

Intellectual Disability and the Interdependent Expression of Self-Determination

by

James F. Kelm

A thesis submitted to the Faculty of Graduate Studies of
The University of Manitoba

In partial fulfilment of the requirements of the degree of

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Dedications

The completion of this thesis was not possible without the dedication, support and encouragement provided by my partner in life, Candace Kowalyk. Thank you.

And mom, you are not here to share this accomplishment, but you helped lay the foundation necessary for all the achievements I have and will realize in life. Thank you.

Abstract

The expression of self-determination is not an act of independence, but an expression of causal agency in an interdependent environment. For a person with an intellectual disability, self-determination is expressed through interactions with a support network often comprised of family, friends and paid staff. This study examines self-determination in the context of relationships between people with intellectual disabilities and the staff paid to support them. The theoretical guide for this enquiry incorporates a social model of disability that recognizes impairment; interpreted through the lens of interdependence and the feminist ethics of care. Data were collected through semi-structured interviews with two relationship groups comprised of a person with an intellectual disability and the staff supporting them. People being supported were recruited first, and they were asked to recruit staff. The findings reveal decision making domains and processes, as well as relationship characteristics that impact the autonomy of people with intellectual disabilities. Self-determination is presented as an expression of relationships between people who require support and those who are paid to provide it.

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Chapter One: Introduction and Theoretical Framework

Having an intellectual disability has been defined in the literature as intellectual functioning that is significantly below average, limitations in two or more adaptive skill areas (i.e., communication, self-care, independent living skills, social skills, academic skills, use of community resources, health and safety, leisure and work) and manifested before the age of 18 (Luckasson et al., 1992). People so labeled experience a paucity of opportunities to make choices and control daily life because they are considered incapable of doing so. There may be some truth in making this claim, but it is an inadequate delineation that disallows people to act in accordance with their own will; a freedom guaranteed to most and considered a basic human right.

In this research project, I look to the association between people with intellectual disabilities and their support staff for a demarcation of autonomy and self-direction as it exists within relationships. Notwithstanding a common perception based on independence, this research facilitates a rich understanding of self-determination that firmly situates the ability of an individual to act with causal agency within the context of a supportive relationship. Given the prevalence of paid support providers in the lives of people with intellectual disabilities, self-determination can be viewed through the lens of interaction – between a person and their social network. My primary research question concerns the interdependent expression of self-determination. Quite simply, how is the self-determination of an individual with an intellectual disability expressed through relationships with paid support providers? And what are the defining characteristics of this relationship that effect the expression of self-determination?

The theoretical guide for this enquiry has been the social model of disability, dividing the self-determination literature into three complimentary yet distinct sections – the individual, the environment and society. In the literature review, each aspect is dealt with separately, using the social model of disability as a tool to critique research aimed at improving the individual and to explore the environmental and attitudinal factors empowering people towards self-determination. To carry this exploration further, a major criticism of the social model is brought forward to better understand how impairment influences self-determination. Authors of the social model (Oliver, 1990 for example) have made a clear delineation between impairment and disability and reject impairment as a cause of disability. Although this division has served the disability community well by weakening the hold of the medical model, it has been criticized for limiting important discussion about impairment and keeping intellectual disability an inadequately developed subset of the model. This research draws attention to the important function of impairment when decisions are made by a person within a network.

Paid staff often complement the daily life activities of people with intellectual disabilities because their impairment requires the assistance of others. In addition to informal support networks generated by family and friends, staff in residential community placements often act as primary relationship partners inextricably connected to the autonomy and decision-making ability of their charge. Considering both the role of impairment and the social model of disability, self-determination is portrayed as an expression of autonomy amidst relationships with others. For people with intellectual disabilities, an interdependent self-determination framework will characterize decision making in a supportive environment. The modern notion of independence that casts a person as a solitary entity requires rationality and intelligence, traits not often considered prevalent among people labeled as having an intellectual impairment. For

the purpose of this research, however, the fulfillment of self-determination will be put forward as cooperation with others, recognizing that we are all dependent on one another for support and direction.

Conceptual Framework

My position from an ontological standpoint stems from a belief that objective, knowable truths about the human condition exist and that pillars of human morality stand at the centre of behaviour and thought. However, my objective is not to gauge the absolutes of human behaviour, but instead to uncover the thoughts and actions expressed by two specific groups of people as they interact in a given social context. This is a subjective inquiry. Human behaviour in this context can be best understood as a variety of different approximations of human standards dependent on the interactions that grow amongst people. This conglomeration of human attributes creates a plethora of situations to explore that are vastly different and dependent on cultural and historical compositions. Qualitative methods are best suited to this sort of inquiry. The focus of this research project is the manner in which self-determination is expressed by people with intellectual disabilities in the current relationships they have with people who do not have disabilities. More precisely, I focus on the role of the paid support provider, the relationship that exists between “staff” and “client,” and the resulting manifestation of self-determination produced in that relationship.

A critical perspective is often concerned with promoting change, challenging social constructs and informing political movements and I have adopted this stance to meet my objectives. According to Creswell (1998), critical theory lends itself to the “scientific study of social institutions and their transformations through interpreting the meanings of social life; the

historical problems of domination, alienation, and social struggles; and a critique of society and the envisioning of new possibilities” (p. 80). Critical theory also calls for a power shift in the research process and raises important questions about who benefits from the research (Fook, 2002). Although social researchers have traditionally held power in the relationship with subjects, an emphasis on self-reflexive approaches to research emancipates the object of study and allows them agency in the development and application of knowledge.

Connidis and McMullen (2002) used a critical perspective in their research and identified three important points to consider. First, the social relations of Western civilization privilege some groups more than others. Second, people attempt to exert control over their lives within this system and although they may be marginalized or constrained, they act with agency. And third, “social life is negotiated through interaction” (559). A more elaborate theoretical understanding of people is gained when the emphasis of research is the intersection between personal experience and the greater social context. Acknowledging subjectivity and recognizing the mediating role of social context leads to more valid descriptions of perceptions and experience. The empowerment of marginalized people is achieved through the recognition of difference, the deconstruction of mainstream practices and an understanding of the hierarchies inherent in knowledge production.

A very prominent feature of this paradigm is critical evaluation of the positivist framework that utilizes empirical methods of acquiring social knowledge (Held, 1980; Fook, 2002). First, quantitative methods are not considered adequate tools when dealing with social phenomenon because they do not account for a variety of rich information sources. And second, the positivistic framework is representative of the hierarchical nature of knowledge production. Quantitative analysis will require the researcher to remain objective and distant from the object

of study. But with qualitative research, there is not necessarily an object of study per se, but subjects with whom the researcher must work closely. This is an integral aspect of the research that requires the researcher to not be distant, staying close to the people being studied, disclosing their interactions and influences on the group of people involved and accurately exploring a set of research questions to generate theory (Taylor and Bogdan, 1998). Instead of being an outsider looking in, Creswell (1998) credits the importance of the ways in which the observer becomes an insider.

While setting out to identify the major objectives of this research project, I place considerable weight on the personal aims building the foundation of my inquiries. I have developed many relationships with people who have an intellectual disability, but recognize that these interactions are distinct, and very unlike all other relationships I have formed. Aside from a family member I befriended when I was young, meaningful connections between myself and a person with a visible disability did not occur until I was paid to provide some form of support. Until that time, I knew of people with intellectual disabilities within my social network but always did they remain peripheral. So I find that when it comes to understanding the relationships that exist between people with and without disabilities, I recognize my vantage point as a paid service provider – building relationships only after being hired to provide a service.

I also recognize that for the person receiving support from paid service providers in the community, accessing the community and engaging in commonplace tasks is an act of partnership where there is reliance on a paid support provider – a situation requiring the skill to act in tandem with another person. Societal attitudes and social policies have long subjugated those with intellectual impairments to an existence contingent upon the will of others. While the

advent of a community support system has brought awareness to the development of self-determination, the attitudes and actions of direct support providers remain pivotal in the life available to someone with an intellectual impairment. Social interactions are commonplace in our society but the relationships that develop between staff and client are unique. Being a support provider encompasses a wide variety of duties that transcend the composition of a normal relationship.

This research project has generated insights that I hope will benefit people with intellectual disabilities being supported by paid staff. Uncovering the insights and perspectives of both members of this relationship will hopefully ignite a period of reflection about how support provision should be carried out. While meaningful change in support systems may remain nominal, the influence of a few staff may generate transformations among co-workers which may grow if the results of the study can be shared with self-advocates and others in the field. It is also my intention to improve my own practice based on what I learn, sharing the knowledge with both colleagues and self-advocates. Self-determination is currently limited for people with intellectual disabilities, and the opportunity to develop change must also go beyond the direct service provider, as influence must also reach the policy makers and the community at large. It is my hope that all the personal aims and objectives I bring to this study will translate into the achievement of practical goals promoting change in the current support structure.

I also hope to expand the current conceptualization of the social model of disability to include people with intellectual disabilities. The literature identifies a need for the theoretical model to incorporate and better understand the role of impairment. For those with intellectual impairments, it is necessary to investigate the ways that impairment is dealt with in the current delivery of support services. Developing a social model of impairment that applies to people

with an intellectual disability means uncovering the relationships that exist with paid support providers.

Research Questions

Most people with intellectual disabilities live in the midst of an interdependent support network that involves paid support providers. It is from within this environment that they experience the world and make decisions. Therefore, the primary aim of this research project is guided by the following research questions:

- 1) How is the self-determination of an individual with an intellectual disability expressed in and through relationships with paid support providers?
- 2) What are the defining characteristics of these relationships that affect the expression of self-determination?

A primary intention of the project is to identify the perspectives of people with intellectual disabilities regarding self-determination, as well as the perceived role of the support provider in relation to decision-making opportunities and autonomy.

Chapter Two: Literature Review

A variety of terms have been used to label people with deficits in intellectual functioning, including mental retardation, mental handicap, cognitive delay, developmental disability/delay, and most recently, intellectual disability (North America) and learning difficulty (U.K.). In addition to these academic terms, service providers in Manitoba currently refer to people with intellectual disabilities as “clients,” “consumers” and “individuals.” For the purpose of this literature review, I will use the term intellectual disability as it is the most commonly used and accepted term in recent literature. I concede, however, that these labels are primarily the product of the academic world and do not necessarily represent the views or opinions of the people burdened by them. I use these terms only to present the current literature on this topic as results of the research have yielded more meaningful terms, including person being supported and person needing/requiring support.

To present the literature concerning self-determination and people with intellectual disabilities, I use the social model of disability to differentiate individual and social approaches to the concept, grounding the origins of current ideas in Wolfensberger’s (1972) influential theories of normalization. As was done then, the self-determination literature is segmented into research and theorizing about fostering self-determination by enhancing skills; adapting the environment to facilitate more opportunities for autonomy; and helping people with intellectual disabilities organize at a socio-political level to advocate on their own behalf as a marginalized, yet resilient group of people. But my intention is to move past the social model of disability to consider new understandings about the social aspects of intellectual impairments – including the feminist concept of dependency relations (Kittay, 2001) – to uncover the role of relationships in self-determination. It is my supposition that many disabling features of intellectual impairment

(i.e., ability to take risks, capacity to make informed decisions) can be dealt with if self-determination is not deemed an act of independence, but a product of interdependence.

A General Overview of Self-Determination

Making a choice requires the active selection of a preference from a minimum of two alternatives without being forced to do so and without passively complying with a proposal from another person (Stancliffe, 2001). The literature concerned with the availability of choice for people with intellectual disabilities takes into consideration the mediating role of outside influences such as service providers and societal attitudes. Therefore, scales that measure choice often include the level of control respondents have over a variety of life events from daily decision making to major life decisions. Stancliffe and Parmenter's (1999) choice questionnaire, for example, asks questions such as "who decides what you do in your spare time?" The empowerment factor of Schalock and Keith's (1993) quality of life questionnaire also asks questions in a similar format: "how much control do you have over...?" Although people with intellectual disabilities are often provided with opportunities to select preferences from available alternatives, they may not be free to influence the options. Simply having the chance to make a choice is not equivalent to being in control. When others shape the environment beyond necessity, the freedom to act with inclination, in accordance with individual preferences, is constricted and limited.

The frequency and types of choices available to people with intellectual disabilities is primarily understood through the concept of self-determination. According to Wehmeyer (1998), this term means the ability of people to determine their own fate or course of action, as well as the freedom of a group to determine their own political status and independence. Self-

determination is considered to be the application of causal agency. More specifically, “a causal agent is someone who causes or makes things happen in his or her own life. Causal agency implies that the person is an actor in his or her own life, instead of being acted upon” (p. 11). In essence, self-determination can be framed both at the personal level in the events of daily decision making and major life choices and at a societal level whereby a group is empowered to advocate on their own behalf. Stancliffe (2001) recognizes a third dimension to consider – the environmental variables that either facilitate or inhibit self-determination.

According to Wehmeyer (1998), the concept of self-determination was first discussed in relation to people with intellectual disabilities by Nirje (1972) under the guidance of the developing theory of normalization (Wolfensberger, 1972).

One major facet of the normalization principle is to create conditions through which a handicapped person experiences the normal respect to which any human being is entitled. Thus the choices, wishes, desires, and aspirations of a handicapped person have to be taken into consideration as much as possible in actions affecting him. To assert oneself with one’s family, friends, neighbors, coworkers, other people, or vis-à-vis an agency is difficult for many persons. It is especially difficult for someone who has a disability or is otherwise perceived as devalued. But in the end, even the impaired person has to manage as a distinct individual, and thus has his identity defined to himself and to others through the circumstances and conditions of his existence. Thus, the road to self-determination is both difficult and all important for a person who is impaired (p. 177).

In this work, self-determination is cast as an entitlement to respect and dignity and the right to control events in life within the context of a given social environment. Nirje (1972) used words such as choice, assertion, self-management, self-knowledge, decision-making, self-advocacy, self-efficacy, self-regulation, autonomy and independence to illustrate the concept of self-determination.

A Review of Self-Determination and People with Intellectual Disabilities

Self-determination has been established as an ideal, something that people with intellectual disabilities, as can anyone else, work towards and fulfill. Although a paucity of research has been conducted in this area of late, past research projects have sought to determine the level of self-determination experienced by people with intellectual disabilities. Initial examinations conducted by Kishi, Teelucksing, Zollers, Park-Lee and Meyer (1988) revealed that people living in group home environments lacked the ability to make choices in a host of fundamental matters. For example, decisions about what to wear and what activities in which to participate were extremely limited, especially for those deemed the “lowest functioning.” According to the staff interviewed by Kishi et al. (1988), people with higher cognitive functioning had greater levels of choice in daily life because those with more severe disabilities were thought incapable of identifying a preference. Choice making was denied for many of the intellectually impaired persons involved in the study because staff were apprehensive about the presentation of inappropriate behaviours. “For example, in at least two homes, staff members reported that the most severely retarded residents were not allowed to choose what to wear because when given clothing chosen by staff members, they often refused to put on the item of clothing or pulled it off, and something else would then be offered” (p. 434). According to Kishi et al. (1988), most of the staff perceived active choice making as compliance with the options they present to the intellectually impaired person. More recently, Rogers, Hawkins and Elkund (1998) have shown that older adults living with intellectual disabilities experience a decisive lack of autonomy when transitioning to a retirement lifestyle. The people in this study reported feeling infantilized by the staff supporting them and indicated very little control over their own retirement; available leisure opportunities were chosen by the staff. Again, choice making was

supplanted by an obligation to be compliant.

Additional research by Wehmeyer and Metzler (1995) and Heller, Miller and Factor (1999) have also indicated that decision-making opportunities available to people with intellectual disabilities are likely to be insignificant or trivial. For example, a description of resident autonomy by Heller et al. (1999) revealed decisions that were limited to whether or not to be a part of a group activity, whether or not to stay up late or go to bed early, what to wear and when to invite guests to visit their room. They were involved in policy making to the greatest extent in areas such as setting visiting hours, planning entertainment (i.e., movies, parties), setting meal times and deciding on the décor of public areas. People were least involved in decisions about whether a troublesome or sick resident would be asked to leave, the selection of new residents, dealing with safety hazards and hiring or firing of staff members. Also finding that choices can be of relatively low importance, Wehmeyer and Metzler (1995) found that people with intellectual disabilities can be faced with all or nothing type choices, as well. In essence, activities may be selected by the people paid to supervise the activity, whether it is to a park, mall, movie, theatre or sporting events with a donated ticket, the opportunity to make a choice being limited to going with a group of 4 to 6 people or staying at home. Furthermore, they found that if paid staff did not initiate activity, people were often left with nothing to do. At the extreme, a decision may include eating a hot meal at 5 o'clock or a cold meal later.

Stancliffe and Wehmeyer (1995) examined the availability of choice making opportunities for adults involved in self-advocacy groups. Although many of the people in this study had the ability to make choices in their daily lives, they were disempowered when it came to major life choices such as employment and choosing who to live with. Similarly, Jenkinson, Copeland, Drivas, Scoon and Yap (1992) found that most people with intellectual disabilities are

unable to choose where to live and work, as well as not being able to make decisions about health and medical treatments.

Potential Barriers to Self-Determination

This negative evaluation of self-determination indicates a significant disparity in the provision of support for people with intellectual disabilities. Intellectual disability can be seen as the result of disabling social conditions as inappropriate treatment from others and situational and attitudinal barriers continue to inhibit the ability for people with intellectual disabilities to make choices and control their lives. These barriers have been discussed at length in the academic literature (see Bambara, Cole & Koger, 1998; Heller et al., 1999; Wehmeyer & Metzler, 1995). People with intellectual disabilities often inhabit structured environments with supports provided by over-protective caregivers. Within these settings, a focus on protection and safety outweighs the freedom to allow autonomy and risk. With low expectations from others, no emphasis is placed on opportunities to make choices and decisions or development of decision-making and problem-solving skills. People with intellectual disabilities are also not considered to be capable of assuming adult roles; they are usually not permitted to get married or have children and the wages available for any work or employment are well below poverty level and are often at absurd levels.

According to Jenkinson et al. (1992), the promotion of choice is limited by a perceived lack of available resources and insufficient skills on the part of the resident to support choices. These researchers have revealed that decision-making is often diminished by a scarcity of resources, staffing models and organization structures that inhibit autonomy, poor staff-client ratios and insufficient availability of transportation.

Staff perceptions of their own levels of responsibility, and demanding workloads, often make it easier to or more expedient for the caregiver to make decisions for the resident or at least strongly influence decisions by failing to provide adequate information about alternative courses of action (Jenkinson et al., 1992, p. 1).

While economic and legal constraints, as well as social pressures, serve to limit the ability for most people to make decisions, Jenkinson (1993) has argued that limitations are exacerbated by the controlling role of service providers. Stancliffe and Wehmeyer (1995) likewise suggest that future research should be concerned with identifying “specific staff behaviors and service practices which aid or inhibit choice” (p. 326). Heller et al. (1999), for example, suggest there is often a lack of individualized flexible support services and a lack of trusting, stable relationships with support providers.

Limitations Associated with Intellectual Impairment

The current socio-economic position of people with intellectual disabilities undermines their ability to make decisions because they lack credibility to others. People providing supports do not consider them capable of understanding consequences and take on roles that govern them instead of support them. Resolving this situation is going to be exigent because there are important limitations associated with intellectual impairment that cannot be explained away or disregarded as stigma. Intellectual impairment invokes concern about the person’s ability to take risks, and raises questions about personhood and the capacity to make decisions. Living primarily in supported environments, there is concern that people will default their autonomy in favour of letting their support provider be in control.

Within a social network dominated by paid service providers, Renblad (2002) suggests “that people with intellectual disabilities easily become passive and thereby ‘helpless’” (p. 285). Palmer and Wehmeyer (1998) have associated the concept of learned helplessness (Zimmerman,

1990) with self-determination and suggest it emerges as a barrier for people with intellectual disabilities as they interact with their environment. In effect, having a lack of control over the outcomes of one's actions, limits the ability to make decisions. For example, Jenkinson (1999) separated young adults with intellectual disabilities into groups of high and low learned helplessness based on their responses to a self-report questionnaire. High scores on measures of learned helplessness were related to indicators of poor decision making capacity. More specifically, people labeled with learned helplessness were also not likely to consider the consequences of their actions when making decisions and often failed to seek additional information to aid in making an informed choice.

