Disability and Development:

Learning from action and research on disability in the majority world

Edited by Emma Stone

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Disability and development in the majority world

Emma Stone


Across the world, disabled people are struggling for access to education, jobs and housing, for the right to express their sexuality and to have children, to participate in political and social life, and in the development of our communities. However, the world is a disabling place, and millions of us experience the effects of it every day of our lives.

(Leonard Williams 1995, President of the Disabled Persons Rehabilitation Association, Solomon Islands.)

While people in the rich world are talking about Independent Living and improved services, we are talking about survival.

(Joshua Malinga, leading disabled activist from Zimbabwe and Chair of Disabled Peoples' International, in Beresford 1996, p. 560.)

INTRODUCTION

This book covers such a wide range of topics and perspectives that it is almost impossible to write a short introduction. What makes this task even harder is the hope that those who read this book will come from very different backgrounds. Some readers will come from a disability studies background and will know a great deal about western theories of disability, but much less about the issues facing disabled people and their allies in the rest of the world. Others will have a strong knowledge of international development research and practice, perhaps working for (or hoping to work for) a non-governmental organisation that strives to combat global poverty. There will be readers who are already involved in working with disabled people in some of the poorest regions of the world; and others who are thinking about getting involved in the future. Given such a wide target audience it feels more appropriate simply to set out some issues, highlight other sources of information, and give a feel for what this book can and cannot offer.
WHAT IS "DISABILITY"?

Who defines disability? Who is disabled and who is not disabled? Does disability mean the same thing across cultures and across time? What exactly is disability? Is it a physical or mental condition? Or is it the response of society and culture to people with that condition? Your answers to these questions will have a direct impact on how you approach disability and development in the majority world.

In any book on disability, especially one with a global perspective, definitions are hugely problematic. For a start, there is the inevitable tension between the need for internationally shared meanings that enable cross-cultural information exchange and, on the other hand, the need to recognise cultural differences. There are also tensions between those who fight for the power to define what disability is. Historically, the power to define disability has been held by professionals - mostly western, mostly medical, educational or administrative. But recent decades have seen new and challenging definitions coming from disabled people themselves - albeit mostly western, white and educated disabled people. (See Oliver 1996, Finkelstein 1991 and contributions to Barnes & Mercer 1996 on debates surrounding disability definitions.)

In Britain and elsewhere, disabled people and their allies have developed the "social model of disability" as a radically different way of thinking about disability. In the social model, the problem is not located in the individual, but in a society (economy, culture) that fails to meet the needs of people with impairments. Impairment is the term used for an individual's condition (physical, sensory, intellectual, behavioural). Disability, in complete contrast, is social disadvantage and discrimination. The social model message is simple and strong: if you want to make a difference to the lives of disabled people, you must change society and the way society treats people who have impairments. That change must begin with full recognition of disabled people's civil rights, the full involvement of disabled people themselves in planning and policy that is about their lives, and a commitment to removing disabling barriers that prevent disabled people's participation in society. Hence the slogans: "RIGHTS NOT CHARITY" and "NOTHING ABOUT US WITHOUT US".

The social model of disability has many critics. For some, the social model might be right for politicised disabled people in the west, but it should not be transferred beyond the west. That would be more like imperialism than empowerment (see Miles 1992, 1996; Stone 1997). On the other hand, the
evidence from many disabled people who live in the majority world is that the social model makes sense across cultures and countries. Letters and stories printed in Disability Tribune (newsletter of Disability Awareness in Action) give strong evidence that disabled people worldwide are forming their own organisations to bring about rights-based change.

It would be wrong to downplay the significance of this movement, although it is equally important to recognise how much still needs to change. In Britain, home to many disabled people's organisations, the "individual model" or "medical model" of disability (which sees the individual as the problem, victim, object of charity, and object of professional intervention) still rules. There is a long way to go before the social model is the basis on which policies are made, services are provided, and lives are lived.

Most of the contributors to this book adopt the social model to a greater or lesser degree - although many do not use the 2-fold distinction, tending to use "disability" for both impairment and disability. No editorial changes have been imposed here. It is probably important to make clear, however, that fully adopting a social model of disability does not mean that there is no place for medical or other professionals. As Vic Finkelstein argues in the next chapter, the social model means that existing professions, services and ideologies need to be transformed in ways that promote disabled people's self-empowerment and real social change. Professionals should be allied to disabled people and the community, not allied to medicine or administration.

WHAT IS "DEVELOPMENT"? 

