Autonomy and Moral Obligation:
People with Intellectual or Developmental Disabilities

by

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AUTHOR'S DECLARATION

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

Abstract

In this project I seek to evaluate how social structures and attitudinal norms impact the autonomy of people who live with intellectual or developmental disabilities, and what implications arise from that evaluation. I argue that this particular demographic experiences restriction to autonomy in a way that generates moral obligation for society to mitigate. I then investigate the possibility of a service called Independent Facilitation and Planning as a contemporary example of how the province of Ontario can meet that obligation.

Acknowledgements

Dedication

For my mother.

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1.1 Introduction

In this project I will seek to evaluate how social structures and attitudinal norms impact the autonomy

of people who live with intellectual or developmental disabilities, and what implications arise from

that evaluation. I will argue that this particular demographic has their autonomy restricted in a way

that society is morally obligated to mitigate. I will then offer an interesting contemporary example of

how society can meet that obligation. In order to discuss autonomy as experienced by an entire

demographic, I first need to clarify how I am using the term "autonomy", then consider various ways

in which autonomy in this sense can be restricted, and the question of when such restrictions give rise

to moral obligations for others to eliminate or mitigate those restrictions. Then I will argue that these

conclusions also apply to groups of people, and by borrowing defining features of an unjust society

from Martha Nussbaum, I will attribute that moral responsibility to society collectively. These are the

tasks of the present chapter.

1.2 Developing a Working Definition

Though the concept of autonomy is often discussed, it is notoriously difficult to define. It is generally

agreed that autonomy is related to actions, beliefs, and reasons for acting (Dworkin 1988, 6), and is

often used as a synonym for self-government, critical reflection, and freedom from obligation

(Narayan 2002, 430). Understandably, it is a central concept in discussions of human dignity within

prominent theories of justice (Kittay 2008). Some discussions offer an account with more practical

details, and spell out autonomy in terms of a person's desires, preferences, and choices. It is easy to

see why Dworkin has called it a term of art, and thinks it unlikely that a single underlying definition

persists across the range of uses (1988, 6). What *is* held constant throughout these discussions is that

autonomy is regarded as a desirable quality for a person to have, and that it is threatened by force, coercion, and deception.

There has been a significant shift in the ongoing conversation about autonomy, notably between the earlier accounts and more recent feminist contributions. Historically, discussions of autonomy have centered on the rational mechanisms of the individual, namely involving the right sort of mental interplay between a person's will and action. For instance, an autonomous agent in a Kantian sense remains uninfluenced by desires and emotions that arise from the particular social circumstance in which they are involved. For a person to remain uninfluenced in this way, affords them a level of abstraction from their social context, and thus renders them able to have self-originating decisions and actions, *i.e.* be autonomous (Stoljar 2014, §1). This example also shows the underlying commitment to the ideal of self-sufficiency, which is a recurring theme in traditional accounts.

Feminist autonomy theorists have expressed dissatisfaction with the underlying value of self-sufficiency that the traditional views endorse, as well as the emphasis on rational independence. Their contributions bring to the forefront how relational contexts influence people without negating their autonomy; something that historical atomistic accounts of autonomy have lacked (Ibid.). This approach takes into account the various sources that influence an individual's autonomy in their daily life as they form preferences and make decisions. No longer is a person required to have their reasoning detached from their social context in order to be considered autonomous.

Within the accounts of autonomy developed by many feminist philosophers, the internal, or rational, components of autonomy do remain an important feature. Yet external, or relational, factors, such as intimate relationships, oppressive social norms, and other gender inequalities, are also incorporated. By doing so, feminist theories express doubt that any person is ever able to remain

entirely uninfluenced by their surroundings, as well as consider how someone can live autonomously while being influenced by these surroundings in particular ways.

Within these "relational" conceptions of autonomy, there are many theories that develop the notion of autonomy as a feature that people exhibit in degrees, and not an all or nothing quality. These degrees often refer to the strength of autonomy specific to particular areas of a person's life, and the differences are articulated as "episodic" autonomy (Meyers 1987, 625) or "domain-specific autonomy deficits" (Khader 2012, 308). Such accounts differentiate between a person's autonomy being constricted and it being entirely absent.

The theories that include philosophical detail designed to identify degrees of autonomy are what I will refer to as "thick relational" notions of autonomy. These are theories with the depth to assess and compare the degree of an individual's autonomy across the many "domains" of one's life. Each thick conception of autonomy is unique to the author positing the theory, and typically reveals the author's commitments to various other philosophical positions. These commitments include their views of a "true self", or lack thereof, their attitude toward perfectionism,[1] and whether their position involves a substantive evaluation of the content of desires, among others.

I draw from the lessons of feminist autonomy theories in order to define my own working definition. I too will incorporate both internal and external factors influencing autonomy. However, the "thick relational" concepts as described above are beyond what my project requires, and so I will opt for forming a "thin relational" notion. By "thin" I mean one that prescribes the minimal key elements that are considered essential ingredients of autonomy, without committing to (or, more arduously, defending) the prerequisite internal content of a "thick" concept. As I am using it, a thin relational notion is one that focuses on the outer edges of autonomy to distinguish when restriction

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[1] By perfectionist here I am referring to the commitment to the view that the betterment and development (or perfecting) of humanity is objectively good. See Superson 2005.

occurs, rather than measuring the depth and contours well within the margins of autonomy. Although a thin notion is not useful for the evaluation of degrees of autonomy in an individual's life, it provides a working concept suited to this task.

While I will not defend the claim here, I think the thin notion I outline incorporates features that would be recognized as necessary conditions for autonomy by many of the feminist theorists who defend the thicker notions. It is also worth mentioning that while some traditional accounts might be described as "thin" due to their focus on what takes place within any particular agent (to the exclusion of their social context), my definition is thin in a different way, precisely because the factors are built into the core of the concept.

Two key features will constitute the thin concept of autonomy that I will use for the remainder of this project. These features are: that an individual is acting autonomously when (1) they can internally reflect on and deliberate about their desires, preferences, and choices in a manner free from coercion, manipulation, distortion, or deception, whether directly from another individual (Myers 1987), or indirectly as resulting from oppressive social norms (Superson 2005, Khader 2012, Narayan 2002), and (2) the individual experiences freedom from external factors such as restricted access to relevant options and an unsafe environment (Oshana 1998).

These two elements formulate boundaries within which an autonomous individual is able to arrive at decisions via a practice of reflection on their desires and goals, free from social oppression or direct coercion, and has the physical and social safety to make and act on their decisions. Furthermore, impediments to these two features demarcate the outer edges of this thin conception to indicate where autonomy constriction occurs.

1.3 Individual Limitations to Autonomy

The first use I shall make of this thin notion is to clarify how different kinds of limitations to individual autonomy are distinguished; namely, those that are problematic in a moral sense, and those

that are not. Discussing the limitations of autonomy as they apply to individuals will provide us with lessons to understand the hindrance of autonomy suffered by an entire demographic.

Of course there are categories of how autonomy can be restricted that are always problematic, such as forcible confinement, causing bodily harm, deception, coercion, and manipulation. However, I will argue that there are also two broad categories of impediments to autonomy that are not inherently problematic when appropriately configured. In order to support the legitimacy of these categories, I will apply the two features that constitute the thin notion of autonomy as presented above: a person's ability to freely deliberate, and the presence of genuine options in a safe environment.

1.4 Neutral Limitations to Autonomy

There is an important sense in which all people have their autonomy limited due to neutral obstacles by nature of being human. These individual limitations can be separated into two categories: those that are natural, and those that are relational. By a natural limitation, I am referring to how an individual's autonomy is limited by factors such as gravity, or such as the physiological needs to sleep and eat that often dictate the routines of our days.

Beyond these anticipated limitations there are also those that occur within the scope of our human experience, as unwelcomed results of illness, injury, or age. This acknowledges that all people are "temporarily-able" (Carlson 2010, 325), as life is bookended and punctuated by experiences of profound vulnerability, and as such the experiences of all human beings contain instances of heightened limitation to their autonomy. These hindrances upon an individual's autonomy are not inherently problematic in the sense of requiring moral redress, even when they are outside of personal control. A person's options are limited when recovering from surgery, as they are unable to move as they normally would, but this restriction is not a moral problem. This is because the external

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restriction of their options in this way is a result of humanity's mortal and terrestrial status, and not of (for instance) the nefarious actions of another.

Turning now to the second neutral category, we find the features that comprise the relational context of an individual's life. This context, in a broad sense, includes each individual's personal history and the influences of others on their social and psychological development. The impact of their peers, parents, and culture are significant (Dworkin 1988, 12), whether the individual recognizes it or not. A person's social history and their present circumstances contribute to the conditions of their autonomy in causal and material ways, since each of these factors play a role in shaping an individual in both their internal processes of how decisions are made and what they value, and also external factors such as what options are available for them to choose from (Oshana 1998, 96).

In the slightly narrower context of individual relationships, people commit to various roles in their lives that contain degrees of obligation, such as parenting, close friendships, romantic relationships, religious membership, and employment. These roles entail further limitations on an individual's autonomy, in the form of time commitments, responsibility, and professional obligation that stake claims on how a person makes decisions and what they desire amidst the moving parts of their life.

These limitations are in and of themselves neutral, granted the requirements are reasonable on the people involved, and that they have been agreed to in some manner. By agreement, I mean in the way a professional has a reasonable awareness of the code of conduct they will be required to adhere to prior to their placement, or how a spouse recognizes future restriction of choice for sexual partners prior to entering into a monogamous marriage. Of course, complete foresight of these commitments is not possible, but there is a sense in which even some unanticipated consequences fall within the initial scope of agreement. For instance, in the case of a professional who has signed a non-compete agreement, the agreement is still binding although the financial consequence may be higher than

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anticipated in the event that their place of employment were to experience unexpected decrease of demand. Although the professional's options are restricted, their initial agreement precludes this limitation on their autonomy being morally problematic.

It has also been argued that relationships provide the context for autonomy to be developed. This is due to the platforms that are created for a person's autonomy to be expressed, respected, and strengthened when engaging in the compromises and disagreements that relationships often bring. This can be as simple as when two friends disagree about which movie to see together; the discussion to arrive at a compromise will include ranking preferences in a way that would not have occurred had each one attended the cinema separately. Regarding how an individual operates within each particular relationship, there are many interesting perspectives on how one's autonomy ought to be viewed and exercised within these valued social roles (e.g. Westlund 2005). Thus, when discussing instances of impediment to a person's autonomy, it is important to recognize that appropriate relational limitations are of a neutral category.

These two general ways that a person's autonomy can be limited that I have explored above are not inherently problematic in a moral sense. Instead, they are acknowledged as the practical aspects of an individual's physical and social circumstances that influence, enables, and often limits their autonomy.

1.5 Problematic Restrictions to Individual Autonomy

With the existence of neutral categories established, I will begin to demarcate where the natural and relational restrictions on a person's autonomy cease to be neutral and become problematic in a moral sense. To gain some clarity about this matter is important because it will help us characterize those situations with moral implications that give rise to obligations for other people to alleviate the restrictions. By and large, this obligation occurs when the source, content, and degree of these

aforementioned limitations in an individual's life are inappropriate in some way. Again, I will use the thin relational notion of autonomy to locate the boundary lines.

Regarding the category of natural limitations, it is not typically morally problematic for a person's autonomy to be restricted by an illness. However, if one's illness is the result of the neglect or malicious conduct of another individual, such as if their employer fails to label or remove hazardous materials, the subsequent restriction to one's autonomy from the illness generates moral obligation on the part of the employer. The employer is then obligated to redress the restricted autonomy of their ill employee in some way. This may take the form of compensation to cover medical leave, as well as the moral obligation to remove the source of illness and to prevent future reoccurrence. This illness is no longer the simple byproduct of human life on earth, but the result of another person's poor conduct. It is now a case of a person suffering bodily harm at the hand of another, whether by intentional actions or lack of prevention. Due to the source of the illness, this natural limitation is no longer of a neutral kind, and generates a moral obligation to offer restitution.

When considering the relational limitations to a person's autonomy, from sources such as a chosen profession or marriage agreement, these limitations are morally unproblematic insofar as those restrictions are within appropriate boundaries of content and degree. These boundaries are directly connected to the initial choice made by the person to accept the responsibility. For instance, if the professional who signed a non-compete agreement was then also faced with a demand to only accept contracts from people of a certain ethnicity or else forfeit their job, this restriction of his or her autonomy is no longer neutral. In signing the agreement, they committed to being loyal professionally, but when the content infelicitously expands, the agreement now restricts the professional's autonomy by a harmful influence of their deliberation: the option to refuse has a high cost (the loss of a job), and this restriction is neither something they have explicitly agreed to nor an

unanticipated but reasonable extension of the original agreement, and so morally obliges mitigation on the part of those responsible for making the demands.

When considering a monogamous marriage, the limits placed on either spouse include fidelity. To be restricted in their choice of future romantic partners is included in their initial agreement to enter into the marriage. However, if (out of jealousy, for instance) the husband demands that his wife have no male friends, nor even spend time with any other men, the wife's autonomy is being restricted in a morally problematic way. Although she agreed to have her husband as her exclusive romantic partner, the degree of the new expectation is beyond the scope of that original commitment. Hence, there is a moral obligation on the part of the husband to withdraw the demands that limit his wife's autonomy by inappropriately restricting her social interactions.[2]

So far, my discussion of restrictions to autonomy has focused on individual circumstances; namely, the violation of one person's autonomy due to the actions, or the failure to act, of another individual or organization. As in the situations mentioned above, these occur when the source, content, or degree of the restriction is either inappropriate or disproportionate in some way. The result is that instances previously within the inherently neutral category, such as professional responsibility, become morally problematic and require alleviation by the individual causing the restriction. With the individual demarcation of neutral and problematic restriction of autonomy in view, I now turn to the limitation of autonomy as experienced by groups.

