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ABSTRACT

This report explores current assumptions about the social and scientific formulations and treatments of disability that currently underlie the research agenda in the disability field. Formulations that focus on disability as residing in the individual (Individual Pathology) are discussed. Treatment strategies resulting from this definition of disability include the biomedical approach, which emphasizes the biomedical origin of disability, and the functional approach, which focuses on ways of treating functional incapacity through amelioration and enabling strategies to assist people to develop their potential. Formulations that focus on the sociopolitical nature of disability (Social Pathology) are also examined, including the environmental approach, which focuses on the interaction between individuals and their environments, and the rights-outcome approach, which focuses on broad systemic factors that keep certain people from participating as equals in society. The social, economic, ethical, and professional forces that shape research agendas are reviewed. These include the impact of economic neoconservativism, utilitarianism as the underlying principle for research and professional practice, and a research culture driven by objectivity and positivism. The research community is urged to recognize the forces that shape the questions they ask and the criteria of validity they adopt in disability research. (CR)

DISABILITY:
The Place of Judgement in a World of Fact

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DISABILITY: THE PLACE OF JUDGEMENT IN A WORLD OF FACT

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 recognize how significant this is to research generally and in the field of intellectual 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 identifiable and shifting ideological frameworks. Exploring the social and scientific formulations of disability which underpin the research agenda and the ways of knowing disability is therefore useful in understanding the field.

Reflected in the current dominant research paradigm are two very different world views - one which is centralizing and homogenizing and one which stresses difference and diversity (in colloquial terms - the melting pot and the vertical mosaic). 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 the abilities and disabilities manifested by people, as well as the social contribution made by individuals with disabilities. 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 we, as researchers, have to embark on is to uncover and disclose the premises of our 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 ours where the research affects the single most identifiably marginalized class of people. We therefore ought to be more mindful of the potential value judgements and normative standards hidden in empiricism.

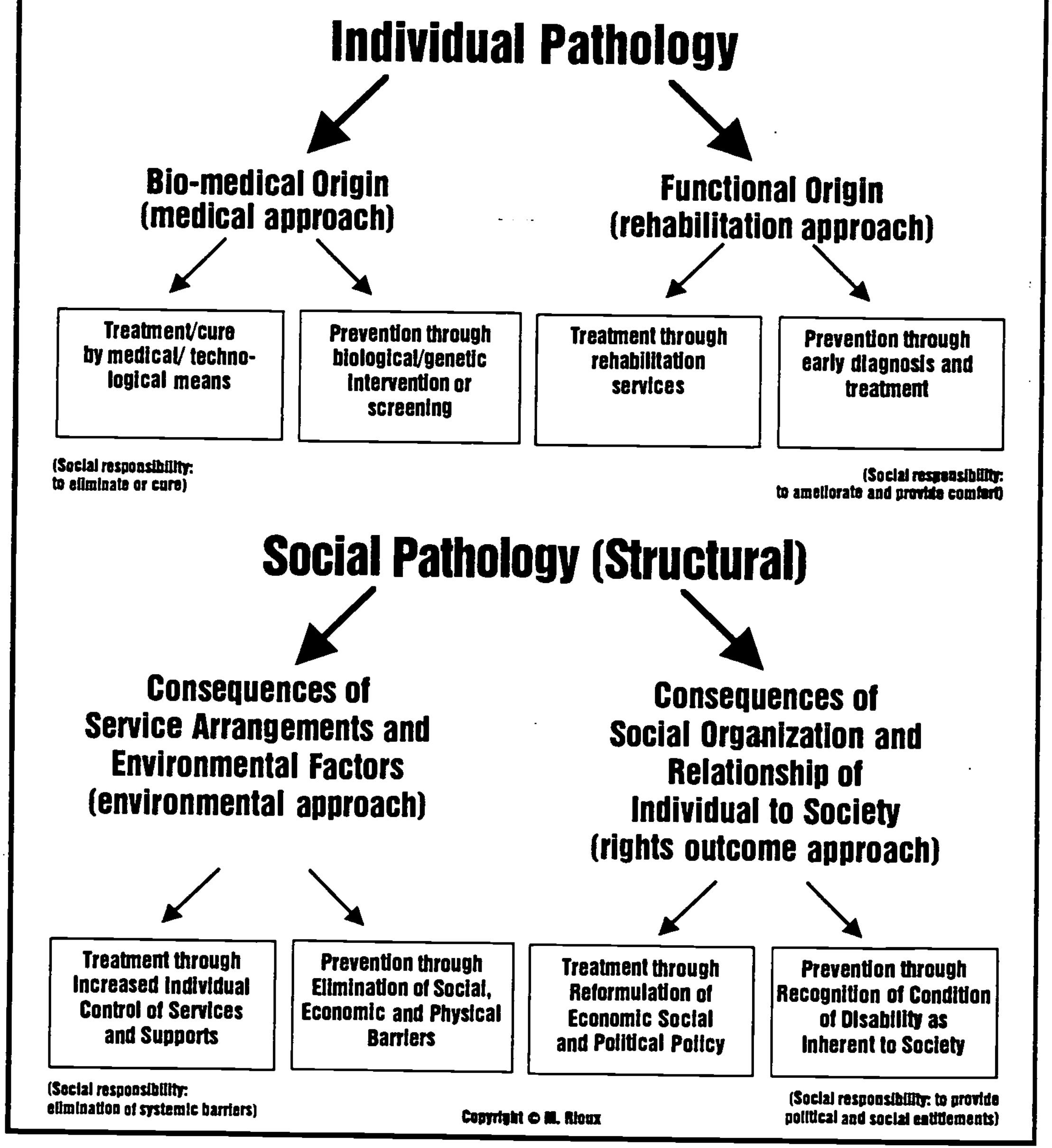
Rather than simply engaging in the debates about one concept versus another, I want to step back and reflect upon the perspectives which underlie the various constructions of disability. It will then be possible to develop a methodologically rigorous and defensible approach to the way research is done in this field.