Additional research has also suggested people with intellectual disabilities are likely to have an external locus of control (Wehmeyer & Palmer, 1997). In studies comparing students with and without intellectual disabilities, those with impairments were likely to attribute their success and failures to external factors rather than their own abilities. It is suggested this situation results from a lack of control growing up. However, this external locus of control may continue to inhibit self-determination and causal agency because empowering experiences may be attributed to factors such as luck (Wehmeyer, 1994). "Students with mental retardation may hold unrealistic understandings and perceptions of causality and excessively external global perceptions of control" (p. 19). The experience of disempowerment may predispose someone to continued inability to control the environment.

Compounding the effects of displaced empowerment, Wehmeyer (1998) has drawn attention to the concept of dignity of risk explained by Perske (1972). According to this notion, the denial of risk is a threat to human dignity that further disallows the acquisition of knowledge through experience. This further disempowers a person and inhibits their ability to control their

own fate. Research by Todd (2000) suggests that staff working in the human services are likely to inhibit the participation of those they support. While it is true that, ideologically, the principles of inclusion are well accepted and understood, many staff display feelings of responsibility for the evaluations that get made by others in the community. Consequently, when people with intellectual disabilities act in a manner that breaks social rules, staff feel it is their role to intervene to protect the person's dignity; "to counteract the stigma potential of intellectual disability" (Todd, 2000, p. 616). The harmful effect of this apprehension on the part of staff is the placement of restrictions on the freedom of people to interact with the environment and learn from experience. The safe interaction zone that gets set up between people with intellectual disabilities and others in the community has the disadvantage of prolonging dependency and limiting control over the environment. According to Perske (1972):

Many who work with the handicapped, impaired, disadvantaged, and aged tend to be overzealous in their attempts to 'protect', 'comfort', 'keep safe', 'take care', and 'watch'. Acting on these impulses, at the right time, can be benevolent, helpful, and developmental. But, if they are acted upon exclusively or excessively, without allowing for each client's individuality and growth potential, the will to overprotect and emotionally smother the intended beneficiary. In fact, such overprotection endangers the client's human dignity, and tends to keep him from experiencing the risk-taking of ordinary life which is necessary for normal human growth and development (p. 195).

Promoting the dignity of risk is a challenging role for staff to adopt. Fears of liability and the overarching sense of responsibility alluded to by Todd (2000) often prohibit staff from maintaining an appropriate level of protection and assistance.

Concerns about the dignity of risk are challenging when applied to people who may need a higher level of protection, with an application of restraints and controls meant to promote a quality of life. Such is the case for many people who have Prader-Willi syndrome, a condition that likely involves an insatiable appetite that leads often to severe overeating and detrimental

health concerns and obesity. Holland and Wong (1999) have discussed the legal and ethical implications of imposing controls on the self-directed intake of food. The dilemma often lies in the assessment of capacity, being sure to apply only the right level of constraint. The 'least restrictive alternative' is advocated, that matters of choice and self-determination cannot be applied uncritically. There is an austere reality that people are not always capable of making independent choices in their lives. Impairments themselves can be disabling; as is the case when the application of control is considered inevitable for people with Prader-Willi syndrome.

Accepting the presence of impairment, a relational model of autonomy has been presented as a preferred method used by parents and caregivers to support children with Prader-Willi syndrome (Van Hooren et al., 2002). A strict dichotomy between the freedom to choose and paternalistic control is too simplistic for the provision of necessary supports. With this relational model, parents follow the practice of promoting self-understanding and self-development around the intake of food to supplant the inability to choose freely. According to Schloss, Alper and Jayne (1993), a preferential model to apply in such cases is a careful analysis of the risks and benefits inherent in the types of choices that get made. However, the application of this balancing procedure should be done in collaboration with the person seeking control of the environment as the goal of the process is to maximize self-determination. Although risk must at times be mediated by others, minimizing the extent to which this is done will help ensure the maintenance of autonomy.

Nonetheless, control over daily life often remains contingent on assessments of ability and external direction of a person's life continues when they are considered incapable of making decisions independently. For example, research has shown a relationship between adaptive behaviour and level of choice that suggests people with higher cognitive functioning are more

self-determined (Heller et al., 1999; Stancliffe & Abery, 1997). However, the current conceptualization of intellectual disability casts the person so labeled as incompetent and the pairing of impairment and incompetence disallows the opportunity to advocate and act as a causal agent in both daily life and the political arena. Is perceived incompetence due to the severity of impairment or other internal attributes, or do external factors play an inhibitory role? Research by Jenkinson and Nelms (1994) has shown that people with an intellectual impairment are less competent and likely to experience greater difficulty when making decisions than people without disabilities. When presented with vignettes of decision-making situations, many responses were described by Jenkinson and Nelms (1994) as defensive avoidant (e.g., deferring the decision to someone else, not considering pros and cons) or hyper vigilant (e.g., an immediate or impulsive decision without considering consequences), while few were described as vigilant (e.g., considering pros and cons, seeking additional information and making a choice that maximized benefits). However, the researchers were reluctant to attribute this lack of ability to cognitive impairment and proposed the following arguments. First, intellectually impaired adults are likely to have difficulty articulating a suitable answer when asked to explain the reasons why they made a decision. As a result, they may have been more likely to appear hyper vigilant. And second, Jenkinson and Nelms (1994) also indicate the probability that most people with intellectual impairments have little experience making decisions.

People with intellectual disabilities are disempowered by the types of services they receive and by the limitations imposed by their impairments. The expression of self-determination is much maligned and far below the standards expected and appreciated by most people. Thus far, self-determination has been defined as the ability to act with causal agency in accordance with one's own will without unnecessary external influence. But a review of support

services suggests people are denied opportunities to exert control because risk is managed by others, contingent on assessments of capacity. For a person with intellectual disabilities, an external locus of control is a common hurdle to self-determination and autonomy. Contemporary support services, although attempting to act in the best interest of their charge, appear to undermine self-determination through a mandate to protect, disallowing opportunities for autonomy to flourish.

Applying the Social Model of Disability to Self-Determination

The social model of disability (Oliver, 1990; UPIAS, 1976) shifts attention away from deficits in decision making ability and provides an explanation for the minimal opportunities available for expressing autonomy. This examination of the self-determination literature is augmented by the social model's separation of social barriers from incapacity and impairment. According to McClimens (2003), "the social model rests on a perceived disjunction between the personal and the social, where impairment is defined as a biological fact and disability is seen as a social form of oppression" (p. 36).

Impairment: Lacking part or all of a limb, or having a defective limb, organism or mechanism of the body; Disability: The disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities (UPIAS, 1976, pg. 3-4).

If so, disenfranchised autonomy can be regarded as a form of disability generated by societal responses to intellectual impairment. The segmentation of the literature into perspectives based on the individual, the environment and society, allows for an examination of potential barriers to self-determination; the social model of disability points to the environmental and societal obstacles that must be overcome and rejects the claim that people are disabled by their

impairments..

The social model directs attention to the fact that social attitudes about the human condition are damaging to the lives of people who have intellectual impairments. Coles (2001) suggests service provision methods informed by the social model of disability are more apt to empower people with intellectual disabilities to advocate on their own behalf. The social model influences service provision so that the individual is accepted the way they are, regardless of their impairment. The focus is removed from the individual's deficit and evaluations are instead made of the service provider's ability to facilitate environments and attitudes that allow the person being supported to act with agency and make choice.

A review of the literature about self-determination reveals a theoretical formulation that is similar in its organizational structure to Wolfensberger's (1972) theories of normalization. As I mentioned earlier, most research and theorizing about the self-determination of people with intellectual disabilities is concerned with the individual, the environment, and society. This breakdown fortuitously invites engagement with the social model of disability, allowing a critical evaluation of individual models of self-determination and exploration of the ways environments and attitudes need to change to enhance people's autonomy. In the following section I will use the social model of disability as a tool to dissect the self-determination literature, highlighting the strengths and critiquing the weaknesses.

Shaping the Individual to Be Self-Determined

According to the popular conceptualization of self-determination, there are four essential behavioural characteristics that empower a person to act with causal agency (Wehmeyer, 1999). The first characteristic has been termed behavioural autonomy, defined simply as acting

independently in accordance with one's own preferences without being coerced by external influences. Second, self-regulated behaviour is considered to be the ability to set goals and monitor or evaluate the progress of achieving those goals. Problem-solving, decision-making and learning from experience are critical aspects of this dimension. A third component is psychological empowerment, a dispositional characteristic that describes an internal locus of control, confidence in one's ability and the motivation to act. The fourth and final characteristic of self-determination postulated by Wehmeyer (1999) is self-realization. This trait stems from Maslow's (1943) theory of self-actualization and refers to the ability to understand and know oneself and one's abilities. Research by Wehmeyer, Kelchner and Richards (1996) has helped to validate this model of self-determination by measuring the personal characteristics of people with intellectual impairments and comparing their scores to measures of self-determination and autonomous functioning. Although the population they chose to study did not exemplify a high level of self-determination, those thought to be more autonomous also scored higher on measures of the characteristics listed above.

Controlled choice: A critique of behavioural psychology

The choice-making opportunities available to people with intellectual disabilities have been a central component of behavioural psychology. However, there are elements of this perspective that can be considered harmful to the overall ability of people with intellectual disabilities to have control over their own lives. Although psychologists have demonstrated an inclination towards increasing opportunities to make choices, self-determination remains inhibited as behavioural intervention strategies often only include choice as a method for reducing maladaptive or challenging behaviours.

Bannerman, Sheldon, Sherman, and Harchik (1990) published an article in the *Journal of*

Applied Behavior Analysis that examined the advantages and disadvantages of allowing people with intellectual disabilities the opportunity to choose and refuse participation in daily activities. The authors challenged the common practice in behavioural psychology of determining people's daily schedules and regulating their access to preferred activities and argued that people would engage in less challenging behaviour if they had a higher level of control in their life. The argument considered the moral and legal issues concerned with risk and concluded that "all people have the right to eat too many doughnuts and take a nap" (86). The magnitude of this conclusion is remarkable because it highlights the audacity of others to assume the right to limit people's autonomy without just cause.

According to a literature review completed by Kern et al. (1998), research on choice has been focused on increasing choice-making opportunities, assessing preferences and using choice as an element of behavioural intervention. While the first two practices can actually be considered helpful and rather benign as inhibitors of choice, the third practice represents a barrier for people with intellectual impairments to be autonomous. For example, applied behaviour analysis (ABA) (see Martin & Pear, 2003) is a method for reducing inappropriate behaviours so they can be replaced by more adaptive or acceptable behaviours. A functional analysis of a given behaviour is intended to discern possible reinforcers in the environment that maintain a negative behaviour so that the reinforcement can be controlled – i.e., awarded only when the adaptive or acceptable behaviour is performed. In effect, practices such as ABA use choice as a controlled reinforcer in order to modify the presentation of inappropriate behaviours. Choice and autonomy are controlled, commandeered by professionals performing experiments. This process devalues people with intellectual impairments and does not actually promote self-determination.

Despite this negative evaluation of behavioural psychology, a constructive and

appropriate approach within this field is gaining wider acceptance: positive behaviour support (PBS). According to Clark et al. (2004), problem behaviours often reflect an attempt to communicate choices or preferences or may occur as an effort to exert control over the environment. Therefore, instead of punishing the behaviour, PBS approaches the situation by understanding the communicative function of the challenging behaviour to reinforce the acquisition of an alternative means to communicate or exert control. According to Brown et al., (1998), important components of PBS include building skills in an inclusive setting, analyzing the communicative function of problem behaviour, using systematic approaches such as pictorial schedules to teach or facilitate communication skills, assessing and modify ecological factors and allowing the person to control the flow of daily events. A recent meta-analysis completed by Shogren et al. (2004) revealed studies using a functional analysis to design choice interventions did not significantly decrease problem behaviours. Instead, it appeared that assisting people to make lifestyle changes that maximize choice over the long term is a more effective means for reducing negative behaviours.

Promoting Causal Agency with Education

Wehmeyer and Schwartz (1997) have conducted a longitudinal study that shows intellectually impaired youth who display self-determined behaviour in a school setting are more likely to achieve a positive outcome in adulthood. Hence, they advocate for the use of educational programs that teach self-determination. Using a model based on student-directed education, Wehmeyer and Schwartz (1997) contend the acquisition of the following skills will increase self-determination and improve the likelihood of more positive outcomes in adulthood: choice making, decision making, problem-solving, goal setting and attainment, self-observation skills, self-evaluation skills, self-reinforcement skills, internal locus of control, positive

attributions of efficacy and outcome expectancy, self-awareness and self-knowledge. Wehmeyer et al. (2000) later field-tested a program for the promotion of these attributes. The program consists of three phases, each presenting a problem to be solved by the student with an outlined sequence for problem solving. In essence, the three phases see the student supported through a process of developing goals to work towards, developing a plan of action to meet the goal and a process evaluating progress and making any necessary adjustments to either the action plan or goal, as needed. This process is facilitated by the teacher with clear objectives and guiding questions such as, "What can I do to learn what I don't know?" Field testing of the program has indicated that most students achieve the educational objective and develop the attributes necessary for self-determination.

Field and Hoffman (2002) have identified a number of quality indicators by which to evaluate educational programs that promote self-determination. Based on their evaluations, participation, choice and risk are all important elements. For example, they recognize the importance of ensuring that staff, students and parents all participate in the development of programming with the promotion of choice at all available opportunities (i.e., the selection of courses, choosing the method to complete assignments). They also suggest students be provided with appropriate opportunities to take risks. And finally, they suggest self-determination skills and attitudes be represented not only in the curriculum but in family support programs, as well as in staff development opportunities.

Environmental Influences on Self-Determination

According to Stancliffe and Wehmeyer (1995), a lack of choice making opportunities is not the result of an intellectual impairment but instead factors associated with the setting in

which people live. To bolster this argument, Wehmeyer and Garner (2003) have more recently suggested that people with severe impairments have less decision-making ability because they are more likely to reside in a restrictive setting. This rationale meets the theoretical influence of the social model of disability and I suggest it represents recognition that identifying and improving upon a person's faults is not the answer to increased self-determination.

According to Stancliffe (2001), the ecological perspective of self-determination contends that there are certain environmental situations better suited for the promotion of self-determination. For example, during a process of deinstitutionalization, Stancliffe and Abery (1997) compared movers and stayers in a longitudinal study of 3-years. Although choices remained low for both groups, they found that those who had moved to the community experienced significantly more choices in life than those who stayed at the end of that 3-year period. In addition, although severity of impairment predicted less opportunity for choice, all people benefited equally from deinstitutionalization (or suffered equally from continued institutionalization). As people continue to move out of institutions and into the community, additional research suggests opportunities to make choices are better facilitated in a residence of smaller size that feature longer periods of time with no staff present (Stancliffe, 1997).

According to Heller et al. (1999), this concomitance between smaller residence size and increased involvement in decision making has also been associated with greater levels of community integration. In addition, Stancliffe, Abery and Smith (2000) have recently shown that people who live semi-independently have the best self-determination skills, possessing attitudes and knowledge that better facilitate choice. In these settings, Stancliffe et al. (2000) found the atmosphere was more conducive to individualization and to consumer and staff autonomy; staff members were more skilled and provided fewer hours of support per resident;

and residents had more money available for discretionary spending. Residents of this setting had a greater degree of personal control.

According to Wehmeyer and Bolding (1999), people living or working in community based settings versus non-community based settings, matched by intelligence, age and gender, are also more self-determined, have higher levels of autonomy, make more choices and are more satisfied with their lifestyle. After interviewing a group of people 6 months before and after moving from a restrictive work or living environment, Wehmeyer and Bolding (2001) concluded that congregate living or work situations limit opportunities for choice and decision making while normalized, community-based environments support and enhance self-determination. Research in Norwegian facilities by Tøssebro (1995) has supported this contention as the quality of life benefits obtained from a smaller residence only occur for living units of less than five people. It appears that reducing the population of an institution does not increase choice but moving into the community does.

Societal Influences on Self-Determination

Just as Wolfensberger (1972) indicated a need to promote normalization at the level of societal systems that shape cultural values, attitudes and stereotypes, Stancliffe (2001) points to the existence of a socio-political perspective of self-determination. At this level, self-determination assumes four main principles: the freedom to choose who to live with, place of residence, and how to spend one's time; authority to control the money used for support services; individualized supports based on a person's needs and desires; and responsibility for the use of resources and making a contribution to the community. These principles are encapsulated in two political movements generated by the disability community, known as the Independent Living

Movement and Self-Advocacy Movements. Within a context of support, a self-advocate is better able and more prepared to challenge disabling social norms and attitudes and take control of their own lives.

The Independent Living Movement

The Independent Living Movement has its roots in the practical application of the social model of disability, sharing the premise that people are disabled by barriers in the environment rather than their impairments (DeJong, 1979). Reviewed in an article by DeJong and Batavia (1992), the movement classifies the disabled or impaired individual as a “self-directed consumer” of the resources and services needed to participate in society. Within this framework, the person with a disability is not a recipient of care and is considered capable of managing their own life. Self-determination is expressed to a high degree, as the person with the disability is in control of the services they receive. Services are not controlled by an external agency and the person has greater levels of decision-making capacity in everyday life.

The opportunity to manage personal assistance is not very common for Canadians with an intellectual disability, but Askheim (2003) suggests the ability to exercise this right is more common in Britain under the direct payments system. There, a greater appreciation exists for the person’s right to exercise self-determination and often people with intellectual disabilities are better enabled to “gain confidence, control and new skills” (p. 326). However, the management of personal assistance is often completed by someone other than the user, with the task usually taken by a parent (Askheim, 2003). In this scenario, the person with an intellectual disability does not have direct control over their support services, but are much better able to direct the course of their daily life. According to Caldwell and Heller (2003), people with intellectual disabilities are also much more involved in their communities when their families assist them in

controlling the support services and personal assistance they receive. In most cases, families tend to hire neighbours, friends and other family members much to the benefit of the person needing support.

The Self-Advocacy Movement

The opportunity to follow the doctrine of the Independent Living Movement is limited to people with intellectual disabilities and other people are often in charge of allocating opportunities to act with self-determination. A prominent alternative for the expression of self-determination in society is the self-advocacy movement. Organizing as a group of self-advocates allows for increased independence from service providers and professionals (Goodley, 2005) and promotes opportunities to disengage from the passive role that society assigns to people with intellectual disabilities (Goodley, 1998). Just as the independent living model represents a practical and political extension of the social model for people with physical disabilities, the self-advocacy movement represents the same for people with intellectual disabilities. In consideration of the ways that people with intellectual disabilities are supported within a self-advocacy framework, Goodley (1998) also emphasizes the importance of support models that are grounded in the social model of disability. The role of the support provider is to promote and maintain the abilities of people with intellectual disabilities to allow them opportunities to advocate on their own behalf.

And just as the physically impaired people developing the social model were able to create a redefinition of disability, Chappel, Goodley and Lawthorn (2001) suggest that self-advocacy groups representing people with intellectual disabilities be empowered to create their own identity, as well. According to Goodley (2001), social theorists of disability must incorporate the collective activism of people with an intellectual disability in the social model.

To all intents and purposes, engagement with self-advocacy groups is the best method to understand social theorizing about intellectual disabilities because they represent a culturally rich environment (Goodley, Armstrong, Sutherland & Laurie, 2003).

The Role of Families

To protect a person's rights, decision making power is often granted to a surrogate or proxy, a person granted the title substitute decision-maker (SDM). According to research by Stancliffe, Abery, Springborg and Elkin (2000), people who do not have an SDM exercise more control in their lives. However, those who have a proxy with limited control over decisions display similar levels of control, implying that restrictive SDM status inappropriately applied to a competent person is likely to constrain levels of personal control. It is recommended that SDM status be reviewed regularly to ensure it does not infringe on a person's decision making-capacity. Field and Hoffman (1999) suggest family members should instead be involved in activities that promote self-determination. This involves teaching and modeling the characteristics of autonomy put forward by Wehmeyer (1998) which include behavioural autonomy, self-regulation, psychological empowerment and self-realization. The role of the family, then, would be limited to augmenting and promoting self-determination – acting as a guide towards outcomes rather than controlling the person's choices and decisions.

