RESEARCH THAT HURTS OR RESEARCH THAT HELPS?
A critical framework for adult education inquiry
and people with intellectual disabilities

by

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A thesis submitted in conformity with the requirements
for the degree of Master of Arts
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Research that hurts or research that helps?
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Master of Arts, 2000

ABSTRACT

The objective of this thesis is to develop a critical framework for emancipatory adult inquiry on intellectual disability, through an understanding of how disability is produced as a social and political category. The literature review includes theories of disability, the political economy of disability, political consciousness and citizenship, and theories of adult education. Using a materialist approach to disability, I discuss ways in which disability is produced and reproduced within the capitalist political economy. I discuss the roles of family and educational structures, and the commodification of labour in the process of disablement. Attention is paid to the legal disenfranchisement of people deemed mentally incompetent. I argue that in order to undertake emancipatory inquiry into intellectual disability issues, it is necessary to employ three key elements: a structuralist framework, attention to voice through a participatory process, and an adherence to social justice goals as the purpose of the research.
This thesis is dedicated to those people who have explained to me what it means to be incarcerated, to those who have shown me what resistance looks like, and to those who have shared with me their hopes for the future. My work starts and ends with you.
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INTRODUCTION

Background

Intellectual disability does not have an objective definition. There is no common group of physiological characteristics, or set of attributes (or lack of attributes) that define it. People are considered to be intellectually disabled by different criteria, depending on which system they are being evaluated by- the school system, the social service system, or the medical community (Roeher, 1996, 21). As well as confusion about definition of intellectual disability, there is also a range of terms that are currently in use. Although social service agencies in Canada, the United States, Australia, New Zealand stopped using the phrase ‘mentally retarded’ in the late eighties, there is still an academic periodical called *Journal of Mental Retardation*. In Britain, where the disability movement is perhaps the strongest and most radical, the term ‘learning difficulties’ is the most recent one in use by progressive authors. There still exists, however, a *Royal Society for Mentally Handicapped Adults and Children*. In the Ontario context, social service agencies and the provincial and federal governments use ‘developmental disability’, but more progressive organizations use ‘intellectual disabilities’.¹

Regardless of the capacity, skills, and abilities of an individual, falling into the category of intellectual disability (whatever it is called) will have a major impact on the material conditions of that individual’s life. The best way to bring intellectual disability

¹ The British term ‘learning difficulties’ is the most preferable because it was chosen by members of the group it describes. However, there is a massive amount of educational writing in Canada and the United States that deals with ‘learning disabilities’, which describes an entirely different construct and category, and I did not want these two terms to be confused.
into focus is to trace the history of the segregation of disabled people from the rise of industrialism, and the present-day dialectic between the educational system and the definition of disability.

**History of segregation of people with intellectual disabilities in Canada**

Although the history of disability before the nineteenth century is contested by different authors, it is commonly believed that the rise of industrialization, and the demand for a standardized workforce able to adapt to mechanization, lead to the segregation and eventually mass institutionalization of disabled people in Europe, Canada, the United States, Australia and New Zealand (Davis, 1995, Roeher, 1996). It is argued that in feudal times, family members of varying ability worked along side each other. With the commodification of labour, peasant households were subject to the external force of market relations “which appraised the worth of individual labour in terms of productivity standards” (Gleeson, 1997, 195). Industrialization “resulted in the production of increasingly disabling environments in Britain and its colonies” (Gleeson, 1997, 195).

The history of intellectual disability, like the larger category of disability, is bound up in

> [the] production of an ‘incapable’ stratum of labour, most of which was eventually incarcerated in a new institutional system of workhouses, hospitals, asylums, and (later) ‘crippleages’ (Gleeson, 1997, 195).

Segregation of disabled people has historically been justified by a series of different ideologies. When Canada’s first institution for people with intellectual disabilities was opened in Orillia in 1859, there was a growing charitable concern for a group of people who were at the time called ‘mental defectives’. The original mission of the institution was to train or cure people and return them to society, but the ideology of segregation soon shifted to reflect social Darwinist theories of superiority based on race,
class, gender and abilities. Beyond European fascism of the 1930s and 1940s, the most dangerous social theory for people with intellectual disabilities has been the eugenics movement. Beginning in England at the end of the nineteenth century and spreading through Europe and North America, the eugenics movement argued that unemployment, criminality and mental deficiency were all genetic attributes concentrated in working class and (in the Canadian context) immigrant families that were not English and Protestant. Institutions that were first built to house people who had been displaced by industrialization were increasingly thought of as a means of protecting society from genetic and moral pollution.

The precursor to the modern IQ test, the Binet-Simon scales were first published in 1905, and were used in the United States to categorize people with intellectual disabilities, then called 'feeble-minded'. In Canada, the eugenics cause was lead by Dr. Helen MacMurchy, who became Ontario’s ‘Inspector of the Feeble-minded’ from 1906-1912. Basing her ideas on sociologist Henry Goddard’s claims about race, class, ability, and the decaying human gene pool, MacMurchy argued for the forced sterilization of disabled women to deal with the “menace of the feeble-minded” (quoted in Roeher, 1996, 4). In 1916 the governments of Manitoba, Saskatchewan and Alberta published a pamphlet calling for selective immigration policy to screen for the ‘mentally defective’, and thousands of Canadians petitioned the Prime Minister to establish farm colonies for ‘mental defectives’ already residing in Canada. In 1928 the eugenics sterilization law was passed in Alberta, followed by British Columbia in 1933. Neither law was repealed until the early 1970’s (Roeher, 1996, 4-5).
Regardless of shifting ideological underpinnings, the economic affects of institutionalization were felt almost immediately. Building plans for institutions were “significant enterprises for economically depressed regions in the country” (Roehrer, 1996, 5), creating jobs both in the construction phase, and as staff once completed. Institutional segregation continued to be the dominant social policy in for people with intellectual disabilities in Canada until the 1980s, and portions of large institutions remain open today, ostensibly because people who still live there have nowhere else to go. Institutionalization of disabled people in nineteenth and twentieth century Canada, United States and Australia must also been seen in a larger context of incarceration of Aboriginal children and Deaf children in residential schools (Davis, 1995, Meekosha & Dowse, 1997).

After institutionalization, the next major trend in for people with intellectual disabilities started in 1950s and 1960s with parents who had been able to keep their disabled children out of institutions. In 1958 they founded the Canadian Association for Retarded Children to lobby for services that would make it easier for them to keep their children in the community. The ideological shift away from segregation came with the ‘normalization’ trend that began in Scandinavia in the 1960s and spread through Europe, Canada and the United States (Meekosha & Dowse, 1997, 60). This phase is characterized by people being moved from institutions and from their family homes into group homes in towns and cities. In the 1970’s there was a push to phase out institutions that was based partly on human rights discourse and partly on government concerns that institutions were too expensive to run (Johnson, 1998, Roehrer, 1996). Although outwardly large institutions and small group homes are different, there are underlying
consistencies. In 1859, the Orillia Asylum for Idiots emphasized “education, treatment and training” (Roehrer, 1996, 3), while a present day Toronto agency of group homes has a mission to provide “care, support and training” (Surex, 1997). These group homes, common in Canada, the United States, Australia, New Zealand, and western Europe, are described by some as another form of institutionalization (Meekosha & Dowse, 1997, 60).

The present day policy of the Ontario government is to reduce or stop funding institutions and agencies, and to instead provide funding directly to the head of the family of the disabled person. The ideology attached to this change is a consumer rights discourse. The change is driven by an overall shift toward privatization, and a reduction in government social spending (Government of Ontario, 1997). There are similar shifts toward ‘Individualized Funding’ in several other Canadian provinces (Roehrer, 1993). Regardless of policy, some institutions remain open in Ontario today. Presently people with intellectual disabilities live in institutions, group homes, their family homes, or independently. Funding comes from the federal government through transfer payments through provincial ministries of Community and Social Services or Health, and as the total amount of government funds diminish, programs seek money from charities and Non Government Organizations. The money is distributed to institutions and hospitals, social service agencies, and families of people with intellectual disabilities, but almost never to the people themselves (Government of Ontario, 1997).

Trends in disability policies of industrialized nations—such as shifting between institutional and community rehabilitation, and funding sources being partially state, and partially NGO—are also present in developing countries. Denison Jayasooria describes

Legal, political, economic, and human rights abuses

People who have lived through years of incarceration in segregated institutions have given eyewitness accounts of life there. Segregated institutions are parallel in many ways to both penitentiaries and locked psychiatric wards. In the past, refusal to take medication, wash, dress, eat, sleep or perform work activities when instructed to by staff or professionals was considered ‘non-compliance,’ and was punished by more restrictions. Those people who still live on locked wards have rarely, if ever been in the community. Furthermore, the lack of social skills and self destructive behaviour that result from years of segregation are often cited as reasons to continue incarceration (Johnson, 1998).

Those who left institutions to live in group homes were subjected to similar regulations and restrictions to their personal freedom. The philosophy of normalization that accompanied deinstitutionalization advocated training through ‘behaviour modification’ to eat, dress, speak and act as close to normal social standards as possible. Today, people living in group homes lack control over what they eat, wear, and what time the go to bed (Diverse City Press, 1996, Hingsburger, 1995). The continuing lack of autonomy people living in group homes have over major and minor life decisions has been attributed both to the infantilization of disabled adults (Hingsburger, 1995), and the
lack of staff and resources to support individual choice. Those who have avoided group homes and institutions by remaining with their family of origin are often wards of parents or siblings who have legal control their money and life decisions.

