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Realising the rights of disabled people in Africa: an introduction to the special issue

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Abstract

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) has now entered into international law. It requires that all governments take cognisance and action to ensure that the human rights of people with disabilities are realised. This will be particularly challenging in some of the poorest countries; a fact recognised by the Convention's requirement that all international aid-giving countries address disability as part of their programmes. This Special Issue of *Disability and Rehabilitation* arises from the first conference of a new network – the African Network for Evidence to Action on Disability (AfriNEAD) – which was established to address, on a regional basis, the 'know-do' gap, in the field of disability. Papers in this special issue address a broad range of themes including the measurement of disability; the involvement of persons with disability in the design, conduct and analysis of research on disability; the role of Community Based Facilitators; the impact of HIV/AIDS on people with disabilities, and the challenges of mainstream schooling for children with disabilities. Promoting the human rights of persons with disabilities places an obligation on us all to ensure that the value of research goes beyond publication, to influence policy and practice. One important way of promoting efforts to collectively achieve this is through networks of disabled people's organisations, practitioners, policy makers and researchers working together.

Keywords: *Disability, research evidence, research networks, evidence-based-action, AfriNEAD, policy implementation*

Introduction

This special issue of *Disability & Rehabilitation* is focussed on the challenges of realising the rights of people with disabilities in Africa. In this introduction, we outline the need to urgently address this challenge and highlight some of the attempts to do so. We pay particular attention to the importance of bridging the know-how gap; of linking research evidence to action, and describing the role of the African Network for Evidence-to-Action on Disability (AfriNEAD). We also briefly preview the contributions to this special issue, which arose from, or were inspired by, the inaugural Stellenbosch Symposium on Evidence to Action on Disability (SSEAD 07) meeting in November 2007. That symposium, and this special issue, constitutes important steps

towards strengthening the capacity of African people with disabilities, researchers, practitioners, disabled people's organizations (DPOs) and policy makers and other civil society formations, to build a stronger evidence-base for realising the rights of persons with disabilities in Africa.

Disability in Africa

Strong empirical research evidence on disability is only now becoming available in few countries [1]. 'Disability is both a cause and a consequence of poverty, and disability is an important factor, along with gender, age, caste and others, that interacts to impoverish people and keep them poor.' [2] The positioning of disability vis-à-vis health services, continues to be controversial [3]. Africa, which has

the greatest ‘burden of disease’ of any continent, also has some of the most poorly resourced health services in the world [4]. Over a decade ago Chamie [5] argued persuasively that disability is not synonymous with illness, and that morbidity is only one factor in a plethora of causes of disability. Although we want to reiterate that people with a disability should in no way be confused with people suffering from a disease, we also want to recognise that some people with disabilities have greater needs for health service than do others in the general population. Furthermore, some people with disabilities have quite specific requirements to assist them in rehabilitating to – or coping with – the environment they live in. Fundamentally, we believe that all people with a disability have a right to equitable and equally accessible health services whenever they have health problems, in the same way that they have rights to education, social services, transport, employment and other socio-economic rights. In short, having access to health and rehabilitation services is a precondition to equal opportunities (Rule 22 of UN Standard Rules for Equal Opportunities) [6] and an essential part of being a valued and meaningful participant in society.

Within the field of international aid and development, disability has, until recently, not been given enough attention. Indeed, it has been argued that ‘Disability is taboo in development, if measured by the quantity of resources committed, or by the quality of analysis and information’ [7; p 156]. However, since the millennium there has been an increasing recognition of disability and its importance to the field of international development. For instance, James Wolfensohn, former President of the World Bank, argued that ‘If development is about bringing excluded people into society, then disabled people belong in schools, in legislatures, at work, on buses, at the theatre and everywhere else that those who are not disabled take for granted ... Unless disabled people are brought into the development mainstream, it will be impossible to cut poverty in half by 2015 ...’ [8]. This reference to the Millennium Development Goal (MDG) of reducing poverty is but one of the goals that becomes unobtainable without the meaningful and real inclusion of people with disabilities [9].

It is not so much that disability has been ‘off’ the development agenda, but that even when it was ‘on’ the agenda, it was poorly resourced. For instance, the United Nations (UN) declared 1982–1992 as the Decade for People with Disabilities, in the hope that it would focus attention on disability, address the effects of social exclusion, and encourage the meaningful integration of disability issues into national development processes. Although that initiative did produce some important successes – for instance, the

formulation of the Standard Rules on Equalisation of Opportunities for People with Disabilities, and the creation of an increased number of DPOs – it is widely accepted that it also fell far short of its objectives. A recent African disability policy document suggested that there were various reasons for this, including a lack of adequate funding, poor monitoring of funding, and a lack of real commitment from many governments [10]. Moreover, ‘a global approach to the problems of disability was used, and the solutions that were offered were general and global or based on the assumption of the availability of economic and technical resources, which later was found not to be the case’ [10; p 7] (Republic of Mozambique, 2006).

