Working for Equity: Issues of Employment for Youth with Disabilities

BY

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ABSTRACT

The purpose of this research project was to explore the past and present experiences of youth with disabilities as they related to their current employment situation. For this research, I documented the experiences of nine youth with physical disabilities as they participated in a six month Employment Training Project.

The data collected through this research process has provided a rich source of information describing the experiences of the young people involved in this project. This study has substantiated much of the previous consumer literature on employment access among people with disabilities. Barriers identified by other researchers, including financial, institutional, educational and training issues, attitudinal, physical access, lack of experience, and bureaucratic barriers were all discussed by the youth who participated in this project. It is important that these systemic barriers be addressed in order to promote equal employment opportunities for all people with disabilities.

This study presents the lived experiences of the youth that have led to their current status of unemployment. Through the presentation of individual narrative, it has allowed young people with disabilities to give voice to their own experiences of barriers. Interaction with family and friends, perception of their disability, and their self-esteem and ability to set goals have all impacted their ability to pursue employment. At times these factors have had a positive influence on their success. At other times, the negative attitudes of family, friends, and society in general have limited their ability to achieve their goals.

ACKNOWLEDGEMENTS

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FIGURES APPEARING IN TEXT

ACRONYMS APPEARING IN TEXT

CCDS - Canadian Centre on Disability Studies

CCRW - Canadian Council on Rehabilitation and Work

HALS - Health and Activities Limitations Study

IL – Independent Living

LDAM – Learning Disabilities Association of Manitoba

MLPD - Manitoba League of Persons with Disabilities

TA – Teacher's Aid

CHAPTER 1: INTRODUCTION

Development of the Research

In December of 1998, I began my acquaintance with the Canadian Centre on Disability

Studies (CCDS) and Dr. Karen Blackford, the CCDS Research Chair. I spoke to Karen of my

intentions to do a thesis in the area of disability, and also of my reluctance to impose my own

research ideas on a community that had already identified areas worth researching. At that time,

Dr. Blackford told me about the CCDS Youth Employment Training Project to be undertaken in

the summer of 1999. This project was to have both a research and a training component.

The Employment Training Project took place over an eight-week period whereby ten young people

with physical disabilities received employment-related training and were then to be placed in a six month

internship. The researchers were to explore issues related to chronic unemployment for youth with

disabilities. They were also to prepare an evaluation of the project.

Working together with Dr. Blackford, my research was designed to be an exploration of the past

and present experiences of youth with disabilities related to their current employment situation. The

research was to be qualitative in nature, consisting primarily of one-on-one interviews with each

participant. Through these interviews, I identified several themes related to employment for this particular

group. Quotations and stories were grouped according to the theme identified, and were analyzed and

presented using a critical model of disability. The themes identified were also used in partnership with the

participants of the training project to develop an evaluation tool.

Statement of the Problem

Despite the efforts of consumers, advocates, and government legislation aimed at providing

people with disabilities equality in all aspects of society, Canadians with disabilities continue to face

issues of poverty and unemployment at rates substantially higher than those for non-disabled Canadians.

Statistics Canada has reported that persons with disabilities are one-and-a-half to two times more likely

to be without jobs than non-disabled Canadians. Many disability and consumer organizations caution that this is a conservative estimate, due to the stigma associated with self-identifying as disabled.

The effect of marginalizing persons with disabilities from economic participation has obvious implications on their material wealth. It is well known that employment status also has wide spread effects on a person's health and overall well being (McLoughlin 1987, Neufeldt 1998). Integrated, competitive employment for persons with disabilities can lead to many benefits, including long term interactions with community and co-workers, increased choice and decision making ability, increased economic earnings, enhanced status, and an overall increase in quality of life (McLoughlin 1987).

Many reasons have been postulated for the exclusion of people with disabilities from the workforce. Lack of education, motivation, and experience, financial disincentives built into income assistance programs, and physical barriers to access have been cited as conditions leading to high unemployment for persons with disabilities (Annable 1992, Berkowitz 1986, Burkhauser 1982). Some of these explanations focus on the individual as a unit of analysis, failing to consider the systemic issues that contribute to unemployment for this group. Organizations representing disabled consumers denounce such individualistic explanations and focus instead on institutional and social barriers. While these studies are often much better at providing systemic analysis for the exclusion of people with disabilities, they are largely perpetrated by politically active consumers and lobby groups. These studies do reflect the voice of their consumers.   However, study samples are often drawn from persons who are open to attending public meetings, and may fail to capture the voices of everyday people and their experiences. Finally, most studies related to employment issues for people with disabilities fail to consider the broader life experiences (such as education and family support) of individuals in their examination. Although these experiences may not be specifically related to employment, they do impact on the self-esteem, motivation, and the success of individuals as they struggle to transition into employment.

While some case studies of employment initiatives for persons with disabilities are beginning to emerge (Neufeldt 1998), almost no information exists which discusses the specific issues faced by youth with disabilities. While this group may share many similarities to their older counterparts, one can assume that the experience of youth with disabilities has changed significantly in the past twenty years. The advancement of medical technology, community and educational integration, and changing social

attitudes will have made the lives of these young people much different than those experienced by older persons with disabilities. Models developed for more senior job hunters may not apply to this generation. Specific initiatives must be undertaken in order to better understand this distinct sector of the population.

Outcomes of the Project

The objectives of this research project were:

_ To document the personal experiences of young people with disabilities as these experiences have impacted their encounters with employment and job training.

_ To develop additional understanding of the wider social barriers faced by youth with disabilities and the supports available for said population in seeking employment.

_ To identify key themes in employment issues to be used in partnership with the participants of the training project to develop an evaluation of this particular training initiative.

_ To empower the participants as co-researchers in the development of an evaluation tool.

_ To provide a forum for reflection and the development of collective action to promote positive employment strategies for persons with disabilities.

The original goals of the research were met with a varying level of success through the project. The information collected through the individual interviews provided a rich source of information regarding the experiences of the young people involved in this particular project. This study has revealed some of the difficult barriers faced by young people with disabilities in finding employment. However, it is difficult to document the lived experience of individual members of the group without violating their confidentiality, especially when dealing with such a small group. It is also extremely

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difficult to appreciate the complex and cumulative effects that their family, friends, education, and a plethora of other experiences have had on their current employment status.

The process of developing an evaluation tool with the participants was successful. Having the opportunity to frame their own questions allowed the youth to ask what they thought was important, using terminology that they fully understood. The participants' evaluation was generally well received by the facilitators of the project, although on one occasion the validity of the data was questioned. Because the participants were easily identifiable through their individual evaluations, the forms could not be shared with the facilitators in order to validate the results. This problem could be resolved by having more than one researcher analyze the results of such evaluations.

Perhaps the most lofty of the aforementioned goals, "to provide a forum for reflection and the development of collective action to promote positive employment strategies for persons with disabilities" has been approached through a variety of methods. During the Employment Project, research was presented back to the participants on a variety of occasions. This provided an opportunity for the researchers to validate information previously collected, to stimulate discussion amongst the youth participants, and to collect further data for analysis. Results of the evaluation were documented in a report published by the Canadian Centre on Disability Studies, entitled "Employment for Youth with Disabilities: Issues and Experiences" and widely distributed to disability organizations in Winnipeg and elsewhere in Canada. Reflections of the project were presented at the Western Research Network on Education and Training Conference in Vancouver, British Columbia in March 2000. The paper presented, "Youth with Disabilities Research Their Past and Present Experiences of Employment" is also available on the World Wide Web at the following address: www.educ.ubc.ca/wrnet/Conf2000/AbsMorris.htm. I was invited to present information based on this project at a conference in Toronto sponsored by the Royal Bank of Canada on disability and employment. Finally, together with the participants, a symposium was developed and presented in Winnipeg, Manitoba in April 2000. This event garnered a surprising amount of media coverage, including local radio, television, and newspaper.

It is hoped that this study will continue to have both theoretical and practical implications. While there exists some literature on disability and employment, there is almost no literature on youth

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employment for persons with disabilities. This study outlines key issues for these youth, provides for them a place to share their experiences and to express concerns, and can potentially guide the development of education, training and employment programs in the future. Practically speaking, the research has offered the participants the opportunity to participate as co-researchers through the development of the evaluation tool, and to co-present the results of the project to a public audience.

CHAPTER 2: BACKGROUND AND LITERATURE REVIEW

In 1980, the World Health Organization estimated that one out of every ten adults in the world has a disability. The 1991 Statistics Canada post-censal survey on persons with disabilities (Health and Activity Limitation Survey (HALS)) revealed that 4.3 million people in Canada (16% of the total population) live with a disability. According to the Canadian Mental Health Association, one in three people will experience mental illness in their lifetime. The Learning Disabilities Association of Manitoba estimates that between 10-15% of the general population is affected by Learning Disabilities and that another 3-5% have Attention Deficit Disorders. As these statistics show, disability affects a large and ever increasing

number of people in Canada. Yet the real social implications of disability (impact on status, employment, health, education) have only recently been examined by social scientists.

Employment and Disability: Background

People with disabilities are and have always been a part of human societies: "virtually every large skeletal population includes one individual-and often several-whose remains show congenital malformations, improperly healed bones, missing limbs, or head trauma" (Scheer and Groce 1990). It has often been postulated that people with disabilities in pre-historic societies occupied special or spiritual positions within their societies. Very little evidence has been found which proves the assumption that people with disabilities necessarily occupy a "special" place in society (Scheer and Groce 1990). However, the existence of people with disabilities living in these societies does imply that they probably occupied productive positions within their groups.

According to Enns (1981), in the pre-industrial period many people with disabilities were occupied in family and cottage businesses, able to contribute to the subsistence of their families in environments which had been made accessible to them. In the industrial age, many people with disabilities were no longer able to produce enough for profit-driven factory owners, and were forced out of the labour market and onto the street, left to beg or rely on the outreach of charitable organizations.

In England, the 1843 New Poor Law gave rise to London's Poorhouses, which were "deliberately made as miserable as possible, segregated the sexes—even married couples—to prevent the poor from producing more undesirables" (Enns 1999). At the same time, the social application of the theories of Malthus and Darwin were widely adopted as legitimate, leading to widespread acceptance of the notion of eugenics (*ibid*.). People with disabilities were institutionalized on a grand scale, and continue to live in segregated institutions in Canada even to the present, although the widespread community living movement of the late twentieth century has seen many people with disabilities return to the community.

Until the early 1900's and the two World Wars, persons with disabilities were not a social priority in either the U.S. or Canada. After the conclusion of those wars, and the return of injured veterans to their homes, governments were forced to create policies in response to the demands of disabled veterans. In the 1950's emerged the field of rehabilitation, whose primary focus was on vocational training for those veterans.

The 1960's saw the emergence of the Civil Rights Movement in the United States. The struggle for equality between blacks and whites became the model for the struggle for equality between women and men, and eventually between the able-bodied and people with disabilities. In the 1980's, the disability rights movement (also referred to as the IL Movement and the Consumer Movement) helped to bring the demands of people with disabilities to the forefront.

In response to these social movements, the Canadian government developed several important pieces of legislation relating to the employment of persons with disabilities. In 1982, the Charter of Rights and Freedoms was added to the Canadian Constitution, which included persons with mental and physical disabilities as groups protected under the law. The Constitution Act of 1982 supported the rights of all Canadians to the opportunity to support themselves. In 1986, the Employment Equity Act was introduced, with the intention to "increase labour force participation and improve the integration of women, aboriginal peoples, visible minorities and persons with disabilities" (Zimmerman 77). However, the effectiveness of this legislation has been questioned by those people with disabilities who continue to face high unemployment rates. In an article written for consumer magazine ARCH-TYPE, Baker states that:

> While [the Act] required employers to collect and submit representation data on numbers of people with disabilities in their workforce, no other obligation was enforceable. Because neither barrier removal nor hiring targets were mandatory, the Act's impact on the employment rate of people with disabilities has been minimal.   B

Although many people with disabilities have managed to obtain employment since this time, many more remain unemployed or under-employed.

Employment is a significant factor in contributing to the overall quality of life for all persons, including those with disabilities. Wolfgang Zimmermann, Director of the National Institute of Disability Management and Research remembers the social atmosphere of the 1970's when he broke his back in an industrial accident:

> There was a total lack of understanding of the additional barriers disabled persons must surmount to find and retain jobs. The common focus among unions was to ensure that disabled workers received adequate pensions. Few understood the emotional, financial and social importance of maintaining a connection to the workplace.   Zimm

In fact, employment plays a major role in defining social status for North Americans: "to a significant degree in our society the value of tasks performed at the workplace reflects a person's perceived value.

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One of the first questions that many of us ask new acquaintances is, 'What kind of work do you do?'"(McLoughlin 1987:14). Integrated, competitive employment can lead to many benefits for people with disabilities, including long term interactions with the community and co-workers, increased choice and decision making ability, increased economic earnings, enhanced status, and an overall increase in quality of life (McLoughlin 1987, Government of Canada 1996).

Employment and disability intersect in the way policy and definitions are created regarding the employment of persons with disabilities. Until the World Health Organization began their process of revising definitions of disability in the 1980's, definitions of disability invariably included a reference to an individual's ability to contribute to their society's economy. The ability to obtain employment continues to hinder a person's ability to qualify for income assistance in Manitoba and other provinces (MLPD 1999).

