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# Poverty and Disability: The Need for Inclusion

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**Canada**



POVERTY AND DISABILITY: THE NEED FOR INCLUSION

by

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*at Wilfrid Laurier University, 2005*

THESIS

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## Abstract

Despite the fact that people with disabilities are disproportionately represented among the world's poorest, they have been marginalized in poverty research and have had minimal involvement in poverty reduction strategies. The current study addresses this issue, by providing an opportunity for people with developmental disabilities to control and direct the research agenda, and to have an active voice on the topic of poverty and disability. Thus, the present study aims to support the development of poverty reduction strategies by raising key issues and breaking down barriers to participation for people with developmental disabilities. This study utilized a social power framework and participatory action research approach, guided by an advisory committee of adults with developmental disabilities. Participants (n=27) included self-advocates with developmental disabilities, 18 years or older, living with low income. Six focus groups were conducted in Brantford, Hamilton and Waterloo region. The findings of this study revealed that the lived experience and consequences of poverty are characterized by a lack of resources to fulfill basic needs and participate in community life. Challenges to overcoming poverty include discrimination, dominant ideologies about disability, lack of employment opportunities and exclusion from participation in decision making about key disability and poverty issues. Thus, participants identified needs and recommendations for change to increase resources, promote participation and elimination of deficit –focused approaches, coupled with dissemination of the strengths-based approach to disability. The study provides increased visibility of people with developmental disabilities to help overcome negative societal perceptions of disability. The implications of this study can be important in promoting preventive social programs and transformative social policy, both which aim to attack the causes of long-term poverty in Canada.

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## Introduction

People with disabilities are among the world's poorest of the poor. The World Bank estimates in 2000 suggested that people with disabilities account for as many as 20% of the world's poorest (Elwan, 1999). In Canada, approximately one million working age Canadians with disabilities are either unemployed or out of the labour force (Dunn, 2006). Access to adequate income is a problem for upwards of two million Canadians with disabilities (Canada, 2006; Statistics Canada 2002, 2007, cited in Prince, 2009). More than 55% of adults with disabilities live below the low income cut-off (LICO) as compared to 19% of adults without disabilities (Bach, 2003). The majority of adults with disabilities have incomes below \$15,000 per year (Bach, 2003). The profound poverty of people with disabilities has been found to be both a cause and consequence of exclusion from social, economic and political life (Bach, 2003; Beresford, 1996; Dunn, 2006; Elwan, 1999; Lord & Hutchison, 2007; Munro, 2007; Prince, 2009; Stapleton, 2009; Stapleton, O'Day, Livermore, Imperato, 2005; White, 2005; Yeo, 2001; Yeo & Moore, 2003). For the proposed study, poverty is defined as those who experience multi-dimensional poverty in terms of income, social exclusion and powerlessness (Yeo, 2001). Moreover, poverty is also described across the life-course, such that insufficient income, social exclusion and powerlessness experienced in childhood and during youth can have implications across an individual's life course (Moore, 2004). In other words, children and youth who experience multi-dimensional poverty may be especially susceptible to persistent poverty (Moore, 2004). Several studies argue that the exclusion of people with disabilities from poverty research and anti-poverty strategies reflects and reinforces the disproportionately high representation of people with disabilities among the poorest of

the poor (Beresford, 1996; White, 2005; Yeo, 2001; Yeo & Moore, 2003). There is a lack of comparable or reliable data on the extent of poverty faced by people with disabilities. What little research that does exist has been done overwhelmingly by European or North American non-disabled academics (Yeo & Moore, 2003). There has been little opportunity for influence of the agenda by people with disabilities. Without the real participation of people with disabilities, research results often misrepresent people's concerns creating mistrust and skepticism as to whether any benefits will be gained from the research (White, 2005; Yeo, 2001; Yeo & Moore, 2003). The present study addresses these issues by providing an opportunity for people with developmental disabilities to control and direct the research agenda, and to have an active voice on the topic of poverty and disability.

The present study has been guided by an Advisory Committee (henceforth referred to as the Committee) of adults with developmental disabilities living with low income. People with developmental disabilities have been selected specifically for this study for several reasons. There can be a number of challenges when working with a variety of disability groups such as physical, developmental, psychiatric, etc., using a participatory approach. For example, White (2005) shared his experiences working with the participatory research model with people from a variety of disability groups and found several barriers that interfered with the process of power sharing. Personal histories and interests frustrated the stakeholder process and it was difficult to meet the specific needs of all individuals. As such, this study intends to work with a more homogeneous group of people with whom the present author is already familiar. The present author has been working in community organizations supporting people with developmental

disabilities for the past five years. This provides me with supportive knowledge of this population group, and awareness of some of the common issues and concerns that affect the quality of life for people with developmental disabilities.

The term “developmental disability” has been chosen by the Committee as the preferred term to be used throughout this text. The actual definition of what characterizes a “developmental disability” is best described by Brown and Percy (2007) as “some restriction or lack of ability having to do with human development.” (p.4).

“Developmental disability” is also sometimes used synonymously with the term “intellectual disability” which refers to “some restriction or lack of ability having to do with the human intellect” (Brown & Percy, 2007, p. 3). Essentially, during childhood and adolescence, people who are considered to have a developmental disability may have reduced intellectual capacity or develop limited ability to do the things that are socially expected of most people. Richardson (2000) notes that people with developmental disabilities, especially those who may have intellectual difficulties, are commonly considered incompetent and unable to adequately speak for themselves, thus requiring care, protection or treatment. He argues that this is because disability is socially constructed, arising from powerful medical, professional and political interests. Consequently, many people with developmental disabilities are excluded from mainstream society and their voices are often disregarded or not heard.

The present discussion will first outline how the exclusion of people with disabilities creates and perpetuates their poverty through an ecological analysis to demonstrate the multifaceted aspects of the problem. As the present study emphasizes transformative change, the macro level analysis will be outlined in terms of

infrastructure, research and poverty reduction strategies. Following this analysis, a guiding theoretical framework is presented to circumscribe the problem of poverty and disability as an issue of social power, such that people with disabilities lack social power to have control over poverty reduction strategies and related processes. The framework is used to outline the present study's purpose, goals and objectives, research questions and results.

### Literature Review

This thesis focuses on the problem of poverty and disability, primarily for people with developmental disabilities. However, much of the literature on the intersection of poverty and disability does not specify the nature of the disability, nor does most of it consider other factors such as race, ethnicity, sexual orientation or gender. Thus, the following literature review includes previous research and knowledge about issues related to poverty and people with different types of disabilities and will be mostly discussed in a generic fashion as "people with disabilities". This generic use of the term is justified, according to the literature, because of the common obstacles people with various disabilities experience (Nilbert, 1995, Prince, 2009). A significant part of this literature review is based on previous reports by Yeo (2001) and Yeo and Moore (2003) who provide the most comprehensive and relevant data for the present discussion. These authors have provided valuable knowledge on the problem of poverty and disability, and inclusion in poverty reduction efforts in the international context. As such, the present study and literature review also includes previous research and knowledge specific to the Canadian context.

### *Ecological Level Problem Analysis*

The following ecological analysis is used to emphasize the problem of poverty and disability in the context of social systems (Nelson & Prilleltensky, 2005).

Community psychologists use this analytical structure in order to understand the qualities of human environments that affect individual well-being (Nelson & Prilleltensky, 2005).

This analysis is important to the present discussion to recognize that our environments affect people with disabilities in distinct ways.

#### *Individual*

Many individuals with disabilities have been excluded from the day to day interactions that people without disabilities have the opportunity to experience. This has resulted in individuals with fewer skills, lower self-esteem, a relative lack of ability to assert rights and poorer health (Yeo, 2001). The literature suggests that the individual focus of the medical and charity models of disability are partly to blame for the lack of self-determination of people with disabilities.

Yeo (2001) describes the medical and charity models of disability in her extensive report on chronic poverty and disability. The medical model focuses on an individual's impairment and ways to alleviate the impairment through medical and technical solutions. The charity model similarly views people with disabilities as pitiful and needing help by welfare approaches. Both models, view disability from an individualistic perspective. Social factors are not accounted for, and there is no recognition of equal rights. The conventional viewpoint that poverty is an expression of the inherent dependence of people with disabilities has been associated with these models.



*Micro System*

Executive Vice-President of the Canadian Association for Community Living, Michael Bach, addressed poverty and disability in his presentation “An Anti-Poverty Agenda for Persons with Disabilities” (2003). Within his presentation, he described the greater incidence of poverty experienced by families of children with disabilities in Canada. Bach noted that more than 28% of children with disabilities live in households in the lowest income bracket, compared to 17% of those without disabilities. This financial stress may further contribute to the existing strain on a family based on the additional needs of children with disabilities who require more care and may not be considered to have the potential to support him or her self (Bach, 2003, Brown & Percy, 2007).

Similarly, Yeo (2001) notes that in an already impoverished family, it may be viewed as economically irresponsible to give a child with a disability a fair share of resources when the child is perceived as unlikely to provide for the family in the future. As a result, children with disabilities often have fewer demands placed on them due to low expectations of their abilities (Lord & Hutchison, 2007; Yeo, 2001; Yeo & Moore, 2003). Also, because of low expectations of their abilities, children with disabilities are at a disadvantage as they are excluded from many of the daily interactions that children without disabilities experience to gain basic social and life skills. Yeo (2001) comments that, particularly in developing countries, children with disabilities are excluded from activities with non-disabled peers for fear that they may stigmatize the family or that they are not a worthwhile investment and others should get priority. As a result, many children with disabilities grow to become adults with limited social contacts and natural support networks. Moreover, “if [children with disabilities] are not included in the community,

then as they grow up, their non-disabled peers may not be aware of their existence, let alone their values and rights as equal citizens.” (Yeo & Moore, 2003, p. 574). Due to family issues and concerns, and limited social networks, many people with disabilities have limited employment opportunities as they lack the experience, education, qualifications and confidence to obtain work (Yeo & Moore, 2003). This places people at increased risk of poverty and further exclusion from society (Yeo, 2001).

### *Meso System*

The exclusion and segregation of people with disabilities is predominant within the education and employment sectors of society. Particularly staggering is the United Nations Education, Scientific and Cultural Organization’s finding that showed 98% of “special needs” children in developing countries are denied any formal education (Hegarty, 1988, 1995, cited in International Disability and Development Consortium, 1999).

Yeo (2001), as well as Bach (2003), describe how exclusion from education results in disadvantages later in life. According to Yeo (2001), children with disabilities in some developing countries, who have an opportunity for education, often do not get the support they need to participate equally, and have low expectations of themselves and from others. Yeo (2001) further suggests that even in informal educational settings, children with disabilities may still learn less than children without disabilities, as they typically have fewer demands placed on them. Bach (2003) also addressed education opportunities in the Canadian context, whereby he notes that 40% of children with developmental disabilities are not integrated in regular classes, and 15% of all children with disabilities do not attend regular school. He comments that this should be of major

concern since participation in social activities and employment income generally increase with education level attained. Bach (2003) states that “Those children who attend special education (as opposed to being integrated into “regular classes”), have a lower level of education; [and] regular education early in life is associated with favourable economic outcomes later in life.” (p. 1). This means that as adults, people with disabilities have restricted income-earning opportunities due to lack of experience, confidence and basic skills such as literacy and numeracy (Bach, 2003; Yeo, 2001).

Thus, lack of education leads to the major cause of poverty which is unemployment and under-employment (Jongbloed & Crichton, 1990). People with disabilities have been excluded from employment opportunities because of several factors already mentioned in this discussion, such as a relative lack of social skills, life skills and work skills, experience, education and self-esteem. Elwan (1999) cites literature from the international context, indicating that people with certain forms of disability, particularly those with “mental handicap” were found to have especially severe problems finding and keeping employment (p.14). According to Dunn (2006), people with disabilities are further excluded because of physical and social barriers to employment and inadequate public policies. As employment is also the basis of social and political status, reduced or non-existent employment income means no influence and powerlessness in western society (Jongbloed & Crichton, 1990). As such, people with disabilities are excluded from political and legal processes, contributing to a lack of ability to assert rights and further reducing income generating opportunities to push people deeper into poverty (Yeo, 2001).

### *Macro System*

The macro level of analysis for the problem of poverty and disability is the most pertinent to the purpose of the present study in terms of causes and consequences of poverty. This analysis is discussed in relation to infrastructure, disability and poverty research, and poverty reduction strategies.

*Infrastructure.* There are a number of challenges related to services and supports for people with disabilities in terms of power and control. The lack of bargaining power and resources available for people with disabilities is exemplified in the difference between program and individualized funding in Canada (Lord & Hutchison, 2003; Pedlar, Hutchison, Arai, & Dunn, 2000). Program funding directs government funding for people with disabilities to community service programs, often through a community service organization that provides support for people with disabilities. Individualized funding on the other hand, directs financial support to people with disabilities and their families who can then select community resources best suited to their needs. Pedlar et al. (2000) found that program funding is the most common form of funding and support in Canada. As such, many people with disabilities are forced to choose among existing services without real bargaining power to choose the most appropriate resources available to them.

There are also a number of challenges in the income support system for people with disabilities. These challenges relate to a lack of support for community structures, which promote vital structures that “facilitate the pursuit of personal and communal goals” (Nelson & Prilleltensky, 2005, p. 57). Many Canadians with disabilities are dependent on Canada’s disability income security system, such as the Ontario Disability

Support Program (ODSP) (Dunn, 2006, Prince, 2009, Stapleton, 2009). Stapleton and colleagues (2005) describe how income support policies create a poverty trap. Disability income support systems are based on the assumption that people cannot work. Therefore people who need financial support must prove they cannot work by not working. The rules of these systems also reduce financial benefits drastically as a beneficiary's employment earnings increase. Stapleton and colleagues argue that there is a self-fulfilling prophecy in the income support system whereby people with disabilities may come to believe that they cannot support themselves through paid employment. This traps people in the system and prevents them from experiencing the personal satisfaction of earning employment income.

*Research.* In spite of the obvious relationship between disability and poverty, there is a lack of research that includes disability issues in major international development journals and reports on poverty (Yeo & Moore, 2003). This appears to be both a cause and consequence of the exclusion of people with disabilities from the research process (Beresford, 1996; White, 2005; Yeo, 2001; Yeo & Moore, 2003).

Yeo and Moore (2003) suggest several reasons why people with disabilities are excluded from research. First, the marginalization that people with disabilities face can make it difficult and time-consuming for outside researchers to locate and communicate with this population group. Also, the materials used to conduct research and to disseminate it can exclude people when formats are used independently, rather than using multiple formats to reach a larger audience. For example, visual materials are inappropriate for people with visual impairments unless they are produced in Braille; written materials pose difficulties for individuals with low literacy levels; and oral

discussions are inappropriate for people who experience hearing impairments. Yeo and Moore (2003) also suggest that when people with disabilities are included and involved in research, their role is often tokenistic in order to add apparent legitimacy to the work. As a result of this token role, the concerns of people with disabilities are often misrepresented. It is a shame that researchers involved in poverty reduction initiatives are not including people with disabilities on a regular and consistent basis. Rather, they are perpetuating the very exclusion, discrimination and marginalization that contribute to the poverty they are trying to work against.

White (2005) claims that distrust and skepticism among the disability community has been created by exclusion from the research process. He states that “Some disability advocates have accused social scientists of siphoning off money for “disability research” that could be better used for advocacy or direct services.” (p. 413). White suggests that although disability research may have rigour, it often lacks practical application for key stakeholders, and recommends actively involving people with disabilities to help offset part of this skepticism. Thus, the present study has actively included people with developmental disabilities in development of the research questions and setting the research agenda to address the exclusion of people with disabilities from the research process.

*Poverty reduction strategies.* Similar to the exclusion from research, people with disabilities have also rarely been asked their views on poverty and anti-poverty action. They have been marginalized in poverty discussions and have had minimal involvement in anti-poverty policy and campaigning (Beresford, 1996; White, 2005; Yeo, 2001; Yeo & Moore, 2003). Beresford (1996) notes that the voices of people with disabilities living

in poverty are often ignored and devalued in the development of anti-poverty policy. Moreover, people with experiences of poverty are under-represented in membership of anti-poverty organizations (Beresford, 1996). Beresford (1996) also comments that in Britain some “disabled people’s organizations” criticized the exclusion of people with disabilities from conventional anti-poverty action by concentrating on “parliamentary pressure at the expense of grassroots involvement and initiatives, and, that non-disabled people set themselves up as experts [on disability related issues]” (p. 557). Beresford further states that “disabled people’s organizations internationally argue that they must be fully involved in campaigning and that poverty should be seen as one expression of the institutional discrimination disabled people face” (p. 557).

People with disabilities are excluded from poverty reduction strategies for various reasons. Those living in poverty, among whom people with disabilities are disproportionately represented, are considered to live in the margins of society, and as such, may be difficult to locate (Yeo & Moore, 2003). Also, as people with disabilities are generally excluded from social, political and economic institutions, people with disabilities lack the power to exert influence on policy-makers and thus have rarely been considered a priority among those in positions of power (Yeo & Moore, 2003). As such, it may be that some poverty reduction strategists have discounted the involvement of people with disabilities as they are viewed as lacking the power necessary to exert influence.

A review by the present author of 15 Canadian poverty reduction strategies also demonstrates the relative exclusion of people with disabilities. Of these 15 documents associated with Vibrant Communities, a community-driven effort to reduce poverty in

Canada ([www.vibrantcommunities.ca](http://www.vibrantcommunities.ca), accessed Apr. 10, 2008), only four mention the word “disability”, and only two actually include active involvement of people with disabilities in the strategy. One striking example came from the Assured Income for the Severely Handicapped (AISH) Public Policy Initiative in Alberta (Makhoul, 2005) where a committee conducted a review of the AISH program and made recommendations to the provincial government to improve the program. The committee consisted of 11 members representing several community non-profit organizations that provided services and supports to several disability groups. There was no representation of recipients of the disability income support program. The committee coordinator was quoted:

We were criticized by some members of the disability community for not including AISH recipients in the committee work, but this was a deliberate decision. AISH was the subject of the effort, but our original intent was to increase organizational capacity in the area of influencing public policy. We held a consultation with the disability community in March 2004 to explain our process and progress, and it was attended by about 80 AISH recipients and service providers from across the province. They made it clear that they felt the process had not been inclusive. We learned that future work should include earlier consultation with affected groups, a mid-term meeting and the distribution of draft documents for comments near the end of the process. (p. 4)

This statement highlights the interest among the disability community to be involved and included in poverty reduction strategies. This also emphasizes a need to learn from previous initiatives that excluded people and move toward a more inclusive process.

Several other initiatives failed to address disability issues within documents that specifically focused on inclusion, collaboration and tackling social exclusion. For example, *Le Chantier in Saint-Michel – Tackling Poverty and Social Exclusion* document (Makhoul, Brodhead, & Leviten-Reid, 2006) targeted its efforts on a few selected areas, including: mental health, youth, family, seniors, food and overall strategic planning, but



did not include disability issues. The British Columbia *Quality of Life Challenge: Inclusion Policy and Procedures* (2007) states that the goal of the policy is to facilitate equal participation in poverty prevention and reduction efforts, but makes no specific mention of disability issues. This document appears to promote inclusion but fails to specify how people with disabilities can indeed be supported to participate.

There is hope and possibility, however, for the inclusion of people with disabilities in poverty reduction strategies. The Fair Fares Calgary initiative (Makhoul, 2005) is an exemplar of such an inclusive process. Based on this initiative, approximately 2,000 Calgary residents who were recipients of the AISH benefits were issued reduced rate monthly transit passes in August 2005. The Fair Fares Calgary committee included membership from both the disability community and employees of the City of Calgary. Each group brought unique strengths to the process. The City of Calgary helped to bring information and issues forward to Calgary City Council, and members from the disability community collected front-line stories from individuals who were struggling to overcome transportation barriers. This is a good example of how the committee worked together to develop an effective solution for their members.

Another promising new initiative is the Awareness of Low income Voices - ALIV(e)- group founded in 2007 by Opportunities Waterloo Region. This group consists of people living on low income, including beneficiaries of ODSP, who educate its members and the wider community about poverty-related concerns and strategies aimed at preventing and reducing poverty. This group helps ensure that poverty reduction work is focused and informed based on the lived experiences of poverty. There has been some noted success with the ALIV(e) group, including increased membership and increased

understanding of the importance of self-sufficiency, sustainability and camaraderie.

Makhoul and MacKeigan (2009) report that Opportunities Waterloo Region would also like to see ALIV(e) members increase their contribution to the Leadership Roundtable and board of directors.

The broader picture of poverty reduction strategies in Canada also appears to recognize the need for an inclusive process in their mission, vision and guiding principles. For example, Vibrant Communities guiding principles state “We ensure that people who have experienced poverty first hand are central to our work.” ([www.vibrantcommunities.ca](http://www.vibrantcommunities.ca), accessed Apr. 10, 2008). Sherri Torjman (2001), vice-president of the Caledon Institute of Social Policy, says a vibrant community is one that: “Provides support that meets the basic needs of all members; Promotes inclusion to enable all members to participate actively in social, economic, cultural and political life; Promotes opportunities for the lifelong acquisition of knowledge and skills by all members” (p. 47). Torjman also specifically mentions that changes must be made to promote inclusion of people with disabilities. As such, Prince (2009) points out that recently, two provincial governments, Quebec in 2002 and Newfoundland in 2006, have introduced general poverty-reduction strategies which specifically include measures for people with disabilities, as well as provide structure and process for regular consultation.

