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17 Research Training and the Organizational Politics of Knowledge: Some Lessons from Training Disabled Researchers in Southern Africa  
*Leslie Swartz*

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Disability and Human Rights: Global Perspectives

Edurne García Iriarte  
Roy McConkey  
Robbie H. Gilligan

[A] comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities will make a significant contribution to redressing the profound social disadvantage of persons with disabilities and promote their participation in the civil, political, economic, social and cultural spheres with equal opportunities, in both developing and developed countries.

UN Convention on the Rights of Persons with Disabilities  
Preamble (y)

Introduction

The first two decades of the 21st century are a critical period in the history of disability and human rights. The first human rights treaty of the current century – the Convention on the Rights of Persons with Disabilities (CRPD) – was adopted by the United Nations in 2006. The signing by 158 countries within eight years of the adoption of the CRPD demonstrates that the world community has embraced disability – at least at an aspirational level – as a human rights issue. Empirical data from the World Report on Disability, furthermore, illustrates that disability is a global phenomenon experienced by more than 1 billion people.

The majority of disabled people, about 80 per cent, concentrate on the developing world and they are among the poorest in developed countries. Disabled people the world over continue to experience poorer access to education, employment and health services, and their outcomes in those areas are significantly worse than the rest of the population. Despite this striking reality, we know little about the disability experience outside developed and Western countries. It is timely, therefore, that the goal of this book is to explore disability and human rights using a global approach.
This book aims more specifically at exploring a number of themes in relation to specific articles of the CRPD and doing it from various global perspectives: with a focus on disability experiences in a variety of countries and socio-economic contexts, reflecting the diversity of impairments, using the voices of disabled people, families and professionals, and providing the evidence for developing mainstream policies and services. The approach of the book is applied, building on empirical evidence and using individual experiences of disability. In this introductory chapter, we seek to provide a common background for understanding the approach and scope of the following chapters. We start the chapter by briefly presenting the CRPD, which is used as a common thread in all the chapters. We also present some of the challenges the CRPD faces in its implementation. We move on to outline the global dimensions that the book aims to convey. We then introduce three key strategies where different actors can collaborate on the implementation and monitoring of the CRPD: advocacy, research and evaluation. The chapter concludes with a brief note on terminology.

The Convention on the Rights of Persons with Disabilities (CRPD)

We have chosen the CRPD as the compass for the analysis of rights in this book because it builds on previous human rights instruments, it culminates decades of work by disabled people across the world and it is the result of ground-breaking collaboration between disabled people, their organizations and national governments. The UN General Assembly adopted the CRPD in December 2006. It is a human rights treaty including 50 articles referring to civil and political rights, as well as economic, social and cultural rights (Quinn, 2009; Schulze, 2010). Rights are basic standards that enable people to have dignified lives and be valued for their inherent worth as human beings. The CRPD does not create any new rights but refocuses on the existing rights within the realm of disability (Quinn, 2009). It effectively shifts the focus from treating disabled persons as objects of charity to seeing them as active holders of human rights. The quote from the CRPD below this chapter’s title shows the scope of the treaty. It focuses on protecting the rights and dignity of disabled people, redressing the social disadvantage they experience and promoting their participation in all areas of life with equal opportunities, covering both developing and developed countries. Explicit in the CRPD is the view that disabled people should experience human rights on an equal basis to non-disabled people and the acknowledgement of their contribution to the overall well-being and diversity of their communities.

Challenges to the implementation of the CRPD. The CRPD provides a completely new framework within which to think and act in relation to disability issues. It addresses many actors. It supports and challenges those actors to embrace new ways of seeing, understanding and responding to disability. But treaties or words on paper do not guarantee actions. The words on the pages of the CRPD represent intentions, but the harsh reality is that intentions are
not always honoured; they do not always translate into actions. Common challenges to the CRPD and other human rights instruments are difficulty in monitoring their implementation, too abstract or ambiguous terminology that can have different interpretations depending on culture, norms, laws and so on and dependence on state resources (Stein, 2007). Yet securing such state resources may become increasingly difficult. ‘Austerity’ has become a guide word in policy-making in many countries. This austerity may come as a response to tackling public debt, or it may represent a new hostility among many political elites to the very principle of public spending on social programmes in general. In such a climate, the role of civil society seeking reform and investment in CRPD inspired disability programmes becomes even more vital. There are many metaphors that can meaningfully be used to emphasize the significance of the CRPD: it serves as a conscience for the global community on disability issues; it serves as a bridge between disability and development issues, especially for developing countries; it serves as a stimulus to ensure that new policy instruments such as the Sustainable Development Goals (successors to the Millennium Development Goals) or national statutes can no longer be silent on issues of disability; it serves as a monitor of key budgetary and policy decisions as they impact on disability; it serves as a gathering point for civil society and other interested actors who wish to promote disability issues and awareness.

