Disability & International Development

Malcolm MacLachlan • Leslie Swartz
Editors

Disability & International Development

Towards Inclusive Global Health

Springer

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ISBN 978-0-387-93843-1 e-ISBN 978-0-387-93840-0
DOI 10.1007/978-0-387-93840-0
Springer Dordrecht Heidelberg London New York

Library of Congress Control Number: 2009926304

We dedicate this book to all those who by reason of their marginalization or social exclusion will not have an opportunity to read it.

Foreword

Until fairly recently, the fields of disability studies and international development were viewed as completely separate. Much of what we know about disability and contemporary approaches to disability was researched and written about in wealthier countries, and it remains true to say that the major debates about disability are dominated by people in such countries. In the international development world, furthermore, the issue of disability was almost completely ignored. Plans for economic development and empowerment of the poorest of the poor in lower-income settings rarely considered issues faced specifically by disabled people.

There is an enormous irony to this situation. We know that the vast majority of disabled people live in low and middle income countries. We also know that there are strong links between disability and poverty worldwide. Disabled people are less likely to be adequately skilled for the workplace, they are more likely to be denied access to work because of prejudice and stigma, and disability itself is costly. Particularly in countries where the state does not provide adequate services and care (and this is the case in most countries in the world), disabled people and their families bear an enormous burden of care and loss of opportunity to work because of care burdens. Many conditions in the majority world, including war, internal displacement, communicable diseases (including HIV/AIDS, malaria and tuberculosis), parasitic infections, famine and civil strife, and lack of access to clean water are all factors which may dispose people to disabilities. It is therefore crucial that the two fields of disability studies and development studies begin to talk to one another so that both can contribute to improving the lives of people (and not only disabled people) worldwide.

There are some encouraging signs emerging. The United Nations Declaration on the Rights of Disabled Persons had been promulgated after a long consultative process, and the Global Partnership on Disability and Development has recently been established. In order for such initiatives to succeed, however, it is crucial that we learn more about disability and development issues on global context. This book is especially welcome in that it covers disability issues in a range of low and middle income countries. It provides a refreshing mix of case studies of country level activities, descriptions of emerging disability research networks and initiatives, and theoretical papers looking at disability research more generally.

It is crucial that disability activists and researchers worldwide join hands to keep disability firmly on the international development agenda, and to infuse disability studies with knowledge about the way in which disability is experienced and dealt with by most disabled people in the world. This book is an important step to reaching these goals, and it is my pleasure to welcome its publication and the possibilities it encapsulates. This book is also a challenge to all of us to do more and to learn more about disability and international development and it is essential that we pay this book the compliment of taking the work of understanding disability and international development forward.

I congratulate the editors and authors of this landmark volume for their excellent and important work. May this be the start of a fundamental change in how we view disability and international development

Cape Town
March 2009

Kudakwashe Dube
Chair of the Global Partnership on Disability
and Development, and CEO of the Secretariat of the
African Decade for Persons with Disabilities

Acknowledgements

An edited book is a collective, but not necessarily a unified, expression of interest in a particular theme. We welcome both this collectivity and the variation within it; as it reflects a much wider community of individuals and groups who share a concern with realizing the rights of persons with disability. As researchers and practitioners we have been inspired by a range of people, especially those in civil society who have done so much to develop this area and have provided such important leadership in recent years. Especially important to shaping our own thinking have been A.K. Dube, Chair of the Global Partnership on Disability and Development, and CEO of the Secretariat of the African Decade for Persons with Disabilities, who also kindly agreed to write a forward for this book; Rachel Kachaje of Disabled People International; Alexander Phiri of the Southern African Federation on Disability; Elias Ngongondo of the Malawian Ministry of Disabled Persons and the Elderly; and Mzolisi ka Toni of Disabled People South Africa.