Canadian policies of confinement have carried over into present day laws on “guardianship and restrictions on people’s right to vote, to immigrate, to marry, to procreate and to own property” (Roehr, 1996, 5). Through being declared mentally incompetent, people with intellectual disabilities are barred from testifying in court, even as witnesses to their own abuse (Hingsburger, 1995, Roehr, 1995). The power dynamics of household and institutional environments combined with an absence of legal and political rights have left people vulnerable to a variety of human rights abuses, including endemic rates of physical and sexual abuse (Cambridge, 1999, Hingsburger, 1995, Meekosha & Dowse, 1997).

Educational segregation

Although it is beyond the scope of this thesis to deal in depth with special education (the streaming of disabled children into separate classrooms), it is nevertheless important to introduce the role of the educational system in defining intellectual disability. Although it seems self-evident that the boundary of intellectual disability is determined by IQ, many children with sensory impairments which preclude taking an IQ test are streamed into special education classes which focus on ‘life-skills’ such as eating and dressing, rather than reading, thinking and socializing. In a dialectic between ability and education, these children are not taught the reading or abstract communication skills that would allow them to achieve a normal score on an IQ test.
Over time, the educational and medical systems have had to adjust the standards by which intellectual disability is judged. The criteria have shifted several times to account for people who emerge from institutions and segregated classrooms and are able to prove a high level of intellectual ability. In his autobiography, Martin Levine states that he spent twenty years in an institution because his epilepsy was considered to be synonymous with mental retardation (Levine, 1993). There are similar stories from people who have autism (Williams, 1992), and cerebral palsy. Mental illness is another category that has split off from the nineteenth century category of mental deficiency, based on the individual’s potential to be lucid, or function within a normal to high intellectual range when on medication.

The most recently created category that acts as a limit to intellectual disability is learning disability, which is largely a product of educational research, and includes people who have mild sensory impairments that inhibit their ability to learn in a standard school setting. The most common medical diagnoses in this category are dyslexia, and increasingly, attention deficit disorder (ADD or ADHD). The learning disabled category has both absorbed some people who would previously have been considered intellectually disabled, and added many new people to the larger social category of disabled (Lloyd & Norris, 1999, Sleeter, 1986).

**Purpose**

The objective of this thesis is to consider which theoretical, political and educational approaches adult educators might employ to combat human rights abuses and further the legal, political and economic emancipation of people with intellectual disabilities.
Because disability is often thought about in terms of the medical model, and in terms of special services, there are many professions that deal with disability issues, in both research and in practice. The fields of medicine, physiotherapy, special education, social work, nursing, speech therapy, psychiatry and psychology all deal with aspects of disability with a focus on helping, training or curing individual problems. Within the field of adult education, disability issues emerge in literacy and vocational training, but much of the vocational and life skills training for adults with intellectual disabilities takes place in regulated group home and family settings, or exploitive sheltered workshop settings.

Through a literature review of theories of disability as a social construct, and an overview of the economic structures and social barriers that disabled people face, this thesis will provide adult educators with an understanding of intellectual disability as a political category. Adult education theory contains many important ideas about democratization, participatory action, and the political implications of education, all of which can be use to critique literature that obscures the material and structural constraints that disabled people face. Through a review of theories of political consciousness and citizenship, I will suggest ways in which adult education theories of community development, learning in social movements, and informal learning might be used to work toward the emancipation of this group.

**Statement of Problem**

People with intellectual disabilities remain segregated, and politically and economically disenfranchised, despite government policies of community integration, a social work
focus on ‘quality of life’ (Rapley & Ridgway, 1998) and greater public awareness about disability as a human rights issue. A vast amount of literature about this group of people is generated by what Rapley and Ridgway calls the “psy-complex,” of psychiatry, psychology and social work, and it conflates what might be called intellectual impairment or learning difficulty with the political economy that surrounds a segregated population. Much of the literature talks about managing people’s behaviour without framing them in their social and institutional context, or talks about goals and outcomes of group homes and day programs without acknowledging that the people in them are heavily regulated. Even authors whose goal is to question and critique the level of choice people are afforded in their daily lives frame them as ‘clients’ who deserve better service, rather than citizens who have rights (Johnson, 1998). There has been a great deal of similar literature produced by community organizations, whose overwhelming influence are parents of people with intellectual disabilities. This literature also maintains a focus on consumer rights, and the struggle between families and government over funding for care giving and support services.

Another body of literature that approaches issues affecting people with intellectual disabilities is that of disability studies. This literature grows out of the disability rights movement and theorizes disability as being socially constructed, with a political, economic and historical context. Although this body of literature contains important theories that highlight how social and cultural systems reproduce ableism, the work is usually focused on physical disability, and takes place within an “arena of intellectual debate” that is inaccessible to people with intellectual disabilities (Gillman, et al, 1997). While providing the essential framework that disability is socially constructed
(and separate from ‘impairment,’ which refers to a person’s physical embodiment), it
does not provide a vanguard for, or even address people who live in institutional or
regulated settings and do not have control over their own money, food or freedom of
movement, or people who have been declared legally incompetent and are in the
guardianship of a parent or social service agency.

Beyond interrogating the framework and assumptions of research on disability,
special attention must be paid to the questions of power and voice. Because many people
with intellectual disabilities have lived, or continue to live in institutions or social service
agency housing, this group is among the most ‘researched,’ or documented in history.
Staff, doctors and therapists have kept records on the most minute details of people’s
daily lives, medical histories, and the treatments and programs that have been applied to
them. These records effectively erase the people’s humanity and render them objects to
be controlled by professionals (Gillman, et al, 1997). Some former staff and volunteers
of institutions and group homes have employed ethnographic writing as an alternative to
medicalized, depersonalized writing (Angrosino, 1998, Smith, cited in Glesne, 1999, 189-
190), but the power dynamics between writer and subject are inadequately
contextualized. In one example, the author examines life at a regulated group home as a
disability culture (Angrosino, 1998). Autoethnography and autobiography have proved
useful for former institutional staff to examine their own positions of power (Blackburn,
1996), but the scope of this kind of work is necessarily limited to the micro politics of
these politically and economically regulated structures.

Ignoring the material realities of people labeled with intellectual disabilities has
resulted in research, policy and practice that locates systemic problems with individuals,
and has failed to address the oppression and exploitation of people with intellectual disabilities. Some tools that have been successfully employed to expose the political economy of disability services is the choice to interview staff, educators and managers within the social service system (Erevelles, 1996, Johnson, 1998, Gillman, et al, 1997), or to critically analyze government and social service policy (Rapley & Ridgway 1998, Pfeiffer & Finn, 1997, Noble, et al, 1997). These approaches make preliminary steps toward grounding the social construct of intellectual disability in a political-economic context. For adult education inquiry, the task at hand now is to draw on and expand theories of participation, political consciousness, informal and collective learning, and citizenship education. With these tools we will be able to critique the way adult education is currently used for vocational and life skills training in regulated and exploitive settings, and to move toward emancipatory and rights oriented practices.

**Research Question**

Adult educators who deal with disability issues are often rooted in the practical aspects of individual education, but adult education theory plays a role in the hegemony of training as the panacea to joblessness, underemployment and social participation. When we keep in mind the structural constraints that face disabled people, and the way that the category of intellectual disability is socially constructed, it becomes clear that adult educators must rethink disability and educational theory and practice. How can we develop adult education inquiry by/for/about people with intellectual disabilities that results in emancipatory political and educational practices?
Methodology

Literature Review

In order to determine the role of adult education in the emancipation of people with intellectual disabilities, it will be necessary to review four topics within the literature on disability: theories of disability, the political economy of disability, political consciousness and citizenship, and theories of adult education. There is only a limited amount of literature on disability within the liberal arts (Linton, 1998), even in disciplines dealing with social theory, such as women's studies (Broun, 1996, Wendell, 1993) and marxist literature (Gleeson, 1997). There are, however, many academic journals devoted specifically to disability issues. The majority of academic journals on disability issues written in English originate in the United States, Australia, and Britain. All of the journals publish international submissions, however most of the papers are from Europe, Canada, the United States, Australia and New Zealand.

Research by and for social workers, medical professionals, and service providers frequently appears in journals including the Journal of Disability Policy Studies from the United States, the Journal of Intellectual and Developmental Disability from Australia, and the Journal of Intellectual Disability Research, which originates in Britain. In Canada, the Roeher Institute located in Toronto has the most complete library on intellectual disability policy. It also publishes its own research and position papers, representing parent groups and service providers.

As special education and learning disability are defined and regulated by educational systems and professionals, there is a great deal of material on intellectual disability in educational journals, most of which originate in the United States. Educational journals publishing research on special education, learning disabilities and
intellectual disabilities are *Exceptional Children, Focus on Autism and Other Developmental Disabilities, Mental Retardation, Remedial and Special Education*, and *Career Development for Exceptional Individuals*. Other non-specialized educational journals such as the *Harvard Education Review, International Journal of Lifelong Education*, and the *International Journal of Educational Research* also publish research on special education.

A third category of disability literature is the emerging discipline of disability studies, which deals with disability as a socially constructed category, parallel to disciplines like women’s studies, or Queer studies (Linton, 1998). *Disability and Society* is published in Britain, and is the leading disability studies journal. Although its articles generally focus on physical disability, it publishes papers on the political economy of disability, citizenship issues, and the definition and purpose of the disability movement.

My review of adult education theory dealing with disability issues, and vocational and citizenship education includes adult education journals such as the *Adult Education Quarterly*, and *Theory and Research in Social Education*, both published in Washington, DC, and the *Canadian Journal for the Study of Adult Education*. Two other Canadian journals that occasionally cover disability issues are the *Social Worker*, and *Canadian Women’s Studies*. The latter publishes feminist perspectives on disability, which often have themes and theoretical approaches that diverge quite sharply from disability studies perspectives (Sheldon, 1999).