1.6 Problematic Restrictions of the Autonomy of a Demographic

A group of people, or an entire demographic of society, can consistently experience problematic restriction of their autonomy. The source of this restriction is not solely from actions of individuals,

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[2] Of course, this obligation is just the first and most obvious one that arises. The obligations that others would have is a less straightforward issue, though perhaps more important to discuss. If the husband's controlling behaviour is not receptive to mild intervention and continues (and even escalates), obligations for friends to confront the husband or steps taken to ensure the safety of the wife and her removal from the situation, arise. However, this is not the place for an extended discussion of this particular case.

but from social norms, discriminating policies, or the lack of legislation. Once these impediments are no longer simply interactions between individuals, it becomes a problem that incorporates the structures and attitudes of society as a whole. To illustrate how the autonomy of a group can be restricted on a social level, I will use examples of how the autonomy of women, and people of colour, have been restricted in North American society.

1.6.1 External Factors

In the United States prior to the 1970's, there were no formal grievance procedures to address the high levels of sexual harassment experienced by women in the workplace. The women who did make an effort to have their complaints heard were viewed negatively by their colleagues (men and women alike), and were perceived to be overreacting (Nussbaum 1999, 145). Hence, when a female employee had her autonomy violated by sexual harassment from her male boss, she was without legal or punitive avenues to address the behaviour. Because of the dismissive social attitude toward episodes of harassment, and the lack of legislation against sexual harassment, it ceased to be an issue only between two individuals (the women and her boss), and implicated other members of her workplace, those in charge of the company, those who had failed to make legislation, and ultimately, members of society for their toleration of the behaviour in this situation. These sources collectively generated the harmful environment.

During that time, women experienced this impediment in the form of their internal deliberation being adversely affected, stemming from the pressure to accept mistreatment in order to ensure their employment. Further, the threat to their physical safety, and resultant reduction in genuine options to participate in the workforce, restricted their autonomy in an external manner.

This example shows how social norms expressed in attitudes and policies (or lack thereof) constitute a restriction of autonomy experienced by an entire segment of society. Such restrictions

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violate the two elements of autonomy as defined above, thus qualifying the nature of this restriction as morally problematic, and caused by American society collectively.[3]

While there are individuals who personally contribute to the restriction of autonomy in direct ways (such as the offending boss), or by lack of prevention (those in charge of the company), members of society are responsible for perpetuating the harmful attitudes exhibited in this example, or by failing to change them as they are in the position to do so. Each member of society, as a moral agent, has a responsibility to attempt to achieve better attitudes and behaviour. This generates moral implications in a similar way as the employer who incurs moral obligation for failing to remove hazardous material from the workplace (even when unintentional), when he or she was in position to do so. However, there is also a moral obligation for society as a whole to mitigate the restriction, as it is the combination of all the above sources that created the harmful environment responsible for the restriction. Hence, society in its own right bears moral obligation to seek alleviation collectively.

1.6.2 Internal Factors

Indeed it is not difficult to highlight social practices and structures that women recognize as harmful to their autonomy, such as the toleration of sexual harassment in the workplace. Where the discussion of autonomy becomes increasingly complicated is when the individuals who experience the restriction of autonomy choose, and even desire, the restrictive treatment. This indicates a shift in how the person experiences restriction of their autonomy. The examples above show how the features of a person's environment can have tangible restrictive consequences and impose interference on mental deliberation, such as when a women's workplace is unsafe. However, the features of a person's environment can deform the desires themselves, and so restrict their autonomy in a different way. When the harmful norms of a society are internalized by the demographic experiencing the

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[3] I say American society only because this example has been borrowed from Nussbaum, who is an American author. The suggestion that this were any better in Canada at the time is highly implausible, of course.

restriction of their autonomy, they begin to desire the treatment and roles that the norms dictate, and in so doing, inadvertently desire the restrictive treatment.

In order to continue, a brief digression is required to clarify the central terms I will be using: desire, preference, and choice.[4] By desire, I am referring to an appetite that the bearer has, but which (qua desire) has not been ranked relative to any other desire, and the content of which may even conflict with other desires the bearer has. A preference, however, does include a ranking of certain desires above others, although a preference is not necessarily a live option to the individual. Choices are those decisions made as expressing an individual's preferred option from what *is* available to them, and these choices will have overlapping content with an individual's desires and preferences more generally. Although much discussion has taken place regarding the details of how these three factors contribute to agent causation, this brief outline is sufficient for my present purposes.

According to feminist autonomy theorists, "adaptive preferences" are those preferences a person has that reflect the limited options they have. These adaptive preferences become "deformed desires" when the evaluative attitudes, desires, and preferences adopted by women, or others, perpetuate their own oppression without intending to. Further, although women claim to desire participation in sexist practices, the practices themselves remain morally and politically problematic (Khader 2012, 302-303). Superson argues that a desire is deformed when it precludes a person having appropriate regard for themselves as an intrinsically valuable human being, and conflicts with the person's desire for their own welfare (Superson 2005, 111). These deformed desires then manifest in a ranking of choices that have adapted to the restrictive options available. As preferences are expressed in choices being made, a person may choose options that perpetuate the subjugation of their own demographic.

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[4] These definitions are taken from Superson 2005, "Deformed Desires and Informed Desire Tests"; Khader 2012, "Must Theorising About Adaptive Preferences Deny Women's Agency?", and Superson 2014, "Feminist Moral Psychology."

For instance, a woman may come to prefer the social approval and favourable treatment from men that she achieves through her submissive role in the various areas of her life. She may make choices to maintain her deferential demeanor, and place high value on passive and malleable qualities. However, through these choices she is unintentionally perpetuating the harmful inequality between men and women, reinforcing the notion of natural male authority, and contributing to the social practices that restrict women as a group. This may not be what the woman intends to endorse or agree with, yet she has internalized the social norms of what constitutes desirable conduct for a woman, resulting in the deformation of her own desires and preferences to adapt to what is available.

The presence of adaptive preferences, or deformed desires, in a person's life indicates that their autonomy has been restricted through interference with their internal deliberation. More precisely, a person's internal deliberation is distorted by the internalized norms that manipulate the deliberation of their desires and preferences through consistent social pressure (such as explicit demands or expectations) to align with morally problematic practices. Although a person can have adaptive preferences in a localized manner, while also having preferences that are free from distortion of their deliberation in different areas of their life – or "domain-specific autonomy deficits" (Khader 2012, 308) – the first feature of the thin working definition of autonomy is violated (deliberation free of interference). This signals that the nature of restriction to autonomy that people experience when exhibiting deformed desires is morally problematic, but cannot be attributed to the actions of any single individual or particular group that can be held solely responsible. While individual citizens may contribute by their actions or failure to act, collectively it is society that upholds these oppressive norms.

By clarifying the ways a demographic can have their autonomy restricted by social practices, I have expanded the notion of when the restriction of autonomy is problematic from scenarios with individuals to entire groups. The restriction experienced by members of a group can take the form of

external factors that limit options and threaten physical safety, but also as norms that become internalized and impede a person's mental deliberation. Although not all of the members of a society actively contribute to the norm by word or action, their failure to prevent the harm produced by those norms is morally problematic and, collectively, society creates and maintains these norms that generate restrictions.

The next task is to unpack what is meant by "social norms" in a way that can be more specific as to the source of these restrictive qualities in society.

1.6.3 Social Factors

When features of a society, such as accepted norms and attitudes, restrict the autonomy of a group in a persistent and prevalent way, these pervasive attitudes can then be internalized, resulting in adaptive preferences, or deformed desires, exhibited by the group experiencing the restriction. Looking now to those social features specifically, I will present a way to identify those qualities of society that generate and perpetuate the restriction of autonomy. By doing so, I hope to offer a more specific account of the social causes of morally problematic impediments to autonomy.

Martha Nussbaum argues that there are three features of an unjust society that can produce the distortion of evaluative beliefs and emotions that are exhibited in deformed desires and adaptive preferences (Nussbaum 1999, 149).[5] These features then also highlight the social source of restriction to autonomy that groups of people experience. I will discuss each of these three features in turn.

First, problematic social norms can persist in a society where accurate information about a particular demographic is lacking, or (worse) where false information is widely believed. This results in the general public having the wrong beliefs about a group of people as a whole, and acting according to that ignorance or misinformation. For example, historically there has been the lack of

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[5] Nussbaum originally applies these categories to the treatment of women.

information and false information in society about the relationship between low intelligence and people of colour, due to poorly designed IQ assessments (Stubblefield 2010, 294). This led to students of colour being treated as though they were incapable within the education system and offered sub-standard programs. Without accurate information, social attitudes perpetuated harmful treatment of the group within society.

The second problematic characteristic of unjust societies identified by Nussbaum is how the members of a society demonstrate a lack of reflection and deliberation about its norms, and as a result continue to obey and enforce them. Continuing the previous example, if a person has adopted the social norm based on false information, they will continue to enforce it in their daily interactions with people of colour, by treating them as incompetent. Without critical evaluation of this accepted social attitude, their behaviour will reflect this discriminating belief in other areas of their life, not limited to matters of education.

The third characteristic arises when the society exhibits a chronic lack of options available to the demographic that is the target of the first two practices. The misinformed treatment of students of colour in the education system begins a trajectory in their lives that limits their options, due to the lowered expectations and investment of their academic careers. Further, this results in restrictive hiring preferences, and perpetuates the social perception of the incompetence of the demographic, as the equal skills of people of colour remained undemonstrated.

These three problematic characteristics of a society Nussbaum has identified for us obviously restrict the autonomy of individuals. The external restrictions they impose are clear. But they are also likely to cause deformed desires and adaptive preferences resulting from the constant social subjugation and mistreatment due to the uninformed beliefs, or the false beliefs of others. For instance, to avoid opposition some people of colour may begin to desire menial jobs that present little confrontation of the social norms, adapting to the restricted options available to them.

The circumstances of both women and people of colour in North American society has improved, although there remain social attitudes and practices that cause great harm to the autonomy of these groups in morally problematic ways. Moreover, that the three characteristics Nussbaum describes applying to women surely also apply to people of colour as a group. Certainly there are more features of a society that contribute to the restriction of autonomy that a demographic suffers, both through the lens of autonomy and without. However, for the project at hand, the three Nussbaumian features are sufficient and identify the ways that harmful social attitudes are formed and maintained by the direct action of some members of society (discriminating hiring choices), but moreso the inaction of many (lack of critical reflection).

I will utilize these features later as an evaluative tool to discern when a society restricts a group's autonomy in problematic ways. Furthermore, these three specific qualities provide a target to focus on when considering strategies for the removal of these impediments to autonomy. It is to the question of when responsibility for finding and implementing such strategies arises, and on whom they fall, that I now turn.

1.7 Moral Implications of Problematic Limitations of Autonomy

I have so far argued that there are features of society that contribute to a group suffering hindrance of their autonomy, and that this hindrance is morally problematic. The last step of this chapter is to clarify, and offer argument for, the corresponding moral obligation that the restriction generates. First I will consider who bears this kind of obligation, and then outline the general ways it can be fulfilled.

1.7.1 Who is responsible?

The impermissibility of violating another's autonomy is a conclusion that can be reached by arguments regarding moral personhood. Theories of moral personhood attempt to establish the dividing line of which entities have moral rights and responsibilities as a person, and those that do

not. The status of having moral personhood entails rights and freedoms, including one's freedom from having their autonomy problematically restricted in the ways discussed above. When the autonomy of one of these moral persons is violated, there are moral ramifications. Hence, when a group comprised of moral persons is subjected to systematic restriction of their autonomy, such as by social norms, moral obligations arise to eradicate the causal features. No longer is a single individual or small group of involved people on the moral hook to alleviate the restriction of autonomy, but rather the individual citizens and their society as a whole.

Demonstrating that a moral obligation exists is much simpler than attempting to assign it; namely, to whom specifically does the obligation fall and to what degree? I argue that there exists a gradation of obligation that implicates all members of society, by nature of their membership in a society that maintains the three Nussbaumian features discussed in the previous section. This includes individual citizens who are active contributors to those norms or those who passively accept the norms that harm others. Furthermore, the collective society also has a moral obligation to mitigate the restrictions as whole, since these restrictions arise from the consolidation of incidents.

I must acknowledge that it is not realistic, or possible, to expect every member of society to treat the impediment of autonomy for a group as their primary moral obligation. There are many legitimate moral obligations toward groups, individuals, and causes. Further, with each personal situation there are other obligations and responsibilities to fulfill, such as those mentioned when discussing the relational limits to one's autonomy. When I speak of the moral obligation a person has, I recognize that they will have more pressing obligations that must remain a priority.

However, with this qualification made, I will present a reasonable way for members of society and as a whole to fulfill their moral obligations to restricted groups by combating the three unjust features outlined above. I will start by dividing an individual citizen's life into two overlapping dimensions, and discuss how a person can realistically fulfill their moral obligation in each. Then, I

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will discuss the moral obligations that are applicable to society collectively, and I will close by offering one additional condition for these moral efforts.

1.7.2 Proximate Responsibility

I will call this first dimension of a society member's life their proximate situation. By this, I am referring to their everyday routines as they occur within different settings and interactions in their community. During these routines, a member of society is introduced to opportunities to redress harmful social norms simply by being proximate to them.

People are often unaware of their harmful attitudes about other groups due to misinformation, or of their own ignorance towards a demographic. However, when coming in contact with people of the particular demographic, or possible conversations about them, there is potential for one to critically reflect on the social norms and their accuracy. This reflection could be as simple as a person realizing, "maybe intelligence isn't connected to race," or "maybe women do have leadership abilities, and what does the word 'leadership' really mean, anyway?" and investigating further. This choice to further investigate can be achieved by intentional critical reflection and information gathering, and is an opportunity for a person to be exposed to correct information about a group. The accurate information can lead them to directly engage in challenging their own false beliefs and subsequent attitudes toward and treatment of, the group in their society.

An effect of this critical engagement is that it often equips the person who reflects with the opportunity to instigate critical reflection in others. For instance, if an individual has critically reflected and begun dismantling their sexist attitudes, when hearing similar attitudes expressed in conversation, such as by a sexist joke, they can invite the speaker to also question the basis of those norms, perhaps through further conversation.

These proximate fulfillments of obligation are modest, but their accumulation can make a slow and gradual impact. The lack of information, and false information about particular groups in

society can be challenged, and the questioning of social attitudes and practices initiated. Each of these contributions can manifest in a change of treatment toward the demographic involved, and are directly preventing the harm of the demographic in question by using their position as member of society to counteract the unjust social norms.

