# CAN INCLUSION AND NEOLIBERAL PRINCIPLES COEXIST?

# UNDERSTANDING THE *PASSPORT* EXPERIENCE: CAN INCLUSION AND NEOLIBERAL PRINCIPLES COEXIST?

By

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A Thesis
Submitted to the School of Graduate Studies
in Partial Fulfillment of the Requirements
for the Degree
Master of Social Work

McMaster University

MASTER OF SOCIAL WORK
(2009)

McMASTER UNIVERSITY
Hamilton, Ontario

TITLE: **Understanding the Passport Experience: Can Inclusion and Neoliberal Principles Coexist?**

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NUMBER OF PAGES: vi, 112

# ABSTRACT

Of relevance to the field of intellectual disabilities is the interest in service provision that increases community inclusion of people with intellectual disabilities. In response to this interest the provincial government has recently developed individualized funding models of service provision for people with intellectual disabilities (i.e. the *Passport* program). The implementation of the *Passport* program has raised questions for the researcher about the effectiveness of individualized funding programs to increase overall inclusion in communities. In particular the researcher was interested in exploring how *Passport* recipients and their caregivers experience this shift is service provision.

Reviews of literature related to individualized models of support in other regions have indicated that the move to individualized service can sometimes support larger neoliberal shifts in social service provision. Results indicated that the *Passport* recipients and their caregivers experienced increased opportunities for inclusion, as was indicated by increased opportunities for social relationships at various levels. But, the experience of positive emotional effects from social inclusion was diminished by consumeristic neoliberal influences on service provision that do not challenge societal attitudes about disability thereby the marginalization of people with intellectual disabilities.

The results inform a need for social work to attribute more value to the lives of people with intellectual disabilities and their families by increasing opportunities for self determination through the promotion of self-advocacy and fostering relationships of value among people with and without disabilities. Results also warn against the erosion of service quantity and quality that accompanies shifts in service delivery which place value on neoliberal principles rather than principles of inclusion.

# ACKNOWLEDGEMENTS

Many thanks to all the people involved in this project. The service providers, and most importantly the families and *Passport* recipients themselves. Thank you for your honesty and interest in supporting this research.

Thank-you also to my supervisor, Ann. Thanks for bringing such a vast knowledge of disability research and study to my attention, and sticking with me through this learning process. Your enthusiasm for research about intellectual disability was a continual encouragement to me.

Special thanks to the many friends who have joined me along the way with this project. To my social work classmates, Jacquie, Katie and Sarah, thanks for inviting me to commiserate and celebrate with you this past year. Thank-you Amy for your honest edits and to Cole for your jokes in times of stress.

Finally, thanks to Laura for you perpetual support and encouragement in this process. Your patience with me has been appreciated, and your faith in me was so important in helping me to move forward.

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# INTRODUCTION

I have a story. It is about a woman who lived all her life with her parents because everyone thought that she wasn't intelligent enough to live on her own. Everyone was happy with this arrangement, except the woman, but she had always been told she couldn't live by herself so she never tried to. Eventually, her parents grew older and their declining health required them to move to a nursing home, so the woman was forced to learn how to live by herself. With some help from her brothers and sisters, she bought a small house in a little town and, for the first time, she experienced inclusion in her community. Not long after she moved out on her own she was invited over to her neighbour's house for dinner, she got a part time job at the grocery store, and started going out in the evenings with a group of women she called her friends. Today, this woman says that she loves her life. This woman is my aunt, and this story is my family's story about how inclusion can change the life of someone with an intellectual disability. This story, along with my professional experience working with adults who have intellectual disabilities , has brought me to the topic of inclusion. In this thesis, I will explore how social service programs can foster inclusion. In particular, I will examine how the *Passport* program does, or does not, support inclusion in the lives of people with intellectual disabilities and what this program means to them.

To contextualize this research, let me first offer some background information. It is important to understand that, in 2006, Ontario's Ministry of Community and Social Services announced a plan called *Opportunities and Action* (MCSS, 2006). This plan represented a shift in developmental services from programming that supports segregated services (the historical and much maligned model of service provision) to services that are inclusive. Within the plan it was written that, for people with intellectual disabilities, "Living in the community is not enough. True transformation will have occurred when people with a developmental disability are part of the community" (MCSS, 2006, 11). The language and power of this promise is the result of decades of work by advocates and self-advocates towards a total shift in the way that service for people with intellectual disabilities is provided in Ontario.

This shift in thinking provides the opportunity for people with intellectual disabilities to be able to experience "full citizenship" in the communities where they have lived for years without these rights. The *Opportunities and Action* plan included the *Passport* program, a program released to embody the province's new perspective on developmental services. *Passport* was designed to provide individualized support to people with intellectual disabilities to support them to engage in community participation. In theory, this is positive for people with intellectual disabilities, but how do we know if people who engage in these services are experiencing “full citizenship”? How do we determine if this shift in service delivery actually changes the way that people with intellectual disabilities experience their communities?

The intended outcome of both the *Opportunities and Action* and the *Passport* program is that people with intellectual disabilities will have more control over the kinds of support they get, and that Ontario will become a better place for people with intellectual disabilities to live (MCSS, 2006). Part of the *Passport* program includes new funding strategies that are designed to give the user more control over services, moving away from paternalistic notions of service delivery. However, this shift also raises questions about whether or not there are underlying motives for employing this type of funding strategy. In some ways the funding model reflects an overall shift in social service delivery towards privatization, decentralization and individualization (i.e., neoliberal shifts) (Brodie, 1999). While analyzing the neoliberal motives for implementing a new service delivery model, of equal importance to this thesis is understanding how this shift is experienced by people with intellectual disabilities and their caregivers. Specifically, I will look at the question of whether or not they experience inclusion through *Passport* and come to some conclusions about their overall experience of the program.

Throughout this text I have situated myself within the topic of discussion. As I alluded to earlier, my personal and professional motivation for understanding inclusion of people with intellectual disabilities is what drives my desire to conduct this research and the theoretical and methodological choices I have made.. I have no illusion that what is written in this text is a full account of all possible understandings of the topic of *Passport* and individualized services. However, this research is an accurate reflection of how I understand these issues and the process I used to come to this understanding.

I will continue this thesis with, first, a reflection on the language that is used. I will then move to a broader review of the history of *Passport* as well as a discussion of relevant literature. This will be followed by a review of the research methods and summary of some of the results of the research. A discussion about the results, with comment on the implications for social work and future research, preface a conclusion.

At this point I am reminded that in my quest for full citizenship and for the inclusion of people with intellectual disabilities in research, what I hope to do is shift the reader's view about what matters. As Bach (2002, 2) writes regarding inclusion for children with intellectual disabilities; "We turn from a child's disability to the ways in which he is recognized by others, to the way others 'react' and know him." My hope is that this research will, in some way, change the way that the reader comes to know people with intellectual disabilities, allowing more room for inclusion to occur.

# LANGUAGE

Traditionally, positivistic language, based in the medical model of disability, blames people with disabilities for their situation. This model would suggest that someone who uses a wheelchair can not access all buildings because of they are disabled, rather than because all buildings are not accessible. One way social constructionism can challenge these views is by using language to reshape our understanding of disability (Rioux and Bach, 1994, vii). In an effort to reflect a social constructionist view, a short explanation about the language used throughout this research is necessary.

Adopting new terms (like 'labeled intellectually disabled' or 'having an intellectual disability') and leaving behind old negative and stigmatizing terms (like 'retarded', 'moron' and 'imbecile') allows us to begin to reshape perceptions of people so labeled. As these newer terms are preferred by people with intellectual disabilities, as a group, their use provides an opportunity for the people who are labeled to redefine how they are understood (Stockholder, 1994, 156). With this in mind, throughout this research project "person first" language is used to avoid labels that construct a historically negative view of people with intellectual disabilities (Tower, 2003) and to demonstrate respect towards the people to whom the label is applied.

Before going further, there is a second consideration about language that I will explain. It is important for the reader to understand that I usually refer to people with intellectual disabilities who were involved in this project as '*Passport* recipients'. However, in the data that was gathered, the *Passport* recipients were not always the primary respondents to the research questions. In these instances, their support person is referred to as their 'caregiver'. Caregivers can include family members as well as paid service providers but, in both cases, this term is used to describe the person who provided support to the *Passport* recipient during the research process.

In situations where quotations from family members are used, the reader will note that adult *Passport* recipients are sometimes referred to as children by these family members. This is typical of paternalistic attitudes show towards people with intellectual disabilities, and although I can not be certain of the parent's intent when using this language, in this work I will refer to adult *Passport* recipients as 'adult children' to be consistent with social constructionist views of disability. This is in line with the social model of disability that views disability as a function of societal discrimination towards people who have disabilities (Rioux, 2009, 203).

Finally, as someone who does not have a disability it is important to note that I have tried to take my direction around language from self advocates and the people who are involved in this research project. With that in mind, I must still acknowledge that my own ableist tendencies will inevitably seep into the text but that every effort has been made to minimize how often this will occur.

# BACKGROUND TO *PASSPORT*

In May 2006 it was reported that 16,400 people who have intellectual disabilities in Ontario were using services categorized as "Day Programs and Recreation" funded by the Ministry of Community and Social Services (MCSS, 2006). This number demonstrates that there is clearly a demand for these types of supports. Coupled with my personal and professional experience of people who have intellectual disabilities, I have been motivated to explore what these services mean to them. At the same time that these numbers were reported, Ontario's Ministry of Community and Social Services also announced their plan called *Opportunities and Action* (MCSS, 2006). As previously stated, the *Passport* program is rooted in the *Opportunities and Action* document, so further understanding *Opportunities and Action* is important to understanding *Passport*.

*Opportunities and Action* signifies Ontario's Ministry of Community and Social Services' shift towards creating services for people with developmental disabilities that are completely community-based and designed to build a "more inclusive province for people who have developmental disabilities"(MCSS, 2006, 2). This plan is summarized by six underlying principles including;

- Citizenship
- Fairness and equity
- Accessibility and portability
- Safety and security
- Accountability
- Sustainability

*Opportunities and Action* was created with “the fundamental vision to support people to live as independently as possible in the community and to support the full inclusion of Ontarians with disabilities in all aspects of society” (MCSS, 2006, 14). Evidence is given to show how far we have come in creating communities of inclusion by spotlighting the closure of Institutions and the development of a service system that works in the community with people who are identified as having intellectual disabilities. The six principles of *Opportunities and Action* are also applied to 12 areas of service where transformation of developmental services will occur. These twelve areas of service cover a wide range of support models for people with intellectual disabilities and, as a result, impact directly on the delivery of day activities for people with intellectual disabilities.

The *Passport* program began in August 2006. The MCSS indicated that, through *Passport,* they planned to begin to fund community participation supports (CPSs) for over 2,100 people in Ontario (MCSS, 2007). CPSs were previously known as day programs, and day programs are generally (but not always) day activities in segregated settings for people with intellectual disabilities. The *Passport* program is unique in that applicants who receive funding can spend it on any kind of CPSs that they choose, by directly purchasing the services that they want from either a public or private provider (MCSS, 2007). So, rather than simply enrolling in a government funded programs that already exists, *Passport* recipients can create their own individualized program using government resources.

# LITERATURE REVIEW

To provide a fuller understanding of the issues addressed in this research, the following literature review will explore some of the current understanding of intellectual disability. This includes the topics of choice, inclusion, and quality of life for people with intellectual disabilities. As well, critiques of neoliberal government in social service programs that are similar to *Passport* are included to round out the reader's understanding of how *Passport* is situated within current social service trends.

## *Intellectual Disability*

Disability has historically been understood as a sickness, and the medicalization of disability has generated an understanding of people with disabilities as being incapable and confined by their impairments (Hughes, 2002). As a society we have come to rely heavily on definitions of 'normal' and 'abnormal', and this has worked against people with intellectual disabilities in the process of being valued (Carlson, 2005). Also, industrialization and the prioritization of a common understanding of 'productive' has also resulted in people with intellectual disabilities being deemed to be less important than their non-disabled counterparts because they can not always meet the social standard of productive. In addition to these overarching stereotypes, people with intellectual disabilities also carry with them stigma, a stigma imposed by others that is directly related to a history of institutionalization (Malacrida, 2009, 181).

This historical understanding of people with intellectual disabilities as unable, has led to professional paternalism – the idea that people with intellectual disabilities are unable to take care of themselves and so must be taken care of by professionals who ‘know what is best’. Carlson (2005) uses Foucault’s example of prisoners to illustrate how the institutionalization of people with disabilities creates ‘disciplinary individuals’; objects to exercise power over. As I alluded to earlier, the normalizing gaze is most effective because socially we have adopted the terms ‘normal’ and ‘abnormal’ to describe people who fit within dominant social constructs and those that don’t. These concepts are still in place and continue to separate people with disabilities from those that do not have disabilities. Today people with intellectual disabilities are often powerless to object to having invasive IQ tests to qualify their need for support. Submission to these tests is often in an attempt to avoid contesting the power of the professional. This is tied to Foucault’s concept of the normalizing gaze which states that professionals have the power to pass judgment about people with disabilities in determining their need for services (Moffatt, 1999). Malacrida (2009) also ties these Foucauldian mechanisms of power and oppression to some of the current understanding and treatment of people with intellectual disabilities, such as the use of IQ tests that is described above.

More recently, our ways of looking at disability have shifted away from the medical model towards a social model of understanding disability. This changes disability from a problem that is located within a person to a problem that is created by society's construction of disability (Oliver, 2009). Further impetus for this change comes from the larger disability movement that is motivated by a desire to change how people with disabilities are understood and treated (Finkelstein, 2001).

### *Inclusion*

Stemming from the mass institutionalization and the consequent exclusion of people with intellectual disabilities from community beginning in the late 19th century and continuing today, self-advocates and family advocates developed a new understanding of how to support people with intellectual disabilities. This new understanding began, first, with the idea of 'community living' - having people with intellectual disabilities living out of Institutions in community - that took hold in the 1950s but then, later, evolved and expanded into the notion of 'inclusion' (Goodley, 2000). Inclusion is a term that has many definitions in various contexts, but it is generally used to describe how people who exist on the periphery of a group are invited to join that group in a way that develops mutual recognition of the differences that define them (Bach, 2002; Bates, 2004). The term inclusion is one that is used commonly in the language of social policy development, but the meaning of inclusion in social policy sometimes offers a superficial definition of support that is different from how it is understood by advocates for people with intellectual disability (Wilson, 2006). Social policy definitions offer an understanding of inclusion as acceptance of people with intellectual disabilities into public spaces, while inclusion, as defined by advocates, presses for social acceptance *and* equal treatment of people with intellectual disabilities.