CRPD and this book. As noted in the CRPD preamble, rights are inalienable, universal, indivisible, interrelated and interdependent. So rather than reading this book as isolated chapters on specific rights, it should be read as one whole consisting of complementary chapters that together provide a unique resource on how disabled people can be enabled to fully enjoy their human rights. The first set of chapters (2–6) examines the main premises around which the CRPD is based. The next eight chapters (7–14) focus on specific articles in the CRPD that are integral to achieving full and equal participation of disabled people in human societies and across the life cycle. The final three chapters (15–17) examine the contribution that family carers, professionals and researchers can make to the realization of rights. In parallel to the analysis of rights, the book provides a broad exploration of underlying themes, which are examined in depth in dedicated chapters and elaborated upon in other chapters: poverty, support and culture.

A billion people experience disability and about 80 per cent of them live in developing countries in conditions of poverty. Ghosh, Dababnah, Parish and Igdalsky present a comprehensive picture of disabled people’s experience of poverty and social exclusion in Chapter 6. This is closely interrelated with war and disability, which is explored by Balcazar and Balcazar in relation to a number of armed conflicts around the world (Chapter 7), and with livelihoods, the focus of Coleridge’s discussion in Chapter 12.

The theme of support in its multiple forms is pivotal in a number of chapters. Gilligan in Chapter 8 offers a thorough review of disabled children’s rights and the support to them and their families in their varied and unique experiences of childhoods; MacLachlan, Mannan and McVeigh discuss health care support through the concept of inclusive health in Chapter 10; Baños provides a broad account of assistive technology as a source of support in
Chapter 11; McCallion and McCarron focus on support in relation to ageing disabled people in Chapter 14; McConkey explores support to family carers in Chapter 15 and Cornielje and Tsengu analyse the role of professionals as supporters of disabled people in Chapter 16.

Through the different chapters, authors analyse and contest the global rights discourse when applied to specific local contexts. Lewis Gargett and colleagues provide a thorough discussion of the cultural dimensions of disability in Chapter 5, a theme later applied by Muthukrishna and colleagues to their critical review of international inclusive education policies as they are implemented in the Global South (Chapter 9); Lamichhane analyses the Japanese independent living model in the Asian region in light of local cultural realities (Chapter 13) and Swartz draws on organizational culture in his discussion of research training to disabled people’s organisations (DPOs) in Africa (Chapter 17).

Although the CRPD is a springboard for the development and implementation of programmes, policies and legislation to ensure disabled people exercise their rights, these are mediated by the lived experience of disability in all its dimensions: the individual experience of impairment, the cultural understanding and culturally mediated responses to disability, the particular ontology of the human being according to various ideologies and its corresponding alignment with human rights and the contextual sociopolitical and economic realities of (un)democratic regimes, war, armed conflict and poverty. These factors play critical roles in deciding how a global disability rights discourse can be implemented or even whether it is desirable for it to be implemented within specific cultures (Ingstad and Reynolds Whyte, 2007).

The book nevertheless does not cover the full spread of articles and rights provided for in the CRPD. Due to limitations of space we had to be selective. We hope that our example will encourage others to undertake a similar review of the articles that we have not featured in this book. A full text of the CRPD can be viewed at United Nations Enable: the official website of the secretariat for the CRPD (http://www.un.org/disabilities/).

Global perspectives

The authors, drawn from all continents, provide readers with global perspectives on disability in four senses. Firstly, they aim to address core issues underlying the denial of disabled people’s human rights and their continuing social exclusion (Barnes and Mercer, 2010; Goodley, Hughes and Davis, 2012; WHO and World Bank, 2011). On a more positive note, they identify practical ways to effect change locally, with examples from a variety of countries in Africa, the Americas, Australia and Oceania, Asia and Europe. Secondly, the chapters bring together examples of the myriad insights of disabled people, professionals, families and carers from across the world. Thirdly, a diversity of impairments is covered including those that require more intensive support – intellectual, physical, sensorial and psychosocial – and this is done within a life-course perspective from early childhood to old age. The similarities in terms of exercising human rights are striking across all these impairment groupings, yet
traditionally they have pursued separate and often competing agendas (Barnes and Mercer, 2010). Fourthly, our focus is on providing the evidence to develop mainstream services and policies that are available to all citizens, in all countries, and that can better respond to the needs of disabled persons. Specialist disability services in the 21st century also need to be transformed globally if they too are to respect and promote the human rights of their consumers (WHO and World Bank, 2011).

Implementation

The purpose of the CRPD is ‘to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity’ (UN, 2006). A core theme throughout the book is therefore the exploration of new ways of thinking about the implementation of the CRPD and how equality and participation in all life areas can become a reality for most, rather than for just a small percentage of, disabled people.