Canadians with disabilities have been marginalized from full participation in the political, social, and economic realms of mainstream society. Canadians with disabilities continue to face issues of poverty and unemployment at rates substantially higher than those for non-disabled Canadians. Of the 2.3 million working age adults with disabilities, (15-64 years of age), less than half (48%) are actively involved in the labour force. The Canadian Justice System and our "Street Population" is highly overrepresented by people with mental and learning disabilities (Young and Martin, personal communications). In 1994, almost 60% of Canadians with disabilities had incomes below Statistics Canada's poverty levels ($20,000/year). The following table describes this data by income level:

Figure 1: Percentage of Adult Canadians with Disabilities (age 15-64) by Income Level

26%	< $5000
17%	$5000-9,999
11%	$10,000-14,999
9%	$15,000-19,999
8%	$20,000-24,999
7%	$25,000-29,999
22%	$30,000 +

In 1986, Statistics Canada's Health and Activity Limitation Survey (HALS) collected data specifically on Canadians with disabilities regarding a large number of issues. Their data on employment revealed that people with disabilities are more likely to be unemployed or not in the labour force than their non-disabled counterparts. Three measures are commonly used to compare rates of employment for people with disabilities. These include the labour force participation rate, and the unemployment rate,

which accounts for all people actively searching for, but unable to find employment. The third rate measures non-participation (also referred to as "not in the labour force"). This calculation measures the proportion of people without jobs who are not actively seeking work (this includes students, parents, people who have chosen early retirement, and those who have given up searching). The HALS data reports that people with disabilities have a labour force participation rate of 56%, while 81% of people without disabilities are active in the labour force. People with disabilities face unemployment rates of 14%, one and a half times that of Canadians without disabilities (10%). The non-participation rate (people who are not participating in the labour force) for those with disabilities is 52%, as compared to 27% for those without disabilities.

Figure 2: Labour Force Rates for Canadians with and without disabilities

While people with disabilities are much more likely to be unemployed than able-bodied Canadians, these statistics indicate that the larger discrepancy lies in the difference between those "not-in-the-labour-force". While some of the people not searching for jobs may have chosen to pursue other avenues such as education or parental duties, the overrepresentation of people with disabilities in the non-participation category suggests that barriers to employment for people with disabilities extends beyond employment-specific barriers. Systemic barriers (lack of physical access, transportation, attendant care, etc.) may seem insurmountable to many people. Repeated encounters with discrimination and attitudinal barriers may have discouraged people from trying to obtain employment.

Lack of self-esteem, motivation, or job-searching skills may keep many people from taking the first step towards employment: the job search.

That Canadians with disabilities face unemployment at rates one and a half to two times as high as other Canadians has both social and economic costs ***royal bank stuff***. The Canadian Government has acknowledged the importance of employing people with disabilities in the document entitled Future Directions: "The social and economic development of our country depends on all Canadians having an equal chance to contribute their gifts and abilities" (Government of Canada 1999:1)

Employment and Disability: Barriers

Several social factors have led to and still contribute to keeping individuals with disabilities out of the labour force. While many of these barriers have been eroded through the challenging of stereotypes, equity legislation and increased accessibility and accommodation in the workplace, many more problems continue to keep people with disabilities under-employed, in low paying or short term positions, or pigeon-holed into working in service agencies for the disabled.

Many reasons have been postulated for the disparity in employment rates. Cyr and Schirle (1999) identify four categories of barriers to employment for persons with disabilities: beurocratic, attitudinal, institutional, and physical. While these issues are all very important, this research has focused only on the political aspects of the problem, and has virtually ignored the individual "lived experiences" of unemployed people with disabilities. In 1992, The Canadian Council on Rehabilitation and Work (CCRW) undertook a study to try to "understand the nature of this group of people and the extent to which they encounter particular barriers" (CCRW 1992:iv). The report included both an analysis of the HALS data and the results of five focus groups conducted with consumers across Canada. The CCRW study divides barriers faced by job seekers into four categories: education, training, lack of experience, and an "other" category which includes discrimination, financial disincentives, and the economy. This study is strongly supported by the large representation of the "consumer voice" through extensive quotation. Surprisingly, however, after having identified that the large gap in employment rates between disabled and non-disabled people is most prominent in the "not-in-the-labour-force" category, no further mention is made of this discrepancy. The discussion fails to connect the barriers encountered by job seekers to the decision not to seek employment. In the following discussion I will outline some of the barriers that have been identified.

A. Issues in Education

Currently, most young Canadians with disabilities have received their education in integrated school settings. Almost no literature exists which describes the experiences that these children are having in their schools. One study recently conducted in England identified several common experiences among children with disabilities in school. The severing of friendships developed in elementary school was a common experience for children who had to transfer to secondary schools outside of their neighbourhoods. All identified having been bullied, often equating being "picked on" with having a disability. And "a striking feature of the study was the high levels of surveillance of disabled children by adults which we observed" (Watson 1999:11). Constant supervision by Special Needs Assistants interfered with the ability of the children to develop friendships with their peers.

Surveillance of children with disabilities has also been commented on by Allan in his Foucaultian analysis of the education of special needs children:

> All children are the objects of scrutiny within schools, but for pupils with special educational needs, the gaze reaches further. They are observed, not only at work in the classroom, but also during break times.
>
> Allan 1996:222

According to Foucault, the evolution of social control can be traced through examining the way it has been exercised over individuals by the state through their physical bodies. The state has changed its focus over time. Absolute power (power of rulers), which Foucault calls "Sovereign Power", emerged as a power over life and death, and required a submission to the absolute authority of those who governed. Failure to comply would inevitably result in death, punishment was the vehicle of social control. This focus on death has been replaced, he argues, with a focus on the control over life. This shift has come in two phases, first through the law, and secondly through medicalization. In The History of Sexuality Volume I, Foucault states that as the law once gained access to its bodily subjects through punitive retribution, science asserts its control through the sanctioning of biomedicine:

> The second [form of power over life], formed somewhat later, focused on the species body, the body imbued with the mechanics of life and serving as the basis of the biological processes: propagation, births and mortality, the level of health, life expectancy and longevity, with all the conditions that can cause these to vary. Their supervision was effected through an entire series of interventions and *regulatory controls: a bio-politics of the population.* Foucault in Rabinow 19**:262

Control is exerted over the populace through both the medicalization and surveillance of life's activities.

Watson *et al.* observed the tendency of adults supervising children with special needs to speak as if the child were not present, and also of their belief that without their interference, the children with disabilities would not accomplish anything at all: "in one school, an adult commented to us that she felt that if it was not for her presence the children would not communicate at all" (Watson 1999:11). These practices serve to further segregate the children, reinforcing other's and their own sense of difference. Allan's Foucaultian analysis states that educational institutes "construct individuals as subjects in two senses: as subject to someone else, through control and restraint, and as a subject tied to their own identity by their conscience and self-knowledge" (Allan 1996:220). Children with disabilities are subjected to main stream perceptions of disability just as their non-disabled peers are. As Sim *et al.* points out in their article on care professionals, "just as disabled people are socialized into adopting the predominant and negative identity ascribed to them, they are also socialized to both blame and see themselves as dependent victims" (Sim 1998:55). Categories of difference and deviance are therefore internalized by the child, who sees themselves as dependent and isolated. These categories are carried with the child into adulthood, and hence into their job search.

Larger numbers of persons with disabilities are now seeking post secondary education. However, as was demonstrated by the HALS data, people with disabilities are more likely than other Canadians to be unemployed for each level of education:

> ...although the unemployment rate for disabled people decreased substantially as education increased, the gap between the disabled and non-disabled increased slightly as education increased, such that the unemployment rate for disabled Canadians with university degrees was twice the rate for non-disabled Canadians with university degrees CCRW 1992:11.

Unfortunately, post-secondary education does not appear to level the field between groups in terms of employment.

B. Issues in Training

Historically, training programs offered to people with disabilities came mostly in the form of "sheltered workshops", training programs designed such that the workers learned manual tasks such as stuffing envelopes and folding flyers under the supervision of trainers. These programs have fallen into disfavor because they often offered sub-standard wages to their employees and seldom if ever translated into paid work outside of the sheltered environment (McLoughlin *et al*1987). Economic sustainability of these workshops often depended on profits generated by the good work of their 'trainees'. Therefore,

placing the trainees into integrated employment opportunities would harm the workshop's bottom line.

McLoughlin *et al.* conclude their chapter on sheltered workshops with the statement:

> Meaningful outcomes are *the* reason that vocational facilitation and employment services exist. These services are not designed to provide employment for administrators, job developers, employment trainers, psychologists, and bus drivers.
> McLoughlin 1987:29

Exploitation through training programs was also identified through the study conducted by the CCRW. Many participants had taken part in training programs involving work placements and felt they had been exploited by employers through these programs:

> Exploitation of government programs to assist employers to hire persons with disabilities--training, work experience, wage subsidies--was raised as an issue by participants in most meetings. Participants told of jobs funded under training grants that provided little or no training, sudden radical changes in employers' evaluations of job performance when the grant or subsidy ended, etc.   CCRW 1992:41

Others felt dissatisfied with the choices offered them through training programs, complaining that most offer only office and computer training: "the tone of these discussions suggested that many agencies prefer to direct the people they serve, rather than empowering them to make wise choices and take ownership of their lives" (CCRW 1992:43). Many people doubted whether training would ever lead them to paid employment, having faced discouragement for extended periods of time. Other training initiatives seem to lack proper emphasis on involving employers. A study of the Westman region of Manitoba revealed that: "Service providers show weak emphasis in their contracting with and support of employers. The employer does not appear to be a full partner in the vocational rehabilitation process" (Westman 1996:27). Many training programs fail to provide solid links to employers. People with disabilities become caught in one training cycle after the next, never achieving paid employment and continually facing disappointment.

C. Experience and Employment Support

According to the CCRW data, participants varied considerably in level of qualification for the jobs they were seeking, 20% were very well qualified, 33% were somewhat qualified. But however much the respondents' qualifications had prepared them for the work force, most "lacked at least one significant qualification, typically experience" (CCRW 1992:29). Although they had had better success in obtaining short-term positions, "these people unanimously expressed frustration that most of the jobs they were able to get were short-term project positions, often with some form of government funding" (*ibid.* 51).

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Most also had experience as volunteers, but were either skeptical of its potential to translate into paid employment, or could not afford to volunteer their time.

People with degrees or certificates in professional or semi-professional fields stated that they have the most difficulty obtaining entry-level jobs. Many feel that they have been "pigeon-holed" into working for agencies that serve people with disabilities, which in itself is viewed as a barrier to gaining employment outside of the disability field. Some people have been forced to take jobs outside of their fields, within disability agencies, and at wages lower than they could expect within their fields of training.

People with disabilities not only encounter barriers with gaining employment, but also face difficulty in keeping employment once secured. Employers who hire persons with disabilities are often willing to provide accommodations or adaptations immediately after hiring, but fail to provide ongoing support. Employers assume that "...once a person with a disability has been recruited and any necessary aids provided or adaptations made to the premises, no further assistance or support will be required" (Smith 1991:18). As illustrated in Dufton's article "Succeeding in the Workplace" (1998), some people's disabilities require that they receive ongoing support and encouragement.

Often, workers with disabilities become frustrated because their duties have not been adapted to their level of ability, which results in feeling of stress, frustration and inadequacy. Organizations rarely initiate support services or facilitate understanding in the workplace. Smith *et al.* cite as a major obstacle:

> ...the 'laissez-faire' attitude of many employers in relation to disability, for example their belief that a person with a disability, once recruited, is responsible for 'fitting in' to the organization or work-group, and that the goodwill of colleagues will surmount any potential difficulties.   Smith

Initial adaptations made by employers may also fail to consider people with degenerative or cyclical disabilities, whose needs may change over time.

D. Financial Barriers

Financial disincentives have oft been included amongst the barriers for people with disabilities when trying to gain employment. Some assert that social security fosters dependence and inhibits some people from searching for employment. Canadian respondents to the CCRW's focus group interviews commented that lack of flexibility in their financial support programs has become a significant barrier to gaining employment:

> I have a pension [C.P.P]. If I start work again, I'll lose my pension; I'll have three months to make a decision. I would let the pension go if I got a decent job. But it's strictly black and white. I've been offered a lot of excellent jobs on a part-time basis; I'm not going to let my pension go for less money. (Marlene, Halifax)

Many people would lose their income security and medical benefits were they to gain employment. The Income Assistance system acts as a further barrier to employment through providing little or no support for people with disabilities to seek employment. Income Assistance staff make assumptions that people with disabilities have neither the capacity nor interest in working (MLPD 1999). Because of the large case-load of Employment Assistance workers, energy is expended on those who are expected to gain employment. "While the worker's priority is to manage the client's case, employment is often not readily encouraged among persons with disabilities" (Cyr and Schirle 1999:10). This differential policy has resulted in a situation whereby persons with disabilities are neither expected nor encouraged to find employment: "Persons with disabilities have been implicitly defined as unemployable" (*ibid.*). These statements must be tempered with the knowledge that the addition of policy geared towards employing people with disabilities could compromise the income assistance for those persons who are unable to work.

E. Other Issues

Other issues have been cited as barriers to gaining employment, including problems with employment agencies (both general agencies and organizations specifically for people with disabilities), discrimination, and the economy in general.

Theoretical and Conceptual Framework

Until very recent years, research on disability issues has taken place in a variety of academic faculties and under a variety of different theoretical paradigms: "due to its interdisciplinary character, no one discipline or academic field has adopted disability policy as its own…" (DeJong 1994:152). Historically, disability has been treated as a medical problem, and any research done in this area has been undertaken using Medical or Rehabilitation Models. Impacted by the Civil, Independent Living and Consumer Rights movements in the 1960's, research on disability issues shifted in the 1970's towards using the Independent Living framework for analysis. This paradigm evolved into the Social Model of Disability, a theoretical framework emerging largely through the work of researchers in the U.K and since widely adopted in North America. Recently, scholars have criticized the Social Model for its exclusion of

the lived experience of disability as a unit of analysis and have incorporated Feminist and Embodiment Theory in their study of disability. These theoretical frameworks will be elaborated on in the following paragraphs.