1.7.3 Responsibility of Resource

Moving beyond the domain of a person's daily interactions in their community brings us to how one uses what I will call, for lack of a better term, their *social properties*. By properties, I do not only refer to land holding or finances, although they do qualify. Rather, I mean the resources a person controls and that can be used to enact change in the environment around them. This could be due to their professional position, ability to vote, finances, and other sources of authority – including, for instance, what is sometimes referred to as their "privilege" due to membership in a demographic or group.[6]

Regarding social properties particular to a professional position, there are people who have the authority to enact change to expand options for, and disseminate corrective information about, people who are part of a demographic that suffer restriction of autonomy. A hiring manager who chooses to implement hiring practices designed to produce a more diverse workforce, or an educator who chooses to highlight to their pupils how autonomy of particular groups is restricted in their society are ways this can be achieved. Furthermore, there are careers that people dedicate themselves to that focus on enhancing the autonomy of an oppressed demographic.

It is often in this sort of connection that privilege is also useful. Often (alas), people in an advantaged group are more likely to allow themselves to be educated about the situation of a

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[6] By privilege I am referring to the advantages, benefits, and immunity a person has by nature of being that particular person, or by being part of a particular group of people.

disadvantaged group when it is someone from their own group[7] who intervenes to point out, for

instance, the bad information they have been relying on. When and how such intervention on behalf

of others is appropriate and helpful (and isn't appropriating somebody else's struggle, for instance) is

a complicated matter, but the point that privilege is a resource that can be employed is one worth

making.

The possibilities for a member of society to fulfill their moral obligations by suitable

employment of social properties are diverse, yet are informed and guided by the results of critical

reflection of social norms as outlined in the proximate obligations an individual person has. The more

a person is aware of accurate information and has critically reflected on harmful social norms, the

more effective they can be in the use of their social properties to mitigate the restrictions of autonomy

a group experiences. This overlap of the two categories demonstrates the importance of each, and

how one's moral obligation to redress social norms that restrict autonomy can be fulfilled in a

reasonable way.

Looking now to how society can fulfill its obligation collectively, as members of society avail

themselves of accurate information and dispel false beliefs, they will be prepared (and hopefully

motivated) to use their social properties to instigate a collective effort for society to mitigate the

harmful restriction of autonomy that a demographic suffers. The most common route to achieve

collective action is through the role of the government, as it is within their role to intervene and

address issues such this.

The social properties common to members of democratic societies, such as the ability to vote,

or have their concerns voiced on a governmental level, can be used to provoke change that applies to

society as a whole. For instance, votes can be cast for or against political parties that may change the

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[7] This is one aspect of what is called "ingroup bias." For more information see Jonathan Moy and Sik Hung Ng's
"Expectation of outgroup behaviour: can you trust the outgroup?", *European Journal of Social Psychology*, 1996.

treatment of a demographic by passing legislation (such as anti-discrimination laws), funding research, advocacy or public education efforts, or implementing programs aimed at improving their situation. On behalf of a society, their government can intervene in order to mitigate the impediments to autonomy experienced by members of a demographic, and thus counteract unjust social norms in a wide-ranging way. While this doesn't replace the individual obligation of society members, government action is an effective and available method of how a society can collectively fulfill their moral obligation.

1.7.4 One Further Condition

When a person or government uses their social properties to directly counteract the restriction of autonomy suffered by a group, there exists a responsibility to ensure that it is a sincere effort on the part of the individual or government, and a worthwhile use of those social properties. By "sincere", I am not referring to the emotional sentiment behind the effort, rather I am referring to the process of taking reasonable steps to ensure that the avenue they have chosen to fulfill their moral obligation is one with a likelihood of success, and that it is an efficient use of resources. Success in this sense would be in proportion with the social properties involved.

I offer this final condition in order to prevent the substitution of genuine effort to remove obstacles to autonomy by hasty or reactionary solutions. For example, if a large company seeks to eliminate bullying behaviour, the CEO may initiate mandatory (paid) departmental meetings so that the concerns of the employees could be expressed to their manager. The CEO may enjoy the bolstering of their reputation for this seemingly proactive strategy, while bullying continues unabated due to employees being too intimidated to voice their complaints in the presence of the perpetrator. Had the criterion of sincerity been a requirement, the resources of time and money could have been better allocated to reduce this problematic behaviour.

Similar lessons apply to the collective as to the individual level. For instance, Uma Narayan discusses how the coercive state intervention in Iran and Turkey was intended to eradicate the practice of veiling, but proved to be harmful and paternalistic in an opposite but equally problematic way (Narayan 2002, 426). The intention was to remove obstacles to women's autonomy, yet in reality it caused women increased isolation and economic suffering (Ibid.). Hence, just as individual uses of social properties must be sincere, so also must efforts made by the government.

Similar to what is implied by Nussbaum's' three features, Narayan argues that changes need to be made in the value framework held by society, and specifically to views held about the demographic. Moreover, she claims that this would come as a result of purposeful education (Narayan 2002, 428);[8] something we can also see reflected in the three features outlined by Nussbaum.

In this way all individual members of a society have a moral obligation to remove the restrictions of autonomy that a demographic endures, due to their contribution to, or tolerance of, those features of society that cause those restrictions. Their fulfillment of moral obligation occurs as they engage in the critical reflection upon social norms, as described in the proximate dimension, as well as fulfilling their moral obligation to use their social properties in a sincere way to bring practical change to the restricted demographic, such as by education. Further, the moral obligation of a society as a whole can to an extent be fulfilled by the actions of their government, such as policy making or funding allocation in the interest of members of the demographic.

1.8 Conclusion

Up to this point, and with the use of a thin notion of autonomy, I have made the case that some of the limitations people experience to their autonomy are morally neutral, and that autonomy is restricted in

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[8] Ultimately Narayan believes that a discussion of liberty is a more useful lens by which to view and critique coercive state regulations than autonomy (Narayan 2002, 430).

ways requiring moral redress when the features of those neutral limitations are disproportionate. Further, these restrictions occur on a larger scale when an entire demographic experiences restriction of their autonomy due to unjust features of their society, and that these unjust restrictions often have their roots in three characteristics of some societies identified by Nussbaum.

I have then used these three features to argue that, just as individual contribution (even if by inaction) to a constraint on autonomy gives rise to an obligation for redress, there is a moral obligation for all members of society to contribute to the mitigation of restrictions on autonomy faced by whole groups, since it is society at large that (perhaps unwittingly) contributes to it and are in the position to change it. Members of society can fulfill this moral obligation in their proximate lives, consisting of individual reflection and conversations, and also with the sincere use of their social properties, including their influence on government. However, effective response to some of these constraints will involve collective, *i.e*. governmental, action, and the criteria by which we evaluate whether government action appropriately addresses the moral obligations of society at large parallel those used to evaluate the responses of individuals.

In the next chapter I will carry forward the conclusions made here, and apply them to the specific demographic of people with intellectual and developmental disabilities.

Chapter 2

People with Intellectual and Developmental Disabilities: History and Evaluation

2.1 Introduction

In the first chapter I reviewed the notion of autonomy, taking advantage of recent insights made in feminist scholarship, trying to identify a "thin" core to the concept. I did this to establish when something constitutes a restriction or impediment to autonomy, and even further when those restrictions were morally problematic and not simply the limitations associated with being a human in relationships. Finally, I considered the moral obligations generated by the problematic nature of restrictions. I considered who bears such obligations, and ways for these obligations to be fulfilled with considerations for knowing when that has been satisfactorily addressed. In this chapter I will use the conclusions of chapter 1 to consider the question of whether another demographic, namely people with intellectual and developmental disabilities, suffer morally problematic restrictions and impediments to their autonomy, and if they do what sorts of obligations this gives rise to.

2.2 A Brief History

When drawing into focus a history of people with disabilities[9] in our society, the offensive language used at different points in the literature conveys the dire circumstances experienced by this vulnerable segment of the population. Yet, it also causes one to pause in gratitude for the striking progress when compared to our present context (however problematic things remain). In what follows, I will recount a thread of that history that includes Canada and the United States, with an eye toward the autonomy of those involved.

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[9] Although I am aware of the ongoing debate regarding how to appropriately refer to people within this demographic, for this project I will be using the People First language of "people with disabilities." I will be doing so since it is the language used by the Independent Facilitation and Planning (IFP) community, and will provide consistency in the following chapters.

Throughout the history of this demographic the work of Wolf Wolfensberger, a German academic and psychologist, played a significant role in changing the landscape of social services in the U.S. and Canada. According to Wolfensberger, throughout history people with disabilities have been cast in differing social roles at different times. These roles include being treated as though they are subhuman, a victim of an illness, a menace to society, an object of pity, a burden of charity, an eternal child, and (what he claims is the only non-dehumanizing option) a developing person (Wolfensberger 1970, 16). Further, he argues that the way a person with a disability is perceived has great impact on how they are treated – a statement confirmed many times over when recounting some of the North American history of this demographic.

2.2.1 1800's – 1990's

The idea that people with various physical, intellectual, or mental "impairments" as they have been called, are a menace to society was especially prevalent in previous centuries (Wolfensberger 1972a, 8). In the early nineteenth century, many writers claimed that the "degenerate" were offspring of those who were "foreign-born," and so demanded stricter immigration laws (Wolfensberger 1972b, 22). It was also an accepted belief that mental and social impairments had genetic causes, and this resulted in fear when combined with supposed research findings that the disabled reproduced more quickly than other parts of the population (Wolfensberger 1970, 18). People's alarm led to claims that unless action was taken, the amount of degeneration would continue to increase until society would suffer widespread inundation of "severe retardation." Thus, it was taught that unless "degeneracy was axed at the roots," society was doomed (Ibid.).

This social alarm fuelled the practice of the forced sterilization of people with disabilities, and more restrictive marriage laws (Ibid.) Prior to the twentieth century, people with disabilities were often imprisoned for social disruption, with no attempt made to distinguish those with a disability from criminals (Boone 2013, 30). However, in 1860-1890 the general public began to feel that people

with disabilities threatened their personal safety, and claimed that those with a disability were also in need of protection from the hazards of society (Boone 2013, 31). [10] Thus, it became common to institutionalize people with various physical and mental "impairments" in asylums instead of prisons (Ibid.).

This segregation was uncontroversial. What's more, the institutions in the mid 1800's were unheated since many believed that the "mentally afflicted" lacked sensitivity to heat and cold (Wolfensberger 1972b, 24). In Canada, the first institutions were built in the 1860's, and upon the directive of doctors, thousands of children were separated from their families and institutionalized over the course of 100 years (Lord and Hutchison 2007, 21).

Given this historical context, it is not surprising that many people with disabilities died due to lack of medical treatment when sent to asylums or institutions (Martinez 2003, §1.2). To avoid the institutionalization of their loved ones, some people hid family members inside their homes, as most states in the U.S. had laws that either prohibited or strongly discouraged disabled people from being a part of public life; some of these laws remained in place as late as the early 1990's (Ibid.).[11]

In 1908, the practice of segregation was at its height (Wolfensberger 1970, 18). This generated a high demand for capacity in institutions, and so it was necessary to build economically. Since land in remote areas with lower populations was most affordable, institutions were built long distances from social centers (Ibid., 19). This made visiting the residents difficult, and further contributed to the segregation they experienced.

The physical structure and services of the institutions were designed to treat menaces to society and those who were seen as "subhuman" (Ibid.). This dehumanizing language is also found in

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[10] Perceptual disabilities such as blindness were not differentiated from other physical disabilities, cognitive disabilities, or mental illness.

[11] Whether these laws were enforced is another question entirely. However, their existence in writing is enough evidence to demonstrate the lack of consideration shown towards this part of the population.

the laws of the early twentieth century in the U.S.; Alabama referred to people with various disabilities as "a menace to the happiness…of the community." In Vermont they were referred to as a "blight on mankind" (Martinez 2003, §1.2). Although lip service was paid to the benefit of the service provided by the institutions to protect their residents, it was arguably the general public who experienced protection from their supposed threat (Boone 2013, 31).

Over time the perspective of the doctors who treated the residents evolved into a medical model in which disability was seen as innate and as a clinical condition requiring treatment (Ibid.). This shift coincided with medical discoveries made regarding preventable causes of intellectual disability such as meningitis, iron deficiencies, and exposure to lead paint (Brosco 2010, 27). The approach had a preoccupation with curability and so all related activities functioned as "therapy" (Wolfensberger 1972b, 28).

While the medical model nowadays has its critics, it marked a considerable improvement over the model it replaced. Unfortunately, this shift was largely confined within the medical profession, and was not reflected in government policy for many years. This was seen in public health reporting in the U.S. as late as the 1920's that combined together "criminals, defectives and delinquents" as a single category, and where important organizations of human services workers combined people with cognitive disabilities with "the deaf, dumb, blind, epileptic, insane, delinquent, and offenders" all within the class of "defectives" (Ibid., 22).

Following the end of WWI, services for adults with physical disabilities and mental impairments improved dramatically as Canada and the U.S. attempted to address the needs of their veterans. This need prompted the establishment of rehabilitation groups and camps (Martinez 2003, §1.3), which served as a context for the wider population of people with disabilities to meet and recognize shared experiences, including experiences of oppression (Ibid.).

The fruit of those conversations was seen in the many charity organizations that formed in the 1920's -1940's with a focus on funding research to find cures for diseases such as polio, paralysis, and cerebral palsy (Ibid.). Organizations for advocacy regarding particular groups, such as for the blind, were also formed (Ibid.). There was evidence of a large positive shift in attitude towards people with disabilities, primarily those who were deaf, blind, or with physical disabilities (Martinez 2003, §1.2), yet great pessimism remained regarding those with an intellectual or developmental disability (IDD) (Wolfensberger 1999, 41). [12]

In attempts to combat the known prejudice against those with an IDD, and what is now referred to as mental illness, tours of institutions were conducted frequently in the 1950's and 1960's in attempt to educate the public (Ibid., 39). However, this strategy was largely unsuccessful due to the unpleasant events occurring within the institutions that the public witnessed on those tours (Ibid.). Overall the sentiment toward institutions and their residents were cynical, and the approach of institutionalization was met with very little critique prior to 1965 (Ibid., 38). Although people were willing to discuss what would make better institutions, the merit of the institutional approach as a whole was presumed (Ibid.).

