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**Disability and Poverty: Stories that Resist Attitudinal Barriers to Inclusion**

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**Abstract**

This ongoing project is about listening: listening to stories of impoverished disabled peoples' lived experiences of exclusion. The project embraces Emancipatory Disability Research (EDR) principles and is grounded in a human rights framework. The project objective is to understand how attitudinal barriers such as stigma and discrimination impact the (lack of) social inclusion in Canada. In-depth interviews were conducted with eight individuals who live with various conditions such as poverty, bi-polar disorder, fetal alcohol spectrum disorder, diverse mobility needs, intellectual diversity, Asperger's syndrome, etc. Stories were audio-recorded and transcribed. Qualitative thematic and content analysis incorporated all story content; derived results include key emergent themes. Results to date indicate that social inclusion is currently linked to the obstruction of individual ability (inability) to scale attitudinal barriers or 'walls' to full participation in Canadian society. Research participants (co-researchers) lived experiences of exclusion encapsulate stigmatization and oppression from others as well as rejection of self. This ongoing project has begun to highlight the dire need to question normative understandings of social inclusion and how those understandings of citizenship violate human relationships in Canada.

**Key Words**

disability, poverty, attitudinal barriers, social inclusion, emancipatory disability research, rights

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## Disability and Poverty: Stories that Resist Attitudinal Barriers to Inclusion

### Introduction

*"I think I am hiding something, I am using my humor as a back-up. I hate reality is as it is. Reality is the way it is for all of us. Reality is how we make it so and I am not a happy camper so I am not making it. What I want to do in society is be able to live with it; I want to be able to do things that I would like to do, like get the family back together, step by step, also to be able to remember things. I am disabled because of my lack of memory and my lack of responsibility and I am not disabled because I shouldn't because I shouldn't think about being disabled."*

(Co-researcher, Traci, talking about disability)

*"Disability is being different. I am normal but different. Some people think they are better than others. People should be treated the same, no matter what is wrong with them, everyone is the same."*

(Co researcher, Marc, talking about disability and attitudinal barriers)

*"If I didn't have the wall, ADHD, FASD [Attention Deficit Hyperactivity Disorder; Fetal Alcohol Spectrum Disorder], I would be quite intelligent. It is important to be smart. I am trying to break through [the wall]. I try to be confident because people said I would fail. I know I do have a disability or something to that effect but I don't see myself as disabled."*

(Co-researcher, Logan, talking about disability and attitudinal barriers)

This paper shares some findings from an ongoing research project that embraces Emancipatory Disability Research (EDR) principles and is grounded in a human rights framework. The project objective is to understand how attitudinal barriers such as stigma and discrimination impact the (lack of) social inclusion for poor disabled people in Canada. In conjunction with Article 1 of the Convention on the Rights of Persons with Disabilities (CRDP), this research's objective is based on the transformative aim of emancipatory disability research, which is "the empowerment of disabled people through the transformation of the material and social relations of research production" (Barnes, 2003, p.6), specifically, barrier removal and individual and collective empowerment (Zarb, 1997). In this ongoing project, the definition of 'disability' is understood, "as experiences from attitudinal and environmental (structural) barriers that result in exclusion from participation because of bodily differences or body forms" (Stienstra, 2012) and as "a process of meaning-making that takes place somewhere and is done

by somebody (Titchkosky, 2007, p. 12). For the purpose of this project, a lack of social inclusion is defined as, “a disintegration from common cultural processes, lack of participation in cultural activities, alienation from decision-making and civic participation, and barriers to employment and material resources” (Reid, 2004, p. 3).

Current global understandings of social inclusion are at risk of reflecting an ideology that is based on taken-for-granted ‘standards of normalcy’ parameters or benchmarks situated within mainstream societal values and lifestyles (Cobigo, Ouellette-Kuntz, Lysaght, & Martin, 2012, p. 77). Social inclusion benchmarks based on ‘standards of normalcy’ reinforce market-driven values of economic productivity and independent living that only serve to powerfully exclude ‘the already excluded’ such as disabled people (Cobigo et al. 2012), but that are paradoxically also powerful enticers (Levitas, 2005; Titchkosky, 2007). Disabled people, those already excluded, are enticed to strive for social inclusion based on taken for granted ‘standards of normalcy’ in order to be productive (i.e. a paid job) and to live independent of state support. Striving for inclusion can lead to further exclusion and self-rejection because ‘standards of normalcy’ benchmarks act as barriers to inclusion for disabled people. In March, 2010, Canada ratified the United Nations Convention on the Rights of Persons with Disabilities (CRDP) with the exception of reserving Article 12 (equal recognition before the law). With its signature, Canada has pledged to protect, promote and advance the rights of disabled people. Article 1 of the Convention on the Rights of Persons with Disabilities (CRDP) states: “the purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promote respect for their inherent dignity”. Although most Canadians are likely aware that all Canadians have the same rights as those stated in the CRDP, current understandings of social inclusion that are based on

