Disability and the Life Course
Global Perspectives

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Disability is a global issue. More than half a billion disabled people live in the world today – approximately one in ten of the population. This number is set to rise dramatically over the next twenty-five years, both in richer technological societies and in the poorer majority (International Disability Foundation 1998). At the same time, disabled people throughout the world are empowering themselves to claim greater participation, integration and equality. Such claims are not only about greater control over individual lives but also about greater influence over the social structures within which such lives are lived. For this reason, it is impossible to disentangle the lived experience of disability from the context of disabling societies. They are part of the same story. The various contributions in this book demonstrate the complexity of this connection and reveal how disabling barriers and enabling strategies interact in a changing world.

Uneven economic and political development means that impairment and disability affect children, adults and older people differently in different societies. According to United Nations (UN) estimates, around 80 per cent of disabled people live in so-called 'developing' countries. More accurately, we might say that most disabled people spend most of their lives in the 'majority world' (Stone 1999). Yet, the academic literature of disability studies consistently privileges minority world accounts (especially, those from Western Europe and North America). The result is that disability (in both medical and social model senses) has been framed within a minority worldview. Consequently, it is important to think about disability issues in the bigger picture. As Majiet (1998: 1) argues:

If one looks at the [disability] agenda, we can ask who sets the agenda globally for human rights. My impression and humble opinion is that this agenda is very much set by the North and that we need to take issue with that.

Similarly, Montero (1998: 1) observes that, 'When we come to the developed countries from the underdeveloped countries we see differ-

ences. We are fighting for different issues.' Such differences can lead to differences in political emphasis between disabled people in different regions. So, for example, while disabled people's organisations in the UK were campaigning against the principle of charitable support from the National Lottery, disabled people in Thailand were protesting to maintain the employment of disabled Lottery ticket sellers. Such differences are not necessarily conflictual but they do illustrate some of the societal influences at work in defining the disability rights agenda.

The issues facing disabled people in rich technological countries, with highly developed welfare provision, are indeed different from those in the majority world. In a global context, most disabled people encounter both disabling barriers *and* barriers to scarce resources (Coleridge 1993). Access to resources is highly gendered, and the life experiences of disabled women require specific attention. Generational issues are also important and the life experiences, or life chances, of disabled children and disabled elders merit particular attention.

Majority world perspectives do exist, particularly within the 'rehabilitation' literature, and within the growing body of knowledge emanating from the international disabled people's movement. However, such contributions are rarely cited within the academic literature of disability studies. In order to address this, a number of contributions in this book relate directly to majority world experiences. In particular, Anita Ghai (chapter three) and Emma Stone (chapter five) seek to re-conceptualise disability and personhood within a majority world context, while Majid Turmusani (chapter sixteen) considers the particular significance of paid employment for disabled adults in the majority world.

The international policy agenda

Over the past twenty-five years, disability has moved from the margins to the mainstream of the international human rights agenda. It was in 1975 that the UN General Assembly made its first Declaration on the Rights of Disabled Persons. Following the Declaration, the UN proclaimed 1981 as the International Year of Disabled Persons (IYDP) and embarked upon the development of a World Programme of Action. In 1985, the Universal Declaration of Human Rights was specifically extended to include disabled people. The focus provided by the UN Action Plan and IYDP gave rise to many debates within the international policy community and the emergent disabled people's movement.

Towards the end of the Decade of Disabled Persons (1983–92) the UN began work to develop a longer-term strategy under the slogan

'towards a society for all' (UN 1983) and 1992 saw the establishment of an International Day of Disabled Persons (marked on 3 December each year). Implementation of the long-term strategy, at national, regional and global levels, also coincided with the development of new *Rules on the Equalization of Opportunities for Disabled Persons* (UN 1993). The UN Rules address participation in eight specific areas of life: accessibility, education, employment, income maintenance and social security, family life and personal integrity, culture, recreation and sports, and religion. Social model definitions of disability also became more mainstream – thus, 'society creates a handicap when it fails to accommodate the diversity of all its members', and, 'People with disabilities often encounter attitudinal and environmental barriers that prevent their full, equal and active participation in society . . .' (United Nations 1994, paras 3 and 4).