Within the international context Yeo and Moore (2003) make several arguments for the benefits of including people with disabilities in poverty reduction strategies. First, they argue that the exclusion faced by people with disabilities bears many similarities to other forms of oppression such as racism and sexism, but has one fundamental difference: people with disabilities may experience reduced capabilities. As such, unless the

additional practical needs of people with disabilities are met, it is more difficult for some people with disabilities to organize, advocate and work to reduce their own poverty.

Secondly, Yeo and Moore note that there are economic costs of exclusion, such that if people with disabilities are unable to contribute to society they are likely to be an economic burden to others. Thus, if people with disabilities “were to achieve equal rights and opportunities, this would contribute to poverty reduction for society as a whole” (p. 581). Yeo and Moore provide evidence of this with several international examples of inclusion of people with disabilities that have contributed to a reduction in poverty in several countries. Third, Yeo and Moore argue that poverty reduction cannot be achieved unless we address the inequities in power relations and discrimination experienced by people with disabilities. This is hard to address, due to a lack of comparable information on disability that makes it difficult for organizations to evaluate different approaches toward tackling poverty and disability. Thus, general poverty reduction strategies may not necessarily work for people with disabilities because of exclusion from social, economic and political processes, indicating that inclusion in the process of developing strategies that fit the needs of people with disabilities is critical to effective poverty reduction.

In summary, there appears to be a shift toward a more inclusive process within poverty reduction strategies. As several documents noted that inclusion was an important aspect of their work, it should be recognized that there is further need to embrace the gifts and strengths of people with disabilities through meaningful participation and control in anti-poverty work. The ecological level analysis highlights some of the specific disability related issues that should be addressed in order to reduce poverty. Although the intention

of inclusion may be written as principles and vision statements, there seems to be a lack of evidence to demonstrate the implementation of such efforts. According to Yeo and Moore (2003), the work itself should challenge power relations, such that people with disabilities have actual control over the processes guiding poverty reduction strategies. As such, inclusion is possible we just need to actually make it happen. There is no better group to advocate for this to happen than people with disabilities themselves. This, however, requires consideration of various theories of poverty and a certain level of social power, which I will discuss next.

### *Theories of Poverty*

The definition of poverty, and theories that explain it, are rooted in research traditions and political values and reinforced by various institutions that have a stake in the issue (Bradshaw, 2009). The following discussion reviews some of these theories to determine an appropriate theory of the causes and consequences of poverty and disability. Explaining poverty has been a lucrative field for academics. Several authors note that there is no one generally accepted theory of poverty (Bradshaw, 2009; Rural Sociological Society, 1990; Wilber, 1975). As no one theory has included or invalidated the other, the range of explanations has expanded over the years (Bradshaw, 2009). As such, this discussion will briefly present various broad ideologies and theories of poverty: individual, cultural and social exclusion, in relation to the intersection with disability.

#### *Individual*

Individual theories of poverty consist of the widespread view that individuals are responsible for their own poverty. Bradshaw (2009) notes that this theory views individual laziness, bad choice, incompetence, and inherent disabilities as the cause of

poverty. As such, poverty is a reflection and result of lack of hard work and bad choices. Bradshaw comments “although scientifically it is routine to dismiss the individual deficiency theory as an [explanation for social inequality], it is easy to see how it is embraced in anti-poverty policy that suggests penalties and incentives can change behavior” (p. 13). This perspective blames the victim for being poor and recommends solutions and policy approaches that emphasize self-help strategies to help the poor pull themselves out of poverty. Bradshaw notes that addressing poverty from this theoretical standpoint has been known to be unsuccessful.

Prince (2009) similarly argues that neo-liberal ideology, as the current political frame of society in Canada, supports the individualistic perspective. Prince argues that neo-liberal ideology promotes marginalization of people with disabilities as it favours self-sufficiency and independence which contrasts the prominent models of disability that conceptualize people with disabilities as dependent and needy individuals. Prince comments “the personal tragedy, charitable and medical oriented notions of citizenship converts Canadians with disabilities respectively into citizens with spoiled identities, as supplicants and as sick patients.” (p.24).

### *Cultural*

Dalrymple (2001) also argues that liberal ideology worsens and perpetuates the problems of poverty (such as poor health, lack of education, lack of family support, crime) that it is designed to solve and aims to fix. This author proposes that poverty is not economic, but spiritual, moral and cultural. This is similar to Bradshaw’s (2009) discussion of cultural theories, which suggest that poverty is caused by a subculture that adopts values that are non-productive and contrary to norms of success. Bradshaw

describes this theoretical perspective as “poverty created by the transmission over generations of a set of beliefs, values, and skills that are socially generated but individually held. Individuals are not necessarily to blame because they are victims of their dysfunctional subculture or culture.” (p. 14). Dalrymple (2001) criticizes the welfare state as essentially perpetuating poverty. He argues that the welfare state allocates economic rewards that promote anti-social egotism. The cultural theory of poverty views the welfare state to be a leading cause of poverty, such that people with low income develop and pass on to others the skills needed to work the system rather than to gain paid employment (Bradshaw, 2009; Rural Sociological Society, 1990; Wilber, 1975). Dalrymple (2001) highlights this point of view, suggesting that the welfare state has “created a large caste of people [living with low income] in which they have nothing to hope for, nothing to gain and nothing to lose. It is a life emptied of meaning.” (p.142). This perspective, however, lacks consideration of social, political and economic exclusion, which as described in the above ecological analysis, is a key element of poverty for people with disabilities.

### *Social Exclusion*

Perhaps more relevant to the present discussion then, would be social exclusion theories, discussed in the literature as an explanation of poverty among particular marginalized groups of people. The Rural Sociological Society Task Force on Persistent Rural Poverty (1990) suggest that this theoretical perspective explicates how groups win or lose legitimacy in establishing rights of access to goods and resources, the presumed bases of those rights, and who is excluded by application of those rules of access. This

theory provides insight into the ideological and moral foundations of political apathy for poverty reduction.

Another key aspect of these theories is the consideration of discrimination as a cause and consequence of poverty. Bradshaw (2009) discusses the economic, political and social distortions, or discrimination perspective, as socially progressive in comparison to other conservative and liberal viewpoints. Bradshaw describes this perspective as a focus on barriers and exclusive practices, and looks to economic, political and social systems that cause people to have limited opportunities and resources with which to achieve income and well-being. As such, the system creates increasingly difficult problems for those who want to work and obtain resources because of low wages and limited benefits. Bradshaw notes that under this theoretical perspective, recent research confirms the link between wealth and power. The theory recognizes the existence of barriers for people with low income to participate in the political system, and, coupled with discrimination, people with low income lack influence in the system that provides access to economic benefits and social justice.

Lott (2002) operationally defines discrimination as cognitive and behavioural distancing from the poor, proposing that distancing is the dominant response to poor people on the part of those who are not poor. Lott states that “the related theoretical constructs of moral exclusion and delegitimization have been introduced in the effort to explain the atrocious and inhumane treatment of stigmatized people by those in power.” (p. 102). Lott further suggests that categorization of groups into superior and inferior is done by those who require this categorization to maintain their power. This prevents others from obtaining equal resources and sustains the myth of superiority (Williams,

1993, cited in Lott, 2002). Thus, it appears that power constructs are integral in understanding the causes and consequences of poverty.

In summary and in accordance with this discussion, Wilber (1975) suggested a number of needs that he felt were necessary in understanding and reducing poverty. Two of these suggestions included: 1) the need for an adequate theory of poverty to serve as a framework for a long-term program for research, and 2) research results that are oriented to give equal importance to academic standards of methodology and theory, as well as research geared to utilization in action programs. Hence, the following guiding theoretical framework aims to inform and lead a long-term program of research and action.

#### *Guiding Theoretical Framework: Three Dimensions of Social Power*

Previous literature argues that poverty is an issue of power (Bradshaw, 2009; Lott, 2002; Prilleltensky, 2003; Prince, 2009; White, 2005; Yeo, 2001; Yeo & Moore, 2003). Prilleltensky (2003) discusses poverty and power, in terms of wellness stating that “the lived experience of poverty, at all levels of analysis is characterized by powerlessness” (p.30). He notes that in the context of poverty, power refers to the capacity and opportunity to “fulfill basic needs, to restrict access to basic needs, and to resist forces of destitution” (p. 21). Furthermore, “poor people must have increased access to economic, political and psychological power to experience wellness.” (p. 31). White (2005), notes that people with disabilities are one of the most disempowered and disenfranchised groups in the community. He states, “for most, the issues raised are intensified because many people with disabilities have low incomes and cannot afford the [resources] required for even a moderate quality of life” (p. 412). He further states that people with



disabilities often have no voice, choice or control in decisions that affect their lives, and community psychologists need to continue to work with people with disabilities to increase their participation and empowerment in the community. Thus, it is important to understand how people with disabilities can increase their social power so that they gain more control over those factors affecting their well-being, especially poverty.

Culley's (2004) adaptation of the social power theory brought forward by Gaventa, (1980), Lukes (1974) and Parenti (1978) is a useful guiding framework for this purpose. Culley developed this three-dimensional view of social power as "emerg[ing] in a cumulative compounding fashion and often exercised jointly" (Culley & Hughey, 2008, p. 101). These three dimensions are 1) superior bargaining resources, 2) control of participation and debate, and, 3) shaping interests (see also Table 1). The three-dimensional view of social power was understood and approved by the Committee for this study, because it resonated with their understanding of power and their own lived experiences of poverty and disability. Next, I will briefly describe each dimension and how it relates to the literature on poverty and disability.

Table 1. The Three Dimensions of Social Power

1st Dimension	2nd Dimension	3rd Dimension
(A) has superior bargaining power and resources which are used to get (B) to do what (A) wants.	(A) defines the terms and conditions of the debate and constructs barriers against (B) and (B) withdraws.	(B) internalizes and is discredited by myths and ideology about their inferiority disseminated (by A).

*First Dimension of Power: Superior Bargaining Resources*

The first dimension in Culley's framework is based on Dahl's (1969) popular, uni-dimensional, view of power. This dimension of superior bargaining resources, encompasses overt use of power by (A: the relatively powerful) to exercise control over and manipulate the behavior of those with fewer resources (B: the relatively powerless). (A) is able to coerce (B) to do what (A) wants via the exercise over control of resources. Bargaining resources are considered to be assets such as money, property, status, influence, experience and competence. These assets are resources used to exert power over others with fewer available resources.

As people with disabilities often live with few resources, for example, low income, high rates of unemployment, low levels of education, and weak social networks, (Bach, 2003; Beresford, 1996; Dunn, 2006; Lord & Hutchison, 2007; Munro, 2007; Prince, 2009; Stapleton et al., 2005; White, 2005; Yeo & Moore, 2003; Yeo, 2001), they would fall into the category of (B: the relatively powerless). Therefore, people with disabilities are vulnerable to overt control, coercion and manipulation by (A: the relatively powerful). According to the literature, the powerful relative to people with disabilities include policy makers, community service organizations, poverty and disability researchers, poverty reduction strategists, government officials, educators and employers (Bach, 2003; Beresford, 1996; Dunn, 2006; Lord & Hutchison, 2007; Munro, 2007; Prince, 2009; Stapleton, et al., 2005; Stapleton, 2009; White, 2005; Yeo, 2001, Yeo & Moore, 2003). The Committee for the present study have referred to the group of the relatively powerful, generally as "people who don't have a disability", highlighting the degree of marginalization people with disabilities face.

*Second Dimension of Power: Control of Participation and Debate*

The second dimension, control of participation and debate, is characterized by the works of Schattschneider (1960) and Bachrach and Baratz (1962, 1970). Culley (2004) describes this dimension as the ability of (A) to determine who participates in debate and decision making processes on key issues. This dimension is demonstrated through setting agendas and erecting barriers to full participation, thereby preventing (B) from raising key issues. This often results in withdrawal from participation before it is necessary for (A) to use their resources from the first dimension of power over (B). As such, this second dimension is often hidden, whereas the first dimension is illustrated by overt actions to control participation.

According to the literature, people with disabilities are often not permitted and/or are prevented from participating in society in general (Bach, 2003; Dunn, 2006; Lord & Hutchison, 2003; Lord & Hutchison, 2007; Munro, 2007; Prince, 2009; White, 2005; Yeo, 2001; Yeo & Moore, 2003). Prince (2009) states “many Canadians with disabilities are effectively absent, lacking full enjoyment of liberty of the person, or freedom of expression and communication” (p.4). As mentioned above, this discussion is not only about rates of income, but also about social exclusion and powerlessness. This exclusion can be partly attributed to various forms of discrimination described by Yeo (2001) as institutional, environmental and attitudinal discrimination. These forms of discrimination work to exclude people through institutions’ day to day interactions, physical lack of accessibility, and prevailing attitudes (discussed further in the third dimension). More specifically, as noted above in the ecological analysis, people with disabilities have had little opportunity for meaningful involvement in poverty reduction strategies and

disability and poverty research (Beresford, 1996; White, 2005; Yeo, 2001; Yeo & Moore, 2003). As such, people with disabilities are prevented from raising key issues in research and anti-poverty efforts that affect their quality of life.

*Third Dimension of Power: Shaping Interests*

In the third dimension of power, Cully (2004) refers to Lukes (1974) discussion of the significance of latent conflict and more elusive systemic forces not set forth by the first- and second- dimensions. This dimension illuminates the myths and ideologies put forth by (A) to shape the thoughts, desires and interests of (B). Power is utilized to form perceptions of what is possible, necessary and required. Culley (2004) notes, “the third dimension of power is achieved when the defeated (B) internalize and are discredited by the ideologies and myths about their inferiority disseminated by (A)” (p. 65).

This notion is echoed in Lord and Hutchison’s (2007) discussion of clienthood and compliance for people with disabilities. When a person experiences clienthood, professionals are in control, and the person is viewed to be in need of services to meet most aspects of life. This is similar to the charity model described by Yeo (2001). Compliance and conformity to the status quo occurs easily when a person experiences clienthood, adhering to a series of procedures and regulations within a service system. According to Lord and Hutchison, the conditions related to the profound poverty and exclusion of people with disabilities demonstrate the deficit approach to clienthood, and the continuum of services and the welfare approaches that sustain compliance. Clienthood and compliance exemplify the negative judgments about a person’s abilities or capacities, which prevents them from fully participating in society. This is similar to Yeo’s (2001) discussion of attitudinal discrimination where prevailing attitudes justify

the exclusion of people with disabilities due to a focus on people as being helpless and powerless, rather than capable and powerful.

These three dimensions work in a cumulative manner that affect the manipulation and determination of the interests of (A: the relatively powerful) over (B: the relatively powerless) by way of social power (Gaventa, 1980; Lukes, 1974, cited in Culley, 2004). In summary, those who are able to exert power using the first and second dimensions are well positioned to shape the thoughts, desire and interests of the powerless, and maximize the interests of the powerful. The three dimensions of social power (Culley, 2004) provide a framework whereby the multifaceted aspects of the problem of poverty and disability coalesce into an issue of power. The present study will attempt to reveal how these three dimensions work to affect the lives of people with developmental disabilities living in poverty. The goal is to eventually reduce the current imbalance in regard to the three dimensions of social power by giving a voice to the lived experiences of people with developmental disabilities living in poverty, by demonstrating how these dimensions may be perceived by people with developmental disabilities, and by making the power concepts that are implicit in their day to day lives explicit.

#### *Purpose, Goals and Objectives*

The purpose of the present study is to support the development of poverty reduction strategies that will meet the needs of people with developmental disabilities. I am working with people with developmental disabilities in a participatory research process and as participants for focus group discussions to address the three dimensions of social power. Below I outline the goals and objectives of the project in relation to the theoretical framework presented above (see also Table 2), as well as my personal goals

and values. The purpose, goals and objectives for this study were developed with and approved by the Committee.

Table 2. Summary of Goals and Objectives for Proposed Study

Dimension of social power	Goals and Objectives	Research Questions	Interview Questions	Proposed Action
1. Superior Bargaining Resources	<p>Increase access to knowledge for people with developmental disabilities.</p> <p>Reduce poverty, increase access to money, property and status for people with developmental disabilities.</p>	<p>What resources do people with developmental disabilities identify as needed to overcome the poverty they experience?</p>	<p>2a 5a 6a</p>	<p>Empower other people with disabilities to become engaged to gain more control over participation and debate.</p>
2. Participation and Debate	<p>Raise key issues and break down barriers to participation for people with developmental disabilities.</p> <p>Fill gaps in knowledge on PAR processes involving people with developmental disabilities.</p>	<p>How do people with developmental disabilities want to participate in decision making on poverty issues?</p>	<p>2b 5b 7 8 9</p>	<p>Encourage future researchers to include people with developmental disabilities in the research process.</p> <p>Promote inclusion of people with developmental disabilities in local poverty reduction strategies.</p>
3. Shaping Interests	<p>Focus attention on strengths and capacities of people with developmental disabilities.</p> <p>Provide increased visibility of people with developmental disabilities.</p>	<p>How do people with developmental disabilities internalize the myths and ideologies about their inferiority?</p>	<p>3 4 5c</p>	<p>Potential to provide positive role models for other people with disabilities.</p> <p>Disseminate knowledge on PAR process and results to demonstrate strengths of people with developmental disabilities.</p>



*First Dimension of Power: Superior Bargaining Resources*

The present study endeavours to increase the bargaining resources of people with developmental disabilities living in poverty through the participatory action research (PAR) process and creation of knowledge. One objective of the proposed study is to include people with developmental disabilities in the knowledge creation and research process from development of research questions, data collection and interpretation, and planning for next steps for action. Processes related to knowledge creation, learning and innovation have been found to have a social impact just as significant as economic initiatives (OECD, 2001). Laszlo and Laszlo (2002) argue that knowledge is a process that can be used for many purposes. They note that knowledge can be used to increase the gap between the rich and the poor, or unleash the creative potential of every human being. As such, knowledge is a powerful resource (Laszlo & Laszlo, 2002). The authors suggest that “it is up to those with access to knowledge to decide how to use that power: as power over others so that only an elite few can enjoy indulgent lifestyles, or power to empower others in order [that] they may engage in meaningful and sustainable forms of social organization” (p. 404). Accordingly, the present study focuses on tapping into the potential of people with developmental disabilities as co-researchers and participants in the research process, and providing opportunity for access to knowledge and information on the topic of poverty and disability. This inclusive process is also intended to encourage using the power of this knowledge for action, to empower other people with disabilities to become involved and engaged in research and poverty reduction strategies and thus, gaining more control over participation and debate.

The ultimate goal of the present research is to change the power structure to reduce and eliminate poverty for people with developmental disabilities. Based on the discussion noted above of the causes and consequences of poverty for people with disabilities, poverty reduction and elimination would increase access to resources such as money, property, status, etc. (Jongbloed & Crichton; Yeo, 2001, Yeo & Moore, 2003). Therefore, as people with developmental disabilities gain more resources, they would be less vulnerable to overt control, coercion and manipulation by (A: the relatively powerful). In terms of research questions, this dimension is addressed when asking about the resources people with developmental disabilities identify as needed to overcome the poverty they experience. As such, the present study aims to support people with developmental disabilities to gain greater access to resources through inclusion and control over access to knowledge for effective poverty reduction.

*Second Dimension of Power: Control of Participation and Debate*

The present study focuses on providing opportunities for people with developmental disabilities to control participation and debate in research and poverty reduction. The participatory methodology and focus groups primarily address the second dimension of power. As people with developmental disabilities participate in the research process and discuss and debate on the topic of poverty and disability, their voices are on the lived experience of poverty. Thus, the present study aims to support the development of poverty reduction strategies by raising key issues and breaking down barriers to participation for people with developmental disabilities. The study specifically aims to 1) identify the needs and priorities of people with developmental disabilities living in poverty, as well as 2) identify any gaps in poverty reduction strategies to effectively

address the needs and priorities for people with developmental disabilities. In relation to the research questions, participation and debate is explicitly addressed by asking how people with developmental disabilities want to participate in decision making processes on poverty reduction strategies.

There are three major intellectual objectives of the proposed research project related to the second dimension of power. The first is to fill a gap in knowledge on the participatory research process involving people with developmental disabilities who are in control of the research agenda. The second objective is to contribute to the understanding of the lived experiences, and raising key issues for people with developmental disabilities living in poverty in Brantford, Hamilton and Waterloo region. These geographic locations have been chosen as they are areas in southern Ontario that are conveniently accessible to the researchers, where I have established relationships and trust with individuals, and have representation of people with developmental disabilities currently living in poverty. The third major objective is to identify gaps in research on poverty and disability, broadly, as previous literature strongly suggests the need for participatory methodology for future research (Dunn, 2006; White, 2005; Yeo, 2001; Yeo & Moore, 2003). As a result, this project hopes to encourage future researchers to consider innovative ideas to include people with developmental disabilities in participation and debate, and continue to increase knowledge on key issues for people with developmental disabilities on the topic of poverty and disability.

#### *Third Dimension of Power: Shaping Interests*

The present study counters the myths and ideologies about the inferiority of people with developmental disabilities by focusing attention on their strengths and

capacities (McKnight, 1995). For this study, people with developmental disabilities are in control of the research agenda and have the opportunity to express their thoughts and ideas on poverty and poverty reduction in focus group discussions. According to McKnight “the most obvious need [for people who have been labeled] is the opportunity to express and share their gifts, skills, capacities and abilities with friends, neighbours and fellow citizens in the community” (p. 104). This strengths-based approach (McKnight, 1995; Nelson & Prilleltensky, 2005) highlights abilities and provides people with control, contrasting the deficit focus of the medical and charity models (Yeo, 2001), as well as the phenomenon of clienthood and compliance mentioned above (Lord & Hutchison, 2007). Moreover, the participatory methodology and focus groups can provide increased visibility of people with developmental disabilities and has the potential to provide positive role models for others to help overcome negative societal perceptions of disability (Yeo & Moore, 2003). The present study also aims to make explicit the myths about the inferiority of people with developmental disabilities, by addressing the research question of how people with developmental disabilities internalize these ideologies.