A social model understanding of inclusion can be gained by considering that inclusion, itself, is a discourse constructed by social, cultural and political forces (Yong, 2007). Simons & Masschelein (2005) add that the discourse on inclusion should be understood in terms of Foucault's construct of modern governmentality. Integral to modern governmentality is the concept of the 'double bond', in which individualization and totalization are linked, that is, in any nation-state people who act as free individuals are linked to other individuals in a totality. In this case, no one is alone in society, we all act and react to one another to create a social construct that is common among us all. To further explain this, Simons & Masschelein (2005) write that, in the context of education, the discourse that moved society towards inclusion began in the 1960s and 1970s with Wolfensberger's concept of 'normalization'. This was a new understanding of disability as something that correlates with environmental factors – by moving people with disabilities into more 'normal' environments a more 'normal' view of disability can emerge. With these new understandings of disability the individualized freedom of people with intellectual disabilities was brought into question therefore the totality of society was forced to consider inclusion because of the effect of the double bond. No longer were people with intellectual disabilities dismissed completely because they held social space among people who do not have disabilities, causing them to reevaluate their social construct of disability.

Another definition of inclusion from Wilson (2006), who cited Schleien, Green and Stone, indicates that it exists on three levels, ranging from physical integration, to functional inclusion, and, finally, to social inclusion. Physical integration indicates that a person is physically a part of community – that they may live, work and/or play in the same communities as their non-disabled peers - while functional inclusion denotes an individual's ability to function successfully in a particular environment (for example, in a work place). Social inclusion is that aspect of inclusion that is made evident by the sharing of positive interactions with others and by social acceptance.

In the literature about initiatives like *Opportunities and Action* and the literature pertaining to other disability policies, it has been suggested that changing policy and creating legislated rights for people with disabilities is not enough to create inclusive communities (Russell, 2003; Young, 2000). Hall & Hewson (2005) show statistical data that demonstrates that, even with a program similar to *Passport,* in Britain very little transformation in access to community was observed as a function of policy alone. Beyond altering policy to reflect the needs of people with intellectual disabilities, in order to reshape practice with people who have intellectual disabilities the discourse about them needs to change for true inclusion to occur. Yong states that;

> "To conquer retardation, then, means not ridding society of 'the retarded' but ridding society of negative attitudes toward retardation; not only educating 'the retarded' but educating all persons; not changing 'the retarded,' but changing society as a whole. The stronger version [of reconstructing disability discourse] also argues for a moratorium on the language of retardation but goes further to insist on full inclusion" (2007,110).

### *Choice and Flexibility in Service Delivery*

Improving community inclusion while expanding choice and flexibility of service are some of the goals of individualized programming as articulated in the *Passport* document(MCSS, 2006). When it comes to quality of life, research has shown that people with intellectual disabilities, who both live in the community and have more choice in their lives, report higher rates of quality of life (Neely-Barnes, 2006). Although the measurement of quality of life is critiqued by some for its attempt to normalize particular groups (Rapley, 1998), I believe that accepting the desire of many for improved quality of life has some value in understanding why choice and self-determination are thought to be important goals in service delivery.

Wehyemer and Bolding (2001) studied the effects of community-based supports, as opposed to supports provided in a congregate setting, on people with intellectual disabilities and discovered that community supports enhanced self-determination and, therefore, quality of life. This is further supported by

Neely-Barnes, Marcenko & Weber (2008), but also complicated by their submission that increased choice in community supports does not necessarily increase experiences of community inclusion when one is concerned with more severe intellectual impairments. Their research suggests that increased inclusion does not always equate to greater quality of life.

Other literature, however, points to the complexities that exist for implementing supports that enhance self-determination. This includes the difficulty in trying to measure how and when self-determination is enhanced (Cummins, 2001). As well, one must recognize that there are varying levels of self-determination that people with different cognitive and adaptive abilities can posses. This brings to the forefront questions of risk for people with intellectual disabilities who may not understand the consequences of their choices. These concerns can, in part, be balanced by an understanding that for everyone, regardless of ability, some risk exists in allowing greater control for decision making (Bannerman, Sheldon, Sherman & Harchick, 1990; Neely-Barnes, Marcenko & Weber, 2008). In addition, capacity building among people with intellectual disabilities should be mentioned here. The support to build capacity among people with intellectual disabilities to make their own choices is critical to their eventual independence in this area (Goodley, 2000).

For some social service programs that have individualized supports in Britain, an increase in choice and flexibility has increased the amount of support that is required from caregivers to serve people with intellectual disabilities. A critique of Britain's *Valuing People* document, which has similarities to *Opportunities and Action*, is that it operates from a romanticized view of people with intellectual disabilities as being independent and involved in community with supportive families (Burton, 2006). This denies the reality that many people with intellectual disabilities continue to reside in out-of-home care. Further, it reveals an underlying understanding that family involvement is always best, but, as Stevens (2004) points out, self advocates have clearly stated that we must consider that family values and interests may be in conflict with the values of a person with an intellectual disability.

### ***NeoLiberal Movement***

The 'neoliberal turn' has increasingly dominated political and economic discourses over the past 30 years (Burton, 2006), therefore, it is important to consider how it has impacted developmental services in Ontario. Neoliberalism, as defined by Finn (2007), can be understood in terms of decentralization, privatization and individualism. In a neoliberal model, "Citizens are individuals, not members of communities or even families, and it is the consumer that is the defining unit of society"(Finn, 2007, 16).

Decentralization is a shift that is typical within the neoliberal movement, is intended to improve equity, efficiency and accessibility of service (Finn, 2007). Decentralization takes the work of coordinating and managing social service supports away from the government and spreads it out in the community, often onto the shoulders of caregivers. Burton (2006) postulates that, in developmental services, decentralization has produced a fragmentation of the infrastructure of support services that currently exists and is allowing a trend of poorly trained staff and unregulated services to emerge.

Privatization of social services within neoliberalism is seen as a way to stimulate the economy by creating a quasi-market out of social service users. Privatization within developmental services has been observed by Reinders (2008), who is critical of social service programs that offer service in a way that appears to empower service recipients by encouraging them to 'purchase' services from a free market, but in actuality does not give them any power. Because of society's historical paternalistic construction of people with intellectual disabilities, a shift to free market and individualized service delivery models that value programs based on choice and inclusion are generally accepted by people with disabilities. Accepting these services is seen as a way to step outside of historical paternalistic professionalism (DiRita, 2008). This acceptance of a social service free market is challenged by Swenson (2008) who highlights the inadequacies of a quasi-market service system that does not account for the atypical needs of people with intellectual disabilities. People with intellectual disabilities may need support to hire staff, manage financial resources or simply to build capacity among people with intellectual disabilities so that they can more independently do these things. Swenson (2008) questions whether the financial and social positions that people with intellectual disabilities hold can even constitute a group of consumers that is capable of creating or sustaining a market.

Individualization is a term used to describe the neoliberal trend in social service delivery that attempts to view each person who uses a social service as an individual user (Finn, 2007). For people with intellectual disabilities this looks like service provision that is measured out fiscally and standardized to match each person's level of support need, like the *Passport* program. There is a growing discontent with the standardization of services that comes out of economic rationality based on utilitarian styles of providing service, styles of service provision that are intended to benefit the largest number of people (DiRita, 2008). The effect of utilitarian provision of service is that, although the moral worth of people with intellectual disabilities is recognized, the funding frameworks on which they are supported have not changed and continue to focus on saving money (DiRita, 2008). DiRita's (2008) description of economic rationality describes how this mentality continues to undercut many of the positive changes that could occur through a move to individualized services. In this way, the value of people with disabilities becomes contingent on their ability to contribute to the economy, not on their moral equality.

### *The Cost of Disability*

Further to understanding the construct of neoliberalism in this context, a recent evaluation of *Passport* (that was funded by the MCSS) highlights some of the *Passport* stakeholders' concerns about how the program has been funded: the dollars devoted to *Passport* were far more limited than had been hoped for. Service providers expressed concern about how the *Passport* program was released and announced. *Passport* was so heavily advertised as the long awaited solution to segregated programming that when it was released, and only a few people benefited from it, families and people with intellectual disabilities were upset by the minimal change that it offered to the problem as a whole (MCSS 2008). Of particular concern was the limited amount of financial resources that were made available to *Passport* applicants. People who were using *Passport* stated that they were troubled by the lack of resources available, and noted that the financial support they received through the program did not fully meet their needs (MCSS 2008). It appeared that there was a disconnect between the cost of what applicants felt they needed and the amount of funding that was actually available to them.

Within the practice of developmental services there is a growing demand for tools that measure how much support someone with an intellectual disability needs to successfully function in community (Smith & Fortune, 2008). This is completely fiscally driven as the desire to measure support need in the community comes from an ideology and related body of literature that evaluates the cost of disability and relates that to social service cost reduction through encouragement of community involvement (Cimera, 1998; Knapp, 2004). This fits with the changes stated previously about neoliberal social service delivery that put an emphasis on empowering people with intellectual disabilities by extending service to them in a way that encourages them to purchase services from a free market (Reinders, 2008).

This type of support channels money that was previously provided to service providers directly to the service recipients to manage as they see appropriate. *Passport* documentation states that the intention of direct funding is to provide flexibility to service users so that they can have choices in the services that they engage in. In addition to providing choice, this model of support also encourages a social service market to emerge from within the public service sector. Again, this mirrors the neoliberal moves to privatization, where competition within a free market is encouraged and government involvement in social service is minimized or eliminated altogether (Finn, 2007). In this new scenario, competition exists amongst service providers, and direct funding has created a system of service provision that tries to be more efficient. Unfortunately, efficiency is sometimes achieved at the cost of quality staff and safety within the service environment (Baines, 2004).

With this in mind it is important to note that within the literature a tension exists between neoliberal principles that operate to cut costs in social services and human service principles that do not take advantage of the tools of market analysis that inspire creativity and efficiency in service (Swenson, 2008). It has been argued that the privatization of service provision has encouraged creativity among service providers. However, when quality of service provision is examined in a system that values privatization, it becomes evident that people who can afford higher quality programming are at an advantage to those with limited resources and complex needs (Baines, 2004). The experience of reduced quality in staff and service is also supported by a study conducted in Northern Ireland (Beecham, McGilloway, Donnelly, Kavanagh, Fenyo, & Mays 1997) that noted financial savings are experienced in the transition from hospital-based supports to community-based supports for people with intellectual disabilities. The same study, however, questioned the quality of support that is provided in community if funding is reduced and suggested that maintaining higher levels of funding support is necessary to create quality community programs.

Considering the goals of the various inclusion agendas, both from the perspective of service recipients and service providers/funders, helps to put the development and implementation of the *Passport* program into context for the purpose of this research. The language of inclusion in public policy and programming matches the desires of self-advocates who want to see communities where people are accepted and included, regardless of their abilities. This appears to be happening to some degree (although there are significant concerns noted in the literature), but the following research will provide more insight into the *Passport* program - how it does or does not foster inclusion, and its meaning for the people who use it - and will add to our understanding of whether or not neoliberal social welfare goals and the goal of social inclusion can be attained at the same time.

As a result of understanding the current literature available, I have created the following research questions:

- Does *Passport* increase choice and community inclusion for people with intellectual disabilities?
- Do people who use *Passport* feel that it has positively affected their lives?

These questions, and the conclusions I come to as a result of this project are described in the following text.

# METHODS

This research takes a qualitative exploratory interpretive approach that is informed by critical theories of disability. The goal of the research from the onset was to develop an understanding of individualized funding models of service delivery by exploring how people with intellectual disabilities have experienced the *Passport* program. This research is exploratory because currently there is not a significant body of research about programs in Ontario, or even Canada, that studies the effect of individualized funding programs on the lives of people with intellectual disabilities. As well, the qualitative interpretive approach has been chosen because current literature indicates that including the voice of people with intellectual disabilities in research that is about them is fundamental to creating research that is valid (Atkinson & Walmsley, 1999; Gilbert, 2004; Walmsley, 2004) A critical lens has been applied to the interpretation of these results and the social model of disability is used to frame the analysis of how people who have intellectual disabilities experience this type of service delivery. The critical lens I use throughout this research is largely informed by the Social Model of Disability. For people with intellectual disability the Social Model of Disability largely states that the interpretation of impairment labels depends on how the identities, roles and labels are constructed (Goodley, 2004). I have chosen to use critical theories of disability because they force a re-visioning of our modern construction of disability, "bringing together interaction, impairment and disability as co-existing social and political artifacts of disablement" (Goodley & Rapley, 2002, 128). It is through this type of re-visioning in research that I expect positive political and social change to occur for people with intellectual disabilities.

Recent literature has shown a shift towards including people with intellectual disabilities in the generation of research in a variety of ways including the use of visual and media arts. This has been seen in participatory action and emancipatory research efforts where people with intellectual disabilities are involved as co-researchers (Walmsley, 2004; Goodley, 2000; Stainton & Boyce, 2004; Atkinson & Walmsley, 1999). Other literature also demands that any study that is conducted *about* people with intellectual disabilities must be done *with* them to ensure its validity (Gilbert, 2004; Stalker, 1998).

This project sought to fully include people with intellectual disabilities themselves in the generation of data to keep in line with current thinking about service recipient involvement in research. However, because the project is time limited (4 months), many of the purer forms of participatory research could not be employed – typically these require months, if not years, of involvement. If given more time, this research would have begun by creating the research question with a community of people with disabilities who are interested in researching *Passport*. As it is, working within the confines of limited research time, the project's main questions were developed by myself, as the researcher, prior to meeting people with intellectual disabilities. The involvement of people with intellectual disabilities within this research project is expanded on below.