The production of this book has also been supported by our colleagues at Stellenbosch University's Department of Psychology and Centre for Rehabilitation Studies; and Trinity College Dublin's School of Psychology and Centre for Global Health, "especially from Michael O'Toole, Hasheem Mannan and Eilish Mc Auliffe and Marcella Maughan". Diarmuid McClean, Vincent O'Neill and David Weakliam, all in Irish Aid, encouraged the Centre's development of work in this area, as have grants from Irish Aid, the Health Research Board (Ireland), the Irish Research Council for Humanities and Social Sciences and the European Union's FP7 programme. Collaborations with Aidan Leavy of International Services (Ireland), the Dochas Disability and Development Group, and especially consortium partners on the A-PODD and EquitAble projects, have also been very important in helping to develop our work in the Centre for Global Health. Stellenbosch University generously permitted Leslie Swartz to be seconded to the South African Human Sciences Research Council (HSRC) for three years, and it was at the HSRC that he developed his interest in disability studies. Emma Sherry (of Capital Letters) provided us with speedy and professional copy editing, and Ian Marvinney and Khristine Queja at Springer have been supportive and encouraging throughout. We should also like to thank our partners and families for their patience.

Contents

1 From the Local to the Global: the Many Contexts of Disability and International Development 1
Leslie Swartz and Malcolm MacLachlan

2 The Effect of Failed States on the Well-Being and Lives of People with Disabilities 13
Mitchell Loeb

3 The Impact of International Human Rights Law on the National Laws of Ethiopia from a Gender Rights and Disability Rights Perspective 31
Theresa Rouger

4 Building an Inclusive National Strategy for Disabled Children in Kyrgyzstan Through an Application of the *BIAS FREE* Framework 51
Mary Anne Burke and Andrea Pupulin

5 Networking in Disability for Development: Introducing the African Network for Evidence-to-Action on Disability (AfriNEAD) 69
Gubela Mji, Siphokazi Gcaza, Natalie Melling-Williams, and Malcolm MacLachlan

6 Building Disability Research Capacity in Low-Income Contexts: Possibilities and Challenges 91
Leslie Swartz

7 Empowerment, Advocacy and National Development Policy: A Case Study of Disabled Peoples' Organizations in Bolivia 105
Marianne Griffiths, Hasheem Mannan, and Malcolm MacLachlan

8 Cultural Challenges in Piloting Disability Surveys in Papua New Guinea 119
Patricia Thornton

9 Disability and HIV/AIDS: A Key Development Issue 137
Poul Rohleder, Leslie Swartz, and John Philander

10 Assistive Technology in Low-Income Countries 149
Arne H. Eide and Tone Øderud

11 Childhood Disability in Burkina Faso and Sierra Leone: An Exploratory Analysis 161
Cliona O'Sullivan and Malcolm MacLachlan

12 Education, Disability, and International Development 181
Petra Engelbrecht, Ansie Kitching, and Willy Nel

13 Listening to the Voices of Disability: Experiences of Caring for Children with Cerebral Palsy in a Rural South African Setting 191
Joanne Barratt and Claire Penn

Index 213

List of Tables

Table 2.1 Education and literacy among persons 5–18 years of age inclusive, South Africa and Zimbabwe Living Conditions Surveys 24

Table 2.2 Employment situation among persons 15–65 years of age inclusive, South Africa and Zimbabwe Living Conditions Surveys 25

Table 4.1 The *BIAS FREE* framework for research 56

Table 4.2 The Form completed by the interviewer after visiting the household 61

Table 4.3 Facilitators' discussion guide for parents' focus groups that focused on the child's education 64

Table 4.4 Revised objectives 66

Table 5.1 Examples of disability networks 78

Table 5.2 Framework for network design of cooperation 86

Table 7.1 Advocacy actions undertaken in Bolivia 110

Table 8.1 Survey areas and methods 123

Table 10.1 Sample 153

Table 10.2 Source of assistive device (percentage of individuals with a device) 153

Table 10.3 Quality aspects of service delivery with regards to assistive devices 154