Traditionally, disability studies fell under the "medical model" or "rehabilitation paradigm". This framework has been criticized for its individualistic focus, its preoccupation with "fixing" the physical or cognitive limitations of the "patient" and enhancing their ability to function "normally" within society (DeJong 1979).

Figure 3: Comparison of Rehabilitation Model to Independent Living Model (DeJong 1979)

Rehabilitation Paradigm	Independent Living Paradigm
Health professional is competent expert	consumer is expert in disability experience
authority/decision making ability is vested in the health professional	management of medically stabilized disabilities is a personal matter
relief of responsibility	assume familial, occupational, civic responsibilities and personal risks rehabilitation promotes dependency-induced relationships between patient and client
disability related to inadequate ADL performance or preparation for gainful employment = Individual Focus	locus of problem focused on environment, including the rehabilitation process, physical environment and society at large
provision of acute/restorative care, including hospitalization and therapy = normalization	advocacy, peer counseling, self-help, consumer control, barrier removal

This model has been challenged through the Independent Living (IL) movement, which has denounced its individualistic focus and sought to define disability in terms of social and environmental limitations. This paradigm shift has promoted the use of advocacy, peer counseling, self-help, consumer control and barrier removal (DeJong 1979).

The relationship between the Independent Living Movement and employment related issues is complex. Originally, the IL Movement concentrated its efforts on the 'severely disabled', often classified as such because of their inability to carry out paid employment (DeJong 1983). The Movement, "while not eschewing the importance of work, does, however, decry the traditional emphasis on measuring rehabilitation potential almost exclusively in work terms (Stubbins 1982, 1987; Cornes 1984)" (Zola 1989). On the other hand, some rehabilitation professionals implemented IL through community involvement for those who they felt were

'unemployable', whereas consumers did not see community involvement and employment as necessarily competing goals (DeJong 1983).

Emergence of the IL movement has inspired the development of the Social Model of Disability (Oliver 1983). This model led theoreticians to center their inquiries on "disabling environments and hostile social attitudes" (Barnes 1996:43), as opposed to individual impairments. This framework turns the focus of the inquiry on "able-bodied society" and "institutional disablism" (Oliver 1986). As Michael Oliver aptly states:

> Disability cannot be abstracted from the social world which produces it; it does not exist outside the social structures in which it is located and independent of the meanings given to it. In other words, disability is socially produced.
>
> Oliver 1992: 101

The Social Model of disability has shifted the focus of inquiry away from individual impairment and society's construction and interpretation of disability. Linton compares the impact disability theorizing can have by comparing it to Women's Studies. When feminists differentiated between 'sex' and 'gender', they allowed gender to be analyzed as a social construction separate from the biological determinants of sex. Similarly, when disability scholars differentiate between 'impairment' and 'disability', the Social Model may also be applied to disability (Linton 1997:536).

The Social Model's critique of the medical model and the housing of disability studies within that paradigm can be compared to many of the studies done by critical medical anthropologists (Rhodes 1996; Schepher-Hughes and Lock1987). Critical medical anthropologists have sought to uncover medicine as a cultural construction. As both feminist and medical scholars have shown (Bordo 1989; Martin 1989), biomedicine has followed the Cartesian trend of separating body from mind, nature from nurture and biology from culture. All things medical/biological remain separated from society and their social implications. Not only are the social implications of being medically labeled (i.e. as depressed or as paraplegic) difficult to extrapolate, but the very social construction of those medical conditions (such as mentally ill or disabled), which have cast those particular states of being under the medical model to begin with become almost invisible. Proponents of critical medical anthropology seek to uncover the

underlying social construction of disease in general. Those who advocate the Social Model seek to expose the social construction of disability in particular.

Disability Studies scholars and Anthropologists, among others, also share their recognition and critique of the concept of "medicalization":

> Medicine is becoming a major institution of social control, nudging aside, if not incorporating, the more traditional institutions of religion and law...this is not occurring through the political power physicians hold or can influence, but is largely an insidious and often undramatic phenomenon accomplished by "medicalizing" much of daily living, by making medicine and the labels "healthy" and "ill" relevant to an ever increasing part of human experience. (Zola 1975)

Increased medicalization over certain women's conditions such as pregnancy has turned a once natural life event into one driven by medical intervention and controlled largely by physicians (Martin 1984). However, for women the experience of giving birth is time-limited. Many disabilities are not. Therefore, the housing of "disability" under a medical framework requires that the person with a disability remain permanently under the direction of medical and rehabilitation professionals. This notion was at the centre of the Independent Living Movement, which promoted decreased medical involvement once medical stability had been established in the lives of persons with disabilities.   In fact, medical involvement has been cited as a major barrier to independence for people with disabilities: "a constant medical presence in the life of a disabled person gives rise to behaviour on the part of both practitioner and patient that induces dependency and thus hinders achievement of rehabilitation and Independent Living goals" (DeJong 1983:15).

The most recent shifts in the theoretical study of disability have sought to include individual lived experiences of those with disabilities, including experiences that recognize the role of the body in disability. Hughes claims that "the social model…actually concedes the body to medicine and understands impairment in terms of medical discourse" (Hughes 1997:326). Wendell (1996) holds that the body be considered before the mind "as a cause of events" (p.103), not just as under the direction of the mind. Body theorists claim that the self includes more than just the mind, and that the body is an integral part of self. Seymour sees great potential for the contribution of people with disabilities in this study:

> ...the disabled body has been seen as a tragedy (Oliver 1990, p. 10)
> because of its failure to conform to the norms of the historically created
> biomedical body. Yet although the word 'catasrophy' refers to a 'great
> sudden disaster' the meaning of the word also includes a 'subversive
> event' (Johnston 1976, p. 122). The old stereotype of a person trapped in
> a lifeless body may be transformed to a perspective where it is the living
> body, freed from many aspects of its social incarceration, that initiates the
> reconstitutionary moves.
>   Seymour 1998:18

She views the departure from socially deemed 'normalcy' as an opportunity for freedom from social

constraints.

Accounts of disability must stress subjectivity and locate the individual within both

the social and the personal context of the disability experience. (Shakespeare 1994).

The emerging literature on embodiment and lived experience does not challenge the

benefit of analyzing the disability experience in terms of the disabling or enabling effects

of the social world. Instead, these critiques offer an additional layer of experience to be

considered in the complex study of disability, which includes a social context, an

individual within that context, and their actions within and reactions to their experiences.

Disability can be experienced differently by different individuals, or even by the same individuals

in different circumstances. Research that includes the lived experience of individuals reflects the

importance of this type of analysis. Blackford (1999) illustrates the way people locate themselves in

experience by both reacting to and further constructing their realities. For the children in her study, their

parent's illness was seen as both "disabling" and "empowering", depending on the social, civil, economic,

etc. environment in which the family lived. Blackford has further developed the work of Abrams (1980) in

her construction of "a typology of the social relations associated with disability":

Figure 4: Blackford's typology of the social relations associated with disability

_____
Structure

The Economy	The State	Civil Society

Continuum of empowerment and disablement in a particular location and time

Social Action	Communication	Imagination of what's possible
		Agency

(Blackford 1999:683)

Under this scheme, individual agency is used to react to situations in either an "empowering" or "disabling" way, depending also on the social atmosphere in which these situations arise. For example, a child having to prepare meals for a sick parent can view that situation as either restrictive (they can't play with other children) or empowering (they have learned a new skill and have become more independent). Blackford's work illustrates the importance of examining both the social environment and individual agency in studying issues of disability, including employment related topics.

Watson *et al.* (1999), in their study of children with disability's experiences in school, have also identified children's differential use of the label "disability": "Children displayed fluidity in claiming disability as an identity: they described how they were not always disabled in every situation" (p. 5). Disability depends on the agency of an individual in reaction to a particular social situation.

Situating individual experience in examining disability issues also necessitates the involvement of people with disabilities in the creation and implementation of research on that population. This sentiment has been echoed through the IL movement's demands for the participation and control of persons with disabilities and their agencies over research. The emancipatory research paradigm requires that researchers surrender their claims to objective expertise and commit to political and social change within the IL movement. This includes an ultimate respect for the subject's expertise in their own situation (Gilgun 1998), as well as a subordinate role in direction and control over research by non-disabled researchers (Stone 1996).

CHAPTER 3: METHODOLOGY
The CCDS Youth Employment Training Project

In May of 1999, the Canadian Centre on Disability Studies (CCDS) undertook a research project in conjunction with an employment training project for young people with disabilities between the ages of 20-29. Training for the project was developed by two community partners while CCDS provided expert advice on disability issues and conducted research and an evaluation of the project.

The youth were to participate in eight weeks of training (including self-esteem training, computer skills training, resume development, job skills, etc.), a two month job internship (with no pay), and finally, four months of paid work with the same employer. The goals of the training team were:

1) To help disabled youth make a successful transition into the labour market by providing them with employability skills, computer skills/technology training, relevant work experience and access to relevant labour market information.

1) To promote the integration of people with disabilities into the workplace, and to explore and document the role technology could play in helping youth with disabilities into the workforce.

1) To assess and document the role technology could play in helping youth with disabilities obtain and maintain employment.

The Participants

Nine participants were recruited for the program through community advertising, agencies that serve people with disabilities, and word of mouth. Interested individuals were invited to attend an information session where the organizers introduced themselves and explained the objectives of the program. Selection of the participants was based on their resumes, application forms, and this initial meeting with the project facilitators. In some cases, the facilitators also had personal knowledge of the applicants. Members of the project team met to choose those most appropriate to the program. Applicants were selected for the program based on their ability to participate in and complete the program, and on their commitment to finding employment. Those applicants with severe cognitive disabilities were not invited to participate, as the coordinators did not feel they had the resources or expertise to provide the necessary support.

The group ranged in age from 18 to 34. Five were male, four female. All had at least a high school diploma, one was enrolled in Arts and Science at the University of Winnipeg, and one has taken classes at the Master's level at the University of Manitoba. All of the participants were single, one was divorced. Five of the participants were from Winnipeg, four from smaller communities in Manitoba. All had lived in Winnipeg for several years.

Criteria for involvement in the program included chronic unemployment and a physical disability of some kind. Four of the participants used a wheelchair for mobility. The other five were ambulatory, some with the help of crutches or braces. At least four of the participants also had learning disabilities. Six of the participants had congenital disabilities, three had acquired their disabilities during their childhood or early adulthood.

The youth came to the project with several objectives, including self development, gaining job skills, learning to job search, learning how to engage and communicate with employers, a job, a paycheck, and increased social status.

Unfortunately, the training program failed to result in employment for all participants but two, who managed to obtain very short terms of paid employment. Neither of these opportunities have translated into long term positions. Although this situation was very disappointing for participants, project facilitators, and researchers, it did offer a unique opportunity for the researcher to witness first hand the many barriers faced by young people with disabilities in trying to obtain employment.

Research Design

Along with the training offered, the youth were invited to participate in the research component, where they were asked to critically reflect on their past experiences with education, job training, and employment and to relate those experiences with their present employment situation. They were also asked to take an active role in evaluating the training program, through designing and completing an Evaluation Questionnaire with the researchers.

My role was both as a student collecting information for a thesis, and as an employee for the Canadian Centre on Disability Studies. In my role as a student, I worked with Dr. Karen Blackford to present a workshop on informed consent and confidentiality, and conducted one-on-one interviews with the participants to discuss their past experiences with education, training, and employment. In my role as an employee for CCDS, I was to conduct an evaluation of the training project along with the participants themselves. This dual role had both negative and positive implications. Ethical issues such as maintaining confidentiality made it difficult to provide feedback to the project facilitators. I had to be careful not to disclose information to the facilitators that could be identified with any particular participant. Interim evaluation reports were carefully phrased so as to protect confidentiality. Due to the sometimes critical nature of performing an evaluation of the training project, the relationship between myself and the project facilitators was at times rather strained. However, these issues were always resolved through the honest exchange of information and by finding a reasonable middle ground.

On the other hand, because of my role as an evaluator, I spent much more time with the participants and was able to observe more of the youth's training and employment experiences. This allowed me a richer and more extensive database of knowledge to draw on for my analysis. It also allowed me to respond to the results of the training project by interviewing employers who had taken participants on a voluntary basis.

A. Consent Workshop

During the second week of the training program, the research team (myself and Dr. Karen Blackford), presented a workshop to the participants. This workshop was designed to introduce to the participants the research objectives, methodology, and to explain the rights and responsibilities of participants and researchers engaging in research activities. I asked the youth to participate in one-on-one interviews and showed the participants a list of potential questions. We explained that after the interviews, a focus group meeting would be held to revue the information from the interviews and to construct an evaluation tool for the training project.

We used this opportunity to explain the rights of the participants to confidentiality. We gave each of the participants a copy of the confidentiality agreement to take home and explained that all information given to us would be shared only after names had been changed or removed. We also made sure that the participants understood the risks of being involved in such a project, including the risk of being identified by others in the group because the group was so small.

Finally, the youth were promised ongoing access to the research results and opportunities to provide feedback. After every evaluation, the youth received a copy of the report in draft format which they were invited to comment on. They were also informed of all public forums during which this research was to be discussed or presented.