### *Personal Goals*

My interest in poverty related issues stems from my own experience. I was 11 years old when my parents' manufacturing business went bankrupt. Watching my parents struggle with debt and basic needs to provide for their children made me want to help them, yet obviously I was too young and without the necessary skills. On and off of welfare for years after the bankruptcy, I experienced the feeling of oppression and marginalization of a low-income family. When I first entered university, I encountered

the financial stressors of post-secondary education. My grade point average at the time was affected by the struggle of re-evaluating my goal of furthering my education and dealing with the estimated financial strain to achieve that goal. However, in the last two years of my undergraduate I focused on community psychology and re-discovered my passion, learning that I could utilize this experience to guide my career. As a result, I registered in directed studies which gave me the opportunity to complete a thesis where I examined the topic of classism in post secondary education.

After graduation, I took time away from academia to thoroughly think through my plans and expose myself to a variety of work situations. This strategy was very valuable to me in rounding out my career plans. I worked with several marginalized population groups, including individuals with developmental disabilities where I found I had the most passion, enthusiasm and desire to create social change. I gained ample experience supporting individuals requiring assistance with daily living and community participation with an emphasis on promoting a sense of self-worth in an individual. I have had the chance to work with people with developmental disabilities for the past five years and wish to participate in the progression towards more positive outcomes for this population.

My personal goal for the present study is to conduct meaningful action research with people with developmental disabilities that has practical applications for key stakeholders and is guided by a set of values that reflect the third dimension of social power. I intend to provide evidence against the ideologies and myths about the inferiority of people with disabilities by demonstrating their strengths and capacities. This work is guided by key values put forth by John Lord and Peggy Hutchison in their discussion of the New Story of inclusion in their book, *Pathways to inclusion: Building a New Story*

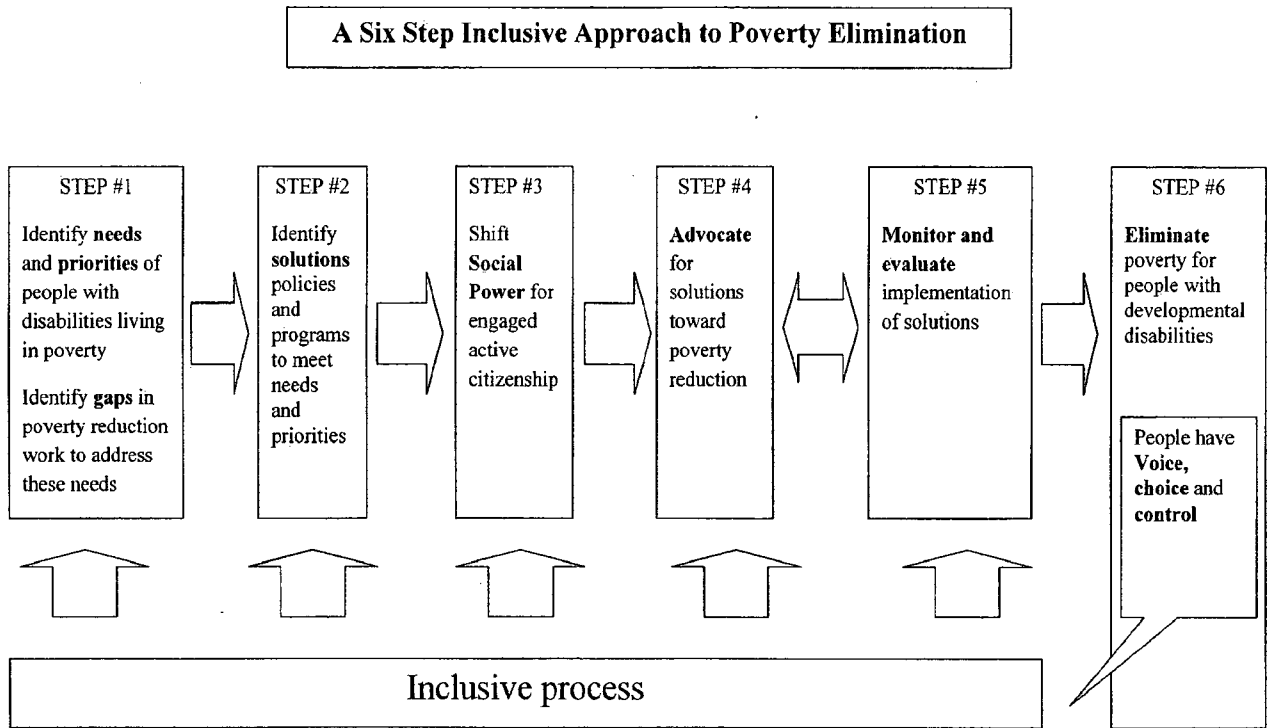
*with people and communities* (2007). These key values include human rights and social justice, diversity and person-centeredness, participation and empowerment, and hospitality and community. The values of human rights and social justice come from a strong belief that “all people should have the same rights and conditions” (Lord & Hutchison, 2007, p. 47). These values are particularly pertinent to the present study as I argue that people with disabilities are disproportionately living in poverty in comparison to people without disabilities. This study aims to reduce the imbalance through the promotion of poverty reduction strategies that meet the needs of people with developmental disabilities. The values of diversity and person-centeredness respects differences among people and reflects a desire for people to determine their own needs and interests (Lord & Hutchison, 2007). To enact these values, I have been working with the Committee to help shape and guide the research goals and procedures and have continued to work with them to collect and interpret data, and disseminate results for knowledge mobilization. As such, participation and empowerment are strongly held values in this study. These values are enacted by intentionally shifting power and decision making toward people with developmental disabilities. This intends to develop personal control and confidence by supporting people to become more informed and aware in order to counteract the myths of inferiority in terms of poverty and disability. Lastly, hospitality and community are also critical values to the present study because, according to Lord and Hutchison (2007), “When hospitality is valued, citizens feel they are respected and welcomed... [and] when community is working well, it can be a place where people think creatively, dream their dreams, and join together with others to share their common humanity” (p. 51).

Thus, the present study is based on the three dimensions of social power and my personal goals to promote inclusion. The Committee and I have discussed and reviewed these goals to align with their expectations and needs for this research. Next, I will discuss how this study is situated as a first step in a long-term program for research and action to eliminate poverty for people with developmental disabilities.

*A Six Step Inclusive Approach to Poverty Elimination*

The present study is just a first step in a needed process of social intervention. Figure 1 outlines the proposed Six Step Inclusive Approach to Poverty Elimination for people with developmental disabilities. As noted in the goals and objectives, two objectives for this study are to identify the needs and priorities of people with developmental disabilities living in poverty, and to identify any gaps in poverty reduction strategies to effectively address the needs and priorities for people with developmental disabilities. The next step in the model identifies solutions to effectively meet the needs of people with developmental disabilities identified in the first step (the present study). Step three requires a shift in social power to promote meaningful and engaged citizenship for people with developmental disabilities toward effective advocacy in step four. This step involves advocating for solutions, determined in step two, to be implemented, followed by close monitoring and evaluation in step five. As implementation takes place, continued advocacy may be necessary to ensure effective action toward the end goal of poverty elimination for people with developmental disabilities. Throughout each step, an inclusive process is necessary to contribute to people with developmental disabilities having voice, choice and control in their lives and to keep a focus on their strengths and capacities for meaningful participation.

Figure 1.





This model reflects previous literature on transformative social interventions. Social interventions are described as “intentional processes designed to affect the well-being of the population through changes in values, policies, program, distribution of resources, power differentials and cultural norms” (Nelson & Prilleltensky, 2005, p. 162). The six step model proposed in this study seeks to create these changes. The present study is situated as step one in the model represents these changes in the values of human rights and social justice, diversity and person-centeredness, participation and empowerment, and hospitality and community (Lord & Hutchison, 2007). The inclusive process underlying the six step approach reflects the strengths and capacities of people with developmental disabilities to participate in poverty reduction strategies, as opposed to focusing on their deficits and needs. The model also represents inclusive policies and programs as solutions (Step 2) to move toward poverty reduction and encourage participation of people with developmental disabilities in decision making processes (See Figure 1: Inclusive Process). The approach aims to shift power toward people with developmental disabilities to become engaged citizens (Step 3) with opportunities for participation in advocacy (Step 4), research and poverty reduction efforts. The inclusive process promotes participation and debate for people with developmental disabilities to raise key issues for poverty reduction. Also, as noted in the goals and objectives, the model indicates inclusion such that people with developmental disabilities have access to knowledge (See Figure 1: Inclusive Process in Steps 1, 2, 3, 4, 5) as a resource for poverty elimination (Step 6) which corresponds to people with voice, choice and control in their lives (Step 6). A participatory and inclusive approach also empowers people with developmental disabilities to recognize their power, value and worth (Nelson &

Prilleltensky, 2005). This relates to the third dimension of power as it contributes to recognition of the myths about the inferiority of people with disabilities.

People with disabilities have strengths and gifts to contribute to the betterment of society. Until the barriers that people with disabilities experience are recognized and addressed, there can be no sustainable and transformative change in the marginalization and poverty that they face in their daily lives (Yeo & Moore, 2003). The implications of this Six Step Inclusive Approach to Poverty Elimination can be important in promoting preventive social programs and transformative social policy, both which aim to attack the causes of long-term poverty in Canada. The present study will highlight the needs and priorities of people with developmental disabilities living in poverty in Brantford, Hamilton and Waterloo region, as well as point out some of the gaps in poverty reduction strategies to effectively meet these needs and priorities.

#### *Research Questions*

This study has been guided by the following research questions derived from the three dimensions of social power. Social power is ultimately about the amount of control individuals and groups have over the affairs that affect their lives. Thus, it is important to understand the lives of people with developmental disabilities and how they are affected by poverty. What are the pressing poverty issues that they face, and what kind of challenges have they experienced trying to get out of poverty? With this context in place, one can then address issues that concern the social power this group has in regard to affecting positive changes to address these issues. This includes their perceptions of what is possible, necessary and required to overcome poverty and increase social power. This study aims to understand how people with developmental disabilities internalize myths

and ideologies about their inferiority, to gain insight into how they feel they are discredited by these myths and how this poses challenges for them. This question clearly informs the third dimension to address shaping interests, and provide evidence against the myths and ideologies of inferiority by understanding the thoughts, desires and interests of this group. Also, this study intends to identify resources needed to overcome poverty to support increased bargaining resources. This addresses the first dimension, and aims to describe the resources needed to increase social power from the perspective of people with developmental disabilities living with low income. The second dimension of power is also explicitly addressed by asking how this group may want to participate in decision making processes for poverty reduction strategies and action for social change. This question aims to support a redefinition of the terms and conditions of participation in poverty reduction and promote greater inclusion in these processes. To summarize, the specific questions being addressed in order to understand social power in the context of poverty reduction strategies are:

1. What are the pressing poverty issues experienced by people with developmental disabilities in the Brantford, Hamilton and Waterloo regions?
2. What are the challenges to escaping poverty experienced by people with developmental disabilities in the Brantford, Hamilton and Waterloo regions?
3. How do people with developmental disabilities internalize the myths and ideologies about their inferiority?
4. What resources do people with developmental disabilities identify as needed to overcome the poverty they experience?
5. How do people with developmental disabilities want to participate in decision making on poverty issues?

These questions have been developed with and approved by the Committee. I will now discuss the methodology and specific ways in which I worked with the Committee to

answer these questions. I will start with the research paradigm, an introduction to the Committee members, and my role as researcher. Next, I will discuss the phenomenological approach to this study, followed by the research contexts, sampling strategy and participants. Then I will describe the methods for data collection and analysis.

### Methodology

This research utilized a participatory research paradigm. I will now discuss this methodological approach and the reasons that it was the most appropriate paradigm for this study.

#### *Participatory Research Paradigm*

The present study has been conducted within a participatory inquiry paradigm (Heron & Reason, 1997). Several studies argue that the exclusion of people with disabilities from poverty research and anti-poverty strategies reflects and reinforces the disproportionately high representation of people with disabilities among the poorest of the poor (Beresford, 1996; Yeo & Moore, 2003; White, 2005; Yeo, 2001). As such, this study has included the thoughts and ideas of people with developmental disabilities in the development of the research questions and setting the research agenda.

*Ontology.* According to Heron and Reason (1997), reality is the corollary of the given cosmos and the mind's interaction with it. As such, reality is co-created by the mind and given cosmos. The encounter between the mind and cosmos is transactional and interactive, and tells us about a being in a state of interrelation and co-presence with us. The participatory paradigm views reality as participative and as a subjective-objective reality. "It is subjective because it is only known through the form the mind gives it, and

it is objective because the mind interpenetrates the given cosmos which it shapes” (Heron, 1996, p. 11, cited in Heron & Reason, 1997).

*Epistemology.* Heron and Reason (1997) note that epistemology under this paradigm is based on critical subjectivity and four ways of knowing. This involves an extended epistemology where a knower articulates the world in at least four interdependent ways: experiential, presentational, propositional, and practical. The authors claim that we attend to our understanding with a critical consciousness, in that we accept our subjective experience (experiential), but are also aware of it in relation to the other three ways of knowing. This critical subjectivity clarifies, refines and elevates our understanding as we are more adequately grounded in our subjective experience. These authors note that knowledge is understood in participatory transaction with the given cosmos, and that findings are co-created. Knowledge is an active construction and co-creation by individuals that is produced by the human consciousness. As such, the participatory ontology and epistemology provides opportunity to explore varieties of oppression and powerlessness, similar to the experiences of people with developmental disabilities living in poverty. According to the authors, this paradigm also allows the researcher to construct relationships with research participants without paradigmatic restrictions.

*Methodology.* Inquiry methodology within a participative worldview enhances critical subjectivity with critical inter-subjectivity. According to Heron and Reason (1997), this is a collaborative form of inquiry in which all involved engage together as co-researchers in democratic dialogue. This means that people collaborate to develop research questions and the methodology to address those questions. The methodology is

applied in the world which leads to new forms of experiential knowing. This experiential knowledge is represented in significant patterns, which feeds back to a revised understanding of the original questions. The authors refer to this process as “research cycling” through the four forms of knowing to deepen our understanding of knowledge. Heron and Reason view this cooperative inquiry as closely related to participatory action research, which is the basis of the present study.

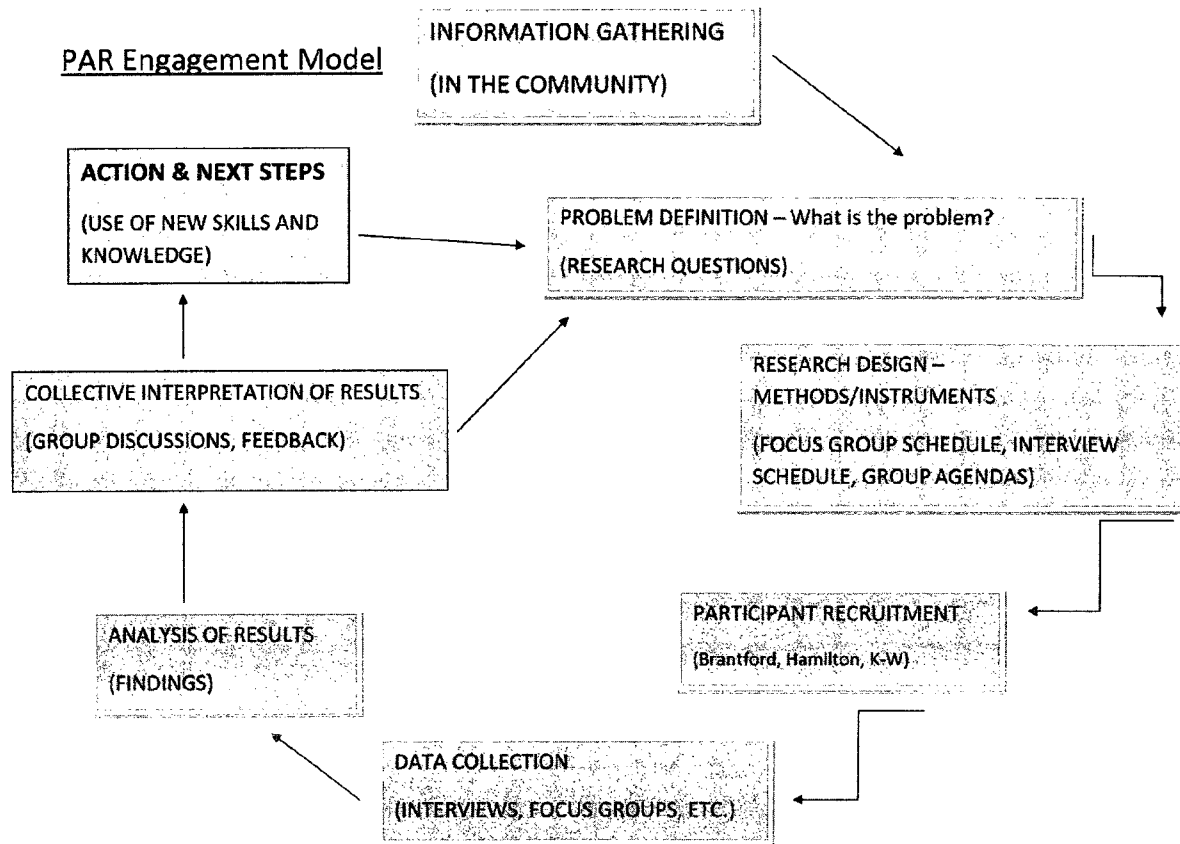
*Rationale and application.* Previous literature on poverty and disability research strongly suggests the need for participatory methodology to promote inclusion of people with disabilities (Dunn, 2006; White, 2005; Yeo, 2001; Yeo & Moore, 2003). Heron and Reason (1997) indicate that participatory methodology emphasizes the importance of practical collaborative action inquiry and the “use of language grounded in shared experiential context” (p.195). Inclusion of people with developmental disabilities is essential to the goals and purpose of this study. Thus participatory methodology is well-suited to the promotion of these goals.

The participatory approach also recognizes the second dimension of social power: control of participation and debate, whereby people with developmental disabilities have an opportunity to raise key issues about poverty and disability. People with developmental disabilities have been actively involved in the research process by setting the research agenda, deciding on the research questions, ethical considerations, assisting with data collection, analysis and dissemination. For example, the Committee has chosen to use the term people with “developmental disabilities”, rather than “intellectual disabilities” commonly used as an alternative label in large community service organizations, such as Community Living ([www.communitylivingontario.ca](http://www.communitylivingontario.ca), accessed

Apr. 15, 2009). The Committee consists of four people with developmental disabilities with whom the present author has already established relationships and trust, through community involvement over the past four years. Control of the research agenda has been inclusive and shared to varying degrees in accordance with the needs and desires of the Committee, thereby challenging the norm of exclusion of people with disabilities from the research process (Dunn, 2006; White, 2005; Yeo, 2001; Yeo & Moore, 2003). According to Mertens (2009), the participatory paradigm is well suited to challenging the status quo, providing further justification for its appropriateness to the goals and objectives of the proposed study.

According to Ward and Trigler's (2001) *Reflections on Participatory Action Research with People who have Developmental Disabilities*, the quality of such a project is increased when participants fully understand the research purpose, process, time commitment and intended outcomes. The authors also suggest keeping the scope of the project small to encourage future participation. As such, the present study's Committee members were provided visual materials to help understand the research process and goals. The Committee have found Fig. 1 beneficial in understanding the purpose and intended outcomes of the project, and the participatory action research (PAR) engagement model (see Figure 2) an appropriate tool in visualizing the research process. Both models were developed by the present author to provide the Committee members with practical visual aids.

Figure 2.





### *The Committee*

As mentioned, the Committee is comprised of four individuals with developmental disabilities living with low income. The Committee members are Michelle, Kathy, Kristie and Jason, and have given me permission to provide a brief introduction.

*Michelle.* Michelle is the youngest member of the Committee. She is 20 years old and very passionate about disability issues related to poverty. Michelle has had extensive experience as a recipient of disability services, with a desire to live more independently. Recently, Michelle has been learning how to separate herself as a person from the labels that have been placed upon her by child psychologists and doctors. She is eager to rally people with disabilities together and have her voice heard against social injustice.

*Kristie.* Kristie is 37 years old. She is an experienced self-advocate, president of the Brantford Kiwanis Aktion Club (a community-service group for adult citizens who live with a disability), a former member of Toastmasters, and involved in several other advocacy projects and committees to support quality enhancement for disability services. Kristie has expressed frustration with uncaring support staff and tokenism in her role as a committee member for community organizations. She is interested in creating social change by working with other self-advocates, and travelling across Ontario to raise awareness among academic and community groups about the problem of poverty and disability.

*Kathy.* Kathy is 52 years old. She has experienced many personal struggles and challenges in her lifetime. She has experienced bullying, ridicule and stigmatization which has motivated her interests in creating social change for people with disabilities.

Kathy is now competitively employed and lives independently. Kathy gets along very well with other people, enjoys socializing and has a strong interest in learning about human rights issues for people with disabilities.

*Jason.* Jason is also an experienced self-advocate, world champion in Special Olympics power lifting, and conducts regular community presentations to local high school students about employment in the disability service sector. He is 40 years old. Jason is interested in raising awareness about the strengths and abilities of people with disabilities through his involvement in community projects and various committees. Jason is competitively employed, part-time, and currently working toward his personal goal of obtaining his grade 12 diploma.