Table 10.4 Types of impairment (%) 154

Table 10.5 Age of onset of impairment (%) 155

Table 10.6 Types of services that are needed and received (%) 155

Table 10.7 Assistive device by gender 156

Table 10.8 Assistive device by urban/rural (%) 156

Table 10.9 Assistive device by impairment type 156

Table 10.10 Assistive device by age groups 157
Table 10.11 Assistive device by school attendance 157
Table 10.12 Assistive device by employment 157

Table 11.1 Health statistics of countries of interest 165
Table 11.2 ICF-CY classification system related to components of "J's" story 168
Table 11.3 ICF-CY classification system related to components of 'P's' story 169
Table 11.4 Summary of research topics 175

Table 13.1 Community profile for Tonga 194
Table 13.2 Summary of living conditions of informants 197

List of Figures

Fig. 11.1	ICF-CY Framework	163
Fig. 11.2	Number and Participants	167
Fig. 11.3	Describing “J’s” Experience using the ICF-CY	170
Fig. 11.4	Describing “P’s” experience using the ICF-CY	170
Fig. 13.1	Relationship between poverty, disability, and macro-, micro-, and shared variables. Some illustrative voices	196

List of Boxes

Box 2.1 Indicators of State Vulnerability (derived from Foreign Policy, 2007) 15
Box 2.2 Determinants of Migration (Derived from: Solomon, 1996) 18

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John Philander, **Dphil**, is deputy principal at Athlone School for the Blind in Cape Town, South Africa. He is a trained educational psychologist and has 15 years of experience of working with adolescents with visual impairment. His special interest is in the area of visual impairment, HIV risk, sexuality, special needs education and disability issues. His doctoral thesis (Stellenbosch University, 2008) is the first known study to evaluate an HIV prevention intervention for youth with visual impairments.

Andrea Pupulin is an international consultant dedicated to helping the most marginalized and unfortunate peoples. Following post-graduate studies in ethics, human rights theory, political philosophy and international development, he worked with orphans and street children in Brazil and in Egypt, and with Caritas, WHO and the Global Forum for Health Research. He is working with the *BIAS FREE* Framework on a UNICEF project in the Kyrgyz Republic, assessing the situation of disabled children and developing a national strategy for an inclusive Kyrgyzstan. He is currently Database Manager for the *BIAS FREE* Co-operative, Inc., and is researching exclusion of Roma peoples.

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Theresa Rouger, **B.A., LL.B**., is an international human rights lawyer and lectures on international law at Université Catholique, Lyon and Centre d'études franco-américain (C.E.F.A.M.), International School of Business Management, Lyon, France and U.S.A. She also lectures on the humanitarian Masters programme at the Université of Lyon 2, France. She is interested in international human rights, disability rights, gender rights, child protection rights and international law including business and human rights. She is currently working on a legal comparative disability project involving child rights with the Law Society of England and Wales. Other projects include a legal and social comparative disability project involving child rights with Handicap International, which will span across four African countries, and human rights and mental health research. She works as a legal human rights consultant for NGOs.

Leslie Swartz is a clinical psychologist and professor in psychology at Stellenbosch University. He is interested in public mental health, disability studies, and issues of identity in higher education. He is currently working on a co-edited volume on HIV and the social sciences in South Africa (Springer). He project managed and co-edited the first comprehensive volume on disability in South Africa (*Disability and Social Change*, HSRC Press, 2006) and current projects include work on HIV and disability, access to health services for disabled people in sub-Saharan Africa, and research capacity training for the Southern African Federation on Disability (SAFOD).

Patricia Thornton has undertaken research on disability and development in Papua New Guinea and latterly in Guyana, as a volunteer with Voluntary Service Overseas. In Papua New Guinea, she piloted methods of surveying disabled people to help establish the prevalence of disability, undertook a review of the VSO Disability Programme there and also carried out a study of national volunteering in Papua New Guinea. Patricia's previous career was in university-based social research, notably as Senior Research Fellow at the Social Policy Research Unit, University of York. She specialises in international comparisons of policies to promote employment of disabled people and in evaluation of UK employment programmes for disabled people.

