

THE BIODYNAMICS OF DISABLEMENT? *

Disability and Rehabilitation Systems Research

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Vic Finkelstein

1. My Brief

When I was approached to present a paper at the *Disability and Rehabilitation Systems Research* workshop in Harare it was agreed that my presentation would cover three important concerns. My *Brief*, then, is the following:

1.1 I will focus my discussion on the current recommended *International Classification of Impairments, Disabilities and Handicaps* (ICIDH).

As is well known a consultation and revision process of the original ICIDH (*World Health Organisation (1980) "International Classification of Impairments, Disabilities, and Handicaps", Geneva, WHO*) is just being concluded. During my preparation for this paper I talked to a few people about progress in the re-drafting of the ICIDH but, sadly, was left with a profound sense of confusion about what had been agreed by the various disabled and non-disabled contributors. It was as though I was hearing two different languages talking about two different documents. Consequently I am not fully confident about the actual status of the document I used in preparing my presentation. In this respect, then, I will start my talk with the following caution:

- I am uncertain about the current status of *ICIDH-2 Beta-1 Draft for Field Trials, June 1997* which I have used for this paper;
- I have been told that suggestions for the revision of the ICIDH are still being solicited and will be considered for a final published version; and
- I have received confusing interpretations about the agreed draft currently in circulation.

1.2 I will examine the ICIDH appropriateness in the cultural context of southern Africa

- I have interpreted this very broadly as 'appropriateness in the context of non-disabled domination of culture in multi-cultural societies'.

1.3 I will discuss the role of qualitative research and the social sciences in disability research

- I have questioned the validity of applying disciplines created by non-disabled people to the field of 'disablement' in the absence of a publicly and professionally recognised mature disability perspective on appropriate research and services.

Finally, I must emphasise that I make no claims that what I am presenting is anything other than a **personal** view.

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2. Two Simple Facts

In addressing my *brief* I have had to take as my starting point two critical facts which have hitherto dominated all understanding and interventions concerning the lives of disabled people. These are the control exercised by ‘people with abilities’ (PWAs) in determining what **is** ‘disability’, and the influence of this control in integrating a ‘disabling culture’ within the prevailing general culture of society. I will discuss these in turn:

2.1 The hegemony of PWA control over disabled people’s lives

Until very recently PWAs have completely dominated the way disabled people have been understood; defined and assessed for access to financial benefits, assistive devices and environmental adaptations; provided with voluntary and statutory health and welfare services; been presented to the general public in all forms of the media; and taught at all levels in educational facilities. To summarise, there surely can be little argument that PWAs have:

1. defined ‘disability’ as an attribute of the individual which causes a complex set of lifelong personal and social problems (eg. ‘mobility problems’ which prevent the disabled individual from gaining access to places of work);
2. created a menu of ‘special needs’ which enable professional experts to ‘prescribe’ and ‘manage’ the solutions for these problems (eg. prescribing wheelchairs for problems in walking);
3. set the parameters for researching the nature of ‘disablement’ (eg. researching the ‘mourning’ process within assumptions that disability is a personal tragedy that is ‘suffered’ by the individual);
4. determined policy priorities (eg. allocate funding for the provision of ‘special’ education facilities and ‘health care’);
5. set up special services which are managed by PWAs (eg. residential homes, special schools, rehabilitation centres);
6. created professions and ‘experts’ within the health and welfare sectors of society who administer services and treat the special needs of disabled people (eg. occupational therapists and care managers); and
7. written the ‘authoritative’ literature concerning the nature and treatment of disability (eg. dominated the literature consulted by parents of disabled children, policy makers and the controllers of resources used by disabled people).