### *ETHICAL CONSIDERATIONS & RECRUITMENT*

In an effort to include people with intellectual disabilities as much as possible in the generation of data, the recruitment process was broadened to allow space for *Passport* recipients themselves to be involved and for their voices to be heard. The use of voice is an important tool in emancipatory research, which focuses on amplifying the narrative of people with intellectual disabilities. Goodley (2004, 120) describes this as "storying one's life" in order to allow a person with a disability the space to negotiate the roles and labels that may exclude them. Historically, people with intellectual disabilities have been very limited in their opportunities to take part in research. Believed to be incapable even as research respondents, they are most often used as research subjects rather than co-researchers (McDonald, 2008; Atkinson & Walmsley, 1999). This exclusion is linked to continued ableist understandings of people with intellectual disabilities as incapable of contributing to society (Carlson, 2005; Hughes, 2002) in any fashion. In order for this research to be most effective I thought that it was vital that people with intellectual disabilities contribute as much of the data as possible, to push against stereotypes of what they are (and are not) able to do. With that in mind, understanding the recruitment process is important to understanding how this project tried to widen the scope of voices that are heard.

My recruitment strategy used purposive qualitative sampling techniques, targeting recruitment of a specific population of people. In this case the research focused on recruiting adults (18 years old and over) who currently use the *Passport* program in the Hamilton and Niagara region. Although there is no age limit for *Passport*, I chose to interview only people who are 18 yeas and older because at this age in Ontario a *Passport* recipient would be considered an adult and able to provide consent for their participation in the project. For a pictorial representation of the recruitment process see Appendix A.

Recruitment was initiated by contacts made at centralized *Passport* administration agencies in 3 communities surrounding, but not including, Hamilton, Ontario. Hamilton has been excluded because my previous employment was in Hamilton working directly with *Passport* recipients, and recruitment from this community could potentially be biased. With sensitivity to the power imbalances that exist historically for people with intellectual disabilities and researchers, initially the goal was for most recruitment to occur through the distribution of a passive letter to *Passport* recipients (Appendix B). Letters were sent out by contacts at centralized *Passport* administration agencies that instructed interested *Passport* recipients or their caregivers to call the researcher to get more information about the project. In this project, no one responded to this passive method of recruitment, therefore a secondary method of recruitment was carried out.

When no one responded to the letters, it was left to the discretion of the centralized *Passport* administration agencies to contact people who they believed might not be able to respond to written letters of invitation by employing a verbal invitation using a prepared script (Appendix C). It was important to the research that any verbal contact from staff of the centralized Passport administration agencies follow this script to avoid (as much as possible) any coercive effects from the power imbalance that exists between service providers and service recipients. The script highlighted the voluntary nature of the research and the fact that it is not a requirement for their continued support from *Passport*. It was through this process that 13 potential participants were identified and their information passed on to the researcher.

After telephoning each of the 13 potential research participants, 7 people did not return the phone call, 1 person decided that s/he did not have time to take part in an interview, and 5 were able to commit to participating in the project. In each case, the person who was identified as the primary contact was not a person who was labeled with an intellectual disability - they were caregivers of *Passport* recipients. In each case, I stressed the importance of including the person with an intellectual disability in the conversation about *Passport,* but, in all 5 situations, the primary contact reported that they did not think that the *Passport* recipient would be able to comprehend the concept that they belonged to the *Passport* program. Four out of the five participants did make arrangements to ensure that the person who receives *Passport* could be present during the interviews, and available to contribute as they were able.

Obviously, a barrier in this research to engaging with *Passport* recipients themselves was the actual ability of the recruitment process to physically locate them. I was obliged to go through service agencies because recruiting participants without the support of agencies among people with intellectual disabilities can be questioned due to the dominant view that people with intellectual disabilities are vulnerable people. As well, the limited response I received from my recruitment meant that I was not able to obtain a sample with the diversity typically found in the population of people with intellectual disabilities and, as a result, I was not successful in recruiting people with ID capable of speaking for themselves. In these cases, the respondents cognitive and physical impairments were such that, in some cases, communicating with them verbally was not possible, nor was there time to pursue other avenues of communication (e.g., augmentative communication systems, etc.).

In planning this research, it was my intent to talk directly to people with intellectual disabilities who were adults with the understanding that adults can provide their own consent. With that understanding, I needed to address the question of informed consent. Informed consent for people with intellectual disabilities is an issue that has been debated in the context of research, medical care and law, but I believe that as Rodgers (1999) indicates, ideas about competence should not exclude people with intellectual disabilities from research. In this project the capacity to provide consent was an area of concern that was addressed by providing three separate avenues for participants to hear the goal of the research and to make a determination about their interest in taking part. When working with people who have intellectual disabilities, determining their capacity to provide consent may be a difficult task because their cognitive impairment could vary from mild to moderate or severe. In this case, providing as many opportunities as possible to explain the research in plain language, and using my own discretion about the respondents' ability to understand the project (based on extensive personal and professional experience with people with intellectual disabilities), were two methods employed to establish each research participant's capacity to take part. These issues were anticipated in the creation of the research project, but in practice it was not a concern because all of the participants who have intellectual disabilities were accompanied by a support person who always provided consent for them. All of the participants with disabilities who took part in the research would be characterized by medical and social service agencies as having moderate to severe intellectual disabilities and, in 2 cases, their disabilities prevented them from being able to verbalize any response. In these two cases the content of the interviews reflected the ideas of caregivers of *Passport* recipients rather than the recipients themselves. Although I was less successful than I had hoped in accessing and including the voices of people with intellectual disabilities, two people did take actively take part in interviews with support from a caregiver and they verbally contributed thoughts and ideas about their own personal experience of *Passport*. I believe that these pieces of information provide some of the most powerful understandings of *Passport* throughout this project.

## *COLLECTION AND ANALYSIS OF DATA*

The interviews were semi-structured, open ended, and took place in the respondents' homes, where they all determined they wanted to have the interviews. The interviews were audio-recorded and field notes were taken after each interview. This information was stored in a secure location while I analyzed the data.

All interviews began with general questions focused on the participant's logistical use of *Passport*, such as, "When did you start using *Passport* and for what?", and "How long did you wait to get *Passport*?" Questions then moved to understanding their experience of *Passport* with questions such as, "Do you enjoy the programs you are using through *Passport*?", and "Do you feel like you are more a part of your community now, and can you explain why/why not?". By asking these questions a sense of how community inclusion is experienced by the respondents and the types of supports people are purchasing through *Passport* was established. See Appendix D for a copy of the interview guide.

I transcribed the recorded interviews myself, and engaged with the text extensively in the process of coding the transcripts. There was approximately 7 hours of audio-recorded interviews, and when transcribed this equated to 46 single spaced pages of text. Qualitative research techniques were used to review and understand the text and open coding was used to assign initial themes to the data. To manage the data I used the TAMSanalyzer data management program. I read through transcripts after each interview and highlighted text that related to common themes I heard during the interviews. After each interview I conducted I would use the knowledge derived from previous interviews and focused subsequent interviews on questions that highlighted the topics of interest. By the end of this process I had developed 8 codes that were commonly found within the text of all of the interviews. I used the TAMSanalyzer program to tag text within each interview that reflected a code, and then compiled all tagged text for each code into 8 separate documents. These codes were expanded upon and from there developed into themes and concepts that were derived from the interviews. Specific codes informed particular themes, and the data for the themes was developed by physically cutting out the text from the coded documents that related to a theme and arranging them in a logical order to create results for the research. These themes are presented in the following results section.

# RESULTS

The eight codes referred to above cover a wide range of issues that can not all be examined here. The codes themselves were titled;

- Social Relationships;
- Inclusion/Exclusion;
- Passport Benefits & Restrictions;
- Attitudes about Passport;
- Staff;
- Service Coordination
- Disability;
- and Community Participation Activities.

The results presented below will focus on three main themes that exist within these codes;

- Inclusion Through Relationships;
- Feelings about *Passport;*
- Caregiver Responsibilities.

The themes are supported by direct quotations taken from the interview transcripts (*in Italics,* with names and identifying information omitted), as well as by summaries of participants' responses around these themes and sub-themes. In direct quotations *Passport* recipients will be referred to as 'recipients', *Passport* recipients' caregivers as 'caregiver' and *Passport* recipients' staff persons as 'staff person'.

Before the above themes are discussed there is a short summary that describes the context of the respondents' use of *Passport.* This information is necessary for the reader to understand the concrete ways that *Passport* is used by recipients. Again, this is not an exhaustive list of how *Passport* can be used but reflective of how the respondents in this research used the program.

## ***CONTEXT***

To set the stage for understanding the results it is important to consider the context of the support that the respondents received from *Passport*. This information is derived mainly from the code of Community Participation. Four out of the five *Passport* recipients interviewed received *Passport* through a direct funding model where funding was managed by caregivers. As I alluded to earlier, *Passport* is a program that recipients can use to direct their own service by purchasing programming that suits their individual needs. Direct funding requires that the *Passport* recipient or their caregiver must manage their funding resources by budgeting their allocation for the year, purchasing programming or staff to run a program, and submitting cheque requests for funding to pay for their program or staff. Alternatively, *Passport* recipients can choose to have an agency services funding model, where funding goes directly to a ministry approved agency that can work with the *Passport* recipient to develop an individualized program for them that is funded by *Passport* resources. The only *Passport* recipient interviewed that used agency services funding was an individual who was also living in a supported accommodation setting with a ministry approved service provider. The rest of the respondents accessed funding through a direct funding model.

Community Participation Supports (CPSs), more commonly known as 'day programs' by the respondents, are activities that the *Passport* program will fund if it delivers service to a *Passport* recipient outside of their home. For four out of the five respondents' CPS activities were supported exclusively by one-to-one workers. In the single case that did not have exclusive one-to-one support, the CPS was used to fund the *Passport* recipient's participation in a program at a centre with other people who have intellectual disabilities. As described by one respondent:

> *Caregiver: "The centre's focus is to provide continuing literacy opportunities, learn math, money and enhance those skills. And then the life skills ... they have to provide their own lunches so in that there is the process of reading flyers, drawing up grocery lists, planning menus, then doing the shopping, doing the cooking, doing the cleanup."*

This particular program was develop by the participant's parents along with other parents who found that funded CPS services in their area were limited and did not provide them with the opportunities that they wanted for their adult children.

For other respondents, one-to-one workers assisted *Passport* recipients to engage in a variety of activities ranging from physiotherapy, supported employment, bus training, and social activities (like line dancing) or support to go for a walk to a coffee shop or the train station. In all cases, CPSs were provided outside of the home because that is a stipulation of the *Passport* program.

## *INCLUSION THROUGH RELATIONSHIPS*

This section will focus on understanding how inclusion occurred for *Passport* recipients and the way that relationships impacted on their experience of inclusion. To set the stage for this discussion first I will highlight what respondents reported about the flexibility of Passport.

### ***Passport* Flexibility**

Overall respondents were pleased with the program's ability to allow them the control to direct funding and services in ways that reflected the recipients' own interests rather than fitting them into services that didn't match their needs, as had been the only option before.

> *Caregiver: "He was involved in a day program, it ran from 9am-3pm, and he got himself in trouble because he didn't fit that square hole, or whatever that saying is. He didn't like sitting and doing crafts, and he got himself if trouble numerous times and they were very sympathetic - but at the end, they said he just doesn't fit in this group."*

The caregiver who provided the above statement points out that flexibility in *Passport* is what made it possible for her son to be able to physically take part in activity during the day. In this case, the *Passport* recipient is someone who exhibited aggressive behaviour towards others, and in a typical day program environment he was considered a risk to others and not allowed to stay in those programs. With *Passport*, his caregiver was able to design a program that accounted for his aggressive behaviour and provided him with support that allowed him the opportunity to have meaningful day activity.

The flexibility of *Passport* was not only considered important to physically allow someone the opportunity to take part in an activity, but it also created opportunities for recipients to psychologically take part in an activity. The following quote describes one respondents sense that Passport allowed her the opportunity to do things that she enjoys, in contrast to programs that she took part in as a youth that forced her to do things she did not enjoy;

> *Question: "So school is over and you are an adult, what do you like about the things you are doing now?"*
> *Recipient: "I like swimming, and my worker."*
> *Question: "Why do you like swimming?"*
> *Recipient: "Because it is so fun, and I get to wear my two piece!"*
> *Caregiver : "And she is a good swimmer. Now she gets to spend more time doing things that she is good at."*

In this case, the *Passport* recipient's caregiver went on to describe how the *Passport* recipient is prone to low self-esteem and that begin forced to engage in activity she is not able to complete impacts negatively on her mental health. In this case, *Passport*'s flexibility was clearly attributed to benefiting the recipient's overall mental health.

### Inclusion Through Relationships

In addition to coming to an understanding of the flexibility permitted with *Passport*, I inquired with each respondent about whether or not they saw a shift towards inclusion with increased flexibility and control of community participation supports. Responses to this discussion varied, with some people stating that they felt inclusion was achieved while others saw inclusion as tokenism rather than a true reality. Although there was not agreement about the level of inclusion that was experienced as a result of *Passport*, there was a common feeling that developing relationships was important in the process of inclusion.

In these discussions, the relationships that indicated to respondents greater inclusion for the recipients are divided into three categories that are expanded upon below:

i. Staff relationships with *Passport* recipients
ii. Community relationships with *Passport* recipients
iii. Friendships with *Passport* recipients

### i. Staff Relationships with *Passport* Recipients

The relationship with a staff person was one of the most talked about relationships. As I noted earlier, the support of a one-to-one worker was overwhelmingly the type of support that respondents used. In the following examples, the staff person who was discussed was typically the one-to-one worker.

Initially, the information I received about staff relationships was centered on the families' responsibility to acquire and manage staff, the administrative work that many families take on when using a one-to-one staff. For example, one respondent discussed having to decide whether or not to find a new staff person when one went off sick, and another respondent talked about some of the challenges they had when they were between staff people. A common complaint about staffing was that skilled staff are difficult to find and keep when funding resources are limited and unreliable*; "I think all those things [transportation and programming] are problematic when you are paying someone very little money - and sporadic, not consistent or full-time or anything";*

One family's solution to this issue was to hire one staff person who was paid from the pooling of all of their various funding mechanisms to provide full time support to their adult child. In this case, they were able to create a full time position for one worker;

> *Caregiver: "We have a worker and she works full time as a full time job - one worker, and that helps us get that consistency. If you have part time workers you get a back up if one is sick, but neither one of them can do it for a living. Whereas we have it that this girl can be paid enough - $30,000.00 per year - because we have $18,000.00 from Passport and $10,500.00 from SSAH, so she earns around $30,000.00 per year, and that makes it her full time job"*

For the respondent where one-to-one support wasn't used, the caregiver explained; *"A one-to-one person I couldn't afford all day, but with day programming [in a setting with other people who have disabilities] I am getting way more bang for my buck."* This is one example where a respondent felt that the amount of *Passport* funding available was not enough to create a full week of one-to-one supported programming for the *Passport* recipient. As a result, support in a setting with other people who have intellectual disabilities was the only option, but for this family is was viewed as a positive option.

