingly extreme rejection of it, are less surprising than they at first seem.

Additionally, as a social category, the way Down syndrome is perceived and the limitations these individuals are assumed to have impacts their opportunities and experiences to a crucial degree. The various ways that the participants relate and respond to the category show how fluid and unstable its ontology actually is. For the young women who reject the category, Down syndrome is primarily understood as a source of stigma, undesirable limitations, and unfair barriers. For the young man who disassociates from the category, it represents a significant limitation which does not accurately describe his experiences. For the individuals who redefine the category, it becomes comorbidities of the syndrome and the reason for their short stature. Finally, for those who accept the category it may be facial characteristics, a difficulty in learning without support, a minor component of their life that does not strongly mark them as different, or the reason for micromanaging and social barriers in their life. In all these cases, by destabilizing Down syndrome's ontology through separating their understandings of Down syndrome from the medical and social understanding which is culturally held as stable, these individuals are insisting on understandings of Down syndrome and their experiences that do not comply with the medical expectation. In that, their independent understandings of the category create space for framing the medical ontology of Down syndrome as inaccurate in its assumption of stability, for framing the social and cultural response to the category as unjustified in creating universal barriers and limitations for

this population, and for thinking about the ways in which the social and cultural position of these individuals disables them much more than their cognitive or physical experiences.

Rejection of Down Syndrome

Rejection of the category came strongest from Jennifer and Carolyn. As I was advised not to talk to either of them about Down syndrome, my understanding of how they reject and resist Down syndrome came exclusively from an interview I did with Ellen and Janet, their mothers, during which we talked about the program and their daughters, and a separate interview I did with Jennifer's father, Collin. When I asked Ellen and Janet a question about how the program negotiates the topic of Down syndrome, Ellen explained:

With Jennifer we've tried, over the years we've tried to explain about Down syndrome and she'll have nothing to do with it, 'I don't want to talk about it' and I've got this really good stuff from a Down syndrome association in Scotland, and it was just this great like a social story, nothing to do with it, 'I will not discuss this with you'.

In his interview, Collin suggested that this might be changing for Jennifer:

We've talked to her about it, but she doesn't like talking about it. We've told her and we've talked about it and gone over it a few times. There was a time when she didn't like to hear the word mentioned, I think she's more comfortable with that now.

While In Carolyn's case, Janet explained that she has:

Said to me stuff like 'I just want to be normal' when she's had a bad day or whatever, so I always turn it back on her and say, 'well what is normal? You know, her sister's 6 feet tall... I said who do you know that's completely normal? Everybody's got a little something,' so I try to turn it back that way.

In parallel with Janet, Ellen added, "and Jennifer will say 'I want a normal life'."

In both Ellen and Janet's stories their daughters assert normalcy as a counter to

Down syndrome. The desire to live a normal life seems to require a rejection of the Down syndrome category. If they want to flourish and have the same opportunities as a young adult without Down syndrome, then they must assert their separation from the category or risk being limited by a Down syndrome label and confined to the medical ontology. This is suggested by Carolyn's declaration of wanting to be normal when she has had a bad day, as this assertion shows that she recognizes that there is something making her days difficult and causing her frustration that she wants to separate from. As Janet explained later in her answer, "she definitely knows she's different," but she clearly refuses to identify with that difference.

From both Collin and Ellen's answers to my questions, Jennifer's assertion of wanting a normal life goes beyond basic life goals. Her assertion of wanting normalcy is about a desire to take control over her life. As Collin explained, "I'm not sure she really understands what [Down syndrome] means other than she's different. And she sees that as in the way of her being independent or us letting her be independent. So she would see it as a control thing". He talked about starting a family and driving:

My [two other] daughters both have babies, so I'm sure it makes her mind spin. And not driving a car when other people are driving their cars. So there are things that she's aware that she's different, I'm not sure if she sees them as being limitations, as much as she sees she's different than other people in that way, or she's not allowed to do that stuff.

In both these statements Collin emphasized a lack of control and independence for Jennifer. Jennifer's feelings of a lack of control over her life were also mentioned by Ellen when, during our interview, she told a story about a career placement test for individuals with intellectual disabilities at a local college, which told Jennifer she could "be an airplane pilot or she could work in a bank," the unrealistic results of which have

become career goals for Jennifer which Ellen thinks she sees her parents as “standing in the way of”.

For Jennifer, then, it is possible that adopting a Down syndrome identity is equivalent to renouncing control over her life. Having Down syndrome means being prevented from living the “normal” life she would like to live. For Jennifer, this life includes moving out from her parents’ house, moving in with her boyfriend who is also a participant at the program, potentially driving and starting a family, and progressing in her work. She identified these things to me when I asked her about her future aspirations, identifying her dream job as “a job I want to do is work at the bank and take some money out in the city,” and identifying a desire to move out on her own with her boyfriend by the time she is 32, if not immediately. While on other occasions Jennifer also identified working at Canadian Tire and a grocery store as jobs she would enjoy doing, progressing in work and moving out on her own remained consistent parts of her life aspirations.

Similarly, as her parents both identified, a feeling that her parents are standing in her way often came up when we talked. Jennifer’s mother helped start the program, which aims for further independence than is currently normally offered to young adults with Down syndrome. So, while she assigns the blame for the lack of control and independence she feels in life to her parents, it is unlikely that they are intentionally preventing her from accessing the control she desires, although they may be unconsciously perpetuating ableist social barriers. Instead, they likely represent the many social and cultural barriers that create a general feeling of powerlessness and frustration for Jennifer. Rejecting a Down syndrome identity means rejecting the dependence and powerlessness that the term implies, and so refusing to acknowledge or discuss the

identity becomes a means of asserting independence. By rejecting the identity, Jennifer is able to focus on the ways she is being prevented from accessing what she desires by the disabling society and culture she is a part of, rather than by her Down syndrome.

In Carolyn's case, her resistance to the label and the implications of having Down syndrome is furthered by the way she relates with strangers who also have Down syndrome. Janet explained that when Carolyn is out in public:

And somebody approaches us that has Down syndrome, someone she doesn't know, but she knows they have it. She gets this look on her face, and she doesn't want to look at them, and she's pretty snooty about it. But when she comes to [the program], I'm sure she knows that all her friends are disabled too, but they're a completely different story... when she goes to a special Olympic swim meet say, the people on her swim team, that's all cool and everything, but then the other people who are acting disabled she just kind of looks at them like "hmmm". It's pretty funny, she's kind of snooty about it, but with the people she's around she would never do that to them because they're friends, and I'm sure she knows Jennifer has Down syndrome, but it's really weird.

Carolyn not only rejects a Down syndrome category, then, but she also rejects strangers who have it as well. She clearly recognizes the physical indicators of the syndrome, and, as her mother guessed, likely recognizes it in her peers, but she feels the need to separate herself from people who are "acting disabled". Part of seeking normalcy, then, is placing herself above strangers and disassociating from a wider community of intellectual disability. Complicatedly, she is participating in a program that is creating a community of particular adults with intellectual disabilities within the larger community.

Ellen interprets Carolyn's behavior as "once she gets to know the individual who has the disability, the disability disappears," but I think Carolyn's perception of her peers is more complicated than that. Ellen's assertion that the Carolyn acts snooty towards people who are "acting disabled" coupled with her strong rejection of a Down syndrome identity, suggests to me that Carolyn can separate herself from the category of Down

syndrome, those to whom it normally applies, and an overall disability identity without having to separate herself from her friends by making a distinction between the insiders she accepts and the outsiders she rejects. The insiders, her peers, are those whom she knows and so are normal and are associated with a normal life. They have similar goals, minimal support needs, and do not put her in danger of being associated with the behaviour and limitations of Down syndrome or an even more disabled identity. The outsiders, the ambiguous stranger at the mall and the unknown members of the opposing swim teams are inherently risky. They may be too disabled, may require too many supports, and may not have the maturity and level of ability that Carolyn has. Associating with them puts Carolyn at risk of being grouped with them into a category of disability she rejects, and so they are inherently in contradiction to normalcy and a normal life as long as they remain strangers.

Disassociation from Down syndrome

While Carolyn and Jennifer completely reject a Down syndrome identity, Kyle, another participant at the program, accepts it for others, but not for himself. He disassociates from the category in a similar way to Carolyn, except that he is willing to acknowledge that the identity exists, that his friends and strangers have the syndrome, but he is not necessarily willing to apply it to himself. I was able to separately interview Kyle's mother and father and ask them about Kyle's relationship with the term. When I asked Kyle's mom, Sylvie, if Kyle is aware of his limitations, she told me, "we'll say something about Down syndrome, like 'does that person have Down syndrome too?' and he'll say 'yes they have Down syndrome, but I don't' and he's never actually come out and said that he has Down syndrome". When I asked Kyle's father, Nathan, if he thinks

that Kyle knows he has Down syndrome, he answered with a strong yes. However, he also suggested that it might be more ambiguous for Kyle than that, since when I asked how he thinks Kyle feels about it, he answered, “I think he sees that he looks, physically, he looks a little different than mom, he looks a little different than dad, but similar in some ways,” then went on to tell a similar story about Kyle answering yes or no when asked if someone else has Down syndrome. Similarly, Kyle’s mother explained that while he will not apply the term to himself, and she does not “think he cares either way, whether it is Down syndrome, whether there is a reason why he can’t do things,” he does acknowledge limitations he experiences: “He does know that he can’t do something because he’ll say ‘my legs aren’t fast enough’ or ‘my fingers won’t do that’”.

Both Kyle’s mother and father suggest that while Kyle deflects a Down syndrome identity and will not identify with it when asked, he does not completely reject it. He is comfortable with acknowledging that his peers have Down syndrome, identifying it based on physical characteristics, and identifying that he has limitations, but he still negotiates the ways in which the category is applied to him. Sylvie’s depiction of Kyle acknowledging that his “fingers won’t do that,” suggests that Kyle understands his limitations as a non-troubling aspect of who he is. In the same vein as someone might be a fast runner or be a poor athlete, he just is not particularly skilled at certain things, but it is not because he has a disability. This resistance allows him to imagine himself outside of the imposed limitations of Down syndrome, as it does for Carolyn and Jennifer. However, in Kyle’s case a general feeling of happiness with his life and identity was emphasized by his parents, rather than the strong refusal to talk about the subject identified by Ellen and Janet.

Redefinition of Down syndrome

While Kyle negotiates a Down syndrome category through reassigning the reasons for his limitations onto skillfulness and an unwillingness of his body to meet expectations, other participants at the program negotiate the identity by reassigning the meaning of Down syndrome to something other than the medicalized, social understanding of the term. Greg is a participant at the program that I was able to ask about Down syndrome. We talked about the term while he worked at a gym one afternoon. I started by confirming with him that he would be comfortable talking with me about the subject. I then asked him, “What does it mean that you have Down syndrome?” to which he responded, “It means, I think it means that something part of my body’s not growing”. I asked Greg if all his peers at the program have Down syndrome, and he confirmed that some do, but not everyone. So I asked him how he knows who does and he told me, “cause I figure it out,” when I asked how he does this, he told me, “I just knew if they’re tall or not”. So, while Greg understands that he has Down syndrome and that some of his friends do as well, he understands Down syndrome as being the cause of short stature. This is interesting, as many individuals with Down syndrome are significantly shorter than the other adults in their families, and so Down syndrome does tend to cause short stature.

It is likely that Greg and Kyle struggle to understand the cognitive impact of Down syndrome. As Jennifer’s father suggested when I asked him about it, “I’m not sure, you know again, that cognitive piece, I’m not sure she really understands what that means other than she’s different”. Understanding the cognitive impact is difficult, particularly when it is being experienced and has always been experienced by the individual. While

she is comfortable identifying as having a disability, my sister misidentifies the meaning of having Down syndrome in a similar way to Greg. When I ask her about it, she struggles with identifying what exactly Down syndrome means, guessing that it means she is short or cannot walk long distances, conflating it with her health problems which are co-morbidities of Down syndrome, and so an aspect of her Down syndrome diagnosis. She also identifies as being good at math, a good reader when it is not “high level,” and a quick learner. While she will identify as having Down syndrome, for her Down syndrome is not a cognitive, bodily disability, it is pulmonary hypertension (a comorbidity of the syndrome), short stature, and low stamina, as these things are the only major limitations she perceives in her life.

The participants are well aware that they have been segregated into special education classes and are being prevented from accessing higher education. So, while their redefinition could be attributed to cognitive limitations and a lack of understanding, I think that the stigma associated with intellectual disabilities should be considered as well. This stigma exists in larger society as well as within the disability community, and functions to denote intellectual disability as one of the most, if not the most, denounced category of disability. Even disability activists like Eli Clare have a tendency to insist on their intelligence in order to avoid being misidentified and oppressed as intellectually disabled based on their physical disabilities (2009:82-83). So while the participants struggle with articulating the intellectual limitations they experience through having Down syndrome, I believe that they are also avoiding acknowledging cognitive limitations and are purposefully identifying with intellectual capability.

Even as my sister identifies as a good reader, she simultaneously acknowledges that she does not enjoy reading when I encourage her to read at home, and accepts my help with reading text when we are watching movies and playing video games. However, she will not incorporate her struggles with reading into her identity, beyond grouping all the reading she struggles with into the category of “high level,” and exceptional, reading. Being able to claim intelligence is a source of pride for my sister, and most of the participants. Acknowledging limitations in intelligence, then, would be a source of shame and stigma, significantly more than acknowledging minor stature limitations or more legitimately medicalized health problems. So, while my sister recognizes that she has a disability, I think it is fair to argue that in only articulating the physical limitations she experiences and stressing her cognitive successes, she is resisting the cognitive implications of that disability.

Regardless, in both Greg and my sister’s cases, their relationship to the category, identities as people with Down syndrome, and comfort with talking about Down syndrome are all in terms of Down syndrome as comorbidity and bodily impact. When they are agreeing to speak about Down syndrome with me or are acknowledging that they fit within the category of a young adult who has Down syndrome, they are doing so in terms of Down syndrome as a cause of short stature, heart and lung conditions, and low stamina. They are correct in identifying that they experience these things because they have Down syndrome: the majority of individuals with Down syndrome experience shorter stature than their siblings and heart and lung conditions are common in newborns with Down syndrome. However, what I’m trying to emphasize is that when they accept a

Down syndrome identity, they are not accepting an intellectually disabled identity. As for Greg and my sister, Down syndrome is not intellectual disability.

It is, arguably, the cognitive experiences of young adults with Down syndrome that are used as the basis of most of the limitations put on them in society. Their prevention from learning to drive, working particular jobs, accessing paid work, and having children are all based on how general society and their caregivers perceive their cognitive, rather than physical, limitations. Greg, Kyle, and my sister all root their experiences in the physical, and whether that is intentional or because of a misidentification of what having Down syndrome means medically, this physical rooting avoids acknowledging the impact it has on their cognitive experiences. By refusing to acknowledge any cognitive limitations, these individuals can be understood as refusing to accept the barriers imposed upon them. They create a position for themselves that allows them to negotiate their lives as individuals with some physical limitations, but without cognitive limitations. They are intellectually capable and so can still eventually have the full lives they expect.

If rejecting a Down syndrome category, disassociating from it, and redefining it are all forms of resistance as I argue they are, then I think it is necessary to think about what resisting the category allows for these individuals. For Jennifer and Carolyn, resistance can be understood as creating space for these individuals to negotiate a “normal life”. In the present this looks like volunteering and working towards, or gaining, paid employment. It looks like having romantic relationships with other individuals with intellectual disabilities or aspiring to have romantic relationships. For many of them, it also includes a future where they are living apart from their parents. Less realistically, it

would include driving a car and maybe even an airplane. Resistance also creates the space for them to imagine ideal lives. For example, for Carolyn an ideal life would include moving to New York City, working at a fashion magazine, potentially going to university, and with some luck, running into some of the cast members from Glee, on the streets of New York. For Greg, it would include becoming a Special Ops agent or a fire fighter.

Acceptance of Down syndrome

In contrast to the previous three approaches to a Down syndrome identity, some of the parents suggested that while their son or daughter sensed limitations that they were experiencing that their siblings or other adults were not, they did not feel upset about or strongly resist the category. In Susan's son Eric's case (who did not end up a participant in my research), she explained that he has an idea that he has Down syndrome, telling me, "I don't know if he really understands exactly what it means, but I will tell him... he's aware that there's something that makes him not the same as everybody else". In response to another question she identified limitations she thinks Eric probably notices, such as his awareness that he will not get a driver's license and the fact that, unlike his brothers, he has to have a plan and permission if he wants to go out. However, when I asked how he felt about it, she responded:

I think that for the most part he's ok with it, but like I say I know that he realizes that there are things that he isn't doing or can't do that other people are doing, and I think that that's one of the reasons why it is really important to make sure that he has enough things to do that make him feel like he's doing something or that there's positive things in his life.