While the CRPD signposts the direction of travel, there are a myriad of starting points for the journey and countless means of travelling on what can be a difficult and bumpy road. The World Report on Disability (WHO and World Bank, 2011) marks a common path for change, both nationally and globally, to help accomplish the goals of the CRPD. One of its recommendations is the collaboration of different actors – governments, civil society organizations, professionals, the private sector and disabled people’s families – around various areas as summarized in Table 1.1.

Following on this recommendation, the focus of this book is on change primarily at the micro level of interactions between disabled persons and those closest to them: family, carers, fellow citizens and professional workers. This is one of the levels where a significant impact can be made in enabling disabled people to live dignified lives. Thus the book provides both a conceptual and practical understanding of how empowered disabled persons, professionals, families and carers can contribute to the ‘bottom-up’ implementation of the CRPD within specific local contexts at differing stages of the life cycle and around key themes of poverty, civil conflict, education, health, assistive

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<td>8. Improve disability data collection</td>
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technology, livelihoods and independent living. Cooperation between these key players is an essential contributor to success (WHO and World Bank, 2011).

The chapters of this book articulate, in various ways, the collaboration between these key stakeholders – disabled people, professionals, carers and family members. Three strategies prove to be particularly significant at enhancing the interaction between these stakeholders so that they work together to achieve disabled people’s goals and improve the life chances of those who experience disability: advocacy, research and evaluation. The brief introduction given to them here will be further developed in later chapters.

**Advocacy**

The role of advocacy cannot be overstated in the passage of disability anti-discrimination legislation, change of attitudes towards disability and equality of disabled people both nationally and internationally (Bickenbach et al., 1999). Advocacy is about using political participation to influence decisions about political, economic and social systems and organizations. Further reviewed by Malinga and Gumbo in Chapter 4, advocacy is perhaps the strategy most widely used worldwide by disabled people, and their families, to ensure they are active agents in change.

Disability movements across the world have been major drivers of change (Barnes and Mercer, 2010; Bickenbach, 2009; Goodley, 2011). Indeed, disabled people’s activism has helped to shift international approaches to disability from individualized to social responses and put disability on the human rights agenda since the 1970s (Barnes and Mercer, 2010; Goodley, 2011; WHO and World Bank, 2011) – a theme developed further in Chapter 3. Chapters 3 and 4 explain how the CRPD emerged from the intense lobbying and engagement with disabled activists from around the world. The goals of the disability movement have therefore been embedded in the CRPD through the active participation of disabled people and international disabled people’s organisations (DPOs) (Schulze, 2010). For example, the goal of independent living was incorporated into Article 19 of the CRPD, ‘Living independently and being included in the community’ (see Chapter 13). Moreover, a broad coalition of DPOs and allied non-governmental organisations (NGOs) formed the International Disability Caucus, which developed into the strongest civil society voice in the negotiations (Schulze, 2010). Thus, the process of negotiating and drafting the CRPD and the final document honour with each of its articles the disability maxim ‘Nothing about us without us’ (Charlton, 1998).

Advocacy, then, is a strategy led by disabled people, in which professionals and families/carers can offer support in various forms. In essence, this supportive function requires a radical reappraisal of professional and familial conceptions of their role in relation to disabled persons from ‘doing things for them’ to supporting them ‘to be in charge of their own lives’. More profoundly, it entails a deepening appreciation of disabled persons as ‘rights holders’, of disability as a form of social oppression and of the multiple oppressions experienced by disabled people, especially in relation to poverty. Along these
lines, professional advocacy aligned with disability rights is recommended in Chapter 16. The book provides examples of this spirit of empowerment which needs to be replicated at a local level with leadership coming from disabled persons, supported and empowered by families and professionals with the engagement of local and national politicians (WHO and World Bank, 2011).

**Research and evaluation**

Research and evaluation are two additional strategies that have the potential to enable the interaction among various stakeholders in order to promote the exercise of disabled people’s rights. In recent years research endeavours have taken on a new dimension by involving disabled people in research and evaluation through participatory approaches. In this way the stakeholders involved contribute their knowledge and expertise, increase their awareness of the issues being tackled and learn technical aspects as they participate in the identification of the problem, data collection, data analysis, report writing and so on. This involvement aims to ensure that these processes are relevant to all; that findings can be applied to address disability issues; and that disabled persons can gain ownership over the resources, process and outcomes of research and, in turn, influence advocacy. A major focus of such research is to assess the extent to which disabled people’s rights are respected and enforced as provided for in Article 31 of the CRPD (‘Statistics and data collection’).