Within this changing global policy framework there has been a great deal of uneven regional development. In 1995, the Danish Council of Organisations of Disabled People commissioned an index to monitor implementation of the UN Rules (DCODP 1995). The results of this research, in forty-six countries, provided a very patchy picture of progress towards the universalisation of opportunities for disabled people. There was evidence that some states with a relatively long history of addressing disability issues through public policy (such as the Scandinavian countries) still had a long way to go, while others with less disability policy history (such as South Africa and Uganda) had made good progress. However, a further UN survey of eighty-eight governments (Michailakis 1997) suggested that at least 80 per cent of states had reformulated their thinking on disability issues in response to the UN Rules.

Since IYDP and the introduction of the UN Rules, more and more states have introduced anti-discriminatory legislation. However, as Masemene (1992) notes, such legislation does not arise spontaneously within state constitutions, which are generally framed to protect majority interests, and 'This process must be preceded by sensitisation/ politicisation or conscientisation of society or the community'. The self-organisation of disabled people has been the major catalyst in these processes. Ironically (from a Western perspective) progress towards civil rights in developing countries has sometimes proved easier than in richer parts of the world, although implementation has often been difficult (O'Toole and McConkey 1995).

For example, little attention was paid to disability issues during the first twenty-five years of the European Economic Community (EEC). Verney (1996) notes how the founding Treaties on European Union

failed even to mention disability (up to and including the much-vaunted Maastricht Treaty). Indeed, it was not until a report published for the 1996 European Day of Disabled Persons that disabled people were overtly recognised as citizens, consumers and workers within the Union (Waddington *et al.* 1996). Under concerted pressure from disability organisations, the EU finally made disability rights 'visible' in the 1997 Amsterdam Treaty (e.g. Article 13). In the majority world, issues of economic survival can easily outweigh the apparent benefits of such legislation on paper (Nkeli 1998).

Disabled people's self-organisation

Mirroring the global context of disability, disabled people have organised on an international scale. The primary mechanism for this has been the development of Disabled Peoples' International (DPI). Officially founded in Singapore in December 1981, the main purpose of DPI is 'to promote the human rights of disabled people through full participation, equalisation of opportunities, and development' (DPI constitution; see also, Driedger 1989). As an international representative forum, DPI now has consultative status with the UN, the ILO and UNESCO. Within DPI, national and regional assemblies represent the interests of disabled people in each member state. DPI includes organisations from some 130 countries, although there are still about thirty countries with no national assembly of disabled people.

Speaking at a seminar in Sweden in 1998, Kalle Könkkölä (then chairperson of DPI) emphasised the significance of DPI's mission as a human rights organisation in the majority world.

As chairperson I have felt that DPI's meaning is more important in the Southern, Eastern and developing countries than in the Western countries especially when we look at the level of commitment. Of course the organisations in Western Europe have a commitment of working together but it appears as if the expectations on DPI are greater outside of Europe than in Europe. (Könkkölä 1998)

In this way, the disabled people's movement has adopted an internationalist perspective from its inception, seeking to draw on the common strengths and diverse experiences of disabled people throughout the world. As Heumann (1998) argues:

We need to focus more on what each country is respectively doing and to look at ways that we can benefit from the different political and philosophical approaches that countries are taking. We need to look at the actual work that is going on within those countries and to learn about strategies that those countries are taking. We have to have some meaningful discussions about where we feel

we are being successful, what we believe success is the result of and what we believe needs to occur in order to allow us both in our individual country and across the world to be a more powerful movement. (Heumann 1998)

Although the development of disabled people's organisations in the USA, the UK and parts of mainland Europe has been well documented in the disability studies literature, there has been much less awareness about developments elsewhere. Yet, disabled people's organisations have been very active in the majority world. For example, Jayasooria and Ooi (1994) analyse the development of the disabled people's movement in Malaysia, while Shah (1990) examines some of the issues for self-help organisations in Pakistan. Here, negative cultural attitudes and the problem of communicating with those in rural areas raised many barriers to mobilisation.

The 'African Decade of Disabled People', was launched by DPI in December 2000, organised by the Pan-African Federation of the Disabled (PAFOD), with the aim of effecting 'permanent positive impact for the region's population with disabilities' (Wong-Hernandez 1999). Jogie (undated) describes how the development of self-help groups led to the formation, in 1984, of Disabled People South Africa (DPSA). The issues facing disabled people there included negative stereotyping, lack of access to apartheid services for black disabled people, widespread poverty and violence. Nkeli (1998) provides a specific account of the Self-Help Association of Paraplegics in Soweto (arising from disabled survivors of the government massacre there in 1976) and their subsequent politicisation within the independent living movement. In her chapter for this book, Ruth Morgan (chapter eight) draws directly on the life experiences of three black disabled people during these developments.