Recognition of the Individual and their Impairments

A growing focus on the social aspects of disability has helped create a more inclusive social order that fosters greater participation for people with disabilities. The ability of a person to act with autonomy and express causal agency is augmented by making changes to the environment and fostering self-determination in society and politics skills. A large portion of the

research about self-determination and people with intellectual disabilities looks beyond their abilities and explores the disabling components found in environmental and societal attitudes. This tradition is a derivative of the social model of disability and relocates the barriers to self-determination outside of the person, looking instead at the people and places surrounding them. The social model provides a critical evaluation of the medical model's treatment of the individual and their impairments but risks abandoning the topic to the detriment of people with disabilities. Ongoing development of the social model has recognized this result and attention is returning to the individual with recognition that impairment is real and cannot be ignored. With that, attention will now turn to recent progress in the development of the social model.

A Social Model with Impairments: An Alternate Approach to Self-Determination

The social model of disability has brought increased awareness to the environmental and societal sources of disability and helped social theorists recognize the problems inherent with attempting to ameliorate impairment. A comprehensive review of the self-determination literature has reflected this division. But there are critics of the social model that challenge the outright denial of impairment as a contributing factor in the experience of disability (e.g., Goodley et al., 2003). Disability and impairment have traditionally been separated within the social model and this is often considered a fundamental problem and shortcoming that must be addressed (Hughes & Paterson, 1997). While critics recognize that the social model must maintain a united front to encourage wider acceptance of the model (Shakespeare & Watson, 1997), it is becoming increasingly apparent that it needs to consider the role of impairment and personal experience associated with being disabled. "Impairment is part of our daily personal experience, and cannot be ignored in our social theory or our political strategy... We are not just

disabled people, we are also people with impairments, and to pretend otherwise is to ignore a major part of our biographies” (Shakespeare & Watson, 2002, p. 11). Impairment is real; people are disabled not only by society but by their impairments as well. Ignoring this calls social theories of disability into question. There is no longer the same political impetus for ignoring this factor (Shakespeare & Watson, 1997). The focus has shifted to the environment and society as the original social model intended. Allowing discourse and social theory to also incorporate impairment will help create a richer understanding of the experience of disabled people.

Goodley (2001) urges the acceptance of impairment as a primary (or at least a significant) basis for the disablement of all disabled people, be it intellectual or physical in nature. Without doing so, he warns that we risk leaving the treatment of disability in the hands of professionals guided by the medical model. Accepting the role of impairment in social theory can influence the work of professionals focused on improving the condition of those with impairments. If disability is placed firmly in the realm of society, the medical model may continue as dominant with the social model viewed critically. For example, Dewsbury et al. (2004) have discussed the challenges of putting the social model into practice in the design of assistive technologies for people with impairments. They depict the model as “radical sociology” and downplay its strength as a meaningful and useful theoretical construct. Undermining the ‘experts’ that deal with impairment will encourage neither acceptance of the social model, nor a greater understanding of the experience of disabled people. As Dewsbury et al. (2004) assert, “the problem of design rests not on theoretical notions of how we define disability, but on ensuring the needs of the person are translated into appropriate design that should be empowering to the user” (p. 155). And there is some merit in this statement – impairments can and should be addressed for the purpose of empowerment. But without a social model that incorporates

impairment, this process (as Dewsbury et al. reveals above) may not incorporate a full understanding of disability because it is incomplete and disconnected from the social aspects of impairment.

The Social Model and Intellectual Disability

For people with intellectual disabilities, it is the contention of many theorists that the social model is an inadequate paradigm to guide research and practice (McClimens, 2003; Goodley, 2001; Goodley & Rapley, 2001; Rapley, 2004). More thought to the actual limitations of intellectual impairment is necessary to alleviate the social barriers faced by people with an intellectual disability. The social model may not be able to adequately absolve the role of an intellectual impairment when its severity is a major influence in the capacity to make decisions and participate in society – we are “[forced] to consider how some conditions cannot be ameliorated by rearrangement of the social furniture or even alteration of the conceptual landscape” (McClimens, 2003, p. 37). If an accessible entrance grants more participation in society for people with physical impairments, what alterations are needed to ensure access is available for people disabled by an intellectual impairment? Developed through the political and social agenda of people with physical impairments, McClimens (2003) argues that people with intellectual impairments exist as a subset of the disability movement and some issues are at risk of being incorrectly addressed under this model – “within this dilemma people with intellectual disabilities remain adrift from the tides that drive theoretical work” (p. 43). Rapley (2004) suggests the issue of intellectual impairment is tagged on as an afterthought within the social model. Both the medical model and the social model attempt to encapsulate the global experience of people with disabilities when the groups of people being treated by these

theoretical frameworks are too complex to be compartmentalized (Rapley, 2004).

A social model of disability relevant to people with intellectual disabilities accepts and considers the role of impairment. According to Goodley (2001) we should “reconsider the epistemological orientation of the social model of disability, wherein impairment is considered as equally social as disability and therefore includes people with learning ‘difficulties’” (p. 201). Awareness and understanding of intellectual impairment goes beyond the expression of individual pathology when it is recognized in terms of interactions and influences in the propagation of social norms. A deficit in intellectual functioning is not just an attribute to be diagnosed, but a quality that helps shape the personality expressed by the person (Rapley, 2004) and the relationships they develop with others. Marking out a role for impairment, Goodley (2001) invites consideration of the social milieu surrounding people with intellectual disabilities. This involves examining the social, historical and political components of the diagnostic criteria used to define intellectual impairment and locates impairment in the social and personal narratives of people with intellectual impairments.

The Interdependence of Self-Determination

Attempting to surpass Shakespeare and Watson’s (2002) critical stance on the separation of impairment and disability, Hughes (2007) has recently shifted focus to “the existential landscape of non-disability” (p. 680). While attempts are being made to enhance the social model to ensure all people with impairments are adequately represented in theoretical concepts of disability, Hughes (2007) reminds us that the ontological backbone of the non-disabled world, “where there is no room for difference and diversity” (p. 682) contributes to the creation of disabling environments. A substantial component of western ideology is the notion of

independence. For example, Reindal (1999) attributes modern conventional views about personal autonomy and self-determination to ideas drawn from Enlightenment philosophy. Citing Corbett (1989), independence is equated “with the ability to do things without help or assistance, such as cooking, washing, dressing, toileting, making the bed, writing, speaking and so forth. However, real independence has nothing to do with cooking, cleaning and dressing oneself” (Reindal, 1999, p. 353). What we are experiencing at present is an independence-dependence dichotomy, where the former is cast as the human ideal - the latter, a devalued state to be avoided or put right. Carnaby (1998) discusses the practical application of an interdependent support model for people with intellectual disabilities and recommends increased recognition of the relationships between people with and without disabilities.

Dependency is integral to human life (Kittay, 2002) and we are wrong to think of self-determination as an action carried out by an independent person; it is incorrect to regard self-determined behaviour as acting without assistance from others. Considering the numerous misinterpretations of the concept of self-determination Wehmeyer (1998) discusses the faults inherent in casting self-determination as independent action and having complete control. Having an intellectual impairment requires supports from other people and self-determination is manufactured through interdependence within the context of a support user and provider relationship. Within this relationship, the person with an intellectual disability has control and makes decisions without being coerced or influenced by the support provider. This means that self-determination does not require self-sufficiency, but the ability to act as a causal agent with support from others. Beyond the simple matter of making choices throughout the day, self-determination for people with intellectual disabilities requires active participation from a support provider that maximizes one’s control over the environment. What follows is an application of

feminist ideas about providing care to help put together a framework that encompasses an interdependent expression of self-determination.

Exploring and validating the personhood of people with intellectual disabilities, Kittay (2001a) demonstrates the value of relationships in considering independence. We all exist in an interdependent environment with assistance from others and guidance from peers. But claiming rationality as the integral component of personhood disallows membership in human society. People with intellectual disabilities are denied opportunities to express their human rights of free will and choice because they are not independent, rational and self-sufficient - attributes that commonly define human ability. But as Kittay (2001b) so eloquently puts, "being a person has little to do with rationality and everything to do with relationships... My daughter is a person. She is, after all, my daughter. How can she be anything but a person?" (p. 568). This redefinition of personhood values the person with an intellectual disability and recognizes their right to self-determination in the context of relationships formed with others.

Intellectual impairment produces dependency on others; the extent to which defined by the severity of impairment. And while the traditional social model of disability does not accept the causative role of impairment in shaping the presentation of a person's disability, we are free to do so in a social model of impairment that accepts "relations of dependencies" (Kittay, 2001b, p. 570). Self-determination and choice are not functions of an independent person, but the product of interdependence where a person interacts with others to express their will and act as causal agents in a cooperative manner. "In acknowledging dependency we respect the fact that as individuals our dependency relations are constitutive of who we are and that, as a society, we are inextricably dependent on one another" (Kittay, 2001b, p. 570)

To further extrapolate this representation of self-determination, Goodley and Rapley

(2001) argue that we should rethink competency within an interdependent framework. Working with a network of others, the person labeled with an intellectual disability is more capable than otherwise considered. According to Bach (1998), exclusion from self-determination occurs because it is a skills-based conception rather than rights-based. “As long as self-determination is seen as a skill... it will be left up to the researchers, psychometrists, and service providers to determine when people reach the threshold of skill to recover their citizenship” (p. 1).

Acknowledging that people with intellectual disabilities have a right to self-determination regardless of their skill-level disallows a gate-keeper system and changes the focus to ways to augment a person’s skill set to ensure their will is expressed. To achieve this end, Bach (1998) feels that it is necessary to employ both individualized funding and individualized support provision, returning the discussion to socio-political elements of self-determination.

Interdependence Theory

Interdependence theory is a conceptual framework that helps analyze interpersonal situations. An integral aspect of this theory is, termed the “mutuality of dependence,” is articulated by Rusbult and Van Lange (2003). According to their review of the literature,

The concepts of dependence and power are inextricably related, in that to the extent that one person is relatively more dependent, the partner is relatively more powerful. The vulnerability deriving from high dependence (and the power deriving from low dependence) is exacerbated to the extent that dependence is nonmutual (p. 355).

Although this literature was not written to address the population being studied in this project, it applies to the potential power inequalities that exist in interactions between people with intellectual disabilities and the staff supporting them.

Partnerships in Self-Determination

Independent living and self-advocacy, the ultimate expressions of self-determination, are facilitated through interdependent networks of people. Even at the socio-political stage self-determination is influenced and driven by relationships. Here we move away from the ‘personal tragedy’ representation of intellectual disability and empower people through recognition of their abilities and acknowledging and validating their support network. In research by Goodley (1998), a social model of staff support in self-advocacy groups recognizes people’s abilities, validates and addresses their concerns and does not assign a role for the professional. Significant value is placed on interdependence in this article as “paternalistic notions of ‘empowering’ people” (p. 445) are put aside for a practice built on relationships. For self-determination to be present in a social and political context, support provision from others must bolster the voice of people with intellectual disabilities; recognizing that staff are only to act as advisors. Similarly, the independent living movement for people with intellectual disabilities must define a role for the support provider.

Self-determination can also be achieved for people with intellectual disabilities through the ideology and practice of person-centred planning. According to Westgate and Blessing (2005), this process takes into consideration the capacity of the person in order to link them to the community and promote the realization of personal goals and dreams. Sanderson (2000) provides a thorough outline of many of the key features of person-centred planning. Most notably, the locus of power is shifted to the person with an intellectual disability, ensuring an appropriate balance is created between the person and important stakeholders in their social network. As a result, an interdependent context is developed where self-determination and decision making opportunities are situated in a network of friend and families. Plans developed

in this process are meant to reflect what is important to the person, focusing not on their deficits but on what is possible given their capabilities. According to O'Brien and O'Brien (2000), the practice of person-centred planning in community-based support networks increases the availability of choice, takes the emphasis off "de-personalizing labels," respects the voice of the person with an intellectual disability and the people that know them best, builds relationships and encourages community agencies to provide individualized services based on high expectations.

A very common person-centred practice used by people with intellectual disabilities and their support networks is called Planning Alternative Tomorrows with Hope, abbreviated as PATH (Pearpoint, O'Brien & Forest, 1993). PATH provides a method to lead people towards the realization of their dreams by developing possible goals and identifying strategies to achieve them (Sanderson, 2000). It is a very visual format for planning that pairs discussion with illustrations, facilitating increased participation by the person at the centre of the dialogue.

Feminist Ethics of Care

According to Watson, McKie, Hughes, Hopkins and Gregory (2004), common notions of care are disempowering for people receiving assistance because they are commonly viewed as passive and dependent recipients as opposed to consumers of services. The authors recognize the need to build in the notion of interdependence across the lifespan in order to create an emancipatory model of care that bridges the gap between the independence promoted by the social model of disability and feminist perspectives of care. According to Morris (1997), for example, independence is not necessarily a matter of being able to accomplish tasks on your own, but having control over how help is provided. Providing care may be helping another person, but self-determination cannot be achieved if the provision of care places the recipient in a

dependent role. Having a disability and requiring assistance from others often means that self-determination must be realized through relationships with others. According to Sprague and Hayes (2000), empowerment for people with disabilities is a characteristic of the relationship developed between the recipient and provider of care. In essence, a level of equality must be reached between the two parties that allows for the development of identity and self-direction. Empowering relationships are based on mutual respect and trust, with no hierarchical delineations that put the control of choice in the hands of the support providers. Instead, self-determination becomes an expression of the relationship; with the will of the person being supported communicated “through [the] dialogue and careful listening that occurs in a relationship” (Sprague and Hayes, 2000, p. 684), empathy and understanding, and the celebration and recognition of difference. This perspective is a product of a growing feminist literature on the aspect of caring.

Relationships with Paid Support Providers

Using interdependence to understand the expression of self-determination means an examination of the social network available to people with intellectual disabilities. Self-determination is limited to people with deficits in intellectual functioning and the cause of, and need for, change can be found amongst the interdependent relationships formed with support providers. For example, Skar and Tamm (2001) examined the relationships that children and adolescents develop with their assistants because of the importance of their presence when it comes to enabling the child to participate in the community. The support provider for adults with intellectual disabilities, although assuming a much different role, is charged with the same level of responsibility for enabling self-determination. It is within this relationship that many

important aspects of self-determination are expressed.

According to Renblad (2002), the social networks of people with an intellectual disability are limited primarily to the staff supporting them. In fact, Schalock and Genung (1993) suggest that support workers are often considered to be the most frequent and long lasting relationship partners available and are most often the ones who facilitate the availability of social interactions. Robertson et al. (2001) recently collected information about the social networks of people with 'mental retardation' and found that 83% of their sample included a staff member in the composition of their social network. This proportion was greater than family members at 72% and other people with 'mental retardation' at 54%. Outside of paid support providers, the median size of all social networks was only 2 people.

Unfortunately, there often exists an imbalance of power as support providers retain the power that a person would normally have in exerting influence over one's life (Renblad, 2002). However, Bambara et al. (1998) have provided some valuable insight by outlining four essential components of enhancing self-determination. First, it is imperative that support providers get to know the person well so that preferences and methods of communication can be better understood. If self-determination is to occur within an interdependent context, people with intellectual impairments must be comfortable with their support providers and establish a relational trust. An option rich lifestyle is also encouraged so that decisions can get made without excessive staff involvement. This involves making necessary adaptations to the household so that tasks can be completed independently with minimal assistance from others. A third component is the promotion of daily living skills, communication ability and assertiveness rather than passivity or aggression. And finally, Bambara et al. (1998) suggest the creation of supportive contexts where staff roles are reduced to being a facilitator of decisions made by the

person. With the role of the support provider defined in this manner, power is shifted back to the person requiring assistance and balance is restored to the relationship.

Intellectual impairment limits a person's ability to make meaningful choices and dictates the level of assistance engendered from support providers. We know this to be true. But these limitations are not fixed and do not remain static. Self-determination and causal agency are expressed in an interdependent context through relationship – acting independently does not necessarily constitute self-determined behaviour. In fact, the relationship with a support provider is integral to both the form and expression of self-determination. In today's world, having an intellectual impairment often requires the presence of another person who facilitates and assists with many aspects of daily living. Amidst these 'dependency relations' are choice and autonomy, expressed as a function of the relationship. The social model of disability situates barriers to self-determination in the environment surrounding the person with an intellectual disability. Paying attention to the social aspects of impairment, support providers become inextricably tied to the expression of self determination. The will of a person, when they are at the centre of a network of people, is expressed through the relationships they develop with others. And given the predominance of paid support providers in the lives of people with intellectual disabilities, it stands to reason that self-determination can be better understood as a function of supportive relationships.

Gaps in the Literature

For people who have been labeled as having an intellectual disability, there is both limited opportunity and limited ability to express self-determination. A major gap in the literature is the misattribution of concepts like autonomy and independence to the expression of

self-determination. No person is independent of the social norms that surround them, and the ability to act in accordance with one's will is expressed through and mediated by a social milieu. The decisions that get made and the types of choices available to people with an intellectual disability are influenced and shaped by the social norms driving support services. Claiming that people with an intellectual disability are not independent has very little bearing on whether or not they are able to act with causal agency. Promoting independence is inappropriate when relationships are the medium through which self-determination is expressed. Attention needs to be turned to the theoretical development of a means of support that maximizes autonomy and supports self-determination.

A second gap in the literature is evidenced by the application of the traditional social model of disability to the circumstances of people with intellectual disability. Support services established in the community have improved circumstances for people living with roommates and paid staff. However, it is evident that they have also not adequately addressed the fact that intellectual impairment presents limitations that influence the expression of autonomy. Making informed decisions is an action still requiring assistance from others. Those adhering to the social model of disability have sought to ignore impairment, locating disabling factors outside of the person. But a significant recognition of impairment is mounting in the literature concerned with intellectual disability. To develop a support service that facilitates autonomy, the social aspects of impairment must be explored. This involves a study of interactions and relationships.

Unfortunately, a major limitation in the study of self-determination has been an insufficient connection with current thinking about relationships and interdependence. People are interdependent and autonomy is influenced by and expressed through relationships with others. Formulating the concept in this manner is empowering because autonomy is not

dependent upon intellectual capacity. If decisions are made on a daily basis amidst supportive relationships, self-determination is instead contingent only on the type and degree of support required. To achieve maximal levels of self-determination, then, attention must be focused on understanding and enhancing the relationships developed between people with intellectual disabilities and their support staff. This study is a preliminary exploration of the way that self-determination is expressed amidst these relationships.

Chapter Three: Methodology

This research project is designed to elicit an enhanced understanding of the relationships between people with intellectual disabilities and their paid support staff. It is within and through this interdependent support network that decisions are made and autonomy is expressed. I have uncovered defining characteristics of the relationship influencing the expression of self-determination and identified the perspectives of people receiving supports regarding self-determination and the perceived role of the support provider in relation to decision-making opportunities and autonomy. Using a qualitative research design, a critical evaluation of the social model of disability has been used to collect and interpret the data.

Sample

A small sample of two relationship groups was recruited to elicit rich data about a select few people. Relationship groups were comprised of a person with an intellectual disability and the support provider(s) that assists them. The participants chosen for the study were receiving residential services from agencies in Winnipeg providing paid support from their staff. The support providers were chosen by the people with intellectual disabilities participating in the study. The first relationship group was comprised of a woman in her mid thirties, and she asked the manager of her support team to participate. The second relationship group consisted of a man in his mid thirties and he asked both the manager and one of his preferred staff to participate. Although the initial aim was to recruit a dyad, I followed the request of the participant to include both staff. This fortunately enriched the data and provided more perspectives to explore.

Site and Access

To recruit participants for this study, I distributed 'invitation to participate' posters to three sources that outlined the general objectives of the research, criteria for participant selection and my contact information. Two organizations were contacted, the local chapter of People First of Canada and Community Living – Winnipeg, as well as a colleague with strong connections to people with intellectual disabilities in the community. Once two people were recruited to participate in the study, I asked them to recruit a staff member that supports them at home to participate in the study, as well. Once support providers were identified, I made arrangements to begin data collection and provided all participants with information about the study. Initial interviews were conducted at the public library and a coffee shop, and subsequent interviews followed at the participants' homes.

