

Editorial

Disability, poverty, human rights and the need for accurate data to promote action

*Handicap, pauvreté, droits de l'homme et le besoin de
données précises pour développer l'action*

In May 2008, the UN Economic Commission for Africa (UNECA) and Leonard Cheshire Disability (LCD) organized an international meeting in Addis Ababa, Ethiopia on the UN Convention on the Rights of Persons with Disabilities with a specific call for action on poverty, lack of access and discrimination.¹ This edited volume of *Alter* includes a series of papers from that conference, which provide a solid starting point for future discussions of the links between human rights, poverty, lack of access and discrimination for persons with disabilities.

The research presented here is both significant in itself and important because the goal of the conference was to underscore the need to address global disability issues within the larger context of international development policy. As part of this effort, the need for accurate data to complement, fortify and amplify the call for human rights found in the new Convention was emphasized.

Importantly, the convention not only affirms the rights of persons with disabilities but also calls for solid research and empirical data to ensure that these rights are achieved and maintained. The need for empirical data is imperative if persons with disabilities are to be effectively reached by programs that address social inclusion and poverty reduction. This need for solid data is all the more important as the field of global development is currently framed by the Millennium Development Goals which emphasize the need for measurement, monitoring and evaluation to track progress or identify impediments to progress. Empirical data has become the lingua franca of global development.

The global Disability Rights movement is not alone in finding itself called upon to provide empirical data in order to identify needs, allocate resources and prioritize issues. Other social movements and advocacy groups from those who work on behalf of women or children, to the HIV/AIDS advocacy community and indigenous peoples' groups, also find themselves called

¹ The UN Convention on the Rights of Persons with Disabilities: a call for action on poverty, lack of access and discrimination, organised by UN Economic Commission for Africa (UNECA) and Leonard Cheshire Disability (LCD). United Nations Conference Center, Addis Ababa, Ethiopia, 19–22 May 2008.

upon to link broader discussions of rights and entitlements to more specific discussions of “what” rights and “what” entitlements are needed and how these can be measured, assessed, evaluated and monitored.

The increasing emphasis on the need for empirical data for persons with disabilities, particularly in developing countries where there has been relatively little attention or funding for such research, might thus be seen as a step forward. Building a body of data on persons with disabilities in the developing world to answer the call put forth by the Convention is a process that should enhance dialogue with global organizations, regional and national governing bodies, local governments and civil society—groups that have had, until recently, little meaningful interactions with persons with disabilities or their organizations.

Be it the Washington City Group’s attention to the inclusion of persons with disabilities in national censuses, the WHO–World Bank’s forthcoming World Report on Disability, the work of bilateral agencies, the solid research coming from DPOs, NGOs, or the increasing amount of research from the academic sphere, a growing body of information is beginning to make it increasingly easy to allow advocates and policy makers to discuss disability issues based on empirical data in support of the rights now guaranteed in the Convention. The paper in this volume represent further contributions to this discourse reflecting the span of work presented by the assembled scholars, advocates and policy makers at the conference.

In the following papers, the reader will find the issue of poverty and disability is the dominant theme. The paper by Dubois and Trani is an important contribution to the literature, placing the issue of disability within the larger framework of Amartya Sen’s Capability approach. This framework, intended to address poverty through a human rights perspective, has received growing attention over the past few years. Dubois and Trani’s paper helps to more clearly elucidating how this approach can be used specifically to strengthen disability research.

Braithwaite and Mont’s paper is also a significant contribution to the literature. Noting that while disability and poverty are assumed to be closely linked, there have been few attempts to examine these links, they propose and test a methodology to empirically examine poverty and disability in line with both the WHO’s International Classification of Functioning and Sen’s Capability model. Using data from the World Bank’s Poverty Assessments, Braithwaite and Mont provide an innovative and intriguing approach to a more nuanced interpretation of available data.

The links between disability and poverty need to be understood not only at global levels, but also at the individual and the community level. For that reason, the paper by Boyce, Raja, Patranabish, Bekoe, Deme-der and Gallupe is of particular note. Their study from Ghana, of the association between an individual’s ability to maintaining employment after the onset of mental illness and that person’s ability to maintain stability or see an improvement in their health condition, is significant. The finding that people with mental health concerns do better both clinically, socially and economically if they are able to retain employment after the onset of their illness should come as no surprise—continuing social, professional and economic relationships can provide meaning and stability to life. Assuming that this is the case and actually having the data to prove it however, are two different things. This is especially true for the developing world where, until recently, so little information on specific groups and subgroups with different types of disabilities has been available. While the body of research on the social and economic ramifications of mental health impairments from developed countries is daunting, by comparison, there has been a striking lack of empirical data from developing countries. This paper helps fill that gap.

The paper by Schneider, Dasappa, Khan and Khan on measuring disability in the South African census also represents this movement towards evidence-based discussions. They begin their paper with a quote from the South African Minister of Finances, who writes: “if you can’t measure it, you

can't manage it"—a statement which clearly echoes the efforts of the UN's Washington Group to carefully enumerate the number of persons with disabilities on local, regional and national bases. The link between enumerating the number of people with disabilities in a population and the political, social and economic implications this has for rights and full inclusion is clearly addressed in the Convention. The importance of this "measuring" has also led to a series of meetings, conferences and study groups around the globe which are now attempting to overhaul censuses to include disability components. This is exacting work—and given the long-standing debate about how to identify who is and who is not disabled and what the consequences of being disabled means on a daily basis, the actual task of verifying the accuracy of the questions asked for census collection purposes takes on particular importance. The paper from Schneider and her colleagues therefore is important not only because it gives insight into what is going on in South Africa, but also because it provides a model that will be of interest to researchers, government officials and advocates working in other countries as well.

The paper by Lang broadens the debate. In this paper, Lang bridges the worlds of "rights-based approaches" and "development-based approaches" by arguing that how these two approaches are to be combined, as we move forward, warrants careful thought. Reviewing the political and intellectual antecedence of disability policy and practice, Lang concludes that while the Convention is an important step, it is a necessary but insufficient instrument to alone ensure real change. Lang's argument links well with the other papers in this volume. He argues that we will need more than words, we will need programs—and empirical data about these programs that reflect what is happening in the real world—if we are to effectively design and monitor policies that make an actual difference in the daily lives of people with disabilities.

Finally, the piece by Kembhavi adds another dimension to this set of papers—the importance of participatory research and of collecting data directly from persons with disabilities themselves. In this study, the question of framing a participatory research project is even more significant because it involves a group from whom we hear all too little, even within the realm of disability research—adolescents with disability. In Kembhavi's study, these young people have taken research into their own hands—quite literally—by photographing and then interpreting the world in which they live. Highlighting what makes them happy, what makes them sad and what they would like to change in their world—simple questions that frame complex and insightful answers—Kembhavi shows how these young people are able to share new insights and thoughtful commentary on the world in which they live.

In summary, this edited volume represents a solid contribution to the growing field of disability research. Researcher Dr Jean-Francois Trani is to be commended for ably guiding this edition into print and bringing together such a solid group of research papers. I am confident that the readers will not only find these papers of interest, but that the research reported here will provide readers with new ideas and interesting insights for future research, programming and advocacy.

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