B. The Interviews

One-on-one interviews were conducted with each of the nine participants during the second and third week of the training project. The interviews lasted between one to two-and-a-half hours each, and were tape-recorded. Each of the interviews took place in the office of one of the facilitators, adjacent to the training room used for the project. Participants spent time away from training to take part in the interviews.

A semi-structured interviewing process was followed[1]. Semi-structured interviews follow short "question stems" which reflect the researcher's general knowledge or previous hypothesis on the subject, yet allow the informant to respond in their own words (Morse 1995). When responses led to topics not considered by the researcher in the original design of the questions, the participant was encouraged to explain their response in great detail. In this way, the interviews took on a "snow-ball" effect, with one

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[1] For a list of questions used, see Appendix **

topic leading to another. All participants were asked all questions on the list in order to provide continuity

and a basis through which to compare responses.

The interviews were transcribed and a preliminary analysis took place. Important themes were

drawn out for use in developing the questionnaire. Three themes were identified, each with three sub-

categories[2]:

> **A. Personal Relationships**
> 1) Self (self-esteem, expectations)
> 1) Close Others (family, peers, co-workers, teachers)
> 1) Community (contribute to society, community awareness)
>
> **B. Employment Specific**
> 4. Employer Attitudes (awareness, willingness to employ people with disabilities, expectations)
> 5. Job Experience (lack of work experience)
> 6. Long Term Positions (failure to achieve long-term employment)
> **C. Systemic**
> 7. Integrated Education vs. Special Education (awareness vs. stereotyping)
> 8. Transportation (reliability, flexibility, awareness, priorities)
> 9. Home Care (flexibility, awareness)

Quotations that seemed to illustrate these themes were presented following each category. Any

names or identifying information from these quotations was changed or deleted.

C. Focus Group Meeting

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[2] These themes were subsequently revised, see Chapters 4, 5, and 6.

Information from the interviews was presented to the participants during a focus group meeting[3]. The participants were asked to discuss each category and agree or disagree with the researcher's analysis of the information. In this way, information from the interviews was validated by the participants.

Once the categories had been revised according the wishes of the participants, they were asked to develop questions for the evaluation. Using each category as a guide, they constructed questions to address each issue. For example, the participants had identified "self-esteem" as an important factor in their ability to secure employment. For the questionnaire, they designed the question: "The training helped me to feel good about myself, built my self-esteem and independence, and helped me to expect more from myself from life."

D. Employer Interviews

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[3] For a copy of participant's instructions for Focus Group, see Appendix **

Because of my continuing involvement with the training project, I was able to observe the results of the training and the work placements. Although all of the participants did obtain some voluntary experience through the program, none have achieved long term paid work. However, their voluntary internships provided me with an opportunity to explore issues of employment for these young people while actually on the job. I therefore modified my research methodology to include formal interviews with two of the employers involved in the project. I also interviewed the program coordinator of the training project who herself had worked with one of the participants as an employee. These interviews were similar in format to those conducted with the participants, following a semi-structured style and lasting between one and one-and-a-half hours each[4]. I was also able to contact two other employers and speak to them on a less formal basis about their experiences.

Work Placement Observations

The training project formally drew to a close in October of 1999. However, my involvement with the youth continued as we worked together to prepare a presentation on employment for people with disabilities. I continued to pursue employment for the participants and facilitated a two-week placement for one of the youths at a retail outlet. This placement was not without problems, and presented another opportunity for me to observe first hand some of the difficulties experienced by the participants in gaining employment.

This work experience took place over the busy Christmas season, and the General Manager of the retail outlet agreed to create a "Greeter" position for one of the participants. The job would involve greeting shoppers as they entered the store and passing out catalogues to the customers. Unfortunately, a few days into the placement, the catalogues ran out. The manager then asked the participant to help customers to pick out products in the store, a task made very difficult by the small size of the store,

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[4] For a copy of employer's interview questions, see Appendix **

the throng of shoppers, and the participant's electric wheelchair, which was too large to fit through the passageway at the back of the store.

The problems culminated when the store manager witnessed two of her employees helping the youth to don her outer clothing at the end of a shift, a task that kept them away from the store's customers. It must be noted that the participant did offer to provide her own assistant to help her dress at the beginning and end of her shift. At the time the participant was placed in the job, the manager did not foresee a problem with having other staff members provide assistance. However, on that particular day, the manager felt that this activity was not appropriate, and informed the participant that she was not longer needed in the store.

Devastated, the participant asked me to speak with the manager. After discussing some possible options, she agreed that the participant could complete her placement at another store that was less busy and was large enough to accommodate the participant's wheelchair. I was later able to talk to the General Manager about this experience, who brought several other issues to my attention, which will be discussed in the following chapters.

Another participant was hired through CCDS to provide administrative assistance for a small research project and was under my supervision. This participant relied on Social Assistance for income and received only a small amount of money for his work at CCDS. As the income assistance program does provide a clothing allowance for those people who are working, I encouraged the participant to apply for that incentive. Unfortunately, instead of receiving encouragement from his Case Worker, the participant was required to submit documentation not only of his current employment, but of all previous training and educational experiences. I placed a phone call to the

Case Worker to provide some information about the participant's term of employment, and was told that due to the part-time nature of the job, the participant was not eligible for the incentive.

Analysis

The interviews (with participants and employers) and the focus group were tape recorded and transcribed. Material from the participant interviews was analyzed twice. A preliminary analysis was conducted in the two weeks following the interviews in order to pull together themes for verification and use during the focus group interview. They were revisited following the completion of the project and analyzed against the broader context of the participant's employment experiences and the outcomes of the project.

My personal observations were documented in a journal. These notes were reviewed periodically and used to recall specific events, contextualize comments, and to measure my own biases leading up to, during, and after to project.

CHAPTER 4: PAST EXPERIENCES

In the following three chapters, I will present the experiences of the youth participants as they were presented to me through one-on-one interviews and through my own observation of events. Much of this information will be presented in the form of quotations. By quoting the young people who participated in this research, I hope to allow them the opportunity to voice their own experiences. I will attempt to provide some context for these quotations through providing the research questions asked by myself in the interviews. Please note that words appearing in italic are those of the researcher. In this way I hope to acknowledge my own role in soliciting the comments provided by the participants.

In this chapter I will present the broad life experiences of the participants as they relate to employment. The youth made reference to a variety of events and circumstances in their lives that they feel have impacted on their ability to secure jobs. Some of these include their relationship to and within their family, their experience in attending school, including college and university for some, their disability, their relationship with their peers, and their goals and dreams.

Family

I started each interview by first telling the participants about my own experiences, family, education and background. I then invited each participant to tell me about themselves. Many of the youth used this opportunity to speak of their families and home lives. The role and influence of family varied with each participant. Three live at home with either one or both parents, the others live independently. Most maintain close relationships with their parents, visiting at least monthly. Many of the participants spoke of a dual relationship with family and parents, at times getting along well with family members, at other times struggling with relationships. This dual nature is certainly not exclusive to people with disabilities, however, certain problems identified are directly related to disability, especially concerning independence and goal setting.

Many of the participants spoke of the support and encouragement received from their families. Some cited this as the root of their success:

What else has made you successful?

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Family, encouragement that they give me, like 'you can do this, you're gonna do well.'

What has helped you to be successful in your life?
Positive influences.
Like what?
Mom and Dad, my sisters, grandma, and my aunts and uncles.
What do they do that's positive?
They just encourage me, say 'You can do it.

They have high expectations for me, my mom comes from a – not a well-to-do family, but she has a good job. My dad has a good job, so the expected the most. And I couldn't get away with much because my mom was a nurse and was dealing with a whole bunch of disabled people, so my scams didn't work on her.

What has helped you to succeed?
My family, and my friends, and myself.
How has your family helped?
They are encouraging.

Some spoke of the limitations placed on them by family, both regarding general life skills and specifically regarding employment. Certain comments reflect the struggle for independence faced by the participants:

I'm looking into getting onto self-management[5], um, but,…when I was living at 10-10, I had all my skills, I could pay my own bills or whatever, and when I got married, my ex took it all over, so I've lost all those skills. And now my mom is doing the same thing that my ex was doing, and I've tried to get her to stop, to teach me how to do those things, because I don't know the price of the food or anything like that, and I said to her, 'well, you know, let me do this, or teach me how to do this'. And she's, like, 'No, no, you have too many learning problems'.

Well, my dad, especially, to this day cannot see me as an adult, even though I'm nearly 28 years old. My dad still thinks of me as a kid, a little kid who needs to be told everything, given directions for everything, for general living. I don't know… He thinks that's what I need, but he's doing the opposite of what I need.

Family members often discouraged the youth from seeking employment:

My mom and other people in my family say 'You're never gonna find employment, or if you do, because of your overall health, you're not going to be able to keep it'.

If I drop out then I will hear from my parents and my whole family 'I told you you can't do nothing.'
Is that something that your parents tell you?
'You'll be on welfare for the rest of your life.'

I've had, you know, like I say, my mom, and other people in my family say, 'well, you're never gonna find employment, or if you do find employment you know, because of your overall health" (because I've had pneumonia a couple of times) 'you're not gonna be able to keep it, or, …the employer's not gonna understand that"

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[5] Self-Managed Care: Where the consumer accepts full responsibility for meeting their assessed care needs by coordinating, managing and directing those non-professional services assessed as needed to maintain an independent community living lifestyle (from the Independent Living Resource Centre of Winnipeg's Self-Managed Care Brochure)

The interactions of these young people with their families are more or less the same as any young person, with or without a disability. At times, the relationships were described as loving and supportive, at times they were characterized by friction and misunderstanding. Unfortunately for some young people with disabilities, the attitudes of their families reflect all too clearly the discriminatory views of society against disability. Discouragement of the youth by their families does impact their self-esteem, and ultimately their ability to find and keep employment.

School

I asked each participant to tell me about their range of educational experiences. All had completed high school, and all had participated in integrated education. Some of the participants had attended college or university as well. The participants spoke of their educational experiences, from Kindergarten to University, in great detail. All reflected on some aspect of school which they enjoyed – a kind teacher, a field trip attended, a lasting friendship. However, overwhelmingly the participants' responses focused on the difficulties they had faced in school. Some comments revealed their feelings of isolation and inadequacy:

> High school was my worse time, I just kind of felt awkward, you know.
> Everybody was, kind of, looking down on me 'cause everybody was 'up
> there' ...at one point I was the only handicapped person in this one class,
> so I felt kind of awkward and didn't know, and looked at the teacher and
> said 'I'm gonna drop this course'.

Another participant described returning to school after having undergone major neuro-surgery at the age of 16:

The first semester back in school, I took what they considered a full load in school, four classes a day. And, uh, out of those four potential credits, I only received one, and that was only because the teacher was very understanding and very giving, a very good teacher.

That was a hard semester. I felt so inadequate. I couldn't seem to learn the way I used to, before the surgery. Of course I was always forgetting about things, forgetting about homework assignments…

Almost all of the participants had a Teacher's Aid. Most of the time, this was simply a matter of course:

I always had an aid write for me in school. I'd tell her the answer and she'd write it down because it, the simple fact that it's faster. Not that I don't know how to write, I know how to write and make myself understand it, but not for somebody else to understand what I wrote.

However, at times Teacher's Aids were problematic:

I had two teachers, I wanted to play with the other kids. They didn't want me to because everyone thought Encephalitis is contagious.
The Teacher's Aids thought that?
Yes

Some of the participants were accused of cheating in school because of the use of Teacher's Aids or other accommodations. One of the participants had a learning disability. He described a school exercise where the students were given blank maps and told to label them. Because of his disability, he was not able to distinguish the water from the land. The teacher compensated by colouring the water blue for him, but leaving the rest of the map blank. This allowed him to finish the exercise, however, the other children then accused him of cheating:

The kids had a problem with that, briefly, but once they realized I had a problem… no problem. And we showed them that the blank map, all it is is coloured. I guess they thought I might have been cheating.

Others related similar experiences:

Did you have a good relationship with the other students?
Some, most of them. There again, they would think, the odd one, not so much in university, but the odd one would think that I was cheating on exams because I would have to go into another room and they [teacher's aids] would have to write my exam answers for me.

How do you know that they thought you were cheating?
All the time they would say 'you must be able to score 100 or 99 because the woman just speaks to you, she probably gives you the answers.' That's something you have to live with when you can't write yourself.

The experiences of the youth in relation to the presence of Teacher's Aids reflect the findings of the Watson *et al.*(1999) study. Continuous supervision of students with disabilities alienates them from their peers, making it very difficult for them to form meaningful relationships with other students.

I asked the youth to describe the teachers they had worked with. Many of them described

positive experiences:

The teachers were helpful and accommodating to my needs.
Can you give me an example?
They carried my typewriter to my classes and sometimes I would get notetakers for my classes.
How did you feel about having notetakers?
They were helpful because I can't write, I need a typewriter or a computer.

How were the teachers?
Very understanding. Very understanding and would do anything for me to make it easier for me, such as longer exam times, um, because somebody would have to write for me and I would have to verbalize my answers. When I had a spare or time off between a class, they would work with me to get caught up with homework and stuff.

Certain teachers and their methods were not as helpful. At times the participants felt that

they had received a substandard education:

Their methods or approach of teaching me was, didn't work for me, didn't seem to work for me.
What kind of methods were they using?
Um, well, actually, I kind of felt they were trying to push me.
Push you to do what?
To learn this stuff. And I, it didn't work. I, well, it just made me feel more inadequate and frustrated.