Following the disappointing results of the UN Decade for People with Disabilities, the Organisation of African Unity (OAU) sought to heighten attention on opportunities for people with disabilities in Africa through adopting the African Decade of Persons with Disabilities (1999–2009) at its Algiers session in 1999. In 2002, the African Union (AU) adopted the Continental Plan of Action for the African Decade of Persons with Disabilities in Durban, South Africa. The Decade Secretariat is mandated to facilitate the implementation of the Continental Plan of Action for Africa. It seeks to build capacity, both in its own services and among its member organisations, formulate and implement national policies, advance legislation and programmes that will promote the full and equal participation of persons with disabilities, and lobby and advocate for inclusive planning and implementation of disability programmes at regional and continental levels.

The UN Convention on the Rights of Persons with Disabilities (2006) [11], which has now entered into international law, is perhaps the most significant – moral and practical – step toward realising the rights of people with disabilities. The Convention seeks to address discrimination, change perceptions and combat stereotypes and prejudices. Article 32 of the Convention states that ‘Countries are to provide development assistance in efforts by developing countries to put into practice the Convention’. This article places an obligation on people in high income countries to not only put the Convention into practice in their own country but also to ensure that their country assists in it being put into action in low-income countries as well. Disability and development is now everyone’s responsibility! Recognition of this can now be found in the documentation of an increasing number of aid organisations. For example, the European Commissions’ Guidance Note on Disability and Development for European Union (EU) Delegations and Services (2004), which states that the MDGs, and particularly that of poverty

reduction, ‘... cannot be met without considering the needs of disabled people, yet disabled people are still not sufficiently included in international development work funded by the EU’ [12; p 3]. Most emphatically, the Commission argues, ‘If the interests of disabled people are not recognised then the key goal of poverty reduction in developing countries will not be achieved’ [12; p 3].

Despite a slow and often faltering evolution, the situation of people with disabilities is now starting to be featured on the international development agenda. We are in a new and exciting era of awareness, activity and commitment in the sphere of disability, both in Africa, and beyond. Disability is a clear concern of the Economic Commission for Africa (www.uneca.org); it will be the theme of the forthcoming World Health Report (2009) (<http://www.who.int/whr/2007/en/index.html>); UNESCO/ILO/WHO have collaborated on developing new, and more socially elaborated, community-based rehabilitation (CBR) guidelines (www.who.int/disabilities/cbr/en/) which are about to be launched; and there now exists a Global Partnership on Disability and Development, among a plethora of other interesting, exciting and innovative initiatives. These all hold the promise of contributing fundamental building blocks to realising the rights of disabled people in Africa.

What these lofty and worthy initiatives will actually achieve will be influenced by many factors. Their chances of success will be strengthened if they are powered by an evidence base that reaches into policy decisions and practical actions; which engages with disabled people; through them, being with them, and, not only about them; and, where possible, being undertaken by them.

AfriNEAD

Despite the many progressive statements promulgated in recent years the extent of meaningful change in the actual quality of life of persons with disability in Africa remains limited. Even in a country with the relative wealth of South Africa, with an internationally acclaimed inclusive Constitution and established national strategies and policies (for instance the Integrated National Disability Strategy White Paper, (1997) [13]; and the Employment Equity Act, 1998 [14] the possibilities for disabled people to have ‘equal rights and dignity’ remain distressingly illusive. In South Africa the majority of people with disabilities are not yet experiencing meaningful change in their quality of life, access to equal rights and level of community integration, despite a favourable policy environment and a limited, but supportive, research evidence base. Thus, the historical exclusion of people with disabilities from society

still persists. Real change and social development are still required to realise a truly inclusive society.

Research in itself will never be enough and some disability research already exists on issues relating to health, welfare, access to services, as well as the facilitators and barriers to inclusion in mainstream society, of people with disabilities in Africa. Furthermore, there is a danger that the research community – injected with international aid ‘cash’ – may simply accumulate evidence without developing practicable solutions to address the ways in which society can become more responsive to, and more inclusive of persons with disability. The challenge is clear: it is not just more research that is needed; it is ‘improved’ research and research that can be translated into policy and practice. Translating research into evidence-based advocacy, policy, practice and products – particularly in the pan-African context – needs to be systematically addressed in a co-ordinated, coherent and consistent fashion. A wide range of stakeholders need to be included in the process ranging from asking the appropriate research questions through to utilising the research outcomes – that ultimately feed back into asking further relevant research questions.