impassable 'standards of normalcy' benchmarks ensure that we as disabled people will continue to be subjected to "violations of human dignity"(World Report on Disability, 2011).

I argue in this paper that because social inclusion has 'perform to norm' parameters such as acquiring a paid job, poor disabled Canadians face oppressive violations of human dignity, attitudinal barriers and exclusion from full participation in society.

### **Social Inclusion and Human Rights**

As Canadians, we are recipients of statistical interpretations of complex social situations. A statistical interpretation of our lives situates some of us in places of exclusion where conditions such as disability and poverty are both exemplified and amplified to matter (Overboe, 2009, pp. 80-83). Statistical information projects the conditions of poverty and/or disability as 'causes' of social exclusion (Levitas, 2005), as something that resides within the individual that needs to be held accountable for some reason to someone. This statistical information is informed by ideas of 'normal' human standards that establish evaluative parameters to measure social inclusion. Statistical information based on predetermined societal norms and standards compares poor disabled persons with non-poor non-disabled persons. Conditions of poverty and disability are statistically presented as 'performing below norm' or 'functioning below average'. Examples of this type of statistical information are: 25% of disabled Canadians are living in impoverished households; further, that an impoverished disabled woman will survive on less than 50% of what an impoverished disabled man would in Canada (Dawn-RAFH Canada, 2010). In addition, "The poorest people in this country [Canada] are women and children with disabilities"; 75% of adult Canadians with intellectual disabilities who do not live with families are living in poverty (House of Commons, Federal Poverty Reduction Plan, Canada, 2010, p.33).

According to Statistics Canada, disabled Canadian women and children are more likely to live in poverty than non-disabled Canadian women and children. In addition, statistical information indicates that Canadians who live with an 'intellectual disability' and who do not live with a family member are more likely to live in poverty than Canadians who live with an 'intellectual disability' who do live with family.

We are advised that one third of Canadians who are homeless, many of whom are women, live with mental health conditions (Haniff-Cleofas & Kehdr, 2005, p. 3). Further, women, are potentially at risk of developing emotional problems due to multiple factors: “Limited participation in public life, restricted decision-making, devalued role expectations, poverty, violence and sexual abuse undermine the potential for emotional well-being” (Canadian Mental Health Association, 2012 (b)). For all Canadians with mental health concerns, the loss of resources such as income, employment and housing can increase the risk of diminished mental health or even relapse of mental health concerns, and enable a life of ongoing chronic poverty and ill health (Canadian Mental Health Association, 2012 (a)). Canadians with severe mental health concerns or urgent needs with substance abuse histories or ongoing issues of homelessness, often overshadow the needs of other Canadians with physical, developmental and/or mental disabilities (Wellesley Institute, 2012, p. 20). Statistical information about Canadians situates the disabled and poor on the exclusionary fringes of society that leave poor disabled people open to ongoing oppressive evaluations of individual disadvantage and moral relevancy (Terzi, 2009).

In Canada, the statistical information that describes how Canadians fit within ‘perform to norm’ parameters supports a neo-liberal understanding of social inclusion that inherently equates full participation in society with quantifiable indicators such as attachment to the labour market

(Levitas, 2005). One must question, how can a society support civil, political and social equality if social inclusion is firmly entrenched in something like waged work? According to Levitas (2005, p.128), when attachment to the labour market is designated as a primary indicator of social inclusion in society, then employability becomes an obligation, a duty for all citizens to achieve, rather than as a human right to economic well-being. Full participation or inclusion in society is relegated to the responsible participatory power of the individual (Titchkosky, 2007, p. 148) to acquire the necessary skills in order to attain a paid job; being outside of the paid workforce is to be considered socially excluded. Such a situation may indeed lead to forms of social exclusion; yet waged work is not and should not be (or be posed as) the only pathway to social inclusion.

