

MAKING THE CASE FOR AN ABI COMMUNITY
ECONOMIC DEVELOPMENT

ACQUIRED BRAIN INJURY (ABI) AND EMPLOYMENT: MAKING THE CASE FOR
AN ABI COMMUNITY ECONOMIC DEVELOPMENT

BY

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ABSTRACT

Employment is highly valued in our society and is an important determinant for mental and physical health, and ultimately, self-determination, however acquired brain injury survivors (ABI) experience significant employment barriers.

Current Federal and Provincial government disability and mental health policies and programs promote the full social inclusion of disabled persons in Canadian society however, they do not address the disability-specific employment needs of many ABI survivors, particularly those with more serious disabilities. A non-government employment initiative that started within the mental health disability community and that has demonstrated notable success in assisting with the disability-specific employment needs of members of this group is the consumer/survivor community economic development approach (CED).

This study explored the gaps in our current disability and mental health employment policies and programs in meeting the employment goals of ABI survivors, and examined the viability of the consumers/survivors CED approach for members of this group. This study was consistent with critical social science methodology and was based on a qualitative study of 4 ABI/mental health service providers, 6 consumers/survivors, and 10 ABI survivors.

The interviews with these three groups combined with the literature reviewed in this paper, reveals the systemic, societal, and structural barriers that maintain the exclusion of people with disabilities. Conversely, an examination of the consumer/survivor CED approach reveals principles and a value proposition that facilitate the social inclusion of people with disabilities.

This exploratory study is intended to serve as a catalyst for the advocacy of government support for a CED designed for, with, and by ABI survivors. Correspondingly, this thesis argues that disability policy-makers must acknowledge the need for changes to our capitalist system of labour, and in our country's understanding of citizenship, because both are responsible for the continued restricted citizenship or non-citizenship of non-working marginalized groups.

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Glossary

1. Serious and persistent mental health issues (SPMHI): Persons with SPMHI can be described as individuals who experience mental health issues, that are often related to a diagnosable disorder (such as schizophrenia, delusions, paranoia, and manic depression), and that may result in serious harm to themselves or others (Canada: Government of Ontario, MOHLTC, Making It Work, 2001, p.5).
2. Supported employment (SE): The concept of SE has evolved within recent years as an alternative for persons with severe disabilities who cannot get a job or hold a job without permanent follow-along support placement. SE may involve a host of different arrangements within industry or outside of industry, in different occupations, and with different staffing patterns. Major characteristics of supported employment are: Real pay for work – not work experience (Wehman, 1990, p. 186).
3. Empowerment: Empowerment can be defined as the process of assisting persons to “exercise control over their lives to the fullest extent possible...enabling clients to gain or regain the capacity to interact with the environment in ways that enhance their needs gratification, well being and satisfaction” (Hepworth, Rooney & Larsen, 1997, p. 460). Furthermore, empowerment includes the “development of a critical consciousness of the causes of injustice and powerlessness” (Gutierrez, 1994, qtd. in Hepworth, Rooney & Larsen, 1997, p. 461).
4. Positivist social science research (PSS): PSS research can be defined as research that seeks to “discover and document universal laws of human behaviour, and also to learn how the world works so that people can control or predict events” (Neuman, 1997, p.63).
5. Insider: The term insider in this paper has the same meaning as that given by Uma Narayan where insider refers to a member of an oppressed group, and correspondingly, the term outsider refers to non-members. Narayan explains that: “ People are insiders or outsiders only with respect to specific forms of oppressive social structures –racism, sexism, compulsory heterosexuality and so forth. An individual who is an insider with respect to one form of oppression (say being a woman) may be an outsider with respect to another form of oppression”(Narayan, 1994, p. 177).
6. Praxis: Praxis is when the oppressed reflect on their oppressive situation, take action towards changing the situation, and critically reflect on the consequences of the action taken, with the goal of taking further action towards change. Hence, praxis can be understood as the continuous process of reflection-action-reflection that the oppressed engage in towards changing their oppressive situation (Freire, 1970, pp. 52-53).
7. Poverty Line: A poverty line can be defined as way to describe who is poor and who is not in a given society. Poverty line in this paper, refers to the market basket measure (MBM), “which attempts to calculate the amount of income needed by a given household to meet its needs, defined not just in bare subsistence terms, but also in terms of what is supposedly needed to approach “creditable” community norms”(Jackson, 2001, pp.3-5)

Introduction

In Canadian society, persons with disabilities are generally afforded more opportunities to lead full independent lives than ever before. Much has been achieved since *Obstacles* (1981), the landmark report of the Special Parliamentary Committee on the Handicapped and Disabled (Canada, Human Resources Development Canada (HRDC): AIPD, 2002). The Canadian government's leadership in facilitating the inclusion of persons with disabilities in the economic and social mainstream of our society was recognized by the United Nations in 1998, when the Prime Minister accepted the Franklin Delano Roosevelt award, honouring our country's achievements in improving opportunities for persons with disabilities (ibid). However, the government of Canada report, *Advancing the Inclusion of Persons with Disabilities* (2002) asserts that, "With all our successes, we cannot rest on our laurels. Complex issues remain unresolved and new issues are emerging" (ibid). One complex and unresolved issue is the employment barriers facing many members of the disability community. Employment is highly valued in our society and is an important determinant for mental and physical health, and ultimately, self-determination (Canada, Gov of Ontario, Ministry of Health & Long Term Care (MOHLTC): Making It Work, 2000, p.1). However, the 1991 *Handicap Activity Limitation Survey* (HALS), found that only 56.3 per cent of people with disabilities were part of the Canadian workforce, compared to 80.9 per cent of persons who did not define themselves as having a disability (Wilkerson, 2002, p.12). Similarly, the 2001 *Participation Activity Limitation Survey* (PALS) noted that only about half of all persons with disabilities from age 15 to 64 have some employment income (HRDC: PALS, 2001).

Current provincial and federal government disability policies promote the full inclusion of disabled persons in Canadian society. Recent examples of such policies include *Future Directions* (1999) and *In Unison* (2000). These policy documents highlight the need for disability employment services to more effectively target specific employment needs of individuals from across various disability groups. The joint Federal/ Provincial *Employability Assistance for People with Disabilities* (EAPD)

initiative (1998-2001) and the subsequent Federal/Provincial/Territorial *Multilateral Framework for Labour Market Agreements for Persons with Disabilities* (LMAPD)(2003) that guides the bilateral agreements on disability employment programs between the governments, provide strong examples. In the field of mental health in particular, the Ontario government Ministry of Health and Long Term Care (MOHLTC) has introduced *Making It Work* (2000). This policy framework outlines the Ministry's plans to reduce the outstanding unemployment level of 75-89% among individuals who experience serious and persistent mental health issues (SPMHI)⁽¹⁾ (Wasylenki, et al qtd. in MOHLTC: MW, 2000, p.1). Government awareness that members of this group (who make up 3-5% of the mental health population) need more specific employment services and supports, grew out of findings in mental health medical, community, and government research in mental health reform, that persons with SPMHI, have specific employment needs that were not being met by the operating employment services.

Another disability sub-sector that is facing high levels of unemployment is persons with moderate to serious acquired brain injury (ABI). An ABI can be defined as "a compromised brain function resulting from a specific event (e.g. stroke, accident) that is not associated with injury at birth" (Vandiver, Johnson, & Christofero-Snider, 2003, p.457). While there are currently no Canadian studies on ABI and employment barriers, there are numerous American and British studies that report that there are numerous employment barriers facing ABI survivors (Gamble & Moore, 2003; Kreutzer et al, 2003; Vandiver et al, 2003). Consequences of ABI are wide-ranging, affecting physical, cognitive, psychological and behavioural capacities (Gamble & Moore, 2003; Simpson & Schmitter-Edgecombe, 2002; Ylvisaker, Jacobs & Feeney, 2003), and yet neither federal nor provincial Canadian disability or mental health employment policies currently mention ABI as a target group.

Alongside government efforts over the past two decades to increase the participation of disabled persons in the work force, non-government disability employment initiatives have also demonstrated some success. One initiative that was started within the mental health disability community, and that has grown over the past

two decades, is the consumer/survivor community economic development approach (CED). Consumers/survivors are individuals who have experienced or continue to use the services of the mental health system, and who have been diagnosed with one or more mental health issues (Ontario Council of Alternative Businesses (OCAB), 1995). A consumer/survivor CED can be generally understood as a business that is designed to provide employment for consumer/survivors (particularly those who have been considered “unemployable” as well as “mentally ill”), and that depends on government and other sources of funding to assist in operational costs (Church, 2000, p.7). Consumer/survivor CEDs are successful in assisting consumer/survivor employees with their disability-specific employment goals, as is demonstrated by the MOHLTC’s decision to continue to fund these initiatives.

While the objective of current Canadian Government disability and mental health policies is to increase the participation of disabled persons in the workforce, many persons with ABI continue to face employment barriers. The study undertaken in this paper was to explore if a CED created for, with and by persons with ABI would, as in the above example, be a viable employment alternative for ABI survivors who are unsuccessful in securing meaningful employment in mainstream or supported employment (SE)(2). The following will begin by presenting the varied perspectives on disability and concepts influencing disability employment policies and programs. Then I will discuss the growing social problem of employment barriers facing the disability subgroup of ABI survivors. Utilizing Gil’s policy analysis framework, I will briefly examine how helpful the LMAPD and the *Making It Work* policy frameworks, are in facilitating the employment of persons with ABI (who can have both mental health and physical disabilities). I will then present the consumer/survivor CED model, explore its effectiveness in assisting ABI survivors to meet their employment goals, and suggest the CED employment approach as an effective and necessary economic and social inclusion model for ABI survivors.

Perspectives Influencing Disability Employment Policies and Programs

There are three dominant conceptual perspectives that influence opinion on disability employment goals: The medical perspective of disability, the economic perspective, and the social perspective. Disabilities, are usually first identified by healthcare professionals (Miller & Sammons, 1999, p.34). Therefore “The most commonly held concept of disability is based on a medical orientation that emphasises medical criteria and pathological functioning” (Veldheer, 1990, p.314). This perspective regards disability as a physical or mental impairment of the individual concerned. Hence, if a person’s abilities are minimal or reduced, this is due to physiological or psychological conditions, which means that they are not capable of assuming complete control of their lives and require outside assistance from medical experts (Fitzpatrick, 2001, p. 149). Persons with disabilities are expected to adjust to the norms and expectations of society, which regulate them to second-class citizenship and dependency when their impediments are not curable (Veldheer, 1990, p.314).

The economic perspective of disability is designed to rehabilitate the individual to their highest possible level of functioning for vocational purposes (ibid). Hence vocational rehabilitation or income maintenance programs are considered the main solution to the problems facing persons with disabilities. As with the medical perspective, the economic perspective of disability suggests that modification of the individual with disabilities is the most appropriate way to assist them in meeting their social and economic needs (ibid, pp.314-315).

The social perspective of disability, argues that it is not that the individual is disabled but that he or she is made disabled by a society that does not accommodate varying levels of ability (Fitzpatrick, 2001, p.150). Therefore, this viewpoint requires society to include persons with disabilities rather than for disabled individuals to learn to live within a segregated society (ibid). Although, as Fitzpatrick notes, the social perspective has been criticized for detracting attention from the lived experience of impairment, this perspective supports the case for equitable employment provisions for persons with disabilities desiring employment. Social Policy analyst Northway’s

differentiation between the terms “integration” and “inclusion” provide further understanding of the goal of the social perspective of disability. She explains that whereas, the term integration implies “that one ‘part’ is currently segregated and that action is required to bring it into the ‘whole’, the term inclusion implies “the recognition that the whole may comprise many parts but, none the less, still form part of the whole and should be regarded as such” (Northway, 1997, pp.158 & 164). Furthermore, while integration implies that the marginalized must change, inclusion implies that society must “embrace a wide range of diversity rather than requiring conformity or assimilation”(ibid, p.164).

Recent Concepts Influencing Disability Employment Policies and Programs in Canada

Over the past decade in Canada, the concept of “social inclusion”, and an emphasis on “public health” have been influencing disability policy documents and programs (Canada, Health Canada: Population & Public Health Branch (PPHB), 2000, p.1). Examples of these can be seen in *Making the Case for Economic and Social Inclusion* (2002), and the *Population Health Approach* (PHA) of Health Canada. The concept of social inclusion in social policy has its roots in the French and by extension Durkheimian prioritizing of human development over economic activity, and is the basis of the current European Union (EU) approach to health and welfare programs in Europe (Silver, 1994 in Abberley, 2002, p.121; PPHB, 2000). Simply put, social inclusion means to be accepted and to participate fully within our families, our communities and our society. Conversely, to be excluded, whether because of poverty, ill health, disability, race etc, is to not have the opportunity for full participation in the economic and social benefits of society. Hence, the term social inclusion implies both social and economic inclusion (PPHB, 2000, p.3).

Alongside the growing social inclusion approach to disability and employment issues in Canada, the PHA developed by the MOHLTC, is another approach that supports

the case for the full social inclusion of the disabled in society. The PHA was officially endorsed by the federal provincial and territorial Ministers, of Health in 1994 in the report “*Strategies for Population Health: Investing in the Health of Canadians*” (PPHB, 2000, p.5). The overall goal of a PHA is to maintain and improve the health of the entire population and to reduce inequities in health between population groups. In this approach, the entire range of known factors and conditions that determine population health status – and the interactions among them – are taken into account in planning action to improve health (ibid). This is exemplified in one underlying assumption of the PHA that states: “Strategies to improve health must address the entire range of factors that determine health” (Canada, Health Canada: Population Health Approach (PHA), p.2). Many of these factors are outside the health care system. These “determinants of health” include income and social status, social support networks, education, employment and working conditions, physical environments, social environments, biology and genetic endowment, personal health practices and coping skills, healthy child development, health services, gender and culture (PHA, p.1; PPHB, 2000, p.5). A PHA offers a way of taking action on the determinants, emphasizing as it does the need to work with other sectors to ensure that the collective policy environment supports health. The fit between this approach and the concept of social inclusion is a very good one: The concept of social inclusion addresses all 12 determinants of health, and a PHA stresses that a healthy public relies on the development of healthy public policy. Both approaches emphasize the importance of engaging partners from all sectors of society, of recognizing the interrelation between the 12 determinants of health, and of considering the ways in which these determinants interact (PHA, pp.2-3; PPHB, 2000, p.5). The concept of social inclusion and the PHA provide the framework that supports the argument in this paper for the development of employment alternatives that meet the employment needs of ABI survivors who cannot secure mainstream employment.

Nature and Scope of the Growing Social Problem of ABI

An overview of acquired brain injury (ABI) provides a contextual understanding of the growing social problem of acquired brain injury. Some researchers make a distinction between a traumatic head injury (TBI) (a head injury associated with a motor vehicle accident, an accidental fall, an assault, an industrial accident, or a sports injury) and an ABI (a head injury caused by conditions such as tumours, anoxia, strokes and infections), however recent research reporting that both types of head injuries produce similar consequences, comprise the two definitions under one definition (Ontario Brain Injury Association (OBIA), 2004; Vandiver, et al, 2003). In this view, an ABI is generally defined as a “compromised brain function resulting from a specific event (e.g., stroke, accident) that is not associated with injury at birth” (Vandiver, et al, 2003, p. 457). This is the definition used for the purposes of this paper. Brain injuries can be closed or open head injuries: in a closed head injury, the skull is not actually penetrated, whereas in an open head injury, the skull and dura are penetrated. The type of injury (open or closed), where the brain receives the most damage (in the brainstem, frontal lobe, centre, or all over), and the severity of the damage (mild, moderate or severe) affect the overall outcome of the individual’s recovery. Studies have shown that even with the most trivial insult to the brain, axons are damaged throughout the brain and result in diffuse degeneration. Furthermore, recovery is never 100%, no two, brain injuries are alike, and the majority of those who suffer a traumatic brain injury are young men between the ages of 18 and 30 (Monahan & O’Leary, 1999, p.269; Webb, 1998, p.541).