Development is another problematic, although less often problematised, word. Think about the terms "developing countries" or "underdeveloped countries". Implicit in these terms is the concept of a ladder of development, with the west occupying the highest rungs while the rest of the world is balanced on the rungs below. Those at the very bottom of the ladder are often referred to as LDCs - the Least Developed Countries, with the longest way to go before they approach western standards.

It is the value-laden nature of the term "developing" that has led to my personal and political preference for "majority world" (developing countries, the South, the Third World) and "minority world" (the west, the North, industrialised countries). The majority world is the world that the vast majority of the world's people live in, yet they have access to a fraction of the world's wealth and
power. In contrast, the richest countries of the world with a minority of the world's people exploit the lion's share of global resources. (Again, use of these terms has not been imposed on contributors.)

The term "majority world" also gets away from geographical notions about wealth and power. There are pockets of great deprivation in countries of the North, and pockets of incredible wealth in countries of the South. This is particularly relevant when talking about disability since, worldwide, disabled people are often among the most marginalised people in a community.

Finally, using the word "majority world" also enables a clear separation between western-dominated notions of progress, and the workings and study of processes of development where "development" is shorthand for change - social, economic, political, cultural, for better and for worse, complex and contradictory. It is in this second sense of the word that "development" becomes a useful and critical focus for understanding disability in the majority world and in global perspective, just as it has been for disability theorists and activists focused on the minority (western) world.

**MAKING CONNECTIONS BETWEEN DISABILITY & DEVELOPMENT**

The most frequently made connection between disability and development (and the connection has been made many times) is actually the link between poverty and impairment in the majority world (see Beresford 1996, Coleridge 1993, Boylan 1991 for example).

People with impairments in the majority world are more likely to be poor for two reasons. First, because the root causes of impairment in majority world countries - malnutrition, poverty, landmines, lack of services, etc. - hit the poorest people hardest (Chambers 1983). In fact, a considerable proportion of impairments in the majority world are a direct result of poverty, injustice, and exploitation by the minority world.

- Over 100 million people have impairments as a result of malnutrition.
- 250,000 children go blind every year through lack of Vitamin A.
- 800 million people are at risk of preventable learning difficulties through lack of iodine.
- 100,000 women in Africa acquire impairments through childbirth complications.
• 40% of hearing loss in children in the majority world would be preventable by early identification.
• There were 100,000 new cases of polio in 1994.
• Six million people worldwide are affected by leprosy.


Secondly, people with impairments worldwide are more likely to be poor because of the disabling barriers that prevent them from getting an education, a job, access to appropriate support and services, and so forth. Some of these barriers are rooted in local attitudes and responses to impairment. Others are rooted in the broader structural processes of poverty and injustice that produce disability as well as impairment.

The question still remains: how can disabled people have equal opportunities in developing countries in the face of rapid cultural change, worldwide recession, armed conflicts, continued imbalance of trade, structural adjustment and the ongoing rapid technological advances of the modern world? (Kisanji 1995, p. 199, in Zinkin & McConachie).

Here we move from connections between poverty and impairment to the connections between disability (as defined by the social model) and development.

In western disability studies, leading theorists have linked the social construction of disability in the west to western development (e.g. Finkelstein 1991, Oliver 1990, Albrecht 1992, Bickenbach 1993, Stone 1984, Barton 1996, Davis 1997). Whilst different theorists put forward very different analyses, there is a general argument that runs through all: disability is socially constructed, a product of western development processes and the dominance of certain professional élites. Urbanisation; industrialisation; the rise of medical and rehabilitation professions; the creation of a welfare state premised upon divisions between disabled and non-disabled people; western concepts of "normalcy"; western concepts of charity; the creation of ever larger mechanisms of social control; and so forth. These are just some of the processes that have been used to explain the construction of disability in the minority world.

Whether or not you agree with these theorists, it is surely indisputable that social and economic development processes will impact on the lives of disabled people. How can they not?
Several within the disability/development field have started to argue for a more critical approach to disability in the majority world that incorporates political, social and economic factors. For example, Momm & König (1989) suggest the following framework for collecting data prior to undertaking any disability projects:

- geographical, organisational, economic, political, social, linguistic, tribal and other community characteristics;
- socio-economic modes of organisation and production with an understanding of the impact of socio-economic change;
- relations between the community and the outside world, from a neighbouring village to national government; and
- the nature and impact of outsider interventions whether through trade, aid, services, or tourism.

Few have met Momm & König's expectations. Nonetheless, the message seems to be seeping through that global and local factors impact on perceptions of and responses to impairment and disability. Take (and I use one example only) Nicolaisen's (1995) study of disability among the Punan Bah of Borneo.