Current global understandings of social inclusion that focus on an inherently 'economic' aspect of inclusion (i.e. paid job) ensures a shift of the social inclusion agenda away from human rights and equality as the "highest level of social inclusion in all aspects of life appears unattainable" (Cobigo et al. 2012, p. 79). In essence, social inclusion is confined within parameters that focus on 'normal' expectations of individual economic productivity levels. A taken-for-granted 'normal' expectation for full participation in society intrinsically manifests itself through exclusion and marginality: an expectation that we as disabled people are seduced into thinking is the only viable mechanism to attain full citizenship (Titchkosky, 2009, pp.46-48). Attitudinal barriers to social inclusion are thus substantiated via an assumed 'standard of normalcy' that ensures exclusion and denies economic, social, cultural, civic and political rights.

## **Emancipatory Disability Research Principles**

This paper describes an ongoing research project (purposive, snowball sampling) that includes Emancipatory Disability Research (EDR) principles (Barnes, 2008). EDR principles reflect critical disability theory that examines powerlessness and context. Not only is disablement about issues such as impairment and functional limitations but also about issues of social values, institutional priorities, and political will; how Canadian society understands who and what is valued, and who is, and when one is, socially excluded. Critical disability theory maintains that all persons with disabilities are entitled to equal access to all aspects of social life and to key sites of power such as the site to employment (Barnes, 2003). Exclusion from critical sites such as employment has negative implications for other social aspects of life such as housing, transportation, leisure, education and other community involvement (Galer, 2012). Exclusion or lack of full participation in society can also impact one's identity, self-worth and mental health (Canadian Mental Health Association, 2012 (a)).

In addition, critical disability theory is contextual in the sense that knowledge is garnered from the lived experiences of people with disabilities. It is a "form of embodied theory" (Pothier & Devlin, 2006, p. 15) that looks deeply into the contexts of inequalities based on disability. Although human rights and equality are an integral element of critical theory, Meekosha and Shuttleworth (2009) believe that equality and human rights are grounded "...in a more general understanding of human protest of suffering, and human need for both autonomy and social participation" (p.52). Kalyvas states that the issue of what actually constitutes 'autonomy' and its 'relation to social participation or inclusion' is an ongoing debate (as cited in Meekosha & Shuttleworth, 2009, p.53). Thus, a critical perspective of disability "...means being able to see beyond the status quo, looking beyond symptoms and labels, seeing the reality of people's



situations, and understanding how they are linked to attitudes, policies and systems” (Lord & Hutchison, 2007, p. 14).

Emancipatory disability research (EDR) has four principles: 1. accountability, 2. social model of disability, 3. choice of methods, and 4. empowerment. The first EDR principle of ‘accountability’ requires that the research be accountable to those with disabilities. In this project the principle of accountability is addressed because the co-researchers live with many conditions such as poverty, mobility needs, asthma, drug and alcohol addiction, bi-polar disorder, Asperger’s syndrome, fetal alcohol spectrum disorder (FASD), intellectual diversity, attention deficit hyperactivity disorder (ADHD), and acquired brain injury. As Zarb (1992) notes, increasing participation does not constitute emancipatory research: those with disabilities must all control the research and decide who will be involved and in what ways (p. 128). Macbeth (2010) states, ‘insiders’ are those with disabilities, while, all others, regardless of expertise, connection or allegiances in the disability field, are considered, ‘outsiders’. Emancipatory disability research has been criticized in the research community because of its emphasis that those with disabilities ‘must control all of the research’ (Zarb, 1997, p. 128). McColl, Adair, Davey, & Kates (2013) suggest that emancipatory disability research can include both ‘insiders’ and ‘outsiders’, and still “...satisfy the ideological principles of emancipatory research” (p. 75).

For the principle of accountability, it is important to locate my - self in this project because ‘...positionality, storying and re-storing ourselves comes first’ (Absolon, 2011, p.13). In this project, I position my - self as a disabled person conducting (learning to ‘do’) emancipatory disability research. I am a white, middle-aged, middle class, heterosexual, educated disabled women speaking about poor disabled men (two are First Nations) and one poor disabled woman. I am disabled because I live with a ‘physical congenital impairment’: a little left arm that

narrows into a tiny thumb with no fingers. In this research, it is my intent to be accountable for my critical analysis and for my conscious and responsible use of power to the co-researchers and to myself (Reid, 2004).