Brain injury victims are taken to hospital and undergo numerous tests and assessments to determine the severity of damage. Those with mild head injuries are discharged, while those with moderate to severe head injuries undergo longer treatment and inpatient rehabilitation. Discharge from hospital inpatient ABI rehabilitation units, generally occur when head-injured survivors are able to walk, comprehend language, maintain personal hygiene, and eat independently (Kreutzer, Bruce, & Harris, 1990, p.50). Following inpatient rehabilitation, ABI survivors were traditionally discharged to

their homes where family members subsequently assumed the long-term burden of care (ibid, p. 50). The past three decades have seen the development of community ABI rehabilitation programs in North America. These programs have been created in response to improved knowledge of the behavioural consequences of ABI and the impact that this life-long disability has on the individual, their family, and on health care systems. The objective of these programs is to help ABI clients return to maximum independence in the community (ibid, pp. 49-50).

Individual, Family, Health Care, and Social Impacts of ABI

Moderate to severe head injuries generally have devastating and long lasting consequences on the individual that include: Visual, balance, co-ordination, and motor impairments. Although a brain-injured survivor may recover physically, there are also cognitive and/or psychological changes that preclude him/her from returning to her/his previous lifestyle. These changes may involve changes in personality, behaviour, and emotions. Brain- injured survivors often complain of forgetfulness, irritability, slowness, poor concentration speech impairment (e.g. slurred speech, incomprehensive speech), fatigue, dizziness and headaches, mood swings, apathy, depressed mood, and anxiety. The most obvious and devastating consequences of brain injury are: Emotional withdrawal, impairment in self-appraisal, cognitive impairment e.g. long-term or short-term memory loss, poorer planning skills, decreased or lack of inhibition, aggressive and impulsive behaviour, lack of control over emotions, sexually inappropriate behaviour, the development or enhancement of psychiatric issues, verbal and/or physical abuse, attempted suicide or suicide ideation (thinking of suicide), schizophrenia or schizo - affective disorders and psychotic episodes (Tate & Broe, 1999, p. 713; Vandiver et al, 2003, p. 458).

The negative impact of acquired brain injury (ABI) on family dynamics and functioning has been the subject of much research over the last three decades (Stebbins & Leung, 1998, p.15). These studies have demonstrated that “Much familial distress was attributed to behavioural, cognitive, and personality changes in the brain-injured family

member” (ibid). Significantly, families reported that as time since the injury progressed, their brain-injured family member exhibited increasingly disturbing/challenging behaviour (violence, verbal aggression, inappropriate social behaviours, and dependency), which greatly challenged the family’s ability to cope (ibid).

The healthcare and social implications of acquired brain injury (ABI) are also significant. This is demonstrated by the fact that ABI represents a growing disability worldwide (Upton, Fontan, Premuda, Lorenzo, & Quinteros, 2002, p.1). More than 11,000 Canadians die as a result of a traumatic brain injury (TBI) annually, up to 4,000 of these people will die in Ontario. Moreover, 6,000 Canadians become permanently disabled after a traumatic brain injury annually (OBIA, 2004). Many who would normally have died in the past from injuries now survive, because of advances in emergency healthcare technology (Degeneffe, 2001, p.257). The majority of survivors have a normal lifespan and many have persistent functional limitations that require long-term health care (Dikmen, Machamer, Powell, & Temkin, 2003, p.1449). Furthermore, young, previously healthy adults comprise a large proportion of those injured (18-30 years) (ibid). The direct and indirect healthcare costs associated with Traumatic Brain Injury are estimated to be \$3 billion annually in Canada (\$1 billion in Ontario) (OBIA, 2004). Behavioural problems resulting from moderate to severe acquired brain injury (e.g. verbal/physical aggression, inappropriate behaviour/language) result in psychosocial problems for many ABI survivors. Furthermore, the combination of functional impairments with psychosocial and mental health issues, have resulted in high rates of unemployment among ABI survivors (Gamble & Moore, 2003, pp.31-32; Tate & Broe, 1999, pp.721-723; Vandiver et al, 2003, pp.457-458).

ABI has wide-ranging affects on physical, cognitive, psychological, and behavioural capacities. Therefore, when examining policies and programs that can assist ABI survivors in their employment goals, both disability and mental health employment policies and programs are relevant. The following briefly presents current Canadian Government laws and policies that could assist persons with ABI in their employment goals.

Canadian Government Legislation, Disability Employment Supports, Policies and Programs

According to the Government of Canada, the Canadian Government “has been a leader in ensuring that persons with disabilities are included and able to participate in the economic and social mainstream” (AIPD, 2002). Canadian government social policies that reflect a social inclusion approach to disability and employment issues include the *Ontario Human Rights Code*, the *Employment Equity Act* (1996), and the inclusion of persons with disabilities in the *Canadian Charter of Rights and Freedoms* in 1986. The *Ontario Human Rights Code* protects all Ontarians against discrimination in the areas of goods, services and facilities, housing, employment, contracts and membership in vocational associations and trade unions (Canada: Gov of Ontario, Ontario Human Rights Code (OHRC), 1990). Part 1: Freedom from Discrimination, of the *Ontario Human Rights Code* under employment, states: “Every person has a right to equal treatment with respect to employment without discrimination because of race, ancestry, place of origin, colour, ethnic origin, citizenship, creed, sex, sexual orientation, age, record of offences, marital status, same-sex partnership status, family status or disability” (Ontario Human Rights Code (OHRC), R.S.O.1990, c.H.19, Part 1, s.5 [1]). The code allows employers if they wish, to implement “special programs” intended to “relieve hardship or economic disadvantage.” This “special programs” provision allows employers “to assist disadvantaged persons or groups to achieve, or to attempt to achieve equal opportunity” (ibid, Part 2, s.14 [1]). Similarly, in the current *Employment Equity Act* (1996), persons with disabilities are one of four designated groups specifically mentioned (Graham, Swift & Delaney, 2000, p.80). This legislation required federally legislated employers to implement equity programs and report regularly on their results (ibid). Since the inclusion of people with disabilities under the *Canadian Charter of Rights and Freedoms* in 1986, Federal/Provincial/Territorial policies have approached disability as a citizenship rights issue, which means that persons with disabilities have equal rights to participation in all aspects of Canadian society, as do non-disabled persons (HRDC: AIPD, 2002).

However, as the Roehrer Institute asserts, in spite of the above achievements, “Canadian society has not framed employment as a citizenship right in the same way that access to education and to health care are considered basic entitlements” (Roehrer Institute, 1996, pp. 82 & 83).

In addition to government laws, there are a number of government disability supports programs that promote the inclusion of disabled individuals in the labor force. One example is the Office of Learning Technologies (OLT) program (1995) run by HRDC. OLT was established to support initiatives in new learning technologies, and is currently building on its Community Learning Networks Initiative to build networks that will support individuals to acquire technology skills and overcome special learning needs or barriers to learning (AIPD, 2002). Another significant example is the federal government’s requirement that all jurisdictions in Canada monitor the development of information technology standards on accessibility. Furthermore, as outlined by the Treasury Board Secretariat (TBS) policy (2000) known as the “Common Look and Feel Guidelines”, all Canadian websites are required to be accessible for persons with disabilities (ibid). Canada is the first country in the world to require all its websites to conform to web content accessibility guidelines. Additionally, the federal government has improved access to information on government of Canada programs for persons with disabilities through its online initiative “Persons With Disabilities Online” at www.pwdonline.ca (ibid), and the more recent Federal/Provincial/Territorial (FPT) “Disability Weblinks” service: www.disabilityweblinks.ca. Both websites provide access to information on a variety of disability-related topics including accessibility, education, employment, financial support, personal support health, rights and so forth (ibid). Through Transport Canada and the Canadian Transportation Agency (which regulates the transportation system under Federal jurisdiction), the government of Canada continues to play a leadership role in resolving issues of access to the air, rail, intercity bus and marine transportation modes. For example, Transport Canada supports on-going research and development projects, which aim to enhance accessibility for persons with disabilities, and the Canadian Transportation Agency continues to develop and monitor

accessibility standards for the transportation industry by way of regulations, codes of practice, as well as tools to increase accessibility. For example the “reservation checklist” which increases awareness and familiarizes the travel industry about the travel needs of persons with disabilities (ibid).

The above social inclusive policies and measures demonstrate the Canadian government effort to support members of the disabled community in their economic and social goals, however, the reality is that laws and policies certainly protect and promote a person’s rights to employment, and disability technology and societal supports facilitate the social inclusion of disabled persons, yet these measures cannot guarantee an increase in the employment numbers of disabled persons. The inclusion of persons with disabilities into the *Canadian Charter of Rights and Freedoms* was in 1986, similarly, the *Employment Equity Act* was enacted around the same time. However, more than 15 years after these undertakings, the 2001 PALS survey noted that only about half of all persons with disabilities from age 15 to 64 have some employment income (PALS, 2001).

Cognisant of the continuing high unemployment rate among disabled persons, the Canadian governments have introduced a number of policies and programs designed to increase their participation in the labour market. One such program is the Opportunities Fund (OF) offered by HRDC. OF is a program that assists persons with disabilities who have had little or no labour force attachment (thus who do not qualify for employment insurance (EI), with their employment goals. OF funds a number of disability employment services and interventions that include counselling, case management, wage subsidies to employers, and income support for establishing new businesses (AIPD, 2002; MOHLTC: MW, 2000, p. 1). However, there are persons with disabilities for whom this and other disability employment programs and policies have not been helpful. For example, *Making It Work* points out that many persons with serious mental health issues “require employment-related supports and services that are more intensive and long-term than those provided by more generic government programs (MOHLTC: MW, 2000, p.2). The following explores two recent government measures that are designed to focus on the more individual needs of their target populations: the *Multilateral*

Framework for Labour Market Agreements for Persons with Disabilities (2003) and the *Making It Work* policy frameworks (2000).

Analysis of LMAPD and *Making It Work* Policy Frameworks: Main Objective, Goals, Theoretical Positions and Target Segments

Making It Work is the most recent Ontario government policy advance regarding self-determination and employment equity for individuals with SPMHI. This policy framework has its roots in *Making It Happen* (1999), which was a three-year plan to reform Ontario's mental health system. *Making it Happen* identified employment supports as an important part of the continuum of services required by persons with serious mental health problems, and highlighted the need for policy directions in this area. *Making It Work* was developed to respond to this need. The MOHLTC funds about forty programs, services and businesses created to provide employment supports for mental health consumers. *Making It Work* therefore is a strategy to guide all forty ministry-funded initiatives in the provision of employment supports that are comprehensive, provide the specialized supports needed by people with serious mental illness, and reflect evidence-based practices (MOHLTC: MW, 2000, p.2).

The *Multilateral Framework for Labour Market Agreements for Persons with Disabilities* (LMAPD) is a FPT initiative that builds on the successes of the Multilateral Framework: *Employability Assistance for Persons with Disabilities* (EAPD) that has been operational since 1998. LMAPD has recently replaced the EAPD framework in 2004. The EAPD framework was a strategy to assure that all government-funded vocational employment programs and services place a stronger focus on employment. Similar to the *Making It Work* policy, LMAPD aims to ensure that disability employment supports programs are comprehensive, more focused on the individual client employment needs, and reflect evidence-based practices.

Objectives and Goals

While the main objectives of the LMAPD initiative include enhancing the employability of all working age adults with disabilities and increasing the employment

opportunities available to them, the main objective of *Making It Work* is to enhance the employability and economic participation of the specific disability sub-group of persons with SPMHI (Canada, Gov of Canada, Social Union: LMAPD, 2003, p.2; MOHLTC: MW, 2000, p.2).

Both policies establish similar goals: To eliminate employment barriers facing their target population. To this end, programs and services funded by LMAPD provide the skills, experience and related supports necessary to prepare people with disabilities for economic participation and employment in the labour market, and to help them attain and/or maintain employment (LMAPD, 2003). Similarly, *Making It Work* programs are designed to assist service users in their employment goals. Furthermore, both policy frameworks establish increasing SE initiatives as a desirable goal. Unlike the LMAPD framework however, the *Making It Work* framework stresses the additional goal of encouraging consumer/survivor- run businesses (MOHLTC: MW, 2000, p.2).

A key principle of the LMAPD is that the programs focus on assisting persons with disabilities, find 'real jobs'. To this end, the LMAPD framework notes that it no longer funds programs and services which are primarily oriented to medical treatment or services provided in a sheltered workshop, which do not demonstrate preparation of persons with disabilities for entry into the labour market (LMAPD, 2003, p.3).

The covert objective in both overt policy objectives appears to be that persons with disabilities would have an opportunity to reduce their dependency on income replacement/supports under the Ontario Disability Supports Program (ODSP), which is an EAPD (LMAPD) program.

Theoretical Positions

The LMAPD framework demonstrates the influence of both the social and economic conceptual perspectives of disability: The influence of the social perspective is seen in the LMAPD principle that "Co-operation and partnership between governments, persons with disabilities, community-based organizations, labour, aboriginal, Metis and Inuit peoples and other stakeholders" is necessary in order for the framework to achieve its objectives (ibid, p.2). Another example is the employment supports component of

ODSP. Through the provision of employment supports, this initiative recognizes that people with disabilities want to work, and can work if specific disability-related barriers are removed. Additionally, the policy framework is committed to promoting self-employment and entrepreneurship (ibid, p.7). The influence of the economic perspective on disability can be seen in the policy's assertion that programs and services, which do not demonstrate preparation of persons with disabilities for entry into the labour market, are not funded under this initiative (ibid, p.3). The medical perspective of disability has much less presence in this policy framework, and the role that it plays is primarily one of support. This is seen in the ODSP-income supports component, that is designed to provide income supports to persons who because of their disability are not able to adequately provide for themselves, and need financial assistance to assist with living expenses, medications and/or the services of medical professionals.

Making It Work notes that the MOHLTC employment supports for individuals with SPMHI, range from medical organizations and supports to consumer/survivor-run initiatives (MOHLTC: MW, 2000, p.2). This implies that the policy framework supports both the medical and social perspectives of disability. Identified employment supports that uphold the medical perspective include community mental health agencies, hospitals, and provincial psychiatric hospitals (ibid). The social perspective on disability in this policy framework is seen in the fact that eligible mental health service users can utilize the employment supports services of the ODSP program, as well as acquire government financial support for self-employment businesses through HRDC programs such as the Opportunities Fund (OF). Furthermore, the MOHLTC provides funds and support to consumer-operated alternative businesses, self-help groups, members of the business community, and the OCAB (ibid, pp.1-2).