So while Eric recognizes that he has Down syndrome, and recognizes that he experiences exceptional limitations, he does not necessarily actively resist or contest that identity.

Debra's description of her daughter Laura's relationship with the term was similar. When I asked if Laura is aware of her limitations, Debra was the only guardian that suggested that her daughter was not aware of her limitations, answering:

For the most part no. I think for the longest time I thought she doesn't see herself as being any different. She doesn't catch on that she isn't doing things that other people are doing, or not understanding them at the same level or being able to do them at the same level. I don't know if it's unaware or what it is, I guess that's what it is.

Through subsequent questions about Laura's awareness of having Down syndrome and feelings about it, Debra depicted Laura as accepting the identity and her lived experiences:

She does [know she has Down syndrome], I think understanding what that was or what that meant was kind of a slow realization and it was kind of us explaining it to her. I mean she certainly doesn't understand the whole physical aspect of it or how does Down syndrome happens, but you know, that it's more difficult for her to learn new things, more so that aspect than anything else, but she never voices that she feels like she is different or can't do something as well as somebody else, or anything. She's kind of accepting of it. Or something. I don't even know how to verbalize it other than that. She'll say something every now and then about Down syndrome, not very often... So, I think basically it's just that 'oh it takes me longer to do things, I need more help to do things or to learn how to do something'... She doesn't really verbalize much about it. I don't think she thinks about it one way or another. From my perspective I don't think she thinks about it, dwells on it, is too concerned about it, thinks about it one way or the other. Like it's a fact. And I don't think she's given it much more thought than that.

Debra's explanation suggests that unlike Kyle and Greg, Laura has a fairly strong understanding of what Down syndrome is and how it might impact her perception of the world. Debra suggests that Laura does not attempt to negotiate the term in anyway, or

have strong feelings of resistance or connection to the category, nor does she negotiate the implications of the identity or disassociate from it. Debra is the only parent who did not list things that Laura cannot or does not do which she might wish she could. While Kyle's parents emphasized his feelings of content, his desire to have a girlfriend and drive were still brought to my attention.

I think it is interesting that even in the cases of Eric and Laura, where they seem to largely accept Down syndrome as a component of their selves, or at least do not actively resist or negotiate the identity, neither of them strongly identify with the category. Laura comes closest with her willingness to start a conversation about or ask something about Down syndrome on occasion, but I did not get the sense from Debra or my two months spent getting to know Laura that she strongly associates with the category to the same degree that Jennifer and Carolyn strongly resist it.

Identifying Down syndrome

Interestingly, although the cognitive aspects of Down syndrome came up with some parents, when I asked parents about their child's understanding of Down syndrome, they often rooted proof of their son or daughter's knowledge or understanding exclusively in the physical. However, rather than their stature, habitus, health, or skilled movements, the parents were using their children's ability to identify the typical facial characteristics associated with Down syndrome, the epicanthic eyelid folds for example, as an indicator of understanding. Susan, a mother I interviewed, talked about asking her son to identify Down syndrome based on appearance. Unlike Nathan and Sylvie who ask Kyle if strangers or friends have Down syndrome, Susan talks to her son Eric about it when they are watching television by saying "oh look that person has Down syndrome

too,” when they see somebody with Down syndrome on the screen. Additionally, Debra told a long story about realizing that Laura recognized she was different through her connection with the appearance of a stranger:

For the longest time I didn't think she thought she looked any different from anybody else or she recognized that there was any difference physically from herself to somebody else. But I knew that she knew enough that she recognizes other people. But I, I thought, does she not see herself? Like when she looks at one of the other kids at the program who has Down syndrome, does she recognize? Like she recognizes that they look different, but does she recognize that she looks different? And then one day we were at the dentist's office, and we were sitting there waiting for her name to be called, and I guess a young kid had been in the dentist's chair and had finished and was coming out to meet her mom, and this young girl had Down syndrome, so Laura all of a sudden says “that girls got the same face as me” and I was shocked because up until then she didn't ever really acknowledge any kind of recognition of how she looked or that she looked different from anybody else. She never differentiated herself from someone else... or well I'm different, or I look different from them, she just kind of always acted like she's the same as everybody else.

While Debra had never used other individuals with the typical physical characteristics of Down syndrome to gauge what Laura thought or understood about Down syndrome, Laura's recognition of her facial characteristics in another young girl was a significant moment and signifier of understanding for Debra. For the parents, the recognition of facial characteristics seems to be a crucial indicator of their child's understanding and acceptance of Down syndrome.

Sylvie argued during our interview that the physicality of Down syndrome, which is unique in its recognisability, is socially beneficial to the young adults:

Down syndrome's actually a good thing that way, that people can recognize, and I don't think you'd hear all parents say that, because I think years ago there was a big drive to do facial construction things and change the shape of the eyes and change the tongue and all sorts of things to make them look more normal. But for me I think Down syndrome is, it's nice that people can see that and maybe just take a step back if they are a little over-zealous about something, take a step back and say “oh, yes, ok” whereas I think people with special needs that look perfectly normal may

have a harder time fitting in out there because people's expectations are higher for them.

So while rooting Down syndrome in their physical bodies is a means of reassignment and resisting an intellectually disabled identity for the young adults, for the parents the physical facial characteristics are a signifier of Down syndrome which connects their children with their peers and strangers, influences the way they are treated and the expectations placed on them, potentially protects them from negative judgement, and which they see as an indicator of understanding and recognition for their children. Yet, for their children, rather than a means of resistance, the facial characteristics work against the young adults who wish to separate themselves from a Down syndrome identity.

While, the physical characteristics of Down syndrome, particularly the facial characteristics, can function to identify the participants as occupying the distinct category of intellectual disability, the degree to which this is true is ambiguous. While I was watching Kyle work at a community clothing store run from the church which the program works with, I spoke with a volunteer at the store about my project. She asked me to describe it, and upon hearing that my research was focusing on young adults with Down syndrome and finding out who my sister was, she asked me, "your sister doesn't have Down syndrome, right?" and proceeded to be surprised when I corrected her by saying that she did. Her comment was unexpected. I would assume that most individuals who recognize the characteristics associated with Down syndrome would immediately identify my sister as having it.

In fact, my interview with Ellen and Janet furthered this assumption, as Ellen asked if my sister gets stared at when we are in public, and I told her that she does. I often meet the gaze of strangers when we are in public together. Ellen expressed surprise at

this, explaining, “I do notice with Jennifer if we are out some place, she doesn’t get stared at a lot, I don’t see her getting stared at... and I’ll let Jennifer walk ahead”. Ellen’s comments suggest that the general public is more likely to respond to my sister as if she has a disability, and so assume her limitations, create barriers, and potentially also have more allowances for her, than Jennifer. The above anecdotes suggest that the identifiers of Down syndrome can vary in their recognisability between individuals, in that it seems as though in the same context my sister is being read as abnormal enough to gawk at, but Jennifer is not. However, that my sister is read as having the characteristics of Down syndrome in a public space, but not by a volunteer who interacts with her and her peers on a regular basis, and so is very familiar with the syndrome’s characteristics, suggests that even in one individual the characteristics of Down syndrome can be ambivalent and have inconsistent consequences.

The Program’s Approach to Down syndrome

Given that all the participants attend the same program, I was curious as to how the program’s approach to the participants, their limitations, their desires, and the topic of Down syndrome might impact the ways the participants conceptualize and relate with the identity. Collin suggested that Jennifer’s gradually increasing comfort with the term, something he identified that his wife Ellen did not, might be “partly probably because she’s here at [the program] and there are so many people with Down syndrome here, it’s used a lot, and so I think she’s just got used to it now”. Kyle’s father also specified that it was not until Kyle was 20 or 21, around the age he would have started at the program, that they could begin trying to approach the topic with him. So, when I interviewed Ellen and Janet, I asked them about their approach to the term:

Me: You mentioned to me when I first started at the program that some of the participants don't like to talk about the fact that they have Down syndrome, so how does the program approach those topics? Or the reasons why the participants aren't working independently or going to school?

Janet: I guess we don't really approach those topics at all...

Ellen: ...this is where you're at

Janet: With my three daughters I talk about them differently with their strengths and weaknesses. Carolyn has strengths and weaknesses, she's no different than the other two. With exclusion to going to university and driving a car, those two things have always bothered Carolyn, but I think otherwise she feels that she is the same as anybody else in our family.

Janet, then, sees the appropriate approach of the program as being similar to that taken in her family, which is one where differences are not necessarily acknowledged. Ellen's comment "this is where you're at" suggests that they acknowledge the participants' current abilities and goals, she later continued: "I can't say we do directly, we've done the abuse prevention course [which was specifically because they are vulnerable], but it doesn't come up that this is a program for people with disabilities". That Janet uses her approach as a mother to articulate the program's choice to avoid talking about the topics of Down syndrome and disability suggests that the founding director's experiences as mothers directly inform the program's structure and discourses. If they had daughters who related to the category more similarly to the acceptance exemplified by Laura or the redefinition and comfort expressed by Greg, they might have adopted more overt discourses of Down syndrome and disability and had an influence on the participants' relationship with the term. Given what Ellen and Janet told me, it is unlikely that the program's approach to the topic of Down syndrome directly influences participants' perceptions of the term. However, Ellen and Janet cannot speak to the ways in which their peers and the supportive, specific environment of the program might influence their relationship with the term and the ways in which having Down syndrome is or is not a component of their identity.

When discussing the influence the founding directors' relationships with their daughters has on the program, I am not suggesting that opting to avoid talking about Down syndrome and disability is a negative or wrong choice. Nor am I suggesting that having an influence on participants' relationship with the term is positive or negative. However, their choice to avoid these discourses potentially has an impact on the disciplining possibilities of the program, which will be discussed in the next chapter. By avoiding talking about the participants' categories of disability which are essential to their program membership, the reasons for their membership at the program, the power structures enforced by the program, the support required by the participants, and the disciplining that takes place are implicit aspects of the program which must consistently go unacknowledged. Additionally, their intersecting position as founding directors and mothers, specifically mothers of daughters who strongly resist the category of Down syndrome, also had a direct impact on my experiences at the program and the possible discourses and information I could access as a researcher.

The program, then, attempts to protect the participants by avoiding communicating about the shared categories that are necessary for their membership. However, these shared categories, that of having an intellectual disability, in many cases of having Down syndrome, of being able to use transit independently, and of having a desire to work, are all understood by their parents and necessarily common amongst all of them. By being required by the program, they become an imposed part of their perceived identity, if not of their personal identity. I argue that by avoiding acknowledging their imposed categorization, the program allows for the continued resistance toward a stable Down syndrome category by participants. Participants are able to imagine a "normal"

life, work towards the goals that make up this life with support and with peers, and negotiate their understandings of their progression towards adulthood, without having to reconcile these with the implications of a Down syndrome identity.

Conclusion

In this chapter I have articulated the complicated, varied relationships the participants at the program have with the category of Down syndrome. While each of the participants relates with the category in unique ways, the lack of a prideful adoption of the identity or full acceptance of the identity is consistent amongst all of them. This is important, as while understanding the full cognitive implications of the syndrome is a struggle for most of them, understanding the stigma associated with the identity and the limitations and barriers they face as result of their membership to the category clearly is not. Taking up Goffman's stigma theory, the participants do not necessarily internalize a spoiled identity and respond with shame or victimization, as Goffman suggests people labeled with a "stigma term" (2009:5) like Down syndrome would. Instead, they resist the spoiled identity, although their self-image is still impacted by the negative stigma, beliefs, and discrimination attached to the category. By resisting full adoption of the identity, whether through firm rejection of the identity and refusal to acknowledge it, disassociation from the identity and refusal to adopt it, redefinition of the category and refusal to recognize the cognitive limitations associated with it, or acceptance but not embracing the category, the participants are insisting on determining for themselves the implications of being a young adult with Down syndrome, and what aspects of their categorization they will accept. They are also undermining the dominant understanding of

the syndrome and showing through their lived experiences how unstable its ontology actually is.

There are varied implications for the impact their categorization may have on their identity when Hacking's looping theory is applied. In the case of Jennifer and Carolyn's rejections of the category, the implications for looping are complicated. While they understand that they are being categorized as having Down syndrome, they reject that categorization. By rejecting it, and asserting a normal life in response to it, they are reacting to the human kind. Through their reaction to the kind, it undergoes a wandering and influences and shapes their behaviour, and is influenced and shaped by them (Hacking 1995:374). Their reaction to their kind is unlike the rejection of the self-ascriptive kinds which Hacking describes, who reject certain labels and adopt new ones they chose themselves, allowing them to take control of the category and be the main knowers about the kind (1995:381-382). Instead, their rejection of the kind is in terms of a rejection of any sort of abnormal categorization at all; they are refusing to occupy a category of human kind through their assertion of a desire for normalcy.

Those who resist the kind by rejecting it or disassociating from it, are also resisting the looping effects that Hacking argues are internalized through being grouped into the kind. Those who redefine the kind are likely to accept the internalized looping effects of the aspects of Down syndrome they recognize, those that apply to their reduced height or medical issues, but resist those they do not. The dominant understanding of Down syndrome includes the idea that these adults cannot do math, read books, or perform other cognitive-based tasks. However, if these adults who reject, disassociate, or redefine the kind are in denial of that aspect of their imposed-kind, and the program and

parents who support them are willing to support that denial by incorporating literacy, math, and intellectually stimulating puzzles into their daily life rather than denying them access to intellectual development (as many past institution models and workshop program models do), then they have the possibility of increasing their literacy skills beyond the limited expectation. The result of this is that participants like Carolyn are able to read novels like *The Hunger Games*, rather than expecting to have limited literacy skills because of her imposed identity and the tendency to fulfill its expectations.

While the participants who reject, disassociate, or redefine the kind are asserting normalcy, or at least cognitive normalcy, in place of the kind, there are other authorized knowers, who have more authority and sway over the kind, which prevent them from having the power to abolish the kind altogether. The industrial bureaucracies which created the category of Down syndrome, including the medical industry, continue to hold the kind, and their definitions of the kind, as a relatively consistent and stable thing. That the majority of programs available for this population do not allow for the capabilities and accomplishments that my fieldwork program did is a symptom of this dominant kind. Additionally, that their kind is tied to particular facial and physical characteristics, makes complete resistance to the grouping a difficult task. While they may be able to renegotiate the implications of the kind, and resist the negative implications, separating themselves from the kind completely seems unlikely.

Additionally, at the same time as these participants are reacting in defiance to the kind, the program is acknowledging the kind and understanding it as having a particular set of implications. These implications are different from the dominant kind, in that they allow for an understanding of Down syndrome that is capable of work, varied lives, and

community inclusion, and so the program's understanding of the kind is closer to the participants' ideal. So, the participants who reject the category are simultaneously acting in response to and rejecting the kind, being required to meet particular standards because of their categorization within the kind, and being treated in particular ways because of the program's and larger society's different understandings of their kind.

The participants who accept the kind or otherwise relate with it experience looping which is influenced by the program. By living with Down syndrome and participating in their community they are presenting a lived experience of Down syndrome that is outside of the general expectation. They are largely embodying the program's Down syndrome ideal, which argues for very different treatment, support, services, and expectations for people with Down syndrome than is currently available within other program models and so is in contradiction to the general perception of the kind. This program ideal, which I call the ideal Down syndrome subject in subsequent chapters, is central to the disciplining that I will explore in the next chapter. By embodying this ideal they are encouraging the larger community to adjust their expectations of Down syndrome. When the community begins to adopt these changing perceptions, a looping effect will occur of more possibilities being offered to this population, allowing them to further prove themselves, resulting in more and more community members changing their understandings of Down syndrome. While the young adults are proving that they are individually capable of these adjusted expectations, the looping effect has the potential of changing larger society-based expectations of the general population with Down syndrome, increasing their opportunities, and reducing the

stigma as they continue to thrive and succeed in the community and independence based model.

