

## **EDITORIAL**

### **Knowledge and disability inclusive development**

*Charlotte Scarf, Fiona Budge and Rosamond Madden*

One billion people or 15 percent of the world population live with some form of disability, or significant difficulty in functioning in their everyday lives (WHO & World Bank 2011). Improving quality of life for people with disability is of particular concern in low and middle income countries which are home to nearly 80 percent of people with some form of disability, the vast majority of whom live in poverty (WHO & World Bank 2011). This situation reflects a strong enduring link between disability and poverty whereby more people living in poverty have some form of disability due to factors such as inadequate housing, sanitation, nutrition and unsafe work conditions, as well as widespread barriers to services including health and education; and more people with some form of disability live in poverty due to factors such as unemployment and expenses required to manage their disability. Across all countries and income levels, people with disabilities have lower health status than the rest of the population (WHO 2014), and frequently face discrimination in their everyday lives (WHO & World Bank 2011).

The international community has signaled its commitment to address the disadvantages experienced by people with disabilities through the promulgation of numerous treaties, policies and action plans. Among these, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is preeminent (UN 2006). The UNCRPD is an international legal and normative framework and policy guide to ensure people with disabilities have the same rights as everyone else to be treated equally under law, to access the same quality of services, and to have the same opportunities to participate in social, economic and political life. As of September 2016, the landmark treaty had been ratified by 167 countries (UN Division for Social Policy and Development 2016)

Disability inclusive development is emerging as a global priority, as is evident by explicit reference to persons with disabilities in the 2030 Agenda for Sustainable Development (UN 2015a). Persons with disabilities are specifically included in five of the Sustainable Development Goals (SDGs), namely: Goal 4 to ensure equal and accessible education by building inclusive learning environments and providing necessary assistance for persons with disabilities; Goal 8 to promote inclusive economic growth and full and productive employment, allowing persons with disabilities full access to the job market; Goal 10 to

empower and promote the social, economic and political inclusion of persons with disabilities; Goal 11 to create accessible cities and water resources, affordable, accessible and sustainable transport systems, and universal access to safe, inclusive, accessible and green public spaces; and Goal 17 to increase availability of high-quality, timely and reliable data and monitoring of the SDGs, emphasizing disability disaggregated data (UN 2015b).

This Special Issue explores the role of knowledge and knowledge processes in disability inclusive development in low and middle income countries. Disability inclusive development requires negotiated understanding and synthesis of ‘multiple knowledges’ (Brown 2011) to address the multiple forms of disadvantage experienced by people with disabilities in diverse settings. To this end, contributors to this special issue share a concern with various ways in which different types of knowledge are recognized, valued and shared by different stakeholders in the development process, to generate new insights and evidence to inform policy and program planning to address disability-related disadvantage in different contexts. The purpose is to enhance understanding of how we can create fertile conditions for insightful learning and meaningful action among all stakeholders concerned with disability and development who have different ways of knowing and experiencing the world.

This focus has been precipitated by new understandings about disability, challenging the medical focus on physical or intellectual impairments. In line with the UNCRPD and the World Health Organization’s International Classification of Functioning, Disability and Health (ICF), which provides a standard language and framework for describing and organizing information about disability, we recognise the important role of environmental factors in affecting people’s functioning (WHO 2001). Environmental factors include physical factors such as climate, terrain and building design, and social factors such as attitudes, institutions and laws, which may exclude people with health conditions and functioning difficulties from full and equal participation in society. Personal factors such as race, gender, age, educational level and employment may also be relevant, and this is recognized but not classified in the ICF. Through this bio-psycho-social lens, disability is understood as a dynamic interaction between a person’s health condition and the physical and social environment. This put the onus on knowledge and knowledge processes that can shed light on these interactions and inform actions needed to improve people’s functioning in vastly different contexts.

