

CHAPTER 7 (In 'Disability Studies: Past, Present and Future', edited by Len Barton and Mike Oliver (1997) Leeds: The Disability Press).

**When Myths Masquerade as Science:
Disability Research from an Equality-Rights Perspective**

By Marcia H. Rioux

The 10th anniversary of *Disability and Society* is important not only because the survival of a journal and all those who make it happen is, in itself, a feat worth celebrating - just getting the journal out on time and succeeding to do the number of promised volumes in a year is, in the disability literature somewhat unique. But *Disability and Society* has done much more than that. It was the first journal and remains one of only two or three periodicals around the world that challenge the fundamental assumptions of disability as it has traditionally been theorised. In the face of the transnational disability industry and the professional hegemony of medicine and therapy, this is a significant contribution. There is a lot more money to advertise "Self-Injurious Behaviour Inhibition Systems" (SIBIS) - an aversive-therapy invention for redirecting or repatterning the behaviour of people who abuse themselves developed in the United States - than there is for a journal that takes a critical perspective on the field.

In our library and information service, we have approximately 75 journals and 100 newsletters - all related to disability. Of the journals approximately 50% highlight rehabilitation information and research; about 40% are service-oriented; and somewhere around 10% are rights-oriented journals. So the uniqueness of *Disability and Society* is not hard to see in the field. For those of us who have been working from a similar perspective and trying to develop a critical theory of disability, it has consequently provided a kind of oasis in a desert.

PERSONAL REFLECTIONS ON RESEARCH

I did not start my career in social policy, in the disability field - I started in the feminist movement doing feminist research - in the late 1960s before there really was movement. So my background was a systemic analysis of society from a gender perspective.

Starting to work in the field of disability policy in the late 1970s, I was therefore surprised to find that the "problem" (as it was always defined) was the individual and the research was focused in three main directions, all aimed

at finding ways of preventing disability. The first direction was biological and medical research; the second was therapeutic intervention and the third was the production of services and service delivery. I could find very little literature about poverty, housing, unemployment, abuse, marginalisation, power imbalance, tax policy, and service monopolies. But for some of us, those are the research questions. And the contribution of *Disability and Society* in publishing work done from this perspective has made it possible for us to keep abreast of others carrying out parallel research; it has provided a forum for theory, research and methodological discussion that would have been absent otherwise.

The research agenda that is evolving from a systemic perspective of disability argues that disability has been poorly theorised. The traditional approach, dominated by the medical model, emphasises disability as an individual problem and, fails to conceptualise and develop variables to - measure the wider political, social, and ethical environment and its effect on the lives of people with disabilities. Poverty, marginalisation, disempowerment, unemployment and a number of other social constraints are not analysed as critical factors in disadvantage. Disability gets defined rather as a health and social care issue and researched debated on those terms. As an alternative, research from a systemic perspective emphasises equality, empowerment, inclusion, community and diversity and develops measures for those variables. How research and policy questions are framed is a quick barometer to the theoretical framework or paradigm from which the researcher begins. It is clear from even the most cursory examination of the journals which specialise in issues of disability that the majority of research and policy still reflects a theory of professional practice and functionalism.

In the journals we find articles with such themes as "Subgroups in autism: are there behavioural phenotypes typical of underlying medical conditions?"; "Measurement of Attention Deficit: Correspondence Between Rating Scales and Tests of Sustained and Selective Attention"; Clomipramine Treatment for Self-injurious Behaviour of Individuals with Mental Retardation: A Double Blind with Placebo; "A Comparison of Methods of Functional Assessment of Stereotypic Behaviour"; "Epidemiology of Challenging Behaviour"; "The use of Evaluation in the Development of a Staffed Residential Service for Adults with Mental Handicap"; and "Reduction of Multiple Aberrant Behaviours and Concurrent Development of Self-care Skills with Differential Reinforcement".

Research that reflects the emerging paradigm has such themes as: "Discrimination, Disability and Welfare: From Needs to Rights"; "Rights, Justice, Power: A Culture of Diversity"; "Some Ethical Issues Associated with

Genetic Engineering for People with Disabilities"; and "Class and Disability: Influences on Learning Expectations".