When probing deeper about what was important about staff relationships I began to discover that the staff person being referenced was almost always the person that mediated the *Passport* recipient's involvement in the community. In this way, the relationship with the staff person became vital to the *Passport* recipient's experience of inclusion in community. There was an overall sense from respondents that without a staff person who could understand them and empathize with them, the *Passport* recipient's experience of community inclusion would be limited.

Looking closer at the relationships between a *Passport* recipient and a staff person, it was communicated that a staff person who was outgoing and well connected to the community could gain access to certain places for the *Passport* recipient that allowed more involvement in community;

> *Caregiver: "I was lucky to find someone who was already plugged into the community and who has the initiative to go and do this, and is very creative. Really, I have the adult equivalent of Mary Poppins. Someone who is really inventive, and tries new things and has a great personality gets her to do things that very few other people have been able to get her to do."*

This caregiver went on to explain that the staff person had access to a variety of community shops and knowledge about local recreation that the family did not have. These connections and knowledge were considered invaluable to the parent who did not think that her daughter would have had as much involvement in the community if the staff person didn't have them.

Finding a staff person who is open and has similar interests to those of the *Passport* recipient was also considered important to the depth of relationships that developed between each *Passport* recipient and their staff person. Some examples provided by participants described situations where the line between 'staff' and 'friend' would become blurred and, rather than being viewed as a staff person, they could be viewed as a friend or family member. One recipient, who is quoted above saying *"I like swimming, and my worker"*, went on to explain that she and her staff had a common interest in horses;

> *Question: Do you and [staff person] get along pretty well?*
> *Recipient:Yeah*
> *Question: Does she like horses too?*
> *Recipient: Yeah, she likes horses, I can tell you that much, she likes horses!*

Although the Passport recipient did not link her common interest in horses to the depth of her friendship with the staff person, she smiled and spoke enthusiastically about their common interest in horses. The Passport recipient's body language and tone clearly indicated that their common interest in horses was important to her relationship with the staff.

The following example describes a situation where parents specifically hired a staff person who was the same age as their daughter to provide support to her so that they could spend their time together doing things that were of similar interest to them;

> *Caregiver: "When we hired the worker we had her design the program - and the guidelines we gave the worker were, if you didn't have to go to work all day . . . how would you fill your day? Then [we told her to] take [the recipient] with you and do what you would do if you didn't have to go to work."*

In an attempt to better understand why the *Passport* recipient and the staff person described above had such a close relationship I asked her caregiver to provide an understanding of how their relationship developed. The caregiver's answer is as follows;

> *Caregiver: "I think that it developed partly because what they do together is what a person would do if they weren't a worker - they go shopping, they go to the movies, they go the beach. The staff's mom and dad and her family go with them - they go to the library, to the park and just do things together."*

Following this example I was shown a picture of the *Passport* recipient in the wedding party of the staff person mentioned above. The caregiver noted that *"She [the staff person] considers [the Passport recipient] her little sister."* This relationship had evolved beyond a staff-client relationship into one of friendship between two women. Again, in this case the *Passport* recipient was seen by their caregiver to have been experiencing inclusion as a result of their very close familial type relationship to the staff person.

Finally, the ability of a staff person to get along with the caregiver of a *Passport* recipient was also cited by one respondent as important to the relationship between the staff person and the *Passport* recipient themselves;

> *Caregiver:"The staff and I get along famously, she'll put her coat on the chair and sit and we will natter on about things we have in common. He*

> *[Passport recipient] will pick up her coat and pass it to her and say it's time to go."*

Upon hiring a staff person this caregiver talked about how she spent time looking for someone that she felt was a good fit for the *Passport* recipient and herself. In this way, the quality of the ongoing relationship between the worker and the *Passport* recipient also appeared to be linked to the family's relationship with the *Passport* recipient's family.

### ii.Community Relationships with *Passport* Recipients

According to respondents, individualized programming allowed for more chances to be in community, and being in community was cited as useful in moving towards a sense of inclusion even if it was not always considered inclusion. One caregiver noted; *"[Passport] has certainly opened the door to her being part of the community - no questions, we have felt that a lot. The potential is there to build and expand on that over time [to have inclusion]".* The relationships between community members and *Passport* recipients acted as an indicator of when community involvement had occurred, but there was discrepancy among respondents about whether or not this constituted inclusion.

One person's experience of being in community that led to a feeling of inclusion was described by the example of going to the local coffee shop:

> *Caregiver: "Staff [funded by Passport] will walk with him down here to the coffee shop and [the Passport recipient] has his own table - or he perceives it to be his own table. And, he will go, and if someone is sitting there he will still sit with them. The staff will say 'Oh, I'm sorry, but this is*

> *where he sits normally'. And [the customer] will say 'well, let him sit here', and they are welcoming to him, and the staff will interpret what he is saying."*

In this example the caregiver noted that prior to Passport her son would not have sat down and interacted with people in the community. Following this example she explained that because of the routine they have developed going to the local coffee shop the staff at the coffee shop know her son, and often have his order ready for him before he even gets to the front of the line. To this respondent, being known by community members was an expression inclusion towards her son.

In addition to this example were numerous other examples of caregivers and staff who are constantly surprised by the number of people in the community who come up to *Passport* recipients on the street to say "Hi". As well, many examples of times when parents felt that their children with disabilities were being "watched out for" or "looked after" by community members were cited. In all cases respondents stated that they were happy to feel that people in the community were familiar with the *Passport* recipient. Yet, when asked directly if people felt that *Passport* increased inclusion for some respondents there was a hesitancy to agree that it has;

> *Question: "Would you say that she is being included in community?"*
> *Caregiver: "It's a close step to inclusion. It's not inclusion."*

Looking more closely at this, one clear response to the question of why people don't feel true inclusion is being experienced in the community relationships (even when opportunities to be in the community are expanded), was that societal attitudes remained a barrier:

> *Question:"What are some of the challenges you faced when you tried to foster inclusion initially? Maybe some themes about those challenges."*
> *Caregiver: "There was society's attitude - number one - that [the Passport recipient] didn't belong in a lot of places."*

Further to this is an example provided by one *Passport* recipient who was quick to describe his knowledge of the people in his apartment building with whom he has positive relationships with but, when asked about times that getting to know people in the building was difficult, he became quiet and looked uncomfortable.

> *Support person: "When people are in the elevator and they are not nice to you - remember, there are a few people in the building who are not very nice. How does that make you feel?"*
> *Recipient: "Sad."*
> *Support person: "How do you handle that?"*
> *Recipient: "I walk away."*
> *Support person: "You tell us and we work through it, right?"*
> *Recipient: "Yeah."*

During the exchange recorded above, the recipient's demeanor changed drastically, his gaze went to the ground and he looked uncomfortable discussing this topic. He actually requested that we discontinue this line of conversation because he was so uncomfortable with it. He later explained, with help from his support person, that the majority of the people he meets are friendly to him and that he attributes this to his skills in greeting others and starting conversations. His ease in communicating with people was exhibited as he walked me back to my car following the interview, during which time his greetings were happily received by everyone we saw in the apartment building and parking lot. But his obvious discomfort with feeling unwanted or disliked indicates that attitudes towards him are not always cordial, and judging by his negative reaction to this topic those interactions may even at times be disparaging or discriminating.

The previous example was the most vivid exchange during the interviews that provided evidence of how societal attitudes can exclude people with intellectual disabilities, but certainly in every interview examples of exclusion were provided. Some other examples are; programs that Passport recipients couldn't take part in because of the severity of their impairment; generic services that did not outright exclude Passport recipients but also did not support them to be engaged; and the sense that community members are negatively judging *Passport* recipients and their families because of their disability. The barrier of societal attitude was consistently presented by respondents, both directly and indirectly, as the reason that inclusion could not exist.

From these descriptions it appears that *Passport* has created opportunities for new community relationships to develop, but that societal attitudes about disability can continue to act as a barrier to community relationships developing positively.

### iii.Friendship

Finally, in every discussion I had about *Passport* that dealt with relationships the idea of friendship was present. The definition of 'friend' varied from situation to situation, but the theme of having friends was closely linked to the feeling that inclusion exists. Here I offer the words of two different respondents that speaks to the connection between 'friendship' and 'inclusion';

> *"But it doesn't matter [the age of her friends] because I have friends that are a lot younger than me and friends that are older than me. The fact is that she has friends that are looking out for her."*
>
> *Question: "What is inclusion to you?"*
> *Caregiver: "Inclusion? Ah, my ideal thing would be for [the Passport recipient] to have a normal friend, but it never happens, to be totally included."*

In this final example, a 'normal friend' was understood to be someone without a disability who was not paid to be with the *Passport* recipient.

Another respondent attributed a barrier to friendship as resulting from the *Passport* recipient having missed out on typical life stages, such as access to post secondary education and employment;

> *Caregiver: "And the problem with an inclusive environment once you leave [high] school is that your peer group is either still in school or they are out working all day. So, how do we find a peer group for [the Passport recipient]?".*

This feeling was shared by another respondent who said *"Our biggest problem is finding people the same age. Peers for her in this community - that seems to be the trouble."* In this sense, it was reported by respondents that a lack of peer friendships to them indicated that *Passport* recipients were disconnected from typical community environments where peers lived and worked. So conversely, a goal to see peer friendships develop was linked to the goal of seeing *Passport* recipients included in their community.

In most cases respondents described situations where *Passport* recipients have friends who also have disabilities;

> *Caregiver: "He sees friends at line dancing, and he has definite likes and dislikes - of course he grew up with most of the people that go to line dancing, and they are in his age group, and they went to school with him and they all have disabilities and they come with their staff."*

Although having friends who also have disabilities was not regarded as negative, when talking about inclusion most often respondents referred to friendships with people who do not have disabilities. When asked about whether or not *Passport* recipients have friends who do not have disabilities, respondents described relationships with staff or relationships with community members. The following responses from two different caregiver's provides examples of this;

> *Caregiver: "She has a tremendous support group - the worker's family, which is a huge Italian family, and all of the worker's friends from high school and their boyfriends - she just has this really large circle of people who are not just friends with her but they are there to support her."*

> *Caregiver: "People are looking out for her in that community because that is where she does her work and she makes friends with the people and the people of course they think they are a support group too."*

Despite the fact that families face challenges when supporting the *Passport* recipient to find friendships, they do identify that sometimes they view staff and community members who are familiar with the *Passport* recipient as friends.

> *Caregiver: "But in terms of getting to know people going to the Library, the community centre, the skating rink - most of the two workers she has have tried to include her in their own families. Both were very good that she went not just during Passport time, they would include her at other times. That actually opens doors that way."*

So, depending on how friendship was defined by the respondent - either as a personal relationship or a social familiarity - respondents could either see or not see friendship as a result of using *Passport*. Overall, the importance of friendship was clear and attributed most often to feeling a true sense of inclusion.

## *FEELINGS ABOUT PASSPORT*

For all respondents some common themes about how they feel about *Passport* quickly emerged. I have divided the most common emotions about *Passport* into three categories;

*i.* Guilt About Receiving *Passport*

*ii.* Gratitude And Good Fortune For Receiving *Passport*

*iii.* Entitlement To Support From *Passport*

### i.Guilt About Receiving Passport

In all interviews, respondents indicated that they were aware that *Passport* resources were limited and that since this funding was made available very few people have actually received funding. Respondents would compare their situation to those of other people who had not yet received *Passport* and, from this, feelings of guilt about how much more they had were common;

> *Caregiver: "You know, I think we are one family out of 17 out of something like 300 people who applied for that funding. I know we are part of a very small group that actually got the funding, and I know other people who need it just as much."*

Feelings of guilt were most clearly articulated by those respondents who personally knew other people who have or who care for someone with an intellectual disability in their community but who had not yet received *Passport* funding. The following quote came from a parent who cited a local person that he knows who has a disability as profound as his own child's but who receives only a fraction of the support that he, himself, receives; *"Sometimes I feel guilty when I see that [other people] get, I don't know, something like 2-3 hours per week from SSAH."*

One caregiver also commented on their disbelief that they would actually receive funding when it became available. There was also a feeling of mistrust of the service system that provides *Passport* resources because the opportunities to receive these services are typically so rare.

> *"Within a couple of weeks of me applying they phoned and said; 'You have it!' and I said; 'Maybe I don't want it.' I was very hesitant because it just seemed too good to be true and there's gotta be a catch in here somewhere."*

### ii.Gratitude and Good Fortune

Feelings of gratitude also arose out of situations where people compared their access to resources with that of other people. In these discussions, rather than expressing their guilt about having resources parents of *Passport* recipients expressed gratitude. The following excerpts describe a few situations where gratitude was expressed by various caregivers;

> *Caregiver: "Well, for families it can be problematic [to coordinate Passport], but the families who don't have anything my heart goes out to those families who didn't get anything - so as I say, I'm very grateful that I have this."*
>
> *Caregiver: "And my complaints about [Passport] are small, compared to the complaints of people who have nothing, and so I am grateful, but grateful for small mercies - and it is a small mercy."*
>
> *Caregiver: "I'm very thankful for what I get. I know I have a lot friends that don't get Passport and would love to have Passport"*

Gratitude also came in the form of feeling fortunate or lucky to have received *Passport*. This type of gratitude contains an element of cynicism, where people emote thankfulness for receiving passport while at the same time commenting on the scarcity of the resource. These comments from both staff and parents happened with surprising frequency The following are examples of how luck was described by a number of respondents;

> *Caregiver: "And I guess I was lucky, because [the Passport recipient] already had special services at home, with a number of support staff";*
>
> *Caregiver: "We have no problems. We are really lucky.";*
>
> *Support Person: "[Our agency] rents five apartments, and [the Passport recipient] lives on his own - he was lucky enough to get funding";*
>
> *Caregiver: "We are one of the lucky families that got Passport";*
>
> *Caregiver: "So everything here, I mean most things, [the Passport recipient] has to be driven to ... so again, I was very lucky to find someone who has a car."*

As described by these examples, feeling fortunate was expressed in the statements that address their receipt of *Passport* resources. But, luck was also discussed when referring to having access to staff who could do the work that was required or having the resources necessary to purchase particular programming. These comments clearly reflect that the respondents are grateful for what they have. Nonetheless, they also point to their understanding that what is available is really quite scarce.