Contributors to this special issue all share this focus, despite the dominance of medical and other social and cultural approaches to disability in many of the contexts that are explored in their research. Study sites range from grassroots communities to entire countries and regions in Africa, Asia, Central America and the Pacific Islands. Persistence of differing approaches to and treatment of disability in many of these settings has resulted in considerable research

and policy neglect of environmental barriers to inclusive development which many of our contributors seek to highlight by uncovering often neglected forms of knowledge. Appropriately, their papers cover a broad range of topics. These topics move beyond the usual concern with including the perspectives of persons with disabilities in the formulation and implementation of community-based development projects to encompass a much broader range of stakeholders, operating at both the micro and macro-levels. To accommodate a large number of contributions expected to be of interest to KM4Dev readers, the special issue has two editions. This first includes eight papers that highlight the variety of knowledge and knowledge processes that are required to advance disability inclusive development.

**The first paper by Sunil Deepak and colleagues** focuses on the sharing of life stories by persons with intellectual disabilities in the rural Mandya district of Karnataka, India. The authors adopted an emancipatory research approach to enable persons with a variety of intellectual disabilities to be active contributors in defining their own social issues or problems and identifying strategies for overcoming them, as part of an impact assessment of a local community based rehabilitation (CBR) program. This is novel for two reasons: firstly, application of emancipatory research in the context of CBR has been extremely limited; and secondly, persons with intellectual disabilities have largely been excluded from disability research more generally. By engaging persons with intellectual disabilities in emancipatory research about CBR, the paper underscores the substantial local knowledge they are able to bring to development.

**The second paper by Michael Millington and colleagues** discusses CBR monitoring as a potential source of ‘empowered knowledge’ for inclusive development. It focuses on a collaborative research project involving a team of disability and development researchers and CBR practitioners from 7 countries in Asia and the Pacific who contributed to the development of a CBR monitoring toolkit. The authors (who include both academics and practitioners) posit that empowerment is the defining feature of CBR, which recognizes people with disabilities, their families and communities as experts of their own experience. They contend that this orientation is not currently complemented by CBR monitoring which is often imposed on communities by external experts with little lived experience of the issues they aim to address. Seeking to address this, project partners came together in a learning community dedicated to advancing good practice in CBR monitoring, which they conceptualize as striking a balance between the need to build systematic evidence about CBR and the need to ensure local control of monitoring systems and information design to reflect the changing needs and priorities of local stakeholders. Through the lens of their experience designing and building a CBR monitoring toolkit to balance these objectives, the authors argue that “Monitoring is empowerment when people, process and knowledge are united in community.”

**The third paper by Beth Sprunt and colleagues** reviews current approaches to disability data disaggregation of Education Information Management Systems (EMISs) in 14 Pacific Island countries. Disability disaggregation of EMISs is important to build government knowledge systems that can inform evidence-based planning and implementation of national disability-inclusive education policies. It is also important for measuring progress against global and regional commitments to improve access to quality education by children with disabilities, including the SDGs. In this study, the authors identify and compare approaches by which most countries in the Pacific disaggregate their EMISs by disability to some extent, paying particular attention to data on environmental barriers. They also compare EMIS capacity, or the degree of modification required, to enable reporting against global and regional indicators. The results indicate that, despite considerable progress to strengthen EMIS capacity for disability disaggregation and data analysis, most Pacific Islands countries require adaptations to align their EMISs with new understandings about disability as spelled out in their global and regional commitments to inclusive education. Extensive recommendations are provided to promote such adaptation and provide better data to improve access to quality education for children with disabilities in the region.

**The fourth paper by Elena Jenkin and colleagues** focuses on the largely untapped potential of film to serve as an accessible method for disseminating research findings to children with disabilities and their communities. Children with disabilities remain largely excluded from development research, particularly when it comes to dissemination which often takes place via academic publications and reports. The authors argue that researchers have an obligation to disseminate their findings to research participants who contribute to knowledge development and to communities that are most affected by it, in a format that is accessible to them, to respect their investment in the research process and to stimulate uptake of the findings. They report on their experience using film to report back the findings of their study on human rights challenges and concerns of children with disabilities in the Pacific Island countries of Vanuatu and Papua New Guinea. The medium of film, they claim, resonated with the story telling traditions of local communities, and supported awareness raising of the human rights challenges faced by the children who participated in the research.