2.2 The pervasiveness of the PWA disabling culture

The sum total of PWA hegemony in the control and interpretation of the meaning of disabled people’s lives has been so pervasive that it has penetrated and become fully integrated into the general culture. The clearest evidence of this is the compelling view that changing public attitudes (ie. PWA attitudes) is the most important priority in affecting positive changes in the lives of disabled people. This, of course, contrasts with the **real** need to change disabled people’s attitude that their ‘incapacity’ and dependence on PWAs is a natural component of ‘being disabled’. PWA dominance in the control and interpretation of disability then, in my view, can be characterised as a very important element in supporting a ‘disabling culture’:

- it is a one-sided *ablist* view of what is considered to be, or ought to be, important in the lifestyles of others (eg. it is thought progressive to encourage PWAs to *think of ability not disability* when assisting disabled people, rather than assist disabled people realise their own lifestyles in *their own terms*);

- it emphasises the dependency of disabled people on PWAs (eg. PWAs regularly present themselves with public honours and awards for helping *needy* disabled people, whereas disabled people who have made heroic efforts to oppose and remove segregated facilities, such as Cheshire Homes, remain unrecognised);
- it obscures the dependency of PWAs on disabled people for earning their living and their career development (eg. there is a never-ending demand for more and more health and welfare professionals to *care* for disabled people while the latter remain unemployed or regarded as unemployable);
- it prevents a more imaginative and effective approach to the removal of social and environmental barriers which ‘disable’ people with impairments (eg. scarce resources are diverted to expensive Health Services when more healthy living might actually be achieved by the removal of disabling barriers);
- it encourages the general population to adopt distorted values and aspire to unrealistic goals in their personal and social development (eg. people are esteemed for their body appearance rather than for their behaviour: people cultivate acquisition of material things rather than friendships and close personal relationships).

Because the ‘disabling culture’ is comprehensive and affects all our lives it is possible to pose questions about the ‘biodynamics of disablement’ in this presentation in any number of key areas, such as employment, education, health and welfare, etc. I will however, broadly try to follow my brief in the areas of ‘the recommended ICIDH’, ‘rehabilitation in the community’, ‘researching the special’, and ‘cultural diversity’.

3. The Recommended ICIDH

3.1 Improving communication - in whose terms?

In the new ICIDH draft we are told (page 5):

‘The overall aim of the ICIDH is to provide a unified and standard language to serve as a frame of reference for the “consequences of health conditions” ...’

Since a major criticism of the original ICIDH was that it did not facilitate communication, because the classification was based upon a ‘medical model’ of disability rather than the real life experiences of disabled people (as expressed in the social model of disability), sharing an agreed language for communicating about ‘disability’ is an aim to which most of us would agree. However, developing a language concerned with disablement which is to serve as a frame of reference for the “consequences of **health conditions**” (my emphasis) surely already presumes that ‘disability’ is a health condition! In which case the new ICIDH draft cannot be anything else than a re-wording of the ‘medical’ model of disability in order to include some words from the ‘social’ model and thereby placate the criticism of disabled people. Let us look more closely at the way games are played with words in order to maintain the fundamentals of the medical model of disability in the new ICIDH.

The solution attempted to harmonise the different interpretations of disability within a single classification is rather ingenious. *Firstly*, the different models of disability ‘proposed to explain and classify disablements and functioning’ are acknowledged. This is an improvement on the original ICIDH which did not even mention different models, simply because the dominant medical interpretation was unthinkingly accepted. However, in the new draft the models are conveniently identified simply as the ‘medical’ and ‘social’ models. This is misleading because the contemporary view from disabled academics and researchers

is that it is the ‘individual’ model that actually contrasts with the ‘social’ model of disability (and the medical model is a subclass of the former).

If I may deviate briefly for a moment here, for your reflection at a later time, I would like to suggest that in the reality of providing services to disabled people it is arguable that contrasting the ‘individual’ with the ‘social’ model of disability is also a simplification. In my view we could just as well identify **two** social models which are competing for dominance in our understanding of disability. In the first, the one that historically and in many respects still currently dominates all interpretations of *being disabled* and providing *services*, disabled people are fundamentally seen in various degrees as personally and socially dysfunctional (ie. they are ‘socially dead’). The primary social task, then, is to manage their lives for them. This I have called the ‘administrative model of disability’. However, because the role of managing disabled people’s lives has been predominantly allocated to the medical and paramedical professions their administrative control has been interpreted as falling within a medical model rather than within a special variation of the social model. This can be contrasted with the social model more recently developed by disabled people. In this model disabled people see themselves as a socially oppressed minority group and their lifestyles impeded by the way society, in all its major attributes, is organised for able-bodied living.