Chapter 1
From the Local to the Global: the Many Contexts of Disability and International Development

Leslie Swartz and Malcolm MacLachlan

1.1 Introduction

A few months ago, one of us participated in a disability workshop held in a southern African country. The workshop went well, and it was clear from the inputs from people at the workshop that there is an assertive and vibrant disability movement in some very poor countries, some of which are only tentatively emerging from decades of war and civil conflict, and some of which continue to face deepening economic, political and governance challenges. The meeting was held at a hotel that has conference facilities. The building was not fully accessible to wheelchair users but was the only venue the organization could find and afford in that African capital. While we were there, the leadership of the organization told the management about the difficulties in getting to and from the conference room, as there was a small step close to the entrance to the conference room that could not be negotiated by wheelchairs. We struggled with this environmental barrier, but were delighted to emerge from one of the later sessions of the meeting to find that the hotel management had arranged for a concrete ramp to be built there and then, so that wheelchair users could more easily access the conference room. The concrete would not be dry by the time our meeting was over, but the ramp would be there for later users.

The makeshift ramp that was built at the hotel was subject to no plans, no designs, no building regulations, and no local or national laws or policies complying buildings for public use to be accessible to disabled people. The fact that our meeting was held where it was, and the reaction on the part of some people to issues of impairment being made visible, tells us part – and an important part – of the story of disability and international development. Most countries in the world are poor and far from the rarefied world of high-income countries with substantial provisioning for disability. But daily activism of an almost routine nature, and receptivity to this activism, can and does make a difference.

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M. MacLachlan and L. Swartz (eds.), *Disability & International Development: Towards Inclusive Global Health*,
DOI 10.1007/978-0-387-93840-0_1,

After the meeting, many of us were on the same flight to a hub from which we would go our different ways to our home countries. The airline we were using was a well-known international airline, subject to international regulations. Ground staff of the airline could not have been more rude or oppressive towards those of us with visible impairments. They talked only to people with no obvious impairments, offered no help for a number of blind people and wheelchair users to navigate their way through security checks and customs, and claimed inaccurately that the airline had not been informed that disabled people would be on board, even threatening not to allow disabled people to board. There are, for good reason, international safety regulations about having disabled people on aeroplanes – there must be adequate provision so that, especially in an emergency, there is minimal danger to all passengers. Whether this was part of the concern of the airline staff we do not know, but even if it was, there was no excuse for the rude, and indeed disablist, way in which members of our group were treated. We suspect that it would be very unlikely that employees of the same airline working in high-income countries would have behaved in the same way.

These two images of how disabled people are treated and live their lives in low and middle-income countries are to an extent emblematic of more pervasive images of disability in these countries. On the one hand, we have an image of disabled people being exceptionally badly treated, locked up, shackled, and even killed in low and middle-income countries; on the other there is a view that people living rural lives far removed from the dehumanizing reaches of the global formal economy are tolerated and given meaningful roles in a world more tolerant of impairment and diversity. These images resonate through much of the literature on disability in poorer countries in general, and in the literature on specific areas, such as the literature on psychiatric disability (Swartz, 1998).

Somewhere between these two extremes of complete oppression and complete idyll, disabled people live their lives. Part of what is confusing about thinking about disability in such contexts is that, commonly, both images hold an element of truth simultaneously. There is no longer any question, for example, that poverty and disability are reciprocally related, with poor people more likely to be or become disabled and disabled people not only more likely to be poor but also to bear a burden of high costs of care and resources in countries where these are not provided (Emmett, 2006). There are cycles of impoverishment and disablement – consider for example a parent of a child with a serious mobility impairment in a low-income country. The parent may have to take off work to care for the child, and in the absence of assistive devices and free accessible transport, the parent may have to carry a growing child (even an adolescent) on her back when the child needs to go anywhere. Because of the difficulties of getting around, the child (especially if the child is a girl) may have interrupted schooling or no schooling at all, even if the school is prepared to accept disabled children. The child then loses opportunities to learn and train in order to support him/herself and the family in years to come. The parent, meanwhile, may come to have chronic back problems as a result of the sheer physical effort of caring for the child and carrying the child around, and may also develop a serious and disabling mental disorder because of the anxiety and

demands of the situation. The parent may become less able, even when opportunities are presented to earn a living and support a family.