The Centre for Rehabilitation Studies, in the Department of Interdisciplinary Health Sciences at Stellenbosch University in South Africa has promoted the development of AfriNEAD. In this, it has been supported by its African civil society partner, the Secretariat of the African Decade for Persons with Disabilities, and its northern research partner, the Centre for Global Health, at Trinity College, Dublin, Ireland. AfriNEAD has become a project with multiple partners and collaborators and seeks to become a significant contributor to addressing the needs of people with disabilities in Africa. It seeks to achieve this by assisting in translating existing as well as new research in the disability arena into meaningful evidence-based advocacy, practice and products which can inform policy. This is a network, uniquely African in nature and seeks solutions to its own obstacles and barriers within an African context, AfriNEAD can contribute to increasing the participation and inclusion of persons with disabilities in all aspects of society. AfriNEAD will do this by focusing on bridging the ‘know-how’ gap across a broad range of issues relevant to realising the rights of people with disabilities in Africa. Capitalising on the combined impetus afforded by the United Nations Convention of Rights for Disabled Persons and the African Decade for Persons with Disabilities, the focus of this network will be on how to combine research, policy and practice in order to realise the rights of disabled people.

The network will explicitly seek to develop a multi-perspective and interdisciplinary approach to

addressing problems facing persons with disabilities. The AfriNEAD is proposing a range of activities commencing with the establishment of Working Groups, which are tasked with identifying action pathways and producing Best Evidence-to-Action Research Practice Guidelines. This will include working with member countries to develop a methodology for profiling their own local situation regarding persons with disabilities and the services available to them, the existing available research, research that is currently being undertaken and research that is required. An important aspect will be to identify facilitators and barriers for turning this research evidence into action.

The First Stellenbosch Symposium on Evidence-to-Action in Disability (SSEAD 07) was held in November 2007 and was attended by a range of international delegates, many of whom were people with disabilities. Delegates came from 14 different African countries, as well as from North America and Europe representing governments, institutions of higher learning, DPOs, non-governmental organisations (NGOs), businesses and research funders. A significant proportion of the speakers were persons with disabilities. Debate was positive, constructive and vigorous and affirmed the need for just such a medium of interaction. There are plans to run further symposia for the AfriNEAD network – to keep planting the ‘seeds’ – every second year, the next being in 2009. For the first symposium, we invited papers around the general theme of ‘realising the rights of people with disabilities in Africa’, and this special issue presents some of the papers that were presented at the conference or inspired by it.

Major themes arising from the conference

Before commenting on individual papers we briefly note a number of broad issues that arose from the conference papers and debates. The timing of the conference in relation to the recent publication of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) was fortunate and there was a strong sense of urgency for action to capitalise on the momentum it has produced within the international community, as well as regionally and locally. Although many of the speakers were rehabilitation professionals their presentations were generally made from a stance that acknowledged that the rehabilitative potential of many interventions is limited by the lack of opportunities for disabled people to be included in, and to be meaningful participants in society. This mixture of papers concerned with ‘individual’, ‘medical’, ‘social’ and ‘emancipatory’ models was perhaps greater than at conferences

outside Africa, where the lines of demarcation and engagement are more distinct, and perhaps less problematic.

Many speakers stressed the need for a shift towards more equally balanced partnerships between researchers and people with disabilities, and for the need to facilitate this through ‘emancipatory research’; allowing people with disabilities to gain greater influence over the process, resources and outcomes of research. In 2007, the United Kingdom (UK) based government development agency, Department of International Development (www.dfid.gov.uk), provided the Southern African Federation of the Disabled (SAFOD) with a substantial programme grant to commission research projects in the region. Thus, possibly for the first time ever, people with disabilities have been put in the ‘driving seat of the research bus’, as expressed by the SAFOD Director, Alexander Phiri.

Researchers were encouraged to assist in building the capacity and confidence of DPOs to facilitate people with disabilities being able to adopt a more directive role. In this way ‘user-led research’, which is jointly produced by professional researchers and people with disabilities, can become more authentic and responsive to the needs of the target groups.

Other factors limiting the production of good research partnerships, and therefore relevant research findings, were outlined and delegates were encouraged to find ways in which research and activism can work together to effect change. It was stressed that delegates should attempt to investigate how research can be used as part of an argument to change policy. The importance of being aware of the value of different roles within the research enterprise was highlighted. For example, ‘outsider/objective’ researcher, *versus* ‘insider/subjective’ activist. These roles were also seen as possibly being complimentary in creating a ‘theatre of evidence’ which will tell as convincing a story as possible and also make it possible to ‘speak to’ different constituencies. Major concerns regarding the current lack of quality, disability-related research evidence in the pan-African context and the need for relevant research of a high quality was stressed. The need to produce rigorous research evidence that is capable of countering the lack of political will, attitudinal barriers and resource constraints was also a recurrent theme.