Momentum for reform gathered when the human rights movement of the 1960's raised awareness of the living conditions within the asylums and the social impacts of disability (Boone 2013, 31). Parents' rights groups began to form and advocate for deinstitutionalization over the 1970's and 1980's, and the contribution of Wolfensberger's work has been called the "final push" to enact structural change (Ibid.). Wolfensberger contrasted the entrenched medical model of disability as a "client" model preventing independence, with the idea of "normalization," that people with an IDD and other disabilities have every right to participate in society, just as their "normal" peers do

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[12] Wolfensberger went as far as to call the attitude nihilistic, an attitude even shared by advocates (Wolfensberger 1999, 39).

(Ibid.). He argued that social services ought to discourage dependence and encourage growth. This statement was in direct opposition to the then current system (Ibid.).

As the process of deinstitutionalization began, the strategy to meet the needs of people with an IDD shifted to community agencies that provided care through programs and services. The services offered were those that were deemed necessary by professionals for people exiting institutional life in the 1970's and 1980's (Boone 2013, 32). The objective was to create a large number of these community-based services, called the "continuum of services," and was most prevalent in the 1970's.

The continuum of services prescribed steps for people to complete in order to enter community life, but with an expectation that only the least vulnerable of the demographic would succeed and be integrated (Lord and Hutchison 2007, 31). These programs were highly structured and required that people with disabilities comply with the routines and procedures to receive the support (Ibid., 30). Consequently, the familiar role of compliance performed by people with an IDD remained, as professionals held the authority to permit their progress in the continuum toward community participation (Ibid., 32).

In Canada, forward political strides were made for the rights of people with disabilities in the late 1970's and early 1980's. The social model of disability that was developed in Canadian Disability Policy included aspects of Wolfensberger's updated "normalization" theory called Social Role Valorization.[13] This changed the perspective to focus on what society could do to accommodate people with disabilities in order to enable participation (Boone 2013, 33). In 1982, the Charter of Rights and Freedoms designated people with disabilities as a disadvantaged group (Ibid., 31), and The

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[13] Wolfensberger's Social Role Valorization theory is an evolved form of Normalization and centers around the idea that "positive life experiences are associated with holding a valued societal role," and since people with IDD are either devalued or at risk for being so, they are more likely subjected to negative experiences in their lifetime such as rejection, abuse, and violence (Boone 2013, 33).

Education Amendment Act ensured that children with IDD would receive education in community schools to avoid segregation (Ibid., 33). Further, The Coalition of Provincial Organizations of the Handicapped (now called the Council of Canadians with Disabilities) formed to be the first politically active organization on a national level that represented the interests of people with an IDD and other disabilities (Ibid., 31). Finally, in 1987 the government of Ontario declared closure of all 16 of its residential institutions for people with IDD over the course of 25 years (Ibid., 32).

2.3 Present Situation

In the last 25 years, policies regarding people with an IDD have evolved to adopt a framework based on human rights, and focus on the integration of people into communities rather than services to meet crises (Boone 2013, 30). This has been accompanied by the development of "independent living" organizations. The independent living movement brought from California and established in Canada in the 1980's, began offering programs based on the concepts of choice, control, freedom, and equality for people with disabilities (Hasler 2003).

Although the amount of official institutionalization has significantly decreased for people with disabilities,[14] and many independent organizations have been formed, the services offered in communities to people with an IDD often maintain the institutional structure. This has been criticized as being "community institutionalization" (Lord and Hutchison 2007, 21). For instance, many adults with an IDD who would have previously been in an institution are now residents of a group home. These homes have the outward appearance of being like all other homes comprising the community they are in but, on the inside, the majority of residents still comply with controlled routines of meals and bedtimes, and rely on prearranged transportation in large groups to participate in their community

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[14] An exception to this may be the increase in elderly residences and age related disabilities (Lord and Hutchison 2007, 21).

(Ibid., 22).[15] This approach still maintains a level of control by professionals over the residents, and fosters segregation reminiscent of traditional institutions.

Community institutionalization is also criticized for the overwhelming focus placed on the deficit of the individual, as services are offered from the programs available once the need is defined (Ibid., 27). Often the needs focused on and met are primarily physical, and require that the person comply with preset procedures in order to receive the support (Ibid., 29). Compounding this issue, Canada has experienced cutbacks of funding for social services in the 1990's, leaving many organizations without sufficient funding to develop and instantiate new ideas that may mitigate the aforementioned downsides of the present system (Lord and Hutchison 2007, 33).

Further critique of the current methods are found in research that shows how segregation and community institutionalization contribute to isolation, which causes poor physical health and low wellbeing in many areas of a person's life (Ibid., 24). Additionally, people who live in institutions or congregated services, such as institutional style group homes, are more at risk of financial, physical, and emotional harm than those fully integrated within the community (Ibid., 20). These risks exacerbate the negative outcomes that exist by nature of the structure of care itself.

That people with an IDD are no longer subjected to completely controlled environments (as in an institution) is a vast improvement. However, the residual community institutionalization, found in group homes and structured programs and services, continue to restrict the autonomy of people with an IDD. As outlined above, community services maintain a structure requiring compliance to participate in the program offered based on the need. This results in de-individualization, since mass management precludes a person getting what they need and want, when they need and want it (Wolfensberger 1998, 33). Discrimination and external social conditions, such as the lack of accessibility or accommodations, are also daily realities for people with an IDD (Lord and Hutchison

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[15] I recognize that not all group homes function in this way.

2007, 19). These aspects further constrict a person's autonomy regarding the everyday routines they wish to perform.

In reviewing this history, one experiences simultaneous appreciation for the amount of change that has occurred, as well as critical awareness of the residual elements of institutionalization remaining in our society.

2.4 Evaluation of Autonomy Restriction

With the above context in mind, I will evaluate how the autonomy of someone with an IDD is restricted in the present social context. To do so, I will utilize the thin notion of autonomy offered in the first chapter, consisting of its two features: that a person is free from interference with their deliberation to reflect regarding their preferences, choices, and desires; and that they have access to a reasonable range of options consistent with physical safety. I will show that individual people with an IDD experience these problematic restrictions, and are therefore morally entitled to redress.

First, there is evidence that people with an IDD experience restriction of their autonomy through interference of their deliberation about important choices. This occurs when professionals continually prescribe the priorities that a person with an IDD ought to have, focusing on their needs for health, housing, employment and finances. Further, as when people with an IDD participate in excessively structured environments that preclude their own autonomous choices as when daily activities such as meals and bedtimes are preset by a support professional.[16] This consistent treatment can have harmful effects and a distorting influence on their internal deliberations. For instance, if a person desires to try a new activity, they may discredit their own capabilities to succeed and therefore

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[16] This is not to discredit the usefulness of routines to support people with IDD to enhance their independence. What I have in mind here is the excessive amount of structure and routine imposed on people even when a person is capable of forming their own routines.

not consider it an option, since the structure of the programs they participate in reinforce ideas of their own dependence.

Additional evidence that interference with internal deliberation frequently occurs is seen in the fact that people with an IDD often exhibit deformed desires and adaptive preferences in the form of compliance. When a person is consistently rewarded for compliant behaviour, as the history of people with an IDD has shown, their desire to be affirmed and accepted can be deformed toward desiring to behave in ways likely to gain that affirmation, and so choosing further deferential behaviour. Although people, in general, default to compliance with the wishes of an authority figure,[17] the prevailing social attitudes towards people with an IDD result in adults with these kinds of disabilities being accustomed to the directive authority of another adult, such as from family or a paid support provider (Lord 2015). These relational attitudes and aspects of community institutionalization that reward compliance lead to the conditioning of a person with an IDD to be excessively submissive and to internalize these values as their own preferences.

The second of the two features of autonomy is that of access to options, and is a category that will be revisited in the next section. Restricted access to choices is a chronic problem for many people with an IDD. These restrictions arise from their dependency on structured programs, by living in institutional style group homes, and by limited access to other activities within the community caused by their lack of transportation.

Restrictions to autonomy such as those just described qualify as morally problematic. The impediment to autonomy experienced by a person with an IDD is the result of the actions of others, and is not the result of their own decisions (unless the decision is itself based on a deformed desire).

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[17] For an interesting discussion of this see "The Milgram Paradigm After 35 Years: Some Things We Now Know About Obedience to Authority," by Thomas Blass, in *Journal of Applied Social Psychology,* 1999.

Therefore, a moral obligation to mitigate these restrictions is generated. The question now arises as to whether this is an individual moral obligation, or a social one.

2.5 Symptoms of an Unjust Society

With this evidence indicating that the restriction of autonomy a person with an IDD faces is of a morally problematic nature, I will now turn to the evaluation of society. As demonstrated in the first chapter, there are particular features of a society that indicate injustice towards a demographic within it, resulting in a group experiencing the restriction of their autonomy in a morally problematic way. The presence of these features indicates that the moral obligation to redress the restriction of autonomy applies to individual members of society, and to society as a whole. The reader will recall that the three features of an unjust society I will consider here are borrowed from Martha Nussbaum's discussion of deformed desires (Nussbaum 1999, 149).

These three features are defined as the lack of information, or presence of false information about a particular segment of society, society's lack of critical reflection of its own norms, and, lastly, that there is a lack of options available to the particular demographic in question. In what follows, I will argue that the current prevailing social norms and practices pertaining to people with an IDD exhibit these three features, and so indicate that people with an IDD suffer from the restriction of their autonomy as a group in a way that generates moral obligation for individual members of society, and collectively.

First, the lack of information, or presence of false information, can be found in the common attitudes of society with respect to people with an IDD. On a large scale, people have false information of what a person with an IDD is capable of, or are ignorant of their capabilities altogether. Common "othering" language[18] is used when referring to this demographic, and can be

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[18] For an interesting discussion of language used to describe people with disabilities see Tanya Titchkosky's, "Disability: A Rose by Any Other Name? 'People-First' Language in Canadian Society," in *Canadian Review of Sociology*, May 2001.

seen in the summarization of diverse groups of people by stereotypical limitations, captured by labels such as "special," and as frequent targets of sympathy.[19] These stereotypes demonstrate social commitments to perceiving people with disabilities in one of the dehumanizing roles listed by Wolfensberger (see §2.1).

A striking example of how lack of information and false information can result in harmful social role attribution is found in the phenomenon that some parents of people with Down syndrome call "sweetness porn."[20] These parents use this phrase purposefully to capture the objectifying media representation of people with Down syndrome as overwhelmingly young, happy, and above all, *cute*. This grossly limited view of people with Down syndrome misinforms society with depictions of a monolithic demographic, and further encourages one dimensional treatment of a person with the syndrome. The underlying concept at play in "sweetness porn" is the casting of a person with Down syndrome in the dehumanizing social role of an eternal child. The false information and lack of factual information provided by the media skews the social norms formed with respect to people with Down syndrome, and translates into infantilizing behaviour when interacting with an adult with this IDD.

Second, the presence of community institutionalization reveals mistaken value commitments, illustrating that society lacks critical reflection of their social norms pertaining to people with an IDD. Although great change has occurred in the social service field, there remains a lack of reflection regarding the overall approach for how to provide support for people to live autonomously, as evidenced by the methods used. Many independent organizations have formed with this express goal in mind, yet they remain a minority in both availability and as recipients of government funding.[21] So

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[19] See Stella Young's, "I am not your inspiration, thank you very much," (presentation at TED˟ Sydney, Australia, April 26, 2014) for a great example of this.

[20] For an example of this see David M. Perry's "Down Syndrome isn't just cute." *Aljazeera America: Opinion*, October 15 2014, http://america.aljazeera.com/opinions/2014/10/down-s-behind-thesmiles.html.

[21] While a shift toward support of this nature of has been articulated as a goal by the Ontario government, the impact of this statement is still in early stages regarding availability due to cost and accessibility. See the Ministry of Community and

long as the traditional organization of services remains the only – or only financially feasible –

option, and compliance to prescribed services a prerequisite for support, then there remains a norm

that generates restrictions on people's lives that are long overdue for reflection and deliberation.

Finally, the third feature of an unjust society is demonstrated by the persistent lack of options

for people with an IDD to integrate into their community. Beyond the lack of options a person

experiences individually as mentioned above, there are broader features of society that produce these

limitations. For instance, the environment in the community is also a common source of restricted

access to people with disabilities. This can occur when the physical landscape is impossible to

traverse, when instructions are delivered in a way that is not conducive for the person receiving them

to understand and so don't enable their participation, or when a financial cost is unfeasible on a

government income. In general, when activities and locations are designed only with the use of a

normative form of embodiment in mind, they contain qualities that unintentionally exclude people

with an IDD.

Further, the prevailing attitudes of society also influence the lack of options extended to

people with an IDD. Research has shown that the employment rates of people with disabilities are

significantly lower than their non-disabled peers (Lord and Hutchison 2007, 22). Although great

success has been recorded when people with an IDD have been included in the workplace,[22] if a

person with an IDD is perceived as an object of pity, or in another dehumanizing role, their invitation

to participate in social activities, such as gainful employment, reflects this and their options are

greatly reduced.

Social Services website for more detailed information:
http://mcss.gov.on.ca/en/mcss/programs/developmental/improving/index.aspx
[22] For more information regarding the success of inclusive work environments see "Working wisdom: How workers with disabilities give companies an edge" *The Globe and Mail,* Friday*,* Feb. 27, 2015, http://www.theglobeandmail.com/report-on-business/working-wisdom-how-workers-with-disabilities-give-companies-an-edge/article23236023/.

The examples provided here demonstrate that the same social features that restrict the autonomy of other demographics, such as with women, are found in the treatment of people with an IDD. Thus, the impediments to autonomy that people with an IDD experience generate a moral obligation that does not merely fall on any particular individual, but instead implicates all of society. Moreover, this moral obligation applies to members of society due to their individual actions to perpetuate these norms, or their failure to prevent them, as well as implicating society as a whole for the collective harm done to the autonomy of people with an IDD. Although this is only an initial review of the history and present situation of this demographic, I suspect more evidence to support my preliminary conclusion could be found should a more detailed analysis occur.