**The fifth paper by Emma de Wit and colleagues** discusses ‘vicarious learning’ as a strategy to improve the quality of education for children with disabilities at remote rural schools in Ethiopia which often struggle to meet their commitment to provide disability inclusive education. The authors present three case studies of initiatives based on vicarious learning principles – the idea that learning from the modeled experience of others can help people find solutions that fit their own unique context. These initiatives were developed and implemented by the authors to address the identified needs and priorities of particular schools to overcome environmental barriers to education by children with disabilities. The initiatives included: the

narration of stories to advance teaching skills on special needs; a reflection and learning workshop to improve classroom interactions; and a play to raise awareness in the wider community. The authors argue that these and other vicarious learning initiatives have strong potential to aid the advancement of disability inclusive education by distributing rich, vivid, practice-based evidence to remote settings.

**The sixth paper, a case study, by Alexandra Lewis-Gargett and colleagues** focuses on the relationship between Western health-related rehabilitation and traditional health practices for people with disabilities in the Pacific Islands where there is little extant research on this topic. The authors outline broad trends in the uptake of different cultural approaches to healthcare, and pose questions for further research that can help to improve understanding and facilitate the coordinated integration of these different approaches as a means to improve the health and wellbeing of people with disabilities in the region.

**The seventh paper, a story, by Mark Spreckly and colleague** provides a personal reflective account of the challenges encountered, and the unique contributions made, by a researcher with moderate bilateral hearing loss when undertaking a field study on the impact of hearing loss in Guatemala. Spreckly is a doctoral student based in UK. His story also captures some of the complexities involved in undertaking disability research in a very different economic, cultural and linguistic context to one's own.

**The eighth and final paper in this special issue by Donruedee Srisuppaphon and colleagues** is a 'tools and methods' piece which reviews and critiques the disability inclusiveness of the Healthcare Accreditation Programme for hospitals in Thailand. Comparing the program against key elements of the UNCRPD, and with health-related rehabilitation accreditation programs in the USA, UK and Australia, the authors argue that revision is important to improve access to quality healthcare for people with disabilities in Thailand.

Together these papers highlight the enormous variety of knowledge and knowledge processes that are relevant – and indeed essential – to improve the quality of life of people with disabilities in low and middle income countries. The complex and multi-dimensional nature of this goal demands the breaking down of barriers between different types of knowledge and knowledge processes that bring them to light, in order to generate new insights and strategies to accomplish this shared imperative.

### **Our thanks**

Finally, we would like to thank all of the contributors who have written papers for this issue, and all of the colleagues who reviewed papers and provided feedback to authors. We are very

pleased with the quality of the contributions and would like to thank the authors for the efforts they have made to view disability inclusive development from the perspective of knowledge.

*Charlotte Scarf (Lead Editor), Fiona Budge, Rosamond Madden, Sunil Deepak, Beatriz Miranda, Penafrancia (Penny) Ching and Maya Thomas with Sarah Cummings*  
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## About the Guest Editors

*Charlotte Scarf* is an independent researcher, writer and editor based in New York City, and an Honorary Research Fellow at the Centre for Disability Research and Policy at the University of Sydney. Her research is concerned with the politics of inclusion in knowledge-based development initiatives. She is interested in questions about power, partnership, participation, communication and learning in North-South encounters in the context of inclusive development. She holds a PhD in International Studies, a Masters Degree in Communication, and a Bachelors Degree in Economics with Honours in Political Economy. Email: [charlotte.scarf@sydney.edu.au](mailto:charlotte.scarf@sydney.edu.au)

*Fiona Budge* is an independent researcher, trainer and facilitator. Born in New Zealand, she has lived and worked in Nigeria, Indonesia and Europe. She is a former supervisor and lecturer at the VU University in Amsterdam and a researcher for Disability Studies in

Nederland (DSiN). She holds diploma's in Occupational Therapy and Comprehensive Nursing (Technical Institutes in NZ), a Bachelor in Cultural Anthropology and Public Relations (USQ, Australia) and a Masters Degree in Medical Anthropology and Sociology (UvA, The Netherlands). Email: fionabpost@yahoo.co.nz