Ways of viewing disability, of developing research questions, of interpreting research results, of justifying research methodology and of putting policies and programs in place are as much about ideology as they are about fact. It is important to recognise how significant this is to research generally and in the field of disability in particular. The roots of scientific and socio-economic justification for the allocation of research funding and for political (or state) action based on the research findings can be found in these identifiable and shifting ideological frameworks. It is therefore useful to explore the social and scientific formulations of disability which underpin research questions, methodology and findings.

Reflected in the current dominant research paradigm are two very different world views - one which is centralising and homogenising and one which stresses difference and diversity. These discrepant world views are particularly relevant when the issue is disability. The normative standard that ensues from either of these has consequences in terms both of the importance placed on either abilities or disabilities manifested by people, as well as the social contribution made by individuals.

Empirical questions are driven by these implicit normative premises, despite the claims of objectivity so readily embraced by empiricists. To some degree, then, the enterprise that researchers, have to embark on is to uncover and disclose the premises of the research. I would argue that this is important because the social, economic and political pressures are pervasive in research in this field. But I would also argue that it is a moral imperative to disclose the normative basis of the research in a field like disability where the research affects the single most identifiably marginalised class of people. Researchers must be up front about the value judgements and normative standards hidden in their empiricism. They must also, I believe engage valid arguments to justify the particular normative foundation of their research.

Rather than simply engaging in the debates about one concept versus another, I want to step back and reflect upon the perspectives which underlie the various constructions of disability. How disability is perceived, diagnosed and treated, scientifically and socially, is reflected in assumptions about the social responsibility towards people with disabilities as a group and the research agenda. The assumptions or postulates about disability I will discuss are not mutually exclusive nor have they been temporally chronological. Some disciplines, in their research, have continued to characterise disability as disease or as a personal deficit while others have adopted a framework of disability as a social and political condition. There are any number of hybrids

of these two major schools of thought. Consequently, policy, programming, treatment and care and research reflect these shifting understandings of disability.

SOCIAL AND SCIENTIFIC FORMULATION OF DISABILITY

There are four identifiable social and scientific formulations of disability that are reflected in the treatment of persons with disability in law, in policy, in programs and in rights instruments and in research agendas. Two of them emanate from theories of disability as a consequence of individual pathology and two from disability as a consequence of social pathology.

These approaches have implications for both the formulation of research questions and the methodology used in research.

FORMULATIONS THAT FOCUS ON DISABILITY AS RESIDING IN THE INDIVIDUAL (INDIVIDUAL PATHOLOGY)

Within the context of disability as an individual pathology two broad approaches can be identified - the bio-medical approach and the functional approach. These formulations have a number of common characteristics:

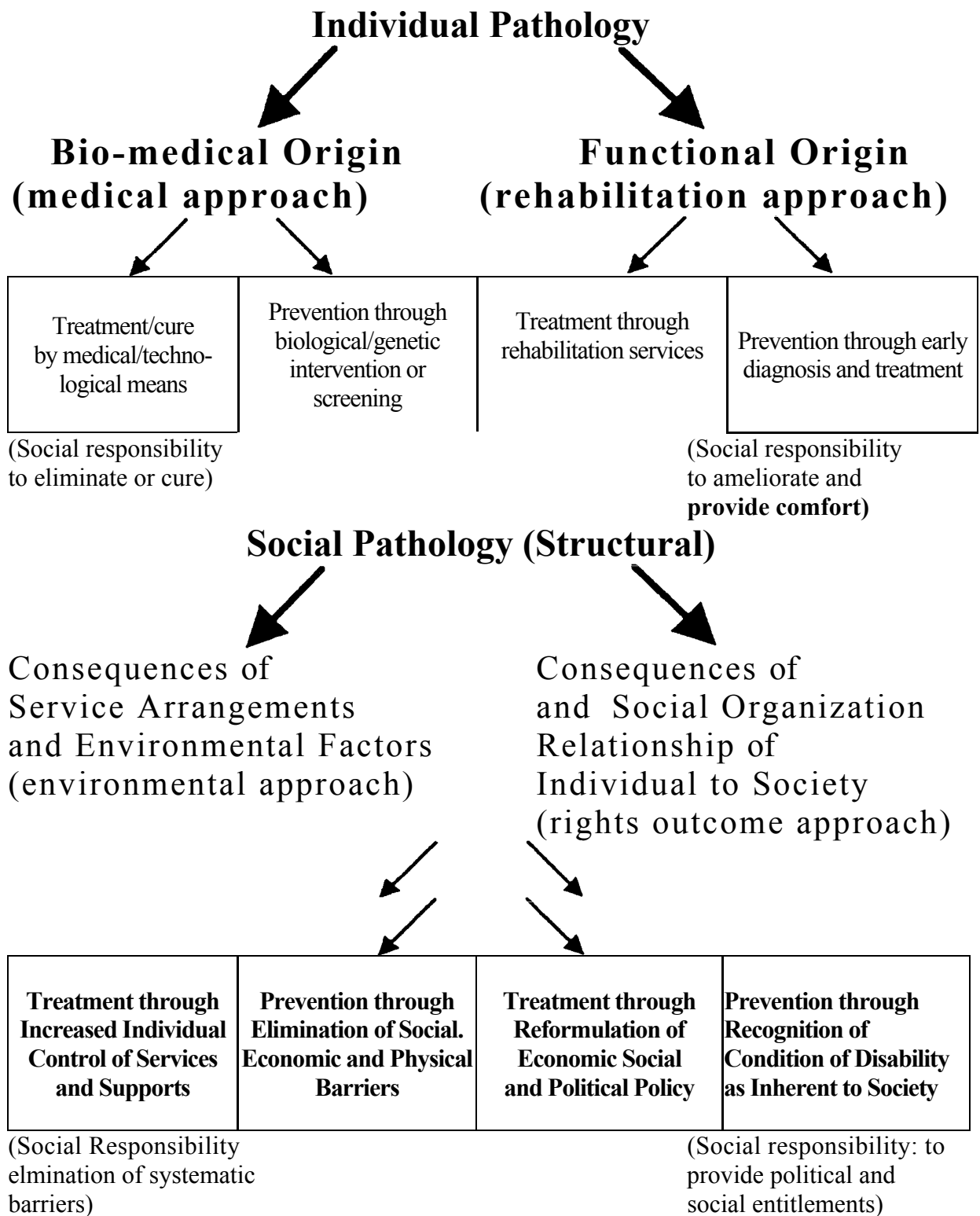
- they approach disability as a field of professional expertise
- they use a positivist research paradigm
- they emphasise primary prevention including biological and environmental conditions
- they characterise disability as incapacity in relation to non-disabled persons: comparative incapacity
- disability is viewed as anomaly and social burden, including costs
- the inclusion of people with disabilities is seen as a private rather than a public responsibility
- the unit of analysis is the individual
- the point of intervention is the individual condition

THE BIO-MEDICAL APPROACH

The bio-medical approach to disability research has been a powerful influence in determining disability policy, practice, and research. Throughout the nineteenth and early twentieth century, infectious disease was the major cause of illness and death.

The advent of the "germ theory" of illness and disease facilitated the capacity to more correctly diagnose symptoms and led to the pre-eminence of biological

SOCIAL AND SCIENTIFIC FORMULATIONS AND TREATMENT OF DISABILITY



science as the basis for diagnosing disability, influencing treatments - and guiding access to disability benefits.

From the perspective of molecular biology and the attendant bio-medical approach, it has been assumed that disability is caused by a mental or physical condition that can be prevented or ameliorated through medical, biological or genetic intervention. In such a characterisation of disability, the condition itself becomes the focus of research attention. The aim of the researcher is to decrease the prevalence of the condition in the general population. Treatment and prevention occur by means of biological intervention and critical care, including surgery, drug therapy, pre-natal screening and genetic intervention. Commonly, then, the individual or the foetus is viewed as sick, injured or afflicted and research is directed to the cure.

With the rise of institutional facilities and public benefits, medical science became established as the mechanism for gatekeeping those who are legitimately to be considered disabled. Assessments became a scientifically justified activity extending to various aspects of an individual's range of disability such as educational, training and work capabilities; fine motor skills and hand-eye co-ordination; the need for financial benefits and mobility aids and devices; as well as access to rehabilitation.