Target Segments

As already mentioned, the primary target population identified in *Making It Work* is individuals with serious and persistent mental health issues (SPMHI), and the primary target population of the LMAPD framework is all persons with disabilities.

Secondary target segments described in both the LMAPD and *Making It Work*, include the programs and individuals members 'who can make it happen' from the business community, community-based organizations, labour and persons with disabilities (MOHLTC: MW, 2000, p.4; LMAPD, 2003, p.2). *Making It Work* adds targets that include: OCAB, consumer/survivor operated alternative businesses, family members and advocates of disabled persons, district health councils, hospital, community and provincial psychiatric hospital service providers (MOHLTC: MW, p.4).

The non-target segment mentioned in the LMAPD framework, focuses on employers. For example the LMAPD framework will "Enhance education and awareness strategies to address employer concerns related to hiring persons with disabilities" (LMAPD, 2003, p. 7). *Making It Work* extends the non-target segment to include all members of the workplace with negative beliefs and attitudes regarding persons with disabilities, and the public (MOHLTC: MW, 2000, p.10).

Unsought Consequences & Limitations of the LMAPD and the Making It Work Policy Frameworks & Suggestions for Further Policy Development

Both policy frameworks recognize that their primary target population segment may face additional structural barriers to employment besides that of having a disability (LMAPD, 2003, p.2; MOHLTC: MW, 2000, p.1), however neither policy delineates how certain additional structural barriers might be addressed when assisting the client with their employment goals. For example, the LMAPD mentions measures to address the structural barriers of education and skills, yet no mention is made of other structural barriers such as race, culture, age, class, disability gender and sexual preference. *Making It Work* states that employment supports will "demonstrate sensitivity to the gender, race, language, and cultural needs of individuals with serious mental health problems" (MOHLTC: MW, 2000, p, 10), however it does not indicate how "demonstrating sensitivity" might assist service users to attain their employment goals. In other words, how can demonstrating "sensitivity" to the structural barrier of race support the policy's overall objective to "increase the total number of consumers who find jobs" (ibid).

The case of individuals with SPMHI and an acquired brain injury (ABI) provides a strong example. Numerous studies on brain injury and rehabilitation have documented the increase in challenging behaviour post ABI as negatively impacting the return to work (RTW) success among ABI survivors (Simpson et al, 2002, p.1075). Challenging behaviour may involve: Changes in personality, behaviour, and emotions such as emotional withdrawal, decreased motivation, impairment in self-appraisal, forgetfulness, mood swings, depressed mood, increased irritability, lack of inhibition, aggression and verbal abuse, fatigue, dizziness, headaches, apathy, and anxiety. Besides possible changes in behaviour following ABI, other changes often include physical and cognitive impairments (Tate and Broe, 1999, p.713; Vandiver et al, 2003, p.458). Therefore, when assisting a person with SPMHI and an acquired a brain injury in their employment goals, a service provider may need to consider in what ways the additional structural barrier of brain injury may be contributing to the employment disadvantages of the individual, and in consequence determine how to effectively assist the client to work on managing the personal behaviour challenges in addition to the structural barriers an ABI. If neither policy frameworks propose measures (other than that of providing support through demonstrating sensitivity to additional structural barriers) to assist service users in fighting all the structural barriers that prevent them from realizing their full economic potential, how can they effectively support service users in their employment goals?

Making It Work and the LMAPD policy frameworks propose to ensure evidence-based best practices in their employment supports programs and services. 'Best practice' in the context of community services can be "considered to be activities and programs that are in keeping with the best possible evidence about what works" (Canada, Health Canada, Clarke Institute, (RBPMHR), 1997, p. ix). Thus, the government believes it possible to measure the success of a social service in terms of quantitative information (Northway, 1997, p.169). Examples of evidence-based best practices measures that *Making It Work* will use to measure the success of its programs include documenting the number of people who actively participate in a program and/or business, the number of people who successfully complete a program, and the number of people who are

employed as a result of their participation in a program or business (MOHLTC: MW, 2000, pp.4-5). Using an example from the LMAPD initiative ODSP, data evaluating the employment supports component program in the first year of its operation (1999-2000) shows that 60% of clients who completed their employment plans in 1999-2000 became employed and over 30% of clients, who completed their employment plans were able to maintain employment during a job crisis (EAPD, 2002). While an evidence-based best practices approach can measure the number of people with SPMHI who become integrated into various work settings, it does not tell us about the negative influence of diverse additional structural barriers (e.g. race and physical disability) on the employment chances of service users. Thus, how can the 'evidence-based best practices' approach, which tends to focus more on quantitative information than on qualitative data, effectively support *Making It Work* and LMAPD program service users to combat the additional structural employment barriers that they may face?

The LMAPD and the *Making It Work* frameworks fail to acknowledge and address the implications of their main objective of increasing the employment of the target populations, on the social, political, and economic sectors of society. With regards to the social and economic implications of increasing the employment of persons with disabilities for instance, neither policy frameworks consider the unintended consequence of public reaction to measures such as an increase of disabled persons in mainstream employment, an increase in SE programs, or the development of businesses that are operated by persons with disabilities within their communities. *Making It Work* for instance, asserts that it will work with the business community and the public to address the issue of stigma in the workplace. Unfortunately, this policy framework does not recognize the connection between the mental health system's stigmatization of individuals with serious mental health issues, with the stigma in the workplace and in society in general. Increasing the employment of individuals with SPMHI also requires changes in the mental health system's policies, and practices to eliminate the stigma of serious mental health issues. An exploration of public opinion and the contributing role that various societal ideals may play in shaping the exclusionary attitudes towards

disabled persons, and proposed measures to begin to encourage public support is necessary, particularly as numerous research studies pertaining to community acceptance of individuals with mental health problems, have noted that closing or scaling back institutions has not necessarily lead to integration or to inclusion (Roehrer Institute, 1995, p.30). Furthermore, the prospect of improving the quality of life and self-determination/self-sufficiency for persons with disabilities has been balanced against the cost of accommodating these individuals in the community, and although a number of authors on the issue believe that social inclusive measures can lead to cost savings in the long run, others question whether even the most comprehensive system of community-based services, employment supports, and opportunities could ever ensure inclusion (ibid pp.31-32).

Making It Work and the LMAPD policy frameworks also ignore the political implications of their main objective: Increasing the employment of disabled persons could be met with resistance from members in other economically marginalized groups, because could afford members of these groups more social privilege and entitlements than themselves.

While the main objective of the LMAPD and the *Making It Work* policy frameworks is to increase the employment of persons with disabilities in the Canadian labour force, neither policy frameworks considers how improving employment supports for persons with disabilities does not necessarily translate into securing employment. Factors such as our capitalist economic system of labour, and the employment insecurities resulting from the growing trend towards the globalisation of economies, may seriously negatively impact the employment chances of persons with disabilities: A capitalist system of division of labour, thrives on competition and on maintaining a level of unemployment in the general populace (since a surplus of idle individuals tends to depress wages, to increase profits, and to check inflation), and the job insecurity resulting from the trend towards economic globalization, means that people will increasingly find themselves competing for jobs (Abberley, 2000, p.131; Gil, 1979, p.87). Persons with disabilities therefore will increasingly find themselves competing with non-disabled

persons for jobs (many of whom may have more skills, experience, and aptitude than many persons with disabilities, in particular those with more serious disabilities seeking employment. Therefore, while these policy frameworks propose that employment supports will assist persons in their employment goals, this is only half the battle, for employment supports can only prepare a person for work, not assure employment.

As earlier explained, while integration implies that the marginalized must change, inclusion implies that society must “embrace a wide range of diversity rather than requiring conformity or assimilation” (Northway, 1997, p.164). A key element of inclusive policies is including members of marginalized groups in the decision-making processes (ibid, p.169). Unfortunately, in both policy frameworks, the primary target populations are excluded from the decision-making and evaluation processes of the policies: The *Making It Work* policy framework’s Mental Health Implementation Task Forces, that will review and make recommendations on current employment supports programs and businesses do not include individuals with SPMHI (MOHLTC: MW, 2000, p.4). Instead, these Task Forces will “work with mental health service providers, consumers and their families, and the business community on the implementation of this policy framework” (ibid). Similarly, the extent of participation among members of the disabled community in the policy-making process of the LMAPD was limited to the consultation process (LMAPD, 2003). Excluding the participation of persons with disabilities from the decision-making and evaluation processes of policies that concern them, denies them the opportunity to ensure that all their employment needs are addressed. Social policy analyst Leonard proposes that for human welfare to flourish, social welfare policies need to involve discourse on both common needs (universal needs) and specific needs (needs that are culturally specific and concretely related to diverse identities). Moreover, specific needs are best articulated by those directly affected (Leonard, 1997, p.167). This suggests that social welfare policies concerning the well being of citizens must no longer exclude ‘subjects of welfare’, but must involve policy-makers, service providers and service users in debate, dialogue, and listening to others. Leonard asserts that it is such activity that may lead to sufficient consensus upon which

to build emancipatory social policies (ibid). I support Leonard's argument for the inclusion of service users in discourse and decision-making on social policy, but recognize that many hurdles must be overcome before this ideal can be realized. Social policy analyst Graham demonstrates this when he states: "Social policy is about making decisions that are, in the perception of those making them, in the best interest of Canada and Canadians" (Graham, 2000, p.3). From the staggering 75-89% unemployment rate for people with serious mental health issues (40 years after the start of deinstitutionalization), and the fact that half of all disabled persons in Ontario are unemployed (Wasylenki, et al qtd. in MOHLTC: MW, 2000, p.1; PALS, 2001), we can deduce that it is not members of these groups that are making social policy decisions. Creating an equitable policy response to employment barriers for persons with disabilities requires the inclusion of members of these groups at all levels of disability employment-related policy-making processes.

Making It Work and the LMAPD policy frameworks promote the economic inclusion of disabled persons, however, neither policy framework acknowledges that their failure to include all stakeholders in the policy decision-making processes, nor the inability of the capitalist system of labor to effectively meet the employment needs of all citizens, are significant barriers to the realization of their main objective. One type of initiative that is cognizant of the barriers to full social inclusion facing persons with disabilities under our capitalist system of labor, and that recognizes the necessity of including all stakeholders in policy decision-making processes, is consumer/survivor community economic developments (CEDs). The following uses Gil's policy analysis framework to examine the objectives, goals, theoretical influences, and target segments of consumer/survivor CED initiatives.

Analysis of Consumer/Survivor CED Objectives and Goals, Theoretical Positions, and Target Segments

Background

Prior to the mid 1900's people who had been diagnosed and labelled as "mentally ill" were generally placed in the care of state-run psychiatric institutions. The 1960s provincial government policy of deinstitutionalization and subsequent policies for community re-integration demonstrated the public's understanding that barriers to social inclusion for persons labelled "mentally ill," violated their right to equality, equity, and social justice. However, de-institutionalization gave rise to the social problem of the need for sufficient and effective community supports and initiatives (including employment initiatives) in order to successfully include members of this group into society. Throughout the 1980s and 90s, the provincial government demonstrated support for mental health consumer/survivor organizations through the distribution of policy documents, namely the *Graham Report* (1998) and *Putting People First* (1993), and through seed funding. Notably, in 1991 the Ontario Ministry of Health established the Consumer/Survivor Development Initiative (CSDI) (now called the Ontario Peer Development Initiative (OPDI). The purpose of OPDI is to financially assist consumer/survivor groups in developing self-help, mutual aid, and business initiatives. Consumer/survivor businesses receive funding from the OPDI initiative. This program receives annual provincial funding valued at \$4 million dollars and currently supports 36 consumer/survivor-run programs and social businesses (Clarke Institute, (BPMHR), *Situational Analysis*, 1997, pp.28-30). The OPDI was initially headed by professionals in mental health, but is now uniquely run by consumers/survivors (Church, 1996, p.3). OPDI funded 42 proposals from psychiatric survivor groups in the first year of its operation, 7 of which were CEDs. Funding for consumer/survivor CEDs has been sustained over the years and is critical to their survival (ibid). There are roughly 8 –10 consumer/survivor-run businesses in Ontario, all of which are coordinated by the umbrella organization OCAB (Church, 2000, p.3).

Community Economic Development (CED), what is it?

CED is a young field with roots in economic development, which evolved as a concept and deliberate policy practice during the post-World War Two reconstruction of

Europe and the Westernisation of newly independent former colonies (1950s-1960s) (Perry & Lewis, 1994, pp.1-2; Shragge, 1993, p. viii).

The concept of community-based economic development was initiated during the 1960s in black American inner-city ghettos to encourage self-determination among black Americans and soon thereafter, spread to Canada, Great Britain and other Western European countries (Shragge, 1993, p. viii). Whereas the general concept of economic development is that a specific nation is the arena for economic development, and decision-making power is restricted to the funders and decision-making authorities, CED perceives the community as the arena for economic development, and correspondingly, decision-making includes members from the local community (Perry & Lewis, 1994, p.2). Additionally, while economic development is defined as a wealth producing activity for a nation, CED views economic development as a wealth-producing activity that strives to provide resources for “the whole round of life” in a particular community. CED initiatives thus link the social with the economic, which implicitly suggest that the role of CED is to build both economic alternatives and assist the local community to gain control over broader economic and social processes (Shragge, 1993, pp. i- ii & 2-5).

Two dominant principles that underlie all CED initiatives are empowerment and epistemic knowledge (OCAB, 1995; Shragge, 1993). Empowerment (3), a process that occurs at a personal and a political level, involves changing power relations between individuals and groups and social institutions. Furthermore, empowerment involves personal change, as individuals take action on their own behalf and then redefine their understanding of the world. Narayan defines epistemic knowledge as the first hand knowledge that members of an oppressed group have concerning ways in which oppression defines the space in which they live and how it affects their lives (Narayan, 1989, p.320). Hence, epistemic privilege implies that those most affected by the problems of marginality in the society are the ones with the best ideas for solving their problems.

Consumer/Survivor CED, Objectives and Goals

Consumer/survivor CEDs are businesses that are created for, with and by psychiatric consumers/survivors. Consumer/survivor CEDs in Ontario were built on the

growing belief in the 1980s that formal vocational rehabilitation services like SE, were only one paradigm for helping psychiatric consumers/survivors and that non-service alternatives, such as self-help and mutual aid were also valid and should be supported (Clarke Institute (BPMHR), Situational Analysis, 1997, p.26). The main objectives of consumer/survivor businesses are to employ psychiatric survivors and to improve the holistic health of employees through economic development (Church, 2000, p.7).

Theoretical Underpinnings

Consumer/survivor CEDs demonstrate the influence of the social and human rights perspectives on disability, and also the influence of the concepts of social inclusion and population health. These influences can be seen when we look at the CED model from which consumer/survivor CEDs developed (Perry & Lewis, 1994, pp.1-2; Shragge, 1993, p. viii). Consumer/survivor CEDs fit roughly within the “progressive” perspective of CED, which emphasises the empowerment of marginalized people and institutional change (Church 2000, p.7; Perry & Lewis, 1994, pp.6-7).

Target Segments

The target segments in CED are based on the “community base” on which a CED rests. A community base is defined in terms of a locality, or in terms of individuals. In a locality community base, the focus is on the recovery and empowerment of a marginalized locality, and benefits are often designed to be indirect and collective. In an individual community base however, the focus is on the recovery and empowerment of marginalized individuals, and social and economic benefits are often designed to be direct and individual (Church 2000, pp.8-11). Consumer/survivor CED businesses in Ontario sprung from an individual community base framework.