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. The assumptions or postulates about disability I will discuss are not mutually exclusive nor have they been temporally chronological. Some disciplines have continued to characterize 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 - both within the professional sphere and coming from government - reflect attempts to accommodate these shifting understandings of disability.

SOCIAL AND SCIENTIFIC FORMULATIONS OF DISABILITY

There are four social and scientific formulations of disability that can be identified and which are reflected in the treatment of persons with disability in law, in policy, in programs and in rights instruments. Two of them emanate from theories of disability as a result of individual pathology and two from disability as a result of social pathology.

SOCIAL AND SCIENTIFIC FORMULATIONS AND TREATMENT OF DISABILITY



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

I am going to look both at the bio-medical approach and the functional approach. These formulations have a number of common characteristics:

- professionally dominated approach
- positivist paradigm
- primary prevention including biological and environmental
- disability is incapacity in comparison to non-disabled: comparative incapacity
- disability as anomaly and social burden, including costs
- inclusion of people with disabilities is private responsibility
- unit of analysis: individual
- point of intervention: individual

THE BIO-MEDICAL APPROACH

Of the two formulations of disability emanating from an individual pathology, the first emphasizes the bio-medical origin of disability. The bio-medical approach to disability research has been a powerful influence in determining disability policy and practice. 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 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 characterization of disability, the condition itself becomes the focus of attention. The aim of the professional or 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.

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 extend to various aspects of an individual's range of disability such as educational, training and work capabilities; fine motor skills and hand-eye coordination; the need for financial benefits and mobility aids and devices; as well as access to rehabilitation.

The bio-medical model, 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 formulations of disability as an individual pathology can be called a functional approach. Like the bio-medical model, the underlying presumption is that the deficit stems from an individual condition or pathology. However, this approach looks at ways of treating the functional incapacity through amelioration and enabling strategies to assist people to develop their potential.

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 (Wolfensberger, 1972; Meyer, Peck & Brown, eds, 1990). 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 able-bodied 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, prevocational 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 (Koegel, Koegel and Dunlap, 1996). The approach is also used to eliminate behaviours deemed inappropriate or ineffective for adjusting to the demands of everyday living. Developmental programming 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 maximize their developmental potential Allen,*et al*, 1994).