**Data Analysis**

This thesis is divided into three chapters corresponding to the topics I am reviewing in the literature: 1) theories of disability, 2) the political economy of disability, and 3)
political consciousness and citizenship. The conclusion deals with implications of the literature for adult education research and practice. I am separating professional/medical discourses about disability from social theories of disability. The professional/medical category includes professional discourses from rehabilitation, psychology, and to some extent, social work and education. I will address these professional discourses in the chapter on the political economy.

The first chapter of the thesis deals with social theories of disability, including feminist, anti-racist, materialist and disability studies approaches to disability. I will discuss the theoretical underpinnings of the different approaches to disability in terms of idealism, which is an approach that "presume[s] the human environment to be the product of ideas and attitudes" (Gleeson, 1997, 183) and materialism, an approach that sees "the production of people's natural (physical) needs as the motive force in human history" (Gleeson, 1997,197). Explaining segregation as being the result of non-disabled people's psychological aversion to disabled people is an example of idealism. Explaining segregation as being the result of the commodification of labour is an example of materialism.

From my review of articles that describe the organization of group homes, institutions, sheltered workshops, and employment initiatives, I will give an overview of how disability services function as an industry. I will also consider the professional discourses that inform disability services, and the class relations of caregiving. My objective for this chapter of the thesis is to integrate an understanding of the political economy of disability services with theories of how relations of production and distribution create and recreate the category of disability.
From the literature on disability, political consciousness and citizenship, I will be considering two questions. First, are rights claims based on consumer rights, claims made to the state, or demands for community inclusion? Second, I will consider the motive of the citizenship educator: does the educator present political consciousness as something that is good for an individual’s self esteem, or as something that is essential for the emancipatory struggle? From the literature on adult education, I will consider how adult education practices follow from the way the educator conceptualizes disability. For example, if the author believes unemployment is due to a lack of skills, do they advocate vocational training? If the author believes that disabled people are unemployed because of ableist attitudes, what course of action do they suggest? My conclusion will discuss adult education strategies that follow from a materialist understanding of intellectual disability.

Plain Language

A limitation inherent to the academic format that this thesis is presented in is that it is inaccessible to the group it speaks about. To render this thesis in a more accessible form, I am including a plain language synopsis of some of the key points. People with intellectual disabilities have noted that the complexity of legal and political documents has “hindered them from making informed decisions” (Canadian Association for Community Living, 1997, 1). In Canada, several plain language books and pamphlets on disability issues have been published by the Roeher Institute in Ontario, and Diverse City Press in Quebec.

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2 See “Appendix: Plain Language Version” below.
I am using the guidelines for plain language set out by the Canadian Association for Community Living, which include: limiting paragraphs to one idea, cutting out unnecessary words, using larger print, addressing readers directly, and using shorter words (CACL, 1997, 9-13). Simplifying the language does not mean simplifying the content, but rather presenting complex ideas in a clear way. The “issue of discursive clarity and accessibility must not be confused with the need for theoretical substance in analyses of disability” (Gleeson, 1997, 183).

Although writing in plain language will make the text more accessible to a wider range of people, it still requires literacy. Many people with intellectual disabilities have not had access to adequate literacy instruction, and many others may have a limited capacity for exchanging ideas through text. Other possible forms of information sharing are video, audiotape, performances, and discussion groups. For the purposes of this thesis however, I will be submitting text, in accordance with standard academic practices.
CHAPTER ONE: THEORIES OF DISABILITY

Disability Movement/Disability Studies

Much of the work being done to develop a framework for disability studies as a distinct area of study appears in the journal *Disability & Society*. Simi Linton “looks at guiding principles from the [disability movement] itself as the basis for delineating a robust liberal arts-based inquiry into disability, distinct from traditional interventionist models” (Linton, 1998, 525). The “disproportionate amount of information on disability in the applied fields” does not respond to the “educational and medical interventions the disability community deems important” (Linton, 1998, 529-531). To Linton, disability studies is parallel to and informed by women’s studies, lesbian and gay studies, cultural studies and traditional liberal arts disciplines. Part of Linton’s rationale for a distinct area of study is based on a critique of studies that see disability as an individual problem, that medicalize disability and objectify disabled people, and use deterministic ‘biology is destiny’ arguments. Linton also notes that there has been “insufficient attention to the minority group status of disabled people, and the cultural, social and political meanings of that status...” (Linton, 1998, 539).

Fran Branfield advocates a disability movement lead by and accountable to disabled people, rather than non-disabled professionals who have traditionally dominated the literature on disability issues and have a personal stake in a continuing system of disability services. Addressing her comments to able-bodied academics who criticize the use of meta narratives to explain disablism, Branfield describes the movement as an

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3 Branfield uses the words ‘disablism’ and ‘disablist’ where others have used ‘ableism’ and ‘ableist’ to describe the system of oppression of disabled people.
"[e]mancipatory political project" with a "principal aim...of overcoming the subordination of disabled people." As such, the disability movement should "necessarily rest on certain basic value judgements and truth claims." Branfield asserts that a "glib rejection of meta narratives...contribute[s] to academic discourse rather than to contributing to social change" (Branfield, 1999, 401).

Oliver and Barnes do not suggest that "only disabled people can or should do disability research..." but they are concerned that "disabled people's opportunities to participate in disability research, despite the emergence of an emancipatory agenda, remain very limited." The authors state that

The insidious and apparently unstoppable commercialization of research [means that]...the economics of the research process play an ever increasing role in determining who is able to do disability research and who is not, as well as what kinds of disability research is funded (Oliver & Barnes, 1997, 811).

An increasing number of disabled researchers have graduate degrees, but because the costs of assistive devices, interpreters and transportation are not included in research proposal budgets, many of these researchers remain unemployed. Their absence is detrimental "not only in the field of disability research, but in research generally" (Oliver & Barnes, 1997, 812).

Feminist and Anti-Racist Theories of Disability
The feminist articles I reviewed had sharply different theoretical approaches to disability. Susan Wendell argues that the "idealization of the body is a major force in excluding the physically disabled the mainstream" (Wendell, 1993, 50). Wendell uses psychological arguments to suggest that disabled people remind non-disabled people of the existence of pain (Wendell, 1993, 53). She also suggests that some non-disabled people want
someone to carry the burden of the negative body so they can then “resist the assimilation of most disabled people” and thereby distance themselves from pain and negative bodies (Wendell, 1993, 55). This pseudo-psychological approach, in which disabled people are theorized as tropes or symbols, is a strand that has run through writing on disability since Goffman’s influential work on stigma, and has emerged as a dominant line of thinking in postmodernist writing about disability.

Mary Runte takes a liberal feminist approach to autobiographical accounts of barriers she encountered in business school and in her corporate workplace. Runte attributes lack of promotion opportunities to barriers in higher education and to managers believing that disabled employees are already working as hard as they are able to in the positions they are in (Runte, 1998, 104). Runte’s goals are to level the playing field so there can be fair and open competition for jobs within private sector workplaces.

In their chronicle of the birth of the disabled women’s movement in Canada, Pat Israel and Fran Odette list some of the factors that prompted feminists with disabilities to split from the larger feminist movement. They cite the academic language of feminist journals, inaccessibility of workshops and conferences, and the poor attendance of disability issues workshops by non-disabled feminists as some examples of the inaccessibility of the feminist movement (Israel & Odette, 1993, 8). The DisAbled Women’s Network (DAWN Canada) first met in 1985, and their agenda included violence against women with disabilities, role models for girls with disabilities, self-image and parenting issues, and providing a voice for disabled women in Canada (Israel & Odette, 1993, 7).
In her thesis entitled *Inclusion of Disabled Women's Voices: Towards a Complete Feminism*, Leslie Broun rejects a feminist emancipatory methodology because she did not wish to place herself in the position of change agent. Broun opts for feminist oral history to see how participants life histories “reflect various theories, definitions and politics of disability.” The thesis discusses “notions of existential and aesthetic anxiety, as they affect the able-bodied population...” and concludes

that reasons for exclusion are part of the fundamental human condition, but which may be influenced by conscious, intellectual effort, and by mandated inclusion of disability issues in feminist, as well as popular feminine, publications and anthologies (Broun, 1996, cited in Masters Abstracts International 35/03, p. 725, June, 1997).

Some anti-racist and anti-colonial academics have theorized ways in which race and disability have been mutually constructed. These theories stem from the observation that practices of segregation and institutionalization of people with disabilities were concurrent with the incarceration of First Nations children in Canada and the U.S., and segregated schools in the U.S. Sarah Hale’s thesis traces the development of segregationist policies from 1848 to 1930 out the American Eugenics Movement and the Psychological Testing Movement. Hale argues that theories of inferior genes were focused on “lower classes and minority races” and “promoted pseudo-scientific legitimization for national segregation in education and perpetuated racism” (Hale, 1985, cited in Dissertation Abstracts International-A 47/01, p. 147, July, 1986).

**Historical Materialism and Disability**

After reviewing literature on physical disability, B.J. Gleeson finds four areas of theoretical weakness in the field of disability studies: “the detachment from major social theory; idealism; the fixation with normality; and historical unconsciousness” (Gleeson,
Gleeson proposes an historical materialist account of disability that starts with the social construction of disability arising “from the specific ways in which society organises its basic material activities (work, transport, leisure, domestic activities)” (Gleeson, 1997, 194). Gleeson argues that because disability studies have “trivialized the past to the point where it is little more than a reification of the present” (Gleeson, 1997, 185), we have failed to recognize “that different societies may produce environments which liberate the capacities of impaired people whilst not aggravating their limitations” (Gleeson, 1997, 194).

Anne Borsay’s study of the Bath Infirmary before the Industrial Revolution is a detailed historical study of disability. She challenges “the hypothesis that disability was essentially manufactured by industrial capitalism” by showing there was a mercantilist agenda “to return patients to the community in a state of physical and moral fitness.” Although she does not explicitly choose idealism over materialism as an explanation for the construct of disability, she implies that the mercantilist ideology contained ideas of bodily norm, and foreshadowed “medicalisation that was to mature in the modern state” (Borsay, 1998, 660).