2.6 Possible Objections

At this stage in my argument, there are potential objections that I can foresee being raised. These are objections pertaining to certain assumptions I have incorporated thus far; namely, that people with an IDD *have* the capacity for autonomy, that they *are* moral persons, and that I have correctly identified the nature of impediments to autonomy as problematic. In this present section I will clarify the nature of these objections, and respond to them by drawing from common arguments found in the literature.

Some philosophical work has included assumptions that people with severe IDD[23] are incapable of meaningful attachment and don't possess the ability to mentally conceive preferences, choices, and desires in a way that would qualify as autonomous. Furthermore, some critics attribute instances where autonomy is attributed to people with severe IDD to the romantic tendency for humans to project qualities on what they value and love that are not actually present (they often site unwarranted attributions of grand schemes to pets, for instance). This implies that people with a

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[23] Until now I have purposefully left the degree of cognitive disability unspecified. However, this objection is only a legitimate concern in the case of a severe to profound level of intellectual disability.

severe form of IDD lack the cognitive capacities required to be autonomous, and therefore discussing the restrictions to autonomy that they may experience is unnecessary.

Due to the nature of individual minds involved in this discussion, there is an epistemic responsibility to know the subject being discussed before pronouncing such conclusions. People who actually spend significant time with people with an IDD argue that fulfillment of this responsibility is frequently lacking in discussions that support the conclusion above (Kittay 2010, 405). It is argued that claims regarding capacity are to be tempered by practicing "loving ignorance," meaning the humility to acknowledge how even people who are very familiar with someone who has a severe IDD may continually be surprised by their abilities (Carlson 2010, 326). Hence, when considering the present topic, one must be aware that their preconceived notions of the ability of an individual with an IDD requires both empirically correct information, as well as epistemic humility.

Related to this previous objection is that some may disagree that there are any moral obligations to redress autonomy restriction in the manner presented, since people with a severe IDD do not qualify for moral personhood. Without this status, there are no grounds to attribute moral obligation to relieve this kind of oppression for some members of the demographic. This objection may be expressed by drawing on the argument of "speciesism," which claims that attributing moral personhood to humans with cognitive disabilities is problematic if one at the same time withholds moral personhood from animals with higher cognitive capacities, because mere membership in a species is not reasonable grounds for a morally significant distinction and, so it is argued, some animals have the morally relevant properties in greater degree than many people with an IDD (McMahan 2010, 350). Thus, unless moral personhood is likewise extended to animals of significant intelligence, it is an unwarranted title for other beings of equal or lesser cognitive ability.[24]

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[24] It may be argued that this is a contemporary example of the attribution of the "subhuman" role for a person with a disability.

There are common themes found in responses to this line of reasoning in the literature. The first is to reject that a threshold of cognitive functioning is the single qualifying feature to gain the status of moral personhood, or a reliable feature at all. One reason for this rejection is that the distinction of "normal" intelligence for a human being is an arbitrary one, and that it reflects a common ability in our present generation (Brosco 2010, 40). This is because measurements of intelligence rely on IQ tests, where intellectual disability is diagnosed when a person scores under 70 points. Yet these tests have continually shifted over the years to maintain the median of the bell curve at a score of 100 (Ibid., 48-49). This entails that both the average intelligence, and what is considered an intellectual disability from a mild to profound degree, changes in accordance with the average of the bell curve (Ibid.). To base a threshold of human function on the bottom edge of these tests is susceptible to the same instability. Hence, using a measurement of intelligence is an unstable foundation on which to base moral personhood, and a questionable criterion to be included at all.

A second kind of response found in the literature is to highlight other important capabilities that ought to be included when defining moral personhood. Most commonly mentioned is a capacity for empathy, as qualities such as mercy and pro-social behaviours play a predominant role in moral agency; perhaps even more so than the traditional idea of reasoning through moral issues (Harris 2010, 68).

A related way of incorporating this notion of empathy is that moral personhood could include the personal obligation that every parent has toward their child, whether they have a disability or not. Society also plays a role by recognizing the worth of the child and fulfills that role in providing children with what they need (Kittay 2010, 410-411). This requires society to grant moral value to each child equally (Ibid.).

These are by no means definitive answers as to how moral personhood ought to be decided, but these examples do show that a reasonable account will include more, and more stable, features than simply intelligence.

Although there is not space here to fully investigate the nuances of moral personhood, or how to determine a person's capacity to be autonomous, there is an important caution in this project pertaining to both of the objections discussed so far. The caution is that it is far worse to be mistaken in the denial of moral personhood, and the corresponding ability to be autonomous, than it is to be wrong it its attribution (Wong 2010, 142). Since moral personhood is a topic both sensitive and fraught, erring on the side of caution for human beings, and establishing an inclusive society, is a more worthwhile project than trying to pinpoint a person's exact cognitive ability, and how that ought to relate to their autonomy and moral status (Ibid.).

Even if a reader were to grant my argument and give me the benefit of the doubt for the present regarding ability and moral status, they may still question my choice to consider the obstacles of autonomy faced by people with an IDD as morally problematic. They may view the autonomy limiting experiences of a person with an IDD as more akin to the neutral limitations experienced by physiological realities as discussed in the first chapter. They may concede that there *are* harmful social attitudes, but that they can be addressed as a separate issue of discrimination.

To say that the limitations of autonomy that a person experiences due to IDD are more aptly considered neutral is to disregard the history of treatment and equate the impact of living with an IDD to something like that of an illness, such as a heart disease. These kinds of limits to autonomy are part of what it means to be human. This would affirm that there are indeed limitations to the person's autonomy, but stop short of saying that there are moral obligations to alleviate them. When someone's autonomy is restricted due to natural sources, mitigating those limitations as far as possible is not something society is obligated to do. Just as a person with a heart disease organizes

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their life in order to maximize their own autonomy in spite of their health challenges, so too should someone with an IDD.

I disagree that heart disease and IDD have relevant similarities pertaining to my present project which imply, since the first generates natural, and neutral, limitations of a person's autonomy, so too does the second. Furthermore, I disagree that the limitations to autonomy that a person with a heart disease may suffer are solely neutral, an assumption required in this objection. I will continue the comparison in order to explain. If a person has a heart disease, the practical limitations to their autonomy arise in ways such as their diet being restricted, and consistent appointments that interrupt their schedule. Yet, heart disease can also cause restrictions of mobility and the need for a person to use a transportation device, such that their ability to access locations and services becomes limited in a problematic way. This further result of restriction to their autonomy does implicate society in a moral sense to mitigate the barriers according to my argument presented above.

While there are natural limitations associated with having an IDD, such as certain health risks and potential career limitations, there are moral obligations generated by restrictions that come as a result of how a person with an IDD is treated, and the ways society impedes their autonomy in practice and by physical design of the community's landscape. Hence, just as the autonomy of a person with a heart disease can be restricted in a way that generates social moral obligation, so too do the prevailing negative social norms toward people with an IDD, and the way social practices restrict their autonomy, is problematic in a moral sense.

By restrictive social practices (apart from those mentioned above), I am referring to how members of society experience external support for their autonomy in their daily lives, in ways unavailable to people with an IDD. For instance, in the event that a person needs healthcare, the information is provided and decisions are supported in ways conducive to a person's autonomy, and ensuring their consent is achieved. However, the way this information is provided would likely not be

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in a form that supports a person with an IDD to do the same, such as in lengthy printed information. This is where the restriction of autonomy becomes problematic for a person with an IDD, and dissimilar to the experience of a person with heart disease. It is not the limitations of the disability that generate moral obligations, but the subsequent restrictions produced by society.

An individual with an IDD may require external support of a different sort in their decision-making, but external support is a common feature for all people that live autonomously, as illustrated in the comparison to a person with heart disease. Hence, the limitations to autonomy experienced by people with an IDD, and those I am discussing here, are not of a neutral category, and to meet their need for external support is not supererogatory. Although people without disabilities may take for granted the ways they experience support of their autonomy in society (DeVidi 2013, 13), access to this nature of support is an appropriate expectation for all members of society, and its lack is a cause to consider the subsequent limitation of autonomy a problematic restriction, rather than a neutral one.

The first of these two objections highlights active philosophical discussions that warrant consideration in light of my current project, but are beyond its present scope. However, if a reader is willing to accept my preliminary responses, I hope to have dispelled the more acute objections that prevent me from moving forward. Therefore, I will maintain the philosophical commitments that people with an IDD are capable of being autonomous, and are moral persons for whom problematic restriction of their autonomy generates moral obligation. Further, I maintain that the nature of the restrictions to their autonomy they face, due to being members of a group, is indeed problematic, and so they generate a social obligation to alleviate it. I will now address the nature of this moral obligation directly.

2.7 Moral Implications

In the previous sections I argued that, as a demographic, the situation of people with an IDD generates a moral obligation to mitigate the restrictions they face to their autonomy. This social

obligation is directly connected to how individual citizens contribute to the features of society that

produces and perpetuate those very obstacles, and to how society as a whole produces and sustains

the unjust circumstances. In the previous chapter, I outlined general avenues for members of a

society, and society collectively, to fulfill their moral obligation to a demographic experiencing

restriction of their autonomy, and I will now apply those categories to this particular social issue.

Recall that a member of society has two classes of moral obligations, which correspond to

two dimensions of their life: the proximate sense of their daily interactions, and the dimension where

they use their social properties, such as political and professional influence. Although the former of

these categories guides the latter, sincerity[25] of effort is required to fulfill one's moral obligation with

respect to their social properties.

To fulfill the first of these categories of moral obligation, an individual citizen must critically

reflect on the social norms regarding people with an IDD, and avail him or herself of true information

regarding their capabilities. This includes gaining knowledge of history to identify any inheritance of

negative attitudes they may be bearers of, such as how problematic historical themes can be enacted

on a personal basis by presuming to have a position of authority over the person with a disability.

Through self-reflection and overcoming ignorance, a member of society will be able to interact with a

person with an IDD in a range of contexts that remove obstacles and support their autonomy.

Proximate moral obligation is further fulfilled when one challenges the attitudes and false beliefs of

others who contribute to the perpetuation of those social norms that restrict the autonomy of people

with an IDD. This is performed as is appropriate within a social setting.

The opportunity for a person to use their social properties in this situation is vast. For

instance, professionals in various capacities, within the field of social services and without, can

contribute to the removal of residual dehumanizing methods found in certain treatment of people with

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[25] And again, by sincerity I mean having reasonable evidence that the use of social property will be effective.

an IDD. It is plausible for health care professionals, educators, community activity leaders, and media contributors to use their positions to either directly remove obstacles to a person's autonomy by treating them appropriately, as well as instigate further reflection and challenge the unjust features of society by providing correct information. Awareness of the history regarding treatment of people with an IDD and the misconceptions that generate practices that restrict autonomy will inform the fulfillment of one's moral obligation with respect to how they use their social properties.

A person could also use their political vote, or other avenues of influence over a government such as lobbying, to initiate policy changes and funding directives toward mitigating the obstacles to autonomy that people with an IDD endure. This political engagement can provoke the government to take action on behalf of society as a whole to remove the restrictions to autonomy that people with an IDD face. These actions could include changes in the amount of funding allocated to particular efforts, or the initiation of new programs and services. While individual society members are still obligated to engage in their moral obligation in a proximate way, and with appropriate use of their individual social properties, the government can intervene on behalf of society to remove obstacles to the autonomy of people in order to fulfill the moral obligation society has collectively.

Regarding the particular efforts made to alleviate these restrictions, both individual and those of a government on behalf of their citizens, the moral obligation must be fulfilled with sincerity. That is, the methods and opportunities an individual citizen chooses to invest in, endorse, vote for, and work toward must have a reasonable probability that they will be successful in removing the obstacles to autonomy that people with an IDD experience. Likewise, when government initiatives are made to remove restrictions to autonomy on behalf of the collective, investigation is needed to ensure that the efforts are sincere and are an effective use of the resources used. Hence, the honest evaluation of guiding principles, methods, and expected efficacy of efforts are required from both. History offers many lessons as to what has not been successful on both fronts, how good intentions of change can

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actually be recapitulating old errors, and also how great progress can be achieved when true social beliefs align with appropriate governmental action.

2.8 Conclusion

This chapter applies the framework developed in Chapter 1 to the situation of people with an IDD. Using the thin working definition of autonomy, I argued that people with an IDD have their autonomy restricted in a way that generates moral obligation on others to alleviate the restrictions. These restrictions can be seen in the way their deliberation involves deformed desires, and in the chronic lack of options available to a person with an IDD stemming from what I have called, borrowing a term from my brief review of the history of conditions for people with an IDD, community institutionalization.

By applying the features of an unjust society borrowed from Martha Nussbaum, also discussed in the first chapter, I argued that the way autonomy is restricted for people with an IDD is a social problem, and thus generates a moral obligation to be mitigated, both by the individual members of society and by society as a whole through government action. Society has harmful norms and prevalent false beliefs about people with an IDD based on ignorance, and there is a persistent lack of critical reflection on these norms and beliefs, evidenced in the phenomenon of "sweetness porn." These negative social attitudes toward people with an IDD translate into the lack of social options they have access to, in the form of underemployment, and in their needs being overlooked in matters of community participation and accessibility.

There are arguments against how I classified the nature of autonomy limitation that people with an IDD experience, and this demographic's claim to moral personhood and their capacity to be autonomous. However, in the absence of space to fully address these objections, I gave persuasive reasons to, at the very least, err on the side of caution and consider people with an IDD as moral persons, who we often underestimate the capabilities of.

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The moral obligations that are generated by how this part of our population is treated can be fulfilled by a person's efforts to eradicate the unjust features of society through their proximate lives, and through the sincere use of their social property. However, the social nature of the obstacles also requires large-scale changes, such as could only be initiated by the government on behalf of society. Just as an individual using their social property to meet their moral obligations is required to have sufficient reasons to expect that their effort will be effective, so too do a government's efforts need to be sincere to meet its moral obligation. In the next chapter, I hope to make these social obligations explicit when they are demonstrated in a contemporary example.