War and peace

Armed conflict and political instability have had a dramatic effect on disabled people's lives. Indeed, as Driedger (1987) notes, 'Disabled persons' rights as human beings are violated in wars and armed conflict every day around the globe'. Today, there are millions of disabled refugees and displaced persons in and around war zones such as the Middle East, the Balkans, Central Africa and South East Asia. For earlier generations, war was a significant factor in Western Europe and North America too, yet it may never be an issue for younger disabled people living there today.

In many parts of the world, war is a major cause of impairment. Consequently, world peace has become a disability issue. For example,

at least 2,000 people are killed or injured every month by landmines in more than seventy countries around the world, and much attention was focused on this issue at DPI's 1998 World Assembly in Mexico City. Similarly, a visit by the DPI World Council to Hiroshima (site of the first atomic bombing by the United States) resulted in an International Peace Declaration by disabled people's organisations.

War and political upheaval have a variety of impacts on disabled people's lives, not all of them negative. For example, Montero (1998) draws on the Sandinista revolution in Nicaragua to illustrate how political circumstance can influence the life course pathways of disabled people (*see* also, Bruun 1995). As with other conflicts around the world, many Nicaraguans became disabled during the war. However, veterans experienced disability in very different ways to those who were disabled before the revolution. Making comparisons with Vietnam veterans in the USA, Montero notes how, 'These disabled people were practically considered national heroes and were given all the opportunities possible to develop and strengthen their own organisations' (and not only to those on the Sandinista side).

Similarly, the dramatic political changes sweeping through the countries of the former Eastern block since 1989 have not been entirely negative for disabled people. Thus, Brichtová (1998) argues, 'The vision of democracy has affected also the lives of people with disabilities. Maybe for the first time in our history, their views and desires for real civil involvement and participation have been heard in public'. Those who have lived through these changes are witness to such impact in their lives. Thus, in chapter nine Elena Iarskia-Smirnova reviews her research into the life course events surrounding the self-empowerment of disabled people in post-Soviet Russia, while in chapter ten Kaido Kikkas tells his own story, of life as a disabled person in both pre- and post-Soviet Estonia.

Work, education and poverty

In the modern world, work and employment are major signifiers of independent adulthood (particularly male adulthood). Yet, disabled men and women throughout the world continue to be disproportionately unemployed, underemployed and underpaid (along with young people and women), resulting in conditions of extreme poverty for many millions of their families. In 1983, the International Labour Organization (ILO) adopted a convention of international standards to ensure equality of opportunity and treatment for disabled persons in relation to employment and social integration. Article 4 notes that:

The said policy shall be based on the principle of equal opportunity between disabled workers and workers generally. Equality of opportunity and treatment for disabled men and women workers shall be respected. Special positive measures aimed at effective equality of opportunity and treatment between disabled workers and other workers shall not be regarded as discriminating against other workers. (ILO 1983, Article 4)

As global markets and technologies develop in new ways, access to education becomes ever more important, particularly for children and young people. Yet, many disabled people have been denied educational opportunities to develop the knowledge and skills required for survival in a changing world (Peters 1993). Many millions have been excluded from formal education altogether. Shah (1990: 51) draws on her own life experience, as a young blind woman in Pakistan, arguing that, ' . . . disabled females, children and girls are not considered fit for education and according to general belief its utility is nil'. These barriers to education leave many young disabled women in poverty and dependent upon their families in many countries. Others have found themselves segregated in socially stigmatised special schools. Negative attitudes and access to resources both play a part here (IDDC 1998). In addressing these issues, the UN seeks to:

Ensure equal educational opportunities at all levels for children, youth and adults with disabilities, in integrated settings, taking full account of individual differences and situations. (World Summit on Social Development 1995, Commitment 6f)

Differential access to the benefits of work and education means that world poverty is a key issue for disabled people (Beresford 1996). Indeed, the first priority in DPI's current action plan (1999–2002) is, 'to eradicate poverty so that people with disabilities enjoy a good quality of life along with their communities'. As Majiet (1998) argues:

In the South's reality we are looking at basic rights, at survival. Many of the rights, and fruits of freedom that you enjoy in the North are well beyond survival. At this stage there is this gap and we would need to close it in our relations to make sense between North and South . . . We are talking about worlds apart . . .