Through her research of a charitable organization for the disabled in India, Nirmala Erevelles compared the material/class position of the caregivers to the position of the recipients of care. Erevelles saw a dialectic relationship between the caregivers and clients that showed disability is an ideological discourse “produced by the...exploitive economic conditions of capitalism” (Erevelles, 1996, 520). Erevelles argues that the “ideological category of disability is constructed so as to justify
oppressive practices that are also implicated in the production of race, gender, class and caste oppression, as well” (Erevelles, 1998, cited in DAI-A, 59/08, p. 2921, Feb.1999).

Structuralism

In an evaluation of feminist disability politics, Alison Sheldon argues that a structural approach is necessary for feminist and disability politics to move forward together. Sheldon evaluates three different feminist approaches in relation to disability politics: structure, culture, and individual experience. Sheldon notes that although “cultural representations of disabled people are undoubtedly worthy of study...structural forces are also at work” (Sheldon, 1999, 646). Authors who focus on social barriers have been accused of “denying [the] personal experience of disability and of impairment,” however, focusing only on the personal can lose the focus of removing social barriers and changing social structures (Sheldon, 1999, 648). Focusing exclusively on individual experience “represents a very narrow view of feminism,” while including a structural approach offers “a more effective way forward for disabled people, women, and people from other oppressed groups” (Sheldon, 1999, 643).

Gleeson argues that a focus on changing the material structures should be the “central emphasis for a transformative political practice” (Gleeson, 1997, 97). To Gleeson, structures include not only the surface layer of social organization (for example, the physical layout of a city), but also the deeper set of economic relations that are responsible for the way the physical and social landscape is organized. Oppression of disabled people begins with “the political-economic structures (notably, employment markets) which economically devalue disabled people and thus expose them to ideological marginalisation” (Gleeson, 1997, 193).
More insight into a materialist understanding of structure is provided by Allman and Wallis' reading of Gramsci. Following Marx, Gramsci did not see the structure of society as reified, objective forces,” but instead as “social relations between classes comprised of people.” The most important, or constitutive social relation in a capitalist society is the labour capital relation, while other relations (such as gender or disability) are secondary. Therefore, tactics to change secondary relations must be linked to a strategy to abolish labour/capital relation, or “we merely reproduce, albeit in conjuncturally different guises, the structure” (Allman & Wallis, 1995, 128). In a materialist reading of disability such as Gleeson’s, transformative political practice must keep the labour-capital relationship as the focus.

**Materialism vs. idealism**

All of the literature reviewed in this chapter conceptualizes disability as socially constructed—meaning there is no set of pathological or essential characteristics that separate disabled people from non-disabled, and as a category of oppression—theoretically analogous to gender or race. However, the literature diverges, sometimes explicitly, sometimes implicitly, on whether disability is conceptualized a “product of ideas and attitudes” or as a result of relations of production (Gleeson, 1997, 197). Idealist explanations of disability have been dominant in literature from the 1960s until the present. One of the most influential conceptualizations of disability was Erving Goffman’s 1963 book entitled *Stigma: notes on the management of a spoiled identity*, in which he argued that a disability is a social stigma, and the disabled person must learn to manage or negotiate a positive self identity in the face of their imperfection.
Within the feminist literature, both Susan Wendell and Leslie Broun have an idealist understanding of disability that echoes Goffman’s theory of stigma. Wendell sites the “idealization of the body [as] a major force in excluding the physically disabled from the mainstream” (Wendell, 1993, 50). Wendell argues that disabled people are segregated because they remind able-bodied people of the existence of pain, weakness, and inability to control the body (Wendell, 1993, 53-55). Leslie Broun argues that “existential and aesthetic anxiety” in the non-disabled population suggest “that reasons for exclusion are part of the fundamental human condition” (Broun, 1996, cited in MAI 35/03, p. 725, June, 1997).

Idealist explanations of disability are also prevalent in the dominant ideologies of social work and rehabilitation, including ‘normalization’ and ‘social role valorization’ (Gleeson, 1997, 184). These service philosophies purport that if people act normally, and infiltrate valued social positions, they will be able to integrate into mainstream society, and reduce discrimination against disabled people. This position is conceptually equivalent to the belief that negative attitudes cause ableism, and is evident in many adult education strategies of sensitivity training, and familiarizing non-disabled people with disability issues as way to make workplaces more accessible to disabled people.

Allman and Wallis attribute the prevalence of idealist explanations of social relations to Gramsci’s concept of common sense, which contains ideologies that reflect current social relations, as well as ideas that are “residues of previous social relations.” These residual ideas give “the appearance that ideas pre-exist and even cause social reality: an appearance that results in idealism, or idealist as opposed to materialist reading of historical change” (Allman & Wallis, 1995, 122). Gleeson argues that disability
studies authors are guilty of a kind of reverse process of idealism, due to an ahistorical understanding of disability. Disability theorists have reified the past based on the present construction of disability (Gleeson, 1997, 185). This ahistorical approach has lead to an essentialized view of disabled people as needing services, and as being unable to perform work.

**Producing and reproducing disability**

While a materialist understanding of disability does not conceptualize ideas and attitudes as the *cause* of ableism, ideas and attitudes do have an important role in the reproduction of ableist structures. Christine Sleeter’s 1986 study of the history of educational streaming provides an example of how ‘Discourse and symbolic representations reproduce disablement’ (Gleeson, 1997, 194). Sleeter’s paper clearly demonstrates how labour-capital relations coupled with discourses of race and disability construct and reproduce racism and ableism in the educational system.

In the US, educational tracking grew up in the early 1960s, responding to the demand of the government/military/aerospace industries that schools produce highly skilled technical workers. Children that could not keep up to the more difficult curriculum were classified as slow learners, mentally retarded, emotionally disturbed, culturally deprived, or learning disabled (Sleeter, 1986, 48). US school systems defined children with IQ test scores between 75 and 90 as slow learners, and below 75 as retarded (Sleeter, 1986, 49). These categories are underpinned by race and class, because they are determined by IQ tests which have been proven to favour white, middle class children (Sleeter, 1986, 50).
As a result of civil rights activists protesting the over-representation of Black children in the retarded category, US school systems “lower[ed] the maximum IQ from one standard deviation from the mean to two” (Sleeter, 1986, 52). Thus we can see how state and industry demands on the school system to produce certain types of workers interacts with constructs of race and class to create categories of disability. We also see that these categories are not only socially constructed, but are also altered in the dialectic between labour and capital. Far from being a static category, the parameters of intellectual disability, and disability in general, are defined by structures (educational) that are reproduced and recreated by the social relations of labour and capital, race and gender.

It is also interesting to note that when streaming was contested by civil rights, the categories were not erased, but shifted. This fact echoes Allman & Wallis’ assertion that until we abolish the labour/capital relation, “we merely reproduce, albeit in conjuncturally different guises, the structure” (Allman & Wallis, 1995, 128).
CHAPTER TWO: POLITICAL ECONOMY OF INTELLECTUAL DISABILITY

The first two sections of this chapter outline the political economic forces at play in the daily lives of people with intellectual disabilities. The final section unpacks some of the theoretical questions surrounding disability and work.

Regulated Homes

The population of people with intellectual disabilities in large institutions has decreased greatly over the years, but institutions still remain open, both in Canada, and elsewhere. In her description of an institution in Australia, Kelly Johnson notes that “in the locked unit, it was not possible to get a drink of water without asking staff for it, and without three doors being unlocked” (Johnson, 1998, 380). Many community-based group homes are also severely restrictive, especially for people who come to them with case histories of having 'behaviour problems', or of being ‘non-compliant’. Johnson states that when it was time for people to leave the institution, they were often placed in community services with similar levels of restriction:

The question which was being asked (and answered) by many of the processes involved in this institution’s closure was: ‘Can this person be managed or constrained within the community?’ (Johnson, 1998, 381).

In her account of the closing of the institution, Johnson argues that the incompatible discourses of rights and management make deinstitutionalization a problematic process. However, the examples that Johnson gives of the ‘rights’ side of the debate are already so close to a management discourse that there seems to be little difference. Johnson cites this example of a ‘rights’ approach to deinstitutionalization:
[Deinstitutionalization recognizes an inmate’s] right to individual treatment, their values as individuals, their rights as citizens and the importance of integration as the guiding principle in the planning of services (Booth, cited in Johnson, 1998, 376).

This citation is not calling for human rights, it is talking about considering citizenship rights, in tandem with: treatment goals that are set by professionals and service providers; ‘integration’, which is a rhetorical and ill-defined concept; and the service planning process, which the service users have no part in. These are the considerations of managers, not human rights advocates.

Johnson admits the underlying reason for the government’s decision to close the institution was “the costs of maintaining and renovating institutions” (Johnson, 1998, 377). Johnson also refers to a deal that the government had made before closing the institution to “place half the population in other institutions” (Johnson, 1998, 383). The decision as to which people would go to group homes was made by deciding which people could be “managed or constrained within the community” (Johnson, 1998, 381).

Although Johnson presents the process as a tension between rights and management approaches, she also alludes to the fact that a consultation process (including advocates and family members) was set up to give the appearance of democratic process. Since the time line had already been set by the government and institution, and the deal to send half of the people to a new institution had already been made, the consultation process could only decide which people would get out and which people would remain in locked wards (Johnson, 1998, 384).

In a study on physical abuse of intellectually disabled adults living in group homes in England, Paul Cambridge attributes the abuse to “hierarchies of power and status” created by “the professionalisation of care” (Cambridge, 1999, 308). To
Cambridge, it is not the size or location of the institutional setting (whether it is a small
group home in the city, or an isolated locked ward), but the political economic situation
of disabled people that recreates the climate of abuse:

The abuse of people with learning disabilities in all its horrible forms will
never be eradicated in a society...where dependency relationships
themselves become a means of economic production (Cambridge, 1999,
308).