Secondly, having ignored any discussion on the diverse models of disability that are currently being raised in ‘disability studies’ the new ICIDH draft then forces the abundance of controversial interpretations into a simplified tension between only **two** models: the medical and social models of disability. With this grand disregard for analysis the ICIDH authors conveniently then go on to say that we can express the

“various models proposed to explain and classify disablements and functioning ... in a dialectic of ‘medical model’ versus ‘social model’.”

With this distortion of the social model and consequent simplification of disablement it is an easy task to assimilate **all** models into medically dominated language concerned with the ‘consequence of health conditions’ (in place of the word ‘health’ in this most significant of phrases, of course, we should read ‘medical’).

Thirdly, common features between the apparently contrasting medical and social models can then readily be identified in an artificial ‘thesis - antithesis opposition’. The purpose of seeing the two contrived models as a ‘dialectic’ of thesis - antithesis opposition is to take the next step in this word game and propose a harmony between the opposing models through a process of ‘synthesis’. This effectively results is a new model of disablement - a ‘biopsychosocial’ model. The new ICIDH draft, then, tries to maintain that the problem of the opposing medical and social models of disability can be solved in

“a harmony of synthesis especially if one tries to capture the integration of the various dimensions of disablement in a ‘biopsychosocial’ approach.”

Leaving aside whether a synthesis ought to be a

biopsychosocial
 psychobiosocial
 psychosocialbio
 sociobiopsycho
 sociopsychobio

approach, in my view the medical and social models (in the ICIDH draft’s interpretation of these models for this word game) are not in fact an opposing dialectic of ‘medical model’

versus 'social model' but merely variations of the *medical* model. Let us look at this more closely:

3.2 Problems - in whose terms?

The 'medical model' is put this way (p.6, my underlining) ...

The *medical model* views the disablement phenomenon as a "personal" problem, directly caused by disease, trauma or health conditions, which requires medical care provided in the form of individual treatment by professionals. Management of disablement is aimed at the person's better adjustment and behaviour change. Health care is viewed as the main issue and at the political level it is health care policy that needs to be modified.

The 'social model' is put this way (p.6, my underlining) ...

The *social model* of disablement, on the other hand, sees the issue mainly as a "societal" problem from the viewpoint of the integration of persons with disabilities into society. Disablement is not an attribute of a person, but a complex collection of conditions many of which are created by the social environment. Hence the management of the problem requires social action and it is the collective responsibility of society to make the environmental modifications necessary for the full participation of people with disabilities into all areas of social life. The issue is, therefore, an attitudinal or ideological one which requires social change, while at the political level it is a question of human rights. Hence the issue is highly political for all intents and purposes

As you will note from my underlining in these quotes both models share the view that disability is about problems. This, of course, has always been an essential characteristic of the medical model. Medical professionals and professionals allied to medicine (PAMs), then, have always seen themselves as problem-solvers in relation to disability and their assessment procedures have been designed to facilitate this approach. The *undistorted* social model of disability, on the other hand, interprets the constraints imposed upon disabled people as a result of 'barriers' to functioning and the issue is the removal of barriers rather than the management of problems. In fact, a characteristic of the social model is that it does not associate disabled people with problems. In taking this stand the social model is differentiated from the *negative* assumptions integral to the individual and administrative models of disability. The ICIDH interpretation of the social model, in my view therefore, is a distortion designed to enable its incorporation into a classification system that otherwise would be quite impossible.

I expect that you will have noted, too, that whereas the description of the medical model makes reference to 'health conditions', thus leaving no schism with the wording of the ICIDH aim (ie. 'consequences of health conditions') the social model described in the above quote has no such reference and consequently can only be made to fit into the ICIDH classification by distorting the model.

The presentation of problems as a common feature in the medical and so-called social models means that no 'synthesis' was needed to accommodate differing interpretations of disability into the ICIDH. On the contrary, the distillation of this common feature ('problems') in apparently opposing models means that we have actually been presented with two versions of the *same* model. This *blurring* of the models to serve the ICIDH aims is taken to its next logical step when we are faced with another important characteristic of the medical model - its concern with the management of the problems created by disability (ie. the 'consequences of health conditions').

3.3 Management - in whose terms?

The ICIDH 'medical model' you will recall included the following (p.6, my underlining) ...

Management of disablement is aimed at the person's better adjustment and behaviour change. ...

The 'social model' included (p.6, my underlining) ...

Hence the management of the problem requires social action ...

Once again, a critical feature of the medical model is also attributed to the new ICIDH version of the social model. 'Management', as disabled people know all too well, is an essential component of the medical model and drives the 'cure or care' approach to the need for continually expanding services. It is precisely this need which creates an extravagant growth in the 'caring' professions, staffed by PWAs, as they administer to the problems a world designed for PWA lifestyles creates for disabled people. It takes no particular aptitude to appreciate that the efficient *management of problems*, conveniently identified by the new ICIDH draft in both the medical and social models of disability, creates the need for a comprehensive classification system. From this point of view, there is absolutely nothing **new** about the new ICIDH draft. Despite the change in language, and recognition of the social model of disability, *ICIDH-2 Beta-1 Draft for Field Trials, June 1997* is just as firmly rooted in the medical model as the original ICIDH version. Its peculiarity is that it has *bent* the social model to fit into the original classification philosophy.

In fact, a social model of disability is not about problems and management - it is about lifestyles. Distorting this model so that it can be accommodated within an aim to provide a unified and standard language to serve as a frame of reference for the 'consequences of health conditions' cannot possibly succeed. We are simply not talking the same language!

4. Rehabilitation in the Community

There are perhaps few people who would disagree that 'rehabilitation', as a time limited approach concerned with the treatment of impairments, may well assist a specific individual gain bodily improvements. In this respect we could agree that the individual and medical models, when applied to 'impairment', can provide an appropriate framework for interventions and that some form of classifying impairments might serve a useful purpose. However, there is also a worrying negative side.

In my view the migration of 'caring interventions' including the rehabilitation philosophy and approach, which is of particular interest to us in this workshop, into the community threatens to *regulate* disabled people's civil rights. By this I mean 'community based rehabilitation' (CBR) brings with it, from its origins in the medical institutional setting, the PWA ideal of not only attaining physical and functional 'normality' but also to be and behave as 'normal' as possible. In this respect the focus of rehabilitation interventions not only readily shifts from 'impairment' to 'disability' and back again, confusing this important distinction, but invariably muddles everyone about the line between an appropriate intervention focused on impairment and an inappropriate pressure on disabled people and their supporters to regulate (or *manage*) their aspirations in accord with medical concerns (or *problems*), values and policies. We are encouraged, for example, to use and highly value the PWA mobility (*walking*) aid, **shoes**, while disabled people's mobility aid, **wheelchairs**, are negatively valued.

It is the innocent adoption of these values and policies that fertilises campaigns to put pressure on governments for an ever-expanding increase in 'cure and care' interventions (ie.

variations of rehabilitation, para-medical therapy and medical treatments ‘in the form of individual treatment by professionals’). The fact that CBR workers do not have to be ‘professionals’, should not obscure their role in promoting the same disabling attitudes and ideology that confuses ‘impairment’ with ‘disability’ and equates ‘medical care’ with ‘health care’ (as can be seen in the interchangeable use of these terms in the ICIDH draft document outline of the medical model quoted above). The movement of rehabilitation into the community, quite independent of the community based services actually being created by disabled people, is part of the same PWA highly political and persistent promotion of an expanding medical intervention in *health care* that is draining health and welfare resources into a bottomless pit. The development of the ICIDH can be viewed as part of this process and characterised as an important political instrument in the medicalisation of disability as a ‘complex collection of conditions’ (ie. problems) to be managed in the well-established manner by PWAs rather than as unique lifestyles that require unprecedented, original and creative support systems.

It is perhaps no accident that the highly *political* demand for a continually expanding health and medical service consistent with the medical model is attributed to the social model (in the ICIDH draft) and projected into the ideological aims of disabled people trying to create their own natural services and professions. Of course, political concerns are raised by disabled people when the re-direction of resources away from health and welfare approaches are canvassed to replace what are considered to be traditional and unworkable forms of intervention. The **real** problem to be managed in modern times is that traditional PWA ways for servicing disabled people’s needs are so well established that any opposition appears to contradict the obvious and natural and therefore seems to be highly political.

In practice the politics of the medical model, then, involves an increasing insertion of specialist workers into the community (eg. CBR workers) who instinctively promote the view that disability consist of a complex series of personal and social **problems** that need to be **managed**. When rehabilitation workers and parents place a high priority on this PWA cultural view of ‘disability’ there will be little opportunity for the advantages of a disability lifestyle and culture to emerge. In these circumstances

- (a) the construction of an accessible environment cannot become *the* priority,
- (b) disabled people may well *regulate* their own behaviour so that personal aspirations are reduced to fit in with PWA expectations of what is appropriate, and
- (c) the demand for civil rights, as independently defined by disabled people, is then also likely to be interpreted as a quite separate issue to that of managing the problems of ‘disability’ in the community.

For example, PWA mobility aids such as shoes, motor cars, aeroplanes, ships, elevators, roads, sidewalks, steps and staircases, trains, carpets, etc., etc., are all seen as attractive personal possessions or desirable environmental adaptations. None are defined as *assistive devices*. None are defined as meeting *special needs* and, while all may contribute to healthy living, none are legitimately prescribed by medical professionals or PAMs. Such mobility aids have evolved over time as PWAs imposed their own lifestyle aspirations on the natural world. The workers who enable the provision of such aids are neither health nor welfare personnel, although they do indeed contribute to the health and wellbeing of the general population. Access to these mobility aids is an integral part of civil rights and it would be absurd to suggest that these aids should be prescribed in a rehabilitation programme, guided by a ‘medical model of ability’, to assist people to become *able* in the community. For this reason *fashion* may guide the design and choice of an aid or adaptation even if there are negative health and medical implications in what is chosen. A good example is the way PWAs often select their shoes for appearance rather than comfort and anatomical support.

Despite the fact that there is no difference in disabled people's right and need to impress their own lifestyle on the structure of society to that of PWAs our aspirations are narrowly placed in the context of 'consequences of health conditions' and seen in terms of 'societal problems'. What should be a natural process of integrating aids and adaptations required by disabled people into the material and cultural fabric of society is artificially attributed by PWAs to the responsibility of a specialist community-based rehabilitation service. In a CBR centre wheelchairs are hardly likely to be chosen on a basis of fashion! In the prevailing disabling culture wheelchairs are 'chairs with wheels on' and seen as 'assistive devices' used by those who sit because they cannot walk - wheelchairs are provided to compensate for an inability to walk.

5. Researching the Special

The way in which common human needs are satisfied has a very precise impact on the configuration of society. Transforming disabled people's needs into a special set of **problems** means that the satisfaction of this group's needs will also be translated into a special check-list of interventions. It is the **management** of these interventions that has had a lasting impact on the structure of society. This, I believe, can be identified in the way interventions to meet disabled people's needs have been systematically diverted into the welfare and rehabilitation services (and more recently the CBR services). In this context, 'CBR' can be interpreted as a particularly muddled service approach to disabled people's medical, welfare and general lifestyle needs. Its main characteristic is that disabled people's lifestyle needs are segregated from, and treated separately to, the general population's lifestyle needs. Consequently, our support systems are viewed as quite separate from PWA 'public' (or 'normal') support systems.

PWA research feeding CBR services, then, paints support systems to maintain disabled people's lifestyles with a welfare-coloured ethos (currently promoted as 'care in the community') and carefully segregates this from the support systems needed to maintain the general population's lifestyles. It is logical, once 'disability' is construed as involving an exclusive set of **problems** to be **managed** by specialist health and welfare workers, for PWA dominated research in this area to take a unique form and become the preserve of a select group of researchers. They are then free to apply research methods from well-established PWA disciplines to an *artificial* 'disability' enclave in health and welfare service provision. Behind this boundary rehabilitation research has been able to flourish free from the criticism of disabled people and those who do not see 'disability' in terms of 'consequences of health conditions'. Because of the absence of disabled researchers rehabilitation research has also been free from their control over its nature and direction. This contrasts with research into public support systems which has a direct PWA input into research that directly affects their own lifestyles.

Until the recent emergence of *disability studies* created by disabled academics and researchers it has been all but impossible to challenge the inappropriateness of PWA disability-related research and to suggest alternative methods.

PWA dominated research concerned with rehabilitation has been 'problem' orientated, with a primary focus on managing an individual's return to PWA defined 'normality' with the aid of assistive devices which compensate for inadequacy. The modern approach to research developed by disabled academics, however, is concerned with the lifestyle aspirations of disabled people and has an *emancipatory* objective. It is emancipatory because it aims to remove the systematic apartheid imposed on all aspects of disabled people's lifestyles. This challenge to the endemic disability apartheid means that emancipatory research also has to

integrate the involvement of disabled people in the control and nature of any research that affects their own lifestyles. This is not the place to elaborate on ‘emancipatory research’ but what I will say is that its final objective is the construction of emancipatory rather than *caring* services. Such services are the logical outcome of the social model of disability and stand in contrast to PWA derived administrative approaches integral to the health and welfare services. (For more discussion on emancipatory research see **BARNES, C. and MERCER, G.** (1997) *Doing Disability Research*. Leeds, UK: The Disability Press.)

Disabled people did not invent CBR; it would have been an extraordinary contradiction of our life experiences if we had spontaneously adopted this PWA orientation to intervention in our own lifestyles. Cultivating the growth of CBR, through research consistent with the important ICIDH objective of better management of disability-related problems, is bound to clash with disabled people’s fundamental aspiration for the removal of the prevailing cultural view that disabled people invariably require **special** assistance for **special** needs. This emphasis on the **special** in all matters pertaining to disabled people’s lifestyles not only locates our services behind a boundary but limits creative thinking about disability and ties down scarce resources in a flawed attempt to make us appear, behave and aspire to be as ‘normal’ as possible. From this critical viewpoint it is quite futile focusing research on the development needs of CBR services. On the contrary, what is needed is emancipatory research which locates ‘disability’ within mainstream social issues that constrain the aspirations of all people in realising their basic human needs and rights.

This requires research that is firmly rooted in the promotion of cultural diversity.

6. Cultural Diversity

In my view there is a clear communication barrier between the advocates of the ICIDH (and promoters of other special forms of intervention in the lives of disabled people), and those who see no need to maintain that disability requires special interventions separate from the public support systems that non-disabled people have created in meeting their ‘normal’ aspirations. In other words, the creation of a healthy *human* environment requires the impact of all population groups on the structure of society and the public utilities that can be accessed by anyone.

Accepting the notion that all societies include diverse population groups and encompass diverse cultural lifestyles not only faces the reality of ‘multi-cultural’ societies but enables cross-cultural fertilisation of needs and ideas in a way that can only have positive effects on all our lives. If making the environment accessible to disabled people is acknowledged as more often than not also ‘better’ for non-disabled people then moulding the support systems according to disabled people’s aspirations should also be to the advantage of PWAs. Emancipatory research that is relevant for disabled people should also have emancipatory implications for non-disabled people.

Sadly, history teaches us that despite the criticisms of disabled leaders, researchers and academics PWAs in the welfare, medical and allied professions (PAMs) will continue to view disability as a concern involving the management of problems separate from mainstream support systems. In this context as long as disabled people’s involvement in all aspects of their own emancipation is not recognised and actively supported the special care of disabled people in the community will continue to be seen as a necessary, but expensive, social burden. This will inevitably see disabled people responding to their health and welfare needs with their own concepts and services in parallel with that provided by PWAs:

- Alongside the administrative, individual and medical models of disability we have already seen the emergence of the social and emancipatory models
- While PWAs have created care in the community and community based rehabilitation services disabled people have created centres for independent/integrated living services
- ‘Objective’ quantitative (‘scientific’) research and ICIDH labelling have been challenged by the development of emancipatory research
- And now we can expect that the caring professions will be increasingly rejected as the services created by disabled people require a new kind of supportive or emancipatory profession.

Becoming a disabled person is neither positive nor negative. It takes hard work to overcome the PWA prejudices that make us want to curtail our aspirations according to PWA perspectives, avoid asserting our identity in preference for PWA body fantasies and suppress our cultural development in favour of PWA dominance.

END