In the closing paragraphs of her account, Nicolaisen considers the impact of extensive logging on the Punan Bah economy and society. The large extended households that once facilitated the integration of individuals with impairments are now breaking up into smaller units with decreased capacity to provide support. Increased reliance on waged labour has undermined the role of many people with impairments in economic production. Meanwhile, expectations and attitudes to beliefs and rituals are changing, to be "more in tune with the capitalist Western values that imperceptibly permeate [the] Punan Bah view of themselves and the world"...

This may save the life of children impaired like the spirit boy, but it may well make the lives of many others considerably less fulfilling and more difficult (Nicolaisen 1995, p. 54, in Ingstad & Whyte).

The point is important. Change is not only complex but may also be contradictory. Where some members of a household or community may benefit from new economic opportunities, others find previous social roles removed or redundant, or are set apart for special intervention where once they were integrated. Benefits may accrue such as literacy, mobility aids or the
organisation of community groups, but they accrue at the risk of undermining previous forms of social accommodation, weakening the role of the extended family as the main source of social security, threatening local strategies and healing systems, and creating a class of "disabled" people that did not exist prior to outsider involvement in rehabilitation, surveys or research (see Burck 1989, contributors to Ingstad & Whyte 1995 for example).

The impact of "development" must not be ignored when considering disability in the majority world. Yet most who write on disability in the majority world fail to explore these issues to sufficient degree. Governments, television, newspapers, professionals, ideologies, institutions, structures, schools, modes of production, disability policies and state-social definitions of disability do not exist in the west alone. Many majority world countries have institutional and ideological legacies that stretch back over millennia. All of these will have an impact on perceptions of and responses to impairment (and thus the social construction of disability). All of these are subject to processes of rapid and often skewed under/development. Now more than ever.

**THE GLOBALISATION OF DISABILITY**

Globalisation has been the buzzword of the 1990s. We live in a global society: MacDonalds, Coca Cola and the Internet are the hallmarks of a global culture; the United Nations, World Bank and multinational corporations like Glaxo and Microsoft wield more economic and political power than most national governments. Development can only be understood in global context. And there is ever growing demand to think about disability in a global context too.

1981 was the International Year of Disabled Persons. The United Nations Decade of Disabled People (1982-1992) followed. During that decade and in the years since, there have been successive waves of new initiatives targeted at disabled people living in the majority world. Some of these initiatives have been developed specifically for the majority world, often by western or western-trained professionals. Community Based Rehabilitation (CBR) is a good example. The concept of CBR was originally championed by the World Health Organization with the aim of making rehabilitation services available to grassroots communities in a cost-effective way. It has spread like wildfire and has been adopted, adapted, contested and reworked to cover a wide range of projects in an even wider range of settings. It is one example among many. None of this is new or surprising. What is happening in the 1990s is simply an updated, less obviously imperialistic, version of what missionaries were doing in
the 1890s. Well-meaning, but not always carefully considered, sensitively implemented, or appropriate to local practices and perceptions.

New initiatives require funders, planners, implementers and evaluators. The emergence of CBR (and other outsider-led interventions) has fostered the emergence of CBR training programmes, training manuals and professional trainers, not to mention CBR workers, managers and evaluators. There are growing numbers of western or western-trained professionals working in disability and development, facilitated by international circuits and international journals.

The past two decades have also seen a dramatic increase in organisations controlled by disabled people. Local, national and international organisations of disabled people have taken a strong role in promoting social change based on their own analysis of disability and society. There are international networks and newsletters here too - such as Disabled Peoples' International (the international umbrella organisation for disabled people's organisations, see Driedger 1989) and Disability Awareness in Action (a project led by disabled people to increase networking among disabled people and their organisations worldwide). Minority world disabled people and their organisations have generally been the key players, given greater access to resources.

Researchers have played their part too. There is a small but growing body of reports and publications that explore disability in the majority world. For the most part, these are practitioner-led and practice-based. The focus is on interventions (social, rehabilitation, education, income generation, etc). At best, this literature offers useful evaluations of processes and outcomes, but little space is generally left to explore wider issues such as attitudes, life chances, local strategies and responses, beliefs, social expectations, cultural perceptions. Fortunately, that is beginning to change. There are now a handful of studies that look behind interventions to consider local meanings of impairment, and to identify ways in which local (and global) values and structures disable people who have impairments. (A proper literature review is beyond the scope of this chapter, but useful texts are listed at the end of this chapter.)

Is the globalisation of disability good or bad? Where activists, academics and practitioners are from or trained in the minority world, working in or with people in the majority world, there will always be risks. Whose agenda dominates? Whose ideology is put into practice? Whose definition of impairment or disability rules? Whose cultural or religious values? Whose social systems? Whose ways
of working?