There is a growing number of parent advocacy groups lobbying for government
funding to be released not to group homes, but directly to “each of the individuals and
their support circles,” where the support circle is comprised of “family and friends”
(Chernets, 1995, 260). In Ontario, the government also favours this model of family and
community responsibility for funding decisions (Government of Ontario, 1997).
However, there is no evidence that this approach will reduce the instance of abuse of
disabled people, in light of the fact that people with intellectual disabilities are usually
under the legal guardianship of family members. The idea of a collective support system
is an excellent one, if the disabled person has the legal ability to veto decisions family
and community members make, and to make testimony in court if they are abused or
assaulted. Until people with intellectual disabilities have equal legal and political rights
to non-disabled people, the shift to family funding merely means shifting power from
public structures to family structures.

Sheltered Workshops and Supported Employment

The literature on work and intellectual disability is dominated by a discussion of
sheltered workshops during the 1980s. Sheltered workshops are run by social service
agencies or charitable organizations. In Canada, they are funded by provincial social
services ministries. As the workshop budgets are part of larger social service agency or association, some supplementary money comes from charities like the United Way, and local fund-raising. Workshop managers or agency directors negotiate contracts from the government or private industries, who will agree to pay a price per piece that is assembled. The work is carried out by people with intellectual disabilities who are supervised by vocational counsellors or group home staff.

There are a number of incentives for private industries to use sheltered workshop labour. The building overhead, worker training time, and supervisors are all funded by the agency or association, even though some workshops work exclusively on one contract for several years. The contract usually stipulates that the vocational staff will either check the products for quality control, or that the contractor will pay a few cents less per piece than they would to non-disabled home workers doing the same work. Because of agency mandates to provide ‘meaningful work’ and vocational training, agencies continue to run workshops, despite the fact that workers make a fraction of minimum wage. During the 1980s, service planners believed that workshops would develop into real job alternatives for disabled people, and the literature of the time contains virtually no analysis of how sheltered workshops for people with disabilities paralleled the lowest waged, or super-exploitive “sweatshop” sector of the economy.

In an article titled “Should Workshops Pay a Minimum Wage?” author Derek Hum argues that they should not, based on the amount of money that the operations were losing. Hum points out that the median annual generated income for all workshops in Canada was $35,525 and three out of four generated $90,000 or less, while the median annual operating cost was $126,343 (Hum, 1986, 64-67). Many authors searched for
non-economic explanations for the failure of workshops to provide real training and employment opportunities. In the *Journal of Rehabilitation*, Stephen Moore, et al. argue that the low professional skill level of the workshop staff accounts for the workers' “one-in-ten chance of moving from the workshop to the competitive labour force” (Moore, et al., 1988, 67). The authors point out that “77% of all direct service providers were paraprofessionals” rather than accredited social workers or occupational therapists. The authors do not outline what additional training or therapy the professionals would be able to provide that would help disabled people move into the competitive workforce.

Sheltered workshops failed to produce graduates who entered the mainstream workforce, failed to become viable businesses on their own, and gradually became more controversial due to small groups of disabled workers who began to organize and protest the super-exploitive wages and the segregation. Although the literature, written almost exclusively by and for social service and rehabilitation professionals, had completely shifted its focus to a discussion of ‘supported employment’ by the end of the 1980s, sheltered workshops in Canada, the United States, and Europe continue to operate, especially under the guise of vocational training. A November 20, 1989 Globe and Mail article with the headline “Workshops for disabled condemned” says

more than 100 Canadian workshops which cater to people with intellectual, psychiatric and physical disabilities, and pay $1 to $3 a day for envelope-stuffing or simple assembly line work are “disguised as training centres” with the purported goal of providing rehabilitation and a conduit to real work...(Erika Rostenfeld, 20/11/89, Globe and Mail).

Through the early 1990s, Canadian and U.S. literature on intellectual disability and employment is dominated by the concept of supported employment. This concept and practice was developed as an alternative to the segregation of the sheltered workshop,
and as an attempt to find a minimum hourly wage for workers with intellectual disabilities. This work is structured in the same way as sheltered workshop labour, except the work is performed at the employer’s work site. Again, managers, directors, or staff of the social service agency or community living association negotiates with private or public sector organizations to obtain job placements. The employer agrees to hold a part time position for the agency or association, and the agency agrees to send a staff person with the disabled employee to ensure the employee fulfills her job requirements. The employer pays for the hours the disabled employee works, and the agency pays the wage of the staff, who acts as supervisor and trainer on the job.

Although supported employment arrangements were originally conceived of as temporary bridging programs, the employer rarely agrees to continue employing the disabled worker without the support staff, and rarely increases the hours from occasional to a full or part time position on par with the non-disabled workers.

In an U.S. longitudinal study attempting to predict earnings of supported employees, Frank Rusch, et al. find that

intelligence, prior earnings, and federal job subsidy predicted future earnings. Statistical controls applied to the stratified sample show that job placement, job type, subsidy and means of transportation had little influence on earnings (Rusch, et al, 1997, 630).

As the supported employment model has failed to solve the problems of workforce exclusion and exploitation of people with intellectual disabilities, the most recent literature has shifted to the idea of supported self employment. Supporters of this idea advocate people with intellectual disabilities starting their own businesses in order to solve the problems of underemployment and exploitation. It remains to be seen how

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4 See "Co-opting Consciousness" below for more on the People First movement.
viable this strategy is, considering that small or self-run businesses do not usually earn enough to provide a living wage within the first few years, and that they are often threatened by large businesses and corporations.

Disability and Work

Disability has a pivotal relationship to work that can be broken down into several interconnecting pieces. For adult education, a central concern is how to think about or justify vocational training programs if the commodification of labour plays such a central role in structuring disability. Backgrounding this issue is a set of industries that have grown up around disability. Another piece concerns how support work is performed and conceptualized. How many hours of support work are required by a person’s impairment, how many are required by social mandates of normalization, and how many hours are spent overcoming social barriers? Questions about support work all hinge on the fact that people with intellectual disabilities often have little say in who performs it, and how, and in what work needs to be done.

Relations of production and distribution

In his outline of an historical materialist view of disability, B. J. Gleeson argues that through a reification of present social relations, and without evidence, many disability scholars have adopted the view that all impaired people were beggars in the pre-industrial era” (Gleeson, 1997, 188). Gleeson also criticizes the belief in “the historical existence of dual distributive systems in societies,” one for those who produce sufficient value to meet their own needs, and one for those who cannot. From this assumption, “disability is explained as a juridical and administrative construct of state policy which is aimed at
solving this supposed redistributive predicament” (Gleeson, 1997, 189). Gleeson argues this in only relevant in societies where a direct reciprocity is assumed between individual work and individual reward. My concern with explaining disability as a distributive dilemma goes further, as I disagree that individuals are rewarded in relation to work in the capitalist system. Whether we define work in hours, or effort exerted, or the amount of commodity that is produced, there is no correlation between work and its value in a capitalist economy. If we leave the assumption of distribution according to work, we can begin to see disabled people as workers.

The notion that in a capitalist economy the “value of work varies according to supply and demand” (Marx in Bender, 1986, 81) is more useful for understanding the relationship between distribution and disability. The commodification of labour requires us to shift our focus away from interrogating whether disabled people can work as efficiently or productively as non-disabled people, to whether their labour might be in high supply, or low demand. Segregation can interact with the supply and demand for labour by providing a more available supply of workers, or by removing workers’ opportunity to compete for wages. The issue is not so much the relations of distribution, as it is the relations of production. The commodification of labour means that “more inflexible workers were devalued in terms of potential for paid work” (emphasis mine) (Gleeson, 1997, 195), which should not be conflated with an individual’s capacity to perform work. Separating the commodity value of someone’s labour from their capacity for productive work explains the paradox of workers in sheltered workshops being able to produce as many units as non-disabled workers, but getting paid less.
Disability and work: finding the class relations

There are three conflicting ideologies about work that are negotiated through the state as social services policy: that everyone has the right to engage in productive work, that people using social services accrue a debt to society, and a belief that unemployment is a result of lack of training. These three conflicting expectations impact how work is done by people within the social service system, and how much or whether workers are paid for it.

Workshop directors negotiate contracts with companies to have items delivered to the workshop for assembly. The company agrees to pay a few cents per item assembled. This rate is lower than what they pay non-disabled piece workers, based on the argument that workers at the sheltered workshop are likely to damage the product even though the rate paid to non-disabled piece workers is already far below minimum wage. Under this system someone working steadily for six hours a day, with regular lunch breaks, five days a week, earns about thirty dollars. This amounts to a rate of pay of one dollar per hour. Usually even this wage is not forwarded to the workers in its entirety. Many agencies appropriate part of the wages to go toward operating costs of the workshop, which is already funded by the government and donations. Some organizations appropriate the entire wage by claiming that the worker is participating in a training program and therefore need not be paid. Thousands of dollars in wages are appropriated every year by agencies, and thousands of dollars in extra profit are realized by the private companies contracting the work because labour costs are negligible.

People living in institutions and group homes also are required to perform unpaid domestic and maintenance work under the guise of either skill training or behavioural
treatment. People are required to do laundry, food preparation and serving of food, shopping, cleaning, photocopying, supply room management, lifting and loading of supplies and painting and sanding. All of these activities are unwaged and are required as part of household maintenance for residents of group homes and institutions. This work is considered to be domestic work that parallels unwaged work done by people living in their own homes, but there are important factors that differentiate this work from private housework. First, there are paid staff in both group homes and institutions that would complete this work if the residents are unable to do so. When residents complete the work, paid staff act as supervisors and are still waged for the time in which the work is completed. Second, people who are able to perform certain tasks are generally asked to do so for the entire household, not just for themselves. For example, someone who is skilled at doing laundry will do it for themselves and for other people in the house as well. Using Fraad’s analysis of household relations, we might say the work is appropriated in use-value by other residents, or that it is appropriated by the waged worker as a reduction in their own workload, or it is realized on the level of management as a reduction in the amount of money spent to employ staff (Fraad et al, 1994).