Did you graduate from High School?
From, um, Special Needs, yes.
But you didn't learn how to read or write properly?
That's right.
Why not?
They say its part of my disability. Like, they…in elementary they tried making me read. I could read but I wouldn't remember the next day what I read, so I would have to re-read it every day and it would slow the other people down so they gave up. Or, as Pat would say, I gave up on myself.

Many of the participants had been discouraged from setting goals or having even moderate expectations for themselves. Some felt they were treated as "stupid" and were held back from trying certain activities:

> They [teachers] seem to have the attitude that able-bodied people can do more that disabled people...I'm not stupid, I would ask for help if I needed help.
>
> The whole reason I went to that school was for the auto mechanics course. I passed, but the teacher was so afraid that I'd hurt myself,...I don't think he...he thought I was stupid or something...not gonna ask for help and hurt myself, and that kind of thing.

Certain participants felt that their goals had been discouraged by teachers and by others:

> *When you were in high school, what were your goals and expectations?*
> I think in high school I wanted to go to university, and I was always told 'no, no, no, you have perceptual problems, you'll never do it'.
> *Who told you that?*
> My teachers, and some of my peers, and some of my family members.
>
> *You talked about teachers holding you back from taking certain classes. Can you*
>
> *suggest anything for changing that situation?*
>
> I think what they need to do is interact with the students more. Find out exactly what the students want, and let them try. Let them decide whether it's for them or not. And I think students have to be more open minded, rather that close-minded, and let them try. And if the student honestly can't do it, well then the student's not going to stay in something just to frustrate themselves. It's kind of stupid. But if they're gonna do it, then let them try and see what happens. I wish they would have let me try, because they held me back, I felt, a lot, and they don't think that a person holding you back is gonna affect you later on down the road, but I've found it's affected me quite a bit, with the fact that I don't have the grades or the education that I need to get to the U of M at this point. And I blame that all on the teachers and the school system, and I think that it's high time that we got treated like people, and not something that's got a disease.

Others had faced outright discrimination in their schools and by their teachers:

> I even gotten told in school, that I would never be employable, and I think that's a bunch of bull.
>
> *How do you feel about the teacher in that class?*
> Well, we don't see eye-to-eye, so...I think he's a little narrow minded when it comes to handicapped people, so...
> *What do you mean?*
> Like 'He's got crutches, how can he work on a car?', you know? 'He's got physical disabilities, how can he do this, how can he do that?'
> *So he didn't think you would be able to do these things?*
> He wrote a letter 'Not suitable for this course next semester.

Other participants spoke of their education with a great deal of frustration, having been faced with systemic problems:

> I flunked out of University anyway, because even though they wanted to help me, even thought they wanted to make changes for me, they couldn't.

> In order to have the government put me through [university], because I was on assistance, I had to take three full courses. And I was told by all the psychiatry people and psychologists and whatnot that "Three? You're pushing it, big time."

Again, the descriptions of the educational system encountered by the participants reflected a range of normal experiences. Sometimes they got along with teachers, at other times they did not. Some agreed with the methods used by their teachers, others felt they were inappropriate.

The continuous presence of Teacher's Aids is an experience unique to children with disabilities. While to youth recognized the value of the help provided be the TA's, their presence also had an effect on peer relations.

Finally, the lack of knowledge and understanding of a few teachers and TA's led to certain circumstances of discrimination towards these students. Although these incidents were in the minority of those described, they do illustrate the need for further training and education regarding disability and the potential of all students in a diverse educational setting.

Peers

When I asked the participants to describe relationships with their peers, a few mentioned having many friends and acquaintances:

> *Can you tell me about you experience at high school?*
> It was positive. I got along with the other students and I had lots of friends.

Others spoke of their peers as friendly, but did not feel they had made real friends in school:

> I don't have many friends. Not good ones anyways.

Many described the absence of friends, or worse, being teased and bullied at school:

> When I was in school and when I tried to take the electronics and that there, the other people in the class treated me like I was some, like I was totally stupid or

something…I was with a bunch of guys who were a year younger than myself. And they treated me like I was stupid or something…it wasn't very nice.
Why did they do that?
It was because I was a year older than them, and I was very forgetful, and slow.

…there were a lot of disabled people, but for whatever reason they didn't like me, 'cause I maybe sat crooked in my chair, or they just didn't like me.
Who didn't like you?
People in general. I ended up skipping a lot of classes, uh, not showing up for school. I would go there and they would knock me down if I was walking with my walker. Or call me horrible names that I had to deal with for three years before my mom pulled me out of that school.

I had surgery in grade 6, my first surgery when I was in grade 6. And they called me 'Martian' all the way through school.
Why did they call you that?
Because I had brain surgery.

In Grade 10,11,12 my grades went higher.
You switched schools?
Ya…and my grades went, sky rocketed.
Why?
I wasn't around people who made fun. There were only three disabled people in the whole school, and I was well accepted.
So in [other school] there were a lot of people with disabilities?
Ya.
So you think that's what the difference was?
Well, I think so, but I lived in Fort Gary, so I went to school in Fort Gary when I went to [new school]. And I was integrated when I went to [new school]. But, I don't know, people, kids are just cruel to kids in general, but they are especially cruel to kids with special needs. I had a teacher's Aid who wrote all my notes for me, and I would always get accused of cheating on tests, or something, because it would take me extra time to write a test because I have to verbalize everything I'm saying, and they would write it down for me.

The youth spoke of being pushed or shoved out of their wheelchairs and off of their walkers. One was

shoved outside in the snow for over an hour without her wheelchair.

Some participants spoke of the difficult transition from elementary to high school:

I could get along with teachers or the other students because I was more at home in elementary school because I went there for seven years, and I cried when I left. I got along with everyone.
So it was hard to make that transition?
Yes
Do you think there was something about the schools that made it different?
All the kids in elementary school didn't look at the wheelchair, they looked at the person. And because I was the only wheelchair person in high school they looked at me different for the last, till the last year of school. Then they started getting used to the wheelchair.

Despite the difficult relations between them and their able-bodies peers, the participants were overwhelmingly in favour of integrated schools:

> [High School] was a good experience because I was in integrated classrooms, like, I wasn't just always with people with disabilities, I was with people that had no disabilities, and I really enjoyed my Junior High years.

> The government demanded that Allan Douglas [a segregated school] be closed down, and we all go to our community schools. So, we were forced into public school, private school, whatever, but with mainstream society. And for me that was the best thing going. *Why?*
> Because that got me into the community, I saw what the community was like, I made friends other than handicapped friends, I realized that there are people that are normal and different than me, where it kind of hurt that they could go out and play football all the time, or hockey or something, and I couldn't. But I had…it actually opened me up to more experiences.

Most of the experiences described under this section are disheartening, to say the least. The inability to cultivate peer relationships had led many of these youth into social isolation and has impacted their ability to act in a socially acceptable manner, both in social and employment situations.

The violent acts of bullying experienced by many of the participants are appalling. Action must be taken within schools to see that children with disabilities are not subjected to such forms of abuse.

Disability

During the interview, I asked each participant to tell me little about their disability, if they felt comfortable doing so. Some of the following comments followed my question. Disability came up outside of the context of this question as well.

The concept of disability was discussed in a variety of different ways by the youth. In some contexts, disability was acknowledged as a normal part of everyday life. Some described it as an advantage in certain situations, for example, by having developed other skills to a greater degree in order to compensate for lost abilities. Others spoke of disability in a broader sense. Public attitudes and awareness of disability were often seen as barriers to success. At times, family member's understanding of disability was problematic.

For the participants in this project, disability was mainly seen as a normal part of their lives. Some of the participants did describe brief periods of adaptation and coming to terms with their disability. One participant viewed her disability as a positive influence in her childhood development:

> …on an unconscious level, I knew something was different, so I would focus on the strong points. But when I was 6, 5 or 6, I knew I was different because people would be walking around and I would still be on the ground.

Another participant had returned to school after having acquired a disability and undergoing surgery. He described his tendency to blame every negative aspect of his life on his disability. When a friend pointed this out, he became aware that his disability was not always the problem:

One of the guys in my electrical class told me once, and at that point I had been using my surgery as an excuse for all my problems, and he told me 'it's not an excuse'…he sort of turned a light on for me…I was hiding behind my surgery…I was blaming my surgery for all my problems. And it wasn't to blame, really, for a lot of the problems I was having, the surgery wasn't to blame.

Not all participants were so easily able to overcome the difficulties associated with acquiring a

disability. One participant described her struggle:

Do you consider yourself to be unemployed?
No, I consider myself to be disabled.
What do you mean by that?
Unable to do anything.
But you know that you're able to do things.
So people tell me...
So you don't like the word 'disabled'?
No...
Are you able to tell me why?
Because I've spent so many years recovering from my surgeries… I'm still not perfect
…It means you can't do anything.
Why does it mean that to you?
Because I haven't found a job since I had those operations and became disabled.

It is interesting to note that while the first two participants were able to view their disability as part of the continuum of what it meant to experience their own lives, the third participant measured disability against an external standard, that of finding employment. In the first two situations, the participants were presented with an empowering scenario which included family or peer support. In the other situation, the participant was not able to engage in economic activity. This limitation resulted from the inability of the social environment to provide an opportunity for this person to find employment, and she therefore felt disabled.

Many of the youth expressed frustration over common attitudes and misconceptions held by others about disability. For example, that people with physical disabilities also have cognitive disabilities, or that they would rather stay on welfare than work. Many of these comments centred on employment:

No one will give us the same opportunities or the same chances as everybody, and because we need special things done or special equipment, they don't want to take the time to look at purchasing it. We might need an orderly come, that might disrupt them, then they don't want to deal with it. Or they don't think we're capable, even if we...because some of us might tire faster than others, and they don't want to give us the opportunity or training, just like any other job.

Other participants spoke of more personal experiences of encountering negative attitudes:

How old were you when you started Kindergarten?
My parents said I was nine but they asked me how old I was and I was nine but I said six.
At school you said six?
No, my parents go "I was nine" but to me I was six years old. So I'd lost a couple of years because of the illness.
Do you not remember very much of that time?
No, I try not to neither because I don't want to because my life was happy then and not now. Like, I would like to run and play like normal people, but even my Grandma says, and she told my Mom this, and my Grandma didn't think I was hearing, but she said everyone in a wheelchair should be dead.
How do you feel about that?
I felt hurt.

> …my dad…he's great, he can pull out all the stops, after he got over the shock of producing a crippled kid, 'cause that really destroyed him. And my mom and dad's marriage.
> *Why do you say that?*
> I heard them fighting. And I know exactly what happened.

The participants experienced disability differently during different situations. At times, disability was not a factor in their life experiences. At times, their disability was beneficial. In other instances, their physical differences were impacted by negative circumstances (i.e. unemployment or negative attitudes) and became disabling in their result.

Goals and Dreams

When asked to describe their goals or dreams, most of the youth were unable to. Many felt that they had been so discouraged as children and adolescents that they were not able to see a positive future for themselves. Self-esteem was often mentioned as a barrier for setting goals. All participants felt that they had low self-esteem:

> Right now I have a really hard time with self-esteem because even now I've done something [achieved post-secondary education] but I've never really put it anywhere. So I have my degree, so I don't think of it as a big deal because I'm still in the same spot I was in grade twelve, not knowing where I'm going after I have my degree....I don't have any job experience, except for that small volunteer stuff.
> I do not think that it is very feasible for me to be a [employment choice] right now because my self-esteem is low because of the experiences I've had with other people, such as that individual not giving me a chance to prove myself, even before he doubts me.

The most poignant demonstration of low self-esteem during this project came when one of the participants attempted to commit suicide. At a later de-briefing session, seven of the eight youth remaining admitted to having attempted suicide as well. This knowledge had an extremely sobering effect of the project facilitators and on everyone involved in the project. Although the participants cannot be claimed as a representative sample in the scientific sense, the effects of low self-esteem on this population must be considered in a more thorough manner.

Some participants did, however, feel that the employment training they were receiving was helping to improve their self-esteem:

> People, I know I am sometimes, are far too critical of themselves…I don't have to be that critical of myself. I can do this, I can accomplish this.

> *What do you hope to gain from this training project?*
> A job, and self-esteem, and courage.
> *Why courage?*
> The fear of failing, of not failing, the privilege to fail, the right to fail and feel good about it.
> It's OK if you fail, you shouldn't always feel bad about it.

While most participants were not able to describe concrete goals, several hoped that they would one day be able to show themselves, their parents, and society in general their potential:

> *You would rather have a job [than be on Social Assistance]?*
> Yes, so I can make my own money and be proud of that.
> *Why would that make you proud?*
> Because I would be earning it, earning my own money. That would make you feel good, don't you think?

> I want to show them [my parents] I can do it without them.

> If I, or if someone here, has the capability to do it, then there shouldn't be anybody, including ourselves, or anyone, trying to take that dream away from us, because I believe I've taken from the government long time to go through school. I've taken through the government to buy me equipment that I need to live a very independent lifestyle to the best of my capability. Now it's my chance, and my right, and my need, and my sense of belonging to put back into society after I've taken out, and start paying taxes like everyone else.

The idea of goal setting was elusive for the youth participants, as it is for many young people. Many felt that the discouragement they had tolerated for many years had led them to develop low self-esteem and made it difficult for them to overcome the many barriers facing them. However, many of the participants expressed their desire to take their rightful place in society, to hold down a job, contribute to the community, and make it on their own.

Conclusion

The incidents described in this chapter reflect the lived experience of the youth participants. These experiences reflect a broad range of events and circumstances, from family and peer interaction, to school experiences, to goal setting and dreams. These types of events are important in the lives of all people, with or without disabilities. Disability is not always a factor that impacts on the lives of these young people.