On the other hand, and equally true, we know that there are other stories. Duncan (2007) for example carefully documents case studies of how disabled people living in extreme poverty and with what seem to be no resources can and do organize their lives such that they not only find ways of surviving but also find a dignity in the way they live their lives and spend their time. In his now classic writings, Werner (1987) demonstrated how, with considerable ingenuity and at almost no cost, very poor people made their own assistive devices from what others would regard as waste or worthless materials. Local emancipatory practices have been shown to have the potential to improve people's lives and livelihoods (Lorenzo et al., 2007).

There is a real danger that we may romanticize the difficult lives of poor people, especially by drawing on idealized and unhelpful ideas about "culture" (Daniels and Swartz, 2007; Swartz, 2007, 2008; Tomlinson and Swartz, 2002). But if we look to the empirical evidence, we can see impressive examples of the ways in which in many poor parts of the world people with disabilities have taken an active role in advocating for their rights and in putting disability at the heart of the international development agenda. In southern Africa, for example, the Southern Africa Federation on Disability (SAFOD, which represents national Disabled People's Organizations (DPOs) in ten southern African countries, is internationally known as an important player on the disability and development scene. Once again, this vibrancy and effectiveness takes place against a backdrop of almost inconceivable challenges for many readers of this book. SAFOD coordinates a network of ten national DPOs, and recently launched its groundbreaking SAFOD Research Programme (SRP), groundbreaking because it is led by a Disabled Person's Organization (DPO). This programme, with significant donor support, is situated in Bulawayo, Zimbabwe, where, at the time of writing, there is a high degree of political repression, severe hunger, a cholera epidemic superimposed on the HIV/AIDS epidemic, almost total collapse of educational and health services, and no consistent supply of any basic services – including supply of water and electricity, and removal of rubbish and sewage. To say that SAFOD leadership are not suffering at present would be inaccurate, as it would be inaccurate to say that the particular struggles faced by disabled Zimbabweans are not more challenging than those faced by non-disabled Zimbabweans (for more discussion on this issue see Loeb, Chap. 2).

Under extremely difficult circumstances though – circumstances that must not be overlooked – organizations are contributing to important and exciting developments in how disability is viewed within the international development context. Key role-players in Disabled Peoples International (DPI) include disabled people from low-income countries. The African Decade on Disabled Persons, one of the offshoots of the UN Decade on Disabled Persons (Chalklen, 2006), has now become a misnomer as it has been extended (into a second decade) and it continues to link struggles for disabled people in sub-Saharan Africa with global struggles. The UN Convention on Disabled Persons was drafted in part by disabled people from low and middle-income countries. The recently established Global Partnership for Disability and Development (http://gpdd-online.org/disability) embraces not only the vibrancy of these African DPOs, but also the parallel

and equally impressive developments that have taken place in South America, Asia, the Pacific and elsewhere. The GPDD statement on disability and international development is uncompromising:

> The chronic and vicious cycle of disability and poverty is a critical threat to the eradication of poverty and the enhancement of sustainable development in several of the world's poorest regions. Many poverty reduction strategies and ambitious development projects that seek to achieve the Millennium Development Goals (MDGs) and a critical reduction in poverty around the world fail to capture the necessity of incorporating the needs of people with disabilities, and their voices, in the design and implementation of these programs.
>
> Studies have shown that a majority of existing Poverty Reduction Strategy (PRS) papers fail to address the needs of people with disabilities, and often relegate disability issues to side programs without considering them within the mainstream strategies targeted at the general population. Additionally, there is a significant lack of monitoring and evaluation of benefits and outcomes of PRS for people with disabilities.
>
> Exclusion from mainstream reforms and systems has marginalized people with disabilities for generations, and it is vital that measures aiming to improve well-being and standards of living, reducing poverty, and increasing means of economic sustenance include them at every stage of the process. Development projects centred on disability issues, such as special education schools, tend to be fragmented, and mostly relegated to select ministries or departments.
>
> (Downloaded from (http://gpdd-online.org/disability January 19th 2009)

The GPDD seeks to address the devastation of disabled people's lives in poorer countries, with oppression and exclusion of disabled people being an omnipresent feature; however, once again, the fact that there is meaningful representation by people from low and middle-income countries on such a body is a cause for great optimism.