A third category of unwaged or underwaged labour is work that is considered to be therapeutic to the individual performing it. This work often entails difficult or repetitive tasks, and is generally a method of exploiting individuals' hobbies or frequent actions. For example, someone that frequently tears paper when they are bored or anxious may be required to tear stacks of paper to make crafts with. Some people are even encouraged to do repetitive tasks that are non-productive, like filling a bag then emptying it, supposedly with the therapeutic goal of remaining occupied. Being asked to do non-
productive and non-reproductive work would not be classified as exploitation, but under the broader category of oppression.

Social relations of caregiving

Alison Sheldon describes a rift between feminist politics and disability politics, hinging on issues of caregiving. Non-disabled women have argued for the institutionalization of disabled people based on the premise that women perform the caregiving work for family members who are disabled (Sheldon, 1999). There is a class dimension to the feminism/disability debate, as many of the women fighting for individualized finding and against institutions are arguing from a middle class perspective. These are the women who have had the means to keep disabled relatives at home.

Harriet Fraad argues that a household where a wife performs the housework for her family has feudal class relations (Fraad, et al, 1994). Currently in Ontario, there is a tension between downloading caregiving to the community (Government of Ontario, 1997) and the rise of privatization of services. This tension is between capital driven lowering of government spending on social programs, and capital profiting from privatized group homes, nursing homes, and home care agencies. A fusion of both the reduction in social spending and profit potential is for profit homemaker agencies. In the Ontario context, both an overall reduction in spending and profit from caregiving is achieved through exploitation of highly skilled, underemployed health care, and social services professionals. Social services is a category that includes a range of services, and different jobs in the field have a different status and purpose attached to them. I would like to roughly divide social service jobs into four categories to show how caregiving is
raced, classed, and gendered, and to show how social services/health services operate as an industry with a hierarchy of managers based on credentialism, which is also raced, classed, and gendered.

The first category includes front-line workers in group homes, shelters and hostels. These workers make from ten to fifteen dollars an hour when they are employed directly by the agency, and seven dollars an hour when they work for a homecare agency that hires workers out to both agencies and private homes. The second category includes front line staff working directly for government ministries. This category includes welfare workers, and tasks include enforcing government policy and policing people’s claims for welfare or employment insurance cheques. These jobs often require applicants to be registered social workers, and have salaries averaging around $40,000 a year. The third category includes case managers and professional counsellors that work for agencies. These workers are registered social workers, psychologists or counsellors, and they have salaries between $40,000 and $80,000 a year. The forth category consists of the managers of the first three groups. Across all sectors, managers have a salary range of $40,000 to $80,000 a year, and are predominantly white and male.

Because of immigration policies and professional protectionism in Canada, managers often have lower levels of formal education and client-related experience than the workers they manage.

Statistics show that visible minorities in general have a higher level of education than non-visible minority Canadians, and some university programs have more women than men...[If] employers continue to use employment systems and practices that exclude designated groups...they won’t hire the best qualified individual (Stephenson, 1996, 237).
These individuals are hired, but because their credentials aren’t officially recognized, they end up doing front-line work. There is a system of immigration and professional association policies that ensure that highly trained workers enter Canada, but are not able to compete with Canadian trained professionals. Doctors, nurses, social workers psychologists and teachers are only able to register with professional associations in Canada if they were trained at “recognized” universities. Usually professional programs of study at western European, Canadian, or American universities are the only ones recognized. This ready availability of highly qualified front-line workers supports three systems of caregiving: the feudal household system through homecare, the social services sector, and the for-profit sector, which includes agencies hiring out homecare workers, and for profit nursing homes.

Nirmala Erevelles’ article provides an excellent framework for understanding the dialectic between people with disabilities and their caregivers. She has done her research at a charitable organization for the disabled in India, where she compared the material/class position of the caregivers to the position of recipients of the care.

By reading, dialectically, the material relationships between the female carers and their disabled clients, [Erevelles] demonstrate[s] how disability can be re-understood as an ideological discourse which is also produced by the same exploitive economic conditions of capitalism and structures the discourses of race, caste, class, gender and sexual orientation along the axes of disability (Erevelles, 1996, 520).

Erevelles interviewed the women working at the organization to determine what attitudes they held about their jobs and the people they took care of. Workers expressed a range of opinions that one would expect to hear from front-line workers in group homes here in Toronto: some of the women saw their work as spiritually redeeming because of
the sacrifices involved (low pay, very high work load, low social status); some said it was
the only job they could get; some were there because they were dedicated to improving
the social conditions of their clients (Erevelles, 1996). The women working in this
organization are paid substantially less than workers in the same sector in Canada, but
what can be compared is that the material conditions of the clients are comparable to the
material conditions of the workers in both the Indian and Canadian contexts.

I do not mean to compare the levels of oppression of workers and clients- many
people that live in group homes in Canada experience isolation, lack of personal freedom
and abuse. However, the funds available for strictly material conditions- housing,
clothing, shelter- are comparable to the wages of the workers. In 1995, an average of
$18,000 per client was spent on living conditions at Surex Community Services (although
the clients usually only had access to a small allowance- decisions about the rest of the
money were made by the agency directors). In 1995, I earned $18,000 as a full time
overnight counsellor at the same agency. In contrast, I worked for Spectrum Health Care
in 1993. I made seven dollars an hour (the hours were on call, and I was never paid for a
full forty hour week) to care for people with AIDS in their own homes. My wage meant
that my material living conditions were comparable to many of my clients, who had very
low incomes because they had been ill and off work for years.

The work of overcoming social barriers

There is a dialectic between social barriers and caregiving. The more inaccessible
society is to disabled people, the more support work will be needed to negotiate those
barriers. The line differentiating work that is required due to an impairment, and work
performed because of ableist structures is blurred. But what happens when someone who
usually has support workers learn to perform the work on their own? A support worker might get paid for calling to find out which restaurants or theatres are wheelchair accessible, but when the person using the wheelchair does it, they are not compensated. When someone learns to make their own work modifications, or finds their own job, they are not compensated. So should this work be commodified and compensated?

There are two dimensions of oppression at play regarding support work. First, society is structured in such a way that disabled people must do more reproductive work than non-disabled people (i.e. work to do with eating, doing household errands, buying food, housework). Second, because support work is organized by family, state-funded, or for-profit structures- structures in which disabled people have no power- disabled people are not the ones who decide what work needs to be done, and who will do the work.
Citizenship

An understanding of disability and citizenship is important in terms of understanding barriers to political participation, and barriers to recourse through the justice system. Adult educators must incorporate an understanding of barriers to citizenship for disabled people into the way we think about citizenship education and community development.

Most of the literature on citizenship and disability deals with physical disability. As outlined in the introduction, legal and political exclusion is very different for people with intellectual disabilities, because of the legal categories of incompetence and guardianship. However, an examination of literature on citizenship and physical disability is useful for understanding how disability and citizenship are constructed as mutually exclusive categories.

Within the literature on disability and citizenship there is a range of definitions of citizen, and a range of opinions on what constitutes political participation. For Kay Fletcher Schriner, political participation means work for political parties or organizations, running for office, or contributing money to a campaign (Schriner, 1998, 2). For Lisa Schur, political involvement also includes “efforts to change or enforce institutional rules and practices, and outreach or educational work” (Schur, 1998, 3). Other authors define citizenship not as a process of participation, but as a category that is defined through the exclusion of disabled people (Davis, 1995, Meekosha & Dowse, 1997). The breadth of the citizenship/disability debate can be understood by recognizing that people with
disabilities experience barriers to self-determination and participation within family, community, educational, economic, legal and political structures.

The contradiction of the disabled citizen

The public imagination conceives of most people with disabilities, especially women, as passive citizens. They represent a source of increasing demand for services in an environment of ever-diminishing state and public finances (Meekosha & Dowse, 1997, 50).

Conceptualizing the disabled as "the cared for" (Meekosha & Dowse, 1997, 50) highlights the conceptualizing of distribution in terms of compensation for work- in terms of the dilemma of distribution rather than the relations of production. The needs of disabled people are seen as demands because it is commonly assumed that disabled people do not participate in the productive economy. Singling out people with disabilities as the ones who are cared for allows the perpetuation of the cult of individualism, and the belief that our economy compensates individuals based on the amount\footnote{Capitalist economies compensate labour based on the supply and demand value, not the amount performed.} of productive labour they perform.

When disability is theorized as a distributive problem, demands for the fulfillment of disabled people's needs are framed in ways ranging from charity, to human rights to be negotiated through the state as a redistribution of wealth.

Dominant ideologies within the disability arena are changing from welfare to rights, yet people with disabilities still do not appear as active members of the community. Forced to claim 'special rights', their status as citizens with existing rights (albeit unacknowledged/ inaccessible) is negated (Meekosha & Dowse, 1997, 50).

These rights are seen as 'special' because of two dominant discourses regarding the attainment of citizenship: citizenship is either accrued through remitting part of the
proceeds of productive labour (the discourse of the ‘tax paying citizen’), or through property ownership (which is the original conceptualization of citizen in a bourgeois state). Meekosha and Dowse acknowledge that disability activists engaging in making demands as a marginalized group “may effectively constitute token negotiations around citizenship” (Meekosha & Dowse, 1997, 67). Disability politics will continue to hinge on the concept of ‘marginal’ until we rethink ideas about distribution and work.