#### *Role of Researcher*

Participatory action research has been described “as a way for researchers and oppressed people to join together in solidarity to take collective action...for radical social change” (Hall, 1993, cited in Nelson & Prilleltensky, 2005, p. 249). I have been working with the Committee of people with developmental disabilities, to uphold the key feature of PAR, which is to work in solidarity with disadvantaged people (Nelson & Prilleltensky, 2005). As such, research is being conducted *with* people with developmental disabilities, rather than *on* them. This places the researcher in the role of learner, to better understand participants’ experiences with respect to their disabilities and poverty (Nelson & Prilleltensky, 2005). Nelson and Prilleltensky recommend that an advisory committee should consist of at least 51% membership from the community of interest as an accountability mechanism to ensure strong representation in the research process. The present study Committee membership consists of only people with

developmental disabilities (n=4) to provide strong representation from the community of interest.

For this study, the present author is the primary investigator, and co-researcher with people with developmental disabilities. These roles have been determined through dialogue and consensus among committee members. Discussion among the Committee was partly based on Stoecker's (1999) suggested questions in determining the role of participatory researchers in the research process. Specifically, Stoecker suggests that the role of the researcher be contextually dependent on the values, desires and needs of the community (people with developmental disabilities), how much participation in the research the community needs and wants, and the skills of the researcher. The present author was chosen as primary investigator due to previous knowledge and formal education in the research process as well as familiarity with previous literature on poverty and disability. As this project is also a Master's thesis, this was another consideration for the Committee to determine the present author as primary investigator. In addition, I have recorded a detailed journal of observations and field notes about this participatory process to document learning. The Committee members were interested in learning about the research process and being involved in all stages of the process, thus being referred to as co-researchers. The role of co-researcher in the study also upholds power sharing as all Committee members have representation and decision making power in the research (Nelson & Prilleltensky, 2005). See Table 3 for an overview of this study's participatory process. As reported in this table, I met in person with members of the Committee on more than 22 occasions over the past 14 months. This table highlights the activities in which the Committee chose to be involved, as well as the determinations and decisions

that the Committee made throughout the process. However, I also spoke with members of the Committee on several more occasions as we frequently talked over the phone to check in on a regular basis and discuss project details.

Table 3. Overview of Participatory Process

Date	Frequency of meetings	Activity	Determination
Feb.2009	1	Formed committee	Problem definition and information gathering
Mar.2009	2	Research agenda development	Development of research questions, design and methods
May 2009	3	Proposal development, Advocacy –raising awareness of poverty and disability	Committee approved proposal, attended Brant Roundtable to present research proposal, met with roundtable coordinator
June 2009	2	Thesis proposal approval meeting	Attended meeting to demonstrate support of proposal
July 2009	1	Ethics review	Assisted in development and approved all ethics application materials
Sept.2009- Jan. 2010	1	Participant recruitment	All members assisted in recruitment of Brantford and Kitchener participants
Nov.2009	1	Consciousness raising - WLU Presentation	Assisted in development and co-presented 'Poverty and Disability' presentation to MA students
Oct. 2009- Jan.2010	6	Data collection	Assisted in facilitation and observation, provided reflections
Feb. 2010	1	Analysis of results	Approved codebook with minor revisions
Mar. 2010	2	Consciousness raising - WLU Presentation, Dissemination of results	Co-presented 'Poverty and Disability' presentation to BA students Co-presented findings to Brantford Kiwanis Club
Apr.2010	2	Dissemination of results	Assisted in development and co-presenting at two provincial and national conferences
Feb.2009- present	Ongoing	Action	Ongoing discussion, Committee determining action and next steps

### *Phenomenological Approach*

The present study focuses on subjective human experience and the meaning that people with developmental disabilities make of their experiences living in poverty. The phenomenological approach (Miles & Huberman, 1994) is used to describe but not explain the perceived factors associated with poverty and disability in terms of social power. The phenomenological tradition is a useful approach for this study, as it focuses on the concept or phenomenon of inclusion and power of people with developmental disabilities in poverty reduction strategies. This study is exploratory in nature. As such, there are no specific hypotheses laid out in the present study. The intention of this study is to describe but not explain the phenomena of interest for the study which are: 1) the needs, priorities and experiences of people with developmental disabilities living in poverty, and 2) the support, or lack of, from poverty reduction strategies for people with developmental disabilities.

According to Creswell (1998), the phenomenological tradition allows the researcher to explore and describe the experiences of individuals toward the phenomena of interest. This form of study is well suited to the goals and objectives of the present study in order to understand the meaning of individuals' experiences living in poverty and how these meanings can be strategically analyzed into a specific description of their experiences. Creswell's discussion of "other factors" for consideration in a choice of tradition (p. 39), have helped to justify this choice. In terms of the "background question", referring to training in the inquiry approach, the present author has had training under the supervision of an academic supervisor for an undergraduate thesis which utilized the phenomenological approach to explore students' perceptions of

barriers to university education. Furthermore, in reference to “the scholarly literature question”, referring to what is most needed in the literature in the field, the present study answers the call for future research to listen to the voices and experiences of people with disabilities living in poverty to contribute to effective poverty reduction (Bach, 2003; Beresford, 1996; Dunn, 2006; Lord & Hutchison, 2007; Stapleton et al., 2005; White, 2005; Yeo, 2001; Yeo & Moore, 2003).

### *Sampling*

The present study conducted focus group interviews with self-advocates in Brantford, Hamilton and Waterloo region. The following discussion will describe the research contexts, sampling strategy and participants for this research, as well as the rationale for this design.

#### *Research Contexts*

Focus groups were conducted in Brantford, Hamilton and Waterloo region. These locations were chosen based on discussion among the Committee to access people with developmental disabilities living in poverty from different areas in southern Ontario. Many of the Committee members live in Brantford and could conveniently access potential participants for focus group discussions. I live in Hamilton, and was able to access potential participants through personal contacts in this area. I also attend Wilfrid Laurier University in Waterloo region, and decided with the Committee to utilize established connections to access potential participants. Consequently, these locations have been chosen to provide some diversity in research contexts, and specifically chosen due to convenience and established connections.

Furthermore, all three of these locations have poverty reduction strategies in place to address the needs of the communities. Therefore, participants were able to share some insight on how they are, or are not, involved in these strategies. Each region will be described briefly below, including information on local poverty reduction strategies.

*Brantford.* Brantford is a city located along the Grand River in southwestern Ontario. The city is geographically within Brant County but is municipally distinct from it ([www.brantford.ca](http://www.brantford.ca), [www.brantfordbrant.ca](http://www.brantfordbrant.ca), accessed Apr. 16, 2009). According to these websites, the city had a population of 90,192 in the 2006 census. In the first half of the 20<sup>th</sup> century, Brantford was an important Canadian industrial centre, but by the 1980's and 1990's several manufacturing closures led to a steady economic decline. More recently, due to completion of highway 403 between Hamilton and Brantford, several large companies have located to the city and the unemployment rate has declined.

Brantford has recently developed a local Brantford/Brant Roundtable on Poverty Reduction. The present author has accessed a one page unpublished document summarizing the mission, vision and values of the initiative from a local community member who is part of the Roundtable. The mission of the Roundtable is to eradicate poverty in the community within a generation. The values highlight compassion, inclusivity, respect and collaboration.

*Hamilton.* Hamilton is located at the head of Lake Ontario between Niagara Falls and Toronto ([www.tourismhamilton.com](http://www.tourismhamilton.com), accessed Apr. 16, 2009). According to the City of Hamilton website ([www.city.hamilton.on.ca](http://www.city.hamilton.on.ca), accessed Apr. 16, 2009), the city had a population of 504,559 in the 2006 census, making it one of the tenth largest cities in Canada. Demonstrating the city's diversity, nearly one-quarter of the metropolitan area



population is foreign-born, making Hamilton the Canadian city with the third highest proportion of foreign-born citizens after Toronto and Vancouver ([www.tourismhamilton.com](http://www.tourismhamilton.com), accessed Apr. 16, 2009).

Hamilton has a high poverty rate in the province of Ontario. As a result, the city has joined the pan-Canadian Vibrant Communities poverty reduction initiative ([www.vibrantcommunities.ca](http://www.vibrantcommunities.ca), accessed Apr. 10, 2008). Hamilton's plan for poverty reduction focuses on preventing poverty for children and youth. The plan's emphasis on children and youth includes other target groups with higher-than-average incidences of poverty including: visible minorities, newcomers, people with disabilities and aboriginal people.

*Waterloo Region.* The Region of Waterloo is located 100 km southwest of Toronto. Residents are spread out over three cities (Cambridge, Kitchener, and Waterloo) and four rural townships. Waterloo is considered to be a modern, vigorous business and industrial community ([www.region.waterloo.on.ca](http://www.region.waterloo.on.ca), accessed Apr. 16, 2009). There are also two well-respected universities, Wilfrid Laurier University and University of Waterloo, within close proximity to each other. According to the city website, the population for the Waterloo region, encompassing the cities of Cambridge, Kitchener and Waterloo, is 507,000, based on the 2006 census data.

In the region there is a relatively high rate of poverty. The region has also joined the Vibrant Communities network toward poverty reduction in the area. This community strategy is currently pursuing two major initiatives focusing on the working poor, and the development of a Social Purchasing Portal. The framework of the portal is a partnership

of business, government and community working together on social and economic issues to create healthy communities ([www.vibrantcommunities.ca](http://www.vibrantcommunities.ca), accessed Apr. 10, 2009).

### *Sampling Strategy*

The present study utilized a purposive sampling strategy in Brantford, Hamilton and Waterloo region, to recruit people with developmental disabilities living in poverty for focus group interviews. According to Mertens (2009), this strategy is appropriate when potential candidates for participation in research have “life experiences [that] reflect critical cultural or historical positioning in regard to the phenomenon under study” (p. 214). As the phenomena in this study are related to poverty and disability, this sampling strategy provided the opportunity to recruit people with developmental disabilities with lived experiences of poverty. More specifically, a snowball sampling technique (Mertens, 2009) worked well to recruit people with developmental disabilities in the Brantford, Hamilton and Waterloo Regions.

Potential participants were asked to take part in focus group discussions on the topic of poverty and disability. Potential participants were informed of the purpose of the study verbally and in writing, depending on whether they were comfortable with written materials. Written materials may pose challenges for some people with developmental disabilities as literacy skills vary within this population group (Yeo & Moore, 2003). Participants were recruited mostly through service providers that support people with developmental disabilities. I contacted local service providers to get permission to post a recruitment flyer, and/or send a script to support staff. In addition, the Committee members and I personally recruited some participants with whom we were already familiar with in the Brantford area. In Hamilton and Waterloo region, I also contacted

local self-advocates to support recruitment and share information about the project with their peers.

Participants were invited to participate in the research via three mechanisms. The first was a recruitment poster, indicating the nature and purposes of the research and the requirements expected of participants (See Appendix A), and participants self-referred. Second, service providers from community agencies approached clients during their regular visits to the respective site, informing them of the research, and providing them with information about how to participate (using the script in Appendix B). If a participant was interested in the research, he or she was directed to contact me and allowed to ask questions before agreeing to participate. At this time, participants were asked to participate fully in the focus group discussion, due to the limited number of participants and importance of hearing from as many people as possible within a relatively small sample size. This was also due to the time sensitivity of the research for completion of a Master's degree such that there is the need to gather quality data in the time frame allotted for collection.

There was one occasion in Hamilton when a community organization representative requested that the recruitment flyer be modified to read: "A student from Wilfrid Laurier University (WLU) and a group of self-advocates are inviting you to share your voice about poverty and disability," eliminating the use of the label "people who have experienced poverty and labeled with a developmental disability" and replacing it with "you". The rationale behind this was because service recipients from this organization had been researched many times in the past and become hesitant to participate in research that labels or categorizes people based on their disability or

socioeconomic status. The organization representative suggested that we change the flyer to encourage greater participation. I reviewed this request with the Committee and they agreed to the revision for the sake of participant recruitment at this site. However, when participants arrived, we mentioned that the focus of this study is on the voices of people with developmental disabilities as their voices often go unheard. But, we also emphasized that we did not wish to exclude anyone who wanted to participate and share their voice.

The present study recruited 27 participants in six focus groups (see Table 4 for participant breakdown). Two groups were conducted in each location, Brantford, Hamilton and Waterloo Region, for a total of six focus groups.

Table 4. Focus Group Participation

Focus Group:	Group 1	Group 2	Group 3	Group 4	Group 5	Group 6
# of participants	5	4	4	5	7	2
Location	Brantford	Hamilton	Brantford	Hamilton	Kitchener	Kitchener

The number of groups was decided among the Committee and with advisement of my academic supervisor. As data collection also utilized a participatory process, there was more time required to train Committee members to assist moderating and analyzing each group discussion. Training for Committee members included informal explanation of the process by the present author. The rationale for limiting the current study to six groups is based on time commitment for data collection and feasibility for a Master's thesis.

In terms of focus group size, Smithson (2008) discusses some of the benefits and limitations for using smaller focus groups (four to eight participants), rather than larger groups (up to 12 participants). For the proposed study, smaller may be more beneficial than larger groups for eliciting discussion from all group members. Smithson suggests that larger groups may hinder participation from all members, while smaller groups can provide an environment where all can participate actively in the discussion. The present author and Committee decided that groups should be no larger than six participants due to previous experience in group discussions with people with developmental disabilities. The Committee decided that more than six participants per group would present difficulties in obtaining quality data as some people with developmental disabilities may have speech difficulties, or take more time to articulate thoughts and ideas, posing difficulty in maintaining an appropriate pace. This allowed groups to discuss the topic of interest within a reasonable amount of time. The Committee decided that each group would aim for a 90 minute time length. There was one group in Waterloo region where seven participants arrived for the group discussion. The Committee members present did

not want to exclude anyone who had arrived and wanted to participate. As such, we made an exception to the size limitation for this group, but remained within the 90 minute limit.

### *Participants*

The participants of this research were primarily self-advocates for people with developmental disabilities in Brantford, Hamilton and Waterloo Region. Self-advocates are individuals with developmental disabilities who are leaders in their community (Schlaff, 1993; [www.pdd.org](http://www.pdd.org), accessed Apr. 15, 2009). They voice the views of people with developmental disabilities and empower others to take leadership roles in their communities. Essentially, self-advocates are people with developmental disabilities speaking up for themselves and their human rights. As mentioned above, the present study provides an opportunity for people with developmental disabilities to have their voices heard on the topic of poverty and disability. Self-advocates were ideal participants as they are familiar with the line of discussion required to answer the research questions on the topic of lived experiences, barriers and action required to change the status quo of exclusion from society. Self-advocates are also usually very open and upfront about their disability, and work together to create social change (White, 2005).

As participants self-identified as self-advocates, we did not question participants about their advocacy experience, but felt that a few participants may have had less experience than others. In some cases we were unable to recruit from a particular self-advocate committee or group, thus leaving the possibility for participation by those without advocacy experience. This experience was considered a benefit to the research based on the previously noted rationale. However, the Committee did not want to

consider this as an inclusion criterion and did not want to exclude individuals who wished to participate.

Moreover, there may have been a few participants who did not have a developmental disability. As participants self-identified there was the possibility that some participants did not have a developmental disability. For example, Margaret told us that she did not have a developmental disability, rather another disability that she acquired later in life, but still wanted to participate. Although it was important to recruit primarily people with developmental disabilities, the Committee members did not want to exclude people with other types of disability if they wanted to participate. As such, we included her in the group.

The gender of the participants was mixed, with slightly more men (n=17) than women (n=10). Participants were adults, 18 years of age or older. We spoke with nine participants in each location of Brantford, Hamilton and Waterloo Region (see Table 5 for participant demographics). Although we did not strategically collect demographic information, participants did note some personal characteristics and information with us during group discussions. Most participants we spoke with indicated that they lived independently, although a few mentioned living in a group home, lodging home or boarding home. Only three participants appeared to be visible minorities. About half (n=13) mentioned that they were currently unemployed or out of the labour force. Five participants indicated they were competitively employed in a part-time job in the community. One participant told us that he had two part-time jobs in the community, but considered himself to be underemployed, in terms of hours and pay. Four participants



noted that they were working in a sheltered workshop, and five participants did not indicate their employment status.

Most participants demonstrated a high degree of comprehension related to the questions that were asked in group discussions. All participants used words to communicate. Many people showed a desire to talk about the issue of poverty and disability and were open to sharing their personal experiences, challenges and ideas for social change. Most participants shared concrete and insightful recommendations for action. There were only a small number of participants that shared just a few comments in one group in Waterloo Region. However, this group had seven participants attend, which posed some challenges for facilitation, and give everyone an equal opportunity to share their thoughts and ideas. Nonetheless, all participants in this group did have an opportunity to speak, but some spoke much more than others.

Table 5. Demographic Display of Participants

Participant Pseudonym	Gender	Location	Focus Group
John	Male	Brantford	1
Mark	Male	Brantford	1
Brenda	Female	Brantford	1
Mary	Female	Brantford	1
Donna	Female	Brantford	1
Ryan	Male	Brantford	3
Samuel	Male	Brantford	3
Katie	Female	Brantford	3
Martin	Male	Brantford	3
Greg	Male	Hamilton	2
Janet	Female	Hamilton	2
Bill	Male	Hamilton	2
Ted	Male	Hamilton	2
Jane	Female	Hamilton	4
Elizabeth	Female	Hamilton	4
Margaret	Female	Hamilton	4
Jason	Male	Hamilton	4
Don	Male	Hamilton	4
Liam	Male	Waterloo Region	5
David	Male	Waterloo Region	5
Michael	Male	Waterloo Region	5
Nathan	Male	Waterloo Region	5
Jeff	Male	Waterloo Region	5
Tiffany	Female	Waterloo Region	5
Bob	Male	Waterloo Region	5
Kristen	Female	Waterloo Region	6
Aaron	Male	Waterloo Region	6

### *Focus Group Data Collection*

Focus groups were utilized as the method for data collection for this research. Here, I will describe the rationale for this method, as well as the participatory processes involved during this procedure. The Committee members requested participation in this process to assist as co-facilitators and observers, to provide insights and observations from their perspective as individuals with developmental disabilities living with low income.

#### *Rationale*

Smithson (2008) discusses several reasons for using focus groups in social research that pertain to the proposed study. One of the goals of this research is to elicit insight and experiential knowledge of poverty among people with developmental disabilities. As such, the focus group method provides “the possibility for research participants to develop ideas collectively, bringing forward their own ideas and perspectives.” (Smithson, 2008). One of the relevant strengths of this method is that it allows the researcher to have direct access to the language and concepts that people with developmental disabilities use to think and talk about poverty and disability (Smithson, 2008). This method provides the opportunity for people with similar experiences to come together and discuss key issues that affect their quality of life. This is particularly relevant for people with developmental disabilities as they are often isolated in the community (Lord & Hutchison, 2007; Prince, 2009; White, 2005; Yeo, 2001; Yeo & Moore, 2003). In addition, as this is a time sensitive project for a Master’s thesis, focus groups have been chosen as the primary method in an effort to capture as many voices as possible within in a limited amount of time.

### *Procedure*

The focus group procedure followed a semi-structured interview guide (Mertens, 2009; Smithson, 2008) to allow flexibility in discussion for related topics to emerge (See Appendix C). The moderators were the present author and a Committee member who acted as an assistant, and asked relevant questions but avoided commenting during the group discussion. This was to ensure that the Committee member was clear in his or her boundary between facilitator and participant. The moderators facilitated discussion among participants, rather than only directing responses to interview questions. When two Committee members were present, one member acted as co-facilitator asking questions, and the other member acted as observer to provide further insight on the process. Committee members also engaged in debriefing afterward to share observations and insight from the point of view of an individual living with a developmental disability and low income. These notes constituted part of the data.

While maintaining the unstructured format for discussion on the research topics, I prefaced the discussion by displaying a visual representation of the general topics to be discussed in order for the members to be fully informed of the purpose. The visual material was intended to assist participants to understand the purpose, process and intended outcomes of the discussion, in addition to keeping the conversation focused to encourage quality data collection. This rationale is based on previous literature on the PAR model with people with developmental disabilities (Ward & Trigler, 2001), which suggests keeping the scope small and being very clear about the purpose, process and outcomes in order to encourage participation in future research. The topics were displayed on a wall in each room on large chart paper and noted the topic areas:

experiences, barriers and action. The groups were facilitated to promote dialogue on issues related to their lived experiences, the barriers and challenges to overcoming poverty, as well as suggestions for action to reduce the breadth and depth of poverty for people with developmental disabilities in Canada. The discussion was framed in terms of the guiding theoretical framework of a three-dimensional view of social power: superior bargaining resources, control of participation and debate, and shaping interests (Culley, 2004).

There are a few issues associated with interviewing persons with developmental disabilities whereby some participants may have difficulty responding to open-ended interview questions (Boland, Daly & Staines, 2008). Responses to open-ended interview questions can include “I don’t know”, confusion, or no response at all. Therefore, in all discussions, I started each question with an open-ended phrase. If participants did not understand, the Committee member or I would rephrase interview questions to help participants understand, which is another issue discussed in the literature (Antaki, Young, & Finlay, 2002). Because of the need to rephrase questions, there was the danger that we might ask a question in a leading way, or that data analysis would only take into account the way the question was answered, but not how it was asked (Antaki et al., 2002). Rephrasing or clarifying a question is sometimes a necessary process with persons who are not developmentally disabled. However, it is well documented in the literature as something which happens to a far greater extent with people with developmental or intellectual disabilities. Therefore, in order to prevent the problematic issues associated with frequently rephrasing questions from happening in this research, I employed the use of structured prompts and tried not to ask questions in a leading manner. This information

and direction was also shared with the Committee members for cohesive co-facilitation. If a Committee member began to ask questions which I felt may lead participants to a particular response, I politely reminded my co-facilitator to discontinue or re-phrase his or her question.