The primary target segment identified by consumers/survivors CEDs is consumers/survivors, in particular those who have been classified as “permanently unemployable” as well as “mentally ill” (ibid, p.7). Overall, consumers/survivors describe themselves as individuals who have or continue to use the Canadian mental health system whether in hospitals as voluntary or involuntary patients or as voluntary

clients of community mental health services (Canada, Gov of Ontario, MOHLTC: BPMHR: Consumer/Survivor Development Initiative). While some experience SPMHI such as schizophrenia, others experience less serious mental health issues. Consumers/survivors may also refer to themselves as psychiatric survivors (Church, 1997; Church & Creal, 1995).

Secondary target segments include members 'who can make it happen' from the public, the private, voluntary, and informal sectors. These targets include the government, community mental health services, provincial psychiatric hospital services, and district health councils; businesses; mutual aid and self-help support groups, consumers/survivors and advocates (Church, 1997; OCAB, 1995). While consumer/survivor CEDs welcome secondary target expertise, however, they prefer to keep these contributions at an arms length, non-interfering distance, especially if the contributors are mental health professionals or agencies: "Regardless of the good intentions, the work performed by professionals has the effect of controlling, containing and limiting the ways in psychiatric survivors live (OCAB, 1995, p.27).

The non-target segment involves all community members with whom consumers/survivors interact.

Limitations and Unsought Consequences of the Consumer/Survivor CED Approach

Consumer/survivor CED literature demonstrates understanding that structural barriers are not mutually exclusive however, nowhere in this literature is mention made of how consumer/survivor CEDs address, or propose to address additional structural barriers (apart from serious mental illness) that may contribute to employment barriers to (or to advancement within) the consumer/survivor CEDs. It would appear that consumer/survivor CEDs assume that the shared structural barrier of mental health issues somehow 'unifies' members of these initiatives, and yet, even this shared structural barrier of mental health issues, varies in type, and in degrees of severity. Therefore how does a consumer/survivor CED address employment and/or attitudinal barriers that may arise based on the type and severity of a person's mental health issue? Or how about

other structural barriers such as ABI? While consumer/survivor CEDs have been created by people who on account of serious mental health issues understand what it is to live on the margins of society, we cannot assume that these businesses will make provisions for equitable employment. Hence, consumer/survivor CED literature should indicate awareness of these additional structural barriers and measures that strive to assure employment equity.

Another limitation of the consumer/survivor CED employment approach lies in its belief that “all psychiatric survivors can do some form of useful paid work” (OCAB, 1995, p.6). This position derives from OCAB’s value proposition that economic participation in society is fundamental to the well-being of all citizens (ibid). CED is about communities that have been marginalized by the marketplace (ibid). However, the particulars of creating and running CED businesses require certain marketplace skills (e.g. creating a business plan requires literacy, mathematics, and a business sense) that many consumers/survivors (who are marginalized by the marketplace) lack (ibid, p.9; Niagara District Health Council (NDHC), 1999, p. ix). This contradiction has resulted in funding issues for consumer/survivor CEDs. For example in 1993, the Ontario government withdrew its grant to the Toronto CED network when member organizations did not meet the targets outlined by the government. Furthermore, consumer/survivor CEDs are under increasing pressure from government to become economically self-sufficient (OCAB, 1995, pp.9 & 30).

One unsought consequence facing consumer/survivor CEDs is that their efforts “to recontextualize the lives of psychiatric survivors” (Church, 1997, p.37) occur in the shadow of a psychiatric treatment system that is dominated by the medical perspective on mental health. Under this perspective, consumers/survivors “are not encouraged to think for themselves or to plan for their futures. Instead, their lives are to be orchestrated: personally, socially, and economically” (OCAB, 1995, p.4). Most consumers/survivor CED employees “continue to have contact with that system, to have their bodies and consciousness shaped by that system” (Church, 1997, p.37). Furthermore, the medical perspective on disability created thousands of jobs for professionals and

paraprofessionals (OCAB, 1995, p.6). Hence, a major difficulty consumers/survivors face in becoming productive “is that they are already a site of production for mental health professionals and paraprofessionals” (Church, 1997, p.27).

About 75-89% of people with serious mental illness in Ontario remain unemployed (Wasylenki, et al qtd. in MOHLTC: MW, 2000, p.1). However, there are presently only 8 consumer/survivor CEDs in the province. For there to be a significant reduction to the unemployment rate among members of this group using the consumer/survivor CED approach, the government would need to provide funding for a lot more consumer/survivor CEDs to be created. However, similar to the LMAPD and the *Making It Work* government policy frameworks, the unintended short and long-range effects of increasing the number of consumer/survivor CEDs in the province, on non-target segments include possible objection from various sectors of society to the increased presence of consumer/survivor businesses in their communities. Additionally, a significant increase in consumer/survivor businesses in Ontario could result in objection from other disability groups, who fear it could afford members of these groups more social privilege and entitlements than their own. Fitzpatrick illustrates this point with the statement: “The recent militancy of certain sections of the disability movement are likely to alienate public opinion if carried too far: public opinion may exhibit a patronizing attitude towards disabled people, yet this also implies that they are more deserving than most other claimant groups” (Fitzpatrick, 2000, p.150). Hence, although consumer/survivor CEDs, like SE programs appear to be well received in their communities and sufficiently supported by the provincial government, the Roher Institute identified that further development of services and disability-related businesses is the most critical contemporary policy challenge in the disability field (Roher Institute, 1995, p.31).

Is the Consumer/Survivor CED Business Approach a Viable Employment Alternative for Persons with an Acquired Brain Injury?

Background

There is presently no Canadian research on the level of unemployment among brain injury survivors, nor on the factors that influence employment outcomes following ABI, nor on what existing employment supports are the most effective for members of this group. The March of Dimes (community program that offers vocational rehabilitation) recently funded a research project by Brain Injury Community Re-Entry program (BICR) in Niagara, on effective employment supports for persons with ABI, but the project has not yet been published (communication with March of Dimes in Toronto, June, 2004). ABI literature in Canadian Universities, databases, and ABI organizations is primarily American. Consequently, articles reviewed for this paper are primarily from American brain injury and rehabilitation journals followed by British journals.

American researchers Kreutzer and colleagues, note that the rate of employment following ABI varies widely from study to study. For example, “Brooks and colleagues found that unemployment levels rose from 14% pre-injury to 71% post-injury. Others have reported similar rates of unemployment after TBI, ranging from 55% to 78%, whereas some researchers have documented much lower levels of unemployment ranging from 10% to 34%” (Kreutzer et al, 2003, p.129). Kreutzer et al explain that there are a number of factors that can account for the variance in reported unemployment rates: Differing definitions of employment is one reason. For example, some investigators include sheltered or subsidized and unpaid work, which includes volunteer, homemaker, and student. Another reason is differences in cohort selection criteria. For example, older age, pre-morbid unemployment, lower levels of education, and early injury severity measures (poor performance on early neuropsychological testing, and on acute rehabilitation-based measures such as the Disability Rating Scale (DRS), and longer stay

in inpatient rehabilitation) have been found to influence post-injury unemployment. Furthermore, recent longitudinal studies have noted that an ABI individual's employment status may change as time since injury progresses (ibid; Oliver et al, 1996 in Possl et al, 2000). Kreutzer and colleagues highlight that ethnicity and marital status may also be factors that influence employment status following ABI, but note that how much of an influence, remains unclear (Kreutzer et al, 2003, p.129).

Earlier in the paper, I briefly touched on the consequences of ABI and the impact that these consequences can have in the health, social, and economic sectors of society. In what regards employment following an ABI, numerous American studies note that in addition to extrinsic factors (e.g. premorbid maladaptive behaviour including substance abuse, social problems), personality changes, including emotional disturbances and increase in challenging behaviour, have also been shown to be involved in determining the employment outcome of persons after ABI (Drotar et al, 2002; Koele, Castillo et al, 2000; Jacobs, 1988 in Possl et al 2000; Schwartz, Taylor, Bloom, Levin, Ewing-Cobbs et al, 2001, in Ylvusaker, Harvey & Feeney, 2003). Notably, recent studies such as that done by Simpson and Schmitter-Edgecombe (2001) reinforced findings in earlier studies that associated cognitive and behavioural deficits with dorsolateral and orbitofrontal areas of the frontal lobe (Simpson & Schmitter-Edgecombe, 2002). These authors note that damage to the dosolateral area tends to result in distractibility, deficits in working memory processes, difficulties with strategy formation, and difficulties with planning skills, cognitive flexibility and the temporal integration of behaviour. Injury to the orbitofrontal area has been found to be associated with social inappropriateness and emotional liability, aggression and arousal and social monitoring deficits (ibid, p.1076). As these studies demonstrate, the deficits in executive functioning and behavioural regulation resulting from frontal lobe injuries could significantly impact a persons mainstream employment chances following ABI.

Changes in communication ability have been noted among researchers as another important factor influencing employment status following ABI. Common communication problems associated with ABI “ include difficulties with discourse (e.g. tangential and

disorganized output), word retrieval, social language, comprehension, rapidly spoken language, communication in challenging environments, abstract language, and verbal learning and reasoning, as well as imprecise language and disinhibition” (American Speech-Language-Hearing Association 1988, in Isaki & Turkstra, 2000, p.442). Another study by Ezrachi et al in 1991, found that awareness and acceptance of capabilities and limitations are other factors that influence a persons work status following an ABI (Possl et al, 2000, p.16).

A recent study that provides a comprehensive picture of the employment situation of persons with an ABI, and contributing factors, is an American study done by Kreutzer and colleagues (2003). The following briefly describes this study to provide a background picture of what researchers are finding regarding the employment situation of persons following an ABI. Seeking to expand upon earlier studies of RTW following ABI, Kreutzer et al undertook a 4 years longitudinal study using a sample of 186 ABI individuals who were employed before their injury. The longitudinal sample appeared to have more severe injuries in comparison to the overall sample selected from, as was indicated by greater length of unconsciousness, greater acute care length of stay, and DRS score. The longitudinal sample comprised 61% severe, 22% moderate, and 17% mild brain injuries, as determined by admission Glasgow Coma Scale (GCS) score (Kreutzer et al, 2003, p.130).

Regarding employment status post-injury, Kreutzer et al found that as time since injury progressed, the proportion of employed people increased, and unemployment rates fell over time. This finding is consistent with research findings by Johnson, Possl and colleagues that employment rates improve over time (ibid). As for alternative work (e.g. homemaker, retiree, SE and, volunteer work) few people fell into this category during the follow up period (from 1% to 5%). Similarly, the number of people in the student category was small (ranging from 4% to 8%). Concerning job stability, Kreutzer and colleagues noted that 34% of participants were employed at all follow up intervals, 27% were employed at either one or two of the three follow up intervals, and more than 39% were unemployed at all follow up intervals. These researchers found the data to suggest

that a substantial number of people are able continue working for a number of years, whereas a slightly larger proportion is entirely unsuccessful. These authors note that their investigation of employment stability following ABI (released in 2003) is the first longitudinal study. Findings from this longitudinal study that are consistent with earlier studies on employment following ABI include: “Nonminority group members were more than twice as likely to be stably employed. Similarly, married people were more than twice as likely to be stably employed, people who completed high school or college educations had similar levels of job stability, and both groups were nearly twice as likely as people without a high school degree to be stably employed” (ibid, p.136).

Kreutzer et al note that the limitations of the study were that the sample group, were all employed before their injury and were recipients of comprehensive inpatient rehabilitation services therefore, generalization to patients receiving different levels of inpatient rehabilitation is uncertain. Furthermore, information about post-discharge rehabilitation services was unavailable. The authors thus encourage researchers to collect such information in future studies to help evaluate the efficacy of post acute services (ibid).

Current research on employment following ABI (e.g. literature reviewed in this paper) tends to focus on improving vocational rehabilitation assessment and rehabilitation methods, and gives little attention to employment alternatives for ABI survivors. Some researchers like Gamble and Moore, and Wehman however, mention the benefits of the supported employment (SE) alternative for ABI survivors who have difficulty securing mainstream employment (Gamble & Moore, 2003; Wehman, 1990). Gamble and Moore for example note that, in view of the low employment and retention rates of persons with severe ABI, SE is gaining favour as an intervention strategy, particularly as SE partakers have greater opportunity for increasing their rates of competitive employment and hence social inclusion than partakers in sheltered workshops and day programs (Gamble & Moore, 2003). This assertion is supported by a study undertaken by these authors where out of 84 ABI survivors, two-thirds returned to competitive employment following SE (ibid). These authors remark however, that SE as a viable employment alternative has

been criticized, not only in regards to ABI survivors with serious enough consequences to make mainstream employment difficult, but also in regards to all persons with serious disabilities: Not only do supported employees who have significant disabilities tend to work for a shorter period of time, earn substantially lower wages, and have fewer interactions with co-workers than supported employees with less serious disabilities, unfortunately, access to SE is often restricted to those perceived to be able to move on to competitive employment. Thus persons with severe multiple sclerosis, cerebral palsy, epilepsy, mental illness and physical impairments remain underrepresented in SE (ibid, p. 48).

Interestingly, no articles on ABI and employment consider the suitability of the consumer/survivor CED approach as a viable employment alternative for ABI survivors, and yet recent literature on employment following acquired brain injury (ABI), demonstrates that persons with ABI, particularly those with moderate to severe ABI, experience similar mainstream employment barriers, as do consumers/survivors, and demonstrate some similar employment needs (literature reviewed in this paper). For these reason, the purpose of the research undertaken in this paper, was to explore if the consumer/survivor CED approach to employment could assist ABI survivors (particularly those who experience significant mainstream employment barriers), in their employment goals. The main questions that this research sought to answer were: is there a need for employment alternatives for brain injury survivors in Hamilton, and if so, is the consumer/survivor CED approach a viable employment alternative for members of this group?

Research Methodology

One way in which systemic inequalities have been and continue to be maintained is through the use of research. Social research and social policy make choices that are heavily influenced by the dominant beliefs, values, ideologies, customs, and traditions of cultural and political elites and privileged strata (Gil, in Graham, 2000, p.112; Mies, in Kirby & Mckenna, 1989, p.15). Positivist social science research (PSS)(4) has traditionally been the methodology that has both enabled and supported these inequalities

(Kirby & McKenna, 1989). A “positivist researcher usually tries to solve problems as they are defined by government or corporate elites without “rocking the boat” (Neuman, 1997, p.74). The dominance of PSS in government efforts to improve the employment situation of persons with disabilities can be seen in the fact that disability employment policies, programs and services, are framed within the largely unchanging status quo of our capitalist system of labour. For example the *Making It Work* (2001) and the LMAPD policy frameworks above described. The result has been that mental health and disability policies and programs to go through cycles of reform, which generate no real change (Simmons qtd. in OCAB, 1995, p.2). The maintenance of this status quo can be deduced from the continuing high unemployment rate of 79% -85% among persons with serious mental health issues in Ontario and an overall unemployment rate of 50% among the disabled population in Ontario, and this after over 40 years since the start of deinstitutionalization (Wasylenki, et al qtd. in MOHLTC: MW, 2000, p.1; HRDC: PALS, 2001).