On the other hand, the long overdue recognition that most disabled people live in the majority world, in poverty and without access to appropriate support, must be welcomed. So too the emergence of professionals who are real allies to disabled people and communities, and researchers who deepen our understanding of the issues. For, at the end of the day, the globalisation of disability must be seen in the context of the continuing marginalisation of disability issues and disabled people in international development work.

THE MARGINALISATION OF DISABILITY AND DISABLED PEOPLE

There is little that can be done to stop the globalisation of disability. If anything, more should be done to support it. After all, the field of disability and development in the majority world is woefully under-resourced. The comparatively few professionals that are committed to working with disabled children and adults are themselves marginalised in the mainstream of development organisations and development studies. Disability is not a "sexy" subject. Indeed, it is often labelled as a "specialist" subject, for medical or special education professionals only. The challenge, then, is how to raise the profile of disability issues in development programmes, research and on policy and practice agendas whilst minimising the risks that this carries.

The best way to do this is to follow the suggestions made by Rachel Hurst (Chapter 3) and others in this book to support the development of disabled people's own organisations, and to learn from disabled people's analysis and strategies for social change. There is also an urgent need for development organisations and funders to get their own houses in order and take disability on board as an equal opportunities issue (as with gender and ethnicity). Why shouldn't all development programmes and initiatives be required to involve disabled people? Or be subjected to a critical analysis to ensure that they do not compound the marginalisation of disabled people and their families? (See Hastie 1997, Coleridge 1993, and contributors in this book.)

It is also important to enable a deeper understanding of disability issues by those involved in the development field, and of majority world issues by those involved in the disability field. At the moment, the situation in Britain is that disability studies courses are mostly western-focused, while development studies courses seldom include anything about disability. This has to change.
Finally, there is a need to promote more networking and information sharing among those who are already involved in both disability and development in the majority world. The UK event on which this book is based is one small example of how that can be done.

**WHY THIS BOOK?**

In April 1998, 25 people were invited to participate in the first UK Forum for Information Exchange on Disability and Development in the Majority World. It was a one-day event, hosted by the Disability Research Unit at the University of Leeds, with an ambitious agenda.

The event aimed to "straddle divides" between activists, academics and practitioners with an interest in disability in the majority world. This was to be achieved through creating a space for networking and for sharing information about new initiatives and new research.

A lack of funds meant it was not possible to support the participation of disabled activists, academics and practitioners who live in the majority world (or, indeed, anywhere outside Britain). One of the presenters and some of the participants were from the majority world, but working in Britain. Even so, the absence of people from the majority world was keenly felt and remains a serious weakness in this book.

The Forum underlined the value of creating spaces for sharing information. It became clear that there was a real need to disseminate the information more widely. Hence this book.

**WHAT THIS BOOK OFFERS**

This book draws on the experiences of people who have been actively involved in disability in the majority world. Many contributors have spent significant periods living, working and researching in the majority world. Some are key figures in the disabled people's movement. Others have amassed considerable experience in planning and implementing disability-related development projects. A few are undertaking or have recently completed doctoral research on disability in the majority world. All share a commitment to removing disabling barriers.

Not surprisingly, then, the contributions span a huge range of interests and
geographical areas - from empowerment to community-based rehabilitation, and from Afghanistan to Jordan. Among other things, the contributions offer:

- Ideas about practical action to bring about social change and remove barriers facing disabled people in the majority world.
- Honest discussions about the difficulties and dilemmas that those researching disability or working in disability-related development work have encountered.
- Analysis of what happens when western ideas and practices migrate to non-western settings - whether brought by western professionals, or bought into by western-influenced professionals.
- Insights into the ways that different cultures and societies respond to impairment and construct disability.
- Discussions of difficult issues, such as: the role of professionals and outsider organisations; cross-cultural transfers of ideas and practice; ways of working with local disabled people; whether or not all development projects should include a disability focus.

**WHAT THIS BOOK CANNOT OFFER**

This book is not a "how to" guide on "doing disability and development in the majority world". In common with other books that seek to straddle divides and promote marginalised issues, this book is more about stimulating discussion than providing solutions. More importantly, anyone who reads this book must be aware of three weaknesses.

First, this book represents minority world perspectives on majority world realities. Where the perspectives of disabled people and their allies in and from the majority world are set out, they are often "second-hand" voices and views, mediated (distorted) by western or western-trained professionals. This book cannot offer the personal experiences and collective analyses of disabled people who live in the majority world.

Secondly, the fact that the contributors write from a huge range of backgrounds and experiences is a weakness in so far as the contributions vary widely in style, content, and sometimes in core assumptions (although this can also be seen as a strength).