However, social conceptions about disability impact these youth in a variety of ways. In some cases, negative attitudes about disability have been adopted by their families, teachers, and peers. These attitudes impact on the youth's self-esteem and ability to set goals. It is impossible to trace the exact effects of these experiences on the employment situations of the participants. However, the complex interaction between the individual, their family and community, and society as a whole must be accounted for when examining the lived experiences of young people with disabilities in their quest for employment.

CHAPTER 5: EMPLOYMENT SPECIFIC EXPERIENCES

For most of the training project participants, the quest for employment was not a new one. All participants but two had actively searched for employment before coming to the training program. The two without job search experience had been attending school full time up to their involvement in the program.

Pre-Employment Experiences

All of the participants had been involved in either employment training, work placements, or volunteering. All saw those experiences as opportunities to increase their employability. However, since none of them had ever held a job, these experiences seem to have failed. Some of the participants spoke of previous employment training. Although they appreciated the new skills they had gained through training, they also spoke of disappointing results. One participant described some of the skills learned through a training program:

> …self exploration stuff, and learning about the world of work, and writing resumes and that there.
> *Was that a good experience?*
> Very good, yes.
> *Did you learn anything, new skills?*
> Well, I learned stuff, yes.
> *Did you learn things that you were able to apply?*
> Ya, I guess, somewhat, ya. But, actually, to this day I haven't really used that knowledge in particular. I haven't particularly had the opportunity.
> *Because you haven't found a job?*
> That's right.
>
> I did go to employment preparation after I moved on my own for three weeks, where they would get us to perform a variety of tasks such as computer skills, which I didn't receive very much, or reception work, or putting things together.   Like, if they gave us a, I don't know, rubix cube, they would tell us 'put it together' and I would just laugh at them.
> *Why was that?*
> Because I'm not very…if things aren't cut and dry, if there's not instructions or something, I can't…if something's broke, I don't bother fixing it…I don't have very good dexterity in my fingers so for me to fix something, unless it has big pieces, I'm unable to. And I have some spasticity, which means I move around a lot when I'm trying to do something.

Many of the youth had taken part in work placement programs. However, finding placements was sometimes a challenge. One participant, who was to be placed through his school, was often told that a work experience could not be found for him because of his disability. He then went on to find his own placements, proving that he could, in fact, perform work related tasks:

> They always had trouble finding me work experiences, because of the disability. That was always their excuse.
> *Why do you think they had a hard time?*
> …I always went and did it [found my own placement]. I'd say "I saved your bacon again!"…I don't know, just lazy…
> *You don't think they were really looking?*
> I think they were just lazy.

Although the participants enjoyed these experiences and felt they had learned a great deal from them, their work placements did not lead to employment. At times, the placements were discontinued after a few weeks or months:

> The teacher found work placements for the students, according to what they liked and that. And I was first placed for this, I was first placed in a manufacturing firm, where they manufacture electronic items for farms, like, uh, light timers, and temperature control modules, and that there. But after a couple of months it just didn't work out with that place, so they discontinued working with me and the program. So then my teacher placed me at another place called Kindale Occupational Centre, where I could, it was actually a placement for me to do some self-discovery in a way. For me to find out more about my strengths and abilities. It was a workshop for mentally handicapped people. And there was quite a number of different things that they do there, which I eventually did during my placement there. It was a very interesting placement, I quite enjoyed it. I also enjoyed the electronics firm though, too. Very good experiences.

Unfortunately, when work placements were terminated, the participants were often unaware as to the reason. This lack of communication has left them unable to improve their skills and prepare for the work force.

Many of the participants had done some volunteer work. They felt that volunteering helped them to gain skills, learn new tasks, meet people, and in some cases, to break down barriers:

> *Why do you do volunteer work?*
> It was basically to break down the barriers, um, to teachers and that, and to the different aids that worked there, to show them that I could do it, as well as to get to know my peers, as well, and it was great experience to interact with my peers. As well as with other aids that were working. I just found that it was more, um, fun to do, something I really wanted to do, and it just kind of amazed people that I could do it, especially with the lifting and whatever…

You said that you worked at the Heart and Stroke Foundation [as a volunteer]? What did you do there?
Public relations, stuffing envelopes, selling of tickets, …It was alright. I wouldn't like to do it as a job everyday.

In other cases, volunteering was done to alleviate boredom:

Volunteering…fills up your time, because I've been out of school now for a year, and I, if I don't find a job, well, I'll be going crazy. I'll probably go back to volunteer, 'cause I can't stay home now. After having a structured life for so long, and not taking a year off until last year, I can't function very well, because you count the hours till the next day, and you do the same thing.

Almost all of the youth had been through previous employment training programs, some had attended up to 4 previous programs. However, information learned in these sessions was seldom, if ever, applied.

Gaining work experience for young people is always a struggle. The situation described by the youth participants reflects that it is no easier for people with disabilities to get employment experience. The youth described many barriers, including difficulties getting placements and the ability of the work site to accommodate their needs.

Employment, Disability, and Social Attitudes

The young people who took part in this research project have all faced discrimination due to their disability. Many cited examples of being bullied and teased in school, others were limited in their choices for education or for vocational opportunities. Often, they would comment on the negative social attitudes that drive these acts of discrimination:

Sometimes I'm proud of myself that way, too, but it doesn't matter if I have letters behind my name. People look at the chair and don't give you the opportunity anyway.

This participant felt that the negative stereotypes often associated with people with disabilities were so pervasive as to override the major accomplishment of attending university and receiving a degree:

There has to be more integration. I mean, I don't know if I'm using the right words, ya, integration, like, we were integrated, so there has to be

more people integrated to understand. More opportunities for them to prove themselves. You can doubt us until you see, but give us a chance to prove ourselves to the able-bodied community before you shut the door in our face. Like, I feel six years of it [university education] has gone down. Why didn't I go to Red River and become a secretary, I'd have more of a chance of getting a job than I would with Social Work.

Most of the participants had engaged in job searches prior to their involvement in the training project.   Obviously, these job searches were not successful. Often, they would be questioned as to the validity of their education and qualifications for the job applied for:

I helped to feed the kids, I helped shredding paper, I looked after the kids. Basically what a Teacher Aid does…I tried to apply there for same position what I'm doing, but with pay, and they said 'Well, do you have a high school diploma? Did you graduate?'
I said 'Ya'
'From what grade?'
'Grade twelve Special Needs'
And they said 'That's not enough.' So I can't even get a job.

Well, they [employers] just think that if you're in a chair, like that person that said 'Don't call me, I'll call you.' He didn't even give me a chance to say anything. I handed him what I thought I had to hand him [a resume] and all that the interview was about was 'How bad is my cerebral Palsy?' Which is OK, I'll answer the limitations that I have for him to, to decide whether or not. But the whole hour, or hour and a half was that. And he didn't even ask me about my...you asked me more about my education in the past half an hour than he did in the whole hour and a half. He didn't want to see anything. The place that I went to is, it was accessible, so it wasn't like he had to do anything to make the place more accessible for me to be hired there. He just looked at the chair and said 'I know Wal-Mart hires disabled people for a job.'

Others have been denied employment simply on the basis of their disability. One participant applied for a position at a local book store. When he was called to come in for an interview he asked the interviewer if the room was wheelchair accessible. Once the employer found out that the participant used a wheelchair, he was denied an interview. Others related similar stories:

Have you ever looked for a paid job?
Oh, lots of times, and I've had employers look at me and go 'you can't do the work'
'Well, why not?'
'Well, 'cause you're disabled'.
And I've come up with that lots of times, they just …
Where these jobs that you would have been able to do?
Ya, like, I had gone back to a daycare that I had worked in, and said 'I'd like to apply for a job' and the gal looked at me and she's going 'You can't.'
I'm going 'What do you mean, 'I can't?''
She says 'Well, you're in a wheelchair.'
And I'm going 'Well, you let me do the job when I was doing it though work experience.'
'Well, I'd never hire you on a regular basis.'
And I went 'Well, why not?'

She said, 'Well, it would be just too difficult.'
'Well, tell me why, don't just say 'it's too difficult', tell me why, explain why."
And she says 'Well, I don't think you have the mental capability.'

I have tried, lots of times, to get jobs at different places. It's more, I don't know if it's a phobia, or if the employer just thinks that they know the answer, or they don't want to hear your side of it. So in other words, they label you dumb or retarded because you're in a wheelchair….

They [employers] seem to have the attitude that able-bodied people can do more than disabled people.
Why do you think they have that attitude?
They have that attitude…it's more of a mind-set that anything. 'He can't do anything, he has crutches, what can he do?'
I'm not stupid, I would ask for help if I needed help. 'Oh, he's gonna get hurt, and I'm gonna get sued, and we're gonna be responsible' and all this crap…

The participants saw a clear need for increased awareness and understanding of disability in the public. This need is especially clear for employers. The discriminatory practices encountered by certain participants have remained unchallenged. When the youth faced such discrimination, they felt they had no recourse and most often let the incident pass.

On-The-Job Difficulties

The difficulties faced by these youth in gaining employment extend beyond the attitudes of employers and of society. Many of the difficulties are systemic, in the way buildings are constructed, the way space is arranged, and the fast pace of production which many employers expect from their employees. One participant was very frustrated by the limitations placed on her by the physical structure of certain places of employment:

> Depending on where the work is, the building may not be accessible. The access into the building may be accessible, but once you get in there the bathrooms may not be accessible, or the lunchroom, or wherever...it makes me mad, when I know that someone could function very well in this building and because it's not [accessible], they can't.

Another participant told me that she often felt that she or her canes were in the way, that she took up too much space, or took to long to walk from one area to another:

> [Employers think that people with disabilities] are slow and they don't know what they're doing, and they get in the way, and their wheelchairs or crutches or canes get in the way.
> *Have you ever felt like that?*
> Yes, when I use a cane.
> *How do you think that that can be changed?*
> Get bigger office space, and other people being more tolerant.

Others felt that employers would refuse the flexibility necessary to accommodate their needs:

Why is it more difficult for people with disabilities?
Because nobody will give us the same opportunities or the same chances as able-bodied, and because we need special things done or special equipment, they don't want to take the time to look at purchasing it. We might need an orderly call, that might disrupt them, and then they don't want to deal with it. Or they don't think we're capable, even if we...because some of us might tire faster than others, and they don't want to give us the opportunity, or training, just like any other job.

One of the youth was participating in a work placement at which he was developing new skills and enjoying the experience. Unfortunately, his disability prevented him from achieving the fast pace expected at the factory:

The reason they discontinued with the training program and me was because my work, the work I had done there, I was slow, they found I was very slow, and the quality of my work wasn't quite up to par. So I can understand their point of letting me go.

If we are ever to have fully integrated workplaces, issues of accessibility must be addressed. The barriers faced by young people with disabilities in searching for employment are compounded by the limited number of jobs available in accessible works sites.

A more perplexing issue that that of physical accessibility has to do with the notion of "productivity" and the difficulties faced by people with disabilities in "keeping pace" with their able-bodied contemporaries. Unfortunately, until we are no longer enmeshed in a fast-paced, capital driven economy, this problem will continue to present a barrier to certain people with disabilities.

Labour Market

It would be misleading to suggest that the participants thought that all of their difficulties in gaining employment were somehow connected to their disability. Some of the problems cited have been encountered by many young people trying to find employment:

So if you know the right people, that's one thing, they'll give you an opportunity. But otherwise, if I just came up to somebody and said 'here, here are my grabbers, here's my education, here this, here that,', they wouldn't give me an opportunity.

Seventy five copies of a resume, and only five chances to prove...and out of the five, four people gave me an opportunity, because the fifth one wouldn't even let me darken his doorway.

If you don't have any job experience, how are you supposed to get job experience if no one's gonna give you an opportunity for experience?

A difficult labour market with high rates of unemployment impacts people with disabilities in much the same way it impacts the public in general.
Conclusion

The participants in this particular employment training project, especially those who had been out of school for a year or more, seemed to be trapped in a cycle of volunteer work, employment training programs, work placements, and job hunting. None had ever received employment as a result of the numerous programs they had been involved in. As a result, they had low expectations for new employment initiatives.

For the most part, the participants enjoyed the programs they had been involved with. They felt they had gained new skills and made new friends. Volunteering was seen as a growing experience as well. However, they had no real expectations for these activities to turn into employment. Those participants who had faced discrimination and systemic barriers for many years held little hope of ever being gainfully employed.

CHAPTER 6: EMPLOYER REFLECTIONS

As part of the employment training program which the youth took part in, they were offered short work placement positions. These placements took place during the summer of 1999 and ranged in length from two weeks to two months. An attempt was made to place the students in jobs suited to their particular interests. The facilitators where able to secure a variety of internships in many locations, including a farm, a call centre, a campaign office, a retail store, an accounting office, a day care centre, and a group home.

These practical experiences were originally intended to last two months each without pay, and then transition into a four month paid position. Unfortunately, only two of the participants experienced paid employment, and only for very short periods of time. Two of the participants completed their two-month trial period and where then let go, three were let go from their positions soon after they started, and one participant quit before completing her placement.

I was able to follow up with five of the employers who worked with the youth, three of whom I formally interviewed. One of those employers was also the program coordinator for the employment training project which the youth took part in.