The bio-medical approach with a focus on altering the biological condition, places less emphasis on the role that society plays in limiting and enabling people.

THE FUNCTIONAL APPROACH

The second of the two approaches of disability as an individual pathology is the functional approach. Like the bio-medical model, the underlying presumption is that the deficit stems from an individual condition or pathology. However, from this approach the way of treating the functional incapacity is through amelioration and enabling strategies.

From the functional approach, the problems experienced by people with disabilities are interpreted as a result of a functional incapacity resulting from an individual impairment. To treat this functional incapacity, services are made available to enable the individual to become as socially functional as possible. For example, the goal of rehabilitation is to increase an individual's range of skills and abilities to function more independently and to become a productive member of society. The success of programs is measured by how closely people who use services can approximate the lives of "normal" people, ' and to what extent they can achieve the skills of non-disabled persons.

Services developed from a functional approach (for example, physiotherapy, occupational therapy, nursing and health visiting) have gone beyond therapeutic programs associated with the bio-medical model to include life skills, pre-vocational training, functional assessments, counselling and job training, as well as skills for independent living.

Behaviour modification and developmental programming are also offshoots of the functional approach to disability. Behaviour modification uses a variety of reinforcement techniques to elicit individual behaviours that have been deemed socially desirable or useful. The approach is also used to eliminate behaviours deemed inappropriate or ineffective for adjusting to the demands of everyday living. Developmental programming research targets knowledge and skills that people usually acquire as they mature, identifies where and why individuals may be falling short of those benchmarks, and intervenes to assist individuals to maximise their developmental potential.

In placing the focus on the individual, a functional approach to disability research loses sight of environmental and situational factors that may limit individuals from achieving their ambitions. In targeting the individual for change, professionals and researchers using a functional approach run the risk of legitimising assumptions about the person's "best interests" that may not always coincide with what the person wants for him or herself.

FORMULATIONS THAT FOCUS ON THE SOCIOPOLITICAL NATURE OF DISABILITY (SOCIAL PATHOLOGY)

As well as the two formulations of disability based on individual pathology, there are two identifiable formulations based on social pathology. Both start from a perspective that assumes that disability is not inherent to the individual. Rather they assume that the disability is inherent to the social structure. The identifiable pathology is that there is something wrong with the society that we have to fix rather than something wrong with the individual (WHO, 1980).

These approaches have a number of shared characteristics:

- they assume that disability is not inherent to the individual independent of the social structure
- they give priority to political, social and built environments
- they recognise disability as difference rather than as an anomaly
- disability is viewed as the interaction of individual to society
- inclusion of people with disabilities is seen as a public responsibility
- the unit of analysis is the social system
- the point of intervention: social, environmental and economic systems

THE ENVIRONMENTAL APPROACH

Advances in knowledge based on an understanding of disability as a social pathology have shown that personal abilities and limitations are the result not only of factors residing in the individual, but of the interaction between individuals and their environments. Increasingly, researchers are demonstrating that the failure of ordinary environments to accommodate people's differences results in disability.

From an environmental perspective on disability, the research focus is placed on the way environments are arranged. For example, research has shown that the absence of ramps into an office building creates an employment handicap for someone who relies on a wheelchair for mobility. The lack of an ergonomically adapted work space, it has been demonstrated, makes it impossible for a person with limited upper body movement to perform job tasks. Similarly, many research studies have shown that the lack of proactive hiring and employment retention policies create disadvantages for individuals who require time away from work because of the fatigue and other conditions caused by impairment. An educational service disadvantages persons with a speech impairment where it fails to provide the opportunity to learn an alternative method of communication (e.g. through Bliss Symbolics or sign language instruction).

Increasingly, research is showing that the impact of disability can be lessened as environments are adapted to enable participation. Building codes, principles of barrier-free design, adapted curricula, targeted policy and funding commitments are being shown in policy research to be useful tools to this end. Research shows that these tools enable modifications and supports to be made in home, school, work, and leisure environments, and increase the participation of people with disabilities in society and limiting the disadvantages they otherwise would face.