Human rights campaigner, Mary Robinson, who gave the SSEAD 07 lecture commended the value of the AfriNEAD. She suggested that ‘networks offer the opportunity for the net impact of people’s actions to be greater than the sum of their individual efforts’. She further asserted that networks offer a mechanism not just of information gathering and sharing but also

for the inclusion, participation and empowerment of people with disabilities.

Preview of papers

Following this introductory paper, the second paper in this special issue addresses a universal challenge – how do we measure disability? Schneider, a prominent member of the Washing Group on Disability Statistics asks about ‘The difference a word makes?’ She notes that there is no consensus on a single definition of disability, and that those definitions that do exist tend to be ‘purpose-specific’; this often accounting for widely different estimates of disability prevalence and service needs. Advocating a move away from narrow definitions, or simplistic ‘Are you disabled – and if so how’ type of questions, Schneider, uses focus groups spanning across eight different linguistic groups in South Africa, to explore peoples’ responses to the much more broadly based ‘Short Set’ of questions developed by the Washington Group. These questions address ‘difficulties’ rather than ‘disabilities’ and this perspective provides a more comprehensive and inclusive measure for practitioners and policy makers to work with.

The third paper, by Mmatli, argues for an enhanced role for disabled people in research. Drawing, in particular, on the situation in Botswana, but with relevance throughout the region, Mmatli is critical of the failure to translate research evidence into evidence-based practice. To achieve this, it is argued that persons with disabilities must be put into the driving seat, as they are truly the ‘experts’ in how disability affects people’s lives. For Mmatli, researchers are in the ‘driving seat’, and so more disabled people are needed to work as researchers, in constructing the research questions, undertaking and interpreting the field research and in achieving its utilisation. These arguments, inscribing research with emancipation, constitute a challenge to the assumptions and working practices of many rehabilitation and health-related professionals, resonating across Africa and far beyond.

The fourth paper by Chappell and Johannesmaier explore the impact of Community Rehabilitation Facilitators’ (CRFs) implementation of CBR programmes with persons with disabilities in South Africa. CRFs are ‘mid-level rehabilitation workers’ who receive a 2-year post-secondary education training that prepares them for physical and social rehabilitation practice, as well as raising awareness of disability and advocating for the rights of persons with disability. Using focus groups, semi-structured interviews and community transect walks through the areas where group participants lived, Chappell

and Johannesmaier, sought the views of persons with disabilities regarding the value of the CBR programmes. They found that although CRFs work with individuals, groups, families and communities, their strongest impact was at the individual level; this presents important challenges for how to scale-up their impact at broader systems and contextual levels.

The fifth paper by Rohleder, Braathen, Swartz and Eide is an important and timely review of HIV/AIDS and disability in the Southern Africa region. They argue that despite the realisation that HIV/AIDS disproportionately affects socially marginalised groups, and particularly the very poor, persons with disabilities have not featured strongly in research on HIV/AIDS. In fact, there is now strong evidence that persons with disability are at increased risk of HIV/AIDS infection in comparison with population norms; that they are as sexually active as non-disabled people, but that health promotion and protection is not targeted at this group in ways that take their disabilities into account.

Following on from the above literature review the sixth paper is an empirical paper by Wazakili, Mpofu and Devlieger asking ‘Should issues of sexuality and HIV/AIDS be a rehabilitation concern?’ The authors clearly demonstrate that young persons with disability live in a sexual world and do have – and should expect to have – sexual relationships. In the context of health promotion and health protection the authors make a strong case, based on individual in-depth interviews, for the need for rehabilitation services to address sexuality, HIV/AIDS and sexually transmitted diseases more generally. They conclude that there is a need, more generally, for rehabilitation practitioners to widen their scope of practice, and in doing so, to facilitate a more ‘holistic’ rehabilitation.

The seventh and final paper in this special issue, by Vosloo, focuses on the extent of genuine inclusion of children with paraplegia/paraparesis in mainstream primary schools in the Western Cape of South Africa. The paper explores the views of the learners, teachers and parents, comparing them in order to identify barriers and facilitators. Cognitive independence and mobility were seen as the greatest challenges. Vosloo sees teacher support and training as essential for keeping learners, teachers and parents motivated and informed, and stresses the importance of physical assistance to the learners being provided in a structured and appropriate way.

These papers represent some of the innovative and crucial research being done on disability in Africa. The scale of the challenge of realising the rights of persons with disability in Africa can seem

daunting amongst the many other challenges – and opportunities – present across the continent [15]. The AfriNEAD network, the first SSEAD from which these papers are drawn, and this Special Issue of *Disability & Rehabilitation*, is a contribution towards collectively addressing some of the challenges and seizing some of the opportunities. We hope readers may be encouraged to contribute to these collective efforts in the future.

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