In placing the focus on the individual, a functional approach to disability can lose sight of environmental and situational factors that may limit individuals from achieving their ambitions. In targeting the individual for change, professionals operating on the basis of a functional approach run the risk of operating on assumptions about the person's "best interests" that may not always coincide with what the person wants for him or herself. The way services are organized can also produce a power imbalance that creates tensions between persons with disabilities and the professional community.

FORMULATIONS THAT FOCUS ON THE SOCIO-POLITICAL 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. They 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. It is a structural approach rather than an individual approach. 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; Rioux,).

These formulations have a number of identifiable characteristics:

- they assume that disability is not inherent to the individual independent of the social structure
- they give priority to political, social and built environment
- they emphasize secondary prevention rather than primary
- they recognize 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 structures and 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 exacerbates the impacts of 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 disability (Roeher Institute, 1992). 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 organized and the relationship of the individual to society at large (Roth, 1983; Beresford & Campbell, 1994; Roeher Institute, 1992; Rioux & Bach (eds), 1994; Canadian Society for 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 and that persons with disabilities do contribute to society. It draws from a variety of disciplines (e.g., anthropology, sociology, economics, law) 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 (Chappell, 1992) 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 marginalizes people with disabilities and how it could be adjusted to respond more effectively to their presence and needs (Oliver, 1992). This approach focuses on the disabling aspects of society, on supporting human diversity, and on empowering disadvantaged individuals.

SOCIAL OBLIGATION OF RESEARCH

The social obligation of research from 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 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.

They 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. Research from each of these formulations has an important contribution to make in ensuring people with disabilities have the support services, social and medical services and income they need. Because of the difference in world view and in fundamental assumptions about disability, each of these approaches lead researchers to have a different view of what is best with respect to disability. Even the understanding of what constitutes disability, disease, health, normality and abnormality are not shared across these approaches* (Caplan, 1996; Whyte and Ingstad, 1995; Hubbard, 1995). Consequently, the formulation of disability leads to different ways of measuring and evaluating success of what is accomplished.

All four approaches to research in disability can be critiqued 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 their exclusive domain. There are few other examples where a marginalized group of people have had to cope with scientific hegemony to this extent.

FORCES THAT SHAPE RESEARCH AGENDAS

If these differences in research approaches to disability are not to dissolve into irresolvable conflicts, we need to understand the forces that shape the research agendas in the field of disability. It is not good enough to critique the molecular biological and bio-medical approach without recognizing the social, economic, ethical and professional pressures that drive this research agenda. In the field of disability research these pressures have driven the research questions, the findings and the practice in a manner that has tipped the scales significantly in favour of information premised on disability as primarily an individual pathology. Research on policy, programs and services that have an impact on individuals with intellectual disabilities have therefore overly emphasized this perspective to the detriment of the broader systemic conditions that disable people. There are a number of factors that are driving the research agenda in the disability field.

NEO-CONSERVATIVE ECONOMIC AGENDA

The first is the neo-conservative economic agenda. In times when, as at present, social policy is driven by economic neo-conservatism (Drache, 1995), funding is much more likely to be allocated to research that reinforces cost-savings. In a climate of scarce resources, if you assume that the individual is the locus of the problem, scarce resources are likely to be invested in lines of inquiry that establish the relative costs and benefits of some private and social investments over others in addressing individual impairment (Doyal and Gough, 1992). For example, there is a body of literature that provides rationales, using an actuarial approach, of the relative cost savings of investments in techniques to prevent biological disability. This research favours interventions such as selective abortion, somatic germ-line therapy over the aggregate costs of supporting a person with a disability over a life-time. For a critique of this position, see Waldschmidt, 1990; Asche, 1994; Lippman, 1991. Other literature argues that the high cost of health care, and the probable incrase as treatments and technologies become more sophisticated warrant rationing of health care based on reduced quality of life (Steel, 1995).