The authors note that ‘disabled citizen’ is a contradiction in terms because of the incarceration of people with intellectual and psychiatric disabilities. I would argue that the contradiction goes much deeper. Disability as category crystallizes around specific areas in which people are considered unable to participate. ‘Disabled worker’ is a contradictory phrase in a capitalist economy. In the context of waged work, ‘disabled’ means “people who may never sell their labour power in a competitive market place...” (Meekosha & Dowse, 1997, 67). Intellectual disability is a category that precludes legal and political participation, because court testimony and voting proxies may only be given by rational, autonomous individuals. The rational subject is defined in opposition to the intellectually or psychiatrically disabled subject.

The legal, political and economic systems of liberal democracies all have limits for participation. Those limits are best summed up by the category of disability. What constitutes a disability may vary as skills and qualities required for workers or political participants change, but disability as a category will always exist, and will always be populated, as long as liberal states and capitalist economies persist.
The problem with taking a multicultural approach to disability rights

Lennard Davis provides an example of taking a ‘special-rights’ approach to citizenship in the conclusion to his much-cited book, *Enforcing Normalcy*. Throughout the book, Davis presents Deaf culture and Deaf nationalism as the most articulated example of identity-based rights claims among the disability rights movements. Davis demonstrates that Deaf identity is based on common oppression, and a common struggle, and is manifested by a common language (ASL). Through the process of making claims based on Deaf identity, a new category of people has become more disenfranchised—deaf/hearing impaired people who do not sign, speak, or read, and who therefore have no formal language.

Davis uses the judicial system to exemplify how this category of people is excluded from citizenship:

This system is set up with the expectation that the people processed through it will be in the possession of some linguistic ability—whether that be Spanish, American Sign Language, or Korean. But when this ‘normal’ expectation is thwarted, the judicial system grinds to a halt (Davis, 1995, 167-168).

Multicultural or identity based rights claims are even more problematic for people with intellectual disabilities. If we understand how the category ‘citizen’ has evolved historically within liberal states to comprise the qualities claimed by the bourgeoisie male, then we can see how ‘citizen’ in a liberal democracy is defined through the exclusion of those who are not medically/legally defined as rational and independent.

Collective citizenship

Commonly held assumptions that people with intellectual disabilities cannot direct their own lives echo the state’s classifications of legal competence and legal
incompetence. Liberal-democratic legal and political systems are based on the idea of singularity. In a one-person-one-vote system, there is a high emphasis on decisions coming from the individual alone, without assistance or support. Recently advocates for people with developmental disabilities have put forward the idea that all of us consult with trusted others when making life decisions. People who make supported decisions and people that use facilitated communication should not be legally disqualified for not being able to maintain an illusion of singularity, since all people are interdependent in a variety of ways (Hingsburger, 1995). Chernets provides a concrete example of collective decision making in her description of a co-operative housing project that includes some members with intellectual disabilities:

No one in the co-op is independent. They are interdependent members of a community where each counts on the others, and the others count on each member (Chernets, 1995, 262).

When we think about supported or collective decision making and disability, it is important to recognize the dialectic between exclusion from decision making, and the ability and confidence to make decisions. In a book providing advice to non-disabled people taking a supportive role with intellectually disabled people, Bill Worrell states:

[It] is important to make a distinction between the effect of a person’s mental handicap on his ability to understand, and the effect of the oppression that he (sic) has experienced as a result of being labelled (Worrell, 1988a, 26-27).

Citizen as Consumer

We have seen in chapter two how legal and political rights for people with intellectual disabilities are conflated with, or replaced by a discourse of consumer rights. Discussion about the right to self-determination is pushed aside in favour discussion about the right
to services. The backdrop to the consumer rights debate are large industries including manufacturers of pharmaceutical and assistive devices, private sector home care agencies and nursing homes, as well as large professional associations including doctors, psychologists, physiotherapists and social workers.

Consumer rights are increasingly framed in a 'Quality of Life' discourse. On surface, this represents a shift away from the medical model of curing individual disorder, however, it is still rooted in the idea of curing individual problems- this time a lack of rights and poor living conditions. Although the focus is shifted away from patient outcomes, 'quality' is still defined and measured by professionals. In an historical study of government and academic rhetoric in the UK, Rapley and Ridgeway argue that QOL is intimately bound up with broader discourses of managerialism and corporatism in contemporary western societies...QOL discourse is shown to be mutually constructed by government and the 'psy-complex' (Rapley & Ridgeway, 1998, 451).

The authors use the term psy-complex to refer to the psychological professions, including psychiatry, clinical psychology, social work, mental health nursing. Further, psy-complex echoes the term ‘military-industrial complex’ to show the “reciprocal, indeed symbiotic, relationship between government, and the regulators and researchers of mental order and disorder” (Rapley & Ridgeway, 1998, 455).

Not only is the discourse focused on services rather than citizenship, but the quality and delivery of services is determined through professional discourse that is circular, and excludes the opinions of disabled people. There has been an abundant literature discussing services in terms of ‘Quality of Life’ that contains no input from the people it speaks about. Stancliffe and Parmenter outline a questionnaire to gage ‘quality of life’ for people with intellectual disabilities that ranks how much choice people have in
their daily living conditions, including: what they wear and eat, when they bathe and sleep, and who they socialize with. The authors then conducted a survey with this questionnaire, and relied on staff to report the answers (Stancliffe & Parmeter, 1999).

Having staff assist in answering questionnaires is also problematic when we recall the high instances of physical and sexual abuse in group home and institutional settings (Cambridge, 1999, Hingsburger, 1995). In a video made with a collective of people with intellectual disabilities fighting sexual abuse, the participants firmly situate sexual and physical abuse in a climate where people do not have the opportunity to make even the most minor choices about what to eat or when to go to bed. (Diverse City Press, 1996). Lack of choice perpetuates and exacerbates a cycle of abuse and oppression.

**Political Consciousness**

The literature on political consciousness and intellectual disability reveals not only a lack of research on the issue, but also attempts to subvert and neutralize political consciousness by professionals using a ‘self-esteem’ or an ‘empowerment’ framework. Two objectives for this section are to highlight how participation and consciousness are being researched, and to demonstrate the gap in our knowledge about political organizing that has taken place.

**Co-opting consciousness**

Most of the research on intellectual disability and self-identity approaches awareness of being intellectually disabled as social and psychological issues, rather than as a political one. This approach dates back to the very influential work by Erving Goffman (1963)
that deals with disability as a social stigma. Through political struggle, disabled people have challenged the idea that the disabled identity is a damaged or abnormal one—rather, it is the non-disabled identity as superior and exclusionary that needs to be challenged.

There is a growing body of literature that deals with physical disability as a social construct, and a political label. However, literature dealing with the rights of people with intellectual disabilities focuses on integration into a pre-existing, unchanged mainstream, and focuses on the act of ‘labelling’ people as the central problem in the struggle for human rights (Roeher, 1996, Worrell, 1988a).

A recent study by Mark Rapley is concerned with assessing the toxic effects of the social identity of being intellectually disabled. The study finds a “person with an intellectual disability can, like any other, avow or disavow such an identity according to the demands of the situation in which they find themselves,” but does not address the political dimensions associated with self-identity (Rapley, et al, 1998, 807).

The 1970s and 1980s saw a strong movement of people with intellectual disabilities that rarely appears in academic documentation. The movement drew critical attention to forced sterilization, to sheltered workshops, and to the public perception that people with intellectual disabilities are less than people. It is difficult to find reliable documentation of ‘People First’—so called to emphasize that members were people first, and disabled second. The first self-advocacy group was apparently started in British Columbia and the second in Oregon in 1973. Gradually local chapters formed throughout Canada and the United States. The organizations took the name ‘People First’ before their first convention in 1974. Some chapters have taken different names like ‘Speaking for Ourselves’ or ‘People in Action’ (Miller & Hays, 1996, 313). In literature generated
by the Canadian People First project in 1988, Bill Worrell states that “People First is a self-advocacy movement whose purpose is to empower the members” (Worrell, 1988a, 17).

People First has been credited with protesting working conditions, and demanding the label ‘mentally retarded’ be dropped from social service agency titles, however to my knowledge there has been no historical documentation of this movement. There is, however, a recent study of the “empowerment potential” of being involved in People First (Miller & Hays, 1996). This study buries political consciousness under politically neutral ideas about self-esteem, and misses an important opportunity to explore the conditions for, and impediments to political consciousness.

In his 1988 book for non-disabled people acting as advisors to People First groups, Bill Worrell states that many chapters of the organization have been appropriated by service providers and parent groups to justify their own programs and agendas:

often People First is used as a substitute for developing user participation in associations...it is not uncommon for an association to set up a People First group as a committee of the board (Worrell, 1988a, 22-23).

Because people with intellectual disabilities have had no access to academic discourse, and because attempts at public organizing have often been co-opted, the notion of taking pride in the political identity ‘intellectually disabled’ is a subsumed one.
CONCLUSION: IMPLICATIONS FOR ADULT EDUCATION

In our perspective, all education is political as it is aimed at either preparing people to liberate themselves from an oppressive and exploitive status quo or at domesticating people to adapt to work individualistically within the given (Allman & Wallis, 1995, 120)

The first part of locating ourselves as educators and researchers involves examining the structures we operate in. Rather than pretend the learning or research situation is power-neutral, it is important to not only state our location, but also to carry an awareness of how educational and social services structures organize and reproduce disability as a category. Too much of the literature on intellectual disability glosses over or masks the oppression and exploitation people experience in their daily lives. As an example, in her study of an institution for people with intellectual disabilities in Australia, Johnson states she spent “hundreds of hours as a participant observer in a locked ward” (Johnson, 1998, 378), but she does not explain whether she was a staff member, or a human rights observer, or a consultant paid to do research.