In-Depth Interviewing

I conducted open-ended in-depth interviews with the sample chosen for this study. For each relationship group, I completed a total of three interviews; individual interviews with each person requiring the support of staff, the staff they chose to participate and then both the person and their staff together. The two staff recruited in relationship group two were interviewed together for each interview requiring staff participation. Interviews were audio-recorded and transcribed, and I kept an interview journal as suggested by Taylor and Bogdan (1998) to capture my thoughts and ideas through the interview process. Although the format of the interview was open-ended and non-structured, I prepared an interview guide in advance with an outline of key areas of interest and possible descriptive and substantive concepts to explore. Using this interview guide to keep the interview focused, I also used probes for more details when needed.

In essence, I tried to adhere to the following instructions provided for interviewing provided by Taylor and Bogdan (1998):

Ask open-ended, descriptive questions about general topics; wait for people to talk about meaningful experiences in their lives or what is important from their points of view; probe for details and specific descriptions of their experiences and perspectives (p. 106).

Once interviews were completed and transcribed, I again contacted the participants to review my results. They reported to me that my interpretation of the interviews was accurate and asked to participate in the defense of thesis. This request was considered an honour and participants have been invited to participate in the process.

Data Analysis

As articulated by Taylor and Bogdan (1998), the data produced by this qualitative research design illustrates the emergence of themes and concepts, allowing for the development of substantive and formal theory. According to Glaser and Strauss (1967), “in discovering theory, one generates conceptual categories or their properties from evidence; then the evidence from which the category emerged is used to illustrate the concept” (p. 23). The data generated by this project has been organized and understood according to the process often referred to as grounded theory (Glaser & Straus, 1967). As expressed by Creswell (1998), a grounded theory study aims to generate or discover theory based on data drawn from a particular situation.

Constant Comparison Method

Concepts and categories were identified by analyzing the similarities and differences found in the data and I compared them with each other during and after the process of data collection. This method of constant comparison (Glaser & Strauss, 1967) remained ongoing throughout the study. To extract meaning from the data, I also used a coding strategy known as

“open coding,” by segmenting the data into areas of most importance. Following the example of Taylor and Bogdan (1998), a symbol was used for coding categories and segmenting all interview transcripts and field notes according to their membership in each category. I then used the cut and paste function of the word processor and re-organized the data into substantive categories in a perfunctory manner before I finished the process of interpretation.

Journal Writing

Throughout the course of this study, I kept a journal to help make sense of the data as it was collected – a method termed analytic memo writing (Glaser & Strauss, 1967; Maxwell, 1995; Taylor & Bogdan, 1998). This process assisted in the explication of meaning from the concepts emerging from the data and the properties and categories used to organize them. In an ongoing fashion, I wrote about possible theoretical explanations of what I was learning during data collection and analysis.

Validity Issues

According to Maxwell (2005), two validity threats associated with qualitative research are researcher bias and reactivity. Rather than eliminate these threats, I acknowledged their influence on the data and considered them necessary components of the research design. The lens through which I conduct this research has been acknowledged through elucidation of my own theories and beliefs and the goals and aspirations I hold for this project. As articulated in Schram’s (2003) concept of “engaged subjectivity,” I attempted to make the most of my involvement in the research by exploring my own reactions to the incidents of data uncovered during data collection and analysis. Schram (2003) also deals with the issue of “selective experience” with the resolution that the researcher decides what constitutes meaningful data throughout the whole process of data collection. In this project, the emergence and recognition

of substantive themes in the data has been driven by the grounded theory method backed by Glaser and Strauss (1967). As for my influence on the participants in the study, Maxwell (2005) again posits that attempts to minimize this factor are less important than attempting to understand how my influence bears on the production of data. Furthermore is the recognition that a researcher's interaction with participants may only uncover an approximation of what is happening in total (Schram, 2003).

This research design has also built in fundamental validity checks recommended by Maxwell (2005). First, I used a process of respondent validation to ensure that substantive theories generated by the data were confirmed by participants in the study. Together, we reviewed the results and I secured their agreement and approval of conclusions drawn from the interviews. Second, I used strategies suggested by Taylor and Bogdan (1998) to search for discrepant evidence emerging from the data. This was an ongoing process.

Chapter Four: Results

Interview data collected from both relationship groups have been organized according to the research questions guiding the analysis. The areas where decisions are made in a collaborative manner among the participants in each relationship group, identified as decision making domains, were established to answer the first research question. Self-determination is expressed in and through relationships with paid support providers and these domains capture the primary instances where the relationship partners work together to establish autonomy for the person being supported. Interview results also produced information about the processes of decision making. Further development and exploration of the decision making domains helped uncover processes followed by the two relationship groups as they work together to express the supported person's self-determination. The second research question was intended to uncover important aspects of the relationship that influence the domains and processes of decision making. In what follows, friendship and reciprocity are revealed as the important relationship elements of both groups informing the decision making process. Results will be presented separately for each relationship group, although a similar format will be utilized for each. Decision making domains and processes, as well as important relationship elements, will be outlined in each section.

Relationship Group One

The first relationship group consisted of a woman in her mid thirties and a staff person that she has known for 16-years who also supervises her support team. What follows is an illustrative account of these two people and what they told me about themselves. I will begin with the person being supported, move on to her chosen support staff and reveal important elements of the relationship they have built. Results will then focus on the two research questions by outlining and describing key decision making domains, exploring important decision making processes adhered to by the two women and identifying the important aspects of their relationship that determine the way they make decisions in a collaborative manner.

Person Being Supported

We started our discussion with an exploration of some her favourite things and she told me, “I like spaghetti... And I like horror movies... scary movies..., shopping and socials.” Participation in these events, from the collaborative preparation of meals to a sociable night on the town, was presented to me as opportunities to spend time with favourite staff. “Friends come on weekends,” but it was evident that staff are an important element of her social network. She enjoys the time she spends together with them and indicated that she feels empowered by the activities they do together. On Saturday, for example, staff “checks on us and we play cards... War. And I’m good at Yahtzee. One time I rolled a dice once... I rolled it once... got a Yahtzee. So I’m good.” The proud tone of her voice indicated recognition of her own self-worth and an established interaction style with staff that she is accustomed to. In addition to her proficient Yahtzee playing, the person being supported by staff in the first relationship group also participates in swimming and bowling with Special Olympics. She also told me she has a long term boyfriend that she one day hopes to marry. “I met him through a friend a long time

ago. We've been together 3 years and we've known each other 27 years" (person supported).

The woman being supported in the first relationship group lives in an apartment by herself. A staff team does not work in her home on a full time basis and she gets herself ready independently on weekdays to attend a day service that prepares her for employment in the community. When I asked what functions she performs independently, she said, "Go to work every day... on my own. I have an alarm clock." She gets up at 6:00 a.m. without staff assistance and takes public transportation across the city to get there. "I have a long haul. It takes me a good hour there, a good hour back, and I'm like, stay awake. Just the other day I'm on the bus and I cannot stay awake." When staff come to her home, they arrive at 4:00 p.m. when she arrives home from her day service and help her prepare supper. "They help me cook, to make supper." They stay to accomplish specified tasks such as meal preparation, medication administration, budgeting and shopping. Staff are also there to help problem solve any difficulties she is experiencing.

The current living arrangement followed after a significant amount of time living with others in a group home. Going to work every day was identified as a mark of independence gained by living on her own in an apartment. An additional benefit of this arrangement includes "more privacy. I get to sometimes shop on my own. Sometimes I will get help." She described the assistance that staff provide in the following way: "They help me make good decisions... She helps me budget what I need, then takes me to the bank and take so much out." I also asked about who decides what the money gets spend on. And she said, "Me. But I ask her if I have enough money to buy something. I have a savings account and then we take money out of my savings account and we go buy it. I bought my own TV and my own hair conditioner." Decisions about groceries, for example, are accomplished in a collaborative manner. She makes

a list of needed items independently, but then reviews it with her staff to complete it. She also participates with staff in a process of price comparison by looking at flyers and visiting stores to compare the prices. Interesting to note, however, when I asked who has the final say when they don't agree, the participant said, "She does. I ask her if I made the right decision or the wrong decision." She considers her primary staff to be a good person to ask these questions, because, "She knows me very well." In fact, "next year, in the year 2010 it's going to be 17 years."

The Staff Providing Support

The staff recruited to participate in the first relationship group knows this participant very well. Although not formally assigned to her support network for the whole period, it was 16 years ago that she started her tenure at the agency supervising the group home she lived in and their relationship has blossomed from there. "Even when I wasn't working directly with her, she would come into my office with problems and say, I want to talk to you. So we'd work through them. So yeah, a long time." She also told me it was a welcome reunion when she became the team leader of the apartment the person moved to seven years ago, returning her to the role of a formal support provider. When I asked her to tell me about her role as a staff, she started by identifying herself as a leader of the support team. "Well, I'm the supervisor of the program, but I'm also the main support worker for the ladies. I'm a role model. So whatever I do inside or outside of their home, I have to keep in mind that they are learning from me." She models what she believes to be correct attitudes and behaviours, which places considerable weight on her moral compass, and the extent to which she follows the mission and vision of the agency she works for. This staff was sure to be clear and direct with her principles, to help guide the person she supports towards making better decisions.

Interviews with staff included an exploration of agency values in addition to staff roles.

This important topic helped to understand the position from which she approaches her relationships with the participants and how she carries out the various tasks in her job. The agency's central values revealed support systems driven by a person-centred approach that recognized that people in their charge were people first and needed to be treated as such. Also identified was the need to ensure safety and promote the person's well-being. For example, staff from the first relationship group described the agency's values in the following way:

I guess our core value is ensuring people's safety and well-being... and nonjudgmental. Sort of at... with what's easiest for them. [We work] with adults with intellectual disabilities and each person is uniquely different. So when you go in and work with them you're not going to work the same with every individual. Whether it's the way you talk, the support you give, whatever ... But the core values is to treat every individual as a human being, kind of like the way that you would like to be treated.

The topics of safety and well-being later emerged as reasons to regulate and set limits on decision making and opportunities for independence. The recognition of the person's humanity underscores the staff's approach to her supportive role in their relationship.

Decision Making Domains

Assistance with decision making in the first relationship group was revealed in five primary domains. In each of these spheres of influence, the staff has important roles to play, providing guidance by suggesting options based on the person's preferences and setting reasonable limits to maintain stability and agency objectives. The person being supported told me that she appreciates and needs this assistance from her staff and relies on her to promote her interests and needs at all times.

Finances

The first decision making domain is the management of finances and staff described her

role in the process and why she is needed:

She is a bit compulsive. Her cheques are deposited because when she was paid before; it would be gone, like gone. Or she has in the past, but not for a long time, given her money away. So it's in place more like a safety or precaution. So when permission... it's not necessarily permission to do that. But I guess the permission that she gives us is to help her, even when she is compulsively saying like I want to buy this now, she's given us permission to say, hold it here's what you wanted to do, it's your plan. So the permission really is helping her to stay on track with what her money is for. Because when it comes down to it, it's hers.

The first participant manages her finances in a collaborative manner with staff. They work together to ensure money is spent in a responsible manner because there is not a large budget to work with. She also admits to being somewhat of an impulsive spender and requires assistance from staff. Therefore, money is kept in a binder and supervised by the staff that I interviewed. According to the person being supported, "We don't overspend. We get our change and the receipt and leave it on the table for when she comes... If I had my own money, I'm kind of impulsive and I'll spend it all. I don't want to handle my own money. Because I'll just buy everything and then I'll be broke." The person supported reported that this arrangement was built on trust according to premade budget plans. "And there is also trust, like I bring home my cheques and give them to her... I'm not allowed to cash them because they're supposed to be for deposit only."

The reason for the strict budget plan was explained by the staff as a method to save for a sizeable vacation in the upcoming year. The following dialogue explains the arrangement that they established together as a team:

Staff:	What are you saving for right now?
Person Being Supported:	A trip.
Staff:	Like what kind of trip?
Person Being Supported:	Cuba.
Staff:	Yeah, Cuba or something. Whose idea was that?
	Who wanted to go?

Person Being Supported: Me.
Staff: So what did we do?
Person Being Supported: We put my cheques in a savings account.
Staff: If someone doesn't have a savings account then we'll open one. So what's different about saving for this trip, though...? How is it different than saving for the summer trip? How much more do you need? Is it a lot or a little?
Person Being Supported: A lot.
Staff: Usually, if she wanted extra money, she could take it from her savings account. But this time around, there is no extra money, she's gonna have to be really rigid. So that's a decision where here's how it's going to happen, and she has to decide if she wants to do it, if she can do that or not. She says yes I can do this, so right now she can't go into her savings account. It's going to be one year. It's probably next winter. There's two other girls that want to go.

The decision to save money was made by the person being supported with the assistance of her staff team. They, in turn, help to set limits to ensure she reaches her goal of saving enough money for the trip. She understands their motivation for being strict at times and continues to look forward to an opportunity to spend her money on a desirable vacation.

As we established the manner in which funds were managed, there was some discussion about the participant's feelings on the matter. Although she trusts her staff to handle her money wisely, and knows that they try to act in her best interest, she expressed some discontent with having another person mediating access to finances. For example, she said, "Well... one time I had a big fight with her and I said I want all my money." The following dialogue ensued:

Staff: Money out of your bank account or from your parents?
Person Being Supported: No, from my pouch.
Staff: How did you resolve that?
Person Being Supported: I don't want to have it all because I will spend it all.
Staff: (speaking to the both the interviewer and participant). Well the way I do it, is go, what did you budget for, what's this much for, what's this much for, and what happens if you spend it all in one place, what are you

going to have? What do you have if you spend it all at once?
Person Being Supported: Nothing.

Although she recognizes the need for assistance, it still appeared challenging for her to make a long range commitment that places restrictions on her finances. The staff appeared to understand this frustration, and maintained a response that set up parameters and respected her right to choose.

Vacations

In addition to the large trip to Cuba, the person being supported in this relationship group also joins friends and staff on an annual trip to a rented cabin in a Manitoba Provincial Park.

According to her staff,

We go to the lake for a week and she saves for that. We rent a couple of cabins. And it's a group of girls that have been going together for years. We've been going for like six years now. There's me and another lady who works with us. It's for that she saves.

Staff know that this is an essential element of the person's summer plans, and help to ensure it happens by making the necessary arrangements with other staff and reserving the site. But the planning is not done independent of the person being supported. Staff "make sure if we go to West Hawk Lake, we make a list of what we need, and they help me pack it" (person being supported). Staff take the initiative to coordinate the event, but the participatory manner of preparation was apparent as we discussed it further. Setting out on a trip like this is the person's aspiration, and the staff's responsibility to make possible. Ultimately, the decision to go on this trip rests with the person being supported, but it is important to recognize the wishes of staff still permeate this domain as indicated by the following statement:

I personally think that she could go on a warm trip. So I've been really pushing that for her because she's never been able to and I think it would be phenomenal for her to do that.

We did not determine whether staff had previously introduced the idea of spending time at a cabin, but the idea to pursue a larger trip to Cuba can be attributed in part to the influence of staff.

Health

Staff support the process of being healthy and have the person's permission to coordinate their access to health care and medical appointments. According to the person being supported,

- Person Being Supported: She phones ahead, makes a doctor's appointment, then takes me and waits with me. She comes with me.
- Interviewer: When you're at the doctor, who does all the talking?
- Person Being Supported: Me.
- Interviewer: If you want to go see the doctor, what do you do?
- Person Being Supported: I tell my staff I need to go see the doctor. And then she'll make the appointment, and then we go.
- Interviewer: So how do you think that arrangement works? Is it good for you?
- Person Being Supported: Yeah.

Again, staff make the occasion possible through coordination and planning, but support in this realm is carried out by promoting the person's autonomy in the situation once there. The person being supported speaks on her own behalf when meeting with medical professionals and requires the staff to do three primary tasks: help choose the doctor, make the appointments and be there in case they are needed. According to the staff,

They have a certain amount of medical appointments every year. Dental is maintained. But if they don't like the doctor, they get to choose another doctor. I know with this new doctor, it was my choice. But he's the type of doctor where you go to meet and greet. If you don't like him, you don't have to go. That's one of the reasons I picked him as the doctor. Because he does give people a choice as to whether they want to see him.

As we discussed the person's health, a more in depth understanding of decision making in this domain emerged when the topic of smoking began. The person being supported in this

relationship group is a smoker and her staff respects her choice to do so. However, the staff knows that it is an unhealthy habit and actively encourages her to quit with a deferential but direct approach.

She used to smoke a pouch of tobacco a week. She started to move toward two and I took the role of, you're not getting any more money for two pouches of tobacco. You're gonna die of cancer, that's not happening. But it's done in a way that it's not like you have to do this because I will say if you really want to smoke that much I can't stop you. But let's go to the hospital and check out some black lungs, you know. So, I will show her pictures and remind her of some people we know who have died of lung cancer. That's what I would expect from someone if I was still smoking. If she really wanted to go and spend \$100 on cigarettes, it would kill me but, that's just an example because she'd never do it, but if she wanted to, honestly, it's her money.

Instead of disallowing this endeavor, the staff help her place limits to keep the habit in check for both financial and health reasons. When asked how much freedom the participant has to make unhealthy choices, the staff told me, "Really, as much as you and I." Staff ensures money spent on tobacco is part of the budget, so that it does not override the additional wants and needs encompassed by it. To promote health, the staff's role is also to provide information to ensure the person is making an informed decision to continue smoking. As is evidenced in the following dialogue, staff have successfully put limits on the behaviour and actively promote alternate activities.

Person Being Supported: No. When I... I used to smoke; I would run out of tobacco on a Tuesday. And I still have some.

Staff: She stress smokes. Sometimes when things aren't going so well, she tends to smoke a bit more, so we try to keep her on track to remind her of something else to do, like go for a walk or something. When she goes for a walk and keeps busy she doesn't smoke. It's when she sits drinking coffee and doing nothing... When she wanted to start smoking two pouches of tobacco and I clearly said no way. I'm sorry; I keep that rule – no way!!! I want you to live a little longer. So, I'm sorry, I'm not going to let you do that.

We're going to take that extra \$10 and put it in your savings account so you can buy a VCR or something. And that has worked out fine because now she is smoking less. But with that, I'm just reminded of what's happening to her lungs. What do I say when I finish telling you something, I always say one thing.

In unison: But if you really have to do this, then you can do this because it's your money and your health.

Staff: But health is one of our philosophies at this agency. So I really try to emphasize the health aspect, especially when she wants tobacco.

The decision to smoke is made by the person who is supported in this relationship. And the staff understands and respects her capacity to make that decision. But she is bound by her mandate as a support staff to encourage healthy alternatives and clearly objects to the person's decision to smoke. "That's something that is part of our job is ensuring health and wellbeing, and so yeah, I'm going to tell her those are cancer sticks. And I do, especially when she starts coughing, I mention that she should cut down" (staff).

Leisure Time

According to participant one, she helps to pick the staff that work with her and enjoys participating in leisure activities with them. It was revealed that an important aspect of this person's social life is time spent with staff. She enjoys going to movies with her primary staff, especially "scary movies," and attends social events with them, as well. I asked her about favourite leisure activities and how she decides where and when to go out.

Interviewer: What do you do when it comes to having fun?
Person Being Supported: We go to socials and movies..., go shopping.
Interviewer: Shopping, movies, socials... how do you decide what to do?
Person Being Supported: Find the time, and what's playing at the movies.
Interviewer: Who does all that? Is that your job or the staff's job?
Person Being Supported: Both of us.
Interviewer: How do you work together to decide what to do?

Person Being Supported: She asks us if we want to watch a movie, then we budget for it, and then we pick a movie, pick a day, which movie we want to see, see what time it plays.

We have a collaboration here that puts the supported person in the centre with the staff providing options and facilitating choices. They spend leisure time together and ensure that activity choices stem from the preferences of the person being supported.