The research objective of this exploratory study is to explore the need for an employment alternative like the consumer/survivor CED approach, in Ontario that meets the specific needs of ABI survivors living in the community and desiring work. Whereas government disability employment-related research is based in PSS research methodology, consumer/survivor CED research leans towards a critical social science methodology (CSS). CSS is research that “critiques and transforms social relations” (Neuman, 1997, p. 74) The influence of CSS research methodology in consumer/survivor research can be seen in that consumer/survivor literature is rich with consumer/survivor history, stories, goals, and efforts to change the marginal reality that many consumers/survivors have, and continue to live. Unlike PSS research that assumes an unchanging social order, and hence defends the status quo of society, CSS research sees “current society as a particular stage in an ongoing process” (ibid). Considering the “social change” objective of this exploratory study, CSS is clearly the methodology most suitable. Moreover, CSS research fits well with the PHA and the social inclusion perspective that make up the conceptual framework for this study. The development of

these perspectives in social welfare and health policy discourse, demonstrate that there is awareness among social and health policy analysts that social relations should not remain fixed and unchanging, particularly in matters concerning the social welfare and health of all citizens. The emphasis in these perspectives for changes to the social relations that permit the social exclusion and poor health of various members of society reflects the goal of CSS research, which is to bring about social change through the transformation of social relations (ibid).

Research Methods

CSS strives to “describe a social order in such a way that it becomes itself the catalyst, which leads to the transformation of this social order” (Fay, qtd in Neuman, 1997, p. 74). This requires that researchers develop a strong understanding of an issue. Acquiring a strong qualitative understanding cannot come from objective research in the form of surveys and questionnaires alone, but calls for qualitative research methods in the form of personal interviews. PSS research methods provide facts about the situation and conditions of groups of people, but without qualitative research it becomes difficult to grasp a comprehensive understanding of the experiences of the research subjects. “The immediately perceived characteristics of objects, events or social relations rarely reveal everything... The events and relations of superficial social reality are based on deep structures beneath the surface of casual observation” (Neuman, 1997, p.75). CSS research is research from the margins, and if researchers do not cross over to the margins, the objective position they hold can only result in an objective solution. The CSS use of qualitative research enables the use of participant stories and experiences to provide colour and depth to their reality, as well as an emotional component that can inspire and motivate researchers to use their findings to affect social change. Thus, in-person questionnaires and interviews were the most appropriate method to gather a qualitative understanding of all participants’ perspectives on the employment situation and areas for improvement pertaining to ABI survivors and consumer/survivors.

Research Procedure

The CSS research approach argues that social reality has multiple layers and that uncovering the deep structures on which the events and relations of social reality are based requires effort: “Intense and directed questioning, a good theory about where to look, a clear value position, and a historical orientation help the critical researcher probe below the surface reality and discover the deep structures” (ibid).

This thesis has presented a historical and contemporary orientation of disability and employment issues in Canada to emphasise the need for employment alternatives that meet the unique needs of ABI survivors not able to find or secure mainstream employment. Additionally, the thesis includes a clear value position and supporting conceptual framework.

Structural Social Work is a theory that applies to the social inclusion and PHA perspectives that constitute this conceptual framework. This theory posits that personal issues come from inequities in our societal structures and institutions. Furthermore, the combination of our capitalist political economy with a liberal social welfare state perpetuates harmful exclusions of various citizens based on class, gender, race, age, sexual orientation, or physical and mental health. These inequities are maintained through oppressive, dominant ideology that individuals partially adopt and that tends to individualize and psychologize problems and solutions (Moreau, et al, 1993, p.2). CSS research requires the underlying theory of a research project to grow and interact with the world it seeks to explain (Neuman, 1997, p.77). One important characteristic of Structural Social Work that enables such modification is the concept adopted from feminist theory that ‘the personal is political’. Making ‘the personal political’ involves working to dismantle structural and systemic inequalities through empowerment at the worker/service user, agency, and social policy levels. The choice of Structural Social Work theory for the conceptual framework of this thesis is to ensure that the data provided by ABI research participants in this study will influence future employment policy decisions in their favour.

For a CSS researcher, intense and direct questioning is not directed only at the research participants but the researcher is also required to engage in direct and intense

questioning of him/herself and their role in the research (Kirby & McKenna, 1989). In CSS research therefore, the researcher does not remain “objective” (as in the PSS research sense), but instead tries to “eliminate the division between the researcher and those being researched” (Neuman, 1997, p. 78). One way in which to begin to eliminate this division, is for the researcher to self-examine and to share with the research participants, his or her reasons for doing the research, and also the purpose of the research (Kirby & McKenna, 1989). Sharing my reason for doing the research and the purpose of the research began in the meetings with ABI survivors, consumer/survivors and brain injury service providers where I presented my research proposal. My reason for undertaking the research study in this paper, developed from a three-year relationship with a person who had previously acquired two brain injuries and who desired employment, but was perpetually unsuccessful at securing a job. This experience demonstrated the lack of employment services and alternatives for ABI survivors, which often leaves survivors frustrated, angry, and feeling helpless. Hence, I have developed a genuine interest in understanding employment barriers facing persons with ABI, in the programs (or lack of) being introduced to assist them in their employment needs, and in necessary improvements.

I recognize that my relationship with a person who had suffered two brain injuries and also developed SPMHI does not entitle me to ‘insider’ (s) status in either the consumer/survivor or brain injury communities. I acknowledge that my social location as an academic and ‘non-disabled’ person may contrast with that of persons in both the consumer/survivor and the ABI communities. However, my structural barriers from being a woman and a ‘visible’ minority provide me with an understanding of marginalization, which can be viewed as a connector across differences between individuals. Moreover, people must work together across differences to cause social change. CSS research requires that a researcher dig beneath the surface of social reality. Hence, I decided to share my personal history and research goals with participants to demonstrate that I have previous ‘insider’ knowledge regarding employment experiences of consumer/survivors

and persons with ABI, and to address possible initial reserve that some participants could have to participating in this study.

The primary research for this study began with employees of the consumer/survivor CED called A-Way Express Courier, to develop an understanding of the benefits and challenges pertaining to these businesses. Although, there is an abundance of available literature resources regarding CEDs, my intention was to visit a CED business and interview employees to gain a pragmatic understanding of the business approach. Moreover, considering that brain injury survivors are not limited to particular class, race or personal ability, and I suspected that there would be consumers/survivors in CED businesses who also have an ABI. The subsequent organizations involved in this study included Hamilton Brain Injury Association (HBIA), Brain Injury Services of Hamilton (BISH), McMaster Outpatient Psychiatric Clinic, and St. Joseph's Mountain Health Care. Upon the study's approval from the McMaster University Research Ethics Board, I contacted the target organizations to present the research proposal and set-up interviews with interested participants.

Using qualitative research, this exploratory study sought to develop a comprehensive understanding of participants' experiences with/perspectives on disability and employment, as well as their opinions regarding existing or possible employment alternatives. Interviews with each participant lasted from 30-60 minutes at their organization location. Correspondingly, the interviews were transcribed with participant permission (specific responses to questions were removed upon participant request). The interviews were semi-structured and incorporated an interview outline to guide the interview process. ABI and consumer/survivor participants were asked open-ended questions pertaining to their brain injury and the resulting employment/life consequences. Service provider participants were asked open-ended questions pertaining to their knowledge of existing employment supports and services in Hamilton for ABI service users, as well as perceived service gaps and possible alternatives.

Limitations of Exploratory Study

The research component of this study initially planned for interviews with employees from the following consumer/survivor organizations: Raging Spoon, Out of This World Café, Rainbow Enterprises, Parkdale Green Thumb Enterprises, and Fresh Start Cleaning Services. However, the lack of funds for an honorarium created a disincentive for consumers/survivors to participate in the study and resulted in one consumer/survivor CED interview organization: A-Way Express (for which an out-of-pocket honorarium was provided). Fortunately, the information gathered from A-Way participants combined with consumer/survivor CED literature from OCAB provided a comprehensive understanding of the health benefits of consumer/survivor CEDs to members, and the organizational challenges that are common to consumer/survivor CEDs.

Additionally, this study did not include interviews with ABI survivors with serious mental health issues. Service users of the St Joseph's ABI Program are generally in a state of personal crisis, and I assumed they would not be interested in discussing employment barriers during this stage of their life. However, their participation in the study may have provided greater insight into the mental health and the cognitive behavioural supports that an ABI survivor CED would require.

Another limitation of this study is that it did not explore the influence of the consumer/survivor CED perspective of viewing the economy as a means to rebuild the lives of consumers/survivors, (as opposed to viewing human development as the means to economic development, as does our capitalist economic system) on members' understanding of and hence, sense of social inclusion. An exploration of whether members subscribe to the consumer/survivor CED's perspective here, would assist in gathering an understanding of whether members' increased sense of social inclusion is on account of doing meaningful work, or is because of the consumer/survivor CED perspective of not viewing work as definitional of human worth.

Finally, this study had limited variation with regards to race, gender, ethnicity, and physical location. The participants were white, urban, English speaking Canadians. Greater participant diversity might have enabled discussion on additional structural

employment barriers facing ABI survivors that include mental health, gender, culture, language, sexual preference, and race, and some ideas on accommodations/supports, for example for ABI survivors seeking employment, where English is a second language.

Primary Research

Interviews with A-Way Employees

The exploratory study included 7 consumers/survivors at A-Way: 1 was the executive director, 1 was an assistant director, 1 was an administrative assistant, 1 was part-time courier and part-time receptionist, 1 was a part-time clerk, and 2 couriers. All were of working age and between the ages of 40-55, except 1 courier who was 30 years of age. Of the 7 participants, 2 had high school education, 1 had completed an undergraduate degree, and 1 (executive director) had completed 2 master degrees. Out of all participants, only 2 were women. The interviews with A-Way participants were designed to provide a pragmatic understanding of the popularity of this employment approach among consumers/survivors over mainstream and supported or sheltered employment. Additionally, this group could provide critical knowledge regarding organizational challenges, and also, participant attitudes to the idea of persons with a brain injury working together with consumers/survivors who do not have a brain injury.

As the participants described their employment experiences prior to A-Way, and their life experiences since working at this CED, a number of key themes emerged relating to the role that consumer/survivor CEDs play in furthering and maintaining the health and well being of consumers/survivors.

Competence

A dominant theme in each interview with A-Way employees was that consumer/survivor businesses emphasise the competencies of consumers/survivors. It was noted that although employment and vocational rehabilitation programs also focus on clients' competencies, the support provided is framed within the boundaries of the limitations imposed on clients' by their diagnosed mental illness. Conversely,

consumer/survivor CEDs encourage employees to raise their expectations for themselves. 5 of the 7 A-Way study participants explained that under the support of vocational rehabilitation or SE programs, the jobs they were deemed competent for were limited to janitorial work, however, the A-Way courier position (which is the entry level job) is much more challenging and demanding than the janitor position, and couriers accomplish their work duties just fine.

The participants unanimously concurred that whereas in vocational rehabilitation and SE programs a person's 'work readiness' and capabilities are examined first, before they are assisted with their employment goals, A-Way employees are provided a position first, then provided with whatever employment support that their peers and A-Way can offer for them to perform the job. Additionally, in vocational rehabilitation and SE programs, service users are assessed by professionals who are external to consumer/survivor communities and hence, who may not be fully aware of consumer/survivor needs (Church, 2000, p.7). The crucial difference between the consumer/survivor approach to employment and that of vocational rehabilitation and SE is summed by one participant's comment that: "in consumer/survivor businesses, people really believe you can do the job, and that's empowering!" This difference is further demonstrated by Church's comment that consumer/survivor businesses "were created to employ psychiatric survivors, particularly those who have been classified 'permanently unemployable' as well as 'mentally ill' (ibid).

Accommodation

Accommodation was also a key theme that emerged in the interviews. OCAB explains that the term "accommodation" involves not only ways to make workplace environments accessible and comfortable for consumers/survivors, but also means that the peculiarities associated with "mental illness" be viewed "not as an inherent part of a sick or bad personality, but as cultural expressions of belonging to a group which merits the same kind of tolerance we would extend to any community of difference in Canadian society" (OCAB, 1995, p.15). According to A-Way participants, there is minimal accommodation for consumers/survivors with regards to SE and mainstream

employment. For example, one courier mentioned that 4 years ago he was working as a janitor, but was fired when he could not do his job well enough. He noted that his employment termination coincided with his development of a serious mental health issue that at the time had not yet been diagnosed. However, the employer had preferred to let him go, than to try to assist him through supports such as 'flex time' and workload management. The lack of mainstream and SE employment accommodation for consumers/survivors is demonstrated by participants' highlighting the fact that there are long waiting lists for employment in all existing consumer/survivor CEDs.

Productivity and Economic Independence

Productivity and economic independence was another important theme discussed in the interviews with A-Way employees. Each participant described lengthy, unproductive periods of unemployment prior to joining A-Way. They asserted that A-Way provides them with a sense of productiveness and contribution -something they did not feel in sheltered employment or while performing menial jobs like janitorial work. A-Way executive director observed this stating, "The real benefit to couriers is that it's a job they can do and its meaningful work- not like "make work" jobs which are jobs that keep people busy, but not productive, and are not rewarding". Moreover, employment with A-Way provides a measure of economic independence for couriers who are permitted to earn \$160 (a single person) a month before ODSP deductions, which the participants themselves acknowledged as helpful and of value to their daily lives.

Social Exclusion

The social exclusion experienced by consumers/survivors and the corresponding feelings of low self-esteem and self-worth were important issues that surfaced in the research interviews. The A-Way participants' emphasised the improvements that working for A-Way had provided to their lives. These improvements included higher self-esteem, self-worth, self-determination, power, control, and overall happiness. Conversely, the participants described their prior employment experiences negatively in terms that included long-term unemployment, hospitalisation, aloneness, and in most cases abject poverty. One participant stated that, "A-Way helps us believe in ourselves and that we are

valuable contributors to the community.” Another participant described the change in himself since working at A-Way as, “a before and after picture” and as “different as night and day.”

Therapeutic Benefits & Sense of Community

The therapeutic benefits derived from working at A-Way were acknowledged as critical to the study participants at A-Way. They asserted that working with peers and receiving training from peers is therapeutic. One participant explained that the demands of the courier job (learning to read maps, learning the city of Toronto, communicating with customers) over 4 years, helped to improve his focus, concentration, and memory. Another courier who had survived two brain injuries (that resulted in a serious limp), observed that since working at A-Way (has been a courier for 9 years) and walking to and from destinations delivering mail, he has improved his balance and co-ordination to the point that he no longer has a discernable limp. For all participants, particularly couriers, there is therapeutic value in working at a job that is ‘permanent’; that is where one is not worried about being fired or about being expected to ‘move on’ to other jobs. All courier participants noted that they appreciate the therapeutic value in peer support and friendship among workers, and also the after work social events and activities. A courier referred to A-Way as a safe and familiar island with a “gentleness to it, which is rare”. Finally, a founding employee (diagnosed as schizo-effective, bi-polar, and with manic depression in his 20s) asserted that he wouldn’t be the same without A-Way, and would probably have committed suicide in the past. He was a courier for over 15 years, but is getting elderly. A-Way has accommodated his changing needs by offering him clerk duties two shifts a week. Thus, in contrast to vocational rehabilitation programs, which offer a set of stringent professional practices that consumers/survivors must adhere to; consumer/survivor CEDs use economic development as a means to recover and rebuild the lives of consumers/survivors (OCAB, 1995).