Recognizing that there are power relations among participants in education and educational research does not mean that educators/researchers are precluded from emancipatory education. Paulo Freire makes a distinction “between professional authority and authority of knowledge” (cited in Kilgore, 1999, 193). Jack Mezirow suggests that educators can provide the conditions for emancipatory learning (Mezirow, 1996). If it is possible to negotiate the power relations between would-be emancipatory educators and an oppressed group, then that negotiation is achieved through close attention to purpose.
The second part of locating ourselves as educators has to do with interrogating the purpose of the educational program or research project. The purpose is related to the structures we operate in, through mission statements and funding mandates, but attention to purpose includes examining the professional discourses that surround the people we are working with, and the political economic function our educational program or research project has. Deborah Kilgore argues that educators and learners are involved in learning “for the sake of the increasing number of social control mechanisms that have developed in our economic, political and administrative institutions” (Kilgore, 1999, 192).

I am using Irene Baird’s 1999 study of a libertory education program in a United States women’s prison as an example of how emancipatory methodologies can be used for social control when we do not attend to the structures we are operating in, and to the purpose of our research. The study does not focus on disability, however, we have seen that there are similarities between the material conditions of people with intellectual disabilities and incarcerated women. Other similarities are the themes of rehabilitation and compliance that thread through the literature on prisoners and disabled people.

Baird’s study of a libertory learning program conducted inside a United States women’s prison is worth considering in detail for several reasons. Baird’s methodology has three pillars: Freirian liberation methodology, women’s/feminist studies, and prison rehabilitative education (Baird, 1999, 103). Her choice to include rehabilitation in her methodology raise several questions. What is the effect of combining emancipatory education praxis with a rehabilitation ideology? In emancipatory learning, participants develop an understanding of how social relations affect and shape our lives, and
simultaneously develop an understanding of how we might collectively change social relations. Rehabilitation focuses on how an individual might prepare herself to successfully negotiate preexisting social relations, by learning how to successfully compete for a job, or developing attitudes and manners that allow an individual to integrate into the status quo.

Baird claims that the women participating in her humanities education program “assumed ownership of their learning, engaged in critical thought and became liberated whilst still in prison” (Baird, 1999, 103). Baird builds her methodology from Freire’s educational praxis of conscientization, and feminist consciousness raising (Baird, 1999, 106), she remains neutral on the subject of incarceration. She does not refer to the power of the state to incarcerate women, or analyze the reasons behind the race, class and gender demographics of incarceration. Instead, Baird matches the writings in the course content to class, race and experience of the participants in order to focus on “individual, personal liberation from the many layers of internal crises that serve as imprisonment and oppression” (emphasis mine) (Baird, 1999, 104).

Baird’s use of emancipatory methodology to achieve individual rehabilitation goals reflects a larger trend in education to bring the language of social movements inside the structures of a capitalist political economy. Along with higher basic education scores, and a feeling of participants having “ownership in the process”, Baird claims that another benefit of the program is that the participants are “less hostile” at the end of the course (Baird, 1999, 107).

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6 In his paper on pedagogy and social justice, Rich Gibson notes that the United States jails one in 250 of its citizens (Gibson, 1999, 135).
As educators, we have a responsibility to understand how "literacy and education for citizenship has potential both as a domesticating tool and as a force for liberation" (Gibson, 1999, 132). There is a parallel between Baird’s work and the appropriation of the disability rights movement by professionals who seek to promote self-esteem and the appearance of self-determination of service users. Baird’s study provides a parallel scenario for adult educators concerned with emancipatory learning and intellectual disability. As outlined in chapter two, adults with intellectual disabilities have severely limited opportunity to choose whether to participate in a vocational or other educational program. Beyond economic and social restrictions to educational choices, many people are confined, or physically forced to be present for education or training programs (Chernets, 1995, Hingsburger, 1995). Adult educators working with people with intellectual disabilities are also operating within or in proximity to agencies and institutions that find ideological reason for being in the rehabilitation model. In the Ontarian context, program funding is granted based on the acquisition of skills that conform to perceived market requirements and social norms (Government of Ontario, 1997).

Why has Baird chosen to combine the opposing ideologies of emancipatory feminist education and rehabilitation? This question is not answered in the text, but there are several possible reasons: the author’s professional training may have provided her with a rehabilitation approach; the author may have chosen to use rehabilitation language to make the program more appealing to prison managers; the author may have personal beliefs that favour spiritual over material emancipation.
This study provides two important caveats to educators involved in work with adults with intellectual disabilities: we must pay close attention to the structures we operate within, and we must carefully interrogate our purpose and our methods.
APPENDIX: PLAIN LANGUAGE VERSION

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Introduction

If you have an intellectual disability, it can have a major impact on your life.

If your doctors, school, parents, or boss think you have an intellectual disability, they might treat you differently than if they think you don’t have a disability.

If you have an intellectual disability, you might not have a choice about where you live. You might live in an institution (a hospital or regional centre); you might live in a group home; you might live with your parents.

If you have an intellectual disability, you might not have a choice about where you work. You might work in a sheltered workshop or go to a day program.

If the police or the judge in a courtroom think you have an intellectual disability, they will have somebody else talk for you, like one of your parents or your worker.
If somebody hurts you or steals from you, the police or the judge in a courtroom might not believe you if they think you have an intellectual disability.

Some terms you might have heard

There are several ways of saying someone has a disability:

- Doctors might say ‘mentally retarded’
- Charities might say ‘mentally handicapped’
- Your social worker might say ‘developmental disability’
- In the introduction, I was saying ‘intellectual disability’
- Schools say ‘special needs’
- In a courtroom, they say ‘mentally incompetent’

Many people dislike the terms I have mentioned. They also dislike words that are used to insult them because they have a disability. Because they fought back, a lot of people stopped using insulting words, and stopped saying ‘retarded’.

Sometimes people with intellectual disabilities also have physical disabilities. For example, some people might use a wheelchair or hearing aid, some people may not be able to see, some people may have difficulty keeping their hands steady when they are trying to do something.
People with physical disabilities are also often treated unfairly at work, at school, and in the community. In this thesis, I often talk about problems that people with intellectual disabilities and people with physical disabilities face. I will usually say ‘disabled people’ to stand for the different terms I mentioned above.

**Rights**

These are some examples of different kinds of rights. Often disabled people have had one or more of these rights taken away from them:

**Legal rights**: people have the right to testify in court, and to decide what to do with their own money and belongings.

**Political rights**: people have the right to vote in elections, and to form groups to fight for better treatment at work, or better lives.

**Economic rights**: people have the right to have enough money to eat, to buy clothes, to pay for a place to live, and to stay healthy.
**Human rights**: people have the right to education, respect, and freedom from abuse.

**Thinking about Disability**

Disability and history

Because not all societies are organized the same way, not all societies have the same kind of split between disabled and non-disabled people. For this reason, it is important to try to find out how disabled people lived in the past, and to imagine how disabled people might live in the future.

A writer named B. J. Gleeson believes that we should pay special attention to how groups of people worked to meet their needs. That includes growing and cooking food, making clothes, building houses, and making all of the different objects people use in their lives. Did people with different abilities work together, or did they work separately (like in sheltered workshops)?

B. J. Gleeson also believes that it is important to think about how people got around in their communities, and how they organized their families.
Disability and work

There are many disabled people working in sheltered workshops, where they get paid a lot less than non-disabled people to do similar jobs.

Not all societies separate disabled people from non-disabled people. Some people who study history believe that before people started building factories to make products, disabled people and non-disabled people worked together. They usually worked with family or community members. There are still places where disabled and non-disabled people work together. For example, I met a woman in Portugal who had Down syndrome. She worked with the rest of her family growing food and raising animals.

People who study history think that when people started working in factories, the factory owners wanted everybody to work the same way, and at the same speed. It was difficult for disabled people to get jobs, because factory owners thought they would not be able to work at the same speed, or be able to work in the same small spaces. Over time, people started to think of disabled people as people who could not work. Because it is so hard for disabled people to get a decent job, many disabled people are poor.
**Systems**

Societies are difficult to think about because they are very complicated. There are a lot of people, and a lot of things going on. Often when we talk about how society works, we break it down into different parts. I am calling these parts systems. Here are some examples:

**The medical system:** is made up of doctors, nurses, therapists, hospital staff, hospitals, and drug companies.

**The social service system:** is made up of government ministries, social workers, managers, staff, group homes, community centres, and counselling centres.

**The legal system:** is made up of laws, lawyers, police, courts, and judges.

**The political system:** is made up of the federal government (in Ottawa), the provincial government (for example, Ontario) and the municipal government (for example, Toronto). People vote for leaders for these governments (for example, the Prime Minister, the premier, and the mayor).
The economic system: is made up of all the ways we make products, and the way we distribute them. For example, you might work at a restaurant making food to sell to customers. At the end of the week you get paid. You go to the store with your pay and buy something. All of that is part of the economic system.

The education system: is made up of schools, colleges, literacy classes, teachers, students, and staff.

Sometimes these systems are called structures.

Many systems in society are set up in ways that make it hard for disabled people to get their rights. Not getting your rights is also called oppression. Thinking about how systems oppress people is also called structuralism.

The job market

B. J. Gleeson believes that the job market is the structure that must be changed in order to stop oppression of disabled people. Job market means the way we find a job, and how much a boss will pay us.
In this society, workers sell their time to a boss when they do a job. For example, they might agree to work for ten dollars every hour. At the end of the day (usually eight hours), they have made eighty dollars.

A system where people sell their work time is called **capitalism**. In capitalism, bosses always try to find people who will work for less money, or who will work faster and do more things at the same time. When the boss pays the worker less, they get to keep more money for themselves.

This job market system is not fixed (that means it changes over time). It is made up of all the actions that happen between groups of people (for example, between workers and bosses). Because it is not fixed, groups of people can change the system when they decide to work together.
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