THE RIGHTS-OUTCOME APPROACH

Another formulation of disability is based on the notion that disability has social causes and is a consequence of how society is organised and the relationship of the individual to society at large (Roth, 1983) (Beresford, 1994) (Rioux, 1994) (Rioux, 1994) (Roehrer Institute, 1996) (ICIDH, 1991) (Oliver, 1990). Research from a rights-outcome approach looks beyond particular environments to focus on broad systemic factors that keep certain people from participating as equals in society.

This research approach finds wide variations in cognitive, sensory and motor ability are inherent to the human condition. It draws from a variety of disciplines (e.g., anthropology, sociology, economics, law) in methodology and conceptualisation, but it frames disability issues through the lens of human rights principles. It assumes that public policy and programs should aim to reduce civic inequalities, to address social and economic disadvantage and also assumes that -various supports, (e.g., personal services, aids and devices) will be needed by some people in order to gain access to, participate in and exercise self-determination as equals in society.

Research from a rights-outcome approach constructs an analysis of how society marginalises people with disabilities and can be adjusted to respond more effectively to their presence and needs. This approach focuses on the disabling aspects of society, on supporting human diversity, and on empowering disadvantaged individuals. It makes the exercise of human rights by persons the dependent variable in the research questions and social structure the independent variable.

SOCIAL OBLIGATION OF RESEARCH

The social obligation of research in this approach to disability is on how to reduce civic inequalities, that is, the degree to which social and economic disadvantage have been addressed through providing supports and aids and devices that enable social and economic integration, self-determination and - legal and social rights. It is distinct from the social obligation of research grounded in individual pathology, where within the bio-medical approach the goal is to eliminate or cure disability and the functional approach that has as its social obligation to ameliorate and provide comfort.

FORMULATIONS AND IDEOLOGY

Research from these social and scientific formulations of disability ascribe different attributes in terms of cause, prevention and social responsibility of the researcher and of society towards persons with disabilities.

Spurious research can, consequently, be legitimated because of the social obligation attached to the ideological framework of the researcher. It may be possible thereby, for example, to legitimate exclusionary practices by the research.

These formulations also provide a mechanism to identify the way in which scientific ideology has provided the justification for particular treatment

modalities, social programs, laws, and policies. Because of the difference in world view and in fundamental assumptions about disability, each of these approaches will likely lead researchers to have a different view of what is best with respect to disability and how to frame the research questions. Consequently, the formulation of disability leads to different ways of measuring and evaluating what is accomplished, and policy and program formulation.

These four approaches to research in disability can be evaluated on the basis of the degree of myopia of the disciplinary limits from which they approach disability. Arguably there is nothing wrong with any one of them in their own right, rather it is the harm they cause by claiming the field of disability as the exclusive domain of one particular discipline. There are few other examples where a marginalised group has been subjected to this degree of scientific hegemony. The tradition of the ethical and scientific 'responsibility of the researcher and the parameters of what constitutes "good research" needs to be made explicit, both in terms of context and procedural methodology. Disability researchers could therefore be usefully evaluated on the degree to which empowerment and reciprocity are central to their research questions, to their methodology and to the sharing of their findings. There is a difference in design, sample and outcome if the question is studied from these different perspectives. Often researchers who use a systemic approach in studying disability are accused of naivete in understanding the degree of physical and intellectual impairment . that some people have - in particular in evaluation research.

There is, however, no reason to deny the need to address physical or intellectual conditions while still understanding that ways are needed to move beyond that as the sole or most important criterion of support. To go further, there are identifiable cases where while research will show success in treating the individual impairment the treatment could arguably be considered a failure - for example, where the provision of services are at the expense of rights. This has major implications in terms of policy, and in particular in terms of policy that provides funding for services or supports provided within segregated settings, or which confer a lesser status on persons with disabilities. Terms such as "uneducable" or "unemployable" or "trainable" which claim scientific validity often entitle people to significant services and state support but they can only be held to be successful in the clinical context in which those distinctions are constructed and enforced. But we must ask, enforced at what cost?

Let me give you an example - the use of aversive therapies on people with clinically defined undesirable behaviours is claimed to be "successful" in reducing an unwanted set of socially problematic behaviours. The important

factors in scientific measures of success are how many times an undesirable behaviour occurs, given that certain stimuli are introduced or removed (e.g., electric prods, time-out rooms, ammonia sprays, and so on).

