
Rachel Gorman

Ontario Institute for Studies in Education/University of Toronto, Canada

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Research that Hurts or Research that Helps?  
A Critical Framework for Adult Education Inquiry and People with Intellectual Disabilities

Rachel Gorman  
Ontario Institute for Studies in Education/University of Toronto, Canada

Abstract: 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.

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 & Ridgeway, 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 Ridgeway 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.

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. The objective of this paper 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.

Toward an Historical Materialist Understanding of Disability

Structuralism

In an evaluation of feminist disability politics, Sheldon (1999) argues that a structural approach is necessary for disability politics to move forward. 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, p. 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). Including a structural approach offers “a more effective way forward for disabled people, women, and people from other oppressed groups” (Sheldon, 1999, p. 643).

Gleeson argues that a focus on changing the material structures should be the “central emphasis for a transformative political practice” (Gleeson, 1997, p. 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, p. 193).

More insight into a materialist understanding of structure is provided by Allman and Wallis’ (1995) 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, p. 128). In a materialist reading of disability, transformative political practice must keep the labour-capital relationship as the focus.

Materialism vs. Idealism
There is a wealth of disability studies literature that 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 as 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 in *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.

Idealist explanations of disability are prevalent in the dominant ideologies of social work and rehabilitation, including “normalization” and “social role valorization” (Gleeson, 1997, p. 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 a way to make workplaces more accessible to disabled people.

Allman and Wallis (1995) 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” (p. 122). Gleeson (1997) 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. 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. Sleeter’s 1986 study of the history of educational streaming provides an example of how “Discourse and symbolic representations reproduce disablement” (cited Gleeson, 1997, p. 194). Sleeter 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 who 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, p. 48). US school systems defined children with IQ test scores between 75 and 90 as slow learners, and below 75 as retarded (Sleeter, 1986, p. 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, p. 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, p. 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.

Disability and Work

*Relations of Production and Distribution*

In his outline of an historical materialist view of disability, Gleeson (1997) 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” (p. 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” (p. 189). Gleeson argues this is 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, cited in Bender, 1986, p. 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, p. 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.

Ideology and the Sheltered Workshop

For adult education, a central concern is how to think about or justify vocational training programs when the commodification of labour plays such a central role in structuring disability. 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 (in workshops and vocational programs), and how much or whether workers are paid for it.

Citizen as Consumer

Within public policy and social service discourse, 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 of 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 the 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.

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 (1999) outline a questionnaire to gauge “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.

Having staff assist in answering questionnaires is also problematic when we consider the high instances of physical and sexual abuse in group home and institutional settings (Cambridge, 1999). 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.

Implications for Adult Educators

In our perspective, all education is political as it is aimed at either preparing people to liberate themselves from an oppressive and exploitative status quo or at domesticating people to adapt to work individualistically within the given (Allman & Wallis, 1995, p. 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, p. 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. Freire makes a distinction “between professional authority and authority of knowledge” (cited in Kilgore, 1999, p. 193). Mezirow suggests that educators can provide the conditions for emancipatory learning (Mezirow, p. 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. 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, p. 192).

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). 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). As educators, we have a responsibility to understand how “literacy and education for citizenship has potential both as a do-
mesticating tool and as a force for liberation” (Gibson, 1999, p. 132). We also must stop the appropriation of the disability rights movement by professionals who promote the appearance of self-determination of service users, rather than working for real change.

References