Thirdly, this book is part and parcel of the globalisation of disability and
rehabilitation mentioned above ... and therefore it must be subject to careful and critical reading.

**PLAN OF THE BOOK**

The contributions in this book have been divided into four groups.

- Challenges from Disabled People
- Programmes and Partnerships
- Evaluating Interventions
- Researching Disability

This has the less than ideal effect of recreating divides, but it does at least break the book up into more manageable chunks. Each group is preceded by a preface that includes an "Overview of the Contributions" and "Discussion Points" to aid discussion and a more critical engagement with the assumptions and messages that are presented.

"Challenges from Disabled People" sets out the perspectives of disabled people who have long been involved in disabled people's movements, locally, nationally and internationally.

"Programmes and Partnerships" is written from the perspective of minority world professionals who work with and for development organisations, like Save the Children UK, or universities. The contributors set out their aims, ways of working, core assumptions, and some of the dilemmas and difficulties faced when doing disability-related development work.

"Evaluating Interventions" goes even deeper into the difficulties involved in disability-related development in the majority world, especially where the nature of interventions has been steered by western ideologies and practice. Importantly, the evaluations in this section consider processes and contexts as well as outcomes.

"Researching Disability" moves away from thinking about specific interventions and considers the meaning and construction of impairment, disability, and disability services in different contexts and using different data sources (including historical records, language, fieldwork interviews, newspapers, etc). The final chapter sets out personal experiences of doing disability research and reiterates the importance to look critically on everything written on disability in the majority world.
WHO SHOULD READ THIS BOOK?

This book is aimed at those who are currently involved, or thinking about getting involved, in disability in the majority world - whether as activists, students, researchers, practitioners, consultants, aid and development planners or funders. It is also hoped that the book will be a useful resource for lecturers and students of Disability Studies and Development Studies. It is time for mainstream Disability Studies and Development Studies courses in the west to take proper account of the important and difficult issues relevant to disabled people in the majority world.

REVIEW

This book is full of strong challenges and practical suggestions for action and research. At times, these may read more like a wish-list, but the importance of building a shared vision should not be underestimated. The different experiences shared by contributors confirm that this is not an easy area in which to get involved, and that particular dilemmas and difficulties arise where minority and majority worlds meet, and conflict. But that should not stop us from moving forwards, and from wrestling with the practical and conceptual difficulties that abound in disability action and research in the majority world.

USEFUL READING

A) Disability and Development in the Majority World

• NICOLAISEN, I. (1995), "Persons and Nonpersons: Disability and Personhood among the Punan Bah of Central Borneo".
• HELANDER, B. (1995), "Disability as Incurable Illness: health, process, and personhood in Southern Somalia".
• INGSTAD, B. (1995a), "Public Discourses on Rehabilitation: From Norway to Botswana".
• TALLE, A. (1995), "A Child is a Child: Disability and Equality among the Kenya Maasai".
• WHYTE, S.R. (1995), "Constructing Epilepsy: Images and Contexts in East Africa".

THORBURN, M. & MARFO, K. (eds) (1990), Practical Approaches to Childhood Disability in Developing Countries: insights from experience and research, Canada: Project SEREDEC and Spanish Town, Jamaica: 3D Projects.
  • AINSLOW; M., JANGIRA, N.K. & AHUJA, A. (1995), "Education:
responding to special needs through teacher development).

- KISANJJI, J. (1995), "Growing up Disabled".
- McCONKEY, R. (1995), "Early Intervention in Developing Countries".
- WILLIAMS, L. (1995), "Rights not Charity".

B) Key Texts and Readers on Western Disability Studies
OLIVER, M. (1996), "Defining Impairment and Disability: issues at stake", in

C) Useful International Journals on Disability Issues, Action and Research

ActionAid Disability News (newsletter of ActionAid India)
Disability International (newsletter of Disabled Peoples' International)
Disability Tribune (newsletter of Disability Awareness in Action)
Disability & Society (international journal on disability studies)
Disability Studies Quarterly (international journal on disability studies)

Also useful are the Information and Resource Kits produced by Disability Awareness in Action. These are available in English, French and Spanish, in English Braille, tape, ASCII on computer disk and via e-mail and in large print in all three languages. Most DAA material has been translated into national and regional languages (see List of Useful Organisations in this book).

There are also several international journals which are primarily aimed at practitioners in different fields (e.g. rehabilitation, education). The contributions vary widely in how far they are based on a disability rights perspective, or on a more individualising and medical model of disability. Examples include: HealthLink (formerly CBR News, focused primarily on the majority world); International Rehabilitation Review; International Journal of Rehabilitation Research and similar journals in the field of special education.