Ultimately, however, this positive looping effect is a long process, and the young adults who are driving it are resisting a long history of being in a human kind that was created because of their evaluation as counter to normal. As Hacking explains, when deviation from normalcy is used to create a kind, moral overtones of the kind as worse are automatically connected to it (1995:372). As a result, the participants are resisting their kind from a severely disempowered position. While the program and guardians who argue for the participants' capabilities and rights are doing so from a less disenfranchised position, they are still hoping to influence perceptions of a group whose position as oppressed, dehumanized, inanimate, and unproductive others, has been looping and impacting their lives and opportunities for flourishing for generations. As a result, the positive impact that the program and the participants are able to have on their categorization within the community is remarkable. This positive impact is demonstrated by new employers beginning to approach the program to hire the participants rather than the other way around, by awards they have been given by the town, by their consistent fundraising success, and by the community's increasing familiarity with the participants. Additionally, the program recognizes that there is a lot at stake for the participants with the work that they are doing to influence public perceptions and encourage their acceptance, and so they have a variety of disciplining mechanisms in place to ensure that the participants succeed and are supported in that success.

Chapter 4: Disciplining Down Syndrome

On my first day at the program I went to the gym with several of the program's participants and one of their leaders, Christina. Once at the gym, I was told by Christina that Jennifer can get "very silly" while on the bicycle, and so I should remind her to focus if I noticed that she was laughing a lot while I was watching her. These types of reminders were later framed to me as helping participants "manage"—that is, manage their behaviours as to ensure they would not lose access to the spaces they currently accessed or the positions they currently occupied, manage to complete the tasks expected of them, and thereby manage not be perceived negatively by the strangers and acquaintances in any given space. However, given that I was being instructed by Christina to help Jennifer stay on task and not being asked by Jennifer for this assistance in staying focused, helping participants "manage" was really adopting an authority role over Jennifer and her peers. Christina's request forced me to confront my role at the program and determine, immediately, whether or not I would be willing to take the authority role she was requesting of me. It placed me in an uncomfortable position as a participant observer, as the participation expected of me in this instance was in the partial role of a leader rather than the role I expected to take of a program participant. Christina's request also deemed me able to determine appropriate behaviour and encourage such behaviour. I was presumed inherently capable of "managing" and of determining what managing looked like.

This request was the first of several instances in which I was asked to assist in disciplining the participants. It was also the first instance to bring to my attention the disciplining efforts of the program. During the two months I spent at the program, there

were many disciplining instances which made me increasingly aware of the ways in which the participants were disciplined into ideal Down syndrome subjects, the ways in which that ideal subject was framed, determined as necessary, and conceptualized, and the ways in which I was increasingly expected to contribute to these disciplining efforts.

While the authority role expected of me was one aspect of this disciplining, I found that the program enforced a variety of disciplining efforts which I will explore in this chapter. The program not only required me to assist in disciplining the participants through my interactions with them, but they also expected me to do this through reporting back to them about things I observed when alone with the participants. They also required me to model the policies and behaviour they deemed appropriate. Participants were disciplined through a variety of methods, including the use of task lists and “plans” to ensure participants do as expected, the use of program-specific policies to enforce disciplining, and the use of program-specific rhetoric to encourage and frame ideal behaviour. Through this disciplining, what being an individual with Down syndrome means, how Down syndrome is defined, and what a Down syndrome identity looks like are all further shaped.

Foucault’s discussion of discipline in *Discipline and Punish* is useful for thinking about the disciplining efforts I will be describing (1995). He discusses the disciplinary mechanisms that were introduced in military and educational spaces to enforce and create disciplined and docile bodies. These included methods such as the introduction of strict timetables, the use of signals to dictate tasks, and requiring the correct use of the body in the form of posture and exact execution of tasks (Foucault 1995:149-154). These methods were used to create productive bodies, and workers were taught to self-

discipline through their enforcement. He discusses the disciplinary mechanisms used to create normalization, and explains that the discipline mechanisms that function to normalize do so through institutions like schools in which every instant “compares, differentiates, hierarchizes, homogenizes, excludes” (Foucault 1995:183). He explains that this discipline based on normalizing established “The Normal” which is taken up in the education system through standardization, in hospitals through the establishment of “general norms of health,” and in industrial workplaces through the “standardization of industrial processes and products” (Foucault 1995:184). Normalization, then, becomes a significant instrument of power and results in:

a whole range of degrees of normality indicating membership of a homogeneous social body but also playing a part in classification, hierarchization and the distribution of rank... the power of normalization imposes homogeneity; but it individualizes by making it possible to measure gaps, determine levels, to fix specialities and to render the differences useful by fitting them to one another. (Foucault 1995:184)

His discussion of discipline as a means of power also explains how people in disciplinary institutions were forced to comply with this disciplinary power and conform their bodies into the docile ideal, as punishment for failures to meet the social and institutional norms is a huge component of disciplinary power (Foucault 1995:184). Individuals are forced to self-discipline their bodies and actions and conform to the norm that is established in various institutions, or risk being punished by the disciplinary power.

My Role at the Program

My position as both a student and researcher left me in an uncertain role while I was doing fieldwork at the program. The program has occasional coop students from a local college who are there to learn about the services being offered, the role of the program staff, and how to work with the young adults with intellectual disabilities who

attend, and so the program has policies and expectations for those students. The program did not have any of these students while I was attending, but they did have a new one starting soon after I finished fieldwork. Although I am a student in my Master's program, I was attending the program as an independent researcher, not as a facilitated student as part of a degree or diploma requirement. I was not attending the program to gain experience as a social worker, and of primary interest to me were the experiences of the participants, not necessarily the work of the employees.

This left me in a liminal space while I attended the program. A normal coop student might eventually take on an authority role while at the program, and so participate in minor disciplining of the participants in the form of "reminders" and "modeling good behaviour," but this was not a role I felt comfortable taking, nor was it a role I felt I had a right to assume. Not only would it have put me in an unfair power position over the participants, but it also seemed in contradiction to the program's goal of treating the participants as the adults that they are. Additionally, it would have created a moral obligation for me to act as an authority even though I did not want to. I was not always certain what constituted 'appropriate' behaviour from the point of view of the program and its leaders. After spending two months at the program it became clear that what constituted appropriate behaviour was complex and contested, as I will show in this chapter.

The authority I was assigned at the gym on my first day might have been expected if I were significantly older than the participants and they were children, but I am, in most cases, younger than they are and they are, crucially, adults. My inherent authority may have been attributed to my known relationship with my sister, a participant at the

program, and so presumed familiarity with “managing” Down syndrome, but I think it more likely that while that may have possibly influenced the quickness with which I was trusted, it did not influence my inherent ability to assume the authority. That I was able to adopt that authority at all was more likely attributable to the fact that I lacked a diagnosis of having an intellectual disability. My lack of a Down syndrome identity, I believe, caused authorities and workers in the program to attribute to me an inherent authority and see me as inherently knowledgeable about, and capable of, determining what managing as an adult looked like.

This was an uncomfortable role for me and one I struggled with during my two months at the program. While I understood that at times helping the participants manage was meant to benefit them, ensure they were safe, or ensure that they would be allowed to access the community (as, for example, inappropriate gym behaviour would likely lead to a loss of membership), I was not an employee at their place of work, their gym, or their program and so my contributing in their disciplining felt inappropriate and the innate authority they assigned me seemed to me unsubstantiated and disputable. Additionally, my being with the participants when they were at work or otherwise out in public alone, likely led outsiders to believe that I was with them as a support worker or authority, rather than as a peer or researcher. As was the case with an incident where a former teacher of Greg’s approached me while I watched Greg working at the gym and, assuming I was there as an authority over Greg, suggested that I tell his teachers that he be “pushed harder” at work. My authority role was complicated further by an expectation that I occasionally report to the leaders about the participants, by a tendency for the

participants to look to me for permission, and by instances when I would witness participants' behaviour while alone with them.

Reporting Back on Participants

While usually when participants asked me for permission I would remind them that I am not in charge of them or would respond neutrally, occasionally this would create complicated situations. For example, one day just before lunch Kyle told me he was going to fix the date written on a small chalkboard in the program's kitchen. Another participant had attempted to write that day's date on it, but had written "TH SAP 26" rather than Thursday, September 26. Kyle brought this to my attention when we were alone in the kitchen together, informing me that it was wrong and telling me that it should be spelt "T-H-U-R-S" while on the chalkboard it just had a T and an H. I told him he was right, and asked him, "What do you want to do about it?". He responded "I'll fix it" and I told him, "That's up to you". Kyle erased the date and wrote "Thursday Sep 26" in its place.

After lunch I found out that Kyle had asked Monica if he could rewrite the date that morning and she had told him that he was not allowed to, because one of his friends had already written it. What I thought had been a conversation about the correct way to write the date and an instance when Kyle was doing something helpful by writing it properly, had actually been an instance where Kyle was using the authority he assumed I had to undermine the authority of one of the staff. While I had attempted to stay neutral by telling Kyle that his choice was up to him, I had actually been condoning his behaviour without realizing it.

The expectation that I report on participants was not explicit or formal, but after I would return from their workplaces or watching them elsewhere, the leaders would often ask me “How did it go?” or “How was work?”, and through that would implicitly encourage me to report back. Reporting back created the potential for my presence at the program to have a direct impact on the participants’ experiences and social relations. The implications of that impact on participants was ambiguous, as my influence on them had the potential to be both positive and negative at times, making my choice to comply with reporting a difficult one. An example of this happened during and after my observations of Joseph at work one day. I was with Joseph at the clothing and shoe store he works at on the first day of a change in his duties. Until this day he had begun his shift by vacuuming the entire store; however, this had been taking him twice as long as it took another participant from the program who also worked in the store. As a result, the program manager and store owners had decided to change Joseph’s duties. He would no longer be vacuuming, and so instead of beginning his shift with sweeping, then vacuuming, cleaning the mirrors, and finally dusting, he would begin it with sweeping and then go straight to cleaning the mirrors and the rest of his regular duties. The manager of the program had met with Joseph to explain this change in duties and they created a new checklist for him to use while at work. As we walked to his workplace together, Joseph showed me the new list and read it to himself several times.

After sweeping, Joseph began to clean the mirrors as his new list instructed. On this day the store owners were not in yet, but one of the managers was. She came over to Joseph as he cleaned one of the mirrors and asked him if he had done his vacuuming yet. When Joseph communicates verbally it is often difficult to understand him, so in

response to the question he pulled out his new list and gestured to it. I could tell that there was some confusion on the manager's part and that she had not been instructed by either the program manager or the store owners about the change. I stepped in to the conversation and explained that Joseph was no longer doing the vacuuming, to which the manager argued that she knew he had done it last week, forcing me to explain that the change was starting today. Had I not been present to explain, I am not sure if the manager would have believed Joseph, given that she did not believe me right away even though I had no trouble explaining the situation to her.

While this interaction with the store manager was relatively positive, in that my being available to 'report' for Joseph likely prevented him from getting in trouble and becoming very confused, later that shift I had a less positive experience when I was asked to report about Joseph to one of the store owners. When he cleaned the mirrors he did all of the mirrors in the clothing section of the store, but did not do the ones in the shoe section. I asked him if he needed to clean the mirrors in the shoe section and he had showed me his two lists, the old one and the new one, in response. Realizing he was clearly confused, I took a step back and he moved on to his next duty. While Joseph was completing his next duty, the store owner arrived and checked in with him about the work he had accomplished that day.

She asked him if he had cleaned the mirrors in the fitting room area. Joseph said yes in response. She then turned to me for confirmation. I told her he had done all of the fitting room mirrors, but not the ones in the shoe section. She responded by telling Joseph that he needs to clean all of the mirrors and then whispered "thank you" to me. Joseph turned to me in response to this exchange and shrugged, to which I said to him "You

missed a spot” and he responded “I missed a spot” before going to clean the mirrors he missed. While this exchange made me uncomfortable, in that I felt as though I was put in a position where I was forced to either tell on Joseph or lie, and in that the store owner was assuming that Joseph might not be telling the truth, but that I certainly would, it did allow me to go back to the program manager and explain that Joseph was clearly confused by the transition. Through my explanation of the events they were able to identify that Joseph had brought both his lists with him that day, instead of only the new one, and that the conflicting instructions on these lists had been causing him confusion. They then solved the problem by taking away his old list.

The first time I watched Joseph at work he had still been vacuuming, and Elizabeth had come in for a job visit. After meeting with the store owner, she came to me and told me the store owner had told her that vacuuming had taken a long time, and that she did not think it was likely that it was because I had been watching him that day. I agreed with her, I had not been asking him questions and he did not seem distracted by me. In response, Elizabeth told me that “It has been a struggle,” and that it is nice having someone here to ask who is present. Additionally, during my interview with Ellen and Janet they told me that the shoe and clothing store that Joseph works at had combined into one big store from separate shoe and clothing stores around the same time that Joseph started getting paid. Janet explained to me that this change was:

A big transition for Joseph [and the other participant who works there] so I think at the beginning there they maybe weren't being seen as as productive. Because the store had changed, and they'd both been there doing their thing, and now they had to do it differently. So that was a bad transition and it happened that they started getting paid at the same time when probably that should have waited until the store had changed and they'd gotten comfortable, and they could say “oh wow you're doing a good job so let's start paying you”.... I think that it was a huge transition

time for [the owners] as well, and I think they thought ‘all of a sudden they are not doing their job all that well and I’m paying them’ so I think that that was an occasion for them to realize that routine for these guys is so important and that that disrupted everything. But I think it has calmed down now.

So, Joseph’s ability to transition well, even with minor changes like the one I observed, is intrinsic to his proving himself a capable employee.

Given that this change was based on his underperformance as an employee, and that Elizabeth had identified that it had been a struggle beyond the weeks I was observing, I suspect that if this transition had gone badly, that is if Joseph had been forced to vacuum or not completed his duties properly, or otherwise been confused about what was expected from him, his employers might have begun to question his salary again, as the larger store transition had only occurred earlier last year. My presence, then, and willingness to step into the conversation likely had a positive impact on Joseph’s status as an employee. His continued precarious employment was about his ability to continuously prove his capabilities as an employee with Down syndrome and to manage transitions and changes with ease. His ability to perform as an ideal Down syndrome subject and adjust to their expectations of him as an employee was intrinsically connected to his ability to keep paid employment. While they were willing to adjust his position when his performance at a task fell short of expectations, they were unwilling to accept that he may just need more time to do a task successfully. Another example of an instance when I would be encouraged to report on the participants is when participants had told the program staff something confusing or seemingly nonsense about something that happened during our time together. When this happened, they would go to me to clarify. This occurred, for example, after the first time I watched Jennifer at work. I had arrived at her workplace separately from her, and so did not know what route she

normally took back to the program. As a result, when we departed from her workplace I asked her to take her normal route back to the program and told her that I would follow her lead. We walked and talked and I assumed that Jennifer was taking her normal route. I left her just before we arrived at the base and went home.

The next day one of the leaders, Monica, asked me what route we had taken back from the workplace. I explained to her that we had walked down the main road most of the way, and turned off at a side street that lead to the program base. Monica explained that Jennifer's plan, that is her expected route, would normally have her turn off at a much earlier side street, and walk down the less busy side streets back to the base. I apologized, explaining that I had asked Jennifer to take me on her normal route, but she must have been following my lead. Monica told me not to worry and that she had only asked because Jennifer had told her that I had taken her on a "short cut" when she had returned to the base the day before. I then witnessed Monica telling Jennifer to stick to her plan in the future, and so my reporting to Monica had certainly led to a "reminder" or mild reprimanding for Jennifer.

Modeling "Good" Behaviour

When I watched participants work, I frequently accompanied them on these work commutes. There was an important incident when I was commuting with Carolyn to the clothing store she works at which involved my reporting back to the program staff, and my witnessing behaviour when alone with a participant, but which also brought my attention to a further type of disciplining responsibility which was expected of me. We bussed there together and back, with Carolyn telling me which bus to take and showing me the way to the stop. As we were waiting for the bus that would take us back to the

program base, I asked Carolyn some questions and took note of her answers on a notepad application on my phone, which I intended to transfer to my notebook and elaborate on later. Carolyn answered my questions, but was also on her own phone browsing Facebook.

I had been keeping my eye on the horizon for the bus we were waiting for between taking notes, but because we were a short distance from the top of a hill, I could only see a short area of road. I looked up after writing a short note and saw a bus barreling towards us. I asked Carolyn if the bus coming towards us was the bus we were waiting for, and she looked up, confirmed it was, and then quickly attempted to signal for it. The bus passed us, but stopped at the other side of the intersection we were waiting at. Carolyn started running towards it and I had to stop her, as the light was green and she was in danger of being hit by the cars leaving the plaza. We waited for the light to change and walked to the waiting bus together. Upon boarding the bus, the driver took responsibility, acknowledging that she had thought that we were part of a group of pedestrians that had been walking past us.