Because I am perceived to be an ‘insider’ to disability, I was afforded some degree of social proximity with the co-researchers in this project. However, being a disabled person does not mean that my research will not be oppressive (Stone & Priestly, 1996). As a disabled researcher, I must be vigilant to minimize the risk of any conscious or unconscious abuse of my power as a researcher. Indeed, this ‘insider’ status has also allowed more awareness of the social dimensions that exist between me and the co-researchers (Devanira & Scott, 2006). Thus, I am painfully aware that my representational efforts (Reid, 2004) to share the co-researchers’ experiences in this project are partially restricted to my values, assumptions and worldview.

The second EDR principle, the social model of disability, focuses on the attitudinal and environmental barriers that disabled people face in their daily lives. Embracing a ‘social model of disability’ in ‘disability research’ must focus on the barriers (i.e. attitudinal such as stigma and discrimination) in society that result in the social exclusion of disabled persons (Deb, Duggal, & Sarkar, 2002). Initially disability research utilizing a social model of disability focused on the structural aspects of the social and material circumstances that disabled persons experienced (Barnes, 2001). Analyses focused on the structures and processes that were associated with discrimination and exclusion, at either policy or state levels or at individual relations in order to develop understandings of the ways that society ‘disables’ individuals with impairments (Oliver & Barnes, 2012, p. 164).

In addition, the social model of disability critiques the idea of normality with regard to average human functioning. There is some debate around this critique of normality since needs

and services are determined based on ‘abnormal functioning’ from a predefined norm (Terzi, 2009, p. 90). In broadening the critique of ‘normality’, Morris (1991) asserts that disabled people do not reject the differences that are important to their identity but that they do reject the meanings that the non-disabled world attaches to disability (p. 15). However, given the stigma and discrimination directed at anyone who falls outside of ‘normal’ parameters and thus faces social exclusion, I believe that the critique of ‘normality’ has relevance for this project.

In the last 20 years there have been growing debates on the influence of social model thinking. Oliver and Barnes (2012) suggest that too much time and text has been devoted to the merits or (dis) merits of the ‘social model of disability’. They suggest that too many individuals use this model as a theory, explanation or definition and too many agencies, governments, charities, etc. promote the ‘social model of disability’ without making significant changes to their practices. For many academics, this model now represents the wrong direction or is counter-productive rather than being a symbol of resistance. For others, the ‘social model of disability’ is a “...useful tool...” that can be used to raise awareness of discrimination and exclusion (Peters, Gabel & Symeonidou, 2009, p. 544). This ongoing project reflects a ‘social model of disability’ because it focuses on the attitudinal barriers of stigma and discrimination that result in the perpetual exclusion of disabled persons in society.

For the third EDR principle, the choice of research methods must give ‘voice’ to participants. This project utilizes semi-structured in-depth interviews: a method that the literature suggests does give 'voice' to participants.<sup>1</sup> In-depth interviews are also important in order to begin to build a place of trust. Rojas and Sanahuja (2011) suggest that ‘giving’ voice to often perceived ‘hidden’ populations such as poor disabled persons may be instrumental in moving

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<sup>1</sup> The in-depth interviews are part of a larger ongoing study that includes digital stories.

them from a place of exclusion and invisibility to a place of inclusion and visibility. Although the co-researchers did not initiate this project, each co-researcher was invited to share his/her thoughts and ideas of 'how' this project should unfold and move forward. No one had been involved in a research project prior to their participation in this project. The co-researchers 'voices' slowly evolved and magnified as the project unfolded. I will share a few of my journal entries of the project that suggests an evolving journey for me as a researcher as I discovered that one does not actually give 'voice' to someone else, as one's voice is a gift to give, not to be given. *"I was painfully aware of the power differential, of how these individuals are controlled by so many facets. Did they see me as a 'leader'; was I running (leading) this show? I was; how do I instill a sense of ownership or at least a partnership? Ownership would entail each participant's input on how we should proceed. I offered my suggestions, asked for theirs; the response was, 'that is good for me' or 'I'm okay with that'. What if you never get to be the leader? What if no one asks you what do you think? How removed would you be from being an equal participant?"* (Reflective Journal, August 9, 2011).