Three main approaches to participation in research have been used with and by disabled people: *participatory action research* (MacDonald, 2012), involving disabled people in research that aims at taking action and producing change; *inclusive research*, in which people with the label of intellectual disability participate as co-researchers (Walmsley and Johnson, 2003); and *emancipatory research* (Barnes, 2006; Zarb, 1992), in which disabled people hold the power over the research process and this process is oriented towards social change (Walmsley, 2001).

Likewise, two main approaches have evolved in relation to evaluation: *participatory evaluation* (Cousins and Earl, 1992) and *empowerment evaluation* (Fetterman and Wandersman, 2005). Underlying both approaches is the involvement of programme participants who contribute valuable knowledge to the evaluation process as experts with the lived experience of the issue being researched – in this case, disability. Evaluation is not only about identifying which activity impacts on what outcome (for example, implementing a disability-awareness campaign to change public attitudes towards disabled people) but about how valid that assumption is (for example, how much evidence is there to suggest that an awareness campaign really produces a change in the public attitudes towards disabled people?). This involves thinking and developing theory about how individual and social change is produced (Lipsey and Cordray, 2000). The collaboration of disabled people, professionals and families/carers in evaluation of programmes, community initiatives and policies within local contexts can enable monitoring of the implementation of the CRPD by civil society as provided in Article 33 (‘National implementation and monitoring’).
Terminology

We appreciate that disability terminology is contested. ‘People with disabilities’, ‘disabled people’, ‘people with impairments’, ‘Deaf people’, ‘people with intellectual disabilities’ and ‘visually impaired people’ are all commonly used terms in disability research, legislation, policy, advocacy, testimonies and so on. In recent years they have come to be accepted as politically correct terms in international fora, replacing the stigmatizing and discriminatory language that can still be present in all societies around the world. The varying terms reflect, however, differing perspectives about disability. The CRPD offers the following description of disability and disabled persons (see Box 1.1).

The CRPD, similar to previous international UN documents, and the *World Report on Disability* use the terminology ‘persons with disabilities’, which emphasizes the human value of people (people-first language) and does not lead to an interpretation that the ability to function as a person has been disabled, as ‘disabled persons’ may imply (Schulze, 2010). Other scholars and activists, however, prefer to call people with impairments ‘disabled people’ to accentuate society’s role in disabling individuals from their participation in various life areas (the disabling role of society is further explained in Chapter 2). Although the use of one or another term (‘people with disabilities’ or ‘disabled people’) often generates vivid debate within Anglophone contexts and among native English speakers, the differences underlying the terms – ‘impairment’ and ‘disability’ – do not necessarily translate into other languages, for example, Nordic languages (Traustadóttir, 2004) or in Zairean Songye terminology (Devlieger, 1995). Although some of these terminological differences are further explored in the book, authors were free to use the various terms above to reflect their own and others’ understanding of disability. We concur with Albrecht, Seelman and Bury (2001) in that ‘the discussion needs to continue, be respectful and aim at understanding’ (p. 3). In the future, perhaps

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**Box 1.1. CRPD description of disability**

**CRPD Preamble (e)**

Recognizing that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.

**CRPD Article 1**

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

Both these statements should be read in combination (Schulze, 2010).
the fundamental distinction between ‘disabled and non-disabled’ that we have inherited from previous generations will gradually lessen as the common rights of all human beings are more fully exercised internationally.

More central to the work presented in this book than the terminological debate is the fact that the CRPD has been officially published by the UN in just six different languages out of the few thousand languages in the world. Further, there is no official easy-to-read version or an official sign language version. The website of the CRPD secretariat makes available non-official translations of the document into spoken languages and sign languages (more than 25 in total) and easy-to-read versions (six in total). The following disclaimer, however, is made: ‘These non-official versions of the Convention ... are for informational purposes only; they do not constitute endorsement of, or an approval by, the United Nations ... The United Nations bears no responsibility for the accuracy, legality or content ...’ As key and basic as accessibility is for the exercise of disabled people’s rights, the sacred text on this matter fails to provide minimal access to those with different language access needs and those speakers of other languages into which the CRPD is not translated. This is yet another example of the work that needs to be done at all levels if disabled people are to become active agents in the exercise of their rights. It is our hope that this volume is a start in bringing this about.

Book structure

The book has been carefully assembled so that readers gain a progressive understanding of disability and human rights. To facilitate readers’ assimilation of ideas and generate critical thinking, each chapter includes a summary of key points followed by study questions. The summary of key points is a refresher of the main issues discussed in the chapter and provides a starting point to work on the study questions. Study questions can be used for individual self-reflection or in group discussions. It is our hope that both the key points and study questions generate vivid debate, further inquiries and multiple responses to local disability issues in all places where the book is read. Such discussions will be all the richer when disabled people invite their professional supporters and students in training to join in the dialogue.

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