When we returned to the program I told the leaders what had happened when they asked about our morning at work. I told them because I had been worried for Carolyn's safety. The leaders asked Carolyn about it and reminded her not to run across the street and I assumed that the incident was over. However, the next day I was called into the office of the directors to talk, which they had never asked me to do before. They opened the conversation by asking me about the incident the day before when Carolyn had "run for the bus." I corrected that she had not run for the bus, she had begun to, but I had stopped her. They then spoke to me about the cell phone policy at the program. They

explained that they expect everyone at the program to “model good behaviour,” by not being on their cellphones and by paying attention, including myself. Not only was I expected to not look at my cellphone during the duration of my days at the program, but I was also expected to help the program staff by enforcing the cellphone policy with participants by reminding them not to be on their phones when I saw them on them. This meeting was the most blatant instance of disciplining that I experienced while at the program. It was meant to both discipline me and to encourage my compliance in disciplining the participants.

The incident and subsequent meeting took place near the end of my two months talking with and observing the participants. Up until this point, the cell phone rules had been relatively unclear. While participants are instructed not to be on their phones during their time at work, at the gym, and during the other activities they do while attending the program, they are supposed to use them during their commutes to confirm with the program staff that they have arrived at various points safely. They also were allowed to have them out during the lunch break. Additionally, I often saw staff with their phones during downtime and lunch, and at times throughout the day. I would often leave my phone with my belongings in a staff closet while at the program, and would retrieve it during lunch or other periods of downtime to check my emails. Occasionally, I would also use it to take vague notes when interviewing participants during our commutes together, as these commutes were often ten to twenty minute periods during which we were alone together and I could engage them in focused conversations. Walking and writing in a notebook is not a very easy task, but walking and typing notes is relatively easy. The applications I used had no internet connection and the notes I took had no

identifying material. The incident with Carolyn was the first time any of the participants had had their phone out as well. While this was technically against the program's rules, using Facebook on a smartphone is relatively normal behaviour for a twenty-something young adult waiting for a bus.

The Risk of Being a Pedestrian with Down Syndrome

Janet, Ellen, and I also discussed the unease that transit training causes for the directors and workers at the program during the meeting. Ellen explained that transit training is the aspect of the program that has given her the most grey hairs. She emphasized that the participants are vulnerable, that in general they are “better pedestrians than the average student,” and that they need to be paying attention because if something goes wrong they need to be aware. They told me that Laura used to crouch down and cover her face at the bus stop to avoid the cold and she struggled to understand why this was not appropriate behaviour now that she is no longer in secondary school, and so no longer in a large, directed, and monitored group when traveling. Janet added that with “self-talk,” which is a tendency some of the participants have to talk to themselves out loud when focused on a task, thinking something through, or, in a minority of cases, when not engaged in a task such as when they are alone on a bus, they have “enough distractions.”

The expectation that the participants be “better pedestrians than the average student” also came up when I interviewed Ellen and Janet. When I asked them “Do you think that participants' presence in the community has influenced the way that the public and community have been relating to them?” Janet explained to me that “One of our big jobs is to make sure they're positively received.” They then went on to give me an

example of an incident which they saw as having a possible detrimental impact on the community's perception of the participants:

Janet: There was an incident at the bus stop down there where some of our guys were waiting for the bus to go home, and there was a can of spray paint there, somebody picked it up and added some spray paint to a mailbox or something that had already been painted.

Ellen: ...and probably like 100 people saw that...

Janet: ...so we're very diligent at making sure they behave properly in public.

This story suggests that Ellen and Janet perceive an increased risk in having the public witness their participants engaging in deviant behavior than the risk assumed by a person who does not have Down syndrome.

There seems to be more at stake for the pedestrian with Down syndrome. If they are witnessed or caught spraying graffiti on a mailbox, they risk confirming to the community that they are aberrant, marginal members of the community and that they cannot conform to social expectations or follow the rules. They also not only risk their individual reputations, but also the reputation of the program, and potentially the way in which the witnesses conceptualize all young adults with Down syndrome, and so the implications of the category. No longer the nice, cheerful, exceptionally well-behaved, ideal pedestrians, they become the immoral Down syndrome subject who needs to be supervised at all times. Given this perceived inherent riskiness, disciplining a young adult with Down syndrome into the ideal Down syndrome subject, or even the ideal general subject, has become a goal of the program, even if it is not a clearly stated goal, which is perceived as both necessary and inherently beneficial to those being disciplined and those disciplining. They can assert that their participants are better than average pedestrians with pride, they can assume the authority role of reminding participants to engage in appropriate behavior and cease inappropriate behavior, and they can insist on the

modelling of good behavior by their coworkers, volunteers, and students for the benefit of their participants.

Reminders

While the acts of preventing cellphone use and ensuring task lists are completed discipline through overarching program rules which are then enforced, there are many daily “reminders” which serve to discipline the participants on a more micro, one-on-one, instance-based level. For example, I witnessed Carolyn being disciplined by Christina on multiple occasions through reminders to keep her fingers out of her mouth. While a reminder to stop the absent-minded habit seems relatively benevolent, the reminders serve to control Carolyn’s behaviour so that she is not seen engaging in inappropriate habits in public. They are enforcing bodily discipline on Carolyn by restricting the ways she is allowed to be in her body when in public. Part of having Down syndrome within the confines of the program, then, is about learning and enacting the bodily behavior that is deemed acceptable and resisting bodily behaviour deemed unacceptable, that is, having docile Down syndrome bodies. They are not just being disciplined to behave as ideal Down syndrome subjects, but also to embody the ideal Down syndrome subject. Were Carolyn not to listen to the reminders, it is likely they would escalate from reminders to commands.

Another example of this type of “reminder,” occurred several times over the course of my observations during instances when Kyle was using the washroom. Kyle would frequently spend longer-than-average periods of time in the washroom. The reason this is an issue is two-fold. First, the extra time spent in the washroom was keeping Kyle from contributing to his various activities and work at the program, and second, there

were only two washrooms in the program base, and upwards of ten people using the space on slow days. As a result, the leaders would check on Kyle when he had been in the bathroom for a while, would remind him to come out of the bathroom and return to work, and would give him a time limit for the amount of time he was allowed to spend in there. Although the program staff would be unlikely to articulate the bathroom disciplining in these terms, it is possible that part of the motivation behind their check-ins with Kyle and others when they spent too long in the bathroom was preventing them from accessing non-surveilled space.

Plans

Another means of disciplining the participants came in the form of individual “plans,” which are reminiscent of the disciplinary mechanisms identified by Foucault (1995). Plans were set through meetings between the parents and the program employees. While I did not see any of the participants’ plans personally, I often heard references to them. A participant’s plan articulates many individualized aspects about their days at the program. It instructs whether or not they take a bus home independently after the program or take a door-to-door local transit car. It determines whether or not they are allowed to buy lunch from local fast food restaurants, and, if they are, which restaurants and what route they will take to get to them and back. It determines their route to work, when they are required to call and confirm their location along that route, and the time they depart to work and from work. Their plan determines what the participants are and are not allowed to do. Some of the plan is influenced by participants’ desires, for example, Laura’s plan changed while I was at the program because she wanted to go buy lunch on her own, and her parents decided she was ready to try. So, her lunch plan on

certain days changed to allow her to go to a sandwich shop and come back to the program base by herself; however, this change was contingent on Laura executing it successfully and proving she could manage. When participants are uncertain if they are allowed to do something that is covered by their plan, the leaders ask them what is in their plans. When participants do something that is counter to their plan, the leaders verbally remind participants to follow their plan or assert that participants know that what they have done is not in their plan. The plan functions as a relatively stable base set of instructions for each participant's day at the program.

These plans are a form of base instruction, but they are also a means of ensuring that participants are safe and know what is expected of them. By having a clearly understood plan that determines the route a participant will take, the bus they will be on, and the end location they will arrive at, the program is able to comfortably allow the participants to independently travel to most of their destinations alone. The participants are also able to feel confident in their route and comfort in their consistent days. As a result, while the participants are clearly still monitored while at the program and there is a clear hierarchal relationship between the young adults and the employees, the degree to which they are monitored is clearly reduced from high school.

In high school, they were largely used to traveling in groups. They mostly spent their days together with the individuals in their special education class and working with an educational assistant. The same is true of the alternate programs available to young adults in the area. As Sylvie explained to me, "at the other program everything was a group, a group is going to swimming, a group is going to the gym, everything is done in a group, they arrive in a van," which she disliked and saw as a reason to choose this

program over that one. While I noticed very clear disciplining behaviour during my time at the program, there were many instances when the participants were unsupervised and so largely without explicit monitoring and discipline. However, during these times they were still encouraged to self-discipline, through methods like their plans, and the threat that the program leaders may find out if they deviate from the rules. This ability to self-discipline, then, is a condition of the ideal Down syndrome subject identity that the program expects of the participants.

Managing Down Syndrome

A third means of disciplining participants came in the form of leaders questioning their ability to “manage,” that is manage themselves as adults, managing themselves at work, when in the group, and when alone, as a means of ensuring that they behaved appropriately. While during my story about reminding Jennifer not to be silly at the gym, “managing” is framed as assisting Jennifer in staying on task and being an acceptable gym member, in many cases being able to manage is intrinsic to being able and allowed to participate in the program. The question of an individual’s ability for self-management is a question of their access to membership at the program. When the participants were having a moment in which they were behaving particularly “silly,” were relating to their peers unkindly, were unwilling to do tasks, or were particularly upset and struggling to calm down, they would be asked by the leaders if they were going to be able to manage to get through the rest of the day or if they needed to go home.

A clear instance of this threat of managing happened the day after Glee aired their tribute episode for Corey Monteith – a star of the show who died over the summer. When I arrived at the program that day, Carolyn was sobbing loudly in the bathroom. I checked

in with her and she told me that she was upset over Corey's death and asked me to get one of the leaders, Monica. I went and got the attention of Monica who was engaged in the morning meeting. Monica left the meeting and came to check in with Carolyn at my request. She told me that Carolyn had been getting upset in front of everyone at the meeting, and so they had instructed her to go be alone, and that Carolyn insists on crying with the door open for attention. After the meeting, Elizabeth, the program manager, went in to check with Carolyn, and after doing so let Monica know that Carolyn was going to be able to manage. Had Carolyn been unable to manage, that is stop crying and calm down in an appropriate time period, she would have faced the threat of losing the opportunity to take part in the program that day, including working at her job. With the question of management comes the question of taking part.

It is fair to say that loudly mourning a death that occurred over three months earlier is not behaviour that can be taken into the workplace without risking job loss, and so is not behaviour that fits within the program's expectation that participants behave like they are at work when they are attending the program. It is, then, behaviour that should be disciplined. However, it is also important to note that the way a young adult with Down syndrome processes death is very particular. They often exhibit a delayed grief response, grieving six months after a death. They also have a tendency to experience grief intensely when they are reminded of it, as for people with Down syndrome the "intensity of emotionally charged events does not seem to diminish over time" (McGuire and Chicoine 2006:73). So when something triggers their memory of the death, they tend to experience their grief as though that death just happened (McGuire and Chicoine 2006:53, 73). As a result, they may suddenly express grief over a death that occurred

months or years ago to a degree that would suggest the death just occurred, as they are “transported back to the time of the loss” even when it has been ten years since the death (McGuire and Chicoine 2006:73). They may be engaged in a completely unrelated activity and suddenly remember the death of a loved one and begin to cry or seek sympathy. To those with or witnessing that person, this may seem sudden and inappropriate behaviour.

In Carolyn’s case we had talked about Corey’s death without any incident during a conversation about her ideal future, with her telling me she would like to run into him in New York “even though he is dead”. However, the tribute episode had caused her to have a significant emotional response, which was triggered by the memorial episode of Glee she had watched the night before. While this outburst may have been partially for attention, as Corey Monteith was not an acquaintance of Carolyn let alone a family member, it was also likely very real emotion, as Carolyn was a big fan of the show and its actors. The expectation of being able to manage in this case was an expectation that she be able to process death appropriately and have the level of emotional maturity expected of an adult. However, it was also a threat. Carolyn understood that if she was not able to calm down, she would not be allowed to stay and go to work. In order to access full community inclusion, the individual must manage, and so must be disciplined.

The ability to manage and behave appropriately, then, is a requirement for attendance at the program. Intrinsic in the explicit program requirements that participants are able to take care of themselves and have a desire to work, is the implicit expectation that they will be able to manage themselves appropriately and professionally. The program, then, requires that participants learn to self-discipline their behaviour. They are

not only being disciplined into ideal Down syndrome subjects through threats and rules, but are also expected to be complicit in that disciplining through the expectation that they self-discipline. This may not happen right away, as interviews with both the directors and parents have suggested that this requirement of self-management is not expected in the school system, and so is something that develops as they attend the program through this disciplining.

Stagnation and School

When I asked about the differences between the program and the Ontario school systems (both secular and Catholic), Janet explained:

I think we're more demanding than the school system. And I could say things about the school system that I shouldn't say, but I think that we look at the individual as a whole, how all the pieces fit together, and we demand adult-like behavior. [We're] working towards the goal of independence. And I don't think the school board is necessarily the same.

Ellen and Janet continued the thought between them, with Ellen explaining that she thinks the participants were treated as separate addition to the school population. Rather than a part of the general student body, Ellen and Janet retrospectively believe they were treated as students who had to be included in the school, but did not require or deserve the supports that would have allowed them to access learning and thrive to the same degree as other students:

Ellen: Our guys are an add-on in school.

Janet: ...and these guys are adults, so it's a big difference.

Ellen: Sometimes I feel, Jennifer went through the school system, and in retrospect I feel she was an add-on, she was a part, but really the support was, it wasn't...

Janet: ...it was more babysitting. And I hate to say that, but I think that's true of a lot of the school system.

In a separate part of the interview, Ellen articulated this "add-on" experience, by explaining that the participants' behavior issues were addressed very differently in

school than at the program, and that people who work with them in school

assume:

Oh well this guy's not going to go anywhere, that's just who he is, or that's just who she is, and we aren't going to challenge that. And I would say that for some of the people here, their behaviour in high school was very dictated by medical problems that were left unaddressed. Because it didn't get discussed, I think, people were just left. And that's been a problem for some of our participants, and I would say that's problem within the school system. Their behavior stuff.

This idea of the school system as not completely meeting the needs of individuals with Down syndrome, or as treating them as an "add-on" was addressed by a number of the parents I interviewed as well. In the case of Susan, she views the time spent in secondary school as wasted time:

I'm not sure if that's a change in his character or just the opportunity that he's been given, as opposed to high school where again working with so many students of different degrees of abilities and disabilities just getting those kids from A to B would have been a logistic nightmare. I honestly think that if [the program] had been started sooner, I would have sent him sooner. Because I think all those many years in high school, most of them are wasted.

Similarly, Sylvie described Kyle's seven years spent in high school as full of frustrations:

I think in high school I've always said they were trying to fit a square peg in a round hole. Even though he was in a special classroom – he was in the public system and he was in a classroom for special needs – but everything was in a group again and you had to do exactly the same things. He was in high school for is it 7 years I think, until he's 21, a lot of years the same teacher, same classroom, same students, same routine day after day. I don't feel that he learned a whole lot... So even though he is happy and smiling I think he was very frustrated with everything going on around him. Never quite felt like he fit in and I think at [the program] he does feel like he fits in... I didn't see a whole lot of difference from when he went in and what he came out. You know, that's a long time of all those teenage years when you think we'd of seen more growth there. We've seen the growth of the last 5 years at [the program], so I'd have to say it's what he's doing now at the program that's given him that maturity.

In all three of these cases the parents represent high school as a negative experience. It is “wasted,” “frustrating,” and the participants were just an “add-on”. In contrast, the program is “demanding,” gives the participants opportunities, is a place of growth and increased maturity, and is where the participants “fit in.”