Chapter 3
Toward a Solution: A Contemporary Example

3.1 Introduction

In the previous chapter I discussed at some length how moral obligations arise to remove impediments to the autonomy of people with an intellectual or developmental disability (IDD). More precisely, I have argued that there are moral obligations for both society at large and individual members of society to rectify unjust social attitudes and practices that restrict the autonomy of people with an IDD. The individual members of society can fulfill this moral obligation as they mitigate the unjust features within their proximate daily life, as well as by intentional uses of their social properties, such as those afforded to them by their profession.

For society as a whole to meet its moral obligation requires larger-scale changes; bringing such change about would seem to require the sort of coordinated effort and infusion of resources that requires the involvement of government. However, government-driven social change has a somewhat precarious history, particularly when it comes to the treatment of people with an IDD, as is clear from the historical discussion in Chapter 2. Exactly how such an obligation is best met is not obvious at first glance.

In this chapter I will explore an interesting contemporary example that has some promise as a way to fulfill society's moral obligation as described in Chapter 2. This example centers on the service called Independent Facilitation and Planning (IFP), which claims to be able to remove obstacles to the autonomy of a person with an IDD. IFP has its source in grass roots developments that include people with an IDD, and their parents and families. In order for this service to be available to everyone who could benefit from it, funding is required, as well as other kinds of coordination and support from the government.

Currently, the Ministry of Community and Social Services (MCSS) is investigating the

potential for IFP to become a government-funded service in Ontario, on an ongoing basis. This

investigation is taking the form of a "Demonstration Project" that involves, among other things,

evaluating the outcomes IFP has for people who receive it from several independent organizations

that offer IFP in Ontario.

In what follows I will outline the claims made on behalf of IFP by its advocates and

practitioners, and specific ways that IFP purports to remove obstacles to a person's autonomy. Then I

will discuss how the possibility for ongoing funding can relate to society fulfilling its moral

obligation to this demographic, including a discussion about how the criterion of sincerity may be

achieved and the challenges it includes.

3.2 Independent Facilitation and Planning: an Introduction

3.2.1 A Social Service in Ontario

In order to understand the service called IFP,[26] I will begin by describing it with respect to its place in

the greater social services context. In the official terms within the MCSS, IFP falls under the category

of "person directed planning." According to Disability Services Ontario, person directed planning

(PDP) is assistance provided to a person with an IDD by a support professional in order to define a

vision for their life, to connect with their community, to identify their own strengths, to make

decisions, and to set goals (Disability Services Ontario 2015).

Although IFP is categorized as a kind of PDP, there are important differences between how

PDP has functioned historically, and how IFP operates according to its advocates. The typical

practice of PDP has sometimes been criticized, both by people with an IDD and their advocates, for

its preoccupation with producing a plan in written form. At some points, a completed document was

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[26] Some organizations that offer this service have begun calling it simply Independent Facilitation (IF). However, I will continue to use IFP as at the time of this writing it is still the most commonly used term in the literature.

even the mechanism for the support professional to receive payment from the government for providing the service (Goode 2015). This overemphasis on a written document is said to have caused the focus within the planning process to shift away from discerning the priorities and goals of the central person, to creating a plan that was easily recorded and quantifiable. According to critiques of PDP, the completion of the written plan was treated as the goal of the service, and was not accompanied by sufficient support for a recipient to implement the plans made. [27] Plans would be recorded, but the lack of follow through is said to have resulted in most plans remaining unimplemented – indeed, without the person who receives the service taking any steps towards accomplishing what the document included. Although there is legitimate need for a service that seeks to support people individually in this way, the typical delivery of PDP is thought to have been limited in its effectiveness.

In response to this perceived problem with how PDP was functioning, and coinciding with shifts in the social services toward individualized supports, IFP was developed to be a more effective approach to providing individualized support to people with an IDD. Specifically, the goal of IFP is to be a service that is able to arrange highly individualized support for people with an IDD.

One fundamental difference between how traditional PDP and IFP operate is that IFP is independent from traditional agencies.[28] Using "independent" in this context refers to the position of the person providing the support, titled the "facilitator." This entails that the facilitator is neither employed by an agency that is in charge of allocating and distributing financial support, nor a representative of funded programs; practitioners of IFP work independently, or with an independent organization. The cost of the service can be met in various ways: through direct payment from the

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[27] It is worth noting that much of how the planning process occurs still depends on the work of each individual support professional. Many may have held to good work practices that benefit the central person in spite of initiatives that stressed the delivery of the document.

[28] By traditional agencies I am broadly referring to the present form of the community-based services initiated in 1970's amidst deinstitutionalization (see chapter 2). These are government-funded establishments that exist for the sole purpose of meeting the needs of people with disabilities.

government to the organization, by the recipient using their government provisions to pay for it, or by the cost being met through the recipient using their own personal funds.

The independent position of the facilitator is said to prevent defaulting to superficial arrangements to support a person in interest of time and financial efficiency, as can happen when a person requires a greater amount of time to decipher priorities and goals before making any plans than is possible given the constraints of a large "caseload". Ultimately, the facilitators' independence is supposed to avoid a conflict of interest that can impede the "community first" approach of IFP. That is, according to IFP practitioners, the community in which the *central person* (the person receiving the support) lives should be the first resort for finding support, rather than programs designed for and populated by people with disabilities. It is argued by IFP advocates that if a facilitator were to be employed by an agency, they would have greater awareness of the services their own organization offers, and bias – conscious or otherwise – towards the supports offered by their employing organization. This is thought to be compounded by the possible time restraints that would prevent an agency-employed facilitator from investing the additional effort to locate comparable opportunities within the person's own community, when similar options are available through the agency (DeVidi 2013, 4-5).

Practitioners of IFP see their service as a decisive reversal of the direction of fit between the person and their options for support as provided in the past. The IFP process is said to begin with the person's strengths, priorities, and goals, then to work outwards toward community involvement in order to meet those goals. As the plans are enacted, support for the central person is introduced as needed, and using as many community-based solutions as possible. IFP advocates describe this as being in contrast with how the traditional "menu" of supports offered by agencies begins, which is that the traditional starting place is the list of available programs, and the person is allocated to the

best option therein,[29] suited to their deficits and according to the priorities of employment, health, housing, and finances.

From a financial perspective, IFP is promoted as a way to increase the efficiency of the central person's use of government-funded support. This service claims to do so by helping a person to determine which supports in their life can only be acquired by paying for them, and where they have opportunities for activities and support within their community on an unpaid basis. The aim of this approach is to allow people to reserve their money, including that which they receive from the government, for priority services that they are unable to receive elsewhere.

IFP is thought to be especially useful when supporting people with more complex needs, such as people with dual diagnoses, and those who have not been successfully supported by traditional agency programs. By not successfully supported, I mean either that a person has participated in the applicable options offered by an agency but remains unsatisfied, or that their life remains unmanageable in some respect. A facilitator is said to provide a person with information about, and help in accessing, a broader range of potential activities and support, while also spending additional time and increased involvement with the person. This individual approach is purported to offer a diversity and flexibility to supporting a person that structured services are unable to match.

Regarding the role of the written document, practitioners of IFP view such a thing as only helpful insofar as it is a useful tool to reach the greater goals of the process (Lord 2015; Goode 2015), such as decision-making. Although planning is said to occur throughout the entire process, it ranges from discreet and tacit planning, to obvious and concrete forms of planning. This sometimes, but not necessarily includes written documents (Ibid.).

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[29] Typically these options include day programs with set activity schedules and sheltered workshops where people are paid small wages to complete repetitive tasks.

3.2.2 The Process

With this general overview of how IFP is situated with respect to other social services in mind, I will attempt to illustrate the IFP process itself according to claims made by advocates and practitioners of the service. IFP is described as a subtle process, and one that adapts to the people involved. Some practitioners argue that the success in the role of a facilitator requires talent, training, and creativity, and the work has even referred to as a craft. I will attempt to show how the service is supposed to support the person who participates, by using the general features of the IFP process as gathered from experienced practitioners and organizations that offer IFP.[30] Specifically, I will discuss the proposed method and goals of the service as they directly relate to the autonomy of the central person receiving the support.

The relationship between the central person and their facilitator can begin when the person with an IDD seeks out the service of a facilitator to use IFP as a tool to move forward in an area of their life. In some cases an agency care provider refers a person to the service when they think the person may benefit from an independent perspective, or when someone close to the person investigates on their behalf. However initial contact is made, from the outset of the IFP process, it is supposed to be entirely responsive to the person receiving the service. A facilitator seeks to support, but not direct, a person regarding pace and focus, and is not to have assumed any hierarchy of needs prescribed by other professionals.[31]

Although the steps and pace of each process are said to be unique to the person involved, the general structure of the service begins with a time of pre-planning in order to build rapport. In this stage the facilitator spends time with the central person in various contexts to build trust and familiarity. This pre-planning time is thought to be crucial to the remainder of the process, since the

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[30] The majority of the information used in this outline is a synthesis from Lord and Hutchison 2007, Lord and Leavitt et al 2012, and "Services Offered: Individuals and Families," www.facilitationwellingtondufferin.ca.

[31] Meaning those of employment, health, housing, and finances.

honest planning and setting of personal goals requires trust between the central person and the facilitator. In conjunction with building a relationship with the central person, the facilitator is also to be observing and gathering relevant information about their current lifestyle, strengths, and interests.

Using the collected information and with support from the facilitator, the central person is encouraged to set priorities and goals, often with the input of family or other important figures in the person's life. [32] This signifies the planning stage of the process, and can take place in various ways, and with varying amounts of structure provided by the facilitator. What is intended to remain consistent in any context that the planning may occur in is that the facilitator carefully observes and supports the central person as they make decisions. This is done in order to recognize and resist superficial interests that are the result of external expectations and pressure, such as those stemming from and indicating excessive compliance. Once ideas are discussed and potential options are weighed, decisions are to be made by the central person as to which goals and strategies they wish to enact.

Experienced facilitators see the IFP process as a long-term commitment, with the early stages being of crucial importance. The successful beginnings of the IFP process must avoid small errors of interpretation of the central person that risk setting a trajectory of misunderstanding throughout the subsequent steps of the process (Lord 2015). These early stages are intended to lay the foundation for the central person to gain confidence in exercising their autonomy, and they are to guide the additional people involved to offer ongoing support in an appropriate way.

When the central person has made preliminary decisions about goals and strategies, the practical steps are to begin. This time of initiating action is referred to as the "facilitation portion" of

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[32] If the central person in question does not have such a support system, a facilitator is said to assist them as they develop one.

the process. This stage is said to generally include the facilitator networking and connecting the central person to the people, places, and groups where the plans made can be set in motion.

While the planning and facilitation stages are conceptually distinct, in practice they overlap and interact. Once plans are activated, there are often changes and compromises to be made regarding the initial goals and strategies, as when any adult sets a new plan into motion. Here the facilitator is to offer ongoing support as needed. For example, more information about community resources may need to be gathered, the central person may need support as they navigate obstacles, or if they change their mind about their previous decisions more support may be needed. Ideally, the involvement of a facilitator does not end when these first steps are made; their role is to be one of ongoing commitment.

Beyond a facilitator's focus directly pertaining to plan creation and implementation, they also intend to support the person through various times of upheaval and important life transitions, perhaps as with the death of a family member or an event such as moving out of their parent's home. This explains both the need for a long-term relationship between the facilitator and the central person, and the varying degrees of involvement the facilitator will have with the person at different times. Over the course of a long-term relationship, there will be times of high engagement and others of very little contact between a facilitator and the person they support. This dynamic is an expected feature of any particular IFP process.

3.3 Proposed Benefits of IFP

I will turn now to highlight those particular features of the service that relate to the topic of autonomy. By drawing on the claims and methods of experienced IFP practitioners, I will discuss the ways that

the successful application of IFP is said to be able to mitigate the restriction of autonomy to the people they support. [33]

Through the support of a facilitator, the process of IFP aims to remove obstacles to a person's autonomy in the practical way of increasing the genuine choices available to a person with an IDD. Since people with an IDD are often participants in programs populated by other people with disabilities, unintentional segregation from the greater community results. This also limits a person's awareness and access to options within the community that are not supplied by agencies or those designed specifically for people with disabilities. Through a successful IFP process, it is claimed that a person can gain the awareness of, and access to, community activities that address the problem of limited options stemming from community institutionalization. Although programs and services offered by agencies remain options a central person can choose, they are no longer the only ones.

An important determining aspect of the number of choices that are available to a person is the number and variation of relationships they are involved in. Available choices are multiplied with each relationship a person has, those ranging from close companions to acquaintances. The more relationships in a person's life, the more opportunities they have to take initiative, and to extend or respond to invitations (Goode 2015). For instance, if a person's social life consists of having tea with their aunt, the accessible choices they are aware of being available to them are limited to making or responding to invitations from one person, to do one activity. However, with a wider variety of connections to people with different interests, the invitations to participate in events, gatherings, and activities grow as their connection base grows. Instead of only having invitations for tea, a person can meet someone with a pool who invites them to go swimming, or a musician who encourages them to learn an instrument, and so forth.

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[33] Although there are many other proposed benefits of IFP, such as relationship building and community inclusion, I will remain focused on the impact IFP has on the autonomy of the people who receive the service.

People who receive the support of IFP often have difficulty forming relationships. This can be the result of pervasive social attitudes towards people with an IDD, but is also often due to difficulties with social interaction that can be part of having a disability. The support of a facilitator is said to offer the benefit of increased connection and interactions with members of the person's own community, not just those within the disability community. Practitioners claim that, as a facilitator, they will support the central person to form relationships in their community by providing instruction pertaining to social interaction, suggesting changes in their routine in order to meet new people, and through introductions that can occur as part of the implementation of the plans that have been made in the IFP process. These connections can create opportunities for the person to meet and form new relationships that were previously unavailable to them, and expand their options in the process.