Relationship Assistance

I asked the person supported in this relationship group if people other than her staff help her with decision making. She told me, “my mom, my dad, my fiancé. They help me make good decisions.” But she does not interact with these important people independent of her staff. The staff chosen to participate in this study indicated that she helps mediate the participant’s relationship with her family, and plays a supporting role in her relationship with her partner. According to her staff, “we don’t tell people what they can and can’t do. Certainly if we see a really unhealthy relationship certainly we guide in the direction of change it.” Although important people exist outside the person’s staff network, the staff still have a role to play in these relationships, and the decisions that get made within and about them.

Family connections are an area where this person requires support from her staff. Living independently of her family is challenging at times, and her staff help her set boundaries with them. According to her staff,

Going home for Christmas... is really complicated. Okay, you don’t want to go home, why don’t you want to go home. They are all valid, really good reasons, but then mom starts pressuring. Okay, so what do you want to do? I don’t want to go. It’s helping her get that decision made. Sometimes it’s sitting down beside her on the phone while she tells people, I’m not coming home... She needs to hear herself, she knows her reasons why she doesn’t want to go home, she needs to say them out loud to help her get past the pressure that she feels from her mother sometimes. And it’s not that her mother is pressuring her, it’s just that they don’t see her, they live like a million miles away. And she

probably hasn't been home in like, three years. She does get to see them when they come in, so that's good.

The role of mediator has been adopted by the staff to help the person navigate her relationship with family. Although she enjoys spending time with them, this staff helps her establish a relationship with them that she can be most comfortable with.

As mentioned earlier, another major person in the participant's support network is her fiancé and she told me staff have helped her develop this relationship in recent years. Staff support the relationship, and are currently helping the person with her plans to get married in the future. This is an important relationship interconnected with her support staff. According to the staff chosen for this study,

Her boyfriend has become a pretty good friend of mine now, too. He and I get along really well. He's really respectful of her and I. So I guess other relationships in her life, you gain that. Your circle gets bigger, the people that you know.

Although we did not speak in detail about her plans to get married, it was revealed that the staff has an important function in the relationship, advocating for her wish to one day get married.

The Process of Staff Assistance with Decision Making

In addition to the domains in which decisions get made, the processes followed by the two people in the relationship also help to demonstrate the way that self-determination is expressed. It was evident that staff in the first relationship group provides assistance with decision making in three important ways: she helps establish a routine that effectively limits the need for full time staff attention and promotes more independence; she assists the process of problem solving by being available to talk things through, finding appropriate solutions to issues and concerns; and she helps break tasks down into discernable steps that focus on and promote

the acquisition of information. According to the staff, decision making processes operate with the following parameters.

She lives in her own apartment. So she gets twenty hours a week. But it's not always direct twenty hours a week; the more she needs the more she gets. Funding hours we can't go over twenty hours. I see her five times, sometimes six times a week. The difference is it's only 20 hours a week of staff and with the program she is in it's really intensely in making healthy choices, healthy relationships, healthy diet.

And when I spoke with both the staff and the person supported, the process of decision making is not about being right or wrong, it is about learning from experience and building on the knowledge gained by choices made.

Person Being Supported:	And sometimes we make bad decisions.
Staff:	We've all learned from bad decisions. You've got to make some once and a while.
Interviewer:	That's what they are there for.
Staff:	Learning experiences we call them.

The processes identified and described below – routine establishment, task analyses and problem solving provide the means for the supported person to be an experienced, informed decision maker.

Routine

The participant in the first relationship group had an established routine for the day and week. The support team works around and within this routine and is not needed to help direct what she does throughout the day. According to the staff, “there's structure, but it's more routine. “ Assistance with decision making about finances occurs, and assistance is provided as a check to make sure important things like meal preparation and medication administration is accomplished – “to make sure I take my medication on time and check my pills and they give me my pills” – staff perform regulated tasks like this to uphold a routine the person follows on a daily basis. With medications, they are given to her once a week and she takes them

independently.

- Staff: It depends on the day of the week. Pick a day and I will tell you what we do. Pick Wednesday.
- Interviewer: Sure, what happens Wednesday?
- Staff: Wednesday I go meet her at home, and then we will go to do her banking. And then after we go banking, she will do her grocery shopping with support.

Every day of the week, the person supported in this relationship group gets ready for work independently, takes the bus to get there, and meets with her staff at home in the evening to ensure the completion of a specified task.

- Interviewer: And you do that together with your staff.
- Person Being Supported: On Wednesdays. Today. We do it every Wednesday.
- Interviewer: So Wednesday is banking day, Thursday is swimming day, and Saturday is bowling day.
- Person Being Supported: That's right.

The participant believes this process meets her needs very well and, as a result, she does not need to have staff with her at all times. She knows each person's role and completes daily living tasks on a consistent basis with their assistance.

Problem Solving

Problem solving is another major component of the way that decisions get made in this relationship group. "We talk problems out and solve problems. I trust her" (person supported).

In this context, decisions get made with assistance from staff. According to the staff,

She's pretty good at sitting down and when you go over the facts of the situation, sort out what's real and not real in her head, then it leads you to get to solve the problem and her being able to pick up from the conclusion for herself without someone telling her here is what you need to do. So you kind of got to give the information. Informative decision making. It's like, here is all the information, what do you think you should do with it? How do you want to work with this? What do you want to see happen?

Although this process was often described in a negative way – "she just has to look a

certain way and I know there is something wrong” – it is an effective method of working through issues that arise during the day.

Sometimes she has a bit of compulsiveness in her which makes the decision making process really important to her because she’s compulsive. In a way we have to slow her down to think before she makes that compulsive decision. Sometimes she struggles with other ways to solve it so sometimes we have to give her the information. But always, always saying this really is your choice, though. You made this decision and it doesn’t make you a bad person. It’s not a great choice, but it was your choice and now you have to deal with the choice you made (staff).

This passage highlights the method of problem solving used in the relationship and draws attention to the way that self determination is promoted through the recognition that the person is responsible for their own decisions – the staff is only there to guide the decision making process, but not make the decisions, or be responsible for them. This form of guidance also helps the person deal with problems with an emotional element.

Sometimes I used to cry and cry. And not deal with it. I tend to push it all away and she’ll say, that’s not gonna work. It’s gonna come back to you (person supported).

As we discussed this topic, I learned the importance of her primary staff when they are able to fill this role for her. She really counts on them.

Task Analysis

Staff and the person supported work together to analyze tasks and gather information.

The following dialogue about recognizing the need for and purchasing a new bed illustrates the method carried out by the two women.

Staff: For me it’s very simple. She makes a request. We figure out a plan. She says what she wants to do, and we see how realistic it is together. We’ve even gone out to get a list of different prices. Like a bed, we’re getting a mattress soon. We’ll go through flyers and stuff first. Because the government doesn’t give you much money to buy

- a mattress, so we have to sort of really go look around.
- Person Being Supported: And that bed I've had from the house I used to live in.
- Staff: So the decision... we'll go and price them out and get a price range and she'll pick the one she wants. But we'll go over all the goods and bads about the particular bed. I think they only give you about two hundred bucks. So I think all she really needs is the mattress. Because a whole new bed would cost like five hundred, six hundred dollars. So it's really just the mattress that's the problem.
- Person Being Supported: Yeah, the springs are sticking out.
- Staff: So she's going to get flyers from downstairs whenever she sees them and then show them to me when I am working so we can start. No second hand. That would be my decision because bed bugs are rampant in the city. Don't want to go that route.

With help from the staff, necessary information is investigated and understood by the person being supported. With this knowledge, she is able to choose from available options within her budget. This breakdown of tasks expands the person's ability to choose effectively. Instead of have someone complete the task for her, staff ensure she is able to make her own informed decisions.

Formal Decision Making

To this point, decision making has been a process primarily carried out by only the two women. Some decisions, however, are accomplished in formal procedures required by the government bodies funding the person's support requirements. These planning procedures are meant to be person-centred and commonly involve either a PATHs (Pearpoint, O'Brien & Forest, 1993) or Individual Program Plan (IPP). A PATH is an event involving a person and their support network where dreams are identified and shaped into positive and possible goals to be achieved over the following year. A facilitator is hired for this process, and the content is

represented in a pictorial format that is accessible and easy to understand by all participating. The latter is the more formal of the two procedures and invites service providers to prepare reports that document the person's needs and support provisions. Goals are still developed and reviewed, but not in the same manner as is done with PATHs. A PATH invites a person to express their dreams to allow support providers to help them make goals to work towards. An IPP, on the other hand, often invites support providers to set goals that meet the person's best interests. The process followed in a PATH was explained by the person supported in relationship group one.

Person Being Supported:	I had a PATH and IPP meetings.
Interviewer:	Who comes to those kinds of things?
Person Being Supported:	My social worker and my staff.
Interviewer:	When it comes to decision making, what does your social worker do?
Person Being Supported:	She helps me make sure I don't miss my pills. Gives me the money I get from the government.
Interviewer:	Does she tell you where that money has to go.
Person Being Supported:	In the bank.
Interviewer:	Who's in charge at your PATH?
Person Being Supported:	The drawing.
Interviewer:	The person who does the drawing?
Person Being Supported:	Yeah.
Interviewer:	And what do they draw?
Person Being Supported:	My future, what's it gonna be down the road.
Interviewer:	When it comes to plans for the future and all those things down the road, who does all the talking?
Person Being Supported:	Me.
Interviewer:	Do other people have good ideas too?
Person Being Supported:	Yeah.
Interviewer:	Do you like making decisions that way?
Person Being Supported:	Yeah.

The person being supported in this context has her dreams recognized by support providers, and they help her set reachable goals to attain them. This process often lays the foundation for vacation plans and this woman was able to start the process of preparing a trip to Cuba with her

staff as a result.

Interview data revealed the staff's perception of this process of formal decision making, as well. In her description of the process, however, this event appeared more relaxed and casual than expected. In fact, it appears the staff prefer an informal arrangement for the IPP meeting.

Staff: We did PATHs for a while, but we're back to doing IPPs. It's more of a sit down around the table. The PATH thing I think the ladies are just kind of tired of it - not that it isn't exciting. When we do the PATH, it's theirs but we are also there to help them through it. If it's her goal to go to Mexico, well my job in the financial department to make sure she is always putting money away.

Interviewer: So if she said, this is what I want to do, then you make sure she remembers that this is where her money is supposed to go.

Staff: Right, my job is to say, well if you get money from your mom and dad, and oh you want to go blow that, what about that trip you want to take. Maybe you should put that in the bank, or maybe put a portion of it in the bank. So give her the idea that a choice is there to make.

Interviewer: So what is your role when it comes to an IPP? How many people are involved with that?

Staff: It depends on who the client invites. [In this case], because she doesn't have a lot of family, it usually typically, unfortunately is just staff. But it is because she doesn't have much family around here.

Interviewer: Does her social worker come out to these things?

Staff: Yeah. There's the family services worker, me and maybe another staff. Other staff have a second job, and so do I, so they are sometimes hard to schedule. They are always after 3:30 now. We don't make any decisions in those meetings ever. We set goals to work towards. So we've never really sat down to say this is what you're going to do. I mean other people do that, like with a financial plan, and somebody from the government comes down with a little piece of paper and says you're doing this, this, this and this.

Interviewer: Is that something that gets followed, or is that something that just goes on the shelf?

Staff: Personally, I don't look at it. I mean, I don't. Honestly, for her financially, she goes on a holiday every summer. We go to the lake for a week and she saves for that.

Although the formal process is required and carried out, this staff knows the person well and

supports her every day according to the goals she sets. It was made clear that this relationship group goes beyond the formal steps taken at this event and incorporates decision making into daily life. The IPP is intended primarily to reinforce the goals they develop as a unit. Decisions are not made at the IPP meeting. Instead, the objectives of future decision making opportunities are established.

Relationship Elements

The preceding section focused on the domains and processes involved with decision making within a relationship between people with intellectual disabilities and their support provider. The second research question turns to the defining characteristics of the relationship which have some bearing on self-determination and the process of making decisions. In the first relationship group, three primary elements were uncovered as important contributors. First, having known each other for more than sixteen years, the depth of their established relationship has impacted the way they make decisions together. The person being supported is more comfortable with the familiarity produced by the long-standing association, and the staff feel confident that their method of guidance is approved by and in accordance with the person's will. The second element can be labeled friendship and it is made possible by the depth of their relationship. Support is provided by the staff and accepted by the person in a manner indicative of friendship. The third building block of the relationship underlying decision making processes is reciprocity. Both members of the relationship contribute support and acquire benefits from one another. The informal processes they follow to make decisions develop from this closeness and influences the interdependent expression of self-determination.

Long-Standing Association

The person being supported in this relationship spoke of the importance of her long-term relationship with the staff identified for this research project. In her words, “I’ve known her for quite a while and they’re easy to work with instead of a new staff.” With new staff, on the other hand, she told me, “I don’t feel comfortable telling them an issue. I don’t know them that well. Should I do this? Should I tell them?” She trusts the opinions of long-term staff and is more willing to accept their guidance and direction. And as we discussed this matter further, she conveyed to me that staff who know her well are more able to promote and support her wishes – “they do what is best for me.” Interviewing the staff together with the person being supported, I was also told this by the staff.

Long-term staff know her well enough to say, hmm... what’s up. And I think older staff, when they say, hey weren’t you planning on saving for a DVD as opposed to buying a pack of cigarettes, that’s just an example. Whereas with new staff, she might say, hey tough it’s my money. Do you know what I mean? Because we’ve seen that happen, right? You’ve done it with me, I don’t care it’s my money. But then with older staff, because we know her better, and we know how badly she wants this stuff, we can push it a little further. We remember that it was her idea and plan and not ours.

The support available to the client is enhanced by the strength of their relationship, and the time it took to create it. This appears to allow the staff to set limits that are acceptable to the person being supported, maximizing her ability to meet goals and live according to her will.

Friendship

Stemming from this long-term relationship, the participants spoke of the development of friendship. According to the staff, “it’s a gained friendship. Like I tell her all the time, if I didn’t work here I’d still hang out with her. You know, so it’s a friendship I’ve gained knowing her for this long.” Our discussion about friendship helped illustrate two important aspects: it influences daily decision making and involves recognition of the boundaries framing the

relationship. The friendship is an important element of supporting the ordinary decisions that get made on a daily basis. For example,

Sometimes comparison shopping is needed and that is more difficult for her. But if it's stuff that she buys a lot of she knows what to get and she can do it on her own. Sometimes we'll go for lunch or just stop for a coffee. Then we'll go back to her place and chit chat, joke around, kind of like what I do with my friends – poke around in the car, or whatever. If we haven't had dinner, we'll make dinner together (staff).

The example of informal decision making in this account appears secondary to regular life events of two people interacting with one another. The second issue was the topic of boundaries. Although they spend time together in the same manner friends do, the following statement demonstrates how they also recognize the support context within which they interact.

She is more of a friend, except there's a boundary, as well. Which we both see and we both know is there but she is, like I said... I don't have clients come to my house, but she comes to my house. We have dinner together at my house; we watch movies at my house. We go to movies a lot more than any other. We've gone out dancing, to the bar together (staff).

So, within this support relationship friendship activities are performed, but this was identified as an exception to normal activities between this staff and her clients. They appear to have transcended the defined roles of staff and client and, as indicated earlier, have benefited each from the development. The person being supported gets to make decisions in a non-contrived fashion, and the staff gains a friend and inspiring role model.

Reciprocity

An awareness of reciprocity was evident in this relationship group and we explored how they help each other in similar ways. According to the staff, "it's there when I have an asthma attack, she's like right there saying, breath, you're okay." Another example, the completion of shopping, for instance, is a regular task completed in partnership by the person and their staff. But the usual arrangement often has the staff doing the assisting and the client receiving the

assistance. I asked the participant how she helps her staff, and she replied:

Person Being Supported: Shopping. Like I help her shop. I help her find things that she wants to buy for herself. And she asks for my advice.
Interviewer: So do you think she trusts you too?
Person Being Supported: Yeah.
Interviewer: How do you help her?
Person Being Supported: What looks good on her or what doesn't. I ask her how her day is, how it's going. If she's upset I give her a hug.

The person receiving supports in this situation was the staff, and the person normally relegated to the role of support recipient had the opportunity to fulfill a valued role. In the end, we have two people that work together to meet both their own needs in a manner that they establish conjointly.

To further understand the mutuality of dependence in this relationship (Kittay, 2001), the staff was asked to explain the rewards and benefits they acquired through their association with the person they support. This produced an emotional response and heartfelt words that focused on what the staff have learned from the people they support. For example,

What I gain from knowing her is to slow down and not take life for granted because everything doesn't come easy for everybody. That's a really big one for me. That's one of the things that I like about this job, in particular in itself. It's taught me to slow down and not take everything for granted because you can go through life going yeah, yeah, yeah and then realizing there is a community out there that doesn't have that, so it makes you look at things in a very different way.

Filling the role of a support person is fulfilling for this person and reflection upon it sparks recognition of her perspective of disability. She has gained respect for people with intellectual disabilities, has been taught to appreciate what she has, and is mindful of other peoples' challenges. I asked the person being supported what she gains from her staff. "I gain trust and honesty and [she is] easy to talk to if there is something bothering me. And telling her the truth.

I think that's it." Her staff agreed and said,

Yeah, I think it's really important, too. Because I know her well enough and she knows she can tell me anything and I'm not gonna go, oh my god. So the trust is tremendous. Sometimes people with intellectual disabilities ... just jump in and tell people a whole bunch of stuff. That's not trust. Whereas when there's real trust, I think most people in her position have to know the person in order to tell them what's really going on.

A reciprocal relationship built on trust is present between these two people, and it allows for the interdependent expression of self-determination for the person being supported. The staff, in turn, gains the satisfaction of realizing the value of her support, and learns to appreciate many aspects of life that some take for granted.

Relationship Group Two

The second relationship group consisted of a man in mid thirties, the manager of his staff team, and a preferred staff. He recruited the preferred staff and asked for the manager to join us, as he counts on both for his support needs. Following the initial interview with the person being supported in this group, the two staff were interviewed together, and then all three met with me at the person's home to explore their relationship further. The addition of a second staff helped shape the findings uncovered in the interview process as their support styles were largely revealed through their interactions with another. The presentation of the second relationship group will begin with the person being supported, establishing his distinctive character and strong personality. The qualities of his two selected staff will be demonstrated next. Moreover, the composition of this relationship will reveal primary decision making domains and uncover their decision making processes. Important aspects of the relationship that influence self-determination will then be presented.

The Person Being Supported

The person supported in the second relationship group is a huge sports fan. He enjoys watching and playing football and has season tickets for the local hockey team, going regularly with family and friends. “When I go to hockey games, my uncle and I go together, or sometimes my friends or workers might go - it depends” (person supported). A strong connection with family members was also identified as an area of importance for the person being supported. “My family is very understanding... I count on my mom a lot” (person supported). According to his staff,

Manager:	Family support is huge. I mean, he’s got a loving family who, I mean his mom is phenomenal. She’s just a fabulous lady.
Support Staff:	And he’s very close with his uncle.
Manager:	Absolutely, yeah... He’s loved tremendously.

Completing this circle of support, the person being supported also told me that he has a girlfriend and enjoys spending time with her; he often invites her over to his home.

Having lived for a time in an apartment with his two roommates, he told me that he had recently moved to a house in a new neighbourhood. He considers this a positive change and looks forward to meeting others in the community. He was not happy with apartment-style living and is happy that he now has a home to live in. Regarding independence, he told me

I come and go as I please. They like to know where I am so if I’m not home by four, then they go oh yeah, he’s here doing something, right. It’s not that he’s just not never calling us and telling us that he’ll be late or he’ll not be coming home. I try and be, I’m going to be out for this time and I should be home by this time.

For example, when we finished our interview at the downtown library, he used his cell phone to notify his staff team what time he would be home. He did not need to ask permission – reporting in occasionally is all that is required.

During the day, this person goes to work in a retail outlet independent of staff support.

Transportation is accomplished independently and he calls home to let his staff know if he is running late or has made alternate plans.