Adult Behaviour and Adult Treatment

There is a sense that the disciplining of the young adults contributes to their growth. As a result, part of the ways the program understands and practices Down syndrome is in terms of the possibility of notably increased maturity and sense of responsibility in adulthood. Due to the general consistency of the participants’ neglected school experience and resulting immaturity, Down syndrome becomes stagnated development, which has the potential for significant changes with the right supports, structures, and boundaries. It becomes something with potential within the program rather than the something without potential or significant possibilities it was in the school system. While the parents emphasized increased opportunities, the demanding nature of the program, and the ways in which the program intentionally treats the participants as adults as the source of their growth, there is a sense that treating them like adults includes disciplining their behaviour to ensure they are behaving as adults. During a conversation with Elizabeth, she mentioned to me how drastic the changes in participants have been since they began attending the program, which she attributed to their accessing the supports they need for the first time. I think it is fair to say that part of this support is this disciplining, which while complicated, gives structure and direction to participants, and holds them to standards that they are not used to when beginning, but which allow them to access means of expressing their desires, feelings of empowerment, and management

of their emotions that they previously could not access. Kyle is an important example case of this change in behavior as the result of support. A volunteer who works with Kyle at one of his jobs described him as being the person whom she believes the program has “had the biggest impact on.” When he first started the program, she explained, “he had no social skills... if you so much as brushed him he would get incredibly angry, now he’ll run across the parking lot to give me a hug.” Kyle’s mom, Sylvie, supported this evaluation by telling me that when Kyle first came to the program he:

Was a concern as far as settling down and behaving and being where he should be when he should be and not being silly. And I think a lot of that silliness has gone away because he’s matured. He’s matured because he’s grown up age wise, but he’s matured because of what he’s doing and the people around him. And he knows he can’t go on the bus if he’s silly, he can’t be at work at a job if he’s silly, so he’s chosen to be more mature which has worked out very well for him.

The volunteer and Sylvie’s separate explanations suggests that Kyle learned what behaviour was expected of him as a member of the program and an employee, which is behaviour that had not been expected of him before, and he learned to model that behaviour. He is aware that behaving in a way that is understood as inappropriate or framed in terms of not managing would prevent him from full participation. He behaves then, because, like with Carolyn, the alternative is exclusion.

Bowker and Star’s ideas in *Sorting Things Out* offer a useful means of thinking about the disciplining efforts undertaken at the program. Through their argument that it is important to understand how “standard narratives which appear universal have been constructed” (Bowker and Star 1999:44) and their explanation that these apparently universal categories are the “result of negotiations, organizational processes, and conflict,” (Bowker and Star 1999:41) they offer a means of thinking about the ways in which disciplining these individuals allows for the ideal, universal understanding of what

having Down syndrome means. The everyday practices of disciplining undertaken by the program in the form of reminders, modeling good behaviour, setting goals and plans, framing behaviour as “adult,” and encouraging reporting are negotiations which construct and influence the apparently universal Down syndrome category.

A big part of this disciplining behaviour and the overall goals of the program is ensuring that participants are behaving like adults. The idea that participants should be treated like adults is a large motivation for the disciplining, as, unlike in high school, the program expects that the participants will be able to manage like an adult and so holds them accountable to adult-like behaviour (such as not putting fingers in their mouths or not crying excessively). However, the acts of disciplining in the forms of monitoring, reminders, plans, and threats seem in contradiction to adult treatment. Given this, I think that the program is, in many ways, a transitional place. While the standards the participants are being held to when they are expected to manage on their own are in many ways adult standards, the expectation that they be exceptional pedestrians and concede to micromanagement are unrealistic and indicative of the submissive, compliant behaviour expected of a school-age child rather than an adult.

An example of this is a conversation I witnessed while eating lunch at the program. Laura and Jennifer, two of my participants, and Christina and Monica, two of the program leaders, were all discussing getting up in the morning. Laura had been explaining that her mother gets her up in the morning, but that she gets frustrated when Laura does not get up fast enough. Monica and Christina chimed in to the conversation with the suggestion that getting up by oneself is “adult behaviour.” After hearing this, Jennifer added that she gets herself up early and makes her own breakfast, which Monica

praised as “adult behaviour.” This caused Laura to add that she had had a shower the night before without having to be told by her mother that she needed one, which she sees as “being very adult behaviour.” Jennifer then attempted to trump Laura by saying she had had a shower the night before as well, and had washed her own hair. In this conversation, the framing of something as adult behaviour made it praise-worthy, and so desirable behaviour. What began as a benign conversation about getting up in the morning, begun by Laura and her amusement over her interactions with her mother in these situations, became a competitive conversation in which both participants were encouraged to behave in adult-like ways by getting themselves up and looking after themselves, and to prove that they are adults based on existing behaviours.

While in the above example, Jennifer and Laura are competing to prove their status as adults, the disciplining of the program is more ambiguous than just upholding an adult standard. The degree of disciplining is itself in contradiction to the independence usually accessed through adulthood. While this disciplining qualifies the behaviour of the participants as appropriate or inappropriate, adult or childish, managing or not, it also gives participants a means of deflecting responsibility for their desires, decisions about their lives, or negotiations about their daily goals away from themselves and onto their leaders or parents. The program has created a transitional space which holds steady these complicated adult narratives, expects mature adult-like behaviour from participants, and gives them more independence and life-control than they typically have access to, while also treating participants as dependents without overarching authority over their own lives who are still child-like and so need to strive to meet an adult-like ideal.

As a result, the participants must negotiate the adult narratives exemplified above, and child narratives and positioning. For example, when I was watching Jennifer at the gym she told me and Christina that she no longer has to use the rowing machine to exercise because her mom told her that it could hurt her hips (Jennifer was in a bad car accident a few years ago during which her hip was broken, making it more susceptible to injury and pain). Whether or not this was actually something Jennifer's mom had instructed or whether Jennifer just did not like using the rowing machine and wanted a way out of doing the exercise was not confirmable in that moment. However, that this decision was at all up to Jennifer's mother rather than Jennifer is attributable to the disciplining of the participants into dependent positions, which gives them more control and success when they invoke people who have authority over them than when they attempt to assert their personal autonomy and desires in certain circumstances.

Another example of this deflection of responsibility occurred over the course of a couple of weeks and also involved Jennifer. While I was attending the program, Jennifer stopped attending the program on Monday mornings for a few weeks leading up to Thanksgiving. When I asked Jennifer about the change she told me that her mom "wants her staying home on Mondays" and that her mom wanted the change, not her. She then told me that her mom wants her to come back to the program on Mondays and that her mom wants her to stop missing literacy those mornings in order to work at her job, but that she was "ok with it [missing literacy]." However, through conversation with Christina and Monica during lunch that same day, I was told that Jennifer wanted to start coming back on Monday mornings, but not to go to work those mornings, and to go to the literacy session at the program instead. Her mother's strong contributions to the

decisions that monitor and control her life allow Jennifer to reassign blame for the changes to her schedule from her own desires to her mother's and to avoid explaining her reasons for no longer wanting to work to me.

This transitional disciplining, that is disciplining that incorporates expectations of adulthood while often treating the participants as children, has a noticeable impact on the ways in which the participants conceptualize themselves, in that they incorporate both adult and child narratives into their self-conceptions simultaneously. I spoke to a number of them about their plans for the future. During almost all of these conversations I got a sense of the participants as viewing themselves as not-yet grown up. I would often ask participants about their dream job or ideal job, but they would often find it much easier to think about and respond to the question when I rephrased it in terms of "what would you like to do when you grow up." To this, all of them had responses, ranging from idealistic jobs to realistic jobs, but in every case a job that was different than their current work. That the participants still understand their future in terms of growing up suggests that their identities are impacted by these ambiguous narratives. They occupy a liminal identity as a result, between childhood and adulthood. Rather than a teenager identity which is not childhood, but not-yet adulthood, the transitional identity that the program creates holds both childhood and adulthood as concurrent parts of their identities. Within this identity, an understanding of full adulthood as an ideal which can and will eventually be reached is crucial.

Additionally, when asked, most of them articulated future plans that included getting married, moving out on their own, and potentially leaving the area. During a conversation with Jennifer, I asked her if she wants to move out on her own, and she

responded “yeah,” to which I asked her “when?” and she responded “tomorrow,” but when I pushed her by suggesting that tomorrow would not be possible and by asking if she had a goal, she answered “Yeah, 32,” which would be six years in the future. Similarly, during a conversation about the living options and other services for people with intellectual disabilities with Laura and a volunteer she works with at the local church, Laura asserted that she would like to live on her own as well. I engaged her and asked, “when?” and “who would you like to live with” to which Laura responded, “I don’t know soon” and “alone or when I am married, with a husband.” The volunteer challenged Laura by pointing out that she does not like to cook, but Laura suggested that she could just order in, and through further questions painted a picture of living nearby, no longer attending the program, doing minor housework, and watching videos on the internet all day. I had similar conversations with most of the participants I worked with, and in every case they imagined futures that were very different from their current reality of living with their parents and spending most of their days at the program.

Although the participants imagine futures in which they have full independence and access to all of the rights and privileges of adulthood, a conversation I had with Jennifer suggests that the participants, or at least Jennifer, are not oblivious to the role the program has in helping them manage. When I asked Jennifer: “If you didn't go to the program would you still have a job?” she answered, “If I couldn't handle it I would get fired from my job,” to which I asked, “So you think the program helps you handle it?” and Jennifer answered “Yeah”. This conversation suggests that Jennifer understands that the program plays this role in her life.

The program is also somewhat aware of the liminal identities of its participants, as it positions itself as a transitional space. The intention is that participants learn to be independent workers, and are eventually able to work with minimal support. However, through conversations with Ellen and Janet, I learned that they are re-evaluating this model, as it is now five years in and most participants are not prepared to move on anytime soon. A part of this move towards independence is this discourse about aiming to behave like an adult, the very presence of which implies that the participants are in transition: they are not yet adults. The program not only articulates to participants what adult behaviour is, as described above with Laura and Jennifer, but it also reprehends them in terms of adult behaviour, a key example of which happened with Kyle after the gym one day when Christina caught Kyle “slamming his stuff around” in frustration and told him “that’s not how adults behave”. That participants feel the need to respond to this articulating and reprehending either by asserting examples of successful adult behaviour or by re-evaluating and modeling their behaviour in terms of what is considered adult, suggests that both participants and program staff accept the idea that being an adult is an ideal which participants do not always meet. When disciplined and instructed in terms of adult behaviour, the participants may assert that they have displayed adult behaviour in certain contexts, but they do not assert that they are, in fact, adults (and so all their behaviour is inherently adult). In terms of discipline, the participants must agree that they are not quite adult, although being adult is their aim, and being treated as an adult is a goal, for it to be successful.

The way this impacts their identity is further complicated by the responses of participants to a series of questions I asked them about whether their employers,

coworkers, and customers treat them as adults, to which all of those asked answered yes, and when I followed up each question with “some of the time or all of the time,” they all responded, “all of the time.” Through these instances, I sensed that the participants would identify as an adult if asked, and would not explicitly identify as “growing up” or in transition. This suggests that they would not articulate condescending customers, monitoring of their behaviour, disciplining, or oversimplified tasks, all things which I witnessed, as in contradiction to their identity as adults. They recognize that being adults is important, and that they should identify as and behave as adults in order to be employable, treated well, and empowered. Suggesting that depending on the context, the stakes of the articulation, and who they are articulating their identity to, the participants see themselves as both aiming towards adulthood (growing up) and also as adults.

Conclusion

In this chapter I have demonstrated that the various disciplining techniques taken up and deployed by the program function to shape and influence the lives and behaviours of the participants in both positive and negative ways. I have discussed the ways in which I was expected to act as a disciplining authority while at the program, was expected to model the behaviour the program expected of participants, and was implicated in the disciplining efforts of the program through the implicit expectation that I report back. I have also discussed the means through which the program enforced ideal behaviour through the use of reminders, plans, and the threat of failing to manage.

What constituted appropriate behaviour was complex and contested at the program. At times, using a cell phone was appropriate and expected, at other times it was forbidden. At times, silliness, child-like behaviour, and dependent relationships were

acceptable and expected, and at other times standards of adulthood and maturity were enforced, resulting in complicated, transitional identities. The failure of the school system to offer appropriate levels of expectation, standards of behaviour, support, and structure, the resulting difficulties experienced by young adults in and after school, and the perceived riskiness associated with being a pedestrian with Down syndrome indicate how necessary some of the disciplining efforts engaged in by the program are.

Discipline and self-discipline at the program function more complicatedly than the oppressive means of social control that Foucault describes. Foucault's (1995) explanation of discipline is in terms of a means of power, controlling mass groups of people, and encouraging those being disciplined to engage in that disciplining. However, while the disciplining of the program functions to encourage the participants to comply with the docile, conforming ideal and social norms of their communities, it also acts as a means to the liberty of full participation and independence in the social and work spheres for the participants. Self-disciplining for people with Down syndrome becomes a means of influencing their community's and society's perceptions of the category and accessing social acceptance, as their disciplined bodies become ambassadors for others in their category. This social acceptance has the potential of leading to greater social inclusion and of influencing the negative response to the presence of other young adults with Down syndrome in the social and work spheres. Compliance to normative behavior is seen by the program as essential to both the goal of having a full and included lives for the participants and the broader goal of social inclusion and reduced stigma for the category.

Ultimately, the program employees, parents, and employers of these young adults not only attempt to impose the same standards on these individuals as society imposes on

someone without Down syndrome, but they impose these standards to an exceptionally high degree. Not only is the individual with Down syndrome expected to follow pedestrian laws, control their emotional expression, and fulfill their work duties, but they are expected to do, or expected to work towards doing, each of these things to an ideal degree. If they fail to meet the standards of everyday life, or if someone else fails and there is no one there to correctly assign blame, they risk fulfilling the public's negative expectations of what someone with Down syndrome is like. They must, as far as the program is concerned, learn to be ideal pedestrians, independent employees, and model citizens if they expect to access full inclusion. The positive reputation of participants is not only crucial to inclusion, but it is also intrinsic to the success of the program and the ability of the program to establish itself as an important, beneficial aspect of the community. The participants must be regarded as positive, contributing community members and not as marginalized or burdening. As the next chapter explores, the workplace and the gym are the two central places where the participants are expected to enact this ideal and influence this reputation, but their presence in these places is also much more complicated than just seeking community inclusion.

The reasons for disciplining them are multiple, and survival of the participants is a significant motivation for the disciplining efforts as well. In order for the participants to be safe and for their inherent vulnerability to be reduced, they must be able to navigate the streets safely and take the transit alone without drawing attention to their presumed vulnerability. Part of flourishing, of course, is surviving, and in order for the participants to survive a balance between independence and monitoring, and between safety and freedom, must be established. Disciplining the participants to behave as ideal workers

and citizens when they are alone is a huge component of this balance. In order for this to happen, micro-practices occur through the program that contribute towards disciplining these young adults into the ideal Down syndrome subject, which become a part of what having Down syndrome looks like and means for these individuals. That participants may not always succeed at fulfilling the Down syndrome ideal is an aspect of this disciplining and constructing of Down syndrome, in that what is important is that the general perception of the participants must be that they can and do fulfill the ideal, or at least are working towards it. So when they fail, it becomes appropriate for the program workers to step in and correct behaviour, as the goal of becoming the ideal adult Down syndrome subject is accepted as beneficial to the participant, and so must be the participant's goal as well.

In the case of the participants, being an individual with Down syndrome means carrying a phone anytime one is in public alone and checking in at clearly defined points on one's commute, crossing the street at the lights and never jaywalking, not leaving the house without permission, not using a phone for entertainment when walking or waiting for the bus, not touching the bus driver or other strangers in public, using a list to track duties while at work, and always expressing and showing a desire to work. An ideal individual with Down syndrome is compliant, law-abiding, and independent. They are happy, easy-going, and social, but only when appropriate. They prioritize maturity and adult-like behaviour, and comply with the authority of employers, parents, and program leaders. The ideal Down syndrome subject understands graffiti laws, street lights, and transit norms, and knows what the standard safe and responsible reaction is to unexpected events when in public. The ideal Down syndrome subject understands and completes his

work duties and easily adjusts to changes in his schedule. The ideal Down syndrome subject manages her emotions and prioritizes employment, work duties, and program attendance over emotional response and attention. They must set an example for the rest of society by being ideal citizens in order to prove that they have a use and the right to be part of the rest of society, and so the program ensures that they do.

Chapter 5: Working and Working Out

Two large components of the program, and the ideal Down syndrome subjectivity the program prioritizes, are working, whether it is volunteered or paid work, and working out at the local gym. Every participant has some sort of work placement through the program and a gym workout plan. The participants must have a desire to work in order to be accepted into the program and the capacity to work relatively independently. The emphasis on work and working out are framed in very particular, intentional ways to the participants. These intentional framings are often different from, or simplified versions of, the actual factors that motivate the program to place such a strong emphasis on working and working out.