### iii. Entitlement

Finally, a sense of entitlement to resources was another common emotion (sometimes competing with gratitude) that was expressed by respondents. The following examples from two different respondents provide examples of how they viewed entitlement to *Passport*;

> *Caregiver: "It's almost like you are part of an elite if you got this program, and I think it should be much more universal than that."*
>
> *Caregiver: "But I also feel that we should not be going on this premise that I am down on my knees grateful for getting this service because you know I think that parents do their bit in terms of saving the public purse in sacrifices in their own lives, their career and their health to care for children with special needs. So, when [children with special needs] become adults it is really time for the government to kick in."*

The sense that *Passport* should be more universally available was articulated by one family in terms of human rights. Using their experience of advocating for access to inclusive education for their daughter as an example, they explained that access to the community in a way that is inclusive fits with upholding the rights of a person with a disability;

> Caregiver: "To my mind, it is similar to education... sometimes school boards say they don't have the money to deliver programs to the disabled.

> And school boards did that for years but the Ontario Human Rights Commission ruled that when your special education budget is gone that is not an excuse for not funding special education."

Respondents understand *Passport* as an entitlement yet the barriers to accessing it reveal that it is not universally accepted as such. The feeling that the program needs to be more universally available and that not allowing people who need *Passport* access to the program is a violation of human rights creates an environment where advocacy becomes important. The feeling of entitlement was not only talked about in terms of believing that people should have access to *Passport* but also with regards to the understanding that families have a responsibility to act so that they can gain access to *Passport*. In this case, one family was able to articulate why they believe the received services; *"At one point for SSAH she was the only person in Brant to have 15 hours per week, most had three or four. And we got that by advocating for her!"*

In all of these discussions about how the respondents felt about *Passport*, there is an overarching theme of respondents feeling undervalued or mistrusted with resources. In some cases, caregivers acknowledged that little is given to Passport recipients to do the work that they feel is vital to their livelihood. They further noted that family caregivers are *"saving the public purse"* by having *Passport* recipients live at home. The sense that caregivers are undervalued was most commonly attributed to their experience that government support of programs like *Passport* is typically very limited.

As well as feeling undervalued, one family expressed that they do not feel trusted by the government to manage resources and coordinate their adult child's care.

> *Caregiver: "Again, it really irritates me that the agencies [receive funding] and governments are willing to give group homes a handsome profit on the kids money... but if a parent might spend a little [on themselves] - and that is the government's biggest excuse about why they don't want parents to have the control of the money - because they can't control it."*

From this respondents perspective it is evident that in addition to being undervalued by a lack of government resource, caregivers are not trusted to manage the little resource that they have. Although this respondent went on to say that he did not find the Passport process for reviewing how resources are used too onerous, he did maintain that the process of receiving support overall tends to make him feel mistrusted.

## *CAREGIVER RESPONSIBILITIES AS A RESULT OF PASSPORT*

In four of the five interviews I conducted the *Passport* recipient was still living with their family, and their primary care was being provided by their parents. In these cases, discussion of *Passport* resources led to discussions about how families feel about their responsibility to their child. I will explore the formal responsibilities of advocacy and administration as they relate to *Passport*, but first some examples of the general stressors expressed by caregivers is provided.

### Caregiver Stress

In some of the interviews, the stress that respondents who care for *Passport* recipients experienced was clearly articulated. The reasons for feeling stress ranged from the fact that caregivers did not know if funding for support would continue to the worry about their own physical safety because of the nature of the impairment of the person they care for.

One respondent noted that in their case they know that the stress of caring for someone with an intellectual disability can negatively impact on the family relationships. This was attributed to the responsibilities that families take on when caring for someone with an intellectual disability;

> *Caregiver: "So we are keeping them at home - but that causes so many other problems, marriages breaking up, families being destroyed, because the workload for some is huge if they are individuals with high needs."*

This sense that family relationships are at risk because of the responsibility of caring for someone was coupled by the same respondent with worry about financial stress. In the following excerpt the respondent tied her stress with the risk of family breakdown to her feeling of loss of financial security;

> *Caregiver: "You know, on a day-to-day if I didn't have [Passport recipient] where my life would be at? It would be totally different. ... I would be in the workforce, where now I have given up the opportunity to make money to help towards a common goal [for the family]."*

Further to these sociological and financial stressors, another respondent spoke about the physical risk she may find herself in because of the nature of her son's impairment;

> *Caregiver: "And his sister says 'Mom - sometimes I worry about you there alone with [Passport recipient]. Are you OK?'. But I've taken non-violent crisis and I know some interventions - so if he came over and he grabbed me - I know how to break that hold."*

Although this caregiver explained that she knew what to do in situations where she was physically threatened by her son, living in constant preparedness to avoid physical attack must present some stress in his home.

In general, high levels of stress were qualitatively reported by caregiver respondents who lived with *Passport* recipients. Although the reason for these stressors varied, the fact that it commonly exists for respondents is helpful for the reader to understand when considering how responsibilities towards the Passport recipient must be carried out in an environment of stress.

## Caregiver Responsibility

A common theme related to caregiver responsibility was the feeling that the *Passport* recipient's needs have been separated from the caregiver's needs, creating an artificial division of support. One respondent clearly articulated their frustration, suggesting that by separating the caregiver's needs from the *Passport* recipient's needs, *Passport* creates a system that doesn't serve caregivers or *Passport* recipients very well;

> *Caregiver: "I think there is a disconnect between programs like [Passport] in terms of what they mean not just for the individual but for the family. For instance, I could not work without Passport and there is no guarantee or promise that it will continue - so at the end of March [when funding allocation is reviewed] I don't know if I'm going to be in total crisis about how I am going to continue to work or whether I'm going to be OK. And no*

> *one can give me that answer....I just think we need to think about taking care of the [family]unit - to make sure the unit survives - because the individual is very dependent on the unit surviving."*

This is further understood by considering the following example provided by a another parent respondent;

> *Caregiver: "For instance ... I was working in the evening so I had our worker come and look after [the Passport recipient] in the evening because I would not get home until 11pm. So this worker took her to the mall and brought her home and wrote on the sheet that she worked until 11pm. So I got a call [from the Passport administration agency]saying that the mall is not open until 11pm, but I said 'yeah, but I was gone until 11pm'. But you see, that is not what the program is for."*

Because Passport only funds activities that happen in the community and not in the home, in this case (as the parent went on to explain), she was required to find alternative resources to fund the 10pm-11pm home support that was outside of what *Passport* resources would accommodate. This situation is an example of how the separation of caregiver needs from the *Passport* recipient's needs creates more administrative and fiscal responsibility for caregivers who are already committing their own time to manage *Passport* resources.

Further to the underlying concern about the division of caregiver and individual needs, respondents noted there are primarily two major responsibilities for families who are engaged in the *Passport* program. These are;

i. Administrative Responsibilities

ii. Advocacy Responsibilities.

### i. Administrative Responsibilities

The nature of *Passport*'s individualized programming and direct funding model creates a need for services to be coordinated. This is recognized within the *Passport* program in a clause that states 10% of the allocated resource can be used as "brokerage" funding. Brokerage can be used to purchase the support of someone who can hire workers, create support plans and generally coordinate community participation supports for an individual. In all of the interviews the brokerage fee was not accessed, and caregivers chose to coordinate services within their own time and resources. Their reasons for not using brokerage services included *"I don't want to take money from [Passport recipient]"*; and *"The administration isn't cumbersome - I don't find it difficult"*.

I discussed the work of coordinating services with everyone and the majority of people who administered funds on their own reported that they preferred being able to do this, and that it was not difficult for them. It appeared that having full control over how service is delivered was more important than the time it took for a family member to administer the plan. The following exerts from various interviews show why respondents prefer to manage their own resources;

> *Question: "Do you feel like Passport is meeting all of your needs at this point?"*
> *Caregiver: "Yes - I have the flexibility to do what I want, I don't know that I would if I used an agency. And I choose not to use the agencies because they charge an administration fee and that's taking from him - so it is good, I haven't had any problems whatsoever"*

> *Caregiver: "The nice thing about Passport was that ... [the Passport recipient] could design a program herself that gave her money and allowed her to have inclusion."*
>
> *Caregiver: "Because I self-administer the funding for Passport I can say he enjoys walking, so I don't let him do running...I can tell staff 'this is what I want - I want him walking, exercising, I what him relaxing at a picnic, going to church, going line dancing...' And, I haven't found anybody to say no yet."*
>
> *Question: "Does Passport meet all of your needs at this time?"*
> *Caregiver: "Yes, I'm gonna say yes it does. It helps us out, I mean, like I said, she has to have a worthwhile day, a meaningful day. And Passport money allows us to purchase that for her."*

So, as indicated by the above comments, control over services was a major benefit to caregivers of people who used *Passport*. The ability to control their programs on their own appeared to be more important than having formal agency support to create programs. In fact, formal agency involvement was seen as negative because it was viewed as taking money away from Passport recipients through administrative fees. The positive aspect of control over resources as reported by caregivers appeared to be that it allowed more autonomy for them to develop personalized programs for *Passport* recipients. This autonomy is further described by the following excerpts:

> *Caregiver: "The best is that it allows him to be out in the community, out and about to the best of his abilities."*
>
> *Caregiver: "It has allowed her to do things like going riding, to do things in the community, I mean she is not going to be able to go and do volunteer work without someone with her, it allows her to volunteer at local schools, planning to go to the library, doing something where she feels she is accomplishing something."*

### ii.Advocacy Responsibilities

Advocacy from the prospective of caregivers was typically discussed in relation to how the caregiver has a responsibility to advocate on behalf of the Passport recipient. Related to advocacy, one family commented on why they thought some families may not like the idea of accessing individualized resources:

> *Question: "So as we have discussed, there appears to be a gap between community living and inclusion, and it seems that Passport is a program that you have used to achieve inclusion. Does it create inclusion for everyone? What are the barriers people come up against?"*
> *Caregiver (parent 1): "I think because a lot of people are afraid to use it in the way we use it."*
> *Caregiver (parent 2): "Well, no I think the problem is that people can't advocate, and advocacy is needed for setting up programs and that kind of stuff."*
> *Caregiver (parent 1): "That's kind of what I mean, a lot of people are afraid to try something like this."*
> *Caregiver (parent 2): "Wouldn't know how to do it. Don't know how to access the money. I mean some of the reason that we got some of the Passport money was because they were afraid [of our reputation as advocates]."*

Another respondent commented on the barriers they see to using *Passport,* barriers that relate to advocacy:

> *Caregiver: "So I think all those parents I would guess the parents I know in another city that have english problems, that were not strong advocates for their children did not get this money for their children."*

When trying to understand what advocacy looks like in the context of *Passport* I was directed by one respondent to consider the application process that *Passport* applicants must engage in to receive funding;

> *Caregiver: "And that is the other thing about filling out those forms [application packages] - you aren't there to make things look good, you are there to make things look needy. And that is how you have to approach the forms to do it. You have to write down all the things that could go wrong."*

This respondent attributed some of their success in accessing *Passport* to their knowledge about how to fill out applications and how to communicate their needs effectively to receive the best response to their request for services. This echoes the experience of another respondent who commented on their active work to locate resources by joining with other families to apply for grants to support their adult children. As well, another respondent noted that they have advocated to the Ontario Human Rights commission at other times for equal access to support, indicating some level of experience in advocacy. Advocacy efforts that respondents described were varied, and show that at times there is tension between engaging in advocacy that can advance the needs of people who have disabilities overall and the needs of a specific individual.

Thinking about advocacy and the skills required to do this in a larger context one family noted;

> *Caregiver: "So even the people that are getting the money are already in a privileged group who are capable of advocacy. And again that creates distinction, because if you are the people who have it are the people who knew how to advocate for it, and hopefully their needs are equal or greater than those who don't have it."*

Advocacy as seen from this perspective highlights that those who have the resources and skills for advocacy may be at an advantage over those without those skills in the actual application process for *Passport*. As a result, the people who are currently in receipt of *Passport* may represent a particular type of applicant.

# DISCUSSION

## *ANALYSIS OF THE STUDY*

At the onset of this research project I endeavored to understand how the use of individualized funding program models affects the inclusion of people with intellectual disabilities. Using the *Passport* program as a model of an individualized funding service, I was able to gather data about the experience of five *Passport* recipients and their families to evaluate whether inclusion is experienced as a result of individualized funding. As was demonstrated in the previous section of this report, the data collected contributes to this understanding by providing information: first, about how using *Passport* impacts on the relationships of people with intellectual disabilities and whether this builds towards inclusion and, secondly, by providing an opportunity to explore the attitudes that *Passport* recipients and their caregivers hold about the program. Thirdly, results also provide insight into the responsibility that caregivers of *Passport* recipients have and what they feel about those responsibilities. These findings are expanded on below. As stated previously my research is presented using a critical lens, specifically informed by the Social Model of Disability. As well, the analysis of the data is supported throughout by linking it to other literature on related topics.

### *Relationship Development*

When I discussed inclusion with respondents, the issue of relationships frequently came up. Some respondents felt that full inclusion in community was experienced through the use of *Passport* while others thought that it had not been achieved, yet all gauged inclusion by the quantity and quality of various relationships that the Passport recipient had. This is congruent with McVilly, Stancliffe, Parmenter & Burton-Smith (2005), who found that in their study of loneliness, adults with intellectual disabilities who had a high degree of social interaction rated themselves as less lonely than those who had less social interaction. As well, Cummins & Lau (2003) maintain that community connectedness through relationships is central to inclusion. They argue that social service programming should focus on increasing community connectedness through relationships as the primary method of increasing a sense of community belonging among people with intellectual disabilities. Milner & Kelly's (2009) most recent participatory action study outlined five keys to belonging as identified by people with intellectual disabilities; Self-determination, Social Identity, Reciprocity and Valued Contribution, Participatory Expectations, and Psychological Safety. The latter four keys to belonging all require an element of relationship with people in the community. This matches with comments from respondents who noted that they felt it was important for *Passport* recipients to make contributions to society, and for them to be know in their community.

Clearly, relationships play an important role in how and if inclusion is experienced.