*Rosamond (Ros) Madden* has worked on disability information, statistics and research since 1992, in government and at the University of Sydney where she now serves as an Honorary Senior Research Fellow. Ros has worked internationally with the WHO on disability and other classifications for 20+ years, was a member of the Editorial Committee for the World Report on Disability (2007-2011) and is a current member of the Editorial Board of Disability, CBR and Inclusive Development (2011-current). Her continuing research interests include: disability measurement and policy, in the framework of the UN CRPD and using the ICF; research and monitoring for community-based rehabilitation (CBR) and other disability-inclusive development programs. Ros was made a Member of the Order of Australia (AM) in June 2014 for her work. Email: ros.madden@sydney.edu.au

*Sunil Deepak* is an independent consultant, currently heading the north-east regional office of Mobility India in Guwahati (India) and is an advisor to Italian NGO "AIFO" (Bologna, Italy). He has been involved in CBR programmes in Asia, Africa and South America for about three decades, especially in preparation of learning materials, implementing training of community workers and participatory research and documentation. He has collaborated extensively with different UN organisations, especially with Disability & Rehabilitation team of the World Health Organisation. He has a Bachelors degree in Medicine, Postgraduate Diploma in Anaesthesia and Leprology and a Masters in Disability Studies. Email: sunil.deepak@gmail.com

*Beatriz Miranda* has been trained as a sociologist and anthropologist (Ecuador-Mexico, Belgium and England). She works at the VUMC University of Amsterdam. Her main field of study and research is development and disability including leprosy. She has been involved in social research and cooperation projects in the USA, Central and South America, Belgium, England, India, China and Indonesia looking at social issues linked to AIDS, disability, gender, religion, street children, post-coloniality, race and ethnicity. She was the study manager of the SARI Project in Indonesia that aimed to understand the life of people affected by leprosy in West-Java towards an improvement of their life conditions. Currently she coordinates the BRIDGES project between Brazil and Indonesia regarding sustainability of small leprosy and disability organizations. She teaches Disability research, Sociological approaches to stigma and Sociology of the body, Medical Anthropology. She is also the coordinator of the Disability Studies on-line Programme at the 17, Institute for Critical Studies in Mexico. Email: mirandabeatriz@hotmail.com

*Penafrancia (Penny) Ching* is a faculty member of the Department of Occupational Therapy, University of the Philippines Manila. She serves as the CBR program head of the College of Allied Medical Professions where she collaborates with various government and non-governmental organizations of persons with disabilities and CBR implementers. She is responsible for the preparation and training of students in different community-based

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programs that integrate community development principles with health programs. Penny has worked in various low-resourced settings especially in the context of disasters and how needs of persons with disabilities and vulnerable groups are addressed. She holds a Masters Degree in Community Development and Bachelors Degree in Occupational Therapy.  
Email: [peching@post.upm.edu.ph](mailto:peching@post.upm.edu.ph)

*Maya Thomas* is the Editor-in-Chief of *Disability, CBR and Inclusive Development Journal* ([www.dcidj.org](http://www.dcidj.org)). With a doctorate in Psychology, she has been an independent consultant for more than 25 years in the areas of policy development and strategy planning related to disability and development, particularly community based approaches; evaluation of disability programmes; and capacity building and training of planners and managers of disability programmes. Dr. Thomas was on the Editorial Committee of the World Report on Disability of WHO and World Bank (2011), and was a member of the Core Group for the development of the WHO CBR Guidelines (2010). Email: [thomasmaya@hotmail.com](mailto:thomasmaya@hotmail.com)

*Sarah Cummings* is the Editor-in-Chief of the *Knowledge Management for Development Journal* which she founded with a group of colleagues in 2005. She is currently working as an independent social entrepreneur focusing on knowledge and development. She is a member of the KM4Dev community. Email: [sarahcummingswork@gmail.com](mailto:sarahcummingswork@gmail.com)