This chapter will explore the various motivations and conceptualizations of work and working out that contribute to the program's prioritizing of these activities, and the ways in which these activities function both as a component of the program and as a broader influence on the lives of these individuals socially and culturally. The emphasis the program places on work is motivated by a variety of factors. They conceptualize work as valuable to the participants because it contributes to a "normal", full life for participants, because they realize the social value gained from employment, and because they recognize the personal value and pride participants gain from successful employment. The program also understands employment as functioning to influence wider assumptions about the capabilities of these young adults, and as having a positive influence on the staff and patrons of the local businesses which employ them. However, they are also subscribing to capitalist notions of success while at the same time reconceptualising the efforts that are deemed valuable and productive in places of

employment. The program negotiates these various understandings of work-based value with a complicated understanding of the financial value usually gained from work. While some participants are paid for some of the work they do, and payment is a clear goal, the program acknowledges that several of the participants are unlikely to access paid work, and the structure of the Ontario Disability Support Program combined with a general fear of losing the support makes the income gained from employment an inconsistent priority.

While payment is a precarious goal of employment at the program, it is a significant end-goal of the exercising efforts accessed through the participants' attendance at the gym. While the participants do not earn individual paychecks through their working out, they do collectively take part in an annual marathon to raise funds for the program. Working out also functions as a component of the full, healthy lives the participants and their families seek to access through the program. It is less transparently a preventative effort in an attempt to counter the early aging experienced by this population, which the participants are unaware of. It is also, potentially, a means of influencing the community's expectations of these individuals and undermining public assumptions about their capabilities. The motivations for the significant time dedicated to both working and working out are much more complicated than initially suggested by the participants' understandings of these activities. Both working and working out influence community perceptions of this population, and they are disciplined into these specific roles as a component of the overall disciplining enacted by the larger society and, by extension, the program. The participants' membership at the program requires that they be willing to take part in both productive work and productive working out on a regular

basis, and as a result discourses attached to being good workers and strong individuals become a major component of their expressed identity when at the program.

Working

Participants must have a strong desire to work in order to be accepted into the program; consequently, the program does not have to actively convince them that working is a necessary, valuable part of life, since being convinced of this is a requirement for attendance. The school system assists in building this strong desire for work through finding opportunities for unpaid work experience at local businesses as a component of the special education programs. The participants are set up to strive for “normal” employment and success through work during their work experiences in the school system; many of these placements continue when the participants first start at the program. In addition to this required default desire to work, there are implicit understandings between the program and the participants as to why working independently is a crucial goal. These include the ideas that the participants must aspire to work because having a job is a part of a normal life, because they can work with the right supports and so should be allowed to, and because being a good employee and worker is important, contributes positively to their self-worth, and is something an adult does.

While the program’s choice to put an emphasis on work as a key goal is informed by the social requirement that individuals work to be viewed as valuable to society, it is also informed by guardians’ desires that the participants be supported in activities that allow them to have integrated, full daily lives. Without a program that supports the participants in working and otherwise contributing to the community the participants

would have very few options. They would likely either be limited to a workshop-based, segregated program model or they would be dependent on their parents' ability to facilitate a busy, interesting life for them, something Ellen, one of the founding directors, called the "What's next mom' program".

When I asked the parents what their son or daughter would do if they were not attending the program, their answers were all fairly negative. Debra depicted life without the program as challenging for her: "You know for her to get out there and have all the different experiences that she's having, I think would be very difficult for me to provide on a regular basis." Susan echoed this, explaining: "I don't imagine it. I think it would have been certainly a lot harder on me, and Eric, but it would have been a lot harder on me to find something suitable for him to do on my own." Sylvie represented the possibility of being without the program as horrible: "I can't imagine what he would do all day if he wasn't getting up and out. Don't even go there, it would be horrible," and her partner Nathan expressed uncertainty and gratitude that the program exists: "We don't know, we're thankful that the program's there, very thankful."

During my final weeks at the program a new individual who had Down syndrome started attending once a week. He provided a concrete example of the possible negative experience an individual might have when attempting to work in the community without the support system that the program offers. After his parents contacted the program asking for a place for him as soon as possible, Elizabeth told me about his situation. He had recently been fired from his unpaid job because after graduating high school he lost the supports he required to do it successfully and so was no longer doing a satisfactory job. As a result, he had been spending his days at home, inactive and drinking a lot of

soda pop, and so was gaining weight and becoming unhealthy. He had only been out of high school a few months at this point. His experiences seemed relatively typical of young adults with Down syndrome after high school, who are often left to work and fill their days without support if they do not have a place in a segregated program model.

The majority of the participants had a positive perception of their employment experiences. For example, Joseph would turn to me unprompted and say “I like my work” and “Carl [his boss] is my pal” when I was observing him work. Additionally, when I asked Laura how working makes her feel, she answered, “Happy, very happy,” to which I pushed “Always?” and she replied, “Yep, when I come in I get a big smile.” Kyle identified work as his favourite thing to do at the program. Greg also identified work as his favourite thing to do at the program, would smile whenever we talked about his jobs, and he expressed particular pride over working at the community gym, as he was working for and being paid by the town and so was working for the community. Similarly, when I asked Jennifer, “What unique thing do you think you bring to your coffee shop job?” she answered, “My coworker treats me like a good worker and I'm good at doing my job, doing good at more work skills. Good reason to do things that I'm proud of,” Jennifer also interestingly understood that employment was a source of pride and largely a positive, significant part of the participants’ lives and identities.

That the participants are accessing positive experiences from their employment is crucial. Although, as I explore in depth, the guardians’ and program’s motivations behind prioritizing work suggest that the choice to prioritize work is much more complicated than the participants are aware of, the fact that working has an overall positive impact on the lives of the participants should not be overshadowed. Ultimately, the program is

aiming to offer a more inclusive, normative, supportive, and successful experience of working and living in the community than is available to participants through other existing programs or independent living. The positive relationship participants have with their employment and the fact that program is fulfilling the participants' desires to work suggests that its unique model is overall successful.

The program emphasizes work, and ideally eventually paid and independent work, as a core component of its structure for reasons that extend beyond the implicit understandings they have with participants. They see working as necessary because they see successful employment as a means of accessing pride and positive self-esteem, and so their presence in the workplace is seen as potentially empowering to the participants. As Janet told me, "I think they get great self-esteem from it. Cause in almost all cases they work with people who appreciate them. And they are all so proud to tell people what they do." The program also sees participants' presence in the work-space as proving their value to the larger community. This proof rests on the understanding that the general perception of people with Down syndrome is that they cannot work, and so just by being in the workplace they are challenging expectations of what an individual with an intellectual disability can do. As Ellen explained, "They bring great morale to other staff, and they are very reliable, and they want to come to work every day to do possibly a pretty menial task. I think that as time goes on, that keeps getting richer and richer that people see the value," and later in our interview, "They get out in the community and people go oh, actually, that person's pretty cool. You know, so they're the best advocates." They see working as beneficial to employers and employees, in that, as Janet explained, "I think employers are in most cases learning the hidden values of having

someone with Down syndrome work there,” and Ellen continued, “I have a sense that the other staff benefit from it. That they learn how to be better mentors, a better peer to somebody.” Finally, they see a working individual who earns a paycheck as understood as inherently socially valuable, and so through working the participants can prove their social value. Being an employee is integral to being included in a community.

Beyond this, there are also very clear capitalist notions that are major factors in the program’s emphasis on paid employment as crucial to community inclusion, which are underlying their approach, but not necessarily specifically recognized or critically explored by the program. They explain in their vision statement that they aim to motivate young adults with intellectual disabilities to reach their full potential through better living and employment, and in their mission statement state that the program participants increase their independence and skills through contributing to their place of employment and the community confidently, and the program creates an environment in which participants are encouraged, live healthily, and can achieve life-long success. In both these statements, notions of employment as central to reaching “full potential” or being successful are clearly present.

In order to understand how these capitalist notions of success have become central to full community inclusion, and so to the goals of the program, I think it is important to understand the ways in which capitalism can be understood as creating the social category of disability. Michael Oliver and Colin Barnes understand the category of disability as a capitalist category, in that because the bodies of those with disabilities could not be disciplined into productive physical bodies by the capitalist market, they were precluded from making a wage from their surplus labour, and so from being a part

of the market society (2012:61). Industrial capitalism, then, created the conditions for the exclusion of people with disabilities from ordinary society, by creating the category of disability where in the past there was no distinct group identified as the disabled (Oliver and Barnes 2012:61). Marta Russell continues this thought by arguing that with industrial production and increasingly mechanized work requiring “precise mechanical movements of the body repeated in quicker succession,” individuals with disabilities were increasingly excluded from the labour market on the basis that they were unable to “keep pace with the ‘disciplinary’ power of the new factory-based production system” (2001:89). From this, Russell contends that the primary basis of oppression of people with disabilities is their exclusion from exploitation as wage labourers (Russell 2001:88). This idea of economic exclusion as central to oppression, and community exclusion, is taken up by the program and the participants’ guardians when they prioritize work, whether it is paid work, or unpaid volunteer labour, as a central means of reaching an individual’s full potential and life-long success. Through making work, and a desire to work, central to their program and the program’s conception of what community inclusion and a full life includes, the program is subscribing to a capitalist understanding of citizenship and individual value. They are, importantly, subscribing to these notions of success because it is the best means of convincing a larger society which depends upon these capitalist notions of success of the value of these young adults.

So, initially, the efforts of the program comply with capitalist ideas about productivity and can be understood as attempting to undo the oppressive, segregating impacts of the creation of the “formal administrative category” of disability (Stone 1984:27, 4) by arguing that certain individuals with intellectual disabilities that are

excluded from the service and information economy are capable of work, and so deserving of inclusion. However, allowing the employment of these individuals to be volunteered, unpaid labour for years until they have proven themselves capable employees, also confirms for employers that they can expect to save on the cost of production if they employ an individual with disabilities (Russell 2001:90). This general conception has stemmed from the sheltered workshop model, a model which has been used to justify below-minimum wages for disabled people historically. The sheltered workshop model is a form of institution which allows individuals with intellectual disabilities mediated access to the labour market with wages that are significantly below the minimum wage, with little autonomy over labour type, and with no possibilities for promotion, which is in many cases still the only supported employment option for individuals with intellectual disabilities (Russell 2001:90).

The program's founding directors created the program in resistance to this workshop model. As Janet explained to me:

We wanted [the program] to be very community based, and part of a lot of the great things that had happened to them already. And not just our kids, you know everybody, but they had all been part of the community through their church, through school, through their recreation activities, and we wanted to keep that up, that they were part of the community as opposed to being sheltered in some shelter-based program, which is a lot of what we visited and [we] realized that we did not want them to be part of a centre-based program.

Ellen described some of the centre-based models they went to see while planning the creation of the program as “really sad”:

Going out and exploring, I think that was the big eye opener for both of us. Having programs recommended to us by people, ‘this is a great program,’ and you go there and you go you’ve got to be kidding. If this is what they’re talking about then... Janet almost fainted in one of the places, I mean literally shaky, and this was a place that had been

recommended to me as a good program, you know. And it was not, it was warehousing, it was really sad.

The program, then, is very intentional in offering a program model that is within the community and requiring employment options for the participants that are within existing, community-based businesses. They are requiring that their participants have autonomy over their labour type, have access to promotions in recognition of their work (by earning wages or adding tasks), work within local businesses and are not segregated from them, and are doing work that produces notable value to the individual, the business, and the community. Even so, the participants are still treated as cheaper, often free labour. The employers are understood as intrinsically benefiting the participants by employing them, in that they are taking a risk and giving the participants experiences, but the participants are not seen as necessarily benefiting the employer by default. They have to prove that their labour is worth wages, and until that point can only be cheap, if not free labour.

Interestingly, however, when the program directors argue for the value individuals with intellectual disabilities contribute to the workplace outside of their labour, through their impact on the work environment, the attitudes and understandings of coworkers, the businesses' reputations, and the general community perception of Down syndrome, they are suggesting that productive work should be reconceptualised to include efforts which produce social value rather than just labour. They are suggesting that employers should join them in conceptualizing these activities which produce social value as benefiting their workplace and general society, and so as worth compensation. They are encouraging a new understanding of productive work and so of the labours required for full, included citizenship which is in resistance to the conception of productive work and citizenship

held in capitalist markets and societies. This reevaluation of what counts as productive work, is something Barnes and Mercer believe is intrinsic to the social rights of disabled people. They argue that the “promotion of the right of people with impairments to exist in society on a par with their non-disabled peers requires a challenge to prevailing analyses of work, welfare, and disability,” (Barnes and Mercer 2005:541) and further that a reformulation of the concept of work is necessary for the inclusion of people with disabilities (Barnes and Mercer 2005:541). For Barnes and Mercer, such an undertaking will eradicate one of the central elements which support the existing inequalities in society (Barnes and Mercer 2005:541). A reconceptualization of work to include alternative productive tasks is a challenge to the capitalist category of disability, the capitalist understanding of value as surplus labour, as well as the alienating conception of what counts as surplus labour. So, the program can be seen as both complicit in capitalist conceptions of citizenship, productivity, and value, and as undermining and resisting notions that are crucial to these conceptions.

While many of the employers clearly do see the value of having a young adult with Down syndrome working for them, Janet and Ellen explained to me that in some cases the participants are working for employers that they know will never compensate the participants. In response to the question “What kind of feedback have you got from employers?,” Ellen answered:

Will it lead to paid employment for some of them? No. And they’re pretty clear about that, that it’s not going to lead to payment. And some of them don’t see the people that are there now as valued employees. And that would be the grocery store, the coffee shop, the stationery store.

Janet continued:

The retirement home, they think we're very valuable in there, but they're there as volunteers. They fill a position that is a volunteer position, so they'd never get paid employment. And Carolyn's second job at the clothing store, I don't know that they would ever. They love having her there, but I don't know that... they think she's just kind of fun to have on a Tuesday... for Carolyn I see that as a goal. That she get more paid employment. For Eric, who is at the retirement home, everybody is just very happy that he's there, and his family included, I don't think they're pushing greatly... he loves it there, he does a great job there. It's a good fit, so.

While in Eric's case it seems that volunteered employment is satisfactory for everyone involved, in other cases it seems to fall short. In the case of John, the only participant I did not observe working at a formal workplace, when I asked him if he enjoyed his volunteer work for the church sorting donated clothes he answered no, and when I asked "No? Is it just today or all the time that you don't like to sort clothes?," he answered "I want to go to work." I confirmed with him, "You want to do to a job?" and he answered "Yes, at Subway."

In Carolyn's case it appears as though she is a novelty employee for the clothing store she works at. This surprises me, as Carolyn works another job at a restaurant and is paid for the work she does there. I watched her working at both her places of employment. On the day I observed her working at the clothing store, I wrote in my field notes: "Carolyn works very independently, without needing any guidance or instruction when she has been given a task to do at the clothing store." It was my perception that she was contributing significantly to the workplace. I watched her unpack, organize by size, and put out new stock and do returns quickly and without much guidance as to where things should go. In fact, I found her less hesitant and in need of instruction, and more confident in her job knowledge at the clothing store job than at the restaurant job.

Several times I heard Carolyn indicate paid work as an important goal for her. When I asked her one day what she likes about working, she said “getting paid.” Later the same day, when I asked “What makes you a good worker,” she answered “getting paid” and several days earlier during a course Elizabeth runs called “Ready to Work,” when asked by Elizabeth, “Why would you like a job,” Carolyn answered “because I want to get paid.” However, Janet and Ellen explained that because of the structure of the Ontario Disability Support Program (ODSP): “For some of our guys getting paid employment means nothing— especially for their family. If they’re receiving passport funding and ODSP then the pressure is off for the paid employment. Not all our families are in that position, but...” Ellen continued, “...but even the people who do get paid, I mean Carolyn gets half of hers taken back, so there is no benefit. And to lose ODSP is everyone’s worst nightmare.” According to the Ontario Disability Support Program’s website:

...you can earn up to \$200 a month without having your income support reduced... If you earn more than \$200 a month, half of your earnings above \$200 are exempt - this means half of your earnings do not affect your eligibility or the amount of money you get for Income Support.
(Ontario Ministry of Community and Social Services 2013)

So, while the program sees value in compensated work for most of the young adults that attend, the reality is that the structure of ODSP prevents these individuals from earning much even when they are getting paid for a portion of the work they do (some of those who do get paid, do not get paid for all of the days they work).