I work three days a week... Monday, Wednesday, Thursday from ten to three. I worked in the warehouse and I also work on the floor... Sometimes I will assist them with unpacking clothes or sometimes maybe hanging them. I may have to put some tables and stuff together. And on the floor, I just help them unpack all the mugs and candy, utensils, that kind of thing. And then someone helps me put it all away (person supported).

He is satisfied with his place of employment but indicated having some difficulty dealing with staff turnover. Expectations change, he told me, when you are working with new people.

There was a lot of change. I would come in and you'd never know if they got fired, or they quit, or... what's happened. So it's kind of hard. I don't like change too much and it really... especially if I get along with them well then that's really hard for me to adapt to, even though I know them I don't know what they're expecting. That part for me is hard and sometimes it can work well for me or sometimes it can be a big disadvantage (person supported).

This is especially challenging when coming to work and finding out that someone has left and a new person has taken their position.

Another key attribute of the person in the second relationship group is the high standards he holds for his staff and his friends. For instance, if staff say, "you know, I'll work on it," he says, "well, don't work on it, go and do it. The following dialogue also reveals his strong convictions in this area:

Person Being Supported: I count on my staff a lot. And some of my friends. I choose my friends very, very carefully. If I'm around them for the first three or four minutes that I meet them, I can sort of get a feel for whether I like them or I don't... I [also] really rely on my workers to be leaders. I want them to make smart choices for us and to help us to understand that they are workers, but also we can become friends – but you sort of have to know that they are there to work. That's another thing about me is that I'm careful... We had a girl one time, she came for an interview and my house manager then really liked this girl. But I had no use for this girl really – she was just too

spinney.
Interviewer: So what did you guys decide?
Person Being Supported: I pretty well said that she better not be coming here to work.
Interviewer: And?
Person Being Supported: She didn't come – which made me happy.

The person being supported helps to hire the staff that work in his home and reports having a good working relationship with his manager. Together, they make decisions that he feels comfortable with and he is content knowing that he is helping to recruit staff that will be good for both him and his roommates.

The man supported in the second relationship group can also be described as an active advocate for people with intellectual disabilities.

Support Staff: He's never had to live in an institution. He's always lived in a family situation.
Interviewer: And he seems sympathetic to that whole situation because he's part of the group trying to close it down.
Manager: Hugely sympathetic.
Staff: That's the thing. He's never been in that situation, yet he fights so hard to...
Manager: He has huge compassion – a very compassionate young man.

Growing up in a supportive family home, he recognizes the need to close institutions and actively contributes to efforts to do so. As a result, he is very busy with various committees and advocacy groups. According to his staff, “there have been times where he is so stressed because he's got so many groups, so many meetings to go to in a week. There's times he has a hard time coordinating everything.” But he seems confident in his ability to manage these responsibilities and is proud of the work that he does.

The Staff Providing Support

Two staff were recruited to participate in the second relationship group. The support staff was first identified and the manager joined us upon request by the person being supported. Both staff had the opportunity to share their perspectives about decision making within this relationship and they appeared very dedicated to the support provided to this man. They started their discussion of roles by positioning themselves as leaders of the team. But they went on to talk about their role in the decision making process, relationship development and the promotion of valued roles for the person being supported. The following dialogue demonstrates their perceived roles in the support process:

- Manager: Well my role is... I'm a team leader. So my role is to not just supporting the individuals, but also to support the staff. So that would be my role – and to oversee the whole community residence. Here is a summary here, if you could just read it out.
- Support Staff: Pretty much well, I'm direct support staff. I work full time during the day with the individuals and I support them in the decisions that they make and I help them make decisions. I also get them out into the community, making friends if they want. We'll join new groups. "Facilitate participation in social roles that lead to integration in typical and valued life in the community" (*reading*). That would be my role.

This staff team emphasized the recognition of rights and a mandate supporting key aspects of self-determination. These perspectives are revealed in the following dialogue:

- Manager: And the core values would be that individuals are supported in their rights, their gifts, in their...
- Support Staff: Decisions.
- Manager: Yeah, I mean.
- Support Staff: Pretty much in everyday life.
- Manager: Anyway, just promoting their supports, their natural support systems, or building natural support systems for them, and not just creating outings or whatever you want to call them. We don't like to use that kind of language. Basically, giving them the quality of life that anyone else

would have, supporting them in their choices. Our agency is totally committed to VPA (The Vulnerable Persons Living with a Mental Disability Act) and individual's choices. Helping them, I mean supporting them in making wise choices, but also letting them make mistakes so they can learn like we do when we make mistakes.

Letting this man make and learn from mistakes highlights their recognition of the dignity of risk (Wolfensberger, 1972) and introduces the manner by which they support self-determination.

These staff are available when needed, but do not impose any authority within the decision making process. The Vulnerable Persons Living with a Mental Disability Act is also mentioned in this dialogue. It is provincial legislation that governs the support provision for people with intellectual disabilities in the province of Manitoba. Instituted in 1996 and reviewed by Lutfiyya, Updike, Schwartz and Mactavish (2007), this legislation is intended to protect the rights of people with intellectual disabilities and is founded on the belief that they should have opportunities to make their own decisions and direct their own life with support from others. The concept of self-determination stands at the foundation of this law and informs the support provided in this relationship group.

Decision Making Domains

The following question was posed to the manager of the person's home, and her answer well represents the assistance they provide to him when it comes to making decisions.

Interviewer: Right, so if he's doing something you don't agree with...
Manager: That's my problem to deal with. It shouldn't be his.
Yeah, that's my problem, it's not his.

In fact, the staff's assistance with decision making in this relationship can be described as peripheral. The person being supported here makes his own decisions about how to spend his leisure time, actively participates in the selection of staff and manages his affairs without much

intervention. The primary area where staff help him out is with his health. They attend appointments with him and promote a healthy lifestyle whenever possible. Additional decision making domains includes behind the scenes support of community involvement.

Community Involvement

According to the manager interviewed for this project, staff provide this man with opportunities to participate in the life of his community. She told me they are,

Looking for opportunities for him to use his gifts and talents in the community he lives in. Because they just moved to this place, they need to now become part of it. So we're looking for opportunities where he can serve in the community.

This assistance is provided behind the scenes and options are presented for him to decide. He is a very active member of the disability community, advocating for the closure of institutions in Manitoba, and staff would like to help him find additional activities closer to home to help balance his time. They are also planning to introduce the person being supported in this relationship, as well as his roommates, to the surrounding neighbourhood by engaging in the regular activities that are common in residential communities. For example,

We're going to have a block party and a big barbeque. That's what we plan on doing. Well, the yard's not that big, but we do have the school ground right behind us that we can facilitate with. If it needs to get bigger it can go there because there are no kids there in the summer. It will be awesome, especially for families that have kids. They can go play on the playground right away in the evening, too. I think life will change for everyone.

The men in the home had not had opportunities like this when they lived in an apartment.

Getting involved in the local community has become a priority as they get settled in their new life in a small comfortable house.

Leisure Time

What the person does in his spare time is for him to decide. Staff do not plan his activities for him and do not often spend that time with him. This style of support again reveals

the staff's ability to step back and allow for independence. He is not alone in the decision making process, but staff know that the process is for him to lead. I asked the staff how they plan the evening's activities and I was told,

- Manager: We don't. The guys are involved in certain things. And this man is involved in having his meetings, or whatever he's doing. And there will be some evenings where he doesn't want to do anything because he's really tired from the day. But we don't over plan anything. We don't have an activity chart that says this is what we are doing today.
- Support Staff: There's never any activity charts.
- Manager: It's up to them what they like to do. Sometimes they don't want to do anything.
- Support Staff: I don't have an activity chart at home.
- Interviewer: No, neither do I.
- Manager: I mean, who likes to live by a calendar posted on the fridge. Lots of people do, families have kids involved in sports and all that kind of stuff. But he has his things. He goes to the Moose games because he has season tickets. He'll go to football games, he'll go to whatever. Or he'll have his girlfriend over. He can have his girlfriend over whenever he wants. He doesn't have to be a certain night. This is their home and they can do what they want. So we don't plan any activities for them.

The staff's proclivity for not applying direct influence over the realm of decision making for leisure time does not discount this category as a decision making domain. In fact, it well defines their approach to the decision making process and establishes the domain. Not planning activities for him is an important method for promoting self-determination. Staff support his choices by allowing him to make them on his own, helping primarily only when asked. I also asked the person being supported in this relationship group how he viewed the need for staff support in choosing how to spend his free time. "They will come and ask me if I want to join them, but otherwise no, they don't have a say in when I stop watching TV or when I have to go to bed, or... when I've got to be home, as long as I let them know where I am if I'm not coming home" (person supported).

Participation in Selecting Staff

This person is motivated to participate in the operation of his home and takes an active role to ensure he has input when staff are hired to work with him and his roommates. He told me,

When staff come to work there, I do the interview with our house manager. For me, that's a bonus, because the other two guys I live with can't speak for themselves, but I can so I'm not only accounting for myself, I'm accounting for them.

As mentioned earlier, this is an area where his strength of character is expressed. He has high standards for staff, and the manager at the home works with him to find people that are most suitable. According to his support staff,

He's pretty good with it – he has quite a few questions to ask. He gets a good feel for the type of person. Like the last person we had come in really didn't like to open up about himself. He didn't really like to talk about family or any of his interests. And he really wasn't too fond of that. He wanted to know about his background and this gentleman didn't want to open up. So he let the manager and myself know how he felt after he left and he never ended up coming to work for us.

Although barriers exist in this sphere of decision making when there is a shortage of staff available, the staff recognize how that may impact negatively on the support he receives. "I would hope that wouldn't happen... I wouldn't want someone coming to my home before I met them" (support staff). They understand that this would be detrimental and consider it only as a last resort, although sometimes they have little control over its occurrence.

Health Decisions

According to the manager working with this person, when asked about important areas of support, she told me the following:

I try to work with him in the area of his health. He doesn't ask for a lot of assistance or support in financial decision making. He's pretty much okay with doing that on his own. He's got his budget and he knows what he can spend.

We do support him in choices of purchasing different things. Like we'll provide him with scenarios and options. But I think mostly in the area of good health – like helping him with that.

Both staff encourage the participant to lead a healthy lifestyle by eating well and staying active.

Being in a new home, as opposed to an apartment, they hope to access nearby green space to play sports – this was discussed as a benefit of the new living arrangements.

Support Staff: He is a huge football fan and now we have a big backyard and a school yard to go and toss the football around.
Manager: It will be better for him.
Support Staff: Right, he'll get more exercise. It's going to be great.
Manager: It's going to be awesome. I'm excited about it.

The attitudes around healthy lifestyles appeared very positive and the staff were eager to explore possibilities in this territory.

According to the person being supported, assistance with medical appointments is a welcome support provided by the staff.

Person Being Supported: I always have somebody with me at the dentist because I don't like the dentist. And if it's like a checkup or something then the house manager comes.
Interviewer: What is their role at an appointment? What do they do?
Person Being Supported: They... if the doctor says, well he needs to do this or that, then we have like I think a form that she has to fill out and put it back in my binder.
Interviewer: Do you know what goes in that binder?
Person Being Supported: Yup.

It appears that staff are following agency documentation guidelines and ensuring that he has access to medical appointments every year and whenever needed. When he goes, they accompany him and have the medical professional sign a form that later gets filed. The man supported in this relationship group appeared knowledgeable with the process and satisfied with his access to information.

The man from the second relationship group is a smoker. I asked him questions about smoking to discern how his staff respond to this.

Interviewer: We talked earlier about smoking. Whose decision is that?
Person Being Supported: Mine.
Interviewer: That's yours. Do staff have anything to say about that?
Person Being Supported: No, because it's my decision.
Interviewer: Is it there place to say anything?
Person Being Supported: No, I don't think it is. If they're concerned about me yes, but if there just gonna sit and nag at me, then no.

The staff respect his decision to be a smoker and do not make efforts to control his habit of smoking. There are no formal plans in place to actively encourage him to quit without it being his choice to do so. But still, staff do not agree with his decision to smoke and respond to the habit in a manner that does not condone it. For example,

Interviewer: Do you guys give him a hard time with his smoking?
Manager: Absolutely – as often as I possibly can.
Staff: Yeah, so do I.

The participant accepts this criticism and knows that the staff only care about his health and “give him a hard time” as they would do with anyone else they care about. Although his decision to smoke is a matter that poses risks to his health, staff are not in the position to control his behaviour. Both the staff and the person being supported understand the risks associated with smoking and respect each other's opinions.

The Process of Staff Assistance with Decision Making

Understanding the ways in which self-determination is expressed involves an exploration into the processes followed by staff as they help the person make decisions. Of the many different ways that staff provide assistance, three primary processes were identified in the

interview data: recognizing and supporting his best interests, assisting with the process of problem solving and participating in formal decision making opportunities.

Supporting Best Interests

The man interviewed in the second relationship group has expectations for his staff regarding their support of his best interests. He wants them to explain the options he has available to him, including the information he needs to make an informed decision. He trusts that they will present options that are beneficial and be given the right to choose.

I expect for them to be fair and honest with me. If they think it's good for me then I want them to tell me that. And sometimes they might say I don't think this is a good decision or a good idea. Well then give some options so that I understand why it's good or why it's not good. And then give me a few options why it is, why it's not (person supported).

The participant in this second relationship group later developed this idea further also told me that he appreciates the assistance he receives from his staff team.

I feel that they both push me in the right direction. Not that I always like it, but they are keeping me safe and making sure that I feel as good as I can about myself in different situations. But it's not always easy for them and they have to understand it's not always easy for me.

The guidance they provide and the options they present are considered to be in his best interest and he accepts what they have to offer.

Problem Solving

This participant benefits by the opportunity to talk things through with his staff. They recognize that he is capable of making his own decisions and know that their role is to help him work through and examine available information.

Manager: Because he is so independent, he doesn't really need people to do things for him, to get things going. He just needs to have someone to talk to about it, or brainstorm with someone so that they can provide him with options that he may not have come up with on his own.

Support Staff: Like [the manager] said, he is extremely independent. He can do everything on his own but what he really needs is someone to talk to. He's a very emotional person, as well. He does get upset quite a bit.

This approach has been helpful and the person being supported in this relationship group had the following to say on the matter:

After she knows that I'm starting to feel down in many different ways that I kind of let her down and we just went somewhere privately and just kind of settled what had to be said and left it there.

Problems get worked out. When difficulties arise, they get dealt with in a respectful manner and do not get left to proliferate and interfere with decision making. According to the staff, they also like to help the participant deal with life stressors and his tendency to make too many commitments.

Support Staff: And there has been times where he is so stressed because he's got so many groups, so many meetings to go to in a week. There's times he has a hard time coordinating everything.

Manager: He doesn't know when to say no.

Support Staff: That's right.

Manager: So we support him in grounding him. We try anyway. So that he doesn't get way out there.

Staff are needed to help review available information so that the participant can be autonomous and not have others make his decisions. Ultimately, decisions are his to make and staff are available only to work through the details, providing cues for him to recognize when he is upset about something. I witnessed this in our interactions together. A subtle gesture or comment by the manager, and the person being supported is able to recognize his heightened level of emotion and remain calm. It appears to be a system that they have worked out together that has been successful.

Formal Decision Making

PATHs and IPPs were explained in the previous section. The second relationship group utilizes these formal processes to help the person being supported make decisions about his future. They are required to carry out these tasks annually, but do so in accordance with the participant's preferences for the format. In the end, it lacks much of the formalities, and is an opportunity to identify the person's goals and dreams. The result of these events are presented to the other staff so that they can remain aware of the types of supports they need to provide.

Manager: Well, he will do a PATH if he wants, or he'll do an IPP, or family services will come every year because we are a licensed, or approved home, so we have to do that. But that part he still dictates what that is. It's just a more formal process of helping him decide what he wants, what he's got, and what he wants his goals to be. But there isn't really a formal process, no. Other than those things that are required.

Interviewer: When you've done that process, and you've got these goals at the end, what's the... what do you do with those goals afterwards?

Manager: We put them into his binder and every once and a while, or every team meeting, we'll talk about it and make sure he is still aware of working on the goals. But ultimately it's still left with him to make the moves. And if he needs help from us he asks us for help. So ultimately it's still left with him, it's not something that we, we just remind him, hey don't forget you wanted to do this, you wanted to do this.

Once the process has been completed, I asked the manager to explain to me how the accomplishment of goals is monitored and kept on track. For example,

Interviewer: What happens if you see that he is straying off course from his goals?

Staff: We just say, it looks like you are straying off course, have you changed your mind? Are you wanting us to pull you back in? Or what do you want from us? That's how we would handle that. We're not going to say to him, look you wanted to do this so you better get at it. That's not our role. That's not what we are about. It's his life, it's his choice.

The formal process of PATHs and IPPs generates goals for the person to meet with staff assistance. But the decision as to whether or not to carry through with goals remains with the person being supported. He has the right to change his mind – staff respect that and follow his lead.

Relationship Elements

The second research question addresses the important ways that relationships impact the decision making process. This relationship group appeared to have developed strong ties to one another within the support they provide and receive and three primary aspects were uncovered by the interview data. First, knowing that changes are often occurring with his support staff, the members of this group know that they must work together to hire new staff, ensuring the person being supported is involved in the decisions that get made. Friendship is the second identified attribute of the relationship, and we explored the impact of being friends while being paid to provide support. Third, the importance of reciprocity was explored by all three members of the relationship group.

Consistency and Change

Relationships in this group appeared very strong and developed although the relationship group members had known each other for a period of less than 2 years. Staff turnover and changes in the staff schedules were highlighted as concerns for the person being supported. He would like to be more informed of changes that occur in the schedule and be more aware of who is working the different shifts. Although he plays a prominent role in the hiring of staff when possible, this was an area where he still wanted more information and participation.

That's another thing that bothers me is these hours... I would also like to at least know what is going on around here. I don't know when... I know that staff start at

seven in the morning and finish at three. That's all I know... And change for me is pretty difficult (person supported).

He experienced this in the workplace, as well, and it was evident that changing staff and uncertainty about who would be spending time with was a point that he would like to address.

With changes occurring in support providers, this man was still in the process of evaluating the different people that entered his life.

Friendship

Regardless of the time that they had known each other, the members of relationship group two indicated a very strong commitment to friendships developed within the paid support relationship.

For me, I call them my friend, because they are. If I were to ever, and I don't think I would, but if I were to ever leave here I would continue on with having a friendship with these guys. The bond is just so strong; I just couldn't see myself not coming here. I'm extremely passionate about what I do. That's the main reason why I got into this field, it's because I'm a big people person. But I never realized it as much until now (support staff).

A friendship commitment to the person was expressed and the staff expects to continue the friendship beyond his employment as a support provider. This developing friendship was reported by both staff, as indicated in the following passage:

Interviewer: Can you talk a little bit about the nature of your relationships with the people here?
Manager: I don't know, I think for myself I know that I'm staff. But I've developed friendships with each one of the men that I provide support for. And that would be life-long for me. It's not just a job. For me I don't leave it here when I go home, they are part of my life. And they always will be, even when I'm not in this job anymore. That's how I feel about it.

Having a friendship relationship with his staff has impacted the decision making process carried out by the person being supported. He is comfortable working with both staff

and shows respect for them. Having a strong commitment to friendship, they are able to be honest with one another and speak openly about issues and concerns.

Nonetheless, an interesting dilemma was raised when the concept of friendship was opened up for discussion. According to the manager, “the boundaries of being staff sometimes interferes with the relationship that you might like to have with any of the guys.” A strong ambivalence was exposed that both staff and the person being supported appeared unclear about. While speaking with participant two, his manager and preferred staff, I found differing opinions about friendship. They all appeared to enjoy each other’s company and their interactions could be described as friendly. They spoke to one another in the familiar way friends do, and called upon humour to identify imperfections in a manner that appeared acceptable to everyone at the table. But some tension was evident as we discussed friendship, as if the three of them had not yet come to a satisfactory conclusion as to how they defined this aspect of their relationship – there appeared to be some slight disagreement. Participant two identified these two staff his friends. While it was true that they performed functions beyond that of a friend and were paid to do so, he enjoyed and looked forward to spending time with his preferred staff. Even when tasks such as shopping – which the staff defined as a work task – were being completed, participant two identified this time with staff to be both perfunctory and an activity carried out with a friend. But the manager viewed things differently, and made sure to intervene in the relationship developed between the person and his preferred staff. The following passage highlights a dilemma:

And he doesn’t like that, maybe. But that is part of my role here is to manage relationships between you and staff. I think he feels that way because he would like to spend more time with certain staff in a friendships type of setting and our role is staff, and although we are friends with him, he is very independent and

can do a lot of things independently. And I think my role of interfering with that is that I would like to see him spend more time with true friendship relationships rather than relying on his staff to be his friends for him. Because staff come and go. So that's my big picture perspective that maybe we don't talk about on a regular basis. And that's my concern about him getting too close to staff is that I would rather see him build relationships with his own friends, then staff friends. That's not to say that you guys don't have a friendship relationship. But he is staff, and until he is not staff, that's part of my role, is to make sure that you don't overstep those boundaries.