The A-Way participants unanimously concurred that there is a sense of ‘being a part of’ and ‘belonging’ at A-Way. This is an essential, positive emotion for consumers/survivors living in a society that is generally not accepting of

consumer/survivor peculiarities. Moreover, the sense of community at A-Way is derived from organizational support for 'flex time'. One participant described the benefit of flex time as, "When, because of personal mental health issues, you need to, you can take a leave of absence –whether its one week, two weeks or two-three months, and you don't have to fear loosing your job." A-Way maintains a large group of couriers that work an average two shifts a week with 2 assistant directors and a number of dispatchers. Furthermore, flex time, is made possible by A-Way's emphasis on peer training. The organization reinforces community and goodwill by providing the Toronto metro pass to couriers, (which is useful for work and personal time as well). This provides a significant cost savings (\$80.00) and freedom for couriers in Toronto who are living off of a limited income (all are ODSP recipients). Participants emphasised that the sense of community is reinforced by the equitable and democratic ways that are characteristics of this CED. For example, the administrative assistant noted that of the 12 board members, 6 are A-Way employees (including couriers).

A Consumer/Survivor CED for/with Persons with ABI?

As already mentioned, A-Way executive director informed that 2 employees are ABI survivors. She and the other participants explained that including persons with ABI in a consumer/survivor CED is not a problem, since the only requirement for working in these initiatives, is that applicants must have (or have experienced) a diagnosed mental health issue.

A-Way Organizational Challenges

A-Way executive director noted that a major challenge A-Way is presently facing is the need for more funding, especially as the cost of business has gone up over the years. The A-Way board wants to increase funds through fundraising, however this is a bit of a challenge, because consumer/survivor CEDs by description are businesses, thus A-Way cannot have a charity number. The main source of finance for A-Way is from MOHLTC and money made by the business (about \$7000 a year), however there has been no increase in funding from MOHLTC, in 10-12 years. She expressed that A-Way

would like to employ more couriers, and generate more income, however, if A-Way were to employ more couriers, it would need to hire more administrative staff and raise administration fees by at least 5%, to cover the costs of involved in hiring and training more couriers. To illustrate this point, she gave the following example: A-Way currently employs 50 couriers, and on average 80 deliveries are made a day. If A-Way were to hire 20 more couriers and increase deliveries to 125 deliveries a day, the only benefit would be that 20 more couriers are hired, for the reality is that without hiring more administration, the increase in courier employees would wear everybody out: the existing administration team will only do more and more work (more paper work, more training and job shadowing of new employees).

Another challenge identified by A-Way's executive director, and one that she identifies as running contrary to A-Way goals of creating jobs that meet the needs of consumer/survivors, is what to do when an employee is not able to meet the specific job requirement and there is no other job and/or no funds to create a job for them that might meet their employment capabilities? For example a courier who was trained and job shadowed for six months, recently demonstrated inability to get to pick up and delivery stops on his own, yet the nature of a courier job does not call for a courier to be job shadowed indefinitely. Therefore, if there is no available job at A-Way that can address the specific employment needs of the person in question, they are obliged to let him/her go. A-Way executive director stressed that such a problem could be avoided if there was more different types of consumer/survivor CEDs, where, with more job opportunities available, consumers/survivors could have better chances at finding a good job match.

One A-Way challenge highlighted by a courier was that of hierarchy within the organization. This participant expressed that persons in administrative positions do not treat couriers (lowest paid position --by commission) the same way they treat each other. To illustrate this, she/he stated: "Administrative staff will sometimes order pizza for lunch and eat among themselves, but the couriers are not invited."

These A-Way challenges are important as they demonstrate some challenges that can happen in community economic development particularly those that like A-Way

combine both economic and social goals (Perry & Lewis, 1994, p.26). Awareness of such challenges is significant to those looking to create an ABI survivor CED for a pragmatic picture of potential challenges, facilitates discussion on possible ways to avoid or address such challenges.

Interviews with ABI Survivors

In the interviews with ABI survivors, similar themes arose to those discussed by A-Way consumer/survivor participants in this study, however unlike in the A-Way interviews where there was a clear sense of empowerment and praxis (6), the interviews with ABI participants revealed a sense of disempowerment among participants. A total of 10 ABI survivors participated in this exploratory study: 6 from the Hamilton Brain Injury Association (HBIA) support group, and 4 from the Brain Injury Services of Hamilton (BISH). Of all these participants, only 2 were women. From brain injury survivors desiring employment, I was looking to learn what their employment situation was like since they acquired a brain injury, in what ways their brain injury has affected their work-related abilities, if they had heard about consumer/survivor CEDs, whether they would be interested in creating an ABI survivor CED and if so, what would type(s) of business could they see themselves doing?

Out of the 10 ABI participants in this study, 6 had been employed for over 5 years at the time of their injury, 5 of which were making good to great wages (truck driver, bank manager, welder, park warden, and independent business consultant), and 1 who had been working part-time (janitor). Of the other 4 participants, 2 had acquired a brain injury when children, and the other 2 were students at the time. All participants except for 4 had above high school education: 2 had an undergraduate degree, 2 had a college degree, and 1 had two Master degrees and a PHD. All ABI participants who had been employed at the time of their brain injury have not succeeded in securing employment since.

The causes of ABI among participants included car accidents, organic infection, projectile injury (where skull is penetrated by an object), strokes and aneurysms. Related consequences included impairments in cognitive abilities such as a loss in organizational

abilities and memory impairments (short and long-term), a decrease in patience since the brain injury (as noted only by the male participants), an increase in impulsiveness, and a decrease in inhibition. Physical changes included discernable limping (only among 2 participants), vision (1 participant had lost vision in one eye, another had partial vision in one eye) and a decrease in dexterity (2 participants).

Competence

As with A-Way participants in this exploratory study, competence was a key theme that arose in the interviews with ABI survivor participants. 5 ABI participants who had been employed at the time of their brain injury, and 1 who had been a student, described their post ABI employment experiences as a painful discovery of their new limitations. 1 participant for example (independent business consultant) explained that following his brain injury, he was told by clients not to come back. It wasn't until after a number of neurological and psychological tests that he learned that his brain injury had left him with extensive damage in the frontal lobes and temporal lobes, (areas that are known for organization and executive abilities).

9 of the 10 ABI participants expressed how the limited perception that vocational rehabilitation professionals and paraprofessionals had of their capabilities, compounded by personal awareness of the consequences of their brain injury on certain abilities, resulted in them, feelings that included anger, sadness, depression, low self-esteem and low self-worth. For example, 1 participant who has been on work disability for 2 years, said that he was recently assessed by the Canada Pension Plan (CPP) disability vocational rehabilitation program, and was told that he was not yet ready to be re-trained for any job remotely similar to his post-injury employment. This participant noted that this assessment reinforced his existing depression over the changes that his ABI has had on his abilities.

Accommodation

Similar to A-Way participants in this study, accommodation was an important issue for ABI survivor participants. Of the 5 ABI participants who were working for an

employer at the time of their brain injury, only 1 said his employer had tried to accommodate him in the workplace. This had involved a trial period for a less demanding position, however when the employee demonstrated serious difficulty and inability to perform, it was a mutual decision to go on disability pension. Excepting 1 participant, the 5 others noted that the consequences of their ABI made it self-apparent that they could no longer perform their previous work duties and hence, they understood why they lost their job. On the other hand, participants noted that what was upsetting, was the lack of success they had in finding jobs in the mainstream labour market, and associated this situation with the consequences of their brain injury. For example, 1 participant mentioned that as a consequence of his brain injury, he has less mobility and dexterity in one hand. He was assisted to find a job placement where he could use some of his previous workplace skills as carpenter, through the help of the March of Dimes vocational rehabilitation services. Although the employer was satisfied with the work he performed, he was not hired, and the reason provided was that he was too slow.

Productivity and Economic Independence

Productivity and economic independence was a key theme discussed among ABI participants in this study. However, unlike A-Way participants where the focus had been on the productivity and measure of economic independence gained from working at A-Way, ABI participants discussed this theme in relation to the loss in productivity and (for 7 of the 10 participants) the loss of economic independence.

ABI participants in this study revealed that their job-search efforts post-ABI followed a similar route as that of consumer/survivors: Through general community employment services, disability employment services, and through the more ABI-specific community rehabilitation services.

All ABI participants expressed that vocational rehabilitation and job search experiences have been both draining and demeaning, and for 7 of the 10 participants, not fruitful at all. 6 participants expressed that they were frustrated with the menial job options that they had been deemed competent for (e.g. janitorial), particularly as their pre-ABI employment positions had been much more demanding and rewarding. 1

participant noted that she manages to secure jobs in sales and as a waitress off and on, but is currently unemployed. 3 participants (2 of whom sustained a brain injury as children, and 1 who was born with a learning disability) who were currently employed off and on in janitorial and cooking positions, though less indignant over the limited job options available for many persons post-ABI, also expressed that they believed they were capable of much more than a 'prep-cook' or janitorial position. As 1 of them explained, "I know some jobs are harder than others, but with training, I know I could do more than janitorial work –after all, I have a child and manage to responsibly take care of him."

As with A-Way courier participants in this study, economic dependency on the limited ODSP monthly income of \$930 (a single person) made living around the 'poverty line' an unchanging reality for 7 of the 10 ABI participants. While they mentioned that they are grateful for ODSP, they expressed frustration at the fact that it is not possible to live above the 'poverty line' while on ODSP. For example, 1 participant said he was on a waiting list for low-income housing for over two years, and was happy when he was offered an apartment where he is only required to pay \$200 a month in rent. However, this reduction in his rent was matched by a reduction in his monthly ODSP; that is, he went from \$930 ODSP a month to \$730 a month.

Social Exclusion

Another possible consequence of ABI, and a key theme that arose during the interviews, was that of social exclusion. Although employment was a significant concern for 9 of the 10 ABI participants, they highlighted that the loss of a job was just one of the many losses they had to cope with. Participants expressed that the loss of certain abilities, the loss of a job, the loss of friends and even loved ones, the loss of independence and the freedom to enjoy social pleasures such as alcohol, smoking, and driving -basically the loss of the life they had prior to the brain injury, resulted in them feeling alienated and socially excluded. For example, 7 of the 10 ABI participants had been in intimate relationships at the time they acquired a brain injury, and at the time of this study, only 1 of the 7, had not separated from his intimate partner. Moreover, those who had children were struggling to maintain their relations with them. Participants noted that the main

reason for their partner's decision to separate was that since their brain injury, the ABI survivor was "no longer the same person"; that they were "quick to anger" and/or said inappropriate things that embarrassed or upset people; and that they were "lazy". In relation to the public, it was noted that the experience of stigma because of the visible consequences of a brain injury or from disclosing consequences such as that of being unemployed, is not uncommon.

The Need for More Therapeutic Venues

One important theme that arose in the interviews with ABI participants in this study, was the lack of venues in Hamilton that enable ABI survivors to continue to work on things they would like to improve on post-discharge from a community or hospital rehabilitation setting. For example it was noted that group work in areas like memory improvement exercises, or exercises to improve balance and dexterity, would greatly be appreciated by many who have difficulty with self-motivation post-ABI. ABI participants from the HBIA support group that meets once a week highlighted the benefits of this peer-group support to their self-esteem, and coping abilities, and also to building a sense of community among the ABI group members.

An ABI CED?

All ABI participants welcomed the idea of an ABI CED, and especially appreciated the notion of "collective employment" where the focus would be on using their remaining skills and strengths to make a business work. Suggestions for an ABI CED included seasonal business such as gardening and snow blowing, pet therapy, a café, and carpentry. Participants' enthusiasm for an ABI survivor CED was however tainted by concerns with a lack of financial incentive, particularly among ODSP recipients (considering the limited \$160 a month on allowable earnings before income deductions). Furthermore, the 2 CDPP recipients highlighted that in view of their disability, they doubt that in an ABI survivor CED, they could generate more income than that provided by their CDPP benefits. A similar response was provided by 1 participant who had acquired a brain injury in a car accident (2 years ago) and who was receiving a comfortable monthly sum in insurance dollars. In spite of the financial disincentive, 9 of

the 10 ABI survivor participants expressed that they would be interested in an ABI survivor CED, if only for the reciprocal therapeutic value of supporting other brain injury survivors, and building the ABI community.

When asked how many hours one would like to work in a week, the responses ranged from as low as 2 hours a day of non-physical work, to a regular 8 hours 5 days a week schedule. This wide range in hours suggests either the diverse consequences of ABI (whereas fatigue is a serious issue for some ABI survivors, but for others is not), or could point to the lack of insight about the self that a number of researcher have expressed as common to ABI survivors (Ylvisaker et al, 2003; Paterson & Stewart, 2002).

An ABI Survivor CED with Persons with ABI and/or Serious Mental Health Issues?

All brain injury participants interviewed said they could see themselves working in a business together with persons with a brain injury and/or mental health issues, so long as the issues are not serious enough to threaten the safety of others, and they could be guaranteed of their safety. This response reflects the stigma that still exists among the general population about serious mental health issues.

The key themes that arose in the interviews with ABI participants in this study revealed that employment services and programs accessed by ABI survivors have not effectively assisted them with their employment goals. Interviews with ABI and mental health service providers involved further discussion of these themes from a service provider perspective.

Interviews with Service Providers

Service providers interviewed included the HBIA support group facilitator, 2 ABI community rehabilitation staff from BISH, 1 social worker from the St Joseph's Mountain Healthcare ABI program, and 1 occupational therapist from McMaster Outpatient Psychiatric Clinic. In choosing staff from both community ABI programs and hospital settings, I was looking to get an overall perspective on the employment services and supports available for ABI survivors in Hamilton, opinion on what the gaps are in these services and supports, whether there is a need for employment alternatives such as a

CED for ABI survivors in Hamilton, and if so, whether service providers believe a consumer/survivor CED approach to be a viable employment alternative for ABI survivors.

BISH and the St Joseph's ABI program service providers described their service users as follows: Service users come from inpatient (hospital) and outpatient (community rehabilitation) programs, and also from the community (those who went straight home following discharge, and those who never were hospitalised nor went to a rehabilitation program). Typically, service users are survivors of closed head injuries, and less often are there service users who are survivors of open head injuries (e.g. projectile injuries). There is a wide range in education among service users, ranging from professionals to those who have not completed high school. A number of ABI survivors that use the services of BISH are employed, and rely on BISH mostly for the support network -These clients typically have mild brain injuries and do not have as much difficulty securing mainstream employment, unlike the clients with more severe brain injuries. Most of the service users of both services are male and most acquired a head injury when in their twenties'. The service provider at the Psychiatry Outpatient Clinic at McMaster hospital, described service users as predominantly consumers/survivors, however, she stated that although the clinic does not target ABI survivors, it does not exclude them either. For example, a couple of current clients of the clinic were brain injury survivors. I found this information pertinent for it demonstrates that awareness of ABI survivors and of their expressed needs is growing among the social service sector in Hamilton.

Competence

All service providers interviewed in this exploratory study acknowledged the devastating impact that serious and persistent mental health issues (SPMHI) and/or an ABI can have on the actual and perceived competencies (including the self-perceived competencies) of a person. Moreover, they highlighted the need for more ABI targeted employment services, better assessment measures of ABI survivors' competencies, and better employment supports such as a strong support network (that includes professionals

that are knowledgeable on ABI to assure that ABI survivors are effectively supported in matters concerning their competencies).