If, however, we opt for another measure of success, we are brought face to face with some limitations that must regulate service and support and evaluation criteria. In this instance, "scientific" success implies an outcome and ways of achieving it that are in keeping with the human dignity and well-being not only of each individual, but necessarily of society as a whole. The kinds of measures of success are embedded in such research questions as: What are society's obligations to ensure that forms of "care" other than the use of behavioural management are made available in meaningful ways to individuals who have a disability and who need service and support in ways that enable them to exercise their rights? To what extent is technology substituted for the changes necessary to enable a citizen to integrate into the social and economic structures?; To what extent are efficient and cost-effective technologies developed and deployed at the expense of rights?

Research evaluation of supports and services that is formulated within an understanding that disability is an individual pathology differs in the indicators it uses from evaluation research that understands disability as a social pathology. What are some of those differences?

INDICATORS BASED ON INDIVIDUAL PATHOLOGY	INDICATORS BASED ON SOCIAL PATHOLOGY
<ul style="list-style-type: none"> ● diminishing of maladaptive behaviours ● increase of daily-living skills <ul style="list-style-type: none"> ● toilet training ● social skills ● communication ● motor skills development ● provision for adequate staffing and support ● extent to which safety and security are enforced ● the administration of medications ● extent to which there is a reduction in deviation from valued and normal social roles ● use of physiotherapy ● the quality of professional intervention 	<ul style="list-style-type: none"> ● capacity of community and social systems to adapt to individual interests ● acceptance of individual by communities ● individual choice and economic control of decisions about support and service <ul style="list-style-type: none"> ● hiring staff ● deciding where to live ● adaptability of job workplace and labour market to account for individual diversity ● extent to which community and government take on the agenda of disability as political agenda

Likewise in research in disability there might be scepticism of the conventional research which was designed to study the non-disabled population. It is not enough simply to add disability as a category to existing studies. Recent research on abuse and violence uncovered an entirely different set of conditions faced by people with disabilities (Roehrer Institute, 1994).

People with disabilities have spawned a research industry that, in the main, has failed to address the fundamental issues of their disenfranchisement. We have barely begun in most countries to deal with the intangible barriers - poverty and prejudice; segregation; and subservience. The research agenda, now, should be how people with disabilities can get a fair footing on the economic ladder, how to fight the kind of discrimination for which there is no recourse enshrined in law, and where to direct the battle for disability equality. To hear in

the last few years of the 20th century people appealing to (scientifically discredited) IQ tests as a basis for classifying people; to hear that therapy and services will resolve the systemic exclusion and isolation of people with disabilities; to hear the inherently eugenic arguments of the genetic scientists with the underlying assumption that society must be rid of disability is disturbing. That these can go on, unchallenged, speaks to the disregard with which people with disabilities are held; it speaks to a failure of rigour in scientific work, and it speaks to a profound misconception of the relationship between ethics and science. The light in this tunnel is sometimes dim but there is a steady increase in disability pride activism. I hang my hopes on that, to build a solid civil rights movement in disability throughout the world, one that can guide the research community to the questions worth asking.

REFERENCES

- BERESFORD, P C. J. (1994). "Disabled People, Service Users, User Involvement and Representation." *Disability & Society*, Vol. 9, No. 3, pp. 315-325.
- ICIDH, C. S. F (1991). "The Handicap Creation Process." *ICIDH International Network* 4(1-2).
- OLIVER, M. (1990). *The Politics of Disablement*. Basingstoke, Macmillan.
- RIOUX, M. (1994). "Towards a Concept of Equality of Well-Being: Overcoming the Social and Legal Construction of Inequality." *Canadian Journal of Law and Jurisprudence* VII(1):pp. 127-147.
- RIOUX, M. H. AND BACH, M. (EDS) (1994). *Disability is not Measles: New Research Paradigms in Disability*. North York, Ont., The Roeher Institute.
- ROEHER INSTITUTE (1994). *Harm's way: The many faces of violence and abuse against persons with disabilities*. North York.
- ROEHER INSTITUTE (1996). *Disability, Community and Society*. North York (Ont.), The Roeher Institute.
- ROTH, W (1983). "Handicap as a Social Construct." *Society* 20(3).