Several months later as the research process was unfolding and a sense of trust and camaraderie began to permeate our relationships, Marc, a co-researcher, and I had gone for coffee and were talking about the research project. My reflective journal entry suggests a move towards me letting go of power and control and thus, opening a space for other voices: *"I asked him if there was anything that I should do differently in the project that would make it better, he [Marc] sucked in his breath and said, "you did okay"* (Reflective Journal, December 15, 2011). I knew from Marc's response that initially I had struggled ( i.e. not done okay) as a guiding researcher but that through time, I was able to 'be' in the research in an acceptable (i.e. okay) place that enhanced rather than inhibited relationship building and knowledge construction with

the co-researchers. I was grateful to have a relationship with Marc and grateful knowing that I had a lot to learn about how to listen, to let go of power in order to “do” emancipatory disability research. I was beginning to understand how each co-researcher discovers his/her own way of researching (i.e. giving voice) and that re-search finds its destination given time. As the guiding researcher in this project, my hope is that I will be useful in supporting the co-researchers in their own ongoing discoveries of re-search and giving ‘voice’.

The last EDR principle is ‘empowerment’. According to Barnes (2008), empowerment is “...defined in terms of revealing social barriers, changing perceptions of disability, and generating political action” (p.9). Empowerment has nothing to do with me empowering the co-researchers; it has everything to do with me letting go of the control of the research process and findings, of listening deeply, in order to free the co-researchers in their journey to address the oppression and exclusion that they experience when their human dignity is continually assaulted (Tregaskis, 2004). The research team has evolved into developing and controlling the research agenda, including data collection, data analysis, and eventual dissemination of findings. In addition, they are currently working on the design of a website, with the assistance of a website designer, that will introduce the co-researchers, share project findings and will be a place for others to share insights and ask questions. This website will be a first step towards revealing the attitudinal barriers to inclusion that co-researchers experience through the sharing of personal stories. This website, a potential social gathering place, will hopefully facilitate change in perceptions about disability and create a catalyst for political action.

## **Methods**

The objective of this study is to understand how attitudinal barriers influence the (lack of) social inclusion of impoverished disabled Canadians. Ethics approval for this study was granted from the University of Regina, Research Ethics Board. The sample (purposive and snowball) is ongoing. Recruitment letters were shared with case managers of an institution for homeless men as well as were posted in the institution. Recruitment letters were also shared with various community members who had a relationship with poor disabled individuals. If an individual wished to volunteer for the study, she/he could contact me directly. If individuals did not have access to telephone or email as those in the institution did not, then a case manager would contact me in order for me to meet with the potential study participant. Potential study participants or co-researchers could either meet with me individually or meet with me with their support person (i.e. case manager or parent). In this paper, the combined analysis of eight co-researchers' data will be presented. Individual ages ranged from 21 years to 58 years (7 males , 1 woman) with a mean age of 38 years.

In-depth interviews took place in my office at the University of Regina during the morning or afternoon on a week day. Interviews were audio-recorded and transcribed. Although I offered to begin the process of story telling at a place of their choosing, all of the study co-researchers stated that they were comfortable in meeting me in my office, and indeed, preferred to do so. Due to lack of transportation for some co-researchers, I transported six of these eight co-researchers to and from my office. The average length of time spent with co-researchers was three and half hours: two interviews or story telling sessions for each co-researcher. This length of time does not include preliminary meetings to discuss the research project with the co-researchers, the time chatting during the drive to and from the university for the purpose of

conducting the interviews, or the time chatting during coffee or lunch outings. In addition, time was spent with co-researchers in reviewing and acknowledging their data.

Prior to the data collection (interviews), I met with the co-researchers: some as a group (five who lived in an institution for homeless individuals) and three individually (two lived with parents and one had parental support and lived in supported housing) in order to explain the research project and how co-researchers could be involved in the study. I offered to speak with each potential co-researcher separately but this group of five initially wanted to meet with me as a group. All subsequent time, including time spent reading through the consent form with each person was completed on an individual basis. In addition, individuals who lived in the institution had the support of their case managers whom they trusted and relied on in the sense that their institution had given ethics approval for the research, and provided co-researchers with the support of their case managers for the duration of the project.