In a global context, poor people are more likely to be affected by impairment and disability, and disabled people are more likely to live in poverty. The causes of such disadvantage are not simply to do with disabling attitudes or prejudice. They are deeply rooted in structural inequalities and conflicts arising from uneven economic, technological and political development (Kisanji 1995). Disabled women are particularly disadvantaged in this way (Boylan 1991). In chapter three,

Anita Ghai graphically illustrates the interaction of poverty and gender in the life experiences of disabled people in India.

In a commitment to eradicate absolute poverty within member states, the UN Copenhagen Declaration on Social Development aimed to, 'Develop and implement policies to ensure that all people have adequate economic and social protection during unemployment, ill health, maternity, child-rearing, widowhood, disability and old age' (World Summit on Social Development 1995, Commitment 2d). To this end the Declaration includes specific pledges on equal educational opportunities for disabled children and young people, access to independent living services and to assistive technology.

Independent living

The concept of independent living (or integrated living) has been a central theme in the development of disabled people's self-organisation, and in disabled people's claims to greater self-determination. As Evans (1993: 63) puts it, 'Life is more than just a house and getting up and going to bed. Independent Living is about the whole of life and it encompasses everything'.

However, a recent review of independent living in forty countries (Doe 1998) shows just how variable the implementation of independent living concepts can be in different socio-economic and cultural contexts. Disabled people in the minority world have claimed independent living resources to maximise individual choice, and to escape from segregated welfare state institutions. For disabled people in the majority world survival often came before issues of equality. In such circumstances, the development of micro-economic enterprises and segregated sheltered employment schemes has been a common user-led response. For example, in Brazil, all of the recently founded centres for independent living are based on employment projects (by comparison, those in North America and Europe have not taken up employment as a major function).

In Western Europe, the concept of independent living has become closely associated with demands for control over the employment of personal assistants. At the first European Independent Living Conference (held in April 1989 at the European Parliament in Strasbourg, France) representatives from fourteen European countries met to discuss personal assistance services. The meeting affirmed disabled people's claims to expertise and self-determination over their own lives, and condemned the provision of segregated services as a violation of

human rights. The conference resulted in the founding of the European Network for Independent Living (ENIL 1989).

Writers in the United States frequently lay claim to the birth of the independent living movement there, in the wake of earlier civil rights struggles. For example, the Centre for Independent Living (CIL) at Berkeley, California (founded in 1973) is often regarded as the first of its kind, although parallel developments in Europe were also important around the same time (*see* Klapwijk 1981; Zola 1987 or Davis 1993). In her chapter for this book, Devva Kasnitz (chapter six) examines the life event histories of disabled people who were involved with the early American independent living movement of the 1960s and 1970s. In this way, she examines the utility of a life course approach in explaining some of the choices and social conditions that led disabled individuals to become political activists at that time.

A matter of life and death

In both majority and minority world contexts, disability is a life and death issue. There is a growing body of knowledge about the diverse policies and practices that result in decreased life chances and life expectancy of disabled people around the world. In this sense, the extermination of disabled people at the hands of Nazi doctors (Lifton 1986) the abandonment of disabled children in Russia (Human Rights Watch 1998) the mass sterilisation of disabled people in Scandinavia (Munthe 1996), eugenic social policies in China (Stone 1996), poverty in the Indian sub-continent, physician assisted suicide in the USA (Dworkin *et al*. 1998), and the eugenic possibilities of the Human Genome Project are not unconnected in the continuing threat to disabled people's lives at the beginning of the twenty-first century. Thus, in chapter four, Gregor Wolbring asks whether we can 'draw the line' between disabled and non-disabled lives.

One of the purposes of this book then is to challenge the concept of 'normal' life course progression in the modern world. The various chapters demonstrate how the diversity of life experience and life style in a globalising world sit uncomfortably alongside policies and practices intended to police the boundaries of normal life course progression. The increasing claims of disabled people for self-determination, choice and control over their lives highlight the significance of this paradox. The lived experience of disabled people in different societies offers an important insight towards its resolution.

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