There appears to be a mediating role for the manager and the staff that risks interfering with the person's own wishes about friendship. The manager felt that she has a responsibility to monitor boundaries to ensure the staff and people being supported don't mix things up. However, an interesting ambivalence was revealed as we talked more about the nature of their friendship.

It's different because I work here. So my friendship happens during my work time. It doesn't happen a lot outside of my work time right now but that's because I see them. So if I didn't, I think my relationship would become what it is with other friends. I make time for them. I don't have to do that now outside of work because I get to have a relationship with them here. And I get to do the same kinds of things that I would get to do with my friends. I don't get to do as much because I'm a team leader- I've got other responsibilities (Manager).

The manager in the second group believes she is friends with the person she supports, but does not engage in friendship activities outside of the workplace because they perform all the required friendship functions during her working hours.

Reciprocity

The person receiving support in group two explained that he had expectations of his staff that were similar to those that they had of him. He defined reciprocity as "a two-way street" and expects staff to tender the same considerations he provides them. For example he stated the following to the house manager:

If I'm out per se, I always phone and I say where I am. Sometimes you won't be here and I will have no clue where you guys are. There is no note, there is no message left for me as to where you guys are and when you're coming back. If you guys want that, then I sort of want that too so that I know that you guys are

okay.

This is a matter of common courtesy and his staff considered it a fair demand during the interview process. They appeared to have the type of rapport that allowed for both parties to express how they feel in ensuring fair and equitable treatment. The participant in group two holds strong standards for his staff, as evidenced when he said, "I like people that work hard and earn their dollar, than somebody that sort of free rolls and shouldn't be...working there." They respect his opinions in matters like this, as does he theirs.

In fact, the staff expressed gratitude for lessons learned from the person being supported, as shown below.

As for my relationship with him, he's been like a teacher actually. I've always been passionate about what I do, but he's really opened up my eyes as to how much someone can really fight for and support individuals that are living with disabilities. I've never seen someone do so much volunteer work, attend so many meetings and not get paid – it's all on your own time. He's really opened up my eyes to it. And seeing that makes me want to work harder (Support Staff).

This staff refers to the person he supports as a source of inspiration, a role model for his own actions. He sees the efforts the man puts forth when he applies himself to an advocacy cause, and measures his own efforts against them. This was evident when we spoke. Both staff in the second group were inspired by him. The impact that he has had is captured quite dramatically in this passage:

I'm getting emotional here. I absolutely love him as a person. He's amazing. He inspires me, he builds my confidence in myself by just the fact that he cares about me. And he's a great friend. And I sometimes have a very difficult time with the boundaries that are placed on me through my agency. Which probably makes me harder on him than I should be, but it's the way I have to cope with the boundaries that I'm faced with. I just, I benefit in so many ways just because he cares about me, and I know he cares about me. He's just an amazing guy. So I benefit, I'm a better person knowing him. I've become gentler; I've become more understanding, more compassionate. I think I've always had those qualities, I don't know about the gentleness, but he's definitely brought that trait

out in me. I'm not just gentler with him but with people in general. More tolerance. I look at what people can do instead of what they can't (Manager).

It appears that decisions are getting made in this interdependent context and both parties are benefitting by the association. The process of getting to know this relationship group revealed friendships, and a decision making process built on trust, respect, expectations and mutual dependence.

In turn, I asked the person being supported to tell me how he benefits by knowing his staff. About the manager, he said,

To me, she brings a lot of; she's sort of like me. I think that's where her and I click. I expect the same as she does but in different ways. But otherwise I think she has a good heart. She's brought a lot to us; she's brought us this new home. My final word is, I'm happy with her. There are just a couple of things that we have to iron out, but we'll be fine. It's gonna take some time. But overall I'm happy with her (person supported).

And for the support staff asked to participate, he told me the following.

I trust his judgment... I benefit because I know that he is going to come to work whether he is sick or whether he is not feeling well. And he's going to do the best that he can for us. He's not going to sit and smoke and joke and say, oh I'm sick I don't want to do that. At least he says, I want to do it, and when he tells us he can't, then I appreciate him at least trying to do it instead of just saying, I'm too sick I'm just going to sit down and let the other staff do it. To me, that's a leader. I'm a leader and I expect a lot from people. And if it's not done a certain way, you both know that I won't be happy with how it's going (person supported).

The person being supported in this relationship group acknowledges the support he receives from his staff, also understands their limitations, and knows that they will do their best to support him.

Summary of Results

The first relationship group focused on decisions they make about finances, vacation planning, health and well-being, leisure time and relationships. The second relationship group also focused on the issue of health and well-being, but brought attention to decisions made regarding staff selection. Staff consult and include the person being supported in the second relationship group when new staff are being hired for support positions. Decisions are also made in formal ways, and both groups spoke about PATHs (Planning Alternative Tomorrows with Hope) and IPPs (Individual Program Plans) as the most common formal methods of decision making. Major processes employed by the first relationship group include the establishment of routines and task analyses that break down tasks into component parts to ensure decision making is informed. The second relationship group discussed the value of acceptance and respect, allowing the participant to make his own decisions even though they conflict with the staff's attitudes and beliefs. Both groups engage in the act of problem solving and emotional support. Staff are available in both relationships to hear what the person has to say in order to provide guidance in the decision making process and to help give voice to their wishes. Relationship elements include friendship, reciprocity and the length and depth of their association.

Chapter Five: Discussion

Three gaps were identified in the literature reviewed for this project. The first, as found in quantitative research focused on people's deficits (i.e., Kern et al., 1998), is concerned with conventional approaches to the promotion of autonomy focused on the individual and the skills they require for self-determined behaviour. This support model is derived from the medical model of disability and often results in the disempowerment of the person requiring support. The authority of support staff and professionals has priority and the person is put in the position of learning the skills needed for independence. Some benefit may be obtained from this approach as it becomes more informed by the burgeoning social model (Coles, 2001), but it falls short by failing to recognize the social aspects of the person's impairment (the interactions with staff that are produced by their impairment-specific support needs) and casts the person as incompetent with a need for staff to intervene on their behalf.

In essence, promoting self-determination by taking steps to improve upon and ameliorate impairments in fact places the person at a disadvantage and limits autonomy. This study has uncovered support services that have not taken this approach. All members of both groups pointed to the existence of impairments and told me about the staff support these challenges might necessitate. They did not, however, identify methods taken to teach or learn self-determination skills. In the first relationship group, for example, the staff was needed to help manage finances because the person requiring support reported that she is impulsive in her spending habits and needs the help. This assistance from staff allows the person being supported to make decisions about how to spend her own money and, consequently, fosters self-determination in an interdependent context framed by her needs. In the second relationship group, the staff are invited by the person being supported to help manage his obligations in self-

advocacy groups.

The support provided by staff in both groups is derived by the needs of the person. Rather than teach the person needing support the skills they need to compensate for their impairments, a relationship is built in accordance with their support needs. And it is this relationship that highlights the second gap identified in the literature – the social model in its original formulation may not be an adequate theoretical model to inform the services available to people with intellectual disabilities. While the medical model adheres to an impetus of fixing impairments, the social model denies their impact, or at the very least, ignores them. The narratives told in this project reveal support services built on relationships derived from the social aspects of impairment – the person requiring the support of others has called for assistance, and the manner in which staff respond has defined the relationship. Ignoring this critical component disallows a complete depiction of self-determination as expressed through relationships between people with intellectual disabilities and staff paid to support them.

Using a social model that recognizes the social aspects of impairment, articulated in the literature by Goodley (2001) and Rapley (2004) for example, relationships unfold as an integral component of self-determination and the process of decision making as carried out by a person being supported by staff. Hence the importance of the third gap found in the literature – a paucity of connections has been drawn between interdependence theory, the feminist ethics of care and self-determination. Recognizing that impairments shape the relationships between a person requiring support and the staff paid to provide it allows for self-determination to be thought of as a product of the relationship, necessitating the need to explore the culmination of self-determination as it is expressed through relationships. I have relied upon the feminist ethics of care (Kittay, 2001) to expand the concept of self-determination within a social model of

disability in favour of impairment.

The Expression of Self-Determination within Relationships

Self-determination is defined in the literature as the ability of a person to act with agency, making decisions in accordance with their own preferences without being coerced by others to do otherwise (Wehmeyer, 1998). Unfortunately, people with intellectual disabilities often have limited opportunities to express self-determination – a situation generated by the actions and attitudes of service providers, as well as the limitations imposed by their own impairments. The social model can be used as a guide to address the limitations imposed by service providers but an advanced conceptualization of the model must be explored to address the role of impairments. Therefore, this project shifts the focus away from the individual, develops a focus on interdependent relationships and invites a critical standpoint regarding the social model of disability. This process sheds light on the impact of impairment on the interactions between staff and a person being supported. Amidst the relationships explored for this project, decision making domains are identified and processes are uncovered, revealing central components of self-determination. The prominent decision making domains demonstrate areas where staff provide assistance and the processes provide insight into the ways staff help a person make decisions and be autonomous.

Relationship-Based Decision Making Domains

Corresponding domains, categorized as decisions about health and wellness and decisions about spending one's leisure time, occurred across the two relationships in the promotion of self-determination. Making decisions about health and wellness is handled in a similar manner in each group; promoting health and dissuading bad habits, attending medical appointments and

advocating for supports. How to spend one's leisure time emerged as another common element although assistance was provided in a different manner in each group. Discussion of these two primary domains will be followed by 5 additional domains not shared between the two groups – finances, vacation planning, relationships with others, hiring staff and connecting with the community.

In both groups, staff feel they have a mandate, granted by the person they support and the agency they work for, to promote health and wellness. Staff in the second group, for example, spoke of the importance of exercise and being active. And in the first group, the staff told me that she helps with meal planning and preparation. In both groups, staff coordinate and attend medical appointments with the person being supported. They do this so that the person can access health professionals when needed, but allow them to speak on their own behalf, providing support to do so. The most salient topic regarding health was the decision of the participants to smoke. The staff in each group would prefer that the person in their charge did not smoke, but respect the person's decision to do so. Their role in this aspect of the health domain is twofold: they provide information about the risks of smoking and actively discourage the habit in a manner analogous to the way they would discourage any one they know from engaging in behaviour that poses a risk to health.

Two forms of assistance were found for decisions made about how to spend leisure time. In the first relationship group, options are presented by the staff that she knows the person she supports might enjoy. The choice is then made by the person being supported – with consideration given to budgetary constraints, of course – and the two relationship partners engage in the activity together. In both groups, the person being supported enjoys spending leisure time with the staff supporting them, although this occurrence appeared more prevalent in

the first group. In the second group, the person being supported spends more time in the community independent of his staff, but reported that he would like to spend more time doing things with them. In this group, decisions about how to spend leisure time were described more in terms of what staff do not do. They are not absent in this domain, but they allow the person being supported to set his own schedule and make his own plans. He will ask their opinion and join them for activities when invited.

Additional domains were not shared by the two groups, yet they are significant references upon which a framework for self-determination within relationships can be established. As mentioned above the person supported in the first relationship group works in a collaborative manner with her staff to manage finances and curb spending habits. She invites the assistance but struggles at times with the limitations on her freedom to spend her money unchecked by others. But the arrangement works well to ensure both her needs and wants are met adequately. A related domain deemed significant in the first group is the preparation and planning for vacations as they annually visit a cabin in the summer with friends. Staff plan and coordinate the event and review packing lists to ensure everyone packs and prepares well, but ultimately the preparation process is under the control of the people being supported. A final domain of noteworthy substance is the assistance staff provide in the realm of relationships with others. Two additional relationships outside of support staff were identified by the person receiving assistance: her mother and her fiancé. The staff is an integral member of both relationships, taking on the role of an advocate and mediator. She supports the person's plans to one day get married and advocates on her behalf on this issue. She also helps the person deal with the pressures of visiting with family around the holiday season, helping the person deal with the pressures associated with expressing her wishes to her mother.

In the second relationship group staff assist the person in equally important domains, focused primarily on the selection of staff to work in his home and his participation in community life having recently moved to a new neighbourhood. Although staff roles in decision making domains appeared more peripheral in the second relationship group, they still collaborate in very significant areas. Not all people labeled as having an intellectual disability who receive support services are able to select or participate in the selection of their staff. This man is able to interview applicants together with the manager and his feelings on the matter are considered before a person is hired. He also reports having the responsibility of choosing staff for his roommates who are not able to participate to the same degree that he can. In the new neighbourhood they live in, staff also report their intention to assist the person in making connections in the community. For example, they are planning to host a barbeque and invite over the neighbours.

These domains represent areas of importance in the support provided to the people participating in this study. Self-determination is expressed in these domains by members of a relationship group consisting of a person requiring support and the staff paid to provide it. Decision making domains did not focus on deficits, but revealed arrangements that foster abilities. Staff did not make attempts to change the person or fix their impairments, they provided supports where needed to uphold the existing aptitudes. To make decisions in these domains, a variety of processes were uncovered – to them attention will now turn.

Relationship-Based Decision Making Processes

Decision making processes were revealed amidst the relationships studied for this project. In the first relationship group, routines are established and followed by both the staff and person being supported; the staff help identify and find solutions to problems; they conduct task

analyses to ensure necessary information is available and understood; and participate in formal decision making procedures. Following these methods, decisions are made by the person being supported and self-determination is expressed. In the second relationship group problem solving was also identified as a key decision making process and the group participates in formal decision making procedures, as well. An additional process from this relationship group was categorized as supporting best interests. The person being supported trusts that suggestions made by his staff are going to be in his best interest. He expects that they will explain the pros and cons of the best possible options to allow him to make his own decisions.

The establishment of routines in the first relationship group plays a part in the type and amount of support provided to the person. Because specific events happen on each given day of the week, the person being supported is better prepared to manage her time without support from staff, allowing her to be more autonomous in daily decision making. The duties of staff are routine based, as well, providing them with specific support tasks to complete and allowing them to minimize the amount of time they need to spend at her apartment. Within this relationship arrangement, established routines appear to foster self-determination. Completing a task analysis together – as demonstrated by the first relationship group’s efforts to purchase a bed – has also been shown to be an effective method for promoting self-determination. In essence, the procedure assures that the person making the decision has all the information necessary to make an informed decision. In the second relationship group, the staff were shown to be in support of the person’s best interests, a channel through which self-determination is also promoted. Trusting that the staff want what is best for him, the person supported in the second relationship group can count on their opinions when he makes decisions. Staff do not tell him what to do – they instead express their opinion for him to consider and he makes his own decision.

Both groups engage in problem solving and participate in formal decision making opportunities. The task of problem solving calls for the staff to be attentive to the challenges and frustrations encountered by the people they support; a skill developed through knowing them very well. The staff hear the person's concerns, help them identify the problem and suggest or confirm possible solutions. The support providers in both groups recognize that the person is able to make their own decisions, requiring only information and support from staff to do so. At times, the person being supported also needs the staff to deliver confidence in the correctness and suitability of the decision made.

The formal decision making processes that service providers are required to facilitate (i.e., IPPs and PATHs) are exhibited as important processes in the facilitation of self-determination, yet they operate in a much less formal manner than expected. Government representatives, and occasionally family members, join the support provider to solidify the goals and expectations of the person being supported. This process, whether it be an IPP or PATH, is led by the person and the staff's role is limited to the following: ensuring the goals and dreams of the person being supported are heard and understood by the entire support network; and following up on the progress of identified goals. The long-standing relationship in the first group has made the staff very aware of the person's goals and she strives to meet them on a daily basis while they interact – the formal process does not generate aspirations that she is not already responsive to. To ensure the person being supported stays on track with her financial goals (i.e., saving for a trip to Cuba), the staff remind her often of the plans she has made for the future and help her to curb impulsive spending habits. The person supported in the second relationship group is also at the centre of this process and the results it generates are his responsibility. If he wants help achieving a goal he will ask for it. If he changes his mind and would like to focus on

something else, staff step back and allow him to make that decision.

These decision making processes underscore the importance of relationships because they are built on trust, understanding and knowledge about the person being supported. As a result, the strong relationships revealed in the sample worked to enhance the effectiveness of the methods they use to promote self-determination. They know the person well and are trusted to provide valuable assistance. Also prevalent in these processes is the proclivity of staff to let the person make their own decisions – information is provided, support is given and solutions are confirmed. And in the end, the person, rather than their staff, is responsible for the decisions they make. A final attribute of the above decision making processes is the manner in which they meet person-specific needs. Some processes were shared by the two groups, but each person requires a different type of support from their staff. Decision making processes are dependent on the person who makes the decisions, and the type of support they require from their support provider.

The Self-Determination Framework

Self-determination is portrayed in the literature at three complimentary yet distinct levels. First, the skills needed for a person with an intellectual disability to act with agency and express their will is researched and discussed. For example, self-determination skills are taught in the education system and key attributes are analyzed for their effectiveness in practical settings. Second, with a focus on environmental determinants, living arrangements, staff ratios and employment scenarios are evaluated according to their ability to promote self-determination. And finally, societal impacts such as attitudes and assessments of capacity to take risks and be rational are presented.

Characteristics of the Self-Determined Person

As outlined in the literature review, Wehmeyer (1999) suggests four essential behavioural characteristics of a self-determined person. Through this lens, the people being supported in this study will be observed. The first characteristic, termed behavioural autonomy, is defined as acting according to one's own preferences without being coerced by external influences. Although many people labeled as having an intellectual disability do not exhibit this trait independently, both the staff and the person being supported report that this attribute is present. But it was difficult to gauge the weight of the staff's influence and it is more appropriate to understand autonomy as it is expressed through their partnership. The ability to problem solve, set and monitor goals and learn from experience defines the second characteristic, termed self-regulated behaviour. As expected, these actions did not get completed independently by the people being supported in this sample. As outlined above, making adjustments to plans and monitoring progress is also an act of partnership.

With a focus on relationships, the third and fourth components do not figure prominently in the results. Entitled psychological empowerment, the third characteristic expects autonomous people to have an internal locus of control, confidence in one's ability and the motivation to act, skills that are not often attributed to people with intellectual disabilities but present within the relationship samples studied in this project. The fourth and final characteristic of self-determination is self-realization, referring to the ability to understand and know oneself and one's abilities. This attribute also did not figure prominently in the results, but it was evident that staff knew the people they support very well, again suggesting that it may not be fruitful to understand self-determination outside of relationships.

The strength of relationships in this sample and the ability of participants to engage in

self-determined behaviour with staff are not necessarily representative of most people with intellectual disabilities supported in the community. The extent to which people demonstrate behavioural autonomy, self-regulated behaviour, an internal locus of control and self realization may be contingent on the type and severity of the impairment. Circumvention of this dilemma takes place, however, when the person is placed in the context of a relationship. Although other people not interviewed in this project may need greater assistance to exhibit self-determined behaviour, it is their relationship with staff and indeed not their individual abilities that self-determination is contingent upon.

Environmental Factors

The environmental factors that influence the self-determination of this sample are similar to those discussed by Stancliffe et al. (2000), and the results would suggest that people who live in semi-independent support systems with fewer hours of staff support – as found in the first relationship group – demonstrate a higher level of self-determination. While the person supported in the second relationship group has staff available to him 24 hours a day, he often does not require their support and participates in the community without their assistance. This, again, supports the position held by Stancliffe et al. (2000), as well as the research of Tossebro (1995) who suggests that quality of life benefits are obtained in living arrangements of less than five people.