Two individuals with parental support, one living at home and one in supportive housing, attended the first meeting with their parent and/or had ongoing communication with me during the research process. I met the mother of a third individual when I visited this individual at their home; there was no further communication with this individual's mother after this individual agreed to be a co-researcher in the project. All of the parents were concerned about their adult child's 'safety' in the sense of vulnerability within the research process and voluntary informed consent. Co-researchers affirmed that building trust before and during the interview process was critical so they [co-researchers] could '*trust what I [guiding researcher] would do what I said I would do*' (Steve).

Another co-researcher said "*I have to trust someone. I got so I couldn't trust anyone. I trusted you would do what you said you would do with my stories. It took me all week to write it*

*[ story] because it was really hard [emotionally]. I would wake up early in the morning and write a few sentences at a time”* (Steve). When Steve read his story, his hands shook, and he had to start over a number of times because of the emotions (sadness, anger, overwhelmed, fright) he felt as he began to read and share his story with me. During his childhood, Steve had experienced severe childhood adversity: ‘abuse, neglect, chronic poverty, family dysfunction and family addiction’ (Hertzman, 2013). Steve trusted me with his deepest most troubling and painful story. Steve said to me, “ *I have a story, if I share it, you will only be the 6<sup>th</sup> or 7<sup>th</sup> person to hear it.* ” “For many disabled people, the status quo is isolation, invisibility, and dependence. Their identity is defined by others.....” (Mount, 2002, p.146). Prior to creating his digital story with me, Steve had shared his story with his case manager where he lives. After Steve created his digital story, he also showed his case manager his copy of his digital story. His case manager told me that after sharing and creating his story with me, Steve seemed to be more content and caring towards others and his environment. It seems that no matter how well meaning the case manager was in sharing his observation of Steve with me, Steve's identity, as Mount (2002) suggests, was being encapsulated within the confines of normalcy. This is troubling as there are many levels of blinders, well-meaning or otherwise, that lock our perception of others into places of continual exclusion. Steve knows who he is; the rest of us (disabled and non-disabled) must recognize that his identity is his to share with and define to others.

Each co-researcher was given a stipend for giving their time and sharing their stories during the interview process. All of the time spent with each co-researcher, including the story sharing time, was important in building a sense of comfort with one another as our relationships began to deepen. I felt that we developed a comfort level with one another that invited increasing depth to our story sharing. When one of the co-researchers broke down and began to weep while



telling his story, stating, "I can't believe that I told you that. I have never told anybody that story before" (Kelly), we were both surprised and overwhelmed, that we had indeed reached a comfort level of such depth. The following 'questions' were asked in the semi-structured interview format in order to initiate the process of story-telling: 1. Please describe what it is like to be a person with an impairment, 2. Please describe activities that you do, 3. Please describe activities that you would like to do but can't do, 4. Please describe what kinds of things or barriers that get in the way or stop you from doing the activities that you would like to do but can't, and 5. Please describe what you need in order to do these things.

As the guiding researcher in this project, I had to examine my lived experience with disability. As Titchkosky (2007) suggests, if I want others to examine their awareness of disability, then I must lead by example. Due to the gentle resistance of the co-researchers, I realized that my lived experience of exclusion and stigmatization from others who had defined me in relation to taken-for-granted (non) normal functional parameters and (non) normal body forms was initially confining the project to 'normalized' expectations rather than to citizenship possibilities that value disability (Titchkosky (2007)). Co-researchers were immersed in the medical community (e.g. therapy, drugs); they did not want to share medically perceived limitations; they wanted to share infinite possibilities. As one co-researcher said, "*I need to tell my story. Psychiatrists and psychologists just prescribe medication*" (Kelly). Another co-researcher shared what his role in the research had taught him about his abilities: "*Even though I am different, I can do stuff*" (Marc).

The co-researchers told me that they did not like the word 'impairment' in the first question. "*I do not have an impairment.*" (Steve). The word, 'impairment' was changed to 'differences' with agreement from all of the co-researchers. The co-researchers did not 'see'

themselves as disabled or impaired; they were not comfortable with societal parameters of disabilities informed by 'perform to norm' standards, thus creating negative identities. "*I know I have a disability or something to that effect but I do not see myself as disabled*" (Logan). In addition, (Vinney) felt that being diagnosed with a disability (*fetal alcohol spectrum disorder*) that he referred to as 'it' was not helpful and his life was worse after 'it' appeared: "*Um, I got it when I was...well, I heard it I guess. I don't know. I heard about it when I was diagnosed at age 14, and having it, uh, gave me struggles with reading, spelling and other things. Um, it has put me in trouble. Yeah.*"