Accommodation

The discussion of the theme of accommodation in interviews with service providers revealed the lack of knowledge about ABI among community employment and general disability employment services providers, and also among employers. For example, 1 BISH service provider explained that a BISH staff sometimes go with clients to vocational employment services, however service providers in these agencies may not know much about ABI, and as a consequence do not effectively assess and assist the client in finding a suitable employment match. The result is the “revolving door syndrome” where previous service users find themselves once again on the doorsteps of ABI agencies. ABI service providers interviewed noted that because their services are uniquely for ABI survivors, they are knowledgeable about ABI. Therefore when assisting a service user with his/her job search, they can support the service user in informing potential employers on their ABI-related employment support needs. ABI and BISH service provider emphasised that this type of support has resulted in a number of ABI service users being successfully accommodated in workplaces. BISH’s examples of workplaces that have successfully accommodated ABI service users with more severe ABI included: Tim Hortons, Fortinos Supermarket, and The Barn.

Productivity and Economic Independence

Alongside the theme of accommodation, a discussion of the theme of productivity and economic independence for ABI survivors, revealed a lack of ABI disability-specific employment services in the Hamilton area, and also a lack in government funding to existing disability organizations in the community such as BISH that has demonstrated success in assisting ABI service users to increase their productivity and economic independence. The employment support that BISH offers to service users is SE services. BISH service providers interviewed, explained that BISH would like to provide a SE program rather than just SE services, however, BISH has not been successful in securing

EAPD (LMAPD) funding. EAPD currently funds employment programs that offer employment service to a wider range of persons with disabilities, than services like BISH that targets only ABI survivors. BISH explained that whereas they would like to provide longer periods of SE for service users who may need it, there is not enough staff or funds (funding is mostly from the MOHLTC and SE is just one of the brain injury services offered by BISH) to enable this support.

All service providers interviewed mentioned that apart from societal barriers, some service users also present personal barriers to employment, the most significant of which is a 'lack of insight' into personal capabilities. For example, 1 service provider explained that, "whereas some ABI survivors have insight into their limitations, there are some that don't and consequently, think they can get a job anywhere. Oftentimes, as time since injury passes, some service users gain more insight into limitations, some however don't". The occupational therapist of the McMaster Outpatient Psychiatric Clinic, also noted that there are some consumers/survivors who 'lack insight' into their abilities. All service providers stressed that a 'lack of insight' is a major personal barrier to securing employment.

Another personal barrier to maintaining employment highlighted by ABI service providers, was the inappropriate behaviour that is common to ABI survivors. Examples of such behaviour include sexually inappropriate comments or behaviour, and verbal abuse of others. ABI service providers interviewed noted that other of ABI-related personal challenges that tend to limit many ABI survivors' mainstream employment chances include as memory impairment, poor concentration, fatigue and a lack of motivation. The St Joseph's ABI program service provider observed however, that some ABI service users of the ABI program have learned to compensate for some impairments, and also to manage their personal issues well enough to secure competitive employment. All service providers concluded that effectively assisting ABI service users in their employment goals requires the combined efforts, and if necessary continued support of ABI professionals, para-professionals, family and friends of the ABI service users.

Social Exclusion

Aside personal barriers to mainstream employment all service providers interviewed, note there are a number of barriers to community inclusion on the whole. One significant barrier is the lack of knowledge on ABI in the general public and among employers, and hence a lack of understanding about ABI. ABI service providers noted that service users are often perceived by non-disabled persons in the community as “mentally ill” or “developmentally delayed” which results in an increased sense of alienation and lower self-esteem among ABI survivors. ABI service providers highlighted that more awareness in the community about ABI is needed to address the misperceptions that persons in the community have about ABI.

An ABI CED?

ABI service providers interviewed strongly supported the idea of an ABI survivor CED, but emphasised that for it to be successful, it would need to assure employment supports that are specific to the particular needs of individual ABI employees. To illustrate this point, 1 service provider gave the example of an ABI service user whose memory of past things learned is intact, but who has lost the ability to retain new things learned, and also the ability to self-motivate. Hence while this ABI survivor can effectively do his previous work duties, he will only do them if someone assists him with motivation, through ways such as asking him how the job he is working on is progressing. Without this support, this ABI survivor (though not intentionally) will simply not do the job. Therefore, while the ‘collective employment’ approach of consumer/survivor CEDs is indeed an attractive employment alternative, finding a good mix of ABI employees so that various employment supports can be guaranteed could be challenging.

All service providers interviewed, in particular those that service mental health/ABI populations, could see the possibility of ABI survivors and consumers/survivors working together. In fact the occupational therapist noted that she is currently involved with a consumer/survivor group in Hamilton that is working on creating a consumer/survivor CED. She indicated that while the CED is intended to be

consumer/survivor-run, it would not exclude ABI survivors who also experience mental health issues.

The main themes that arose in interviews with ABI and mental health service providers, demonstrated a lack of employment services supports and alternatives, that target the employment specific needs of many ABI survivors, in particular those who cannot secure mainstream employment.

Analysis of Research Findings

My interviews with A-Way consumer/survivor CED employees, ABI survivors, and ABI/mental health service providers discovered a series of issues and themes concerned with mainstream employment barriers facing persons with ABI and persons with serious mental health issues. An analysis of the key themes: Competence, accommodation, productivity and economic independence illustrates that current Ontario disability employment programs and services are not meeting the employment goals of ABI survivors and members of other disability groups, in particular, those who by mainstream employment standards have been perceived as presently or permanently unemployable.

Competence

Competence was an important theme that emerged in the interviews with the three groups listed above. A-Way and ABI participants discussed this theme in relation to the misperceptions that mainstream employers and vocational rehabilitation employers have regarding their capabilities. These participants underlined that employment services and programs have limited their employment expectations to less meaningful and less challenging jobs (e.g. janitorial, cooking, and cleaning positions), whereas they believe that they are capable of much more. These opinions are supported by Wright's assertion that "People with disabilities will tell you that the greatest single barrier they experience is not the disability itself, but attitudinal barriers and misperceptions about their skills and ability to add value in a workplace setting" (Wright, 2002, p.2).

Whereas, ABI service providers in this exploratory study shared the same opinion as the ABI participants: That the abilities of ABI survivors tend not to be adequately assessed by general employment and disability vocational rehabilitation services; they highlighted that ABI survivors can also misperceive their own competencies. These service providers explained that an ABI survivor's misperception of his/her own competencies results from his/her 'lack of insight' about his/her abilities post injury, especially in the earlier years. Hence, it is not uncommon for ABI survivors to be capable of much less than what they self-report, and conversely, to demonstrate more capabilities than what they self-report. This finding is consistent with current research that affirms that impaired self-awareness and self-regulation skills are a common sequel of ABI, which consequently has psychosocial consequences (Kolakowsky & Kreutzer, 2001; Ownsworth et al, 2000; Paterson & Stewart, 2002; Ylvisaker et al, 2003). The mental health occupational therapist noted that consumers/survivors may also 'lack insight' into their limitations.

Limitations regarding insight and misperception are not significant under the consumer/survivor CED approach to employment, because its value proposition is that all consumers/survivors are capable of meaningful work (OCAB, 1995, p.6). ABI participants in this study expressed a decreased sense of competence, self-worth, and self-esteem as a result of the consequences of their brain injury, and also their negative vocational rehabilitation and employment experiences post-ABI. A-Way participants outlined the various ways (e.g. peer-support, community building, empowerment) through which A-Way has assisted them to increase their self-worth and sense of competence since working for the courier. Thus, the consumer/survivor CED perspective that all persons are capable of contributing meaningful employment activity to a business could also assist ABI survivors to regain or to increase their sense of competence and worth.

Accommodation

Regarding the accommodation of ABI survivors in the economic market, interviews with 10 ABI participants and 4 service providers, established that there is a

lack of knowledge regarding ABI among employment service staff and employers, which creates misperception, negative attitudes, and misunderstanding about this group among employers. The ABI interview participants perceive that consequences of their brain injuries contribute directly to employers' unwillingness to accommodate them. Moreover, A-Way participants expressed similar feelings of rejection from mainstream employers, which they attributed to their serious mental health issues. These opinions exemplify other studies' findings that "People with disabilities often find employment difficult to attain and feel excluded from the labour market, because of their disabilities" (Kregel & Unger, 1993, Satcher & Dooley-Dickey, 1992 in Gilbride et al, 2000, p.1). Similarly, the 1996 report *The Will to Act* by the Canadian Federal Task Forces on Disability Issues concluded that one of the key barriers preventing many persons with disabilities from fully participating in the Canadian economy continues to be the stereotyping of and negative attitudes towards persons with disabilities (Wilkerson, 2001, p.13).

This finding is contradicted by recent research conducted by the Conference Board of Canada and the Ontario Ministry of Citizenship, which found that "employers demonstrate a high degree of awareness and support for diversity in the workplace and have policies about making their workplace more representative of the general population" (Wright, 2002, p.1). Employers in the study noted that the main reason why they haven't hired people with disabilities is that they lack "experience going outside "mainstream" sources to find and recruit personnel" (ibid). Similarly, ABI service provider participants in this study recognized that there is a need for vocational rehabilitation service providers to create awareness and to educate mainstream employers about ABI, resolve this problem, and increase ABI employment opportunities. These ABI service providers asserted that in cases where they have contacted potential employers, assisted the employer to see the potential of an ABI applicant, and provided knowledge regarding ABI, employers have been willing to employ persons with ABI. This assertion is supported by a study by Gilbride et al on employers' attitudes towards hiring persons with disabilities (including brain injury survivors), which found that employers who hired the most disabled persons were those who were contacted the most by vocational

rehabilitation service providers (Gilbride et al, 2000). Gilbride's study also noted that there were those among employers interviewed, who reported that they were glad that they had hired a person with a disability. Similar employer satisfaction with disabled employees has been noted in the above mentioned report by Wilkerson from organizations that include: Dupont of Wilmington, Delaware (that currently hires about 800 disabled employees), Hallmark Canada, Purolator Courier, Sears Canada, McDonalds, Bank of Montreal, Royal Bank, CIBC Bank, Alliance Atlantis Communications Inc., and Hewlett-Packard (Canada) Ltd. (Wilkerson, 2001).

Although the number of businesses that hire disabled persons is impressive, Wilkerson's report does not indicate the types of disabilities of disabled persons employed in these businesses, and hence, whether these employees include persons with ABI or with serious mental health issues is unclear. Wilkerson's report also suggests that a barrier to mainstream employment accommodation for disabled persons appears to be that "a considerable number of persons with disabilities drop out or never enter the job market" (ibid) Conversely, this statement could be perceived as support for A-Way and ABI participants' overall scepticism with mainstream employers and workplaces. The willingness of businesses to hire persons with disabilities is questionable considering the Ontario Human Rights Commission (OHRC)'s Policy and Guidelines on Disability and the Duty to Accommodate document released in March 2001, whereby companies risk spending time and money in legal matters in the event of allegations of discrimination against persons with disabilities (ibid, p.9).

Another barrier to competitive employment facing ABI survivors highlighted by academic Pepping, is when there are powerful financial incentives to remain 100% disabled or impaired (Pepping, 1998, p.65). For example, when families do not want ABI survivors to work "for fear of loosing disability income, or for fear of jeopardizing the size of any financial settlement in a legal case" (ibid). In such cases, Pepping notes, "these individuals may find it almost impossible to risk competitive employment"(ibid).

Consumer/survivor CEDs target mental health people with unrecognised and/or underdeveloped skills; specifically, those who are considered "unemployable" by

mainstream employment standards (Church 1997). Interviews with ABI survivors demonstrate that their current dependency on ODSP and/or CDPP implies that they are considered “presently or permanently unemployable.” Unfortunately, the “unemployable” are generally not those that are recruited in the highly profitable organizations listed in the Wilkerson report. Consumer/survivor CEDs believe that the optimal way to accommodate the employment needs of vulnerable consumers/survivors is through collective employment (Church, 1997, p.4). Correspondingly, the collective employment approach may be more successful in accommodating the employment needs of “vulnerable” ABI survivors.

A-Way’s executive director explained that collective employment has not always managed to accommodate all employee employment needs, because there has been an occasion when A-Way laid-off a courier, because he/she could not perform the job demand. However, she asserted that if there were more consumer/survivor CEDs and more variety of job opportunities, this consumer/survivor’s capabilities could have been properly matched with a suitable position.

Therapeutic Value of the Consumer/Survivor CED Approach to Employment

Therapeutic value of the consumer/survivor CED approach was a significant theme in discussions with A-Way participants in this study. Their accounts of improved health and self-esteem support consumer/survivor CED literature that stipulates, “consumer/survivors fortunate enough to work in community businesses report that their reliance on medication decreases as a result of being employed” (OCAB, 1995, p.12). The therapeutic benefits associated with this employment alternative for consumers/survivors were discussed with enthusiasm among ABI participants, particularly, with respect to supporting each other to cope with the consequences of ABI (loss of self, loss of intimate partner etc). 9 of the 10 ABI participants noted that although the allowable income limitations of ODSP and CDPP (before income taxes) is a disincentive, the reciprocal therapeutic benefits (a sense of community and peer support) derived from this workplace would make the approach worthy of their attention.

Consumer/survivor businesses have demonstrated that employment in these businesses not only improves the health of consumers/survivors, but also results in cost-savings for the MOHLTC (estimated to be roughly \$13, 000 per year per consumer/survivor through the reduction in use of community services, reduction in hospital in-patient days, crisis contacts and number of hospital admissions) (Church, 2000, p.16). The Roeher Institute notes that the cost of disability for our governments in 2002, was 8 percent of Canada's GDP and that governments transfer an additional \$5.2 billion annually to individuals with disabilities who are not working (Roeher Institute, 2002, p.24). Thus, the consumer/survivor CED employment approach enhances the health of employees, and also reduces government spending on the consumer/survivor population, which could potentially be transferred to the ABI population.

Productivity and Economic Independence

ABI service providers shared a similar opinion to that of ABI participants, that there is a lack of employment supports for members of this group that can effectively assist them in meeting their employment goals. ABI service providers suggested that the multidisciplinary approach appears to be effective, as observed by Vandiver et al, who argue that brain injury survivors can achieve and maintain their employment goals through a range of assessments, and also, the ongoing involvement of a team of rehabilitation professionals, employers, and family (Vandiver et al, 2003, p.458).

Conversely, interviews with ABI survivors demonstrated that they were not interested in the support of rehabilitation or vocational rehabilitation services, but that they would appreciate job opportunities that are not menial and that result in decent income. BISH service provider participants promoted SE as an employment alternative that is successful in assisting ABI survivors to increase their economic independence. The effectiveness of the SE approach in ABI has also been noted by other ABI rehabilitation professionals (Gamble & Moore, 2003). While BISH service providers asserted service user satisfaction with SE services, 3 BISH service users that used BISH SE services to secure employment were working part-time in janitorial positions, and complained that the pay and hours needed to increase.