How and with whom relationships with others developed through *Passport* was more difficult for respondents to define. Some respondents cited relationships with staff as very important, while others looked at having acquaintances in community as equally important to inclusion. Acquaintances in the community ranged from someone at a coffee shop knowing the *Passport* respondent's order before he gets there to a person stopping the *Passport* recipient in the street to say hello. The results of this research suggest that relationships exist on a spectrum - ranging from formal relationships, to acquaintances, and moving to informal relationships. I believe that this spectrum can be paired with the continuum of inclusion written by Schleien, Green and Stone, cited in Wilson (2006); physical integration, functional inclusion and social inclusion. Physical integration indicates that a person is physically a part of community, while functional inclusion denotes an ability to function successfully in an environment. Finally, social inclusion is the aspect of inclusion that is evident by positive interaction and social acceptance. In my own study, for each respondent I understood that inclusion was at the height of its experience when a relationship was considered informal, when the *Passport* recipient developed, what one recipient termed, a "real friend". In this way, I observed that as Schleien, Green and Stone in Wilson (2006) viewed physical integration as the most minimal level of inclusion, I saw formal relationships as the most minimal level of inclusion. Likewise, functional inclusion and social inclusion run parallel in their index of the level of inclusion to the acquaintance and informal relationships defined by respondents of this study. This link will be made clear in the following discussion. At this juncture, let me elaborate further on formal, acquaintance, and informal relationships.

Formal relationships are those that *Passport* recipients experience as a result of someone being hired and required/paid to spend time with them. *Passport* lends itself to developing these types of relationships most often as, typically, in order for *Passport* recipients to be engaged in community they need a staff person who can negotiate that environment for them. Limited verbal skills, mobility issues, behavioural difficulties, and a number of other challenges that people with intellectual disabilities may face can contribute to their physical exclusion from community. A formal relationship with a staff person means that there is someone who can intervene in exclusive environments and create a bridge that supports the person with an intellectual disability to be physically included in their community. Formal relationships with staff existed for all of the *Passport* recipients interviewed, and were clearly the most talked about relationships in the interviews. It is important to note that respondents felt the staff person's skill level was often attributed to their success in engaging the *Passport* recipient in this and other levels of relationships.

Acquaintance relationships are those that respondents described as relationships characterized by familiarity, but are limited by the level of intimacy or personal involvement with the *Passport* recipient. In the results of this study, these types of relationships were most often reflected in community relationships, where the *Passport* recipient had regular contact with someone in the community who might be familiar with them but who did not actually know them. Examples of this included the older adult at the community center who recognizes the Passport recipient who uses the physiotherapy equipment, or the owner of the dress shop who says 'Hi' to the Passport recipient on the street. Feelings about whether or not these relationships could be cited as examples of inclusion were mixed. I believe that in those situations where caregivers felt that this type of interaction was all that the *Passport* recipient could ever engage in (as a result of their impairments), it was considered 'inclusion'. In other situations, where it was felt that the *Passport* recipient could engage in deeper relationship, this was seen as a step towards inclusion but still not 'true' inclusion. In either case, the ability of the *Passport* recipient to engage in relationships was something that each respondent judged differently, and this led to different interpretations of which stage of inclusion was being experienced.

Informal relationships are best defined by the term "friend", someone who spends time with the Passport recipient, not out of obligation but out of genuine interest in being part of their life. This type of relationship was the most sought after but seemed to be the least likely to be experienced among the people interviewed. Success in developing an informal friendship was sometimes attributed to a *Passport* recipient's ability to capitalize on situations where they could interact with people who had similar interests to them. For example, one *Passport* recipient saw someone as a friend because they both shared an interest in horses and often talked about that. In a few situations it was understood that friendship occurred when someone invited a *Passport* recipient to their home, inviting them into their lives.

When considering relationships as indicators of inclusion it is important to note that relationships did not remain fixed at any one stage - they could progress to any stage of relationship over time. The most common example of this was when a staff person grew very close to the *Passport* recipient, and eventually they would consider each other friends. The reciprocity of these relationships was evident for one Passport recipient who was asked to be in the wedding of her staff person because they considered each other such close friends. Although some people would say that a paid staff person can never become a true friend, some respondents argue that when a *Passport* recipient is invited to a staff person's house outside of paid hours, to watch a movie or get to know their family, that true friendship was achieved.

Societal attitude was the most clearly stated barrier to achieving relationships that lead to inclusion. In one case a respondent was quick to respond, and numbered societal attitudes as the first issue that created barriers for Passport recipients. Other respondents frequently referred to feeling they were not invited to join into community life because they were different. This was expanded on by one respondent to include the barrier of 'disability' that limits their access to generic services like recreation centers and local athletic clubs. Specifically, the stigma associated with having an intellectual disability creates a barrier to relationships developing between people with and without intellectual disabilities (Dudley, 2000). Dudley (2000) states that stigma about intellectual disability is perpetuated by social service programs that promote unnecessary dependency and age in-appropriate behaviour. This is further supported by Carlson (2005) who writes that the history of institutionalization experienced by people with intellectual disability continues to carry with it a dominant discourse of inability towards people with intellectual disabilities that is reinforced by medical model impositions like IQ testing. Ultimately, the *Passport* program was cited by respondents as beneficial in providing opportunities for new relationships to develop, but that societal attitudes continue to act as a barrier to deeper relationships.

### *Attitudes about Passport*

All respondents spoke about how having control of the resources available was key to the success they experienced in the implementation of their *Passport* programming. Respondents clearly indicated that they valued the opportunity to design programming that suited the *Passport* recipient – an opportunity made possible by their control over the resources. Literature about service user choice and control contributing to feelings of empowerment are consistent with what was discussed in these interviews. Stainton (2002) espouses that the autonomy found in Britain's *Direct Payment* program is essential to the feeling of empowerment that comes from having choice, and key to upholding human rights for people with disabilities. *Passport,* according to respondents in this study, would similarly, seem to incorporate opportunities for autonomy. Evidenct for this comes from statements about how *Passport* recipients could indicate, either verbally or through body language, what they wanted to do and the program was able to change to meet their interests. Stancliffe (2001) provides insight into factors that impact the effectiveness of self-determination (for example, autonomy and opportunities for choice) but notes that, overall, being afforded any level of self-determination has positive impacts on people with intellectual disabilities.

Although respondents noted the control that Passport provided them was positive, this did not engender a sense of entitlement as respondents consistently expressed feelings of good fortune about having received *Passport*, and being able to successfully implement it. I believe that the feeling that they were lucky to have found the worker they found, or fortunate to have received funding at all, overshadowed the sense of empowerment that they may have felt about being able to control the resources they were given. In this case, the distinction between how empowerment is defined by advocates and service recipients is set in contrast to how empowerment is defined by policy makers and service providers. This difference, as described by Beresford & Croft (1995), is understood as a difference of *democratic* empowerment (empowerment that is concerned with people's rights as citizens) and *consumeristic* empowerment (that uses market ideologies to view service recipients as consumers of a service).

Among respondents the language of luck was so commonly used to describe their experience of *Passport* I might have concluded that people who have *Passport* are unsure of why they have received the services over others (who are similarly in need),or that they even deserve the services they have more than someone else. This of course was not entirely the case: when asked more specifically about how they came to receive and implement *Passport,* respondents could cite their ability to advocate and coordinate service as contributing to their success but the deeper issue of feeling that they may not deserve *Passport* remained unaddressed. This could be indicative of a consumeristic understanding of empowerment - rather than increasing the social power of service recipients, *Passport* actually works to disempower them (Beresford & Croft, 1995, 68).

Questioning the value of people with disabilities and their families is not new to disability literature (Carlson, 2005; Malacrida, 2009), but understanding how the respondents in this research framed that feeling against their experience of *Passport* can help contribute to our understanding of this issue as it relates to individualized funding models. The limited availability of *Passport* funding was one of the main issues that respondents talked about when they explained that they were lucky to have received support. I have interpreted this as respondents feeling that because such little value is placed on expanding the program, that little value is placed on the people who use the program with the consequence that very few resources are given to them.

As indicated by the results, feelings of guilt and entitlement accompanied the language of luck and gratitude in interviews. In addition to feeling devalued because of limited resources, some respondents reported feeling guilty about gaining access to *Passport* over others, but then, at the same time, entitled to this support as a human right. The line between guilt and entitlement was finely drawn and differed for each respondent. The complexity of these attitudes about *Passport*, and people's use of *Passport* are difficult to interpret. I think that the presence of these attitudes and their complexity serves to overshadow the ability of individualized programs to create opportunities for people to feel empowered by the choices they can make in their service. These feelings perpetuate an environment where service recipients feel they are both mistrusted and undervalued by funding bodies, and creates a divide between the service recipient and the funding bodies. An 'us' and 'them' language develops that can act counter to the potential of *Passport* to create an environment where people with intellectual disabilities and their caregivers feel democratic empowerment.

### Caregiver Support Required for *Passport* Recipients

Respondents indicated that, overall, they did not feel burdened by the need to coordinate service for the *Passport* recipients that they cared for. In fact, when one family was asked about their coordination responsibilities, they indicated that they felt the *Passport* program was a very good program because it kept them very accountable to the government. Although no one said that coordinating service was overwhelming for them, all families spent a significant amount of time talking about how they manage their *Passport* resources. This included the minutiae of finding, hiring,and paying staff;determining whether or not they were required to submit CPP or EI; how much they should offer staff for mileage (if they wanted to offer it at all)- the list goes on. Although the requirements *Passport* places on parents to coordinate services were not reported by respondents to be high, the discussions I had with families indicated that they were time consuming. This is supported by Green's (2007) study of mothers' experiences of caring for children who have intellectual disabilities. Green indicates that the financial and time constraints associated with raising a child with an intellectual disability were most often reported as high by mothers.

When respondents were questioned about why they felt they had success in obtaining *Passport,* an issue of family support that was commonly discussed was the need to advocate for the *Passport* recipient. Advocacy took the form of writing letters to members of government, repeatedly calling local service delivery agencies, talking to other parents about their needs, and having, at times, to amplify their children's needs while at other times presenting their children as very capable. The skill of advocacy was what caregivers most commonly attributed their success in acquiring *Passport to.*

In social service models that rely on a factor of consumerism, the main critique is that there is always an assumption that the people who receive the support are competent enough to manage the resource themselves, but that this is an illusion (Askheim, 2005). Sensitivity to other caregivers who do not have the skills to advocate was frequently expressed by respondents. Caregivers who do not have English as a first language, or who are socially or economically disadvantaged, may find that advocacy for their child with a disability is a difficult or impossible task. The respondents I spoke to likely represent a very specific group of people who can ask for support and advocate for service when it is not available to them. This may also account for why the service coordination of this program is reported not to be onerous by the respondents, yet it is a task that requires significant knowledge and skill in a number of areas to implement.

It is important to note that caregivers of people with disabilities are required to take on more responsibility in their relative's life than caregivers of people who are typically developing, and this creates both benefits and burdens for caregivers (Green, 2006; Heiman, 2002; ). In the case of individualized funding, this does not change and, in fact, such models increase the dependency of government on caregivers to create service programming that matches the individual's support needs. This has created a program that places high demands on caregivers, and increasingly lower demands on service providers and government bodies to coordinate and create appropriate programming. So, as one caregiver expressed, the needs of the caregiver and individual are separated by the *Passport* program but, in effect, the program relies heavily on the interdependency of caregiver and individual. Without caregivers, people with intellectual disabilities who have *Passport* would require some alternative support system to help them coordinate the services that *Passport* helps to purchase. As well, caregivers most often help the *Passport* recipient determine how to use their *Passport* resources by assisting them to develop a plan built on their strengths. Without the interdependency of caregiver and *Passport* recipient, *Passport* would not work as an individualized service, it would only serve to fund typical community participation supports that already exist in the community.

This discussion highlights that neoliberal influences have affected the implementation of *Passport* above and beyond the stated goal of increasing community inclusion. These results are similar to studies of the *Valuing People* initiatives in Britain, programs that provide marginalized people with disabilities the opportunity for self-determination, but at the same time promote a neoliberal value of individualism (Roulston & Morgan, 2009). As it is within other neoliberal shifts, the dependency on the government is reduced with the *Passport* program and, in this case, responsibility is placed, instead, on caregivers (Swenson, 2008; Baines, 2004). This is done under the guise of creating programming that is individualized and person centered but which, in reality, moves the responsibility to provide service further from the government and closer to caregivers and *Passport* recipients themselves.

In addition, reductions in service allocations are more difficult to track and coordinate a response to when the responsibility for support is spread out among many people (Baines, 2004). In the case of *Passport,* every respondent indicated that they were aware that *Passport* resources were limited but no one talked about coordinated efforts to challenge this. If funding was allocated more centrally to one or two agencies, then the effect of reduced funding would be more readily recognized and agencies would be better positioned to advocate for change. Also, the task of advocating for more funding can be time consuming, and in addition to the responsibilities that caregivers already take on advocacy is likely one task that would not be prioritized.

The idea that moving toward individualized funding programs is an effort to benefit *Passport* recipients must be balanced with recognition of the overarching trends in social service programming that reflect neoliberal values. Understanding that individualized funding benefits *some Passport* recipients and their caregivers - those who can manage to coordinate services with ease - programs like *Passport* need to take into account how supports could best be offered to those who cannot as easily coordinate their own supports. Without considering this, *Passport* could potentially create a hierarchy of service delivery in which those who have skills to advocate and manage resources are afforded the best service while others are left with little or no say in the programming they receive and the risk that programming they receive will continue to decrease in quantity and quality. This sort of hierarchy of service that is based on individual ability has been observed by Aronson (1999) in her research about older people who receive care at home. In this case, those that could no advocate for themselves received what was perceived to be a lower quality and quantity of service.

## Implications for Social Work Practice

The following implications for social work practice have been derived from the results and discussion of this research. As it is the goal of this research to create positive change for people with intellectual disabilities it is important that I state how I can envision change occurring. The following expands on these four implications for social work;

- Social work needs to recognize that people with intellectual disabilities matter and have value.
- Social work needs to foster relationships of value between community members and people with intellectual disabilities.
- Social work needs to promote equal access to funding resources so that equal access is achieved for all people with intellectual disabilities.
- Social work must work to retain quality of service among *Passport* programs.