As a result of the ODSP system, and the threat that participants will lose access to the payments and accompanying benefits if they earn too much, do not declare their earnings properly, or are otherwise determined to be without need, the participants are kept in a complicated relationship with wages. They are unable to earn too much, as if

they do their ODSP, just over \$900 a month if they live at home and work, will be taken away. The result of this is that even when participants are earning through their employment, they are rarely receiving more than \$1100 a month with their ODSP and income combined. If they did earn enough to be taken off ODSP, they would likely have access to drastically less income a month (my sister earned \$215 through her jobs last month) and potentially no benefits, making any significant income an ambiguously desired component of their employment. The structure of ODSP recently changed, allowing some individuals to keep benefits when their income support is taken away, and allowing the claw back of income over \$200 to be on a sliding scale. Still, ODSP does not offer enough for participants to participate in the community and live independently, and as a result the participants are kept in a position of permanent poverty which is mitigated by their parents, and often must choose between moving out to an assisted living situation and accessing this type of program.

Due to this complicated ODSP structure, the participants are being compelled to be good workers to be fully included in society, but are denied access to the full reward associated with productive work. While the typical capitalist model requires that individuals work for wages, and so for the possibility of social progress and flourishing that accompanies access to a normal wage, the ODSP structure does not allow for significant wages as a reward for work. They are required to be capitalist subjects to prove their capabilities and worth, but even when proving their worth as good workers must be denied the financial reward, or risk a significant reduction in their income and loss of benefits. The result is that the non-economic types of value must be prioritized

when this population works, and their role as good workers and their understanding of successful work must be in terms of these non-financial gains.

By requiring that participants be motivated workers, the program is also able to use the idea of a good worker as a disciplining mechanism and encouraged goal for participants. These discourses are built into many of the components of the program, including the “Ready to Work” course Elizabeth runs. Elizabeth leads the course several afternoons a week with small groups of the participants, and covers things like the participant guidelines at the program, the Workplace Hazardous Materials Information System (WHMIS), practice interviews, and resumes. During a walk on one of my first days at the program, Elizabeth explained to me that “Ready to Work” helps the participants be good workers, which they want. During that day’s course, while they were reviewing WHMIS information, Carolyn read a section out loud that stated: “a good worker puts things away,” suggesting that the discourse of a good worker is built into the program’s discourses.

As a result of the program’s emphasis on the participants as good workers, the participants all identified as good workers in conversations with me. When I asked Jennifer what “unique thing” she thought she brought to her place of work, she answered, “My coworkers treat me like a good worker and I’m good at doing my job, doing good at more work skills.” When I asked Joseph “How would you describe yourself as an employee?” and gave him some basic options as examples, he answered, “I’m fast, good, I do my best, and I have fun, I behave and I work.” When I asked Laura, “What words would you use to describe yourself?” she answered, “I’m talented, I’m doing good work.” Finally, when I was watching Greg at one of his jobs I asked him specifically if he

“thinks he is a good employee?” to which he answered, “yeah, I’m a good employee.” Later in the conversation I asked “What do you think makes you a good employee?” and he explained, “A good employee works hard”. Even when I asked Janet and Ellen about how the participants view themselves as employees, their answer went along with this theme, with Ellen answering, “I think they see themselves as being good employees. They see themselves as contributing.” Working, then, is about modeling appropriate behavior and aiming to be an ideal, “good” employee. Because the participants are aiming to be this “good employee”, they can comfortably frame themselves as meeting this ideal.

Additionally, the program is both complicit in ensuring that participants understand themselves as very good employees and understanding that sometimes employment does not work out. The program directors emphasized to me that it was important that employers discipline and fire an employee with Down syndrome, explaining that:

We’re here for [employers], if this doesn’t work, it is a handshake, it is a goodbye. And we’re going to work with that person to let go. Because Jennifer stole a water bottle from her coffee shop job, [and] they weren’t going to do anything about it. We had to go in there and say no. You do something about that. You tell. You write it up like you would any employee. And with Eric at the stationery store, we had to go and say actually, right now, this guy needs to be fired and were going to help them with that.

At the same time, they seemed to approach the job transition of Joseph, which occurred while I was at the program, as though his change in duties was an arbitrary change rather than deemed necessary by his inability to successfully complete the tasks.

Joseph transitioned out of doing the vacuuming at the clothing and shoe store he worked at because he was taking much longer to complete the task than his co-worker

who also attends the program. However, in conversations with Joseph he identified vacuuming as a task he enjoyed doing and was good at, and as I identified above, he identified as a particularly fast employee. I got the sense that Joseph was not fully involved in the decision, as the conversation about it occurred between the store owner and Elizabeth, and when I was asked my opinion about his vacuuming speed by Elizabeth after my first time observing him at work, it was privately out of earshot of Joseph. While Joseph was content with the change, it did not impact his self-conception as a good, valuable employee, nor his understanding of himself as a good vacuumer. In Joseph's case, he did not identify as an unsuccessful or unsatisfactory worker to me in response to his job changes, and I got the sense that he did not fully understand or was not fully informed about the reasons for the changes.

Additionally, in the case of Jennifer, while there were no issues with her job performance while I was observing her, the program protected her from the reality of her employment in another way. Jennifer, like Carolyn, identified a desire to be paid during our conversations. She suggested to me that she would like to get paid like her other friends at the program do. However, unlike Carolyn, her current place of employment, a chain coffee shop, was not paying her and was one of the places the directors identified as not seeing "the people that are there now as valued employees." Her mother, Ellen, expressed to me that "for some of our participants volunteering in the community may be a better option. That may be more realistic and may be where they are at... I think of that for Jennifer... the pressure at the present position – that's not going to happen. I don't want her to be disappointed." So while being paid was a goal of Jennifer's which she saw as realistic and achievable in her future, and the lack of which clearly made her feel left

out, her mother understands that Jennifer may not find a paid position and certainly is not viewed as valuable enough to compensate at her current place of work. The program and her family protect Jennifer from “disappointment” by opting not to communicate with her the reality of her work.

Through their management of the participants and of the workplaces’ expectations, needs, and desires, the program is able to ensure that working functions as successful, prideful component of participants’ lives. It trains the participants into the subjectivity of a good worker, as a component of the ideal Down syndrome subjectivity, while negotiating the denial of traditional financial value due to the social space created by ODSP and the expectations of business owners. As a result of this denial, alternative types of value gained from work are prioritized and held as the benefit of being a good worker. These include personal value in the form of self-esteem and pride, and the social value gained from proving their social worth as productive workers and active community members. While gaining paid work is still a goal for many of the participants, this goal is about the positive influence gaining pay has on their personal and social worth, and the social equity gained from accessing paid work, rather than the financial value gained from this accomplishment. In a similar vein to the good worker subjectivity, the participants are also shaped into the subjectivity of a productive gym member through the discourses, requirements, and value ascribed to their mandatory gym membership.

Working Out

The reasons for the participants’ active gym participation are also more complex than the reasons presented to them. Working out at the gym is a significant component of the program. All the participants must complete their workout plans at the gym several

days every week. These plans are made by trainers at the gym and are unique to each participant. Monica explained to me that these plans are re-evaluated by the trainers twice each year, and new machines or exercises are added if the participant is completing their list of exercises too quickly or if a participant asks to try a new machine. Each participant has a different means of keeping track of their exercise plans: some use dry-erase markers and checklists, while others use images of themselves doing the workout with simple instructions of the number of repetitions or time duration beside the images. Some of the participants have days when they do not follow their plan, such as the one morning a week when Zumba classes are taught in the gym and some of the participants opt to participate.

The program's workers monitor their completion of the plans and when participants achieve all of the workouts indicated in their individual workout plans they are rewarded in the form of two stickers on a page in their folders at the program. When they have earned the requisite stickers for the month, they are rewarded for having achieved their goal with a small prize. Gym attendance becomes framed in terms of reaching their monthly goal as a result of this tracking and prize-based model, and so a large part of the participants' motivation and reason for going to the gym and working out is the reward and feeling of success that comes from reaching their goal. This reward model allows them to gain personal value in the form of pride and self-esteem gained from individual successes through their gym participation.

The gym participation is also framed in terms of training for a five kilometer walk that the program participants, guardians, and staff do once a year. The walk is part of a larger marathon that many charities use to raise money. The participants and their

families fund-raise for the marathon and then the program workers, participants, and any family members who are registered for the marathon complete it together. The marathon took place while I was at the program. As a result, the discourses around preparing for the marathon and successfully completing the run were fairly prominent while I was there. I also registered for and completed the marathon with the program's group, and I witnessed the collective success of each participant as we crossed the finish line together.

The marathon is a major contributor to the program's funds. They raised over \$35,000 through the marathon I attended, much of which goes towards reducing the cost of attending the program for the participants. Interestingly, their fundraising efforts, then, make more money collectively than their employment. The participants who raise the money are rewarded with gift cards, and so everyone is very invested in setting high individual fundraising goals, reaching those goals, and successfully completing the marathon. The successful completion of the marathon each year combined with the pride gained from successful fundraising, which is increased for those who fundraise the most, contribute significantly to the personal value gained from their gym membership.

The participants also understand their participation at the gym and the necessity that they work out regularly in terms of the importance of being fit, physically healthy, and strong. When I asked Greg how he would describe himself when he is at the gym, he answered, "I go to the gym to get strong, to get lots of girls," and when I asked him, "What do you like about the gym," he answered, "I burn lots of calories." When I asked John to describe himself when he is at the gym he answered, "I try hard," and later reiterated, "I try very hard at the gym." The marathon is also a component of this. The day after completing it, Elizabeth told the "Ready to Work" group that she thought that

“everyone was really prepared [for the marathon] this year, because everyone was walking really fast which means they worked hard at the gym.”

However, the program understands the necessity that participants work and workout in more complicated ways. While in the case of working out, the program sees this as valuable not just because of the general health benefits of remaining active, but because individuals with Down syndrome tend to have extremely early onset Alzheimer’s dementia, often showing signs of Alzheimer’s dementia as early as 30, and regular physical activity is believed to contribute towards preventing Alzheimer’s dementia in older adults (Berney 2009:35-36).

Ellen and Janet spoke to this during our interview. We were talking about the long term plan for the program, given that currently new participants are exclusively individuals who are recently out of high school and looking for an active, full life to replace the facilitated days of a high school environment. As a result, the participants are all close in age, between 21 and 29. However, as participants like Joseph age and remain at the program, the demographic of participants will change. Several of the parents I spoke to cited the significant variety of participant ages at other programs as a major reason why they felt as though these other programs were not a good fit for their son or daughter. As a result, the program has to decide if it will change its structure as these current participants age to better meet their needs, or if they will remain the same with young participant intake, and have changing supports for older participants. Ellen and Janet explained the issues as the participants age:

Ellen: I mean the long term support for people who are aging. With people with Down syndrome the research, it’s premature aging. I mean there are signs of Alzheimer’s at 35, I mean some of our guys – Jennifer’s 26 – that’s soon. That’s soon. When I was at L’Arche, by 55-60 they all had

major signs of aging. So then, what's the role for something like our program? Is it like yeah, those people have a home base, but are going out to a senior citizens community? They're staying physically active. The one good research is – Collin was just at a geriatrics conference – and he said that the big research is that to be physically active throughout your life, that is the key, so we have a rec program. So we don't have models of people with Down syndrome who are that physically active in their young years, so that may have a huge offset that could be good. But I think there is something genetically...

Janet: ...so we've got to see what happens. I mean our guys' minds are much more active than when you were living at L'Arche. I mean Carolyn does the Sudoku every morning in the paper. So you know if you keep doing stuff like that, that's huge.

Ellen: So we don't know, but what, in the past... each generation teaches you more... certainly 90% of people here who have Down syndrome, that's just how it worked... the aging process, and the effect on [it]. So the desire is let's provide as much as we can. When I lived at L'Arche I was a nurse for two gentlemen who had Alzheimer's disease, and these were young men. And when I go back to L'Arche now, people who are my age are full out into Alzheimer's, there is no one who isn't, when they're 60 years old. So you have to look at the past, there is a huge predisposition, so what can we do to mitigate it? And what we're trying to do is mitigate it for the people here. But we could become an old folks' home. With Janet and I still at the helm at 80.

Clearly, aging is a huge concern for the program and the focus on working out has potential implications for the participants' future health in much more crucial and complicated ways than the general emphasis placed on health for the average person.

The participants are unaware that for them working out holds these potential significant consequences for their future health and quality of life. While the program's motivations for their attendance is largely in terms of overall health and future quality of life, it is important to note that by attending the gym regularly, completing exercises independently, getting to know trainers and regulars at the gym, and using the equipment properly without any obvious monitoring or assistance, the participants are likely impacting the community's perception of them, and so positively contributing to their

social value. Janet suggested this when she told me about their experiences finding employment placements for the participants: “And the more we get known in the community, our guys at the gym, you know the last couple people have come to us [to offer employment]. So we’re finding that it is pretty easy. You don’t have to go making too many cold calls.” Their presence at the gym, then, also has larger implications for their opportunities in the larger community.

The gym they attend is at the town’s community centre, and so the community members who attended the gym were of a variety of ages, backgrounds, and athletic abilities. While attending the gym with the participants, I witnessed them engaging with other gym members they did not know in ways appropriate for a gym environment. For example, on my first day of observations, I listened to John tell an unfamiliar woman about his exercises while they worked out on the stationary bicycles together. In response she told him that working out was hard for her and he playfully responded that it is not very hard for him. I also witnessed participants engaging with gym members that they had got to know through attending the gym. These gym members usually only knew one or two of them, and would approach the ones they knew individually to say hello and ask how they were. For example, a few weeks later a man saw John and greeted him, “Hi John! How are you?” to which John answered, “Oh, hi David.” David then asked John how he was again, John answered “good,” and David ended the exchange by telling John it was nice to see him. After David left, John turned to me unprompted and said, “That was my friend David from the gym.”

By regularly attending the gym, the participants are able to build acquaintances with community members they might not otherwise meet. They are also asserting

themselves as a normal part of the community who requires access to the same services as anyone else. They are integrated into the gym environment, rather than segregated from the rest of the community members using the gym, and through that they eventually become a largely unexceptional part of the gym community.

This integration into the gym environment is important, as the participants are an unexpected presence at the gym. This was clearly indicated by centrally placed signs I found on some of the workout machines which came attached to the machines by the manufacturers. The machines unmistakably indicated that a visibly disabled individual is not expected or trusted to use the gym independently, as figure 2 shows.