## **Themes**

Qualitative thematic and content analysis incorporated all interview content. Data analysis revealed several key walls or themes linked to attitudinal barriers, disabilities and poverty that co-researchers felt were impeding or denying their ability to fully participate in society. In this project, attitudinal barriers were negative assumptions and stereotypes imposed upon disabled people by others. The key themes or walls were stigma and discrimination, loss of control or the loss of opportunity to pursue personal goals and the struggle for self-acceptance. These walls were not mutually exclusive and appeared to be interlinked in a complex relationship with one another. One of the co-researchers (Logan) talked about a wall (ADHD, FASD) that he lived with. The word 'wall' was a good fit for describing the key themes as it evoked images of exclusion and division for Logan.

All of the co-researchers experienced the wall of stigma and discrimination. Discriminatory attitudes were experienced in the form of hurtful name-calling which resulted in feelings of rejection and self-induced isolation or exclusion to avoid further abuse. Those without

disabilities were perceived as *“people who don’t really care. Some people think they are better than others”* (Marc). Co-researchers mentioned ‘labels’ and negatively held images and stereotypes that were associated with those labels. Trying to manage the abuse of name-calling with the use of negative labels was difficult and increased the likelihood of further exclusionary behaviors from others towards them. As one co-researcher stated, *“Some people think like a label, like you are ‘r-word’* (original word has been removed as this word is offensive to people with intellectual disabilities); *you might be a smart person, but they just think, ‘r-word’*. *Everyone is so busy calling me ‘r-word’; they can’t see how intelligent I am”* (Marc). Others talked specifically about stigma and assumptions: *“Stigma is always with me. People have my file or have heard about me”* (Kelly). *“Sometimes it is how others see you. Sometimes people have an idea in their head. They jump to conclusions”* (Traci). And, *“because of my walk or gait, they [others] automatically think I can’t do something because I am slower”* (Marc). And, (Vinney) talked about being told he was not ‘normal’ for his age, *“...for my FAS, I have like maybe, um, a slower mind, I guess. Um okay, I was like...how old was I? I was 14, and they said I had like a mind of like, um, a 11 or 12 years old. Yeah”* and how he felt *“more slower”* after this information was given to him. *“I don’t know. I felt ‘r-word’* (original word has been removed as this word is offensive to people with intellectual disabilities) *Yeah. So I’m like 25, so I could like be having the mind of a, I don’t know, maybe younger”* (Vinney).

Loss of control or the loss of opportunity to pursue personal goals was another wall. For example, when trusted others did not support or teach participants how to navigate bureaucratic systems, personal goals, such as pursuing an education or getting a job, were understood to be unobtainable and inaccessible. One co-researcher stated: *My case manager and bio-mom have been under-confident. They say I will fail [attend school]. I don’t know how to register. I can’t*

*receive student loans because I live at the [institution]*" (Logan). In addition, there seemed to be a sense of futility and exclusion associated with the loss of control. *"My life is going nowhere but I can't change that. What I want to do never happens"* (George). Another co-researcher echoed similar strains of futility, *"You can't really do what you want. I want to work in film. I may not be able to do what I want"* (Marc)."

The last wall was the struggle for self-acceptance; co-researchers felt that their various labels of disability obstructed their ability (inability) to negotiate their full participation in society. Co-researchers focused on their emotional, intellectual and physical abilities expressing frustration, a wish to be intelligent and the struggle for acceptance of self and from others. *"My mental stability. I need help with that. I want to be able to remember things. I should carry a book and write things down. I forget everything. It is totally frustrating. I can't remember your name"* (Traci). Another co-researcher stated *"I have trouble voicing what I have to say. I forget things easy. If I didn't have HDHD and FASD, I would be smart"* (Logan). And *"others finally convinced me I am bi-polar. My son doesn't want his friends to know I am bi-polar and a bum--- afraid he might get it too"* (Kelly). And *"People, who are not special needs, are not nice. They talk okay; sometimes they talk too fast, not like we are"* (Jana). *"I have watched like other people, how they talk and stuff, but I don't. Then the scaredness come in because I don't know what to say or how it's going to come out or if I am going to mess up any of the words or the sentence"* (Vinney).