A review of the architecture or function of international development agencies is beyond the scope of this book. There are however a few issues that are particularly pertinent to disability that are therefore worth a brief mention. While there have undoubtedly been "development successes", Black argues that "Instead of creating a more equal world, five decades of "development" have produced a socio-economic global apartheid: small archipelagos of wealth, within and between nations, surrounded by impoverished humanity" (Black, p 13, 2002). We have already noted above, in the form of the quoted GPDD statement, that people with disabilities are among those groups who have been largely excluded from the benefits of "development". One of the key challenges for people with disabilities (PWDs) is therefore their empowerment, to be able to "get on" the development agenda. Barbery (2007, p 76) suggests that "Empowerment is the expansion of poor people's abilities to participate in, negotiate with, influence, control and hold accountable institutions that affect their lives." We believe that the application of the social model of disability to the challenges that many people with disabilities in low-income countries face, has in fact prepared Disabled People's Organizations (DPOs) well for this sort of struggle (see Watermeyer et al., 2006).

Many of the difficulties with "development" actually centre around the "development" institutions that "affect peoples lives." The need to reform these institutions and how they relate to each other has been recognized in major policy documents such as the Paris Declaration and the Accra Accord. The Paris Declaration sought

to harmonize the activities of donor governments, institutions and agencies; align their work with those of the national governments of low-income countries; and increase a sense of ownership among the intended beneficiaries of aid. However, the Advisory Group on Civil Society and Aid Effectiveness (2008) argue that the Paris Declaration "… fails to take into account the rich diversity of social interveners in a democratic society and fails to recognize the full range of roles played by CSOs (Civil Society Organizations) as development actors and change agents" (p. ii). The Advisory Group goes on to claim that "CSOs are often particularly effective at reaching the poor and socially excluded, mobilizing community efforts, speaking up for human rights and gender equality, and helping to empower particular constituencies" (p. ii). While we would want to support these aspirations, we would also stress the need to demonstrate what is being claimed here, to be able to point to research evidence that shows this to be the case. We would also stress that a strong civil society should be a complement to, not a substitute for, strong governmental institutions and services, particularly services that are equally accessible to all (MacLachlan et al., 2010).

The chapter by Griffiths et al., discusses the importance of Poverty Strategy Reduction Papers (PRSPs) as the primary documents that outline a country's development plans, at least in the short to medium term. PRSPs are the development agenda that disability needs to be on and so it is important that the GDPP make the sort of strong and determined statements that we have quoted above. Now that the issue of disability is at the "development" table we need to understand more about how the "development world" works and some of its inherent problems and challenges. MacLachlan et al. (2010) argue that the very term "development" is problematic, as it positions one group as being superior to another, and that development is about changes in relationships between people, rather than simply about technical or material gains, even though these are of critical importance too. MacLachlan et al. (2010) also argue that the international aid system can be understood through a triangular relationship concerning the psychological, socio-political and economic dominance of some parties over others; the injustice of such relationships, of poverty and of how organizations attempt to address poverty; and the implications of dominance, injustice and social and cultural change for the identity of the recipients of aid, as well as its givers and mediators. The themes of dominance, justice and identity also of course resonate with regard to the sort of disadvantaged relationships that people with disabilities often have with "mainstream" society.

1.2 What is this Book About?

The discerning reader will have noted that this is not the first text to address issues of disability and international development. This is both true and something to celebrate. The fact that there are now a number of materials available that address disability and international development (see, for example, Albert, 2006; MacLachlan et al., 2009; Watermeyer et al., 2006; Bhanushali, 2008; Barron and Amerena, 2007) and overarching policy-oriented documents such as the GPDD