A second significant way that the IFP process claims to remove obstacles to autonomy is by offering the external support to the central person that society is not designed to do, and by helping the important people in the central person's life to do the same. Recall from the discussion in Chapter 2 that non-disabled adults routinely rely on external support to be autonomous, but are largely unaware they receive this support since social settings offer it so seamlessly. Due to society being fashioned to support the "average" person's autonomy, those with an IDD do not receive comparable external support from the same sources. Hence, part of how IFP seeks to remove obstacles to a person's autonomy is by offering external support in the way required by the particular individual.

Facilitators claim that the precise shape that these supports take is unique to each person, so that the person has what he or she need to make their own decisions. For instance, the nature of a developmental disability itself includes a spectrum of difficulty for the person to think conceptually. This complicates the visualization of the outcomes of options that is a crucial part of making informed decisions (Lord 2015). These general factors can also be combined with other dynamics,

such as the possibility that the person in question does not communicate verbally, thereby further adding to the complexity of a situation where one's autonomy is the focus.

Experienced practitioners mention many practical methods a facilitator can use to offer support. For instance, to help a person make decisions about the relationships in their life, a map of names can be created for reflection. The proximity of the names of friends to the central person's name on the sheet represents the degree of closeness in the relationship. This physical representation of an abstract subject matter is then used to evaluate where investment in a relationship is desired, and if increased distance is desired in others (Lord 2015). Capturing the contents of the topic on paper in this way provides a visual structure to assist deliberation about (which names to move closer or farther away?) and visualize outcomes of (the distance created or reduced) a previously abstract topic.

A further example of how a facilitator could provide this external support is the activity called "graphic facilitation."[34] This activity uses pictorial representations of the subject matter that can be arranged and shared to indicate options and priorities involved in decision-making. This method does not require verbal or written communication, yet creates a platform for the central person to work through the decision-making process, and communicate their decisions and priorities to others. In both of these examples, a facilitator of the IFP process is equipped with methods to support the central person to make decisions in a way that is conducive to how they receive and evaluate information.

By highlighting the potential positive outcomes of the IFP process, I have shown that there is evidence to claim that the successful implementation of the IFP service would be effective in removing obstacles to the central person's autonomy in practical ways. This also indicates that

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[34] For more information about graphic facilitation, see Jack Pearpoint's *Hints for Graphic Facilitators*, Inclusion Press, 2002.

making IFP an available service to people with an IDD, by permanent funding from the government, has the potential to fulfill a large portion of the social obligation that society has to this demographic.

3.4 A Possible Objection

At this point a reader may accuse me of having too narrow a focus, and think perhaps IFP is not necessary. Showing that one approach has potential does not do much to show that it has *the best* potential, so a critic might suggest that more consideration should be given to what modifications ought to be implemented in the agency setting instead. More pointedly, I can foresee that some may think that a more effective use of government funding would be to enhance the existing services to better mitigate the obstacles to the autonomy of people with an IDD. I interpret this objection of being within the "no need to reinvent the wheel" variety, to which I have two responses.

First, I would challenge such an objector to think through the plausibility of modifying the current agency structure in this way. I do not think it is realistic to expect an agency to provide the same level of individualized support as IFP claims to do, simply by nature of how an agency operates. By this, I mean that the benefit of large programs and services is that they are developed and maintained to include as many people as possible. This approach is supported by an infrastructure designed to meet the needs of the majority of people who access the services an agency provides.

Such broad goals and the need for efficient implementation directed at large numbers are not conducive to provide highly personalized support. Even though agencies continue to become more flexible in their operations, and some have even partnered with IFP organizations to provide better service, the large programs run by agencies are designed to accommodate the majority, not customize support for each individual. This is a matter of the overall design of existing agencies, not of funding and not something straightforwardly changed by any easy 'enhancement.' It is plausible to claim that the overall efficiency of social service delivery requires something like an agency system to deliver some large scale programing, and that many people accessing IFP may opt to participate in some of

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these programs. If that's correct, it makes agencies something like those that currently exist a necessary feature of social service delivery long into the future, but they are not the appropriate vehicle for the individualized planning and facilitation that I am discussing here.

The second response – and what I see as the more important one – is that this objection is not taking into considering the benefits of community inclusion for people with an IDD, something increased funding to agencies would not contribute to. As discussed above, one of the ways that the IFP process aims to alleviate the restriction of a person's autonomy is by connecting them with the greater community. This can lead to an increase of relationships that benefit their autonomy through making available more choices, as well as the potential to increase their awareness and access to options to participate in the community. Expansion of agency support will not contribute to meeting those ends.

3.5 Sincerity

I return now to the task of determining whether the funding of IFP would result in society fulfilling its moral obligation to alleviate the impediments to autonomy endured by people with an IDD. If this obligation is to be met, the criterion of sincerity needs to be satisfied. Due to the nature of the project having both moral and financial ramifications, assurance is needed that the IFP service will be an effective and reliable method to remove the restriction of autonomy for people with an IDD. To determine effectiveness, some manner of measurement is needed to indicate success. While attempting to offer a definitive answer to this question would clearly be a larger undertaking than I can attempt here, and probably would require evidence that nobody currently has, there are nevertheless some useful and interesting things that can be said on the topic.

Obviously, autonomy expressed or experienced by a person is a very difficult quality to measure. Furthermore, in recalling the discussion of autonomy from the first chapter, it is a challenge in itself to achieve agreement on any single definition. Yet, even with a reasonable formulation of

autonomy (such as the thin notion I presented), the task of measuring remains complex. In this present section I will clarify a few of the challenging aspects that exist when seeking to measure this particular project.

3.5.1 Potential Sources of Measurement: Central Person

One obvious source of information about whether something has helped someone is to ask him or her. It therefore seems reasonable for one to simply ask the central person involved in IFP if they are experiencing helpful support in being autonomous, and to view this as a measurement of the effectiveness of the process. Presumably, an inquiry of this sort would be presented in an accessible manner that avoids questions such as, "have you experienced the removal of obstacles to your autonomy?" That would be complicated for any adult to answer. Rather, it would need to be framed as a more practical question from a third party to acquire the information to be measured; ideally, perhaps one that would accompany the implementation stage of the process, and refer to a specific decision when asking, "was that your own choice?"

At first glance this may appear to be a reliable source of information, since it is natural to assume that a person is in the best position to know his or her own experience. Although the central person's perception of the process is of significant importance, there are noteworthy reasons why the person receiving the support of IFP is a not reliable source of information for this particular purpose. Even with a carefully modified approach, the central person's stated answer to questions will likely yield unreliable information to use as measurement. I will expand on two of these reasons below.

First, considering the demographic which the service of IFP supports, there are lasting effects of community institutionalization that have likely instilled the value of compliance into the person involved. There are also prevalent social norms that reinforce the inappropriate authority of non-disabled people over people with an IDD. As mentioned in chapter two, this creates a phenomenon of undue compliance, one that is sufficiently serious that it often qualifies as a deformed desire. Hence, a

simple question directed to the central person will not be reliable in the manner needed to provide accurate measurement, as their response may be reflecting the answer they perceive to be the one the inquirer wants to hear.

Second, the progress made during the IFP process with respect to autonomy is, according to its practitioners, one that begins internally, continues incrementally, and that can occur without the person recognizing it (Goode 2015). When restrictions to the central person's autonomy are removed, and they begin to practice decision-making, the changes may not be in a form immediately recognizable to the central person or, at times, even to the facilitator (Ibid.). For instance, often an important development with respect to decision-making is the reduction of anxiety a person experiences when working through the steps toward making a decision. A person may be unaware that this emotional change has taken place, or that the experience constitutes (and offers information about) an improvement in their autonomy. However, gaining confidence in making decisions is a practical part of how a person's autonomy develops once impediments are alleviated. A lack of anxiety can indicate growth in this confidence, and, as such this instance would be relevant information about their autonomy.

This can complicate gaining information to measure effectiveness, since, if questions are originating from a third party, this third party will be unaware of the kinds of questions to ask that will gather the relevant information. Indicators of a person experiencing the removal of obstacles to their autonomy will vary by person and by situation.

Furthermore, the central person may lack the awareness of these subtle changes occurring in how they exercise their autonomy, regardless of what questions are asked. This lack of recognition does not necessarily mean that the IFP process has been ineffective in removing the restrictions to their autonomy, but the lack of information gathered by questions from a third party may falsely indicate it as being so.

While the awareness of a central person's response during the IFP process is vital to the service, when information is needed for measurement, there are substantial impediments to ensuring that the information gathered is reliable. In soliciting information by questions from a third party, the answers may present instances of a false positive as the result of excessive compliance. This form of questioning may also produce information presenting as false negatives when the progress is either internal or unrecognized by the central person, or if the particular growth is not represented in the questions they are asked.

3.5.2 Potential Sources of Measurement: Facilitator

A second avenue to determine the effectiveness of IFP is to request input from the facilitators themselves. This appears to be a promising option, as by the nature of the facilitator's relationship to the central person they are in a unique position to observe the changes made over time. However, it is an avenue that also presents obstacles in a situation that has financial ramifications (as, for instance, in any evaluation that is part of the current Independent Facilitation Demonstration Project) for it is unrealistic to assume that a facilitator will be impervious to the knowledge that a favourable financial outcome for their profession relies on the positive measurements of the individual IFP processes.

So it seems that simply asking facilitators questions that amount to "how's it working out?" is not an approach likely to produce reliable information. But, of course, the process need not be so simple. Although the facilitator is not a reliable source for a direct measurement, their familiarity with each central person in the process can be utilized as a source of information; this information can then be measured by a third party to determine effectiveness. Unfortunately, as we will see, there are also factors that make reliance on the facilitator for measurable information problematic.

The first potential weakness of a facilitator providing information to a third party is the risk of motivated inferences being made in what information they provide. By this, I am referring to potential subconscious motivations of a facilitator that leads them to make inferences about the

behaviour and actions of the central person in a way that overemphasizes progress. I will draw on the previous example of anxiety to illustrate this: a central person may exhibit emotional fluctuations during the decision-making process that are the result of relational issues occurring in their life, and not a direct result of the process itself. This could be in the form of the central person experiencing conflict with a friend causing anxiety, and then achieving resolution and relief from that anxiety. If a facilitator is subconsciously motivated to gather evidence of progress, they may infer that the reduction of anxiety indicated development, and record it as such. The possibility of a facilitator making motivated inferences, like this one, in the information they provide, threatens to undermine the reliability of the resulting measurement made by the third party.

The second potential weakness arises from the possibility of a facilitator interfering with the direction of the IFP process itself. When the facilitator knows him or herself to be the source of information used for measurement, this knowledge can unintentionally influence them to support the central person in a way that guides the process towards measureable outcomes. For instance, if the central person communicates that they want to try a new activity, but remain unclear of what their interests and goals are more specifically, a facilitator may encourage them to return to activities they have enjoyed in the past in order to have the kind of information that produces favourable measurements.[35] This is in contrast with the less desirable, but more appropriate practice of accepting long amounts of time without results in order to alleviate impediments to the central person's autonomy, and supporting them to identify their own desires, preferences, and choices even when this yields no timely positive information to provide to a third party for measurement.

This second source of weakness is of a different kind than the first. The first was the potential for an IFP process to be misrepresented in the information supplied for measurement. In this second

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[35] Strictly speaking, this should include a qualification such as "what they anticipate to be" favorable measurements, since if we are to avoid the first problem of a potential conflict of interest it may be necessary that the facilitator not know which measures are the essential ones to the eventual evaluation.

case there is potential that the measurements are no longer measuring their intended target. Instead of measuring the effectiveness of the IFP process, as described in the earlier sections of this chapter, the measurements will be of the facilitator's effectiveness to guide the IFP process towards what is measureable. These two related, but different potential weaknesses, show how reliance on the facilitator to provide the information for a third party to measure can negatively impact the measurement itself.

The reliability of information has further bearing on the project as a whole in two ways, since the resulting measurements will be applied to two different but interconnected decisions. First, this measurement can be used to determine whether making IFP available will fulfill society's moral obligation to mitigate the restricted autonomy of people with an IDD. This is because the positive measurement will satisfy the criterion of sincerity, by giving reasonable evidence that the service is effective. Simultaneously, if IFP is considered a sincere avenue to fulfill social moral obligation, the positive outcomes of the measurement will also determine that the funding will be provided to initiate the fulfillment of obligation by making IFP more widely available.

3.5.3 Potential Safeguard

As shown above, the task of determining the effectiveness of IFP to remove obstacles to a person's autonomy is complex and rather difficult. Yet, the kinds of weaknesses that are highlighted when the facilitator is the source of information are not unknown to those in the profession. Experienced facilitators acknowledge and caution other practitioners against the misidentification of behaviour and the temptation to influence the facilitation process toward tangible outcomes. These are threats to the quality of the IFP service provided, not simply threats to accurate information to use for measurement.

Although these pitfalls are likely exacerbated in a context in which the continuing viability of the practice of IFP may be in the balance, these are problems that experienced facilitators have

already devised safeguards against. Can the existent safeguards used to uphold the standard of quality in the profession serve as safeguards against unreliable information to be used for measurement? I will discuss one central method that many IFP organizations already use to avoid the particular hazards of their profession discussed above: mentorship.

Experienced practitioners of IFP hold that mentorship is an essential part of a facilitator performing their role proficiently. Within the confidential context of a mentoring relationship with another professional facilitator – including both peer and more experienced facilitators – a facilitator can verbally reflect on the contents of their IFP relationships. The idea is that this makes the facilitators accountable to one another, and enables them to be made aware of inconsistencies in their practice or thinking, overlooked aspects of the situation, and the opportunity to have any assumptions challenged (Goode 2015). This creates a context in which they can discern if they are leading the IFP process towards what is measureable, or if they are misinterpreting the behaviour of the central person.

Those practitioners who promote the practice of mentorship claim that it increases the facilitator's personal awareness within the facilitating context itself. The facilitator can apply the reflection and feedback gained in mentoring relationships in order to be aware of their own emotions and filters that may influence the process as it takes place (Lord 2015). For instance, returning to the previous example, a mentor may challenge a facilitator about their hasty interpretation of anxiety reduction as an indicator of progress, and instruct them to investigate further before attributing meaning to the behaviour. Overall, awareness of this kind will help a facilitator to avoid making motivated inferences of the person's behaviour as it occurs, and purposefully prevent directing the central person toward tangible outcomes during the decision-making process.