The entire process took approximately 90 minutes to complete. The first 20 minutes was used for an informal opening discussion on the purpose, goals, objectives and values of the project. Guidelines for participation were also reviewed with the group verbally during this introduction period. The introduction intended to provide people with a clear understanding of the purpose of the group discussion to prevent dialogue unrelated to the topic at hand. Participants were also informed that a member of the Committee would be assisting in asking questions, as well as that another member would be observing. The goal was to prompt participants to elaborate on stories and themes that would help us understand how people with developmental disabilities structure and organize their social world in terms of living in poverty (Hughes & DuMont, 1993, cited in Smithson, 2008). The groups were digitally recorded and transcribed verbatim shortly after the completion of each group discussion. Field notes were also recorded to capture contextual factors related to each group discussion.

#### *Analysis Procedure*

According to Smithson (2008), data analysis for focus groups needs to consider fit with the research paradigm. As the proposed study is working within a participatory paradigm, a process of jointly interpreting data with committee members was appropriate. Early steps in analysis occurred during data collection whereby observations were recorded based on my own observations and discussion with Committee member(s)

present at each focus group. Committee members chose not to keep a hand written journal of observations, but contributed insights and personal reflections on the focus group discussions and context. They shared these reflections with me after each focus group concluded and I recorded them as part of the de-briefing process. Committee members requested participation in further analysis, but chose not to assist in the coding process. Rather, they were interested in reviewing the initial codebook and providing insight on surprises or unexpected data that arose during analysis. Based on suggestions from Cashman, Allen, Coburn, Israel, Montano, Rhodes, Swanson and Eng (2008), I provided a framework for questions for committee members to answer and think about when reviewing the codebook. These questions included: In reviewing results, what do you think they mean? What is your understanding of what the data says? Are there any surprises, that is, findings that you did not expect? If so, how do you make sense of them? (Cashman et al., 2008, p. 288). These questions promoted dialogue for feedback and addressed any results that were unexpected. As each member had an opportunity to observe or facilitate at least two focus groups, this provided an opportunity to verify similarities in observations and reflections from the data collection process. This relates to Maxwell's (2005) validity tests for respondent validation and searching for discrepant evidence. All committee members participated in this process and suggested minor revisions and qualifications.

The original codebook was developed with an inductive approach to coding (Strauss & Corbin, 1990, cited in Miles & Huberman, 1994) whereby initial data were collected, transcribed and reviewed line by line within each paragraph. I developed a list of descriptive categories or labels, and a more abstract category was attributed to several

observations. This approach is generally referred to as open coding and axial coding, respectively (Corbin & Strauss, 1990). After creation of descriptive codes, I created a conceptual structure for coding to tie the research questions directly to the data in terms of three categories: lived experiences, barriers and action. I used NVivo to help sort data according to this structure as three categorical parent nodes and created child and grandchild nodes under these categories. During this process I was careful to remain open to emerging themes and codes that varied from this conceptual structure. The codebook was developed and code descriptions were shared with committee members.

Next, I utilized node references from NVivo to develop a Partially-Ordered Meta Matrix as described by Miles & Huberman (1994). This cross-case analysis included all relevant, further-reduced data and condensed it coherently into one place in order to explore data across cases. Data were entered into the matrix with themes in the rows and cases in the columns. Qualifications of data and category-grounding phrases were entered when required to clarify, support and deepen meaning. Categories that required further exploration were partitioned into descriptive categories to gain a deeper understanding of the apparent theme or pattern. Tactics used for drawing first conclusions involved noting patterns, themes, making contrasts, comparisons, clustering and counting. Initial conclusions were checked back against transcripts and observations to consider context, explore areas of uncertainty, and identify negative evidence or rival explanations in order to reach final conclusions. In addition, participants were invited to a presentation of the results and asked to review their quotes for appropriate use in interpretation and context. We also requested their feedback on how well the proposed results represented their experiences. Furthermore, as part of this study's dissemination plan, a plain language



report will be produced for sharing with advocates and advocacy groups. This report will be developed in May 2010 and reviewed with participants for adequate presentation of the problem and results for utility to promote poverty reduction.

### Findings

The findings of this study are divided by the initial research questions. To begin, I will discuss the pressing poverty issues and shared meaning of poverty as described by participants. Next, challenges for overcoming poverty will be described according to four main sub-categories: discrimination, employment and income programs. During my research, I learned that family, friends and support workers can serve an important supportive role in people's lives and I will discuss "support" as a new theme that arose from the focus group discussions. I will also discuss the third research question, based on the third dimension of social power, describing participants' perspectives on myths about inferiority followed by their personal expectations and goals. I will then describe identified needs and resources that are based on the first dimension of power, as well as suggestions for change according to specific ideas shared by participants. Finally, based on the second dimension of power, participation in poverty reduction strategies will be discussed to explore participant's awareness of local poverty reduction roundtables, their interests in participation in the roundtables, and how they would like to be involved. I will only note if there are significant differences between the different cities, otherwise I will not refer to the comparison. Table 6 provides an overview of the main themes and sub-categories.

Table 6. Findings, Themes and Sub-Categories

Research Questions	Main Themes	Sub-Categories
Pressing poverty Issues	Shared Meaning of Poverty	
	Basic Needs	Food
		Housing
		Bills and Debts
		Health, Clothing and Transportation
	Budgeting	
	Children	
	Participation in Community Life	
Challenges	Discrimination	
	Employment	Lack of Education and Training
	Income Programs	
Supports		
Myths about Inferiority	Expectations and Goals	
Identified Needs, Resources and Recommendations	Income Programs	
Participation in Poverty Reduction		

### *Pressing Poverty Issues*

Results from focus group discussions demonstrate participants' daily struggles with a lack of resources for basic needs, careful money management and limited participation in community life. Many participants said living with low income is "hard", frustrating, challenging, and difficult. Persistent worry about providing for yourself and children as well, are primary aspects of the lived experience of poverty. Participants described feeling depressed, humiliated, angry and hopeless due to lack of income. The following discussion highlights some of the pressing poverty issues that participants struggle with and worry about on a daily basis.

#### *Shared Meaning of Poverty*

Focus group discussions began by asking participants to describe the words that came to mind when they think of poverty. They said that "poverty" means being poor, living with low income and "always broke" on an ongoing, continuing basis. Jane from Hamilton said that to her, poverty is "like a [jail] sentence". To her, "poverty" is inescapable and restricts freedom. Poverty was described as humiliating and degrading. Some also used the words: "low life", "bum", and "homeless" to describe what came to mind when they thought of the word *poverty*. Some participants agreed that poverty means "just making ends month to month." Others appeared to have some difficulty understanding the meaning of the word, as Kristen conveyed, "*poverty* doesn't mean anything to me because it's not a plain language word... so it should be something that people understand."

### *Basic Needs*

Participants in all six focus groups discussed their struggles with fulfillment of basic needs such as food, housing, bills (i.e. heat and hydro), health, clothing and transportation. As Katie said, “well I just find that everything costs so much. Like from groceries to clothing...like everything is very, very costly.” Margaret conveyed that “it literally takes all your time just covering basic needs.” Participants described the high economic costs of covering basic needs, as well as other consequences associated with lack of income to afford the necessities of life. The sub-categories of basic needs will be described below in detail.

*Food.* Food and the cost of groceries arose most frequently as a basic need concern among participants in all focus group discussions. Many participants discussed the high cost of groceries as something they worried about or struggle with, and many also discussed their use of community services and food banks as a means of supplementing this need. Don from Hamilton highlighted this struggle in the following quote:

Like you need bread and milk, but you only got enough money for bread or milk. Ya know, and there's also the deal of financially robbin' Peter to pay Paul. And you know what it all catches up. It does for me and what I have to do for a few months a year I have to do it. I do nothing but go to food banks, go to like the good shepherd, the places to eat, and that's my whole day that's my whole week, just living, because I'm totally outta cash.

Janet noted that “I normally worry about when you're low of money, like say you're going out for, um, groceries and you find out as you go along you don't have enough.” Jeff similarly stated that “what concerns me [is] I live on \$44 a month for food”. Several other participants echoed these concerns, some particularly noting the higher cost of healthy food than unhealthy food, and discussed how they have to go to food banks in

order to have enough food for the month. Most discussed negative experiences of food banks where they find poor quality food, experience prejudice, and receive a limited amount of food per person. Jane described her experiences saying, “Like going to these food banks, it’s hard. The people are rude and sometimes you go home half of the stuff ain’t good. It’s bad stuff...so sometimes I go I just put on a brave front.”

*Housing.* The need for quality affordable housing was the next most commonly noted need. Eleven participants in four of the six groups in Brantford and Kitchener described their experiences of poor housing conditions when rent was affordable, or rent that was considered too expensive when housing conditions were adequate. For example, Katie shares her experience in an affordable housing unit in Brantford,

I wish we could change that kind of thing with housing and stuff like that. Because like it’s so hard, like you wanna live in a nice safe neighbourhood, like have nice caring neighbours that you can like watch out for each other. But when they just throw certain people all together because of low income or whatever, you get stuck with violence and that’s what I don’t like and I get scared of.

Housing issues did not arise as a concern among participants within the Hamilton focus groups. One group specifically mentioned that they were not concerned about the cost of rent and did not worry about paying their rent on time. In the other Hamilton group, housing was not discussed as a concern by any participants. This may indicate that participants in Hamilton were satisfied with current housing available in Hamilton. However, further research to compare availability of quality affordable housing between cities would be beneficial to explore this finding.

There were some differing opinions among participants around the affordability and quality of lodging, boarding and group homes for people with disabilities. Greg and Ted from Hamilton shared some positive insight about their lodge home in the following excerpt,

Ted: yeah we live in a lodging home, like we're on ODSP right? We get so much money, but then we have to wait, but ya know, we got food on the table but I mean, like some people got no food like at all!

Greg: No! No food, no bed, no room, no nothing. And we got a room.

Ted: We got a roof over our heads, and a house to live in

Greg: yeah exactly so be thankful for that, really.

In addition, Jason expressed that he felt Hamilton had the “best boarding homes in North America.”

In terms of group homes, Mark noted that there are some protective factors associated with group home living in comparison to independent living, saying that “you get treated fairly, ‘cause there’s always food in the house...But when you live on your own, it’s like if you eat all the food in house then it’s like you got nothing.” However, Ryan noted that “It’s the rent I can’t afford...when I first moved into [the group home], it was \$725. Now it’s like \$895 almost \$900. I can’t afford it.” Kristen and Aaron similarly agreed that living in a group home “sucks” because of too many rules imposed on residents.

*Bills and debts.* Paying the bills arose as another frequent concern and priority for participants in five focus groups. Bills that covered basic needs, such as heat and hydro, were described during discussions about daily struggles and worries. Most participants noted that they worry about being able to afford to pay their bills, but understand the importance of paying all their bills on time to avoid going into debt. John, Donna and Ryan shared their concerns regarding their personal debts and expressed worry about paying down these debts due to low income and associated difficulty saving money. Most participants shared the challenges they experience when managing money to be able to pay their bills. Donna shared her concerns about “makin’ sure there’s always food and the bills are always paid... I used to not pay my bills, so that I could have food in the

house, so you learn... you don't pay your bills, you're on the streets then." Other participants also noted that it was a priority for them to ensure they pay all their bills on time. For example, Chris said, "I make sure the bills are paid, when the bills come in, I make sure to pay it right away."

*Health, clothing, transportation.* These basic needs were discussed by two or three participants across groups. Ryan and Katie were concerned about the high cost of a healthy food diet recommended by their doctors due to health concerns. Elizabeth and Katie expressed concern about the lack of financial coverage for medical expenses, and Margaret appeared upset about the cost of obtaining proof of disability from doctors' letters for income programs to fund her transportation costs to medical appointments. In terms of clothing, Katie and Margaret discussed their struggles with the high costs of clothing, particularly for the winter, such as boots and a winter coat. They did not discuss clothing as a luxury, but as a basic need. Only Kristen noted that the cost of transportation was too expensive for her, pointing out that she is not able to afford a monthly bus pass in Kitchener, namely because of the high cost of her rent, thus unable to afford both. Other participants mentioned that they felt public transportation, such as the city bus, was affordable for them. Ted, however, expressed some strong feelings about the lack of accessible transportation in Hamilton. As a person in a wheelchair, he felt that the lack of accessible transportation available in Hamilton is a barrier to his ability to access and attend social/leisure activities.

### *Budgeting*

This theme developed naturally from the group discussions and refers to the struggles and importance of careful money management when living with low income.

Most participants discussed the necessity of careful money management to try to cover their basic needs. This process involved strategically managing few available resources to fulfill basic needs. Participants discussed the need to plan ahead and the challenges of saving money. This process was described as time consuming and required support when necessary from family and support workers. Some participants in the first three focus groups in Brantford and Hamilton indicated that they receive support from a support worker or family member to budget their monthly income. Ted said he needs the support to manage money because “we can’t do it on our own”. Others expressed that they are able to independently manage their money, but must do so cautiously by first prioritizing food, rent and bills. Greg, Janet, Bill and Ted from the first group in Hamilton asked for more support to understand and learn to manage money. This group seemed to be particularly concerned about learning how to manage money and what they could do to earn more money. They indicated that they were looking for help and support to learn how to manage their budget and “get around” challenges associated with low income. Here is an excerpt from that conversation.

Janet: Um, you know even if we have spending money, even like sometimes when you have spending money, and you’re paying everything you run out some more of your money and you still don’t have enough, that’s all I’m saying.

Ted: and how does that work then right? How does that work?

Greg: how do we get around that issue? About how to get more money and that, like how can we earn more money?

Ted: like we can only make so much

Greg: yeah exactly you can only make so much...then that’s it.

Throughout our conversation, these participants discussed the limited income they receive from ODSP and earnings from employment in a sheltered workshop. During our discussion they continued this line of questioning indicating they were eager to learn how



to budget their money to have enough leftover for themselves in a month and wanted to do something to increase their incomes.

### *Children*

Donna, Brenda and Katie discussed their experiences as single mothers living with low income. All three women worried about not being able to provide for their children, “doing without”, not paying bills to buy food, and not eating to ensure that their children had enough to eat. Katie talked about the need for more information and support from ODSP and social services to support her teenage son with various disabilities. All three women discussed the constant worry associated with providing for children with limited resources and support. Donna and Brenda shared their experiences in the following dialogue:

Donna: With kids, well I did worry; could I give him what he wanted? I couldn't always get what he wanted so we had to live very little. I could not give him everything he wanted so we don't get that luxury, that stuff that most of these, these ritzy people get, ha ha, I call 'em rich people

Brenda: Because I went through the same situation too, with kids but I had two kids and it was hard

Donna: Yeah it is hard, I understand

Brenda: It was hard surviving with two kids

*I: What were some of the things you worried about?*

Brenda: If my, well at that time my daughter was in diapers she was just a baby, my son was goin' to school, if we had enough for, um diapers, clothes for him, not just to take for him to go to school

Donna: Like I used to do without. Bills, I used to not pay my bills, so that I could have food in the house, so you learn.

Brenda: Oh I made sure my kids ate first. I wasn't worried about me, it's just my kids, and then I was losing my weight.

Here, Brenda and Donna are discussing their experiences as single parents raising their young children who are now adults. Katie talked about her son with “emotional disabilities” who still lives with her and the lack of information and funding she receives from ODSP to connect her son to appropriate community resources and supports.

*Participation in Community Life*

This theme is characterized by the lack of purchasing power and access to social activities in the community due to lack of income. All six focus group participants discussed the lack of “spending money” for entertainment and items for pleasure, such as CD’s, DVD’s and nice clothing. Ted mentioned his concern about going into a store to purchase something and feeling unsure whether he has enough money to make a purchase, but did not want to ask store employees for help. Participants also discussed this theme as a process of having to make choices. Mark conveyed the following, “I enjoy a lot of things, but what it boils down to is the money decisions. Like you have to have [to] make a choice...balance out whatever that you can afford, like its always one or the other you can’t do both.” Several other participants discussed the limited opportunity to go out to eat at a restaurant, go to the movies, go out for pizza with friends, or even go out for a cup of coffee because they cannot afford these activities. People discussed broadly about not being able to “buy stuff” or “do stuff” that they want to do, as well as they “can’t go to places where [they would] like to go”. David summarized this experience noting “if you don’t have enough money your lifestyle is cramped. You can’t live the way other people do it...because you don’t have enough money to distribute the funds to the different aspects of life.” Don echoed these remarks: “‘cause financially when you ain’t got, barriers get put up. Like oh you can’t sit here ‘cause you can’t afford the price of a coffee, you can’t ride the bus ‘cause you ain’t got bus fare or whatever. So your world closes in on you.” Hence, participation in community life is limited as a result of low income.

## *Challenges*

Participants noted many challenges to overcoming poverty. They all agreed that it can be very hard to get ahead and have more money in their lives. Some of the most commonly noted challenges were associated with discrimination as a primary cause of unemployment. Other challenges to employment included underemployment and a lack of education and training. Policies and procedures within income programs, including ODSP, were also discussed as a significant challenge to overcoming poverty. Each of these categories will be described below in detail.

### *Discrimination*

Attitudinal discrimination arose during our conversations as a challenge or barrier to employment and overcoming poverty. Fourteen participants from five groups (with the exception of one group in Hamilton) shared the opinion that during hiring and recruitment, many employers discriminate people with disabilities, “labeling people before they have a chance to show what they can do.” Bob shared his experience applying for a job at a local museum, “When I took my résumé to the [museum], the boss took my résumé right to the garbage, and didn’t care! The lady got fired from it. It’s not right.” Here, Bob shared with us that he felt that his résumé was discarded because he had a disability. He felt his rights had been violated and reported the actions of the museum employee, which led to her dismissal. Employment discrimination was characterized by participants as a lack of respect for people with disabilities and prejudiced assumptions about the lack of skills and abilities. Participants indicated they felt this is a significant cause of persistent unemployment. Nathan said “I’m worried about us being judged by our appearance, rather than our personalities. They judge who stands there...they don’t

see the mind...they treat us like we're worthless and soulless." Ryan and Samuel echoed this point about prejudice and discrimination. Throughout our conversation both men expressed their frustrations with attitudinal discrimination as a form of discrediting people with physical and intellectual disabilities. Below is an excerpt from that conversation.

Ryan: It's hard, 'cause when I'm in a wheelchair, people don't even think about what you could do out of a wheelchair. All they see is you in a wheelchair but they don't think about the person in the chair. And that upsets me, because if I go to interviews, they go "OK you're incapable of this job"...

Samuel: That's discrediting you, they shouldn't be doin' that.

Ryan: They don't tell me, but I can tell why or how they're not putting me on the job, 'cause they're worried.

Samuel: They'll do that to anybody with a disability you can't, people who are slow learners they don't want you because they don't want to have to repeat themselves.

Both men also shared their experiences of discrimination as a barrier to employment whereby Ryan noted that he has been unable to apply for jobs due to physical inaccessibility to the location as well as lacking access to information on employers with accessible buildings. Thus, he felt that environmental discrimination and lack of accessibility is another barrier to employment. Samuel shared his experience when he applied to a local employer who told him that they did not want to repeat themselves, thus refusing to hire him. Moreover, Ryan stated in the above quote that "They don't tell me, but I can tell why or how they're not putting me on the job", indicating that he understands that discrimination can be covert. Jeff similarly stated that, "They won't tell you that you don't have a job, they'll take your résumé, they'll hold onto it, but they won't say it to you face to face. If they say it to you face to face its discrimination." Jason also noted this understanding that employers are aware of the consequences of overt discrimination, thus denying people with disabilities an opportunity to work while

avoiding obvious prejudice. Jason said “when you are one on one in the employer’s office, he can say whatever he wants, but if you take it outside the office, he’ll say ‘Well I never said that.’ So who’s on your side?” Jeff and David suggested that employers use more socially acceptable reasons to avoid hiring people with disabilities. They suggest that employers use excuses and claim it is too expensive to hire and accommodate people with disabilities because of the high cost of workplace insurance and greater training costs.

Furthermore, discrimination can also be a challenge for those who have succeeded in gaining competitive employment. For example, Mary had a part-time job in her community, and shared her experiences of discrimination in the workplace in the following quote:

Even that word [retard] that we don’t wanna hear, ya know? And I just hate, I just hate it! And one time, when I started at my job, and my supervisor said it one day, and I just turned around and I told her, I said ‘I don’t like that word at all’ and, ‘I’m sorry but were not, ya know?’ And I, I just hate it... but, they still say it. Not all the time, but just once in awhile, ya know?

Mary indicated she becomes distressed when offensive language is used to describe people with disabilities in any context. Donna agreed and stated that she felt the word “retard” should not be used because, as she said, “I’ve been called that all my life, and I don’t wanna hear that now.”

Although discrimination appears to be a common experience among most participants, Jeff and Brenda also noted that they have learned to live with this challenge. For example, Brenda said, “I just consider where it comes from, ‘cause they’re not better than us.” Jeff conveyed “we’ve got to be very open minded...we’re here to teach people to learn to close their mouths, that I’m no different than you. I’m the same.”