### ***People with Intellectual Disabilities Matter***

If social work is a profession that seeks to balance injustice in our communities, we must not neglect to face the injustice that people with intellectual disabilities and their families experience because the dominant discourse does not attribute value to them. We cannot accept that people with intellectual disabilities and their families feel 'lucky' to have been supported to take part in community through programs like *Passport.* We need to stand with self-advocates and their families to send a message that inadequate resources required to live a full life in community are not acceptable. This is an act that will require both political and practical approaches from the social work profession.

A practical way to change the social stigma attached to people with intellectual disabilities is to begin with the structures within our own social work practice (Dudley, 2000). Looking at what is in reach for us to change - like the language we use and the way we engage with people who have intellectual disabilities - is a simple first step to creating larger changes. Using plain language in the documents that social service agencies produce, and not talking *for* people who have intellectual disabilities but creating space to allow them to speak for themselves, are 'on the ground' ways to begin to create these changes.

Politically, we need to find ways to make it clear to government bodies that human value is measured by more than a person's ability to take part in the work force (. People who know those with intellectual disabilities know the value that they add to our communities and can understand the need for government to place more value on funding programming that supports them to have full lives. Further to this, government needs to recognize the value of families who support their adult children at home. These families recognize that without thesupport they provide to their adult children, the government would need to fund more (and more expensive) services for their children, but that when they do provide this support the government funds less than what they need. The social work profession needs to stand by these families as they advocate for what they need.

Similarly, social workers can seek out self-advocates with intellectual disabilities in their own communities and contribute to their efforts by offering their knowledge of how to advocate for change (for example, acting as advisors for self-advocacy groups like "People First"). Beyond this, social workers can also assist self-advocates who have been working from their own experience of disability to tackle issues of discrimination by joining in the larger disability movement (Goodley, 2001; Dowse, 2001). The joining together of different voices of disability has been observed in other areas of disability studies and has proven to be a useful tool in sharing skills and impacting a larger audience (Rice et al, 2009, 320). I believe that if self advocacy movements join with the larger disability movement it can help to amplify the voice of their collective concerns about inclusion, which is imperative for change to occur. Though there are risks of being marginalized within a larger disability movement for people with intellectual disabilities (Dowse, 2001), I think there are also so many common barriers for people with various disabilities that joining together is a necessary step towards creating a broader understanding of disability.

### *We Must Foster Relationships of Value*

As indicated by respondents, to create meaningful inclusion people are interested in developing not only a physical presence in the community but also friendships in the community for people with intellectual disabilities. Fostering relationships of value between people who have intellectual disabilities and those that do not is vital to promoting 'real' inclusion in communities (Cummins & Lau, 2003). In order to do this social work must challenge stereotypes and negative attitudes about people with intellectual disability. Moving the dominant discourse from a medical model understanding of intellectual disability to a social model of understanding is key to changing attitudes. Without changing how people with intellectual disabilities are viewed in society, as an IQ score or an impairment, how they are treated will not change (Carlson, 2005). Supporting programs that provide opportunities for people with intellectual disabilities to be around people without disabilities in the community, such as *Passport*, is one step that can help this process. But, moving beyond just having people with intellectual disabilities in the community (physical inclusion) we need to encourage dialogue between them – this is what will work towards changing attitudes and promoting social inclusion.

As some respondents identified that having a common interest can provide a starting point for relationship to develop, encouraging people with intellectual disabilities to reach out to those with common interests in the community (or, when necessary, doing so on their behalf) is one way to encourage this dialogue. As well, providing opportunities for someone with an intellectual disability to meet someone who does not is a way to build a connection that has the potential to change attitudes. This is referred to as structured contact in the school setting, and research has shown that involvement of children who have and do not have disabilities in a buddy program increased overall acceptance of students with disabilities (Siperstein, G.N., Noris, J. & A. Mohler, 2007). Programs such as *Best Buddies* (2008), in which university students are paired with people who have intellectual disabilities based on their common interests, provides an opportunity for friendships to develop between people who might not have otherwise met. Finding ways to bridge the expanse between people with intellectual disabilities and people without is a challenge that social workers must take seriously if they expect to change attitudes about disability.

One of the most profound ways the self-advocacy movement for people with intellectual disabilities has challenged the social construct of disability is through the individual action of people with intellectual disabilities. An example of self advocacy in action comes from Goodley's book, *Self Advocacy in the Lives of People with Learning Difficulties* (2000). The following is an account from self advocate Joyce Kershaw who acts to redefine her worth at her Day Centre;

> "Two staff [in the Day Centre] would stand and say which row could go for dinner. But they used to eat their dinner in a little room. So I asked the boss if I could have a word with him. He said, 'Yes, what's the matter?' So I said, 'Aren't we good enough to eat with?" and he said, 'Yes why?' I said, 'Well, it doesn't seem so - the staff eat in a little room of their own.' So he said he'd see what they'd say at the meeting. Then I asked him, 'Can we call the staff by the first name?' He said, 'Why don't you ask them?' So I did. Some said yes and some said no. Those who said no I said, 'Well, call me Mrs. Kershaw.'" (Goodley, 2000, 93)

This example shows how Joyce changed the discourse of disability at her Day Centre by challenging predominate language and the relational environment of her Day Centre to create a place of inclusion. The action towards inclusion in this case was not a grand change in policy, but a subtle change in the social context of the Day Centre that was enacted by an informed self advocate. I believe that, in part, it is by incrementally changing attitudes through activities such as this that we will create truly inclusive environments for people with intellectual disabilities.

Goodley (2004) explains that within a social model of disability the interpretation of impairment labels depends on how the identities, roles and labels are constructed. Goodley suggests that in "storying one's life" a person with an intellectual disability can use the potency of her or his own story to negotiate the roles and labels that may exclude or empower them (2000, 120). As a social worker, promoting these acts among people with disabilities may create a greater social awareness of disability that could eventually, incrementally, alter the larger discourse about disability and effectively change institutional attitudes. This idea of reconstructing identities to move towards inclusion may also be achieved by intertwining the history of people with intellectual disabilities with the personal autobiographies of people with disabilities to create a deeper and broader understanding of disability and inclusion (Young, 2000). This may be true for people with more severe disabilities as well. Bogdan & Taylor (1989) argue that the social construction of humanness for people with severe disabilities is positively affected by the forging of a personal connection by a non-disabled persons and with someone with a severe intellectual and physical disability. In these cases, disability has been viewed as secondary to the humanity of the person (Bogdan & Taylor, 1989)

### *Equal Access to Service Requires Equal Access to Resources*

The process of measuring disability that is used in *Passport* comes out of a desire to fiscally individualize supports for people with intellectual disabilities. However, this system of allocating resources is driven by a paternalistic professional understanding of disability that uses economic rationality based on a utilitarian provision of service to direct the distribution of funding (DiRita, 2008). The underlying effect of utilitarian provision of service is that, although the moral worth of people with intellectual disabilities is slowly being recognized, the funding frameworks on which they are supported remains static and structured around the concept of economic rationality (DiRita, 2008).

In addition to assisting people to make and implement individual choices from individualized funding models, social work has a place in developing systems that can more equitably support access to these resources in the first place. Current processes for applying to *Passport* require that an applicant be able to complete written applications and know how to present their situations in a manner that prioritizes their need. This type of application lends itself to favour a particular type of applicant, often someone that is well educated and speaks English as a first language. If I were to imagine a system where the equality of people with intellectual disabilities was valued, I would expect that the act of measuring disability would be defined by people with disabilities themselves. In practice this means that people with intellectual disabilities and their advocates need to have key roles in developing and implementing policies that affect them. In order for this to happen, funders and policy makers need to be open to challenges to their traditional practices. Creating openness in this manner is a process that is already underway by many self-advocates worldwide, but social work practice also has a role in promoting greater openness about this kind of policy development. Similarly, Goodley (2005) writes that any program developed with the intention of empowering people with intellectual disabilities needs to be developed with the lived reality of self-advocates in the foreground.

Ultimately anyone who requires support such as that provided by programs such as *Passport* should be able to access it, and, as noted above, self-advocacy can help to change that. Realistically, however, resources are limited and finding a way to equitably distribute resources is an issue that many people face today. Social work commonly acts as the mediator between government policy and the personal lives of citizens, so applying social work principles to creating an application process may in some way shift the balance of power away from favouring the most educated applicants to equally serving all applicants.

### *Choice is Important - But Quality Service Cannot Be Lost*

Another clear message that social work can take from this research is that for people with intellectual disabilities and their caregivers choice is important. In every interview choice was the element of *Passport* that respondents most valued:not only being able to decide the type of activities that an individual takes part in but also choosing the staff persons that supports them, the duration of the activity and the schedule of support. Control over every aspect of the support contributes to *Passport* recipients' and their caregivers' sense of empowerment. This experience is parallel to other studies of individualized funding programs that have been shown to provide increased control in the lives of service recipients, improved self-esteem, and deeper and more rewarding relationships with others (Stainton & Boyce, 2004; Stainton, 2002; Pearson, 2000; Stancliffe, 2001).

What I have discovered from this research is that, although the caregivers I spoke to did not have difficulty administering the program to meet their needs as they defined them, the caregivers noted that advocacy and an ability to coordinate resources contributed to their success. As social work endeavors to encourage choice in the lives of people with intellectual disabilities, the specific requirements of people with intellectual disabilities must not be forgotten. Not everyone who qualifies for *Passport* has the intellectual capacity or physical ability to direct their own service, and in the process of making choice the *Passport* program may not always account for this. Social work can meet a need for people who have intellectual disabilities by acting as mediators of the system in situations where people either don't have the capacity to make their own choices or they don't have a family or caregiver to support them to make choices. Social workers come equipped with skills necessary to identify with a *Passport* recipient what their individual goals are and the ability to assist them in putting their goals into action where the *Passport* recipient may not be able to. This runs parallel to what Stainton (2002) writes about social work's role in *Direct Payment* programs in Britain: that social work's position between state and individual can play a pivotal role in supporting a shift from paternalistic service delivery to a model of service delivery that supports the autonomy and common citizenship of a person with a disability. As well, Neely-Barnes, Marcenko & Weber (2008) indicate that social work has a place in acknowledging the varying levels of ability people with intellectual disabilities have and tailoring choice and inclusion in programming to their needs. Practically, social workers need to feel confident and comfortable in their knowledge of disability so that they can have frank conversations about what support each individual requires and that, consequently, programming meets the specific needs of each individual, and not just the general needs that their diagnosis might presuppose (Woodcock & Tregaskis, 2006). I believe that because the field of developmental services in Ontario is moving toward creating individualized models of support, developmental services would benefit from a stronger social work presence to assist with the implementation of this support in scenarios where people don't have all the skills required to implement individualized programming on their own. Social work may also find a role in developing capacity among self-advocates so that they have the skills required to advocate for themselves for changes to programs that affect them.

Finally, it has been argued that the privatization of service provision through a program like *Passport* will generate more creativity among service providers (Swenson, 2008). However, when quality of service provision is examined in a system that values privatization, it becomes evident that people who have skills and resources to negotiate higher quality programming are at an advantage over those with more limited resources and complex needs (Baines, 2004). As noted in my analysis, with individualization of resources the quality of support can decrease for people who have *Passport* but can't advocate for adequate service. Wehmeyer and Bolding (2001) caution that even with the social and emotional advantages of individualized supports, any move towards this sort of programming must ensure adequate levels of support for a sense of inclusion or empowerment to result from such services. With Passport, in an attempt to equally divide up social service resources by measuring physical support needs, it appears that the emotional and social needs are not always accounted for and as a result those with fewer social and emotional supports are disadvantaged within this system. The involvement of social work in the implementation of support may help to identify when and if the quality of support decreases, and social workers can help to challenge policy and practice to establish common standards for service.

## Areas of Future Research

### *Research On Relationships*

How do relationships for people with intellectual disabilities develop? This research has added to literature that states the importance of the development of friendships between people with and without intellectual disabilities in the pursuit of inclusion, but understanding just how it happens is still unanswered. Generally, understanding the development and experience of social relationships for people with intellectual disabilities has not been well researched, and although these may not vary drastically from the ways that typically developing people forge and experience relationships, for people with intellectual disabilities it does tend to happen in a different context. For example, everyone I interviewed had a staff person - someone who was paid to work with them - and, in some cases, this person was considered a friend. Is this type of friendship, even though one party is paid, of equal value to someone with an intellectual disability as a friendship that is unpaid? If relationship is a valuable component of inclusion, knowing how people with intellectual disabilities understand and experience relationships would open up opportunities to create more supports that may eventually encourage more meaningful relationships to develop.

### ***Research On Service Recipient Involvement In Program Development***

The experience of respondents in this research project indicates that people with intellectual disabilities are often supported by some kind of caregiver (parent or otherwise) to develop their individualized programs. More research that focuses in on the level of involvement of people with intellectual disabilities in the development of their programming would highlight if individualized funding actually contributes to a shift in the ability (and opportunity) of people with intellectual disabilities to make choices about their programming. This research indicated that choice was important to the respondents, but respondents were mainly caregivers and service providers of people with intellectual disabilities. As a result, the choice of the individual themselves was hard to assess. Milner & Kelly (2009) provide a good example of how research has endeavored to understand how people with intellectual disabilities are defining their spaces, and more research about how we can assist people with intellectual disabilities to define their services would expand our knowledge in this area. As well, research that helps us understand what constitutes choice for someone who has a cognitive impairment and cannot verbalize their interests or struggles with the concept of choice itself would contribute to a broader understanding of choice-making for people with intellectual disabilities.

### *Research On Family Roles in Adult Day Supports*

Research that further explores what the family must do to effectively support a person with an intellectual disability to take part in the activities related to an individualized program would be able to expand on the findings of this project. This project pointed out that caregivers appear to be willing take on the challenge of creating an individualized program for their family member with an intellectual disability, but that this has a cost for the family. In most cases, caregivers indicated that the cost is, in part, financial, but that it also impacts on their family functioning and social interactions. This is in line with literature that talks about the benefits and burdens of caregivers who support a person with an intellectual disability (Green, 2006; Heiman, 2002). More in-depth research about this as it relates to programs like *Passport* could help people who develop individualized programs to understand what caregivers need to do to create and manage these programs for their family member with an intellectual disability and to support their family member's participation, but it would also give caregivers a chance to say what they are willing to sacrifice for this funding and what they will not, or cannot, sacrifice for it.

