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## Opinion

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### A JUST SOCIETY INCLUSIVE OF 'PEOPLE WITH DISABILITIES'

Peter Gibilisco

It is disheartening, to say the least, when I can still pick up a book or read a call for unity to fight for social justice which omits or does not give equal weight to the disability social movement against oppression (Russell 2002: 1).

A hegemonic power struggle is faced by 'people with disabilities' who are oppressed by a society where ableism is the norm. Society places degrading hardships upon 'people with disabilities', acting as a barrier against their reaching their full potential; and a culture of silence perpetuates their oppression. As Jacobs (2002:60) writes:

The oppressive and alienating consciousness exhausts the critical powers and vivacity necessary for a person to respond to their circumstances. The social outcast, as it were, remains fixed in this bind since they lack the vital resources, motivation and vocabulary to expose and articulate their oppression.

In an email sent on 09/06/03 to the students at the Department of Disability Studies at Leeds University in the UK Colin Revell, who is a 'disabled people's' grassroots human rights activist, campaigner and educator, refers to the problems faced by trying to effect political changes because 'many grassroots disabled people live on the breadline each day and only just survive to meet their basic needs daily and they are unable to become politically conscious due to their social and economic exclusion'.

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\* I would like to pay tribute to two outstanding friends Tim Marjoribanks and Hugh Stretton for helping me to complete this article.

In 2003, *Disabled Peoples International*, according to the International Classification of Functioning (ICF), defines disability 'as the outcome of the interaction between a person with an impairment and the environmental and attitudinal barriers he/she may face'. Some analysts believe that levels of exclusion can be translated into a function of capability (Sen 1999, Zarb 1995). Most of these exclusionary factors are created by society in general and its preoccupation with ableist or likeminded social norms. The functional restrictions faced by 'people with disabilities' are imposed by human distortions of capabilities and opportunities, exacerbated by prejudice, discrimination, inaccessible environments and inadequate support (Crow 1996).

My analysis of these issues has been influenced by the arguments of Marta Russell concerning the political economy of 'people with disabilities'. Her experience and writing adds both pragmatic and theoretically informed insights. Russell has been disabled from birth. She began writing as her disease (Cerebral-Palsy) progressed. She worked in the film industry, focusing on the social and economic aspects of disability. As a producer and photographer, her investigative reporting earned her a Golden Mike Award for Best Documentary from the Southern California Radio and Television News Association in 1995. At the same time Russell has raised a daughter. Her experiences have no doubt aided her in developing an informed and critical analyses of disability policy (Russell 1998).

The 1970s brought the rise of the social model for 'people with disabilities'. This model promoted the use of their personal experience of disability and institutional life to show that it wasn't their impairments which caused the problem, but the way society has failed to make allowances for their differences and shut most 'people with disabilities' away from mainstream society. It sees the problem as the result of any social behaviour or barriers which prevent people with impairments choosing to take part in ordinary life and society (Ideas in Motion 1995). It therefore focuses attention on those aspects of their lives that need changing.

The conservative medical model of 'people with disabilities' assumes that full participation in society for 'people with disabilities' is only to be found through a medical cure, or fortitude. The medical model can be

seen as a main reason why societies that acknowledge the importance of breaking down the barriers facing 'people with disabilities' have nevertheless found it so hard to dismantle them (Crow 1996:58). It is important to understand how this medical model is challenged by the social model. That is the purpose of this short article, leading into the development of a social democratic position on 'people with disabilities'.

### **The Medical Model**

The exclusionary role born out of the medical model for 'people with disabilities' is highlighted by its historically presumed method of medical care. Medical care was firstly acknowledged as a responsibility of the extended family. However, with the increasing professionalisation of medicine, care came to be mainly performed by medical practitioners and hospitals. According to Harrison (2000:160), hospitals were originally institutions of charity that were able to supply medical care to the poor, free of charge. However, Harrison (2000:160) argues that under medical supervision care for the poor was replaced by care for the sick. Therefore 'the sick received free care and hence the clinicians enjoyed more the righteous role of supplying medical treatment to the sick (or unable) free of charge, rather than supplying it (medical treatment) to the poor (or unworthy)' (Harrison 2000:1660).

The biomedical model of 'people with disabilities' focuses on people's impairments rather than their qualities (Zarb 1995). Traditionally, care for a person with disabilities was found within the extended family, and such care was usually provided by the female family members. The carer in most circumstances was described as a martyr or saint, and the person with the disability usually seen as their dependant, under their family or professional control. It is disempowering for many 'people with disabilities' to be treated as care recipients instead of citizens (Harrison 2000:160-161).

The doctor-patient relationship highlights the power imbalance of the medical model, as the doctors' interests do not always lead them to act in the best interests of 'people with disabilities'. Joe Harrison (2000:161) reported a personal example. The event took place during the costly but

mundane medical procedure known as electro cardiogram – basically, you are plugged into a machine that can measure your heart beats. When Harrison happened to have a major convulsion midway during the procedure '(t)he doctor chose to record the seizure rather than assist me, to increase his understanding of my seizure pattern'. The medical model provides for a system where the needs of 'people with disabilities' are not always a priority (Barnes 1996). Pfeiffer (1993: 16) acknowledges another example:

in June 1989 a minister in Washington, DC, who has epilepsy, had a seizure on his way home from work. He was taken to the hospital in an ambulance and when he awoke he got out of bed. Three hospital security guards forced him back into bed and strapped him down. When he protested and demanded to see a physician, he was gagged with a surgical mask. The medical staff at the hospital informed him that, since persons with epilepsy were dangerous, he was being forcibly restrained.

Clear (2000) and Priestly (2001) are among many who argue that 'people with disabilities' are a socially excluded minority that is politically marginalized. For many 'people with disabilities' there is no known medical cure or treatment. To create a just society for all we must therefore alleviate and phase out any forms of social exclusion that hinder the fulfillment of impaired people's lives and citizenship.

In his alignment with the medical model of 'people with disabilities', Harris (2000:102) from the British Medical Association argues that 'there is no reasonable sense in which defining disability in terms of harmed conditions discriminates against the disabled and there is no evidence to suggest that disabled people prefer a social model'. He then impugns their motives as self-centered: 'People with irremediable disabilities of course prefer a "social model" because the medical model is of no further use to them. They want to operate on things that can be changed, not on things that can't be changed'. So indeed do all social democratic supporters of the social model, and of a just society.

I personally am a 41 year old sufferer of a severe disability (Friedreich's Ataxia) that at present cannot be cured. It is my belief, and the belief of many academics, such as Sen (1999), Priestly (2001) and Russell

(2000a), that most capabilities and activities pertain to many norms that arise outside the medical model, but usually within the social model of 'people with disabilities'. Harris above has identified the medical model with all medical procedures. I am sure that there are medical procedures in the daily lives of most 'people with severe, incurable disabilities', but that does not reduce the importance of their social opportunities.

### **The Social Model**

The social model concerning 'people with disabilities' was starting to become influential over twenty years ago, both within the disabled persons movement and as an influential driver in social policy for 'people with disabilities'. For example, when analyzing mobility impairments the social model asks why the environment is inaccessible and how it could be changed to accommodate 'people with disabilities' (Barnes 1996; Zarb 1995). Brian Howe, formerly the Deputy Prime Minister of Australia 1992-95, understands the social model as taking a social approach towards 'people with disabilities':

That emphasizes the capacity of people to relate to others, and to develop their capacities in response to their attitudes to society, as well as societal attitudes towards them. The development of 'people with disabilities' is largely influenced by societal expectations. This is obvious if you think of the changes that have taken place in recent decades (Howe, 2003).

Nobody can deny the sincere empathy and compassion of the collective public contribution of social security benefits to 'people with disabilities'. However, the social model is developed partly to move beyond this paradigm. Like its namesake, the social model is a strand of social science, prompting us to continually appraise the means in order to foster satisfying ends. This is not to deny the need for adequate social security for 'people with disabilities'. The social model recognizes that 'people with disabilities' face many barriers to fulfilling social, cultural and economic lives. As with poverty in many cases, the solutions are more than merely economic. But the economic barriers can be substantial. Living at low levels of subsistence is an unfortunate reality

for many 'people with disabilities', ruling out many of the activities that lift the spirit and encourage self-esteem.

Sarah Supple, a lady I interviewed via the Internet, is 26 years old and was registered blind at 21. Sarah is currently studying for her Doctorate in psychotherapeutic and counseling psychology at Surrey in England. She points out that '[t]he social model is pursuant of society's general understanding of 'people with disabilities', but we will still encounter restrictions, concerning choice and opportunities, both through physical barriers and social exclusion' (Supple 2003).

The social model has raised an element of confusion in some recent debates about its supposed limitations. Critics of its treatment of relations between impairment and disability believe it to have created a false doctrinaire approach concerning impairment in terms of pain, illness, depression, fatigue and so on (Barnes 1996). When disabilities arise from the way society treats physically impaired people, there are two truths which are not necessarily contradictory. The disability would be less if the social barriers did not exist. It would also be less if there was no impairment (Stretton 2003). Any medical reduction of the impairment is good. Any reduction of the social barriers is good. Why need the debaters disagree?

I believe this example highlights the paradox that may prevail when we have too much of one model and not enough of the other. For example, sometime ago *circa* 1987, a friend of mine with Friedreich's Ataxia (the same disease I have) was to be married to the guy of her dreams (an able-bodied individual). However, as she signed the register, she got a bit too excited, had a heart attack and died. The wedding was a beautiful moment, and the embodiment of the social model. In hindsight, however, what should have been done to prevent the heart attack remains the domain of the medical model. In other words, it is the interaction of the medical and social models that is important.

Critics of the medical model accuse it of diverting attention from the social barriers, and encouraging the belief that the impairment is the main or only cause of the disability. Some critics of the social model think it exaggerates some impaired people's capacity for social and economic activity: the medical barriers are such that the social barriers

don't add much to the sufferers' deprivation. Between those views it is possible to disagree about the weight of causation in particular cases, and about the practical possibilities of social reform (Stretton 2003). But none of these problems of judgment, which can vary from case to case, should discredit the social model or excuse a belief in the medical model alone.

In his introduction to the book *Promises Promises*, Clear (2000) discusses the social approach to disability which sees impairment as not being necessarily tragic, though in practice it often is so. Impairment can be seen as a function of human diversity, but it can bring systematic discrimination and exclusion from mainstream society. Clear (2000) argues that the trouble is therefore in *the disabling society*. The lives of people labeled as impaired or disabled have the same value as people who live without those labels. Whilst there are instances where impairment is directly responsible for pain and discomfort, what really disables is the socio-cultural system that does not recognize everyone's right to equal treatment throughout the life course (Wolbring 2001:47). Pfeiffer (1993: 31) states:

The problem is seen as one that exists in the environment, such as the attitudinal, architectural, sensory, and economic barriers faced by persons with disabilities. Often the problem is further defined as overdependence on professionals and others, as well as inadequate support services to overcome these barriers. The solution is seen to be (generally) self-advocacy, system advocacy, removal of barriers, and control by the disabled person, who decides what is his/her desired outcome.

Newell (1999:172) quotes Alison Davis:

If I lived in a society where being in a wheelchair was no more remarkable than wearing glasses and if the community was completely accepting and accessible, my disability would be an inconvenience and not much more than that. It is society which handicaps me, far more seriously and completely than the fact that I have spina bifida.

The medical model has traditionally placed many other stereotypes, stigma and disutilities upon me and many 'people with disabilities'. For

example, I have been pitied, conveniently verbally misunderstood, looked down on for my abnormal structure and characteristics, characterized as a loser. Over the years I have come to understand most people's roles in the barriers to social inclusion as due to their lack of accessible information about disability. If, according to the medical model, such problems are a reflection of my severe disability, what would be the best model to explain the progress of my PhD in Sociology, which I plan to submit early in 2004?

Stretton (2003) points out that the essential factor is the correct balance, a major contributor to a happy and justified life. It is an essential undertaking to try and maintain the correct balance for success and happiness in all of life's pursuits. The correct balance will assist 'people with disabilities' make necessary strategic choices, about how and what to prioritize in life. They must construct their lives around what they can do, not what they cannot. For example, today within the higher education stratum I feel appreciated, and to some degree this has a flow-on effect to other aspects of my life. Hence, you should enjoy what you do, and maybe from there you can develop whatever needs developing.

However, to succeed in today's society most actions by 'people with disabilities' need the adequate collective assistance of the state. And only on rare occasions are such collective state empowered actions driven solely by either the social or the medical model of 'people with disabilities'. We are humans and are therefore too complex to have adequate action sustained by one political approach or paradigm (Stretton 2003).

### **A Social Democratic Model of 'People with Disabilities'**

Social democracy should endeavor to represent all sections of our society and especially to encourage the protection of its disadvantaged groups. Society today is structured differently from the post-war Keynesian period that provided the golden years of capitalism and the provision of welfare (Skidelsky 1996; Stretton 1999). Government assisted welfare for the first time gave individual social empowerment to some members of minorities that they could use as a vehicle for further development



(Harris 1997). That allowed some minority groups, including 'people with disabilities', to express and create independence. Today we live in a society of difference, in which 'people with disabilities' have moved from the political margins to the mainstream (Priestly 2001). However, Gleeson (1997:202) argues that there has recently been a political paradigm shift towards postmodernism and 'new right' theory, linked to a fear and understanding of what globalization may offer or enforce. Most neo-liberal strategies tend to weaken policies based on the principle of social justice by endeavoring to 'reform' them and reallocate their funding, believing them to be nothing more than a hindrance to the outcomes devised by economic freedom (Lane 1991; Balogh 1982).

Neo-liberalism, broadly speaking, prescribes an environment in which business people would find adjusting a job to suit the capacities of a disabled worker an unjustified impediment to profit making (Russell 2000a). It is incompatible with the goal of empowering 'people with disabilities' to enjoy equal access to the same fundamental civil and human rights as the non-disabled population (Clear 2000). As Russell argues:

In an era where both [political] parties have become worshipers of the market and are owned by investors and corporations, the matter has become bipartisan. Neo-liberal and Third Way politics both replace redistributive goals with a market approach catering to business class needs and both adopt the supply-side theory that the economy is burdened by overly-generous welfare provisions which give too much security to workers (Russell 2001: 12).

Social democratic policy, much like the social model of 'people with disabilities,' would endeavor:

- to provide support that will enable 'people with disabilities' to play as full a role in society as possible;
- to facilitate the empowerment and liberate and foster the self esteem of 'people with disabilities';
- to persuade all members of society that 'people with disabilities' are people with rights, hopes, aspirations and feelings;

- to hasten the creation of an equal society in which 'people with disabilities' do not have to fight for their rights, but instead are accepted for who they are, and are allowed to perform real and meaningful roles in society; and
- to endeavor to change negative attitudes regarding 'people with disabilities' (Social Democratic Labour Party - Ireland 1999).

According to Gleeson (2001: 51):

Reflexivity will redefine the 'intermediate' public spaces – the spaces of circulation, for example – whose democratic qualities have long been neglected. Those 'urban technologies' that attempt to make cities inclusive and accessible would no longer be derided as threats to efficiency or even heritage. Rather, the physical markers of inclusion, manifest in city form and function, will be celebrated as referents of social heterogeneity - of embodiment and social identity. The sheer pervasiveness of difference ... will defuse the border-drawing instinct and set the scene for new codes of social belonging.

Social democrats understand that social security benefits will continue as the main source of income for a significant number of 'people with disabilities', even when most forms of discrimination are vanquished. However, 'people with disabilities' are human, and they require benefits because of age, because of their inability to find work, or sometimes due to the nature of their disability. It would be wrong to force such people into poverty, or a lifetime of frugality and despair, as a consequence of their functional restrictions (impairments). They need a benefit system which neither forces them into jobs for which they are ill-equipped nor penalizes them for undertaking voluntary, community or part-time work. As Russell (2000b) points out, because illness (as separate from impairment) can make it impossible for some to work for pay with reasonable accommodation or to sustain a job, those individuals must have a government entitlement to an adequate standard of living which rises with increases in the wealth and productivity of society.

Social democrats acknowledge that success can only be measured over time by the proportion of 'people with disabilities' who are successfully in employment. Nevertheless, social democrats are concerned that

'people with disabilities' are being required to attend job placement interviews or risk losing their benefit entitlements. That imposes a further form of discrimination upon people who may already feel isolated or discriminated against. They seem to be asked 'how do we know you're honest?' rather than 'can we help you to find work?', for example.' When it comes to 'people with disabilities', should mutual obligation be part of the rule for issuing benefits?

### **A Just Society for 'People with Disabilities'**

Raynor (1998) believes that justice within a community requires that privileges have to be earned, and can be challenged. It is transparent within a city where 'people with disabilities' and their carers get the support they need from the community because they need it, not because they can pay for it. Therefore, a just society is one whose citizens believe that some or most forms of deprivation are avoidable. A just community does not assume that everyone has the same opportunity to demonstrate what they are capable of. Instead it ensures that they are given every opportunity to do so. As Raynor (2000) argues, 'it is a community with a moral net of interdependency'.

Currently western moral philosophers think of justice as having two principal dimensions – procedural and substantive. Procedural justice deals with the legal implications, i.e. the justice of equal treatment in the eyes of the law. Substantive justice refers to the justice of society concerning itself with the the distributional effects of the social process, not just the fairness of procedures. 'It is substantive justice that has traditionally been taken to mean social justice: a concern for the the distribution of society's benefits and burdens' (Gleeson 1997:202). As Raynor (1998: 20) put it to the 'Ace Networking Conference' in Adelaide:

The essential value of a civil society is what Ronald Dworkin calls equal concern and respect for persons. According to this principle we must treat people as human beings who are capable of forming and acting on intelligent conceptions of how their lives should be lived, treating other people as worthy in their own right, not as a means to meeting our own needs and desires.

Gleeson (1997:199) argues that for many years in western society 'people with disabilities' have been disadvantaged by societal norms, and by the way such norms harvest discrimination. However, Gleeson (2001:151-152) acknowledges that society has made some progress in the elimination of barriers to physical accessibility for many 'people with disabilities'. That helps to create an *enabling environment*. But the ethos of free-market capitalism remains a formidable hindrance to equal opportunity. Gleeson (1997:200) argues that most 'people with disabilities' suffer from economic marginalization, given the automatic devaluation of their labour power in capitalist production. Russell (2002: 7) identifies normality thus:

The concept of inferiority is rooted in the late 19th century social creation of 'normality.' 'The normal' was used as a means of measuring, categorizing, and managing populations. It informed hegemony, ranking order by the directive of the constructed 'norm.' In turn, normality established the universal, unequivocal good and right from which social, economic, and political rights were granted – rights being a means in liberal democratic societies of mitigating oppression.

In her speech on 'A Just Society', Moira Raynor argued that claims of a 'just society' by politicians are dealt with skeptically by the public. They are told that our priorities should be the economic fundamentals behind global competitiveness. Hence, to be an effective part of society, one must be efficient. To be competitive in a world economy, one must dismantle barriers to competition, such as regulated working hours and special programs for disadvantaged groups. If those who cannot compete fall by the wayside, it will nonetheless be for the betterment of all. In Russell's (2000a: 5) opinion:

The emerging market economy meant that disabled people who were perceived to be of no use to the competitive profit cycle would be excluded from work. There was no room under market tyranny to accommodate disability by providing work schedules or adjusting jobs to fit disabled people's needs.

It must follow that 'people with disabilities' are perceived as not capable of working at all. Most will therefore be excluded from the workforce, driven into poverty, and eventually institutionalized.

Social justice today, by contrast, should be about distributive justice. It must promise freedom from oppression, and must meet any material needs that may arise from social qualities such as gender, race, disability, and so on. That will enable all individuals and collectives to ensure that their basic needs will be fulfilled. Gleeson (1997:206) believes these needs have two dimensions:

- material satisfaction (eg. food, clothing, etc.); and
- social participation (ie. non-exclusion on the basis of social quality).

It follows that material inequality and social exclusion are the antitheses of social justice.

### **Conclusion**

'People with disabilities' are widely acknowledged to have fewer opportunities and a lower quality of life than non-disabled people. Hence, the actions taken to deal with or remove the disadvantage experienced by 'people with disabilities' depend on what is believed to be the cause of the disadvantage.

The experience of disability is usually presented in the context of the medical implications it is recognized to have, and viewed primarily as a particular set of physical or intellectual dysfunctions. In this way the myth is perpetuated that 'people with disabilities' require medical supervision as a permanent factor in their lives.

In recent years some improvement for 'people with disabilities' has been brought about by the coming of the social model of disability and by 'emancipatory' disability research. The medical model of disability sees a disability as a diagnosable set of symptoms which either have to be alleviated or might entail the isolation of the person from wider society. The social model of disability views the physical or mental impairment as being a fact of life, and believes the attitudes and prejudices about it

are compounded by a lack of accessible and socially rewarding information. Social democracy understands and accepts the social model, as reflecting its own philosophy for a just society. That philosophy deserves to prevail, and to consign the less enlightened political processes of the medical model to history.

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