### *Employment*

Challenges to obtaining competitive employment, earning minimum wage or better, arose as a common theme among participants. As discussed above, many participants expressed a desire to obtain employment, thus suggesting that employment was a pathway to overcoming poverty and an opportunity to earn money. Also as noted above, discrimination arose as a significant cause of lack of employment, but participants also noted several other reasons why employment is a challenge. The reasons included a lack of education and training, lack of information on available employment opportunities, age and poor physical and mental health restricting abilities to work.

Underemployment was another concern for a few participants. Bill said he currently had two part-time jobs in the community, but was still not getting enough hours to satisfy his economic needs, currently only working one hour a day, two days a week. Greg, Ted and Ryan shared their experiences working in sheltered workshops in Brantford and Hamilton. All three indicated that they felt they were underpaid and indicated that they understood that their employment was not equivalent to competitive employment in the community. Ryan expressed his frustration with low wages when he remarked “it upset me ‘cause it should be the same as everybody else is getting paid, like regular people. Like giving you like \$0.50 an hour that’s not right.” Greg and Ted had recently asked their supervisors at the workshop for more hours and pay and Ted said, “they wouldn’t give it to us” because they did not work in a “real workshop [where] they could give us eight or eight and a half hours, full time.” Although both Greg and Ted agreed that they were “making peanuts working here” they did not want to “feel bad” for the workshop. Ted said “I love it ‘cause it gets me out of the house.” It is interesting to

note that although they were dissatisfied with the level of pay and hours available, they were still appreciative to have a job and a reason to get “out of the house”.

*Lack of education and training.* Four participants noted that lack of opportunity for education and employment training was a challenge to obtaining employment. Margaret shared her frustrations when she was denied access to a re-training program due to her age and disability. Elizabeth, in particular discussed at length about the inequality she has experienced in the education system. She said “The educational part of it I think gives the most downfall for me...I went to a vocational level all girls school when I was 13 ‘til I was 19 and yeah they told me yeah when I graduate you can get a job...but it’s not equivalent with what you would have graduated with.” Elizabeth suggested that this lower level education, common among many people with developmental or learning disabilities, is a barrier to obtaining competitive employment. Jeff echoed this point, suggesting that without a grade12 diploma, employment opportunities are significantly reduced.

#### *Income Programs*

Several deficiencies in the Ontario Disability Support Program and other income support programs (including Canada Pension Plan and Ontario Works) were described by participants as significant challenges to overcoming poverty. Participants in all six groups agreed that ODSP presents disincentives to upward economic mobility. Most participants indicated that ODSP and income programs do not provide beneficiaries with enough money, thereby presenting challenges associated with poverty. The lived experience of a recipient of disability income support was characterized by a lack of choice and control over one’s own finances.

Several individuals noted that they have no control over the amount of income they receive because “ODSP decides how much you get.” Some said they felt powerless to effect any change because “ODSP doesn’t listen” or they felt the system will never change. As Jane said,

You see the welfare and the ODSP, it’s not gonna change. Those people have a set guideline, and the guideline is something that they keep. And it’s like a knot! And they don’t pull it because they figure ok if you get \$900, if you get \$200 like whatever you get, you either live on it or you die!

Jeff felt that there was a lack of choice and control in the income support system as a result of the hierarchical bureaucracy of corporate overrule holding power over the government. Jeff stated on several occasions that it was important to recognize that the government does not have the power to effect real change because the upper class controls government policies. Here is an excerpt from his remarks,

It’s not the government doing it. It’s the executives of the high class management; the government is a puppet... They don’t hear what you gotta say. Hey I wanna be treated the same as the person who’s not handicapped. As a person who’s not physically challenged. I wanna be treated the same. They don’t see that because the high class men is making people like a puppet! It’s the executives. They come to you, ‘you’ve got too much money.’ If you’re on the disability they go like this to you, ‘You’re rich!’ But you look at them getting \$5 billion, with the big business, and you’re lookin’ at yourself and sayin’, ‘who the hell are you?’ But the point is, these executives put rules to the politicians, in their written contracts: this is what I wanna pay these, they call ‘em "bums!" They don’t call them people, [they call them] "bums!" What they do, they get mad and they let you off; they get mad at the person ‘Oh you’re on welfare, your lazy people. You don’t want to work.’ They’re judging us.

Here Jeff is discussing the power of the upper class over the government and people living on disability income support. Jeff felt that upper class discrimination and prejudice is the cause for lack of adequate income support for people with disabilities and income program recipients. In addition, Jeff and Jane both noted similar opinions that they felt the government prioritizes the needs of newcomers to Canada over the needs of



individuals who are current recipients of income programs. As Jane stated, “what I find with the system in Canada, they don’t cater to the people who is here, they cater to the people who just come... those are the people who get the top priority, we are here, we just get pushed in a corner, into a corner! And the people who just come into Canada, they get everything.”

Many participants noted specific aspects within disability income support programs that present challenges to overcoming poverty. The most frequently mentioned challenges involved claw-backs from employment income and income reductions due to spousal income. There was some debate about ODSP employment incentives, in particular the \$100 work-related benefit bonus, and employment earnings claw-backs. For example, Mary noted that she had a competitive job in the community and said “I’m glad I’m on ODSP it helps out, more for me anyways, for myself.” Mark and Ryan both commented that they were pleased with the \$100 work-related benefit when they were working in a sheltered workshop. However, other participants in the first focus group disagreed with the benefit of this incentive. Brenda pointed out that once a recipient has earned more than \$100 in employment income, the work-related benefit does not improve income level due to 50% earnings deductions from ODSP employment claw-backs. Here is an excerpt from that conversation,

Mark: Well right now I’m happy with ODSP because you get to make \$100 extra on your cheque.

Brenda: But if you make more than that, they take more off your ODSP at each month! So you’re not goin’ ahead of yourself.

Donna: You think you’re ahead.

Brenda: You think you’re ahead but at the end you’re not ahead you’re behind, so it’s not good.

Donna and Brenda point out the misleading nature of the incentives and claw-backs within ODSP employment income policies. Other noted program challenges included lack of support to find and maintain employment, and lack of information on policies, as well as community resources and services for people with disabilities. Interestingly Martin, Samuel and Ryan all noted that they felt there are some recipients of ODSP that do not have disabilities, and “fake it” to obtain income support. They suggested that ODSP “check up on people to make sure they have disabilities when they go and apply for [income support].” However, more participants felt that ODSP is overly “nosy” and “wants to know everything about you”, thus violating individual privacy. Margaret, in particular, made several comments throughout our discussion about the humiliation and degradation she has experienced from social assistance workers in ODSP and CPP. Here is an excerpt from that conversation,

I had my worker tell me that a telephone and having cable are considered luxuries... And I said to her, pardon my language, I'll be damned if I'm gonna feel guilty that I've got a phone and cable... Money is allocated to me, what I do with that money, how I choose to use that money should be my decision, not some worker's... And that's why people feel humiliated and degraded and why they don't wanna have to deal with any [workers], I mean I've seen people deal with a tremendous amount of things just so that they wouldn't have to go deal with a worker.

Margaret, among others in this group, also felt that beneficiaries withdraw from debate with front line staff to avoid conflict. As such, some participants felt that many beneficiaries are displeased with income program policies but are “afraid” to participate in debate for fear that this may result in harassment by program staff. Overall, ODSP and income support program policies and procedures arose as a significant challenge to overcoming poverty. As such, there were several suggestions for change in this program which will be described below.

### *Supports*

During focus group discussions we asked participants how their family, friends and support workers help or hinder their ability to get ahead and have more money in their lives. We learned that, for most participants, family, friends and support workers play a supportive role to help people manage money and cope with low income. Eleven participants across all six groups indicated that they receive an occasional and limited amount of financial support (money or groceries) from family members. Typically, this referred to parents or siblings who provided support when it was necessary to cover basic needs. Most participants mentioned that they did not want to rely on family and preferred to be financially independent, but had no choice, at times, to accept family support. Other participants noted that they did not receive any financial support from their families. John and Donna said they felt they were more independent because they did not receive any support from their families. Margaret mentioned that her family excluded her from many family events because of lack of affordability, “I’m an embarrassment to my son and daughter because well Mom can’t afford to go to anything, so I don’t get asked to anything in the family.” Mary and Mark, on the other hand, commented that they felt their families were over-involved in their lives. They remarked that they wanted more independence from their families, in terms of making decisions for themselves, and wanted more choice in how they spent their own money. Mark highlighted this point in the following quote,

See I’ve got everything that I need. I’ve got a computer, TV, phone, everything. So everything’s great. Like I don’t have to worry about that because my foster mom takes care of all of my bills...[but] I wish I could have the internet, but I don’t because I can’t afford it right now...but it’s not what my foster mom wants.

This was an important point because Mark felt that the internet would provide him with access to recipes that he could use toward his goal of learning to cook and opening his own restaurant business.

Only eight participants noted that they had friends who provided some support in their lives, typically in the form of emotional support as people to “talk to” The number of friends was usually limited and with the same socio-economic status. Some participants who did not have many friends indicated they would like to more friends that were supportive and helpful. Greg said his friends “don’t help at all really. They just say, sometimes they just say, “You’re on your own mister.” Nobody said that their friends provide them with financial support, however, Michael said his friends help him get “gigs” to play music and earn money, Aaron said his fiancée is trying to help him save money and Janet said some of her friends have given her some household items when needed.

Ten participants indicated that they had a support worker and said positive things about their workers. Four participants indicated that their worker helps them budget their monthly income to ensure their rent and bills are paid on time and they have enough money for groceries. Donna said she was very pleased with her worker, and also receives support for transportation to doctor appointments out of town. Janet and Greg said they wished their worker would help them have “more [personal] spending money” every month. Janet said her worker is “ridiculous sometimes” as Janet is uncertain about the reasons for suggested constraints on her budget. Janet, Mary and Ryan also noted that their support worker provides some emotional support, and Aaron said that his worker supports him to access community services and resources. Donna and Tiffany both

indicated that they were concerned about the lack of funding for support workers and would like to have more sustainable funding for their current support workers.

### *Myths about Inferiority*

We asked participants to share their thoughts about the statement: “Some people think that people with developmental disabilities are poor because they don’t have the skills and abilities to work and earn money”. All participants disagreed with this statement, some stating that it was “unfair”, “not true”, and “a bunch of horse manure”. Kristen said she disagreed with this statement because people need “a chance to show that we have skills. So I totally disagree with that, just because people don’t understand or feel embarrassed to be with us, doesn’t mean we can’t do the things that we want to do.” Essentially, many participants said that their skills and abilities are not recognized by employers. Many participants argued that this statement should be qualified with the recognition that there is an incorrect dominant assumption in society focused on the barriers and incapability of people with developmental and other disabilities. Participants argued that they need a chance to demonstrate their abilities and strengths. Most claimed that they personally felt they are capable and were either employed, or could be employed if given the opportunity. Participants argued that many people with disabilities do not have the opportunity to work due to attitudinal discrimination or prejudice, and the dominant ideology focusing on people’s disabilities rather than their abilities to contribute to society. Michael proudly stated:

To me like it doesn’t matter if a person says well “you have a disability”, to me like if a person if any person would try to say that to me I would say ‘I don’t have a disability I’m a person that is a hard worker.’ And I don’t think it has nothing to do with handicap man. It has nothing to do bein’ handicap has to be with having the confidence in yourself! In your heart and your soul ‘cause you

know that you feel it and you know that you are able to do it. And we're able. We are people who are able to make a difference in society.

Myths about inferiority were denied and arguably considered false. Participants expressed pride in their abilities, and considered themselves to be able to work. This myth was denied on the basis of unsubstantiated discrimination and prejudice. However, most participants identified as self-advocates who typically focus on the strengths of people with disabilities. As such, these results may be reflective of this common experience. Participants reflected on a variety of personal goals, discussed next, highlighting their sense of capability and propensity to for more meaningful participation in community life.

#### *Expectations and Goals*

As a follow up to the previous question, I asked participants about their expectations, or goals in life. Participants noted a variety of goals and aspirations. Overall, participants discussed the desire for a higher quality of life with more opportunity and choices. Participants did not indicate that their disabilities were a barrier or challenge to goal achievement. Rather, many expressed that low income may be a significant challenge to realizing their goals.

The most commonly noted goal, shared by 13 participants across all six groups, was to obtain meaningful employment. Interestingly, Mark and Jeff said they would like to have their own business where they would hire people with disabilities to provide people with an opportunity to work and focus on their strengths and abilities. Other dream jobs included becoming a fighter pilot, joining the military and working in the community as a social service worker. Other goals included travelling, going back to school and improving literacy skills, getting married and moving to a rural area or living

independently in a high-rise apartment building. Some participants took time to think about this question and there was some need to facilitate this discussion and probe further for personal goals. Others indicated that they felt they would never achieve their goals due to lack of affordability. Mark, however, said “but everybody has a fair chance at like owning, like your biggest dreams and I’m sure enough like it will happen”. Donna disagreed stating that she felt people with disabilities did not experience equal rights, nor have equal opportunity to realize their dreams and goals. Only one participant remarked that he was realizing one of his personal goals, and said he felt fortunate and excited about this achievement.

#### *Identified Needs, Resources and Recommendations*

This category focuses on the identified needs and priorities for social change described by participants in Brantford, Hamilton and Waterloo region. This discussion promoted shared dialogue about the resources people with disabilities need to overcome poverty. We asked “what do you need to get out of poverty and have more money in your life? What do you think needs to change? Participants responded with a variety of ideas and suggestions for social change to reduce poverty among people with disabilities. Some of these ideas included increased social support to obtain more income and sustainable funding for support workers, as well as increased access to resources, such as training, to support increased employment opportunities. Margaret emphasized this need when she said “I need somebody to take a chance on me. I need somebody to look at me and say ‘yes ok you *can’t* do this and this, but you *can* do this and this and this and we’re willing to help you get started in that process.’ And not penalize me if it doesn’t work out. And not make it more difficult for me.” Margaret was discussing her experiences when she

tried to access employment services and re-training programs that focused on her needs and incapacities, rather than her strengths. All participants from group two discussed, broadly, the need for more help and support to overcome poverty, while Martin, Ryan and Michael from groups three and five specifically noted the need for more government support to help people obtain employment.

Samuel, Ryan, Michael and Nathan suggested that elimination of discriminatory attitudes and practices within the general population, and within government (including policies that promote equality), would help people to overcome poverty. These gentlemen made concrete suggestions to reduce discrimination including public speaking to raise awareness, “take away all the labels” that categorize people according to their disability and “the government should be put in a [wheel]chair...or have them act like they have a disability and see how they feel when people torment them.” Jeff strongly suggested that “we gotta get the policies changed so people don’t treat us like a bum. Treat us like a human being.”

Nine participants in all three cities also discussed the need for increased self-advocacy and pride among people with disabilities to stand up for their rights and “fight for more money.” Katie, Samuel, Ryan and Liam also noted that they need an affordable cost of living including housing, reduced cost of healthy food, and heating and hydro costs. Katie and Don shared the opinion that increased access to participation in community action plans and committees that have real social power to make change. Don also noted the challenges with gathering participation from people living with low income to get involved in social action, he stated “I don’t know what it is but anything that has to do with poverty it’s hard to get the numbers up.”



*Income programs*

Many participants in all six groups identified specific needed changes to ODSP and income support programs. The most frequently shared suggestion involved “more money on our cheques”. This suggestion was followed by concrete recommendations to eliminate employment income deductions, reinstating formerly offered benefits, such as clothing allowances and eliminate income reductions due to spousal income or rent costs. Three participants said they would benefit from annual raises to keep up with the cost of living providing more money for basic needs and food allowances. Four participants suggested that ODSP needs a better employment supports program to assist more recipients to obtain employment. Margaret suggested that there are too many restrictions for eligibility to employment services and supports, and Martin suggested providing incentives to employers to hire more people with disabilities.

*Participation in Poverty Reduction*

We asked participants if they were aware of their local poverty reduction roundtable, what they thought of these groups, and if they would like to participate, if so, to what extent. Most (23 participants) indicated that they have not heard of their local poverty reduction roundtables. Jeff had participated in a community event organized by Opportunities Waterloo Region, and thus had heard of the organization but was not aware of the roundtable. Jane, Elizabeth and Margaret had heard of the Hamilton Roundtable for Poverty Reduction but felt that the group lacked significant action and change and did not benefit their current needs.

Everyone indicated that they may be, or definitely would be, interested in getting involved. Thus, most were interested in learning more about the roundtables and said

they would like to be invited. Margaret provided some helpful suggestions in the following quote for some people who may need support or resources to attend a roundtable.

And if you're going to have discussions about things, groups that want to do roundtables and surveys and stuff, they need to provide transportation for the people attending. And they need to look at the things that people need to be able to attend. A lot of people don't come to things because they don't think that they're dressed well enough. Other people don't come to things because they don't have the bus ticket to go. Other people don't come because they feel like they can't speak well enough, they're not educated enough or that they don't understand the jargon that is being used. And if you can't keep up with that, how are you gonna understand what's goin' on?

Participants indicated that they are interested in getting involved in active poverty reduction work and promoting and seeing social change happen. Several people said they would like to help reduce poverty for themselves and other people with disabilities, for example, getting "more money on our cheques" or "help lower[ing] prices everywhere". Four participants Ryan, Mark, Samuel and David specifically said they would like to raise awareness about disability issues within the roundtable. Ryan said he would like to help make "decisions about like what they wouldn't understand what people like with disabilities goes through." Seven participants across groups said they would like to have some control over decision making processes, but may want to merely be included, at first, to get comfortable with the roundtable and get to know other members before becoming more involved. Mark shared his thoughts about involvement of people with disabilities in poverty reduction roundtables in the following quote,

Sometimes [the roundtable members] may have a question for us, and they can learn from us, and we can learn from them. So like it's equal, but sometimes I sit in things and its like 'what are you talking about?' but then after while I can clue in and be like "oh yeah" now I know what they're talking about and get into the conversation.

## Discussion

Results from focus group discussions demonstrate the lack of choice and control, social exclusion and discrimination associated with the experience of poverty and disability. These experiences and challenges are characterized by a lack of social power. The results reflect previous literature arguing that poverty is an issue of power (Prilleltensky, 2003; White, 2005; Yeo, 2001; Yeo & Moore, 2003). As noted above, Prilleltensky (2003) asserts that in the context of poverty, power refers to the capacity to fulfill or restrict access to basic needs, and resist the deprivation of resources. Furthermore, results also reflected previous literature demonstrating that people with disabilities often have no voice, choice or control in decisions that affect their lives (Lord & Hutchison, 2007; White, 2005; Yeo, 2001; Yeo & Moore, 2003).

This discussion attends to the effects of power, not necessarily the motivations or intentions behind such. Thus, I will focus on the participants' perspectives on the effects of power on their lived experiences, challenges to overcoming poverty and suggestions for social change. The three dimensions work in a cumulative and compounding manner and can be exercised concurrently to affect the lives of people with disabilities living in poverty. In this discussion I will explore the major themes and categories presented in the findings. I will elaborate by tying these findings back to the literature and the three dimensions of social power in order to ultimately present the unique theoretical and practical contributions of this research project. For parsimony's sake I will not discuss everything that I have documented in the findings section but only those themes and categories which beg further discussion in terms of social power.

*First Dimension of Power: Superior Bargaining Resources*

Power in this first dimension stems from the superior bargaining power of one side (A), to defeat the other (B) due to lack of resources. Based on the results of this study, it is clear that participants' experiences are characterized by a significant lack of resources to fulfill basic needs, support their children and participate in community life. According to the social power framework, resources can be used to exert power over others with fewer available resources. Thus, participants would fall into the category of B (the relatively powerless), who are vulnerable to overt control by those who hold superior bargaining resources. This section will discuss the first dimension of power in terms of the lack of resources as a consequence of poverty.

Participants most clearly stated that they felt they lacked money as a primary resource to fulfill basic needs. Participants said that they found "everything just costs so much" and that "it literally takes all your time just covering basic needs." Participants indicated that income program policymakers and employers were the two main groups of people who held power over needed resources for people with disabilities to overcome poverty. Thus, according to participants, A (the relatively powerful) are income program policymakers and employers as they exercise control over and restrict resources for people with disabilities who have fewer resources. This is similar to previous literature that indicates the powerful relative to people with disabilities include policy makers, government officials and employers (Bach, 2003; Beresford, 1996; Dunn, 2006; Lord & Hutchison, 2007; Moore & Yeo, 2005; Munro, 2007; Stapleton, et al., 2005; White, 2005; Yeo, 2001).

Participants noted that they do not receive enough financial support from income programs and denied opportunities to increase income via employment. The consequences of these experiences were described as a process of making difficult choices between basic needs as a result of low income. Examples of these decisions included choosing between basic food items (e.g., milk or bread), between quality housing and affordable rent, between food and paying bills, and between transportation and rent. Thus, results indicate that limited resources contribute to a lack of choice and control and powerlessness. Participants indicated that living with low income was “like a [jail] sentence” and meant struggling on an ongoing, continuing basis, “just making ends month to month.” This is similar to White’s (2005) comments that many people with disabilities cannot afford the resources required for even a moderate quality of life and often have no voice, choice or control in decisions that affect their lives.

Participants also discussed concern about income program restrictions on assets and resources, such as prescribed asset limits and employment income deductions. Several participants noted this as a challenge to overcoming poverty when they are “not allowed” to have assets or savings, thus find it very challenging to increase their income and resources. This reflects Stapleton and colleagues (2005) description of income support program policies creating a poverty trap, whereby the rules of these systems reduce financial benefits drastically as a beneficiary’s employment earnings increase. Participants also stated that employers do not provide equal opportunity to earn employment income, thus perpetuating their dependency on income programs and restricted access to resources.