Another line of inquiry supported in the reductionism of the new economic environment is on research in ways to eliminate individual differences that cause inefficiencies and dysfunctions in the global economic system as it is presently constituted. Comparatively few resources are invested in how to reorganize economies to integrate human differences, to empower marginalized groups and to ensure civic equalities.

The political economy of research is such that well-endowed research projects tend to have an implied practical focus. Governments and private industry invest in research because they want to get something from it. In a neo-conservative economic policy climate, they are pressured to look for cost-savings.

UTILITARIANISM AS THE UNDERLYING PRINCIPLE FOR RESEARCH AND PROFESSIONAL PRACTICE

The second major pressure on research agendas is utilitarianism as the underlying ethical principle for research and professional practice. Ethical principles that underlie research have very different implications for deriving research questions, for methodology used , for the interpretation of research results and for justifying the implied or explicit agenda that results as a basis for treatment, care and decisions-making around disability.

Utilitarianism has been the implicit moral/ ethical premise for much of the bio-medical and bio-technological research and practice in disability in western democracies. Health care, medical triaging, and the allocation of services have tended to rely on the assertion of the principle of utility, that is, that in all circumstances "we ought to produce the greatest possible balance of value over disvalue for all persons affected (the least possible balance of disvalue if only bad results can be brought about) (Childress & Beauchamp, 1994).

Childress and Beauchamp, proffer that the refinement of the concept of utilitarianism, beyond it popular uses, is that it refers to the "moral theory that there is one and only one basic principle in ethics, the principle of utility. An ethical practice is consequently one in which a calculation is made which balances resources and compares the actual needs of everyone affected. "Utilitarians do not believe that this way of calculating imposes something alien or even unusual on the moral life. They think that utilitarianism simply renders explicit and systematic what is already implicit in ordinary deliberation and justification. The utilitarian believes that such reasoning is dominant both in individual actions and in public policy".

In any number of examples, we have seen how this translates into practice for individuals with disabilities - in a recent case in Canada which is only exemplary of similar cases throughout the western world (and possibly elsewhere), a young man was refused a place on the list for a lung transplant on that basis of his having Trisomy 21. The argument was made that in a time of scarce medical resources, there was a clear professional responsibility to give those resources to those who would benefit the most. This is a useful example of the way a utilitarian approach has filtered down from a philosophical system into practical policy decisions affecting medical treatment.

Research on the human genome has been hailed as an important contributor to the advance of knowledge, to the prevention of disability and disease and to improving the well-being of humankind as a whole. Genetic screening has been made available for disabling conditions which can be subsequently identified and eliminated through abortion or non-conception. The decision has been made that there is a clear responsibility to use bio-technology and research dollars to minimize the costs and risks of disabling conditions, in terms of the greatest good for the greatest number.

The question that arises from the use of utilitarianism as a moral theory is "how do we determine what value could and should be produced in any given circumstance?" Most utilitarians would include health, freedom from pain, and the absence of disability as intrinsic values (ie. things that are valued just for their own sake not for something else they produce). But this is the fundamental problem with the hegemony of utilitarianism in the bio-technological research field.

In a recent seminar in Chicago that I attended where prenatal diagnosis and selective abortion were the topic of discussion among 50 genetic counsellors, researchers, disability rights advocates, physicians and government officials, there was no agreement on whether the elimination of fetuses testing positive for Tay-Sachs disease and such severe and life-shortening conditions could be argued to be of utility either to the society as whole or to the potential individual.

The acceptance of utilitarianism as the underlying principle of medical and biological research generally has spilled over into the research in disability where disability is seen to reside in the individual.

Utilitarianism is, however, only one model of moral reasoning (Drover and Kierans, 1993). Under the social formulations of disability, the moral principles that tend to be paramount are principles of justice (including either the Rawlsian notion of justice as fairness (Rawls, 1971) or the notion of justice as equality

(Williams, 1962; Lukes, Dworkin, 1981a; 1981b). Principles of justice are reflected in the research agendas and the funding of research, as well as in the social policy based on that research. As we shift from a utilitarian base to a justice base, tensions will arise that to date have been masked by the predominance of utilitarianism as the basis on which to view disability, undertake disability research and formulate social obligation.