Living Arrangements

Two different styles of living arrangement and staff support are represented in this small sample. The first person is set up in an apartment where she lives by herself without roommates and without full-time staff support. The apartment, although operated by the supporting agency, is considered hers and the staff drop in to provide support. Staff arrive at her home for a

specified reason (i.e., shopping, transportation assistance, budgeting, food preparation), make sure the task is completed, and then leave. At first glance, this appeared to be a very independent arrangement, grounded firmly in the community. The second group reveals a larger support network, a house with roommates and more staff support. The man that I interviewed for this study talked about his two roommates and the staff that work seven days a week, twenty four hours a day in his home. He indicated that he is able to come and go as he pleases and has quite a bit of independence to be out in the community on his own. The composition of these arrangements drew my attention to three important components to underscore. First, living arrangements do not correspond with the expected level of support provided. Second, living arrangements are mediated by the type of resources available to and utilized by the agency. And finally, the people supported in these relationship groups told me of the significant role played by the team leader or manager in procuring their place to live, bringing to the forefront the level of trust they have in their staff.

The process of getting to know the participants in this study cultivated a more complex understanding of the composition of relationships and support. When I first met the two participants, I believed that greater independence naturally occurred in a smaller home environment with less staff involvement – the situation encountered in the first relationship group. This person lives in an apartment and receives no assistance throughout the day as she prepares for and heads off to work on the bus independently. Staff presence in her life at first appeared rather minimal, with staff arriving in the evenings for short periods of time. But in comparison to group two, the support was more concentrated with defined roles for staff. Staff help with meal preparation, grocery shopping, budgeting and figure prominently in social life and leisure activities. Speaking with both members of the first group I learned that an

independent living situation can still be an appropriate base for staff support. Conversely, the participants from group two revealed to me that less structured staff support can be available in a more communal home setting with full-time staff and roommates. This person needed less direct attention from the staff, and was able to function independently knowing they were present and able to respond to his needs. So, type of living arrangement does not necessarily dictate the level of support. Appropriate levels of support can be created and developed in either environment.

The participants in this study expressed satisfaction with their staff teams and support networks. Based on the content of the interviews completed, I presume the agencies supporting these two individuals are each using available resources to best meet the person's needs. To reach this plateau, each recently completed a transition that traversed seemingly opposite paths. Nonetheless, it appeared in this sample that type of living arrangement was meant to be in the best interest of the person but mediated by the type of resources available to and utilized by the agency. Evaluations provided by all parties involved in this study indicated the necessity to move to the current living arrangement and the success achieved by doing so – being autonomous does not equate equally with whether or not you live by yourself.

One of the primary reasons why I focus on this journey and the eventual set up of optimal living arrangements is the perceived role of the staff in making it possible. Both individuals indicated the leader of the direct staff team as an important progenitor for the move to the current situation. Staff were seen as someone who is doing what is best and there was an implied appreciation of and trust in that person generated in conversation with the participants. The participants receiving support in this study allow their staff to assist with health decisions, finances and relationships with other people. They do this because they feel their staff will act in their best interest.

Societal Impacts on Self-Determination

Self-determination can be stifled when the attitudes that drive support provisions deny people the dignity of risk (Perske, 1972). In essence, people are unable to learn from their experiences when support providers intervene with an overzealous attempt to protect the people they support from harm. While these attempts may follow from good intentions, they disallow people the freedom to choose freely among available options and shift the balance of power in favour of support providers. Risk is managed by service providers when their expressed mandate is the protection of people with intellectual disabilities. Assessments of capacity determine the level of intervention, diminishing self-determination for those deemed incompetent. According to research by Todd (2000), service providers also demonstrate a tendency to intervene on the behalf of someone to protect their dignity in public.

The staff interviewed for this project believe that it is their role to maintain the well-being and safety of the people they support. However, they also recognize that these people are ultimately responsible for the decisions they make in life, regardless of the risks they choose to take. For example, the people supported in both groups choose to smoke. And although this choice poses a risk to their health, the staff know that it is not their place to intervene. This attitude was also evident for financial decision making. For example, although staff in the first relationship group help the person establish boundaries around her spending, she is clear in stating that the money does not belong to her and that the person being supported has the final say in how money is spent. Risk is identified and the staff actively promote positive decisions, but in the end leave the person to be responsible for their own actions.

Self-Determination and the Social Model of Disability

The decisions that get made by the participants in this study can be evaluated and understood with an application of the social model of disability. As set down in the principal components of the model, the ability of the participants to express their will and be autonomous is amplified when the staff providing support recognize that they are not disabled by their impairments and instead focus on their own capacity to be good support providers (Coles,2001); when environmental factors such as living arrangements and employment opportunities are conducive to self-determination (Stancliffe, 1997 & 2001; Stancliffe et al., 2000); and societal values about competency and risk, as outlined by Bach (1998), do not restrict access and opportunity to express self-determination.

Prominent models of self-determination and the social model of disability share a similar framework in the literature. Both models have been presented and evaluated at the level of the individual, the environment and society. At a societal level, people with intellectual disabilities have been able to organize and form autonomous self-advocate groups capable of influencing and informing the regulatory bodies developing and guiding their support provisions. This level of self-determination shares roots with the independent living movement generated by the social model of disability, revealing continuity between the two models. Also going well together, both models hold that people with impairments are disabled by the environments they experience and that addressing these barriers will improve conditions. However, compatibility begins to fade when the individual is addressed by each model. As mentioned previously, original formulations of the social model tend to ignore the role of impairments, allowing emphasis to be placed only on the external factors affecting self-determination. Promotion of self-determination, however, is focused on the person as well as the environment and involves advancement of individual

skills needed for autonomous behaviour. Therefore, a modification to each model is necessary to ensure harmony can be established in a model of self-determination that adheres to the social model of disability. First, promoting self-determination must move away from teaching a person being supported the skills necessary to be autonomous and instead focus on the relationships they have with others. The results of this research support the supposition that self-determination is expressed through relationships and additional study is warranted. And second, a change to the social model must involve recognition and acceptance of the social implications generated by the presence of impairments. A shift in the model is already underway and should be cultivated in future theoretical and empirical work concerned with the situation of people labeled as having an intellectual disability.

Interdependent Expression of Self-Determination and a Social Model of Impairment

Interdependence and friendship were unveiled as important contributors to self-determination. The results of this study reveal important decision making domains and the processes that underpin the development and application of self-determination in the context of supportive relationships with staff. The abilities of the participants in this study are not disregarded by the staff supporting them – they are seen as competent individuals who ultimately make their own decisions in life with assistance from other people. But it is evident that recognition of their impairments is the foundation of the support services they receive. The staff teams assisting both individuals recognize that their support role is built on the specific needs of the individual – a supportive arrangement that does not ignore impairment but accepts it, valuing the person and their gifts. These two relationship groups show that a social model that takes impairment into consideration, values interdependence and friendships between the person being

supported and their staff, and invites the guidance of the feminist ethics of care.

Unfortunately, conventional views about self-determination are built on notions of independence – the ability to do things without assistance from others. But independence does not stand alone as the only counterpart of autonomy. This misleading notion was dispelled by Wehmeyer (1998) who argued that opportunities for self-determination need not be predicated by independent actions and abilities. This standpoint has been further developed by Kittay (2001) who argues that we all exist in interdependent support networks regardless of our capacity for rationality and self-sufficiency. She puts forwards a much more multifaceted model that values dependence and cooperation with others. It is within this context that self-determination is expressed.

Relationship Factors Affecting Self-Determination

The results of this study have revealed three primary relationship elements that influence the expression of self-determination: duration and depth of the relationship, friendship and reciprocity. These findings are in agreement with self-determination literature found within the feminist ethics of care (Kittay, 2001) and align well with important components of interdependence theory (Rusbult & Van Lange, 2003).

Duration and Depth of the Relationship

The findings of this research project are in line with conclusions drawn by Bamabara et al. (1998). A strong relationship between a person requiring support and the staff paid to provide it has been shown to impact key features of self-determination. The longer two people have known each other, the greater the level of trust will they have in one another – a trust that allows a person with an intellectual disability to rely on a staff person without surrendering or tipping the balance of power in the relationship. The staff have to play a prominent role in the life of a

person needing support and risks taking on the role of decision maker for the person. Having an established relationship built on trust, the staff is able to know implicitly what the preferences of the person are and can support them. Taking the time to build a relationship is revealed in this study as a way to promote self-determination.

Friendship

An important exploration by Lutfiyya (1993) has recognized and revealed the possibility of friendships between “staff and client.” And as I got to know the groups in this research project, the concept of friendship was identified an indelible piece of the relationship. Staff believed their work involved maintaining and building a friendship, and the people being supported extracted a relationship with their staff largely based on friendship attributes. In fact, staff felt like they gained a friendship with their charge and would likely be friends with the person even if they discontinued working with them. It is within this context that staff support the autonomy of a person with an intellectual disability. The informal support structure existing in friendship can and should be recognized and explored by a person needing support and the staff paid to provide it.

Recognition of boundaries – a barrier not commonly faced with other relationship partners – is necessary, but acceptance of friendship should be paramount. It is an empowering experience to have a friend and denying the person with an intellectual disability the opportunity to establish this connection with their staff may suppress the potential for autonomy. Although staff may establish limits for developing friendships with their charge, when self-determination is expressed through relationships friendship comes forward as an indelible factor to be considered. Friends are mutually dependent on one another, and as Kittay (2001) suggests in feminist ethics of care literature, recognition of “dependency relations” leads to recognition of

competence and ability within relationships.

Reciprocity

To evaluate the interdependent relationship between staff and client, interviews focused on reciprocity and how the two relationship partners benefitted by their association. In conducting this exploration, expectations held by participants about their staff were identified, a definition of reciprocity was unearthed and staff attitudes about relationships were developed. This examination of attitudes helped assemble the features that brought these staff into the realm of support provision, and how they benefit from it. Interdependence, as articulated by Rusbult and Van Lange (2003) includes the dimension entitled mutuality of dependence, describing the extent to which people are equally dependent on one another. It is clearly evident that people with intellectual disabilities are dependent to some degree on their staff, but I also learned that staff are somewhat dependent on the people they support, as well – beyond the need, of course, to just earn a living from their job. Exploring reciprocity with the participants suggested that there is mutuality of dependence in the relationship between people with intellectual disabilities and the people paid to support them. Both the staff and the person being supported shared their feelings about the other person and it was clear that both parties benefitted by the association.

When self-determination for people with intellectual disabilities is situated within their relationships with staff, factors such as friendship, reciprocity and trust become prominent variables in the promotion of autonomy. Instead of teaching skills and focusing on deficits, support providers and self-advocates can instead encourage relationship development between staff and people labeled as having an intellectual disability. This shift, which focuses on the relationship instead of the person, brings both the concepts of self-determination and the social model of disability together for the benefit of people supported by paid staff.

Chapter Six: Conclusions

The disabling features commonly associated with intellectual impairment limits opportunities for autonomy when support services are absent. Representations of a person built on notions of incompetence and inability may also be present when independence is the prime objective of support provision. Self-determination can instead be regarded as an act of interdependence, where one individual works with others to derive and meet goals, and be autonomous, active members of their community. Kittay (2001) accentuates the importance of dependency relations to signify the role that other people play in the lives of an individual. We rely on other people to support us as we carry out the responsibilities of self-determination and autonomous behaviour. Without their support staff, the participants in this study would rely instead on the supports available in their community like others do. But their impairments are such that they require more support than what is naturally found among family and friends. The staff's role, then, is to work in partnership with the person to help them access this variety of available supports, achieving the aims commonly attributed to being independent through an interdependent support network. With these supports in place, the limitations caused by impairment begin to fade, allowing the person to express their will.

Within relationships with staff, people with intellectual disabilities make decisions and express self-determination. Therefore, the primary aim of this research project has been guided by the following research question: How is the self-determination of an individual with an intellectual disability expressed in and through relationships with paid support providers? To answer this question, results were organized to illustrate first the domains where decisions are made collaboratively and second, the decision making processes followed in a relationship group comprised of a person with an intellectual disability requiring support and the staff paid to

provide it. Identified decision making domains converging across both groups include the areas of health and wellness and planning leisure time. Additional domains show that people with intellectual disabilities also join with their staff to make decisions about finances, vacation planning, management and selection of staff, and building connections with people in the community. Decision making processes revealed in the results strengthen the supposition that self-determination is expressed through relationships. While both groups participate in formal decision making opportunities and engage in problem solving, the processes are often informal and built on the knowledge gained through relationships. Additional processes include routine establishment, task analysis and supporting best interests.

The second research question focused on the defining characteristics of relationships affecting the expression of self-determination. According to the participants in this study, the most important aspect of their relationship is trust. Trusting that staff have their best interests in mind allows the people being supported the opportunity to make informed decisions based on the information they receive from staff. With trust as the central theme, important relationship elements exhibited in the results include friendship and reciprocity – fostered through the duration and depth of their relationship. Trust, empathy and respect were revealed in the narratives of both groups.

Limitations

Although most people with intellectual disabilities live in the midst of interdependent support networks involving paid support providers, their expression of self-determination may not rival the opportunities uncovered in this research endeavor. Fortunately, both relationship groups exhibited people in situations that maximize their autonomy. However, reciprocal

relationships built on friendship and trust are not altogether common and many people do not experience these benefits. There also exists a wide range of abilities encompassed within the population of people with intellectual disabilities that are not addressed in this project. Some people, for example, do not use words to communicate. Including this variable in the sample would have been beneficial but was not included due to time restrictions associated with the project.

Final Thoughts

Self-determination is an expression of causal agency in an interdependent environment, rather than an act of independence. For a person with an intellectual disability, self-determination is expressed through interactions with a support network often comprised of family, friends and paid staff. This research has been an exploration of how self-determination is manifested by the relationships developed between people with intellectual disabilities and the staff paid to support them. The literature review divides research on self-determination into three areas of focus: the individual's dis/abilities, environmental influences and societal attitudes and institutions in accordance with the social model of disability and theories of normalization. But I am critical of the traditional take on the social model because it has been accused of rejecting impairment as a cause of disability and has failed to empower people with intellectual disabilities. We must accept that people with intellectual impairments may lack the ability to be rational decision makers if left alone to do things independently. But people have been wrong to deny them their autonomy and self-direction. Decision making domains and processes occur in an interdependent context and the relationship between staff and the person being supported influences self-determination.

Appendix A: Consent Form for Service Organization

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

This research project is an exploration into the ways that people with intellectual disabilities are able to express self-determination when they live with paid support providers in a residential setting. The primary intention is to uncover substantive and formal theories about this aspect of the relationship developed between people with intellectual disabilities and the staff supporting them.

Participation in the study involves three main components. I have begun with an interview with an individual to whom you provide support. They have selected a support provider employed by your agency to participate in this project. Their participation in this project will involve two in-depth, semi-structured interviews alone and then together with the person they support. These interviews should take approximately 45 to 60 minutes and will take place at a time and location most convenient for participants. Please remember that participation in this study is voluntary and if you choose not to participate or to withdraw from the study at any time, you may do so without penalty. You may review interview questions in advance and you may ask for further explanation at any time.

Interviews will be tape recorded to allow me to review and transcribe the discussions. The research advisor and I will be the only individuals with access to this data and all of personal identifying characteristics and the name of the agency will not be included in the final report. Data destruction will take place when the thesis has been successfully defended. However, please note that I am required by law to report the abuse of individuals receiving care to the legal authorities. We do not anticipate the occurrence of any discomforts or risk associated with participation in this study.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and

professional responsibilities. Participants are free to withdraw from the study at any time, and /or refrain from answering any questions they prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

The study is a Master's Thesis being conducted through the Interdisciplinary Master's Program in Disability Studies at the University of Manitoba and the research has been approved by the Joint Faculty Research Ethics Board. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat. A copy of this consent form has been given to you to keep for your records and reference.

If you agree to participate in this research project, please place your name and signature in the appropriate spaces below.

As a representative of _____, I _____
(print name) understand what the study is about and my signature below indicates that the agency will participate in the research.

I would like to obtain a copy of the research report once it is complete.

Yes No

(Please circle).

Appendix B: Consent Form for Research Participant Interviews: Self-Advocates

We are doing a research study to learn about self-determination and the way that decisions are made when someone is supported by staff.

If you decide that you want to be part of this study, you will be asked to

- Do an interview that will last 45 minutes;
- Choose a staff person that we can interview, too;
- Do an interview with you and your staff that will last 45 minutes.

I will write notes and use a tape recorder to help remember all the things we talk about. Only my supervisor and I will listen to it.

When we are finished with this study we will write a report about what was learned. Your name will not be written anywhere on the final report and no one will know these answers came from you personally.

You do not have to be in this study if you do not want to be. If you decide to stop after we begin, that's okay too. You can ask questions if you do not understand any part of the study.

If you have any concerns or complaints call the Human Ethics Secretariat.

If you decide you want to be in this study, please sign your name.

I, _____, want to be in this research study.
(Print your name here)

Appendix C: Consent Form for Research Participant Interviews: Support Providers

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

This research project is an exploration into the ways that self-determination is expressed by people with intellectual disabilities living with paid support providers in a residential setting. The primary intention is to uncover substantive and formal theories about this aspect of the relationship developed between people with intellectual disabilities and the staff supporting them.

Participation in the study will involve three main components. I have begun with an interview with an individual to whom you provide support. They have selected you to participate in this project. Your participation in this project will involve two in-depth, semi-structured interviews first with you and then together with the person you support. These interviews should take approximately 45 to 60 minutes and can take place at a time and location most convenient for you. Please remember that your participation in this study is voluntary and if you choose not to participate or to withdraw from the study at any time, you may do so without penalty. You may also refuse to answer any interview questions and you may ask for further explanation at any time.

Interviews will be tape recorded to allow me to review and transcribe the discussions. The research advisor and I will be the only individuals with access to this data and all of your personal identifying characteristics and the name of the agency you work for will not be included in the final report. However, please note that I am required by law to report the abuse of individuals receiving care to the legal authorities. We do not anticipate the occurrence of any discomforts or risk associated with participation in this study.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

The study is a Master's Thesis being conducted through the Interdisciplinary Master's Program in Disability Studies at the University of Manitoba and the research has been approved by the [insert full name of appropriate REB]. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat. A copy of this consent form has been given to you to keep for your records and reference.

If you agree to participate in this research project, please place your name and signature in the appropriate spaces below.

I _____ (print name) understand what the study is about and what I will have to do and my signature below indicates that I want to participate.

I would like to obtain a copy of the research report once it is complete.

Yes No

(Please circle).

Appendix D: Interview Guide 1: w/ Self Advocates

- Tell me about yourself – your likes and dislikes.
(Favourite foods, music, movies, sports).
- Tell me about the community you live in.
- Tell me about the important people in your life. Who do you count on?
Friends & Relationships
Staff
What do they do?
How long has this staff worked with you?
What is the longest someone has worked with you?
Who picks the staff that work with you?
- Tell me about life at home.
Probe for restrictions/rules.
- Let's talk about money and spending
Does someone help you with that? How?
- May we talk about your health?
Do you have concerns or would you say you are pretty healthy?
Who makes your appointments?
Are you happy with the services you receive?
- What do you do for fun? How do you spend your leisure time?
How do you decide what to do?
Who do you spend your leisure time with?
- Tell me about work.
Why did you choose to work there?
- Discussion about risk

Appendix E: Interview Guide 2: w/ Support Provider

- Tell me about the agency you work for. What are some core values?
- Tell me about the work you do here.
What is your role?
- What is the nature of your relationship with the individuals to whom you provide support?
- Please contrast this relationship with others.
- Tell me about a typical evening at the residence. What do you guys do? At home? In the community?
- I would like to explore decision making processes. Let's begin by discussing the types of choices made by the person you support.
 - In what areas are they able to make choices?
 - How do you participate in the decision making process?
 - What types of choices don't get made by the person?
 - What choices are your responsibility to make?
- Do you know of any formal procedures that allow people with intellectual disabilities to express their will? Tell me more.
 - Have you participated? What is your role?

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