The Canadian governments believe that they promote the economic independence of disabled people, through the various employment support initiatives they have developed. These programs include ODSP and the disability vocational component of CPP. However, all participants in this exploratory study (A-Way, ABI and service provider participants) noted that ODSP significantly restricts recipients from increasing their economic independence. Participants expressed that the ODSP limit on allowable earnings (\$160 a month for a single person before deductions), creates a paradox, whereby the more an individual earns above these limits, the less income replacement he/she receives. However, this limit on allowable earnings before deductions “oversimplifies and ignores the reality that many disabled persons face” (Holden & Beresford, 2002, p.198). In other words, the nature and consequences of a disability limits a person’s ability to work regularly. ODSP-recipient participants in this study unanimously expressed their belief they are capable of meaningful work. “The truth is that many service users want both work and support” (ibid). Without both, ODSP participants could never aspire to live above the ‘poverty line’ (7).

Social Inclusion

ABI and A-Way participants in this study stated that they associated a lack of productivity and economic independence with social exclusion, lower self-esteem, and self-worth. Their opinion is supported by Vandiver et al’s observation that similar to non-disabled and other disability groups, most brain-injured clients perceive employment as a means to community reintegration, self-worth, self-determination, and independence (Vandiver et al, 2003, p. 458). Recent Federal and Ontario government disability employment policies and programs presented in this paper demonstrate government effort to meet the economic and social inclusion needs of disabled persons. Disability policy analyst Abberley argues that policies and programs that focus increasing the labour participation of persons with disabilities, cannot assure the full social inclusion of disabled persons because of the fact that there will always be a number of disabled persons who are not able to produce goods and services according to the demands of the economic capitalist system. Moreover, he predicts that advances in technology and

increased economic globalization will cause increased employment insecurity for the general population, and that disabled persons will continue to be in the forefront of those groups who cannot meet the versatility and work rates that this labour market demands (Abberley, 2002). The following argument by Abberley provides further explanation:

Even in a society that did make profound, genuine attempts, well supported by financial provision to integrate impaired people into the world of work, some would be excluded. Whatever efforts are made, some will not be capable of producing goods or services of social value –that is, ‘participating in the social creation of wealth’. This is so because in any society, certain though varying, products are of value and others are not, regardless of the effort that goes into their production (2002, p. 131)

Hence, Abberley proposes that in order to achieve full social inclusion for disabled persons, it is necessary that disabled persons develop ideas and values that run counter to the dominant culture’s view of regarding “work as the defining characteristic of full social inclusion” (ibid, p.120). Accordingly, there is a need to valorise the lives of non-working persons (which includes, but is not limited to disabled persons who are unable to work) (ibid).

Consumer/survivor CEDs exemplify what Abberly proposes: The consumer/survivor CED employment approach does not subscribe to our society’s labour-dependent conception of humanity, but is a reaction to it: Consumer/survivor literature reminds us that the goal of consumer/survivor CEDs is not the integration of consumers/survivors into the current system of labour, but rather to use economic development as a means to recover and rebuild the lives of psychiatric survivors” (Church, 2000; OCAB, 1995, p. 19). Consumer/survivor CEDs recognize that they can not convert all consumers/survivors into “productive” citizens that do not require financial assistance or medication, because this would threaten some individuals that are dependent on their medication, and also naïve about the possibilities of the current economy (ibid, p. 12). Whereas, our capitalist economic system advocates that human beings be organized around the economic needs of society (Graham et al, 2000, p. 9), the consumer/survivor CED approach regards economic development as the means to human

development (Church, 2000; OCAB, 1995, p. 19). This Durkheimian understanding of society that is concerned “primarily with moral and cultural integration rather than economic activity” (Abberley, 2002, p.121), may prove to be a more effective way of assisting ABI survivors to meet their social inclusion needs than our current government disability policies and programs that emphasize work as an important element of social inclusion. Hence, a CED for ABI survivors may be a more effective mechanism to assist them in meeting their citizenship needs.

Conclusions

“Employment has been associated with higher perceived quality-of-life, whereas failure to return to work (RTW) has been associated with poorer psychosocial adjustment and physical ailments” (Kreutzer et al, 2003, p. 128). Globally and locally, brain injury survivors face significant employment barriers that are both societal and personal. The personal barriers result from physical and cognitive changes following an ABI and in some cases, the development or enhancement of mental health issues. The societal barriers pertain to stigma and to the gaps in government social inclusive policies, and measures for persons with disabilities. Social policy analyst Guilford observes, the terms “social inclusion” and “social exclusion” are appearing increasingly in disability policies and programs in Canada (Guildford, 2000, p.1). Government efforts to enhance the social inclusion of persons with disabilities are reflected in measures, such as transportation designs that accommodate the transportation needs of disabled persons and disability-internet access programs. Such universal measures demonstrate our governments’ position that all citizens have the right to participate in the economic and social fabric of our society. However, other measures such as the recent Ontario government policy framework the LMAPD and the employment supports component of ODSP, are too universal in their approach. Specifically, these policies do not target the disability-specific employment needs of diverse disability groups, such as persons with ABI. One provincial government policy that concentrates on group-specific employment needs is the recent policy framework *Making it Work* (2001). This policy framework is designed to target consumers/survivors with SPMHI, and while this policy has limitations, *Making it Work* represents the government’s growing awareness of the need for employment supports and services that target specific disability groups.

The non-government CED approach to employment is a successful example of an approach that also targets the specific employment needs of consumers/survivors (in particular those who were classified as ‘unemployable’). This thesis argues that the

consumer/survivor CED approach may be effective in meeting the specific employment needs of ABI survivors. Specifically, recent research in the field of ABI has discovered that ABI survivors demonstrate unique service needs that are neither well described by instruments designed for other populations, nor adequately met by general disability services and programs (Brzuzy & Speziale, 1997; Dickmen et al, 2003; Marsh & Sleight, 2002). Literature and research examined for this thesis reveal that there is a growing awareness among ABI practitioners of the long-term disability consequences of ABI for many survivors and the corresponding societal costs. Furthermore, this literature suggests that the most comprehensive approach to assisting ABI survivors with their employment needs is SE. This exploratory study argues that ABI survivors are not satisfied with the current employment services, such as SE and other vocational rehabilitation programs. Specifically, ABI survivors perceive the jobs provided by these programs as menial and non-challenging employment opportunities, which cause negative and unworthy personal and societal perceptions. This results in continued low self-esteem and self-worth among ABI survivors that is directly related to our labour dependent concept of humanity. Hence, while people that have sustainable and meaningful employment feel productive, worthy, and socially included, those that are unemployed or have menial jobs feel unproductive, unworthy, and socially excluded.

The importance of work in our society as definitional of human worth and hence, social inclusion, is demonstrated in the writings of Gill when he states that, "Being a central aspect of human activities, work has evolved into a major constituent of human consciousness. Accordingly, work has significant implications for human self-definition, self-image, and identity and is a medium for human relations, self-discovery, self-expression, and self-actualisation" (Gil, 1979, p. 86).

The consumer/survivor CED A-Way Express Courier has successfully assisted consumers/survivors to reconstruct and rebuilt their lives, by providing them with meaningful and challenging employment that has increased their sense of worth and

social inclusion. Additionally, the sense of worth and social inclusion that consumers/survivors gain as CED members appears to be reinforced by this employment approach's perspective of viewing the economy as a means for human development, which enables an understanding of humanity and of human worth that is not dependent on work. This understanding of human worth is neither new nor unique, as can be seen for example in the writings of late 19th early 20th century French academic Emile Durkheim (Abberley, 2000, p. 124), and in the social work value of respecting the intrinsic worth of all humans (Hepworth, Rooney & Larsen, 1997, p.9). The importance of these views as they relate to the concept of work in particular is that they enable an understanding of work as *one* aspect, as opposed to the *central* aspect of human activity, with the resulting consequence that other human activities (such as peer support and mutual aid) can also be perceived as definitional of social inclusion.

This study has suggested the potential for the consumer/survivor CED alternative employment approach to assist ABI survivors in meeting their social and economic needs, and therefore suggests that this alternative employment approach be promoted for members of this group. However, there are a number of challenges that require consideration to create a successful ABI survivor CED. Firstly, funding is critical to the initial and ongoing success of any long term CED. The A-Way executive director and consumer/survivor literature assert that consumer/survivor CEDs are under continuous pressure from the government to become economically self-sufficient. This economic pressure correlates with the current work ethics mantra of the increasingly residual social safety net of our Canadian governments coupled with the insecurities involved with globalization (Rice & Prince, 2000; Mosher, 2000). Unfortunately, economic self-sufficiency is not a reality for most consumer/survivor CEDs, because these businesses are created to hire the most vulnerable among the consumer/survivor population. Accommodating the employment needs of employees requires employment supports, such as 'flex time' and peer support. These measures are not cost effective and can work against the economic self-sufficiency of a business that is dependent on employees that do not generate enough economic activity to make the business profitable. An ABI

survivor CED would be designed to employ those whose employment goals have not been successfully met in either mainstream or supported employment -Thus, the probability of relying on government funding to assist with the operating costs. On the other hand, unlike many consumer/survivors CED employees, who have “a long and deep history of social and economic exclusion” (Church, 2000, p.8), the findings of this exploratory study and that of the ABI literature reviewed revealed that many ABI survivors neither have a history of social nor economic exclusion. This fact, coupled with the fact that with the help of rehabilitation (cognitive therapy, physiotherapy, counselling, and so on), ABI survivors can learn ways to compensate for some impairments, an ABI survivor CED may have more potential to be self-sufficient.

Secondly, although ABI participants in this study expressed interest in an ABI survivor CED, the ODSP limit on allowable earnings before deductions may be a significant disincentive. Unlike consumers/survivors, many ABI survivors earned competitive wages prior to their injury. Interviewed ABI survivors suggested that the ODSP income cap on earnings before deductions could be avoided with a system of “payment in kind” for services rendered. Hence, instead of paying money for the work of ABI CED employees, the payment medium could assume a form of barter for goods and services, such as restaurant coupons, travel tickets, appliances, and hairdresser.

Thirdly, an ABI survivor CED challenge might involve the assurance of effective employment supports. Although some employment supports may be similar to those provided by consumer/survivor CEDs, ABI survivors may require additional disability-specific employment supports (e.g. compensatory strategies and/or adaptive devices).

This exploratory study has examined the employment barriers experienced by ABI survivors and this group’s desire for social inclusion. Social policy analyst, Paul Abberley, correctly asserts that if our governments truly desire the social inclusion of persons with disabilities, they cannot regard work as its’ defining characteristic (Abberley, 2002). Correspondingly, this requires the development of policies and initiatives that encourage a more social than labour-dependent concept of citizenship. Consumer/survivor CEDs provide human development through economic development.

Thus, this exploratory study is intended to influence and encourage disability policy makers to recognize the value of the CED employment approach, as an effective social inclusion model for ABI survivors, and worthy of further exploration through an ABI CED test research project.

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APPENDIX 1: (Frequently Used Abbreviations)

ABI: Acquired brain injury
CED: Community Economic Development
CDPP: Canada disability pension plan
CPP: Canada pension plan
CSS: Critical social science research methodology
EAPD: Employment Assistance for Persons With Disabilities
FPT: Federal/Provincial/Territorial
HALS: Handicap Activity Limitation Survey (1991)
HRDC: Human Resources Development Canada (recently renamed HRSDC: Human Resources Skills Development Canada)
ISS: Interpretive social science research methodology
LMAPD: Labour Market Agreements for Persons with Disabilities (2003)
MOHLTC: Ministry of Health and Long Term Care
ODSP: Ontario Disability Support Plan
OHRC: Ontario Human Rights Code
PALS: Participation Activity Limitation Survey (2001)
PSS: Positivist social science research methodology
RTW: Return to work
SE: Supported employment
SPMHI: Serious and persistent mental health issues
VRS: Vocational Rehabilitation Services

APPEXDIX 2: Interview Outlines

Interview Outline for A-Way Express Courier Administration Staff:

1. When was this business established?
2. Was process difficult? That is, was it difficult to secure funding? Raise interest? Etc.
3. In the literature on this business, it is described as a Community Economic Development (CED). Can you expand on this?
4. How long have you been involved with this business?
5. What is your role in this business? Is this your first position here?
6. Can you describe how you felt when you first started here?
7. What would you say have been the challenges for this business?
8. What would you say have been the successes of this business?
9. In what ways does this business benefits consumers/survivors?

Interview Outline for A-Way Express Courier Employees

1. How long have you been working at this employment?
2. Can you describe what it is you do; that is, your role at this employment?
3. What is your relationship to your present employment; that is, how did you find out about this business? Were you part of its creation?
4. Is there anything that you appreciate about your job and/or your workplace?
5. Do you see areas for improvement? If so, can you explain?
6. What do you see yourself doing in the future, in the next 5 years?
7. Has working here made a difference in your life for the better? Please expand.

Interview Outline for Brain Injury and/or Mental Health Service Providers

1. Can you describe your service-users? At what stage of rehabilitation are the clients when they come here for services?
2. Out of all the clients you see, how many rehabilitate to the point of being able to do some form of employment?
3. Out of all the clients you see, how many are interested in employment?
4. In your observations, what are the employment barriers that your clients face?
5. In your observations, what are some brain injury-related personal challenges that clients may face in regards to employment? E.g. regarding balance, co-ordination, vision, patience, anger, emotional and mental health etc
6. Based on your findings and observations, do you think that the clients you service would be interested in participating in an alternative employment model like the Community Economic Development (CED) businesses created by consumers/survivors?
7. Do you think the CED type of business is viable for this population segment? What do you think might be the challenges?

Interview Outline for Brain Injury Service Users who are Currently Looking for Employment

Section A

1. What has been your experience job- hunting so far? For how long have you been looking?
2. What kind of job are you looking for? Is there a specific type of job that you are looking for?
3. Prior to the brain injury, were you employed at anytime?
4. If yes, what was your employment?

Section B

1. Is there any job/activity in your past or present that you really enjoyed?
2. Please describe the job/activity?
3. Do you have an ideal job?
4. If you were to imagine your ideal job, what would it look like?
5. How do you prefer to work (please check one):
Alone In a group No preference
6. Have you heard of alternative businesses (sheltered workshops, consumer/survivor businesses)?
7. Would you be interested in working in an alternative business?
8. Would you be interested in creating alternative business together with others?

Section C

1. How has your brain injury affected your work related abilities (on a scale of 1-10; 1 not affected and 10 strongly affected):
 - a. Long-term memory 1 2 3 4 5 6 7 8 9 10
 - b. Short-term memory 1 2 3 4 5 6 7 8 9 10
 - c. Concentration 1 2 3 4 5 6 7 8 9 10
 - d. Patience 1 2 3 4 5 6 7 8 9 10
 - e. Motor 1 2 3 4 5 6 7 8 9 10
 - f. Vision 1 2 3 4 5 6 7 8 9 10
 - g. Balance 1 2 3 4 5 6 7 8 9 10
 - h. Fatigue 1 2 3 4 5 6 7 8 9 10
2. How many hours would you be comfortable working? (Please circle one)
 - a. 5 or less hours 5 days a week b. 5 or more hours 5 days a week
 - c. 5 or less hours 3-4 days a week d. 5 or more hours 3-4 days a week
 - e. 5 or less hours 1-3 days a week f. 5 or more hours 1-3 days a week
3. In what ways do you feel that the brain injury has affected your chances of mainstream employment? For example, are there any skills that have been affected (e.g. typing)?
4. What skills/talents/qualities would you bring to an employment of your choice?

Section E

Age:

Gender: