

## **Challenges from Disabled People**

### **Emma Stone**

From the Solomon Islands to Sweden, disabled people have been organising and campaigning for equal rights and citizenship. Local, national and international organisations controlled by disabled people lead the struggle to make the world a less disabling place. From the Organisation for Revolutionary Disabled in Nicaragua to Greater Manchester Coalition of Disabled People in Britain, disabled people are pushing for change. Change in the way that disabled people are viewed and treated by non-disabled people. And, fundamentally, change in the way that societies (labour markets, services, cultures) operate.

At the heart of the struggle is the social model of disability, which takes the "problem" of disabled people out of the individual and into society. From a social model standpoint, it is time to stop pitying disabled people as victims. It is time to uphold disabled people's rights as citizens.

There is a long way to go before disabled people's vision of a less disabling world is realised. As with any struggle for civil rights, there are vested interests and obstacles to change. Service providers, professionals, charities and development organisations - no matter how well meaning - have often been seen as part of the problem (i.e. a barrier to rights) rather than part of the solution.

In this section of the book, Vic Finkelstein and Rachel Hurst challenge professionals and development organisations to do things differently: to take the lead from disabled people and their organisations about ways of working and ways of bringing about real social change.

### **OVERVIEW OF CONTRIBUTIONS**

*A Profession Allied to the Community: The Disabled People's Trade Union*

Vic Finkelstein has long been involved as an activist in disabled people's organisations and as a theorist in the field of disability studies. Here, Finkelstein offers a short but powerful critique of "professions allied to medicine" and

welfarist notions of service. Finkelstein puts the case for PACs: Professions Allied to the Community. Finally, he warns of the danger inherent when minority world professions and professional ideologies (rooted in a culture of care, cure and expertise) migrate or are transferred to majority world contexts.

### *Disabled People's Organisations and Development: Strategies for Change*

Rachel Hurst, Director of Disability Awareness in Action, also writes as a disabled person with a long record of activism in local, national and international organisations of disabled people. Hurst sets out the importance of learning from disabled people's organisations - about disability, social development and rights-based change. Hurst challenges development funders to invest more resources in building the capacity of disabled people's organisations. She also challenges development organisations to put their own houses in order, and to ensure the inclusion of disabled people in all aspects of social development work.

## **DISCUSSION POINTS**

- Do you agree with the notion of an "international disability movement"? Why, or why not?
- Do you think that the social model of disability is relevant in the majority world, or just in the minority world? Why, or why not?
- What would you list as the key characteristics of PACs - Professionals Allied to the Community?
- Can you give examples of minority world (western) ideologies, practices or definitions that have been transferred to majority world countries? How are they transferred? Are such transfers always wrong? Who decides and how?
- What can those involved in social development learn from disabled people's organisations and their strategies?
- What action should development organisations take to ensure the inclusion of disabled people and disability issues in social development work?
- Do you agree or disagree with the statement that disability is a human rights issue, and a development issue? Why?
- Do you agree or disagree with the view that all development projects should take disability on board in ways similar to being "gender aware" or "child focused"?

## **A Profession Allied to the Community: The disabled people's trade union**

**Vic Finkelstein**

(Chapter 2 in Stone, E. (ed.) 1999: Disability and Development: Learning from action and research on disability in the majority world, Leeds: The Disability Press pp. 21–24).

### **A HISTORICAL PERSPECTIVE**

Human beings, by nature, structure their social relationships in order to assist each other to attain the necessities of life and to enhance the quality of their lifestyles. During the historical development of societies, this has taken many forms, with different groups at different times dominating the shape, meaning and accessibility of social assistance.

This process has embraced the design and provision of helping, or assistive, devices. For example, the invention of the printing press is an assistive device (a special aid) for "the sighted" to exchange information. The growing importance of this invention and proliferation of printed material, however, and the inability or unwillingness of sighted people with abilities to recognise the legitimacy of equivalent forms of information exchange for people with visual impairments, provides a critical context for defining the social meaning of "blindness" and excluding this particular group from the facilities and mainstream events of society.

Control over the shaping and reshaping of social assistance has not only enabled specific social groups to dominate others, but has also enabled them to define what is "normal" and, in so doing, label all assistance required by other groups as "special" and "compensatory". Consequently, people with abilities have come to see access to their forms of assistance as an essential aspect of a normal lifestyle. Deviations from this ability, then, are not only seen as tragic, requiring interventions which aim at "curing" or "caring", but have added a "vulnerable" label to the social invention of non-normal individuals. Where there is not as yet an effective cure, and the provision of care threatens to become a curtailing burden on their own lifestyles, people with abilities have sought to shape the deviant and vulnerable as much as possible in their own image of normality.

## **PROFESSIONS ALLIED TO MEDICINE**

It is in this context that people with abilities have invented exclusive professions to cure the deviant, care for the vulnerable and to control perception of appropriate human attributes and desirable personal and social environments. The result is a National Health Service dominated by professions allied to medicine (PAM s) who work in cure or care services and Social Services dominated by a culture of welfare provision for the "vulnerable". Around this development, people with abilities have created an elaborate "normative" language and culture. This is the language of the health and community care services. In this language, disabled people are seen as having "special needs" that require special expertise; while people with abilities remain totally unaware that the roads, public transport, telephones, television, retail shops, restaurants, etc., created by themselves for themselves, are also examples of special assistive devices and services.

## **PROFESSIONS ALLIED TO THE COMMUNITY**

The growth of the world-wide disability movement has shaken this comfortable cultural dominance. Disabled people in organisations of disabled people (our vehicles for change) have begun to express their human nature by re-defining themselves and inventing their own forms of assistance in this image. In so doing, disabled people have begun a process of engaging in the transformation of the disabling society. There are three things to say about this development for our relationship to the majority world.

- First, the development of our own approaches to assistance not only requires an unpacking of the version imposed on us by people with abilities, but the creation of our own "normal" forms of assistance. Our constructing of systematic forms of help according to our own social model of disability will generate new services and service providers - professions allied to the community (PAC s). I believe that these workers will constitute our own trade union. It is these trade unionists, truly immersed in a disability culture, who will be a vital engine for social change. They will have a crucial role in promoting the national and international criticism of the dominant health and community care ideology that is not wanted by disabled people.
- Secondly, we can be sure that the elaborate culture, language, policies of medicalising health (seeking to "cure" disability), community care policies, community-based variations of rehabilitation, and obsession with

assessing and labelling us (such as the latest World Health Organization's ICDH-2: International Classification of Impairments, Activities and Participation) will be vigorously defended by people with abilities whose careers are shaped within the framework of able-bodied chauvinism. As the struggles of disabled people to create a barrier-free world according to our own image of human functioning advances, we can expect the PAMs and welfare workers' defence of their philosophy (based on the individual and administrative models of disability), and the associated expertise, to be exported to places where they are less likely to be challenged.

- Thirdly, the migration of the cure or care culture and expertise (e.g. as in the "community-based rehabilitation" ideology and the WHO ICDH) are important tools for advancing the able-bodied work ethic of the minority world to the majority world. Maintaining that the marginalisation of disabled people is due to our personal inadequacies (our disabilities) sustains the view that the disabling society is not responsible for creating the barriers that impoverish us. Providing PAMs and welfare workers for our special needs enables the disabling societies of the minority world to further their control of the international economy - free of criticism from the majority world whose established supportive social relationships are being dismantled.

## **FURTHER READING**

FINKELSTEIN, V. (1980), *Attitudes and Disabled People*, New York: World Rehabilitation Fund.

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FINKELSTEIN, V. (1998), "The Biodynamics of Disablement?", Paper presented at the Disability and Rehabilitation Systems Research workshop, Harare, Zimbabwe (29 June 1998).

FINKELSTEIN, V. (1998), "Re-thinking Care in a Society Providing Equal Opportunities for All", Discussion paper for the World Health Organization.