Lack of control over resources administered by income programs and employers was another dominant theme that weaved through most categories developed from the findings. Participants remarked that income programs control the amount of money received as income, as well as the permissible amount of assets and savings. Employers were considered to control access to employment and increased income. As noted in the literature, employment is also the basis of social and political status, such that reduced or non-existent employment income means no influence and powerlessness in western society (Jongbloed & Crichton, 1990). Participants noted that people with disabilities experience unequal opportunities for employment, which contributes to a lack of ability to assert rights and further reduces income generating opportunities to push people deeper into poverty. Yeo (2001) similarly stated in her depiction of the Disability/Chronic Poverty Cycle, that discrimination and disability leads to exclusion from political and legal processes and a lack of ability to assert rights to compound poverty and further exclusion from society.

A new theme arose in the results of this study in terms of support. Participants noted family, friends and support workers as people who provided financial support, thereby connecting participants to needed resources, such as food and money for groceries. This is a new theme that was not initially identified as a resource in the three dimension framework, but appeared to be a resource among participants in this study. This was particularly evident when participants indicated that their support worker provides transportation, and assistance with budgeting to ensure that rent and bills are paid on time and there is enough money for groceries. Moreover, some participants indicated that they need increased social support to obtain more income and sustainable

funding for support workers. Previous literature similarly discusses the profound impact of social support and the relationships that make life easier to live and more enjoyable (Brown & Percy, 2007). Social support is also an important aspect of inclusion for people with developmental disabilities (Brown & Percy, 2007).

Identified needs and recommendations for change included many ideas for increased resources that would support efforts to overcome poverty. Participants suggested that the primary resource they needed was “more money on our cheques” referring to increased income program funding. These suggestions included eliminating restrictions and deductions to support recipients’ capacity to gain more resources in the form of monetary savings and assets. They also suggested annual increases in income to keep up with the cost of living providing for easier access to basic needs. Moreover, the elimination of employment earning deductions would provide a greater incentive to seek out alternative income and promote higher employment rates. These suggestions fit well with a recent paper published by Stapleton (2009) providing recommendations for Ontario social security programs (including disability income support), namely to increase asset limits for recipients. He argues that asset limits present challenges and barriers to moving from social assistance benefits, whereby limits provide incentives against accumulation of meaningful cash reserves. Furthermore, when low-income and asset poor adults are provided incentives and rules that allow them to obtain and retain assets, they become better able to withstand poverty. He points out that current asset policies are not in line with provincial poverty reduction strategies as recipients are forced to deplete savings before receiving benefits and are threatened to be cut off, should they accumulate too much savings. Accordingly, it is important to include people

with disabilities in policy discussions to address these issues and concerns, which I will discuss next in the second dimension of power: control of participation and debate.

*Second Dimension of Power: Control of Participation and Debate*

This dimension reflects the indicated barriers and challenges to participation in debate and decision making on key issues related to poverty and disability. As reported in previous literature, and this study's findings, people with disabilities are often prevented from participating in many aspects of society (Bach, 2003; Brown & Percy, 2007; Dunn, 2006; Elwan, 1999; Lord & Hutchison, 2003; Lord & Hutchison, 2007; Munro, 2007; Prince, 2009; Stapleton, 2009; White, 2005; Yeo, 2001; Yeo & Moore, 2003).

Participants pointed out that barriers are erected to full participation in community life when one cannot financially afford to take part in an activity. Participants remarked that they felt excluded from various aspects of community life (e.g., employment) because of attitudinal discrimination toward people with disabilities. Moreover, they felt that they were also excluded from participation in social and leisure activities in the community as a result of low income (e.g., cannot afford to go out to the movies, a restaurant or for a cup of coffee). As such, people may be doubly excluded from the life of their community because of exclusion associated with disability and because of low socioeconomic status. This finding coincides with previous literature demonstrating the compounding links between poverty, disability and social exclusion (Bach, 2003; Beresford, 1996; Dunn, 2006; Elwan, 1999; Lord & Hutchison, 2007; Munro, 2007; Prince, 2009; Stapleton, 2009; Stapleton, O'Day, Livermore, & Imparato, 2005; White, 2005; Yeo, 2001; Yeo & Moore, 2003). This social exclusion appeared to underlie many of the themes and categories discussed in the findings, including: experiences of limited participation in



community life, challenges and barriers to employment and involvement in poverty reduction strategies.

According to the social power framework, institutional procedures are one of the instruments of power within the second dimension, to erect barriers to participation (Culley, 2004). In this study, these institutional procedures include hiring and recruitment criteria for competitive employment and income program policies. Many participants indicated that procedural barriers and challenges to employment and income program policies posed significant challenges to overcoming poverty. According to Prince (2009), the larger disability movement also strives for greater participation of people with disabilities in the mainstream labour market. A core element of this struggle is access to gainful employment, preferred over sheltered workshops or voluntary service. This preference was duly noted by participants in this study, who expressed criticism of low wages for sheltered workshop employees. Prince (2009) further reports that disability activists also recognize the importance of work incentives in social policy, and condemn work disincentives in various income programs.

Several barriers and challenges to employment were discussed by participants in this study. Some participants noted that discrimination was a covert use of power such that employers are aware of the social consequences of overt discrimination and indirectly or subtly deny employment opportunities without obviously demonstrating prejudice. Participants said that this may take the form of excuses related to the increased cost of hiring people with disabilities because of workplace insurance or greater training costs. Barriers and challenges to employment also included minimum education requirements (e.g., Grade 12 diploma) often above the level achieved by most

participants. A few participants also noted that they were denied access to adult re-training programs or received inferior education in secondary school, posing challenges to meeting competitive employment criteria. Prince (2009) similarly suggests that public hesitance on advancing an agenda of full participation of people with disabilities may derive from seeing the disability movement as a minority issue, advancing the rights of people with disabilities at the cost of others, in this case: employers. In this case, this relates to Lott's (2002) definition of discrimination as cognitive and behavioural distancing from the poor, which may be deliberate and obvious or subtle and indirect.

Income program policies and procedures were also reported to erect barriers to participation in debate on key issues related to poverty and disability. These policies and procedures were described as limiting choice and control over personal finances. Participants expressed that they felt a lack of voice, choice and control over the terms and conditions of income program funding. Several participants noted that they have no control over the amount of income they receive and felt that policymakers and front line workers treat beneficiaries as inferior citizens and scrutinize individuals' money management decisions. Margaret, in particular, mentioned that front line workers criticize, humiliate and degrade recipients by questioning personal finances and spending choices. According to Margaret, this treatment reaches the point that people are discouraged from "dealing" with these workers and would rather avoid conflict, thus withdraw from debate over personal money management decisions and program policies.

Several participants felt there were significant barriers to creating change within the income program system. A few participants said they felt powerless to effect change within income programs to support increased resources for participants. For example, Jeff

and Jane both thought that income programs have been purposely developed with set guidelines and policies to keep people in poverty. They indicated that income program policymakers and corporate bureaucrats hold power over recipients to maintain the status quo. Although many participants said they felt that system change was required, there were a few who felt the struggle for change would be futile. This finding reflects Parenti's (1978) comment that "Anticipatory reaction is the mainstay of power.... to win a struggle is one thing, but to have your way by impressing others that the struggle would be futile, that is power at its most economical and most secure" (p. 78).

However, many participants identified the need for increased participation in debate about key issues, such as discrimination, lack of resources, employment and income programs, to help people with disabilities overcome poverty. Many participants indicated that greater recognition within government policies of these key issues would help reduce poverty. A few participants said that they need more support from the government to include people with disabilities in political processes and develop policies that promote equality. As such, some participants indicated that increased empathy and awareness of the concerns of people with disabilities would promote positive social change. This limited participation in debate is also a key issue in the larger disability movement. The movement may see episodic, possibly tokenistic consultations with the state, but there are relatively few people with disabilities in legislative cabinet roles, judicial appointments or senior bureaucratic posts (Prince, 2009).

Likewise, participants also indicated that they would like to have greater access to community action plans, become involved in poverty reduction efforts and committees that have the power to make change. Some participants expressed a desire to "fight" the

system, but noted that they felt they needed some help and support to engage in advocacy efforts. Many participants indicated that they wanted to learn more about poverty reduction strategies and wanted to become involved in decision making processes, keeping in mind individual pace. Some participants said they would like to become involved in poverty reduction decision making at once, whereas other participants said they would like to “get to know” their local roundtable members before participating in these processes. Four participants said they would like to specifically raise awareness about disability issues within poverty reduction strategies.

Mostly, findings from this study suggest that participants want to meaningfully engage in debate on key issues that affect their quality of life and promote poverty reduction. Meaningful inclusion beyond mere involvement was a key message we heard from participants. Mark highlighted this distinction when he commented that he thought poverty reduction roundtables could learn from people with disabilities, saying that “they could learn from us and we could learn from them.” As such, it appears that many participants we spoke with do not want to withdraw from participation and debate about poverty, but indeed want to fight for their human right to economic security. This, however, requires recognition of discrimination, dominant ideologies and social forces within the third dimension of power: shaping interests.

### *Third Dimension of Power: Shaping Interests*

This third dimension of social power addresses the wider context of systemic elements that exist beyond (yet influence) the individual (Culley, 2004). Results from this study illustrate the effects of discrimination and the deficit-focused dominant ideology toward people with disabilities. Participants indicated that they may be discredited by the

myths and ideologies about their inferiority, but many did not express an internalized belief in these negative societal perceptions.

When asked about the statement: “Some people think that people with developmental disabilities are poor because they lack the skills and abilities to work and earn money”, all participants disagreed with this idea. In general, participants focused on the strengths and abilities of people with disabilities. This was exemplified in the variety of goals and expectations that participants shared with us, demonstrating that they desired a better quality of life and wanted to participate more meaningfully in society. Participants felt that they have the skills and abilities to work and earn money, but do not experience equal opportunity for employment. Participants expressed that attitudinal and environmental discrimination prevents their full participation in society.

Discrimination arose as a significant challenge to overcoming poverty. Various forms of discrimination and prejudiced beliefs were viewed, primarily, as a challenge or barrier to employment as a means to earn income. One participant said that he has experienced obvious discrimination when an employer blatantly discarded his application, whereas most participants indicated they felt discrimination was often used more covertly. This covert use of power took the form of prejudiced attitudes, lack of access to information on employment opportunities, lack of physical accessibility to workplaces and excuses about the high cost of workplace insurance and training. Thus, according to participants, overt and covert discrimination is used as an instrument of power to discredit and exclude people with disabilities from competitive employment. Elwan (1999) similarly noted that employment discrimination has been a recurring theme in much of the literature concerned with income-related aspects of disability. Based on

the findings from the present study, discrimination continues to be a critical issue and concern for people with disabilities.

Participants indicated that the dominant ideologies about their inferiority must be addressed and eliminated to support people with disabilities to overcome poverty. Several participants argued that in order to overcome poverty, increased awareness about discrimination and a shift in ideology toward the strengths and capacities of people with disabilities is essential. Increased participation in debate on key issues would support this objective as a means of demonstrating the skills and abilities of people with disabilities. Several participants conveyed that increased self-advocacy and pride among people with disabilities will support social change. Jeff, in particular, called out to fellow participants to join together for change and share their voices about the social injustice associated with poverty and disability. As such, participants indicated that people with disabilities must resist internalizing myths and ideologies about their incapacities and advocate for their right to economic security, equal opportunity and inclusion. Similar to the expressed desires of the participants from the present study, disability groups in Canada are involved in challenging dominant beliefs and practices about the supposed unemployable status of people with disabilities (Prince, 2009). These groups challenge the paternalistic view of people with disabilities as dependent and helpless, instead offering positive images of people with disabilities as capable of self-development and social contributions, entitled to the same rights and responsibilities as other Canadians.

Some participants noted that they want to “fight for more money” but need “help”, indicating that they are looking for support and allies to assist their efforts. Others indicated a sense of powerlessness and hopelessness to promote system change. Thus, it

is also important to consider the role of supportive allies for people with disabilities to overcome poverty, and create social change. Findings from this study identify family, friends and support workers as meaningful supportive people in the lives of participants. Several authors emphasize the need to be aware of the possibility of unfair shifting of responsibility to those who lack political power (Bradshaw, 2009; Collins, 2005; Lott, 2002). Hence, it is important for researchers and practitioners to share responsibility, and share their own power and accessibility to the policy and change process. It is too often the case that individualistic approaches to poverty reduction expect those with the least amount of power to create transformative change (Bradshaw, 2009). As such, we must be aware of unreasonable expectations on people with disabilities living with low income to work alone to create social change and reduce the poverty they experience.

Overall, results of this study demonstrate the effects of the three dimensions of social power on the lived experiences of people with developmental disabilities living in poverty in the Brantford, Hamilton and Waterloo region. The lived experience and consequences of poverty are characterized by a lack of resources leaving people vulnerable to overt control by others with greater resources. Challenges to overcoming poverty include discrimination, dominant ideologies about disability, and barriers to participation in community life, employment and debate about key disability and poverty issues. Thus, participants identified needs and recommendations for change focused on increasing the social power of people with disabilities in all three dimensions. This shift includes increased resources, increased participation and elimination of deficit –focused approaches, coupled with dissemination of the strengths-based approach to disability.

### *Contributions of this Study*

I will now discuss the contributions of this study in terms of theoretical and intellectual contributions, as well as practical contributions.

#### *Theoretical and Intellectual Contributions*

The present study reveals how the three dimensions of social power work together to affect the lives of people with developmental disabilities living in poverty. This study demonstrates the current imbalance in terms of these dimensions by giving a voice to the lived experiences of people with developmental disabilities in poverty. Results of this study demonstrate how these dimensions may be perceived by people with developmental disabilities and has made the power concepts that are implicit in their day to day lives explicit. Thus, the present study has demonstrated the utility and adaptability of the social power framework developed by Culley (2004) through analysis of the problem of poverty and disability.

The three dimensions provided a useful framework for this research. The social power framework was used to illustrate the problem of poverty and disability as an issue of power. Although much of the literature on poverty and disability implies that power plays an integral role in the lives of people with disabilities (Elwan, 1999; Lord & Hutchison, 2007; Prince, 2009; Yeo, 2001; Yeo & Moore, 2003), it has not been used as an explicit structure as I did in the present study. The framework supported the structure of this document, from literature review, methodology, process, and outcomes of the study. Research and interview questions were defined based on the three dimensions. This framework was also helpful in discussions with members of the Committee in understanding the effects of power in their lives and those of others with similar



experiences of poverty and disability. Moreover, the explicit discussion of power highlighted an important step of increasing social power for people with developmental disabilities in the Six Step Approach to Poverty Elimination.

Similarly, this study has contributed to knowledge about the general understanding of the lived experiences and key issues for people with developmental disabilities living in poverty in Brantford, Hamilton and Waterloo region. This study has also expanded knowledge on the participatory research process with people with developmental disabilities, from development of research questions, data collection and interpretation, dissemination and action planning. As a result, this study has countered the myths and ideologies about the inferiority of people with developmental disabilities by drawing attention to identified strengths and capacities for personal development and meaningful participation in society.

#### *Practical Contributions*

There are also several practical contributions of the present study. First and foremost, this study has contributed to identifying the needs and priorities of people with developmental disabilities living in poverty in Brantford, Hamilton and Waterloo region. This study has also identified gaps in poverty reduction strategies to include the voices of people with disabilities in their strategic efforts. In addition, this research has demonstrated a thoroughly inclusive participatory approach and laid the foundation for future research and action.

Generally, the needs and priorities identified in this study relate to the need for an increase in financial resources to fulfill basic needs, provide for children, and participate in community life. Participants identified discrimination, unemployment and

underemployment as primary causes of poverty that need to be addressed. In addition, income program policies and procedures were considered insufficient and posed challenges to overcoming poverty. As a result, participants indicated that they felt a lack of choice and control and exclusion from decision making processes to determine their personal finances. Participants suggested that these needs, priorities and challenges, as they relate to people with disabilities, should be an integral part of poverty reduction efforts. To do so, participants said they would like to be invited to actively participate in decision making processes in anti-poverty efforts. However, most participants did not know about their local poverty reduction roundtable, thus unable to participate due to lack of awareness.

The overarching purpose of this study is to support the development of poverty reduction strategies to meet the needs of people with developmental disabilities. This project has been successful in demonstrating its potential to support regional, provincial and national anti-poverty efforts. As this study was conducted in Brantford, Hamilton and Waterloo region, these findings are practically relevant for three regional poverty reduction roundtables. Over the past year, the Committee members and I have met and spoke with representatives from each of the local roundtables. We have discussed the purpose of this project and each roundtable has expressed an interest in learning about the results of our study and open to suggestions and recommendations to actively include people with developmental and other disabilities in their roundtable. As such, an important follow up piece of this study will be to present our findings back to the local roundtables and suggest ways to incorporate the needs and priorities of people with disabilities and suggestions for inclusion.

Poverty and disability are also being addressed as a national and provincial concern. Currently, there are several campaigns and advocacy groups focused on the issue of poverty and disability. Here I will discuss two broad initiatives as the results and implications of this research support these efforts. At a provincial level, the ODSP Action Coalition ([www.ODSPaction.ca](http://www.ODSPaction.ca), accessed Mar. 28, 2010) works to improve ODSP by lobbying politicians, making submissions to consultations on the budget or on poverty reduction, trying to get ODSP issues raised in the media, sharing information with recipients and agencies, providing input to the Ministry of Community and Social Services, and by networking with other groups with similar goals. The ODSP Action Coalition is a province-wide coalition of community disability agencies, provincial organizations, anti-poverty groups, legal clinics and people with disabilities on ODSP. As such, given the results of this study pertain to ODSP and poverty reduction, they will contribute to the efforts of this coalition by providing further evidence of the necessity for change. This study also provides knowledge of the theoretical frameworks and empirical evidence to support the recommendations and efforts of this coalition.

On a national level, the Council of Canadians with Disabilities (CCD) and Canadian Association of Community Living (CACL) in consultation with various disability organizations, experts and government officials proposed a national agenda for poverty reduction and inclusion of people with disabilities (Prince, 2009). According to Prince (2009) CCD and CACL recommended the federal government commit to several initiatives including “a study on poverty and disability, especially the income needs of persons with disabilities” (p. 221) and “engagement with the disability community and other governments in developing the agenda” (p. 222). This research study contributes to

these goals by presenting initial data on poverty and disability highlighting the income needs and priorities of people with developmental disabilities in three Ontario cities. Moreover, the present study provides a framework for engagement with people with disabilities and recommendations for inclusion in poverty reduction strategies.

In addition, documenting ways to include people with developmental disabilities in this research is a practical contribution to future research on disability issues. As previously discussed, this population has been excluded from research and poverty discussions in the past. However, by communicating to other researchers and anti-poverty activists that this type of inclusion is possible, I hope that this study will promote greater inclusion within academic processes of research and poverty reduction strategies. Publishing and presenting this project that involved people with developmental disabilities in a participatory manner will not only show other researchers that it is possible and important to include people with disabilities in research, but also that they can help guide, clarify and shape the research process. Therefore, a valuable contribution of this research is its demonstration that people with developmental disabilities have the right to control and participate in research that affects them. As I have just outlined several potential contributions of this study, it is, therefore, important to consider the validity of this study, which I will discuss next.

#### *Validity*

The present study has considered threats to validity from the beginning stages of the research process. According to previous literature, a recognized limitation of disability and poverty research is its lack of inclusion and practical application for people with disabilities (White, 2005). Through the Committee, people with developmental

disabilities have had an opportunity to control and direct the research agenda for the proposed study. They have been involved in the development of this research from establishing the research questions, to proposed methodology and ideas for action and dissemination of results. Therefore, the development has been based on issues and priorities of people with developmental disabilities living in poverty, and what they think needed to be considered in related research. I have been honest with the Committee in terms of personal goals for the research, Master's thesis requirements, and explaining possible biases as a person without a disability. These biases are merely a lack of experiential knowledge of the lived experiences of disability. I have recognized myself as an outsider, but also an ally (Fine, 1994), and as a result have asked people with developmental disabilities to work with me to provide insider knowledge and lived experiences as people living with disabilities and in poverty.

This process responds to Maxwell's (2005) specific threats to validity in qualitative research. He suggests explaining possible biases and how these will be dealt with as a key task of the research proposal, as well as understanding how the researcher influences the participant. As discussed above, I have addressed my personal goals and possible biases as a person without a disability thereby communicating these to the reader and reviewed them with the Committee members. Regarding the latter, I developed a script for focus group participants to express my values, goals, purposes and passion for the proposed study to recognize reflexivity in this process (Hammersley & Atkinson, 1995, cited in Maxwell, 2005). The present study primarily utilizes several tests of validity described by Maxwell (2005). Each of these will be described below in terms of application to the proposed study.

*Intensive Long-Term Involvement*

Becker and Geer (1957, cited in Maxwell, 2005) claimed that intensive long-term involvement with the community of interest provides more complete data about specific situations than any other method. This process provides more data that is direct and less dependent on inference. As noted above, I have been working with people with developmental disabilities for the past five years as a support worker in a disability organization. I have also been working with the Committee from the beginning stages of the research process and will continue through dissemination and action to rule out illegitimate associations and premature theories.

*Rich Data*

Maxwell (2005) refers to “rich” data as that which provides a full and revealing picture of the phenomena of interest. To meet these criteria, the present study conducted focus groups with people with developmental disabilities living in poverty in three separate regions, and provided verbatim transcripts of the discussions. As a further check on the data, a Committee member(s) was present at each focus group to provide additional observations and insights on the data collected. Based on relevant queries put forth by Mile and Huberman (1994) to assess internal validity and credibility, I have provided context-rich and meaningful descriptions to provide a comprehensive account of participant voices and the local context. Also, I have presented data in such a way as to link to categories of prior and emerging theory, particularly in terms of how the measures reflect the construct of power. Moreover, areas of uncertainty, rival explanations and negative evidence was sought for to provide further credibility of the findings.