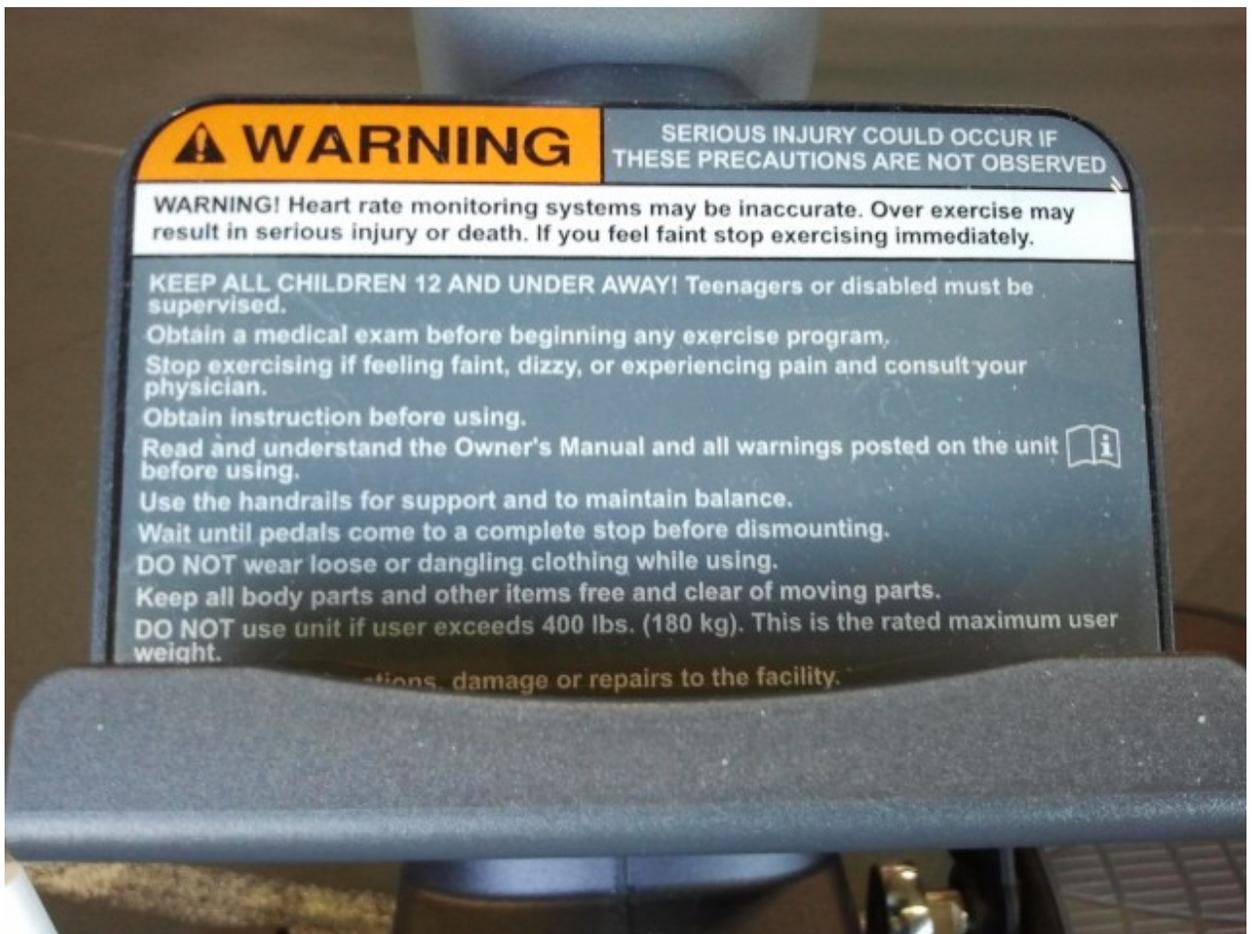


Figure 2.

By insisting through a formal warning that “teenagers or disabled must be supervised,” the gym machines position people with disabilities as permanently within a category of pre-adulthood similar to a teenager. Through this warning, anyone who fits within the category of “disabled” is universally forbidden from working out without supervision, either because they are inherently unable to do so or because they are universally not trusted to do so. Interestingly, the participants are generally not supervised when at the gym. Although one of the program staff comes with the group, she is always completing her own workout at the same time and is rarely directly supervising any of the participants. That the participants all work out unsupervised is subversive to the expectation within a gym, at least as perpetuated by equipment manufacturers.

The participants’ ability to workout independently and be trusted not to steal or vandalize is as uncertain at the gym as when they are being pedestrians. The participants have behaved inappropriately in the past, as Ellen explained, “We’ve had people kick in water coolers at the leisure complex, we’ve had people hit people at the leisure complex... and it’s our staff that have been there to mitigate the damage, to be responsive, and nobody got kicked out.” They have also been treated with suspicion by the gym community in the past, as once Eric was wrongly accused of stealing from the pockets of an older patron’s clothes which had been left in the change room. So, the fact that the participants are largely integrated in the gym environment and are building familiarity with the gym staff and fellow patrons is essential to undermining the gym community’s default expectations and has considerable implications for the community’s overall perception of them.

Conclusion

In this chapter I have shown that the program prioritizes both the participants' employment and their gym participation for much more complex reasons than those understood by the participants, or even the program, and this choice has larger implications than initially presented. While the participants aim to be good employees because it is an aspect of a normal life and a component of being a successful community member, and the program prioritizes employment because they see it as central to community inclusion, there are significant capitalist expectations that are being fulfilled and challenged through the program's emphasis on, and conceptualization of, valuable work. Additionally, while the participants understand their gym membership and workout plans as integral to their health, strength, marathon success, and, again, normal lives, the program understands their gym membership as having much larger implications for their future health and aging process, and as having a possible significant impact on the community's perception of them.

At both the gym and work they are required to demonstrate their productivity through active participation. By showing that they can work and engage in their communities productively, the participants are influencing their animacy positions. As Chen argues, "animacy and its effects are mediated not by whether you *are* a couch, a piece of metal, a human child, or an animal, but by how holistically you are interpreted and how dynamic you are perceived to be" (2012:210). As workers and active community members, they are forcing the community to view them as animatedly contributing and so renegotiate how dynamically they are perceived. However, while they are proving their animacy, productivity, and liveliness, they still occupy a disabled

identity, which is implicitly inanimate. As Chen acknowledges, even when a disabled person “zip[s] right by you in a manual wheelchair,” they are still defined as inanimate (2012:210). In the case of people with intellectual disabilities, their positioning as unproductive, even when zipping right by you while vacuuming the store floor, is a central aspect of their subhuman, inanimate animacy position, and the resulting denial of their subjectivity. So, as workers with intellectual disabilities they are occupying a contradictory space of categorical inanimacy and actual animacy and flourishing (Chen 2012:210).

Through being workers and active community members, they are challenging their animacy positioning. If they cannot be convincingly positioned as inanimate, if they cannot be denied their “existence, emotional life, sexuality, or subjectivity,” (Chen 2012:210) then they cannot be convincingly positioned as subhuman or dead. If they cannot be denied their animacy, they cannot be justly denied access to services, full lives, or lives at all in the form of selective abortions. While this small, local population of young adults might not be changing the larger social climate which allows for the popular abortions of fetuses with Down syndrome and their larger oppression, they are reaching their local community and the neighbouring towns, and showing them that people with Down syndrome are a lot more alive and animate than they assume.

The value gained from their participation in both the work and gym spheres is multiple. They gain positive personal value through the pride and self-esteem they gain in both their places of employment and the gym. This positive social value is tied to their successful continued employment, paycheck for those that earn one, and encouraged self-conception as a good worker. It is also tied to their ability to progress through and

complete their workout plan, their fundraising and completion of the annual marathon, and their encouraged self-conception as a strong, active gym member. They also gain community and social value through their participation in these spheres. Their encouraged positioning as a good worker and good gym member is a component of their being disciplined into an ideal Down syndrome subject, and so the social value gained through their participation in these spheres is a major motivation for these positionings. Just as deviant behaviour is likely to have a negative impact on the community's perception of this population, the positive behavior displayed through their roles as good workers and active gym members gain them social value through positively influencing the community's perception of them and encouraging the community to view them as normal citizens.

Chapter 6: Conclusion

In this thesis I have I aimed to situate the experiences of the particular young adults I worked with within the larger social and cultural context individuals with intellectual disabilities tend to experience in Canada. I have aimed to explore how categories of disability shape the material realities and experiences of particular groups of people. Choosing to focus on young adults with Down syndrome allowed me to explore the experiences of a population that are often left out of disability activism and collective attempts to push back against disability antagonism and oppression. They are a population that is often represented as passive and unable to respond to their oppression, and whose disability status has been biologized and, through that, justified and relatively stabilized for decades. I have aimed to articulate the means through which these individuals actively engage with and resist their categorization and its assumptions. I have also aimed to articulate their experiences living as an adult with Down syndrome, self-advocating for their desires, being influenced and limited by their categorization, and setting life goals that are influenced by or counter to their Down syndrome identity. Within this context, I have sought to raise questions about the lived experiences of a particular group of young adults in a small semi-urban community in Ontario, about the factors and actors influencing their lives, about the experiences of and incentives for disciplining within this space, and about the various motivations for the program's structure.

I have explored the implications of being a young adult with Down syndrome for a group of individuals attending a program which attempts to manipulate and change the limitations created by the Down syndrome category. This research has provided an

understanding of the means through which this category has been created as a distinct category of intellectual disability, shaped, and seemingly stabilized historically. It has attempted to expose some of the powerful actors who have historically been and currently are able to influence and determine the barriers and limitations expected of a young adult within the category. It has shown that the category of Down syndrome is not a stable, universal experience or identity, but rather is varied, complicated, resistible, and manipulable. It has made visible the various meanings assigned to the category of Down syndrome, and the specific, unique meanings of that identity for the young adults attending the program. It has shown the ways in which the program attempts to remove some of the barriers that these young adults experience when attempting to access a full, recognized social role and employment. It has also shown the ways in which the program disciplines the participants into ideal Down syndrome subjects as a means of accessing these normalized life experiences. It has explored the complicated narratives produced by the program surrounding work and working out. Within these narratives, it has exposed the complex nature of a program which attempts to open up possibilities for this population, but in order to do so must comply with a capitalist social system which contributes significantly to the formalized segregation of Down syndrome. It has also shown how future medical uncertainties underlie the program's current priorities. It has explored the disconnect between the Down syndrome categorization, the systems which create limited cultural expectations of them, and their lived reality, allowing for their capabilities and desires as individuals and as a collective categorical group to begin to be exposed.

The Program

Throughout this thesis, I have attempted to avoid making value-judgements about the program and its efforts. However, I think it is important that I reiterate that this program is crucially supporting these young adults in living enriching, full lives. The program offers a level of support, challenges, experiences, and independence for this population that is inaccessible for most young adults with intellectual disabilities in the area. While the participants they accept are very specific, in that they are recently out of secondary school, are capable of self-care, have a desire to work, and do not require attendant services in their daily lives, the program represents a model which has a very positive impact on community perceptions of this population, and could have larger implications for the category over time.

My focus in this thesis is the participants and the limitations that still contribute to their general experiences of oppression and negative categorization. As a result, I am critical of the disciplining efforts of the program and the prioritization of paid work as a means of proving value. I am critical of the disciplining practices because they enforce a degree of self-discipline that I see as directly connected to the participants' disabled categorization. The degree of discipline enforced by the program also precludes those who are unable to meet these disciplinary standards from attending the program. Additionally, I understand the disciplinary practices as contributing towards the positioning of the participants as child-like. However, I hope it is clear that this criticism is largely meant to be based in an understanding of the program as rooted within an ableist, capitalist, neoliberal society, and so I understand their attempts to counter the oppression experienced by the participants as necessarily within the confines created by

that society. Ultimately, the program staff do not conceptualize themselves as activists, but as advocates who are working on directly positively influencing the lives of the participants each day. For them, working within the existing values of their society is currently the best way to do that. Changing the various social discourses and cultural factors that disable and oppress this population is a slow process; however, impacting their general community's perceptions, the participants' access to employment, the participants' feelings of pride and confidence, and their access to their communities have proven to be feasible tasks over the five years that the program has been running.

Significance of the Research

While a small amount of anthropological research has been done involving individuals with intellectual disabilities (Hedwig 2006; Ochs, Kremer-Sadlik, Sirota and Solomon 2004), ethnographies that explore the experiences of individuals with Down syndrome are not currently available. This research begins to fill this gap in anthropological literature using methods that are particularly apt for exploring the experiences of this population. Anthropological methods were particularly useful given individuals with Down syndrome's erasure from history, their lack of visibility and segregation socially and culturally, and the efforts that groups like my fieldwork program and larger scale projects like the Special Olympics and the Canadian Down Syndrome Society are making to create inclusive social spaces and communities for these individuals. It also contributes to the field of medical anthropology, in particular the anthropological research being done on the culture of disability.

The research also contributes to existing literature on the self-advocacy of young adults with Down syndrome. My research explores the self-advocacy of a population of

young adults who have never been placed in long stay hospital wards or institutions, and their work asserting their rights to have full lives and their capabilities recognized with the help of the program. While research on the self-advocacy of individuals with intellectual disabilities exists (Artkinson, Cooper, and Ferris 2004; Spencer and Walmsley 2006; Williams 2006), literature with these efforts as the focus is rare. The young adults at my fieldwork program are pioneers themselves, as programs facilitating the level of inclusion, community presence, and independence of my fieldwork program are currently uncommon. This makes their efforts to bring inclusive practices into the community unique to the members of their particular community and a part of a movement towards programs that better fulfill the desires of these individuals.

Finally, my research explores and makes visible the categories of Down syndrome and intellectual disability, which is work that has not been done with the intentions of this thesis previously. It describes key moments in these categories' historical creation, formalization, and meaning-attribution. I have also attempted to show that the concepts of animacy, looping, and torque are all useful for understanding the work that categories of abnormality do to the populations they are applied to. My thesis shows the ways in which this population's current life experiences and possibilities have been influenced by these categories' historically increased subjected positioning. By making visible the key moments and incentives that have led to the current understanding of these categories, it shows how these categories continue to impact the lives of those who are sorted into them. This is important, as by making visible the work that the categories of Down syndrome and intellectual disability do, this thesis shows how powerful these categories are in creating oppression, instances of torque, and shaping the lives of those they are

applied to. It shows how powerful actors and discourses have worked to wrongly position people with intellectual disabilities as inanimate and as living lives that are not worth living. It shows how looping effects allow the increased negative positioning of these individuals to directly influence their capacities for flourishing. However, it also shows how the program and the self-advocacy of participants allows them to negotiate and resist their category's implications and attempt to destabilize the category again, as we experience "a whole new type of looping effect, when so many of the kinds claim rights to their own knowledges" (Hacking 1995:382).

Further Research

My research has the potential to lead to further research on a group of individuals who have largely been erased from history and segregated from society and who are becoming increasingly visible. My research is a specific case study which shows how access to particular life goals, supports, and community-based experiences can impact self-conceptions. It shows how a particular social and cultural context influences the lived realities, interactions, and opportunities of these particular individuals. It prioritizes the participants who have Down syndrome, and seeks to accurately describe their lives as employees, gym members, program participants, and community members. It articulates the desires of these young adults, but also shows how these desires are shaped by the program and their categorization.

My research opens up a number of avenues for further research. Given that the program is very specific in its structure, membership, and goals, a comparative ethnography that explores the self-conceptions, experiences, and material realities of young adults with Down syndrome in a workshop-based program, in a L'Arche

community, and without a post-secondary school program would be useful. This would allow for an exploration of the influence that opportunities for progression, program structures, program goals, understandings of Down syndrome, expectations of young adults with Down syndrome, and models of support have on the desires, future goals, and self-conceptions of this population. As the program expands into new communities, it would be interesting to track the community changes. Looking at the ways in which community perceptions and understandings of Down syndrome potentially change, from prior to a facilitated Down syndrome presence in their community to after the program has successfully rooted itself and becomes known in a new place, would be particularly interesting to track. It would be interesting to explore the success of participants at reaching their future goals of marriage, employment, and independent living and to see how their success or lack of success as they age influences their desires and identities.

Additionally, this population would benefit from ethnographic efforts that track their lives over longer periods of time. Anthropological, ethnographic methods were ideal for this research as the participant observation and informal interviews I conducted allowed me to work with the participants in ways that prioritized their experiences and lived realities, but did not overwhelm them. These methods allowed me to experience the participants' daily lives in detail, allowing me to better understand the aspects of their lives which they may have struggled to express to me. These methods also allowed me to ask the participants questions based on their current experiences, making communicating their thoughts and beliefs easier. Finally, these methods allowed me to fill in information from interviews with the directors of the program and the participants' guardians, while still allowing the dominant experience of my fieldwork to be that of the participants'

general experiences. I strongly feel as though ethnographic research is the most appropriate way to conduct research on and with individuals with intellectual disabilities.

The scope of my Master's project meant that I could only devote two months to participant observation and interviews. However, as each individual I worked with had unique personalities, speech patterns, and levels of familiarity and comfort with me, I think that understanding these individuals would particularly benefit from longer periods of time spent with them. While I still believe my choice not to formally interview participants as to not overwhelm or upset them was the best choice for my participants, I think that had I had the chance to sit with some of them alone over a coffee and talk, I might have been able to prioritize their voices more throughout the thesis. However, this would have only worked with particular participants, and I ultimately think this thesis gives a strong depiction of their experiences as members of the program and as young adults accessing these types of supports for the first time in their lives.

My research has led to me to ask a number of questions, including: How would a conceptualization of a successful, full life that does not depend on capitalist notions of employability as central to individual value allow for more valuable community inclusion and empowerment for this population? In what ways would a reconceptualization of people with Down syndrome as varied, complicated, human, and animate positively influence their category, potential lived realities, and personal conceptions? What would be required to force the category into another mass wandering that would allow for people with Down syndrome to be viewed as inherently valuable and animate? What would be required to reduce or completely remove instances of torque for this

population? What value would be gained from a program that is led by people with intellectual disabilities, where life experiences and goals are set by them?

While answering these questions was not feasible within the scope of this project, I think they are crucial questions to the futures of people with intellectual disabilities, particularly those with Down syndrome, and the implications of their categorization.

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