Disability is not the Problem

Although none of the placements resulted in employment for the youth, many of the employers felt that the failure of the placement was not related to the disabilities of the youth:

> *So there's nothing really specific to disability or not having a disability?*
> I don't think so. I really don't think so.
>
> *Do you think that this problem was related specifically to her disability?*
> No

In fact, one of the employers felt that the participant's wheelchair gave her a unique advantage in relating to the children in the daycare:

> *What part of her job was she able to do well?*
> She really provided, first of all, one of the things working with children is coming down to their level. Being in a wheelchair she was always on their level which made her very approachable to the children, and of course the fact that she was in a wheelchair made her very interesting to the children. In terms of capturing their attention and keeping their attention her disability in fact created a unique ability, so that was very interesting.

The comments of the employers seem to discredit disability as a contributing factor for the unsuccessful placements of the youth. As far as the employers were concerned, the physical limitations of the youth were not relevant to their ability to perform duties. The problems stemmed instead from their lack of training, inability to understand instructions, and the lack of initiative and responsibility taken by the participants in certain situations.

Training, Commitment to Employment, Understanding of Duties

The placements were not without difficulties, however. The employers felt that the problems resulted from lack of proper training, lack of commitment to employment on the part of participants, lack of real understanding of the duties required, and, in one case, the illness of one of the participants.

The employers felt that the youth required more training, both in pre-employment and on-the-job:

> I don't know that she wanted it to work out once she realized how demanding a job working with children really is. This is again regardless of her ability, we get so many people who come in here and say, people who have no training, and I think that might have been the biggest issue for her is that she really should go back to school.
>
> Maybe with some coaching and some proper training, in a slower period of time we would have been able to spend some time training her, but we didn't have that time to dedicate to training…

…they have to have the skills, the ability to generate results, and the behaviour competencies to fit into the work environment as well.

In some cases, the employer felt that the participant did not really understand the duties of their position. I spoke to the manager of a store where one of the youth worked over the busy Christmas season. She told me that even though the participant said she understood that her job included greeting customers as they entered the store, she did not speak to anyone as they walked in. The manager felt that the participant was not able to perform the duties of the job and was therefore let go. Other employers related similar stories:

> *Is it partially that she needed more training for office skills before she came in?*
> Absolutely, maybe it wasn't more training but, as well she couldn't do something, or she was having difficulty understanding, I think she was having trouble saying 'I can't do that', or 'This is really hard for me to grasp this piece of paper this way, this is not something I can do'. I'm not really sure whether she could or she couldn't.

One of the participants worked for a few months in an office as an assistant. His supervisor asked him to photocopy some materials and then left to attend a meeting. When she returned, the participant presented her with a three-page letter of resignation. The participant had forgotten how to use the photocopy machine, become discouraged at his ability to perform on the job, and had decided to quit the position. In order to resolve the situation, the supervisor re-trained the participant on the use of the photocopier while the participant tool detailed notes for future reference. He was then able to use the photocopy machine without incident. Some of the participants were very unsure of themselves at their work placements. Instead of relying on themselves to try to solve small problems encountered on the job, they would constantly turn to their supervisors for support. Employers felt that the students should take more initiative and try to solve problems on their own.

Other employers were not sure how to handle difficulties:

> *When they were not able to do something, how was that handled?*
> …Basically, I really didn't talk to her about that, because I had some people giving her some extra training. So I though maybe it's just something she just can't do.

One employer felt that the participant they worked with had not really committed to securing employment and therefore were not successful:

> [The participant] came on like gangbusters, she really wanted it to work, and then became very quickly disenchanted for whatever reason. It's unfortunate because we never did have a debriefing, her and I, and I think

that's the way she wanted it, I think she just wanted to get out and that was it. I'm not sure why…

This same problem was reported to the project coordinator by employers through the project:

Some of the reports we got back from some of the employers kind of brought that out, who were saying, you know, they [the participants] didn't take it seriously in their work placements. They would sort of call up in the morning and say 'Well I won't be in today because I have a doctor's appointment', and not having planned or told their employer. It's not that way in the world of work, so they don't, there's no need to work. We work, most people work because they need to have money to pay the mortgage or whatever, so we have a dedication to it. But if you don't have that need because it has been taken care of, then you don't. I guess it has something to do with your work ethic.

Once again employers pointed out that these experiences are not unique to students with disabilities. One described similar experiences with other student internship positions, and did not feel that the attitude of this particular participant was different from other, able-bodied students she had encountered:

…when we realized that early on that there was a lack of consistency quite honestly she became just embellishment to our program here. She simply enhanced the program, she wasn't so much relied upon in the program, and that's quite frequent in any student that comes here.

The participants from this project could undoubtedly have benefited from more employment training. Facilitators for the project continually revised the original training plan to respond to the needs of the participants. These needs were far greater than originally anticipated and included both employment specific skills as well as life skills, social skills, and psychological support.

Just like any other group of students in an employment training program, some lacked the skills necessary for employment. Others did not demonstrate a real commitment to finding employment.

Employer Commitment to People with Disabilities

All of the employers referred to their commitment to hiring people with disabilities:

We're very happy to incorporate, and you're going to laugh when I say this, minority factions which would include men, because there are very few men and there are very few dads involved, people who have disabilities, because many children don't encounter people with disabilities. We're open to all sorts of multicultural and multicultural awareness, so those are things that we very much try to incorporate into our program because that's what our program looks like. We take children with special needs and with disabilities and so we like the people who work for us to reflect our group.

We've been through a disability awareness workshop before. All of us are very much in tune with hiring people with disabilities, and asking what they need for accommodation, how can we set them up to best be suitable in the work environment.

The [organization] is very flexible. We've done other internship programs for people with disabilities…We do have people here in the Centre right now that have disabilities who are doing their jobs very successfully. We have given them some extra opportunities to develop skills.

It is interesting to contrast these comments made by employers to those from the participants on employer attitudes. While the employers and organizations participating in this project were strongly committed to the employment of people with disabilities, employer attitudes continue to be seen as a major barrier to employment by people with disabilities. Some organizations definitely have demonstrated a commitment to employment equity, the experiences of the youth illustrate the need for continued lobbying and public education.

Conclusion

The failure of the work placements was overwhelmingly disappointing for the participants, the project facilitators, and the researchers. However, the comments of the employers involved seem to say that the problem does not originate with the disabilities of the participants. Difficulties resulted from lack of training, lack of commitment, and problems in understanding instructions. These difficulties are experienced by a whole range of people, not just those with disabilities.

Unfortunately, this type of explanation fails to point to any usable solutions to the problem of failed work placements for people with disabilities. Neither does it

help us to explain exceptionally high unemployment rates for this group of people. What it does tell us is that people with disabilities experience the same difficulties as every other group of people who have been marginalized and excluded from economic participation.

CHAPTER 7: EMPLOYMENT AND DISABILITY: WHAT IS THE CONNECTION?
Issues in Employment

In their study, Cyr and Schirle (1999) identified four barriers to employment for people with disabilities: beurocratic, attitudinal, institutional, and physical. All of these barriers were encountered and described by the participants in this study. Beurocratic barriers were experienced when the participants tried to navigate themselves through the income assistance program. One participant, when trying to qualify for the clothing allowance, was made to document every class he had taken over the last five years. In the end, he was turned down for the clothing allowance. Another participant went off income assistance in order to take a two week work position. After her job was over, she waited six weeks to be reinstated to income assistance.

Attitudinal barriers were described by the participants in their relationships with their families and peers, teachers and classmates, employers, and the public in general. Negative attitudes about disability are still pervasive in our society, and at times lead to discrimination. These attitudes impact the lives of young people with disabilities in their ability to set goals and seek employment. They seemed also to impact the self-esteem of the individuals in this study to the point where eight out of the nine participants had attempted suicide.

Institutional barriers were identified when the participants spoke of their educational experiences. The presence of Teacher's Aids in schools impacted the relationship of the youth with their peers. For those who had attended post-secondary institutions, regulations regarding the number of classes that must be taken posed barriers for those who had learning disabilities as well.

Many of the participants identified physical access as a barrier to their ability to gain employment. The already competitive nature of the job market was compounded by the limited number of accessible businesses in which to apply for jobs. The youth also identified the problem of gaining only partial access to businesses, for example, if the front door is accessible but the bathrooms are not.

Another issue that has been identified as a barrier to employment is the lack of useful training programs for people with disabilities. This study also provides evidence to suggest that training for this group is inadequate. The youth had all participated in several training programs prior to their involvement in this study. None of the participants had achieved paid work through their training courses. Many of the youth were seemingly stuck in an endless cycle of training, work placements, and volunteering, none of which ever lead them to gainful employment. It is obvious that the present programs have failed this group of young, chronically unemployed people.

Lack of experience has been cited as a problem for unemployed people with disabilities. Again, the youth identified this as an issue for them as well. However, in the context of this study, this barrier was seen to apply to everyone who is young and looking for work, not just for people with disabilities.

Conclusions

This study has substantiated much of the previous consumer literature on employment and people with disabilities. Barriers identified by other researchers, including financial, institutional, educational and training issues, attitudinal, physical access, lack of experience, and beurocratic barriers were all discussed by the youth who participated in this project. It is important that these systemic barriers be addressed in order to promote equal employment opportunities for all people with disabilities.

This study is unique in its presentation of the lived experiences of the youth which have lead to their current status of unemployment. Interaction with family and friends, perception of their disability, and their self-esteem and ability to set goals have all impacted their ability to pursue employment. At times these factors have had a positive influence on their success. At other times, the negative attitudes of family, friends, and society in general have limited their ability to achieve their goals. This study does not fully analyze the impact that these factors have on the individuals in this study, and neither is it intended to. My purpose in exploring these issues is to acknowledge their importance and impact on the lives of the young people who participated in this study.

Limitations of the Study

This research was conducted with the participation of nine young people with physical disabilities in the city of Winnipeg. Due to the qualitative nature of this study and the small sample size, this research cannot be said to be representative of all young people with physical disabilities. However, several of the issues identified by this group as important to their employment status have been cited in other publications regarding employment for people with disabilities. I hope that this research can make a contribution to the understanding of employment experiences as they are experienced by some young people with physical disabilities.

Recommendations for Further Study

This study has revealed some important issue that deserve further consideration, including:

1) Mental Health issues (including self-esteem and suicide) among young people with physical disabilities.

2) The impact of pervasive attitudes on disability to individual families experiencing disability

3) Integrated education and the development of peer relationships among children with and without disabilities.

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APPENDIX 1: Consent form for Participants

Consent To Be Interviewed

I, _____, agree to participate in the research project described to me by Janalee Morris. I understand that the purpose of this project is for Janalee to gain some awareness of the issue of employment for people with disabilities by understanding people's past experiences with employment and job training, as well as to provide general information which will be used in partnership with myself and others in the project, to evaluate this particular training initiative. This research is being conducted in part to fulfill the research component of Janalee's Masters degree and I understand that she will use the information I provide to her in the presentation and writing of her thesis.

   The interview is being conducted by Janalee Morris, a Masters student in the Department of Anthropology at the University of Manitoba. The assignment has been approved by the Ethics Review Committee of the Anthropology Department.

   I understand that my taking part involves participating in an interview with Janalee and will take approximately one and a half hours. Janalee will ask me questions about my experience, as a person with a disability, with education, training, and employment. I agree that the interview will be tape recorded to allow Janalee to listen carefully to me. Names mentioned on the tapes will be replaced by fictitious names, and all of the information collected will be kept confidential. The audio tape will be erased after it has been transcribed onto paper. I have been assured that all information will be reported in order to preserve my and others' identity.

   My participation is voluntary and I may withdraw from the study at any time by simply telling Janalee. If I feel tired and wish to stop the interview or prefer to continue at a different time, that is fine. I also know that I may also refuse to answer any questions.

   I understand that Janalee can be called at 452-5617 if I have further questions about the study. If I wish to, I can contact Janalee's advisor, Dr. Kaufert, at 789-3798, Department of Community Health Sciences, University of Manitoba.

   Again, I understand that I am free not to answer any particular question and that I can withdraw my participation and interview from the project at any time without any disadvantage to myself.

I agree to participate in this project.
Your Signature _____ Date_____
Interviewer's Signature _____ Date_____

copy 1 to participant
copy 2 to interviewer

APPENDIX 2: Consent form for Training Project Facilitators
Consent to take part in research

I, _____, on behalf of
_____, agree to allow Janalee Morris to conduct
the research project in conjunction with the Youth Training Project. I understand that the
purpose of this research is for Janalee to gain some awareness of the issue of employment
for people with disabilities by understanding people's past experiences with employment
and job training, as well as to provide general information which will be used in
partnership with the participants in the project, to evaluate this particular training
initiative. This research is being conducted in part to fulfill the research component of
Janalee's Masters degree and I understand that she will use the information provided to
her in the presentation and writing of her thesis.

    The research is being conducted by Janalee Morris, a Masters student in the
Department of Anthropology at the University of Manitoba, under the guidance of Karen
Blackford, Research Director of the Canadian Center on Disability Studies. The
assignment has been approved by the Ethics Review Committee of the Anthropology
Department.

    I understand that the participants will be asked to take part in an interview with
Janalee followed by a focus group meeting with all participants. Janalee will ask the
participants to answer questions regarding their experience, as persons with disabilities,
with education, training, and employment. The interviews will be tape recorded. Names
mentioned on the tapes will be replaced by fictitious names, and all of the information
collected will be kept confidential. The audio tapes will be erased after they have been
transcribed onto paper. All information will be reported in order to preserve the
participants and other's identity.

    The cooperation of the participation is voluntary, and individual permission will be
sought from each participant to take part in the research. The candidates may withdraw
from the study at any time by simply telling Janalee or any other members of the training
team, without compromising their ability to partake in the training project itself.