The awareness of these particular weaknesses and the practice of mentorship are longstanding features of the practice of IFP. They long predate the current Independent Facilitation Demonstration

Project, and brought to the foreground questions like the reliability of the facilitator as a potential source of information that can then be used to measure effectiveness. Although on its own, reliance on the professionalism of facilitators and their accountability to one another through mentorship doesn't provide complete assurance, since the *quality* of the mentorship also needs to be confirmed somehow.[36] However, with other supplementation, mentorship is one plausible mechanism to ensure that facilitators are providing the IFP service in the way it claims, free from motivated inferences and underlying agendas. By incorporating the accountability of mentoring relationships as a way to preserve the quality of the IFP service, it can concurrently serve as one of the safeguards against the potential unreliability of facilitators as "measuring devices." This gives reasonable support to believe that by incorporating mentorship and other supplemental features, the information provided by facilitators who practice this method of accountability will be reliable.

Further confidence can be gained by removing possible sources of temptation that would encourage unreliable information. This can be in the form of increased confidence given to the facilitators that the measurements used by a third party will be sensible and attuned to the meaningful outcomes, in addition to not knowing exactly how the evidence will be evaluated. If a facilitator is not concerned about the evaluations being approached in unsubtle ways, and if they do not know precisely how the information will be used, there will be less motivation to steer toward premature conclusions, while also not knowing which features to emphasize in their information.

Of course the goal of proper evaluation is obviously acutely sensitive to successfully identifying what kinds of things could be measured and how the measurements will be used to evaluate success. That's a whole topic unto itself. There currently exists a collaborative effort[37]

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[36] Mentoring relationships that consist of facilitators who permit each other to perform their role in ineffective ways would obviously not qualify.

[37] Comprised of people from the Ministry of Community and Social Services (the ministry that is funding the IFP demonstration project) and the Ontario Independent Facilitation Network.

dedicated to this very goal of designing appropriate measurements for this project, and while it would obviously be interesting to address the methods they come up with, they are at the time of writing still under development.

Any conclusive statements regarding the overall efficacy of IFP to fulfill society's moral obligation must be suspended until the results of the demonstration project have been reviewed, and will include many features I have not even raised here, as I am only discussing one aspect of the question of sincerity. However, when considering the goals of IFP, the practical methods utilized by facilitators to meet those goals, and the plausible safeguards that are in place by many organizations to ensure the IFP process is provided as proposed, there is reasonable evidence to expect that once the Ministry of Community and Social Services (MCSS) project develops an apt method of measurement, it will find IFP to be effective. This anticipated result would confirm that providing IFP to people with an IDD is sincere a way for society to fulfill their moral obligation regarding the removal of obstacles to autonomy, as well as initiate that fulfillment by allocating the funds to make the service available to people with an IDD in Ontario.

3.6 Future Consideration

Let us suppose that the results of the Demonstration Project show that IFP works as well as its practitioners and advocates believe it does, and so can be the central component of Ontario society's attempts to meet its moral obligations to people with an IDD. There are a number of things that can be said about what would need to happen for it to successfully play this role.

Accordingly, IFP would need to be available to everyone with an IDD in Ontario who would want to use the service, and so be available in all regions across the province. The growth in availability will require the increase of the number of practitioners who are able to offer the service of IFP as outlined above. The funding of the service is an important part of its availability, making it

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obtainable without personal cost to people with an IDD, and so it is not limited to those people who can afford the fee.

In order to ensure that the service being spread across the province is the service outlined above, steps need to be taken toward methods of quality control in the unregulated field of IFP. In the previous section I discussed the potential of mentorship as one of the ways facilitators presently safeguard the quality of their service. But there are also other measures currently in place at other IFP organizations that may contribute to the consistent delivery of the service, if adopted province wide. For instance, some organizations adhere to explicit codes of professional conduct, and have developed curriculum for the training of new facilitators, in addition to the practice of mentorship. Of course an undertaking to identify the standards that ought to be applied to any profession is immense, but the likely way to do so successfully will be to work with those in the profession who have already identified needs, and solutions, for ensuring standards.

It appears that in order to preserve the qualification of sincerity throughout the delivery of IFP, a criterion that society requires to fulfill their moral obligation, there needs to be some manner of assurance that when a person with an IDD accesses the IFP service at any point, or in any location of the province, they are accessing a service that is akin to the one originally evaluated and considered effective when funding decisions were made.[38] Furthermore, that the funding provided for the service is a sincere use of those resources. Mechanisms of this nature are required to avoid any disconnect occurring between the service intended and the service received, as ultimately, the person with an IDD would incur any possible negative effects of this risk.

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[38] This is not to say that the further development of the IFP process is precluded, but that essential characteristics of the service are included from the outset. Thus, future changes would be aligned and considered beneficial in accordance with the practice that was initially deemed effective.

3.7 Conclusion

In the previous chapters I have discussed the moral obligation to remove the restrictions to autonomy that a demographic suffers, and have argued that society has this moral obligation to fulfill with respect to people with an IDD. In this chapter I introduced a contemporary example of how this obligation could be fulfilled, through the potential ongoing funding of the IFP service by the government of Ontario.

To this end, I discussed the claims that advocates and practitioners of this service have made regarding the effectiveness of IFP, and argued that, if successful, IFP could practically remove obstacles to the autonomy of people with an IDD. In order to determine how the criterion of sincerity might be satisfied, I discussed two options for collecting information to measure the effectiveness of IFP overall: the central person, and the facilitator. I highlighted the complications involved in gaining accurate measurement of the service, and discussed the need for the safeguarding practices, one of those being mentorship, against unreliable information provided by facilitators.

Since this demonstration project is currently underway, I did not present any decisive conclusions, but offered reasonable evidence to think the project will result in a favourable outcome for IFP. When incorporating a cautionary message regarding consistent delivery of the ongoing service, I maintain that there is reasonable evidence to view IFP as a sincere option for society to mitigate the restriction of autonomy that people with an IDD experience, and to fulfill its moral obligation.

Chapter 4
Conclusion and Possible Future Impact

4.1 Overview

This project began with a brief introduction of the conceptually fraught notion of autonomy, not to bring resolution to debates about autonomy, but to formulate a thin working definition that could be reasonably applied to the present purposes. Drawing from feminist autonomy theorists, I presented a conception of autonomy that includes two necessary conditions for a person to be considered autonomous; first that they are free from manipulation, deception, distortion, or coercion that interferes with their internal deliberation of desires, preferences, and choices. This interference could be the result of the direct interference by another person, or an indirect result of oppressive social norms, as evidenced by deformed desires and adaptive preferences; second, that a person has freedom from external factors, such as restricted access to relevant options or an unsafe environment. These features were used to demarcate the edges of a person's autonomy, and also used to indicate where problematic restrictions exist. I differentiated problematic restrictions as those that occur when the neutral kinds of limitations to autonomy, as from bodily weakness or relational obligations, are disproportionate in some way, such as in the source or degree of the limitation. These are in addition to the obvious ways a person can have their autonomy violated, such as direct bodily harm. Problematic restrictions are those I considered to generate moral obligation to redress.

In order to develop my argument that we can have similar moral obligations to an entire demographic, I borrowed Martha Nussbaum's three features of a society that are unjust in the way that generates deformed desires, and incorporated them as sources of producing the restriction of autonomy for a group of people. These three features are, (1) that the society has false information or lack of information about a certain demographic, (2) that there is the lack of critical reflection on social norms pertaining to the demographic, and (3), that there is a lack of options available to

members of the demographic. I used these features to connect the qualities and practices of the entire

society to the restriction of autonomy experienced by a demographic within it. By combining together

particular social features and individual experiences of restricted autonomy, I suggested a general

framework for when the problematic restrictions of autonomy experienced by a particular

demographic qualify as a giving rise to a moral obligation for society to alleviate.

I next applied this general framework to a particular demographic. I argued that the history,

and present situation of people with intellectual and developmental disabilities (IDD) share the

deciding features outlined earlier. I did this by arguing that the restriction on autonomy experienced

by people with an IDD is morally problematic, and that society does exhibit the three features that

contribute to the restriction. These qualities, I argued, generate moral obligation to mitigate the

restricted autonomy of people with an IDD, both on the members of society and on society as a

whole.

In the attribution of this moral obligation I argued that individual members of society could

fulfill their obligation by purposefully counteracting the three social features. The first way to do this

is in a proximate sense, meaning with critical reflection and accessing correct information about

people with an IDD. The second way is for a person to use the social properties of political influence

and professional authority to remove obstacles to the autonomy of people with an IDD. Society could

fulfill this moral obligation in a collective manner by influencing changes in the government

treatment of people with an IDD, such as in programs and funding decisions. Lastly, I argued that to

fulfill moral obligation, the efforts made must be considered to have a reasonable chance of enacting

the intended outcome. This criterion I called sincerity.

With this social issue presented, and a general direction of fulfillment offered, the third

chapter discussed a contemporary opportunity to fulfill this moral obligation as a society to people

with an IDD. Currently, the Ontario Ministry of Community and Social Services (MCSS) is

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conducting research to decide whether a service called Independent Facilitation and Planning (IFP) is an effective way to support people with an IDD. If IFP is deemed effective, it may become a funded service in Ontario. I argued that IFP has a likelihood of success to remove the obstacles to autonomy that people with an IDD experience. Consequently, if the research regarding IFP performed by MCSS shows it to be successful, there is good reason to think that the criterion of sincerity is satisfied, and the availability of IFP would be an important contribution to Ontario society fulfilling its moral obligation to people with an IDD. However, the potential ongoing sincerity of this service does show the need of a mechanism to assure that the service offered will be consistent; this is due to the risks associated with IFP being an unregulated profession.

4.2 Possible Future Impact

In my closing remarks, I will attempt to come full circle and explore the impact that a service such as IFP can have on the larger context of society. I hope to illustrate that there are many unintentional social benefits of the IFP service, and benefits that can instigate greater social change than initially considered.

First, there is the *direct* impact that IFP can have on the central person's autonomy, by removing impediments and offering appropriate external support. This is the process discussed at length in the third chapter. Second, there is also an unintended *indirect* effect that the IFP process can have on the community around them, as it naturally increases opportunity for other members of society to fulfill their proximate moral obligation by way of interaction. Let me explain.

One of the effects that community institutionalization has had on society as a whole is that it allows most of society to remain largely unfamiliar with and so ignorant about people with an IDD. When people with disabilities limit their activities to programs that are designed for, and populated by, other people with disabilities, the part of the population without disabilities has very little interaction with people of this demographic. This is a practical consequence of groups that remain

separate in their daily lives. This sustained unfamiliarity creates a context where people can easily avoid reflecting on the social norms and attitudes, subconsciously or otherwise, that they hold about people with an IDD. People can comfortably remain unaware of their false beliefs and general lack of knowledge about people they have little contact with. For instance, a joke directed toward a clumsy person that pejoratively insinuates that they have a disability fosters discrimination with little resistance from the hearers when the audience is unfamiliar with how such a joke could offend a member of that demographic. In this environment the social norms that contribute to use restriction of autonomy of people with an IDD can be inadvertently perpetuated.

Suppose we inject into this context a facilitator supporting a person with IDD. Part of the IFP process includes the intentional formation of connections in the community, resulting in a person with an IDD being present in locations in their community where previously they were not. These connections are made as part of the IFP process for the development of relationships and removal of obstacles to the autonomy of the central person. However, as an IFP process functions to support the central person, the method of the service provides others with opportunities to fulfill their moral obligation as well.

Recall that an individual society member ought to fulfill their moral obligation to people with an IDD in a proximate sense. Part of how one fulfills their moral obligation in this way is to critically reflect on the social norms that generate restrictions to autonomy of people in the demographic. This is difficult when a person is never provoked or made aware of the presence of those norms. However, if part of the IFP process includes a person with an IDD entering into an activity one participates in, those involved now have the opportunity to recognize social attitudes and question them. The consequence of successful critical evaluation is that a person would seek out accurate information to correct their misconceptions or ignorance, and encourage those around them to do the same. Moreover, ideally these changes in a person's social attitudes would inform them to use their social

properties, such as a professional authority, to contribute to further removal of obstacles to autonomy that people in this demographic experience.

For instance, a person with IDD may decide to join a public gym instead of participate in the fitness programs offered by an agency. The presence of a person with an IDD at the local gym gives other members the opportunity to learn of their capabilities and individuality. This experience can challenge the social stereotypes that other gym members hold, and further provoke a person to reflect on the norms of their society more generally. This reflective attitude can ultimately be expressed by a change in behaviour towards a person with an IDD, and can aid the correction of stereotypes when perpetuated by others, even beyond the setting of the gym. Thus, an *indirect* impact has been made by the contribution of IFP.

This happy byproduct of the IFP service has great potential to generate social change, through inadvertently offering members of society the opportunity to fulfill their proximate moral responsibility. These instances could accumulate and collectively counteract the features of society that are unjust toward people with an IDD; namely, the lack of information and false information can be addressed, and critical reflection of harmful norms can be instigated.

Upon the multiplication of this byproduct, as more people with an IDD are included in their communities, it is foreseeable that this has the potential to address the lack of options available to people with an IDD on a larger scale. While the facilitator can mitigate the restrictions to autonomy that a central person experiences by expanding their options on an individual level, a larger shift of social attitudes can result in expanding options to people with an IDD more broadly. This can occur when people begin to invest their social properties. For instance, if the social attitude toward an adult with Down syndrome changes so that a hiring manager would perceive them as a capable adult, rather than an eternal child, the opportunity for employment may increase.

This is not to imply that the task of large-scale reversal of autonomy restriction depends on the work of independent facilitators. There are sincere efforts in addition to IFP being made toward this goal, and likely more efforts will continue to be initiated. However, it does illustrate that the individual work of IFP is not only a benefit to the central person receiving the support. The consequence of IFP to engage others in fulfilling their moral obligations can turn seemingly impermeable unjust social features into manageable tasks when fulfilled by many individuals.

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