### **Summary comments**

Co-researchers in this ongoing project have all experienced attitudinal barriers to social inclusion in Canadian society. Attitudinal barriers include stigma and discrimination: issues such

as avoiding or excluding disabled individuals from relationships and activities, and derogatory hurtful remarks and/or uninviting stares from non-disabled individuals who perceive they were better able-bodied/able-minded than the co-researchers. These types of attitudinal barriers exist in Canadian society because of 'perform to norm' exclusionary parameters that deny full participation and enable a lack of understanding, awareness, and acceptance of the unique presence and perspective that each disabled person brings to relationships and to citizenship possibilities. Differences in minds and bodies are perceived as limiting and negative, aspects of personhood to be shunned and ridiculed rather than celebrated (Withers, 2012). In addition, attitudinal barriers such as these are particularly difficult for impoverished disabled persons who are often stereotypically referred to in Canada as 'bums' (Traci), persons who are supported with social assistance. Employability is currently indicative of full participation or inclusion in society; economic well-being is not considered a right but an obligatory duty for citizens to achieve through gainful employment. The stereotypical notion of a being a 'bum' in addition to being perceived as 'limited' or 'functioning below norm' in body and mind further compounds the volume of prejudicial assumptions and discriminatory abuse heaped upon poor disabled Canadians.

Of particular note in this study is the need for co-researchers to be seen as 'smart' (Marc) and not 'more slower' (Vinney) because for them, not being perceived as intelligent enough was something that triggered further negative discrimination from others. Many of the co-researchers experienced intolerably hurtful feelings around the negative discrimination directed towards them and their intellectual abilities, and the need for acceptance that rejected normalcy. For example, when talking about his girlfriend, "*Um, she's wonderful. We've been like together for like two years. Well, next month will be exactly two years, and she understands. She's normal, I*

*guess. Um. She doesn't care if I have FAS.*" (Vinney). For the past 2,000 years, societies have relegated the intellectually disabled to a less than human status (Parmentor, 2001, p. 290). As Parmentor (2001) states, "The presence of an intact intellect has traditionally been seen as the sine qua non for the recognition of full citizenship" (p. 290). Co-researchers were candid in sharing that intellectual and mental health disabilities were a challenge for them. They were aware that these challenges ensured their continual struggle for inclusion and full citizenship in our current society.

Their efforts to be fully included in society were further exacerbated by their struggle for self-acceptance in a world where these co-researchers felt that better able-bodied smart employed individuals were in control of societal inclusion criteria and set too high a standard for them. "*I am normal but different*" (Marc). Co-researchers saw themselves as people with unique perspectives rather than as 'abnormal' people. Is it the current Canadian reality for poor disabled people that one must act, look and communicate within the confines of so-called normalcy and "remove individual identity that emanates from difference" (Mathers, Thwaites, Simkins, & Mallet, 2011, p. 41) in order to be fully included in our society? I say unequivocally--- yes. As Traci shared, "*...disability is a never-ending story...*" thus disability has been and will always be with us. Disability must be accepted and valued not closeted, violated, stigmatized and excluded. As disabled people, we need to be celebrated not in spite of our disabilities but because of our disabilities (Withers, 2012, p. 117). Only then will we deem disabled bodies as non-excludable from humanity, from citizenship (Titchkosky, 2011). As Withers (2012) states, "Because I experience the world differently than many of the people around me, I have a unique and useful perspective" (p. 117).

Poor disabled persons are often 'hidden' populations, just as many of the co-researchers in this study are: living in an institution or a 'gated or protected' community that limits their visibility from mainstream society and hinders their potentially transformative capacities, personally and socially (Parr, 2007, p. 583). Story telling and story sharing has the capacity to visibly politicize and transform current understandings of social inclusion that will reject normative assumptions, and promote the healing of human relationships that include the conditions of poverty and disability. As a guiding researcher, I have learnt so much about the power of stories that champion lived experiences of disability and poverty. "*I am blown away; am becoming a convert of the power of story-telling*" (Reflective Journal, August 24, 2011). Sharing 'voice' through story telling should be everyone's right of citizenship, not something that one fears they will lose or that no one will ever hear, "*what if I have more stories---what do I do with them?*" (Traci). Stories of disability must be told; we must listen deeply so that we can understand the lived experiences of oppression and exclusion that deny inclusion and violate human dignity. As Dossa (2008) suggests, "Our listening must then be directed to the process of how we come to know about the lives of those who tell their stories and what we do with the stories once we have heard them" (p. 91).

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