    I understand that Janalee can be contacted at 452-5617 if I have further questions
about the study. If I wish to, I can contact Janalee's advisor, Dr. Kaufert, at 789-3798,
Department of Community Health Sciences, University of Manitoba.

I agree to allow Janalee's participation in this project.
Your Signature _____ Date_____
Researcher's Signature _____ Date_____

copy 1 to organization
copy 2 to researcher

APPENDIX 3: Consent form for Employers

I, _____, agree to participate in the research project described to me by Janalee Morris. I understand that the purpose of this project is for Janalee to gain some awareness of the issue of employment for people with disabilities by understanding their experiences with employment and job training. This research is being conducted in part to fulfill the research component of Janalee's Masters degree and I understand that she will use the information I provide to her in the presentation and writing of her thesis.

    The interview is being conducted by Janalee Morris, a Masters student in the Department of Anthropology at the University of Manitoba. The assignment has been approved by the Ethics Review Committee of the Anthropology Department.

    I understand that my taking part involves participating in an interview with Janalee and will take approximately one hour. Janalee will ask me questions about my experience as an employer taking part in the CCDS Youth Employment Training Program. I agree that the interview will be tape recorded to allow Janalee to listen carefully to me. Names mentioned on the tapes will be replaced by fictitious names, and all of the information collected will be kept confidential. The audio tape will be erased after it has been transcribed onto paper. I have been assured that all information will be reported in order to preserve my and other's identity.

    My participation is voluntary and I may withdraw from the study at any time by simply telling Janalee. If I feel tired and with to stop the interview or prefer to continue at a different time, that is fine. I also know that I may refuse to answer any questions.

    I understand that Janalee can be called at 287-8411 if I have further questions about the study. If I wish to, I can contact Janalee's advisor, Dr. Kaufert, at 789-3798, Department of Community Health Sciences, University of Manitoba.

I agree to participate in this project.

Your Signature_____
Date_____

Interviewer's Signature_____
Date_____

copy 1 to participant
copy 2 to interviewer

APPENDIX 4: Interview Questions for Participants

1. Can you tell me a bit about yourself?

2. Your are a person with a disability. Can you tell me about that?

3. Can you tell me, in a general way about your education, training and job experience? I will ask you again about these issues separately and in more detail.

4. Can you tell me about your education? Where did you go to school? What was your personal experience there? What were your social relationships like? What were your relationships with your teachers? What were your expectations? What were your dreams?

5. Have you had specific job training? In what? What was the quality of that experience? Did it lead to employment? Did you gain new skills? Did the training meet your expectations?

6. What jobs have you had? Have you enjoyed your jobs? What were your duties? How long did they last? Were you always in the same position there? What was the place where you worked like? How have you found out about employment opportunities? Do you or have you ever considered yourself unemployed?

7. What issues do you think are important to consider in employment?

8. I've read that there are a lot of barriers to employment for people with disabilities. Have you noticed this?

9. Have other people's perception of you impacted your ability to find or keep employment? Have other social barriers prevented you from succeeding in employment? What has helped you to succeed?

10. What financial alternatives do you have to employment? How do you feel about those alternatives?

11. What do you hope to gain from this training project?

12. If you were designing this program, what general areas would you address?

13. Can you make any suggestions for changing the education, training or employment experiences you have had? Can you make any general suggestions?

14. Is there anything else you would like to add that I have not asked you?

APPENDIX 5: Interview Questions for Employers

1.   How much time did the participant spend with your organization?

2.   What was their job?

3.   When they were brought in to your work environment, was any sensitivity or awareness training offered to you or to your staff?

4.   Was it your decision to hire this person, or did your supervisor bring the participant on board?

5.   What parts of their job were they able to do well?

6.   What parts were they unable to complete?

7.   When the participant was unable to complete a task, how was this handled by the participant? Their co-workers? You?

8.   What outside forces made it difficult for the participant to do well in your establishment (unreliable transportation, lack of training time, support staff, …)?

9.   What would have to change to make this young person a valuable employee on your staff?

10.   Have you or would you again employ a person with a disability?

11.   What would you like to say to the participant you worked with?

12.   What would you suggest the Program Facilitators do to make the participants better prepared for the workplace?

13.   Is there anything you would like to add that I have neglected to ask you?

APPENDIX 6: Focus Group Information

INTRODUCTION

The purpose of this meeting is twofold. During the first stage we will review the information that Janalee has collected through her interviews with you, and comment on the way she has organized and understood that information. You are asked to be partners in this exercise, and to participate as co-researchers in this process, much the same way you may be asked to participate in a staff meeting during your job placements. The information Janalee has collected is *your* information. It is important that this information accurately reflects your thoughts and feelings on the subject, not just Janalee's ideas of the way these issues should be seen. The second stage will involve the creation of the Questionnaire. We will use the information from the first part of the meeting to help us decide what is important for training projects. We will generate a list of questions which Janalee will take home to refine and test. The final product will be filled out by you next week, and will also be shared with everyone involved in this training project.

Although Janalee has disguised the information from the interviews, you may recognize some of the participants through their words. Please respect other's right to confidentiality by not discussing any of this information outside of this meeting.

THEMES

Themes will be introduced under three main categories, including Personal Relationships, Employment Specific Themes, and Systematic Barriers (see below). At this time, the list of themes will be presented and clarified, but participants will be asked to withhold discussion of each until all have been clarified. For example, one theme may have different meanings for different participants. This theme could then be separated into two, or made to reflect a particular meaning. The participants will be asked to generate new themes that may have been missed.

Once all themes are understood by all participants, each theme will be revisited in order to generate discussion and to elicit examples of each. During this discussion, the coordinators will make and distribute cards with one theme written on each. Individuals of the group will be asked to rank the themes in order of importance. The group will break while the coordinators tally the ranking. This information will be presented back to the group where the ranking will be discussed and finalized.

CATEGORIES AND THEMES

A. Personal Relationships

1. Self (self-esteem, expectations)

2. Close Others (family, peers, co-workers, teachers)

3. Community (contribute to society, community awareness)

B. Employment Specific

4. Employer Attitudes (awareness, willingness to employ people with disabilities, expectations)

5. Job Experience (lack of work experience)

6. Long Term Positions (failure to achieve long-term employment)

C. Systematic

7. Integrated Education vs. Special Education (awareness vs. stereotyping)

8. Transportation (reliability, flexibility, awareness, priorities)

9. Home Care (flexibility, awareness)

DEVELOPING THE QUESTIONNAIRE

   Participants will be asked to use the themes to reflect on the objectives of job training. These objectives will then be compared to those supplied by the project coordinators. Using these objectives as a guide, the participants will be asked to generate questions which would reflect each of these themes. These questions will be written up on an overhead. Once all possible questions have been generated, the group will review the list to collapse similar questions or elaborate complex ones. Finally the group will rank the questions in order of importance.

   At some point in this process, the Rosenberg Self-Esteem Scale will be introduced as a potential way to evaluate self-esteem.

   Once the questions have been ranked, the group meeting is concluded. The questions generated through this process will be compiled, tested, and distributed by Janalee in the following weeks.

APPENDIX 7: Ethics Statement

To: Department of Anthropology Ethics Review Committee,

As per required for completion of a Master's degree in the Department of Anthropology, I will be engaging in a research project, slated to commence in April 1999. This research will take place through a youth training program co-sponsored by the Canadian Center on Disability Studies (CCDS), M. Jones Consulting, and Lifelore.

This project will recruit ten individuals with disabilities and enroll them in an eight week training program followed by a six month work placement. Along with their training, the participants will be asked to take part in the research component of the project, which will involve individual interviews and one focus group interview. The interviews will have two purposes; primarily to gather data for the thesis, and secondly to develop an evaluation tool in conjunction with the participants for this particular training project.

During the course of this project I will be employed by CCDS as a research assistant. I have received permission from all organizing parties to be involved with this project, and will obtain written consent once the project has been approved by the Ethics Committee.

Sincerely yours,

Janalee Morris

DEPARTMENT ETHICS REVIEW PROCEDURES
The research project as outlined in the Research Proposal will begin on Monday, April 26, 1999, pending approval of the Ethics Review Committee.

RIGHTS OF THE INDIVIDUAL
Both the individual and collective rights of the participants will be maintained through complete disclosure of the purposes and design of the research project. The project will be explained to all participants as they enter into the program, as well as in a group session explaining the purpose of consent and the rights of all subjects to confidentiality, and again before the researcher proceeds with individual interviews. The participants will be given individual consent forms before interviews proceed.

INFORMED CONSENT
The Participants will be informed of the purposes of the research project both collectively and individually, via the forums mentioned in the previous section. Information provided will include the following:

Purpose and Usefulness:
- To gain insight into the issue of employment for people with disabilities by understanding people's past experiences with employment and job training.
- To provide general information which will be used in partnership with the participants of the training project to develop an evaluation of this particular training initiative.
- To fulfill the research component of Janalee Morris's Masters degree, therefore she will use the information provided to her in the presentation and writing of her thesis.

Expected Benefits:
- To develop additional understanding of the barriers faced by people with disabilities and the supports available for said population in seeking employment.
- To empower the participants as co-researchers in the development of an evaluation tool.
- To provide a forum for reflection and the development of collective action to promote positive employment strategies for persons with disabilities.

Methods:
- Qualitative, semi-structured interviews will take place with each participant.
- A focus group will take place with all participants in order to verify the themes collected by the researcher during individual interviews and to develop an evaluation tool.

Possible Risks:
- Although the researcher will strive to maintain confidentiality, the information may eventually be available to service providers and/or members of the "disabled community" in Winnipeg who may personally know the informants.
- The information will be compressed and presented thematically to the participants during the focus group, however, the small size of the group may make it possible to identify individual contributions within the group.

Participants will take part in a workshop developed to explain their rights to confidentiality and to explain the process of giving informed consent. Each participant will be given a consent form prior to the interview (see Appendix I). This form will include the name and phone number of the researcher's advisor (Dr. J.M. Kaufert), and will advise them of their right to refuse participation without affecting their ability to participate in the training program. The informants will be assured of confidentiality through the use of pseudonyms and the combining of information in presentation to the group.

DECEPTION
It is not the intention of the researcher to deceive the participants as to the nature or purpose of this project.

RISK AND BENEFIT
The procedures and methods involved in this research do not involve undue risk to the participants. Any risks to non-participants (such as the coordinators of the training project or third parties mentioned during the interviews) will be minimized through the maintenance of confidentiality.

PRIVACY
The interviews conducted are intended to explore the personal experiences of the participants regarding education, training and job experience. This intention will be made explicit to each participant. Participants will not be required to answer any questions with which they are uncomfortable, and
requests for confidentiality of any of the information divulged will be respected by the researcher.

CONFIDENTIALITY AND ANONYMITY
The researcher will take all precautions possible to maintain the confidentiality of participants and any third parties associated with the research. The tapes of all interviews will be erased after they are transcribed. Transcripts of these interviews will not be available to anyone other than the researcher and her advisor. Pseudonyms will be used in the presentation of this research, and information will be combined or compressed in such a way as to protect the individual identity of the subjects.

Relevant information from the interviews will be summarized and presented to the participants during a focus group. Although this information will be combined so as to protect the anonymity of the subjects, the small size of the research group may make it possible to identify individual comments. The participants will be informed of this possible risk in advance of their participation.

RESEARCH ON CAPTIVE AND DEPENDENT POPULATIONS
The individuals who will be asked to participate in this research project will simultaneously be taking part in an employment training project. The research will be affiliated with the training project, and the evaluation tool which will be derived from the focus group will be used within the training process. The affiliation of the researcher

with the training project may result in a power differential between the participants and the researcher. In order to minimize this effect, the researcher will make every attempt to inform the participants of their right to refuse participation in the research component of the project without compromising their involvement in the rest of the training.

In addition to the participants consent, informed consent will be sought from all parties to the training project, including CCDS, M. Jones Consulting and Lifelore (see Appendix II).

This project will not involve research on children, archival research, acquisition of cultural properties, or research on other cultures, countries or ethnic groups. Therefore I have not addressed these points in this statement of ethics.

APPENDIX 8: Addendum to Ethics Statement

TO: Department of Anthropology Ethics Review Committee
RE: Working for Equity: Issues of employment for youth with disabilities

This letter is to request ethical approval for additional data collection for my Master's Thesis project, ethically approved in April of 1999.

My initial research project included conducting interviews with 10 young people with disabilities regarding their past experiences with employment. These young people were also participating in an employment training program which was to lead to work internships. While most of the participants were placed in temporary work situations, all returned to the project without securing long-term or paid employment. I believe that this experience has revealed some of the real barriers faced by people with disabilities in gaining meaningful employment.

In order to accurately reflect the nature of this experience, I wish to conduct additional interviews with the employers who participated in this program by providing placements for these youth. I will ask them to identify the barriers faced by people with disabilities generally when searching for employment. Finally, I will ask them to make recommendations for including people with disabilities into the workforce. These interviews will be conducted using a semi-formal interview structure (please see Appendix I). They will be tape recorded and then transcribed. The employers and their organizations will not be identified, neither will they be presented as attached to the particular youth they employed. All information from these interviews will be condensed and presented as from the group of employers who agree to be interviewed.

All employers will be asked to read and sign a Consent Form (please see Appendix II) which will insure their confidentiality.

I have received permission from the participants, the facilitators of the training project, and the Canadian Centre on Disability Studies, sponsoring organization, to conduct this additional research.

Sincerely yours,

Janalee Morris