## The Study's Limitations

### *Sample Size and Selection*

This study is limited by the number of people that took part . With only 5 people, the study is truly only reflective of a very narrow group of respondents. As well, the people were recruited based on a self-selection method that may have resulted in acquiring a group of respondents that are representative of only a particular type of *Passport* recipient. To be amongst the few successful applicants for *Passport,* these respondents must share some unique characteristics. Further, to have also stepped forward to take part in a research project may indicate that they share additional attributes. Specifically, because *Passport* is delivered on a 'most in need' basis, the people who have received the funding are typically people who have previously been in crisis or near crisis with their level of support, and who are able to successfully apply and advocate for themselves and their adult children with intellectual disabilities - *Passport* was awarded to them because they could not have functioned without it. In addition, the ability to step forward and respond to a request to take part in research shows that the respondents that took part in this project were able to articulate their needs clearly enough that they could share them with the researcher.

### *Geography*

In addition, the respondents in this case were all from either small communities or rural areas, leaving the experience of urban *Passport* recipients out of the research. This may have affected the respondents' feeling that with *Passport* they have more options because, in most of the rural areas where interviews were conducted, there was only one option for day support – in this case, it is easy to understand why *Passport* might be recognized as having the potential to create additional options. In a larger urban centre options for day support *prior* to *Passport* are already likely to be more diverse than the one program found in rural areas, therefore, assuming that every family feels there are more options with *Passport* (based only on the experience of the respondents in this research) could be too broad an assumption.

### *Language*

Finally, the language of community and inclusion is often used in the developmental sector, but the definition varies widely from person to person and in various contexts (Bach, 2002; Wilson, 2006). Even within this research there was no set definition of what inclusion is used during the interviews. This flexibility in the language was intentional in order to provide opportunities for respondents to identify what it means to them, but,at the same time, I believe that it limits the study's ability to pinpoint how inclusion exists. This is an issue that anyone who talks about inclusion will experience because the word can mean simply a presence in a community or it can mean active participation in a community (Wilson, 2006). My intention in this research was to try to understand what it means to people who use Passport, but innot limiting the definition the content of the conversations fluctuated. In analyzing the data I was able to pull out what I thought reflected inclusion as an active participation in community, as it was described by the respondents, but because language is so varied in this regard it may not, in every situation, be a clear interpretation of inclusion as the respondent understands it.

# CONCLUSION

*Passport* is one example of various program delivery models worldwide that have shifted service to individualized funding resources (Askehim, 2005; Milner, 2009; Neely-Barnes et al, 2008; Roulston, 2009; Stainton, 2002). In Ontario, programs like *Passport* have been relatively un-examined in social work research and this text marks an initial piece of work that has been undertaken to start to understand this program's effect on the lives of people with intellectual disabilities.

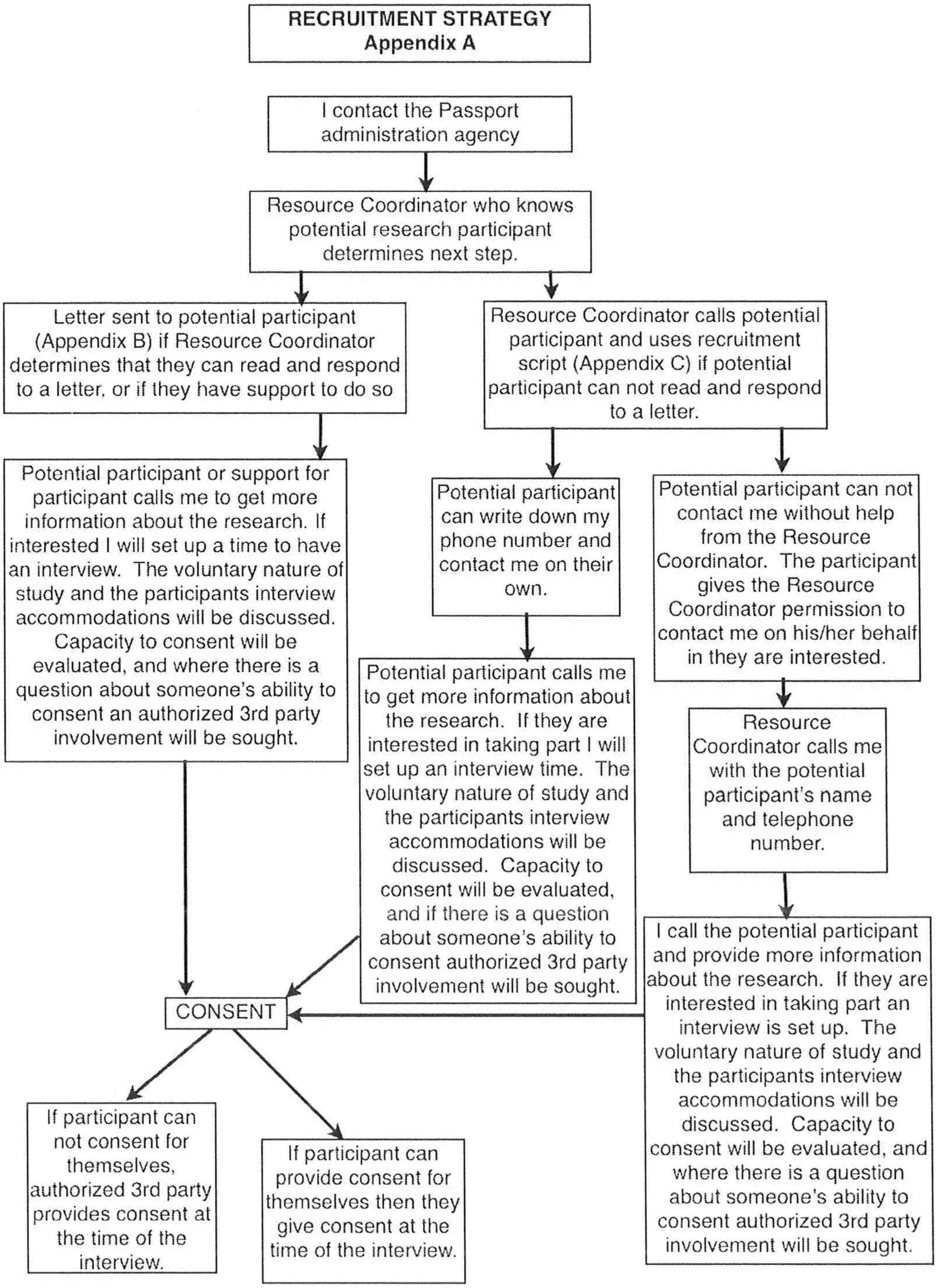
This study has linked increased opportunities for community involvement to the enhanced experience of inclusion for *Passport* recipients. In this regard, *Passport* did allow more choice for *Passport* recipients and their caregivers to create a program of community participation support that matches the needs and desires of the individual. But, the actual experience of inclusion varied between respondents and was based on their own personal expectation of what inclusion means and how the *Passport* recipient may or may not experience relationships in the community.

In addition, this research further verified that the effects of neoliberal shifts in social service delivery that are experienced in other service sectors are also reflected in the experience of *Passport* recipients and their families. This includes shifts towards privatization of service, decentralization of service delivery and the individualization of resources. While some aspects of social service market principles have provided a sense of empowerment to *Passport* recipients and their caregivers, the positive emotions associated with the control they have over service are overshadowed by feelings of guilt and gratitude about service availability and the responsibilities of advocacy required to maintain service. This is reflective of definitions of empowerment that are espoused by neoliberal understandings of consumer-driven social service markets (Beresford & Croft, 1995)

As I alluded to in the introduction, this research is based on the experiences of only 5 *Passport* recipients and their caregivers, so its generalizability to a larger group is weakened. As well, this writer's own personal biases and perspective have inevitably seeped into the text, including my personal and professional connection to family and caregivers that deal with service provision for people with intellectual disabilities daily. But, from my vantage point, standing outside of the text would not serve the purpose of joining with people who have disabilities to confront the oppression that exists. The researcher is either with the oppressed or the oppressor (Barnes, 1996).

There is no posturing that this research will change the face of social service delivery for people with intellectual disabilities and their caregivers. Rather, this is another piece of evidence in the growing case for shifting attitudes about people with intellectual disabilities towards attitudes of inclusion. I expect that this change will continue to occur incrementally, over time, but change needs to occur. It is my hope that this research can be used by social workers and policy makers as a point of engagement in this ongoing process of change.

# Appendix A - Recruitment Strategy



**RECRUITMENT STRATEGY**
**Appendix A**

I contact the Passport administration agency

Resource Coordinator who knows potential research participant determines next step.

Letter sent to potential participant (Appendix B) if Resource Coordinator determines that they can read and respond to a letter, or if they have support to do so

Resource Coordinator calls potential participant and uses recruitment script (Appendix C) if potential participant can not read and respond to a letter.

Potential participant or support for participant calls me to get more information about the research. If interested I will set up a time to have an interview. The voluntary nature of study and the participants interview accommodations will be discussed. Capacity to consent will be evaluated, and where there is a question about someone's ability to consent an authorized 3rd party involvement will be sought.

Potential participant can write down my phone number and contact me on their own.

Potential participant can not contact me without help from the Resource Coordinator. The participant gives the Resource Coordinator permission to contact me on his/her behalf in they are interested.

Potential participant calls me to get more information about the research. If they are interested in taking part I will set up an interview time. The voluntary nature of study and the participants interview accommodations will be discussed. Capacity to consent will be evaluated, and if there is a question about someone's ability to consent authorized 3rd party involvement will be sought.

Resource Coordinator calls me with the potential participant's name and telephone number.

I call the potential participant and provide more information about the research. If they are interested in taking part an interview is set up. The voluntary nature of study and the participants interview accommodations will be discussed. Capacity to consent will be evaluated, and where there is a question about someone's ability to consent authorized 3rd party involvement will be sought.

CONSENT

If participant can not consent for themselves, authorized 3rd party provides consent at the time of the interview.

If participant can provide consent for themselves then they give consent at the time of the interview.

# Appendix B - Recruitment Letter

**MCMASTER UNIVERSITY**
**SCHOOL OF SOCIAL WORK**

Kenneth Taylor Hall Rm.319
1280 Main Street West
Hamilton, Ontario L8S 4M4

289-808-9867
demaitzw@mcmaster.ca

To Whom it May Concern,

I am a Master of Social Work student at McMaster University and I am doing a research project to find out what people think about the Passport program. This letter has been passed on to you because you are currently using the Passport program

I am sending this letter to people who use Passport because I think that to make my research useful it is important to learn from people with disabilities and their caregivers. I hope that the information I gather will help social workers and other professionals understand what people like and dislike about programs like Passport.

**To take part you must:**

- **Receive Passport funding**
- **Be a person with an intellectual or developmental disability or support someone who does**
- **Be 18 years of age or older**

If you want to be involved with this research, I will need to have a 1-hour interview with you to talk about what you think about Passport. Your involvement would be voluntary, this means that you can choose not to take part in the research at any time. Also, when the research is complete I will share my results with you.

**If you are interested please call me at 289-808-9867 or email me at demaitzw@mcmaster.ca**. If you choose to respond to this letter your information will be kept private. I have no connection to the Passport program or the centre that you applied for Passport through.

Sincerely,

Zeb Demaiter, McMaster University MSW student researcher

Zeb Demaiter page 1/1

# Appendix C - Recruitment Script

## Script for Recruitment

*This script is to be used in situations where a potential research participant is identified by their Resource Coordinator as someone who is competent to understand what is required to be involved in this research project, but doesn't have support and would not be able to read or possibly respond to a recruitment letter.*

Hello *(Insert name of potential participant)*

I am calling you to pass on information about a social work student named Zeb Demaiter from McMaster University who wants to do research about the Passport program. He wants to know what people who use the Passport program think about it so he can tell other professionals about what people like and don't like about Passport. He also thinks that it is important to find out what is good and bad about Passport from the people who are using the program.

Our Contact agency is not connected to Zeb Demaiter in any way, we are just passing this information on to you so you can take part in it if you are interested. Participation in this project is completely voluntary. That means that it is up to you to decide if you do or don't want to take part in this project - and that whatever you decide is OK. Also, whatever you decide, your service and support from our agency will not change and your support through Passport will stay the same.

If you choose to take part in this project Zeb will need to talk with you in person for about an hour to find out more about what you think of the Passport program. After he is done gathering all the information from everyone he talks to he will also offer to share information about what he finds out with you. Zeb doesn't work for our agency, and he will keep information about you private.

If you are interested, you can call Zeb yourself at 289-808-9867 *(allow time to write number down*) or you can give me permission to share your name and phone number with Zeb and he will call you back. If you are not sure right now, I will send a letter in the mail to you with Zeb's contact information and more information about the project. Remember, you don't have to participate unless you want to.

Thanks for your time - *(Insert name of Resource Coordinator)*

*****Note that the language used to convey this information may need to be adjusted depending on the needs of the person the Resource Coordinator is talking to. Also - information about the questions that will be asked can be shared, or any other aspect of the research that the potential participant may have questions about.***

# Appendix D - Interview Guide

## Interview Guide:

Individualized Funding for People with Intellectual Disabilities in Ontario:
Understanding the Passport Experience

**Situating the person within the Passport program:**

1.When did you start the Passport program?

2.How long did it take for you to get into Passport?

3.If you had to wait, what did you do while you waited?

4.Were you involved in any day programs (give examples if necessary) before you started Passport resources?
    4.1.What were they?
    4.2.Why did you want to change?

5.How do you get help from Passport (i.e. Direct Funding or Agency Services)?
    5.1.Why did you choose this?

6.How do you use the Passport these days?

**Understanding the person's experience of the Passport program:**

7.Does Passport meet all of your needs at this time?

8.Do you enjoy the activities you are in? Why/Why not?

9.Before Passport what kinds of things did you do in the community?
    9.1. Did these things make you feel like a part of your community? Please Explain.
    9.2.How do you describe/understand community inclusion/ being a part of a community?
    9.3.Does Passport help with inclusion/ being part of a community?

10.What do you like most about the Passport program?
    10.1.What don't you like about the Passport program?

11.Please tell me about the kinds of things you are allowed to use Passport for.
    11.1.Are there other kinds of things you would like to get/do using Passport?

12.Is there anything else about Passport you would like to tell me?

**Zeb Demaiter** **Page 1/1**

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