A RESEARCH CULTURE OF OBJECTIVITY AND POSITIVISM

The third pressure on the research agenda is that driven by a research culture of objectivity and positivism. There is a strong cultural bias in industrialized countries towards scientific positivism in research and policy making. Rationality and objectivity are valued as necessary conditions for the social and economic well-being of society. These cultural biases bring pressure on the research community to rely on strictly positivist criteria to judge validity of research, and to be suspicious of more inductive and qualitative approaches.

For example, there is an important and often debated issue around environmental therapy (and now prospective gene therapy) as compared to aversive therapy, in response to self-destructive and violent behaviour of people with intellectual disabilities (Lovett, 1985). At root, this debate is about the capacity to prove a valid and measurable stimulus-response effect of positive reinforcement. Stimulus-response trials are much simpler to carry out if the intervening variables can be reduced and clinical trials can be carried out in laboratory type settings. It has been possible to show, for example, that electric shock sticks or SIBIS (Self-Injurious Behaviour Inhibition System) reduce particular behaviour manifestations, particularly in clinical or institutional settings. It has been much more difficult to show that particular changes in environment, in programming, in housing, in social setting have reduced particular behaviours. Qualitative studies have been criticized for being unable to determine which of the environmental factors made the most significant differences, thereby limiting the presumed reliability and validity of the research results.

Therapeutic, molecular-biological and medical research which lend themselves to that kind of empiricism are much more likely to receive funding than research which relies on qualitative data, anthropological studies which emphasize the subjective experience of disability, and policy science which tries to deal with a myriad of interacting variables. Even though these types of studies may not receive much profile as a funding priority, they have nonetheless provided the field of disability with important new knowledge and analysis (eg., educational research; research concerning the inclusion of people in the regular labour market; quality of life and health promotion research which sheds light on the dimensions of health for persons with disabilities, etc).

The objectivity of research is sometimes justified by its disassociation from the use of the results. Thus, for example, there are claims made that pure research is socially useful in its own right and ought to be supported, in particular because it is not subject to special interest group pressures. Research that investigates the impact of social, economic and political conditions is less likely to meet this type of test of objectivity on face value.

Pressure for this type of objectivity and scientific positivism create incentives for researchers to present their research designs and research methodologies in ways that mask the complexity of the experience and causalities of disability. There is a built-in bias against making explicit the potential consequences at both the design and the results stage and in the carrying out of the research.

CONCLUSION

In conclusion, the research community in the field of disability has created a world of “disability facts”, but has been relatively <u>un</u>conscious about the judgements it has made in doing so. In creating the world of facts, we have assumed that the place of judgement belongs to the advocates, the policy-makers, the politicians, the courts. I think that we need to reconfigure the place of judgement in the world of facts we construct in the field of disability research. The judgements <u>we</u> make about the causes of disability, about the meaning of the concept, about what factors to hold responsible for the experience of disability, have profound consequences for the directions pursued by advocates, policy-makers, politicians and the courts.

Instead of denying the place of judgement in our research, I think we can become conscious of it and that we can begin to hold each other accountable for the judgements we make. To develop an international research agenda that is conscious of its own judgements we need to recognize the very real forces that shape the questions we ask and the criteria of validity we adopt.

Uncovering the elements of various formulations and approaches to disability and the world views that underlie them as well as the social pressures to research disability from the perspective of individual pathology provides us with an opportunity to rethink the work in this field. Recognizing the relative nature of disability found in the different approaches should provide an opportunity to address the reductionism common to disability research and scientific findings. We can make explicit the inherent biases in unilinear and monolithic approaches found in research methodology and findings. Instead of standing on the laurels of the research done in the field we can work toward correcting the imbalance that has emerged because of traditional understanding of disability and the social pressures on the research community and research funding.

It is a challenge that will be difficult but if the research we do is to benefit those who live with disabilities and future generations of those with disabilities, it is an imperative that cannot be ignored.

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Tenth World Congress of IASSD (Helsinki, Finland, July 8-13, 1996)

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