Scarf, C., F. Budge, R. Madden, S. Deepak, B. Miranda,
P. Ching, M. Thomas and S. Cummings. Editorial. 2016.
Knowledge and disability inclusive development.
Knowledge Management for Development Journal 11(2): 1-6
http://journal.km4dev.org/

EDITORIAL

Knowledge and disability inclusive development

Charlotte Scarf, Fiona Budge and Rosamond Madden

This Special Issue explores the role of knowledge and knowledge processes in disability inclusive development. To accommodate a large number of contributions we hope will be of interest to KM4Dev readers, the issue has been divided in two parts. The first part of the Special Issue was published in September 2016, and contains a more substantive editorial detailing the common objective of contributors to build understanding of the various ways in which different types of knowledge are recognized, valued and shared by different stakeholders in the development process, with the aim of generating new insights and evidence to inform policies and programmes to address disability-related disadvantage in low and middle income countries.

This second edition comes at the dawn of a new year and a new administration in the USA where fears are widespread about the potential impact of so-called post-truth policymaking and programme planning. These fears extend to efforts to protect and promote disability rights, and rights-based approaches to development more generally. During the extended general election, president-elect Donald Trump was widely criticized for mocking a reporter who has arthrogryposis, a chronic condition affecting the joints. The controversial incident subsequently became the subject of a Hillary Clinton advertising campaign, and disability issues took centre stage at the Democratic National Convention in July.

We hope that this unprecedented emphasis on the rights and struggles of people with disabilities during the US election will translate into broader interest and support for policies and programmes to improve quality of life for people with disabilities worldwide in coming years. This edition includes 8 papers that highlight the enormous variety of knowledge and knowledge processes that are relevant - and indeed essential - to inform such policies and programmes and accomplish this shared imperative.

The first paper by Erik Post and colleagues outlines the theoretical rationale and impetus for ‘Participatory Inclusion Evaluation (PIE)’, a framework developed by the authors for evaluating community-based rehabilitation (CBR) programmes. CBR is a community development strategy promoted by the World Health Organisation (WHO) to support people with disabilities, their families and communities in low and middle income countries.

Although CBR is widely acclaimed practice, evidence about efficacy is lacking (World Bank and WHO 2011; also see Millington et al. in the first edition of this issue). In seeking to provide a flexible and rigorous approach for assessing and generating quality evidence about the outcomes and impact of CBR programmes, PIE draws on diverse evaluation theories and methods commonly used in international and community development, in particular Outcome Mapping. The framework has been field tested in Uganda and Malawi, and is notable for its emphasis on participatory and creative mixed methods of data collection.

The second paper by Valerie Karr and colleagues reports the findings of the ‘No One Left Behind’ pilot study of a methodology for assessing the inclusion of people with disabilities as target beneficiaries of international development projects. Using the World Bank as a test case, the paper focuses on the gap between rhetoric and reality of the Bank’s commitment to disability inclusive development based on an analysis of publically available information about active projects from 2009-2015. Only 2% (52 of 2,576 projects) were considered disability inclusive using this method. Of these projects, the majority (24 of 52 projects) were focused on social protection programmes. The authors note that this is indicative of a charity model rather than a right-based approach to disability. They argue that the World Bank needs to place greater emphasis on targeting persons with disabilities as project beneficiaries particularly in neglected areas, such as access to justice, political participation and economic participation, to ensure their full inclusion in society.

The third paper by Zinayida Olshanska and colleagues reports the findings of the My Story My Rights project which tested ‘participatory narrative inquiry’ as a method for strengthening disability rights monitoring in Uganda. Through the project, 197 persons with disabilities shared stories about their human rights experiences, key themes of which were discussed by storytellers and community members at ‘sense-making sessions’ convened by the project team. A selection of findings was shared with the United Nations Convention of the Rights of Persons with Disabilities (UNCRPD) Committee in Geneva to support monitoring of UNCRPD implementation in Uganda, enabling persons with disabilities to contribute to that process. The study suggests that participatory narrative inquiry can add value to disability-rights monitoring by providing a framework for collecting rich information about the experiences of persons with disabilities, and for involving persons with disabilities in interpreting and giving meaning to this information.

The fourth paper by Margo Greenwood and colleagues reports the findings of a collaborative research project lead by Sightsavers UK which gathered stories on the lived experiences of people with disabilities and older people in Tanzania, with the aim of generating evidence to inform policy and programme planning and improve quality of life for these groups. A community-based participatory research approach was adopted, involving community members, including people with disabilities, as peer researchers in conducting and analysing interviews. Findings are framed in terms of physical, social and attitudinal factors affecting inclusion and participation by people with disabilities and older people at individual, interpersonal and societal levels. The paper sheds light on barriers to inclusion and participation experienced by these groups in Tanzania, and provides policy and advocacy recommendations, from their own perspectives.

The fifth paper by Fairlene Soji and colleagues describes a sustainable CBR programme undertaken in 44 villages in the Karnataka District of Bangalore, India. The programme placed strong emphasis on the development of community structures, including self-help groups, children’s parliaments, community education centres, and a disabled people’s organisation, with a view to ensuring ongoing sustainability of a broad range of program activities. Drawing on the findings of an independent evaluation conducted one year after cessation of program funding, the authors argue that the program succeeded in this objective where many do not, due to activities involving the community structures. Reflecting on lessons learned from the program, they reflect on the importance of establishing, capacity building and promoting community structures to support CBR sustainability.

The sixth paper by Jyotishmita Sarma explores barriers to the built environment experienced by women with locomotor disabilities in the Delhi-National Capital Region of India. Drawing on rich narrative data about the life experiences of 12 women with a range of locomotor disabilities acquired at various ages, the paper elucidates a myriad of factors affecting accessibility of the built environment and which hinder the women’s access to education, employment, healthcare and public transportation. Findings are discussed in light of the broader human rights situation of people with disabilities in India, and the recently introduced Accessible India campaign.

The seventh paper by Femke Bannink and colleagues explores family relationships of children with spina bifida in central Uganda. Using a locally adapted version of the ‘Family Relations Test’ to shed light on family structure and dynamics, the study indicates that mothers followed by elder siblings and grandmothers of children with spina bifida play vital roles in providing them with support and care, and facilitating their social inclusion both inside and outside the family unit; fathers are relatively absent. The authors argue for an extended family-centred approach to healthcare and social services for children with spina bifida in which the children, their parents (including their fathers), siblings and other family members are included. In low resource settings where services are weak or absent, direct involvement by these stakeholders is certain to ensure better use of scarce resources in providing necessary support.

The eighth and final paper by Manon Geldof is a case study which presents the preliminary findings of a broader study on the role that parents and other primary caregivers of children with disabilities play in the first line of care, and the issues they face navigating the service system in Ghana. Four individual case studies are provided, highlighting the complexity of the caregiver experience and influences on the service-seeking process. Directions for future research and tentative recommendations for policymakers and professionals working in the field of child disability are provided.

Our thanks

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 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.

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Guest Editors, Knowledge and disability inclusive development

About the Guest Editors

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