### *Respondent Validation*

Maxwell (2005) notes that this test of validity is also referred to as member checks whereby feedback is obtained from the people you are studying. He argues that this is the “single most important way of ruling out the possibility of misinterpreting the meaning of what participants say and do...as well as being an important way of identifying your own biases and misunderstandings of what you observed” (p. 111). I have systematically solicited feedback from the Committee about data throughout collection, analysis, conclusions and dissemination to ensure validation. Maxwell cautions that this type of check-in is not inherently valid, but only evidence of validity. As such the present study utilized respondent validation in conjunction with rich data and long-term involvement as noted above.

### *External Validity/Transferability*

Based on relevant queries proposed by Miles and Huberman (1994), I have also assessed external validity and transferability of this research and have defined the scope and boundaries of reasonable generalization of this study. As this study was conducted with a small sample of participants in Brantford, Hamilton and Waterloo region, I have provided rich data and thorough descriptions to provide a potentially useful framework that could be adapted for future research on a larger provincial or national scale. This would provide more breadth to the findings and explore the dimensions of social power on a larger scale. Similarly, this research could also be repeated within a single location to provide a more in-depth perspective on regional issues. As such, the processes and outcomes described in this study are generic enough to be applicable in other settings. It

is also important to note that the findings of this study are congruent with, connected to and confirm prior theory and research related to poverty and disability.

#### *Utilization/Action Orientation*

As noted, a key component of participatory action research, and a primary goal of this study, is to promote transformative change, ultimately resulting in something of worth to participants (Richardson, 2000). In response to relevant queries (Miles & Huberman, 1994), the present study offers a high degree of usable knowledge. This includes consciousness-raising, the development of insight, and contributions to a theory that guides action based on social power, illustrated in the Six Step Approach to Poverty Elimination. This study has emphasized knowledge capacity development for members of the Committee, and participants, to advocate and promote social change and deepen their understanding of key issues. To do so, value-based and ethical considerations of the participatory approach have been raised explicitly in this research. As noted above, I have shared my personal goals and values, and ensured transparency of the research process for Committee members, participants and readers. Furthermore, the development of a plain language report of this study will be shared with other advocacy groups so that the findings will be intellectually and physically accessible to potential users. Other publications and presentations provide accessibility to the academic community and practitioners to benefit their efforts as well.

In conclusion, many efforts were made to strengthen the validity of this research and provide meaningful contributions to theory and practice on poverty and disability. There are, however, a few considerations that should be addressed in relation to specific aspects of this study.



### *Limitations*

As with any research project, there are a few limitations that require attention and should be noted. First, time constraints for a Master's thesis limited the breadth and depth of this study. For example, there was one focus group that included only two participants. Although, four participants were scheduled to attend, only two people were able to attend and participate. Due to time constraints to complete data collection, we included this as a group, particularly as one of the participants was an experienced self-advocate. There were also no significant differences between this group and the other groups.

There were some challenges associated with labeling people with a particular disability. As described earlier, we may not have had a strict sample of people with developmental disabilities, as some participants with other disabilities wanted to share their voice about their experiences. Also, during recruitment we encountered one occasion where a community organization representative requested we change our flyer to simply note that we were looking for people to share their voice about poverty and disability, rather than specifically noting that we were looking for people with developmental disabilities. Also there were times that we were unable to connect with self-advocate groups or organizations to recruit participants, such that some participants may have had fewer advocacy experiences than others. This affected some of the data as some participants were more aware of the concept of poverty, human rights, power and how these interact to affect their lived experiences as a person with a disability. In addition, the interview guide could have been more focused, with more prompts and clearer definitions of concepts for participants. Moreover, there were some limitations with the focus group process as we limited the amount of time for each discussion. This

time limitation was based on discussion with the Committee who suggested that we keep the discussions to a maximum of 90 minutes. As noted above, we limited the amount of time for each category of questions (lived experiences, barriers and action) to 20 minutes each. There were times when some participants could have talked longer than 20 minutes on a certain subject but were encouraged to move on to another topic. Thus, in future work I recommend also conducting individual interviews to allow more time for participants to share their personal thoughts and ideas. In addition, consensus coding was not utilized based on the Committee's choice not to participate in the coding process. However, consensus coding would have provided higher validity if Committee members chose to participate.

I am also aware that my values informed and may have strengthened how I did this research. I did strive to maintain critical reflexivity through discussions with the Committee, and journaling the research process, which I will discuss next.

#### *Personal Reflections*

I would like to add some personal reflections and a few insights I have gained as a researcher, as well as how I have personally been affected by this experience. My personal goal for this project was to conduct meaningful action research that has practical applications for key stakeholders. As a researcher, I have learned of the value and credibility of the participatory process. There were times, particularly during participant recruitment, that my personal goals were questioned by potential participants and service providers that we asked to support this research. A few service providers were skeptical to support this work as they were concerned about potential participants being "used" for data collection without any power over the research process or outcomes. Thus, in order

to address this skepticism and mistrust, it was necessary to meet with concerned individuals together with Committee members, or a local advocate from the community of Hamilton or Waterloo region. We did this to demonstrate the credibility of the participatory process and assure participants that we intended to continue to work together to promote social action and change. As such, I have learned that the participatory process is not just a choice, but a necessity when trying to gain community support, recruit participants, and demonstrate the value of inclusion.

The Committee members indicated that they were willing to contribute to this process because they wanted people to participate in this study and honestly share their thoughts and ideas. I found that the trust I had established with the Committee was clear to other people who were able to see us truly working together as co-researchers. In my opinion, involvement of the Committee members from the very beginning, from problem definition and setting the research agenda, helped promote their buy-in and yielded positive results later on in the research process. This, in turn, helped us to gain further support from potential participants and community organizations.

Each time I met with the Committee, I felt inspired and motivated. The Committee helped me relax and reminded me that we were doing was the “right” thing. I always felt re-invigorated by their passion and commitment to the project, as well as their excitement of learning about the research process. The Committee appeared to enjoy having the opportunity to travel and speak with other advocates to build momentum for social action and change. When I listened to the needs and priorities of the Committee members and participants, I found clear direction in the vision and values of this research. I started this process because I enjoyed my experience working with people with

developmental disabilities as a support worker but I have enjoyed this experience far more. I have had an opportunity to work with people outside the boundaries, policies and procedures of an organization. We set our own guidelines, developed our own vision, and conducted the study by the values that were important to us. I feel that I have learned a great deal about how I want to work with people in the future. I want to be a resource, an ally, and a support to people with disabilities. I want to stand beside and behind people, not in front of them. When I reflect on my early experiences as a support worker, I remember attending community meetings on behalf of the organization I worked for, as a representative of people with disabilities. I have since learned the value of working *together*, rather than working *for* people. I no longer wish to speak on the behalf of people with disabilities, but want to support them to speak for themselves.

Overall, I have very much enjoyed my experience. I was fortunate and honoured by the honesty and candor of the members of the Committee, as well as focus group participants. I noticed a change in how people interacted with me when I became an individual with a desire to make change, rather than a support staff associated with an organization. I saw a higher degree of openness and honesty, and began to truly understand the importance of inclusion. I did not realize the implicit authority and power associated with paid support staff, until the Committee members told me so. We truly worked together, as people who believe that the problem of poverty and disability must be addressed through inclusion. Our goal is to promote an anti-poverty agenda for people with disabilities to experience voice, choice and control in their lives. We intend to support this goal through dissemination and action that stems from this project. I wish to continue to guide my career by this vision. I hope to promote and encourage the need for

greater inclusion in communities, disability organizations and government. I hope that future research and poverty reduction strategies do the same. As such, I will now outline a few suggestions for future research and action.

#### *Future Directions*

There are several areas for future research focused on the issue of poverty and disability and the need for inclusion. First, in accordance with the proposed national agenda for policy reforms and social change put forth by the CCD and CACL, I recommend conducting a similar study on a large national or provincial scale. The present study serves as an example of participatory action research to address the income needs of people with disabilities that actively engages with the disability community. A larger scale project could incorporate the voices of many more individuals from rural and urban areas, thereby considering other systemic factors not addressed in this study.

Another possible area of research could examine poverty and disability from multiple perspectives, including family members and support staff for people with developmental disabilities to gain a more in depth understanding of the repercussions of poverty. Also, according to the results of this study, there appears to be a need to understand employer discrimination and employment issues to discuss possible solutions to this significant challenge to overcoming poverty. A poverty policy project that focuses on disability income support from the perspective of recipients and policymakers may also provide rich data to inform possible areas for poverty reduction. These studies may provide important insight on solutions, policies and programs that meet the needs of people with developmental disabilities (see also Fig. 1 Step 2)

*Dissemination and action plan.* This stage of the research will be determined collaboratively with the Committee. People with developmental disabilities as Committee members have played an important liaison role with other people with developmental disabilities, so that information can be widely shared for dissemination (Nelson & Prilleltensky, 2005). Some initial ideas have been put forth among the Committee including sharing a plain language final report with other self-advocate groups. Our focus group discussions with self-advocates in Brantford, Hamilton and Waterloo region have laid the groundwork for future collaboration and sharing of information for continued efforts toward transformative change. Furthermore, in accordance with the Six Step Approach to Poverty Elimination (see also Fig. 1), results of this study may be used for development of solutions to reduce poverty for people with developmental disabilities. For example, this research may be shared with the ODSP Action Coalition, CCD and CACL.

Other knowledge mobilization efforts have consisted of one printed publication (Buettgen, 2009), four academic conference presentations, one community presentation, and two more publications to be developed on the process and results of this study. To promote inclusion of the needs and priorities of people with developmental disabilities, the results will also be shared with poverty reduction groups and roundtables, such as the Brantford/Brant Roundtable for Poverty Reduction, and the Vibrant Communities initiatives in Hamilton, and Waterloo Region.

## Conclusion

Through this participatory action research study, I have learned a great deal about poverty and disability. This project has demonstrated the importance of working inclusively to represent the expressed desires and needs of people with developmental disabilities. In conclusion, I will discuss implications and future directions, as this work should not end with the completion of this study.

This study has contributed to knowledge on poverty and disability by identifying the needs and priorities for people with developmental disabilities living in poverty in Brantford, Hamilton and Waterloo region. This research has revealed how the three dimensions of social power work to affect and compound the lived experience of poverty and disability. Participants have had an opportunity to share their voice and have it heard through focus group discussions. Further knowledge mobilization, dissemination and action will insure that we reach a larger audience and raise awareness about their lived experiences, challenges and recommendations for change.

This study has demonstrated the worth and value of inclusion of people with developmental disabilities in the research process. It is hoped that the Committee members have provided positive role models for others to become involved in research, as well as promote researchers to provide opportunity for meaningful participation and inclusion. This research has identified gaps in poverty reduction strategies to effectively meet the needs and priorities of people with developmental disabilities. Participants have identified ways that they would like to be included in anti-poverty efforts as equal partners. Specific poverty issues and discrimination toward people with disabilities arose

as a significant challenge to overcoming poverty. These issues must be addressed for effective poverty reduction.

Implications from this study can be important in promoting preventive social programs and transformative social policy through inclusion of people with disabilities and increased awareness of disability issues as described by people with disabilities themselves. Recommendations for social programs can include increased resources in services that provide support for community participation and meaningful competitive employment to help prevent and overcome poverty. Advocacy efforts could also focus more on employer attitudes by promoting greater understanding about the strengths-based approach to disability. In regard to policy-related issues, participants made several concrete recommendations for change in income program funding. These included eliminating employment earning deductions, increasing asset limits, and standardized policies for all provincial income programs. Transformative processes should involve full inclusion of people with disabilities so that they have voice, choice and control in decisions that affect their lives.

Several participants said they would like to see greater recognition of disability issues within government, including more political representatives with disabilities. There also appears to be a need for greater awareness of the profound discrimination experienced by people with disabilities, as well as the unequal opportunity to gain meaningful employment, and exclusion from participation in decision making over the terms and conditions of income program funding. A key message from this study involves inclusion of people with developmental and other disabilities, in planning and decision-making processes for poverty reduction efforts in order to meet their needs and



priorities. As people with disabilities are disproportionately represented among the poor, these issues must be brought to the forefront of poverty reduction strategies in order to achieve their goals and eliminate poverty.

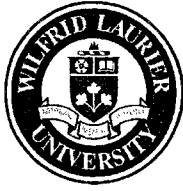
We must work *with* people, not *on* them. As such, researchers and poverty reduction strategists should join forces with people with disabilities to support poverty reduction efforts. Community psychologists can support the development and implementation of poverty reduction through research and practice. Ensuring full participation and inclusion, community psychologists can play an important role in this process through participatory action research approaches to the study of poverty. Participatory research can provide opportunities for people to come together with common conditions and concerns which make possible the confidence to plan and implement changes. In terms of practice, those who are educated in community psychology need to raise awareness of the problem of poverty and disability by listening to and promoting the voices of people with disabilities living in poverty. As the voices of people with disabilities are heard, their opinions will be seen as valuable; this value will be manifest in their ability to advocate for social change in the context of the rights and responsibilities of civic life and citizenship.

Thus, it is important to note how the larger disability movement and the desired new approach to disability issues relate to this study. As noted by Prince (2009) this new approach can be summarized as follows:

Rather than identify clients as recipients who are dependent and labeled “unemployable”, public programs should relate to clients as individual people, as participants with identifiable skills who desire independence and often work; and, in addition to providing necessary income support, have active measures to promote training and skills development, employment and volunteer

opportunities, and thereby enhance autonomy, participation, and well-being. (p. 204)

The voices of people with developmental disabilities that we heard in this study reflect this vision. Moreover, people shared with us that they want to be actively involved in making this vision a reality. They indicated that they would like support and are looking for allies to stand beside them in the fight for social justice and economic security. Let's work together then, to help overcome negative societal perceptions of disability and promote more effective poverty reduction and elimination.



## Appendix A

# Poverty and Disability: The Need for Inclusion

A student from Wilfrid Laurier University (WLU) and a group of self-advocates are inviting **people who have experienced poverty and labeled with a developmental disability** to share your voice about poverty and disability.

### *Why?*

To talk about how poverty affects people labeled with a developmental disability...why it's hard to get out of poverty...and what we can do to take action.



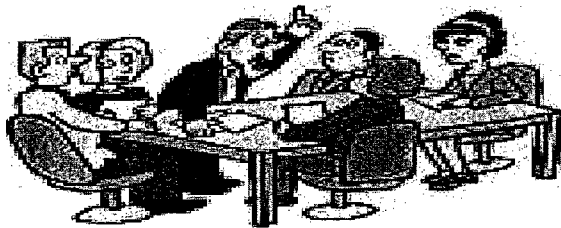
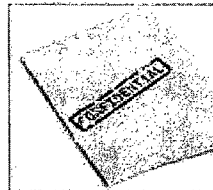
### **WE NEED YOU!**

We are looking for 24- 36 self-advocates and people 18 years or older to talk to us . . .

All information you provide will be kept strictly confidential.

### **How can you help?**

*Group interviews* (90 minutes) will be held during a scheduled time at a community centre in your area.



If you are interested please call Alexis Buettgen, WLU Master's candidate in community psychology at 226-338-1134 or email her at [a.buettgen@gmail.com](mailto:a.buettgen@gmail.com) and we will tell you more about the project and work out dates and times with you.

## Appendix B

### Recruitment Script:

I am a student at Wilfrid Laurier University, a Master's candidate in Community Psychology working with a group of self-advocates and we are inviting people who have experienced poverty, which means people who have little or no money, and labeled with a developmental disability to share their voices, thoughts and ideas about living with poverty and a disability.

We are interested in talking with people about how poverty affects their lives, why it is hard to get out of poverty, which means have more money, and what ideas people have about what can be done to take action!

We are looking for self-advocates labeled with a developmental disability, 18 years or older to talk with us. We are interested in talking with 24-36 people. All information that we hear from people will be kept confidential and private.

If you would like to talk with us about this topic, we will be holding focus group interviews in a community centre in your area in September and October 2009. These group interviews will take about an hour and a half. If you are interested in talking about this, I can tell you more about the project and work out dates and times with you.

## Appendix C

### Focus group with people with developmental disabilities living in poverty (90 min)

#### Set-up and Introduction (20 min):

- Ensure participant(s) have been explained and signed informed consent
- Materials needed: Flip chart paper, markers, audio recorder, snacks and refreshments
- Committee member(s) introduces themselves.

Thank you for taking the time to meet with me. I am Alexis Buettgen and I am a student from Wilfrid Laurier University. I am here today because I believe there are far too many people living with a disability who have to live in poverty. I believe that everyone has a right to participate fully in their community regardless of their differences.

To tell you a little bit about myself, I have worked with people labeled with developmental disabilities for about five years now in supported employment, supported independent living, young adults in transition and improving the quality of support services. Although I have been a support worker for a number of years, I am not here as a worker today. I am here as a student to learn from you. This is not an agency project and I am not being paid by an agency to be here. I am working with an advisory committee of people like yourself, and we have designed this project together, which is why we are also here together. \_\_\_\_\_ [Insert name of committee member(s)] is/are here to help me guide this discussion and may also ask questions.

Remember how I mentioned we break up our discussion into three parts? Well, as you can see up on the chart paper behind me, there are three parts to this discussion: experiences, barriers and action. As I mentioned, we will need to talk about each area and only have an hour here today to talk, I will be guiding the conversation so that we have 20 minutes to talk about experiences, 20 minutes to talk about barriers and 20 minutes to talk about action.

We are very interested in what you have to say about these topics whether it is positive, which means good, or negative, which means bad. There are no right or wrong answers. We are here to have a conversation so don't feel you just have to answer our questions. You can also talk to each other and follow up on something somebody else said. We are here to ask questions, listen, and make sure everyone has a chance to share. If we ask something, and you're not sure what we mean, please ask us to explain. We're interested in hearing from each of you. So if you're talking a lot, I may ask you to give someone else a chance. And, if you aren't saying much, please raise your hand and I can call on you to make sure you have a chance to talk, but I will not ask you to talk about something you are not comfortable with. I just want to make sure we have a chance to hear from all of you. But, you do not have to answer any questions that you do not feel comfortable answering.

You may see me writing some things down; this is just to help me remember important things you say so that I can follow up with that during our discussion. As I mentioned in the consent form, I am also tape recording this discussion, so, when the tape recorder starts you do not have to share your real name or other information that will identify who you are. I ask that you use pseudonyms during our discussion so that you are not identified. Pseudonyms are “fake names” that we should use here so that we can protect your identity.

Oh!! and please do not share with anyone else what has been said by others in the group today. Can we agree to that? Before I start the tape recorder, can we take a minute to do some introductions so that we know we have a chance to meet each other?

Round of introductions.

Ok, are we ready to begin? I’m going to start the tape recorder now.

**Recorded group discussion (60 min):**

- 1) When I think of poverty, I think of BLANK
  - a. Stimulate discussion and shared meaning of ‘poverty’ for the purpose of the focus group.
- 2) Let’s talk about how poverty affects you on a daily basis? What do you struggle with? What are some of the things you worry about?
  - a. Probe for resources: housing, transportation, food, child care, health
  - b. Probe for participation: employment, education, leisure activities
- 3) Some people think that people labeled with developmental disabilities are poor because they don’t have the skills and abilities to work and earn money. What do you think?
  - a. Do you agree with this idea? Why or why not?
- 4) What expectations, or goals, do you have for yourself?
  - a. Probe for: employment goals, personal development (e.g. skill and ability training), education goals, social roles
- 5) Let’s move on now to barriers. What makes it hard for you to get out of poverty? Probe for:
  - a. Probe for resources: money, status, assets, property, knowledge and information, social support
  - b. Participation and debate: Is there anything you are excluded from that makes it hard for you to get out of poverty and have more money? Probe for exclusion from social, political & economic life, poverty reduction strategies, research

- c. Myths and ideologies: How does discrimination and people's attitudes make it difficult to get out of poverty? Probe for: low expectations, deficit focus
- 6) We've talked now about the experiences of living in poverty and barriers to getting out of poverty. Let's talk now about action and what needs to change. So, we would like to know, what do you need to get out of poverty?
    - a. Probe for resources: money, status, assets, property, knowledge and information, social support
  - 7) Are you aware of (insert name of local poverty reduction roundtable)? If not aware, explain the purpose and activities of the roundtable.
    - a. What do you think of these programs or groups?
  - 8) How do you think you would want to participate in this group to lower poverty in your community?
    - a. How would you like to contribute? What would you like to do?
    - b. Probe for: merely inclusion or control over decision making
  - 9) Are there other issues about poverty that you would like to be involved with?
    - a. Probe for: advocacy, disability income support, community services that support people living in poverty, research
  - 10) As we wrap up this discussion, is there anything else you would like to share with us today?
  - 11) Thank you very much for your time, your thoughts and points of view are very helpful. Recording ends now.

**Debriefing (10 min):**

Informal discussion on the focus group between myself, advisory committee member and group members.

What did you think of the discussion?

How do you feel about what we talked about?

Do you have any questions or comments you would like to share now that the tape recorder is off?

Is there anything that we could do differently or better for another group?

I am going to give everyone a list of people to call if you would like support because of feelings you may be having about our discussion. I am also going to give everyone a copy of the consent form I read to you earlier so that you have information about this study and contact information. Please take these papers with you.

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