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CURRENT ISSUES

An African way of networking around disability

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There is a relative paucity of disability-related research emanating from low and middle income countries. We report here on the successes and challenges of AfriNEAD (the African Network on Evidence to Action on Disability), a recently formed network that brings together researchers, activists and other role-players in attempting to develop and support disability-related research in Africa. We introduce the African concept of *ubuntu* (humanness) as an organizing principle to guide respectful engagement amongst people with widely differing skills and experiences with the overall project of collaborating in research and development to make a positive difference to disabled people's lives.

Keywords: AfriNEAD; UNCRPD; disability; research; ubuntu; activism

The question of how best to develop useful research with, for and by disabled people living within the African context is complex. Given the history of exclusion and oppression of disabled people in Africa, many disability activists are suspicious of and hostile towards the entire research enterprise. There are other obvious challenges. There are very few countries within Africa, for example, that offer social security to vulnerable groups such as disabled people, who bear the extra burden of being unable to compete equally on the open labour market (Seirlis and Swartz 2006; Lund 2008). These issues are superimposed on the more general issues in African countries, such as governance problems (Rule, Lorenzo, and Wolmarans 2006), the large disparity between rich and poor, and the difficulties with accessing adequate housing, infrastructure and basic services.

In contrast to these challenges, however, some argue that in Africa there may be a greater acceptance of diversity and social inclusiveness, and that Western concepts of disability that emphasise medical issues may be inadequate (Malinga 1999). The cultural principle of *ubuntu* (as used in South Africa, or other linguistic variations used throughout Africa) refers to a social system of interrelatedness whereby people's humanity is determined not by their personal qualities, but in terms of how they relate to all in their community (Boon 1996). The idea that 'a person is a person through other persons' encapsulates the essence of the *ubuntu* philosophy, contrasting sharply with more individualized Western views. In this regard the notion that disabled people should strive for 'independence' is called into question. *Ubuntu* is a

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more interconnected way of being that locates people not as independent individuals striving for self-actualization but as interdependent beings who are part of a collective, who derive their sense of identity and recognition by making a contribution to the development of others and improving the common good of 'all' (Mbigi and Maree 1995).

Against this background, in 2007 the African Network for Evidence-to-Action (AfriNEAD) was established, with the aim of establishing a diverse 'community of practice' to provide evidence and ways of using this evidence to improve the lives of disabled people in Africa. From the start, AfriNEAD had an ambitious agenda – it was to be an inclusive network drawing on the best skills, expertise, and goodwill of researchers and disability activists. Some AfriNEAD members are prominent researchers, others bring their insider knowledge of what it takes to effect changes for marginalized people in difficult contexts. While the majority of members celebrate in this diversity, the gulf in lived experience amongst members brings its own tensions and dynamics, and requires flexibility to accommodate different perspectives. One of the key roles for the leadership is to help people who may feel far apart from one another, to have a common sense of purpose and to value what each brings to the greater project of improving lives. This is easier said than done and is a long-term project, the outcome of which is by no means certain. What is clear is that integral to the process of developing sustainable networks within an African cosmology is the need to pay close attention to the relationships amongst all participants, and it is in this context that the concept of *ubuntu* is especially relevant.

AfriNEAD was founded at a 2007 Symposium. Of note at this Symposium were the varying views on disability research issues and the differing capabilities in the field. However, all stakeholders agreed on the need for a forum for ongoing debate (Mji et al. 2009). There was also a sense of urgency: people wished to maximise the momentum produced by the 2006 UN Convention on the Rights of Persons with Disabilities (UNCRPD; http://www.un.org/disabilities/convention/conventionfull.shtml), ratified by a number of African countries. In this article we review progress made and challenges encountered since the launch meeting, paying particular attention to the 2009 follow-up meeting and future plans.

AfriNEAD Symposium 2009

The 2009 AfriNEAD Symposium had two primary aims: (1) to demonstrate how the evidence-to-action concept of the UNCRPD could be implemented; and (2) to foster relationships that would make the network attributes of AfriNEAD come to fruition. The Symposium discussions were underpinned by the ABC principles in Section 4 of the UNCRPD Implementation Toolkit, which provided both the overarching theme of the Symposium and operated as a reference point for assessing how far research evidence has come in helping to realize the rights of persons with disabilities in Africa (http://www.icrpd.net/implementation/en/toolkit/section4.htm).

Some central debates of the meeting will now be discussed.

Identity issues

A key concern was around the identity of AfriNEAD: Does it have an activist or a research agenda? It was concluded that research is not a one-dimensional endeavour, but is multi-faceted and should include diverse stakeholders, all of whom have

important roles to play. Seasoned researchers may ensure the authenticity and validity of research method and evidence, but activist voices are important to challenge research assumptions and to link research to broader action challenges.

Evidence issues

Delegates grappled with the questions, 'What is evidence?' and 'What different types of evidence exist?' It was agreed that a wider network of stakeholders with varying research skills must be included in both qualitative and quantitative studies. One of the greatest challenges of research evidence as a commodity (being largely contained within academic institutions) is to ensure that it remains relevant to its constituency. Ideologies and methodologies that follow narrow visions need to be challenged and research evidence must include plans that takes into account resources needed for implementation.

Research process and methodologies

The link between poverty and disability and the meaning of this in terms of research studies was raised as an issue for ongoing reflection. Delegates argued that rather than spend energy discussing the distribution of small research budgets, it is more useful to develop strategies that will facilitate meaningful relationships between researchers and their constituency, and in this way assist disabled people in Africa reclaim their identity and dignity and unlock their potential. Underlying this proposal was a reminder to practice *ubuntu* so as to challenge 'us' and 'them' constructs.

The challenges ahead

It is clear from the papers presented at the AfriNEAD 2009 Symposium that interest in disability research in Africa is flourishing. Challenges still remain such as a lack of funding, as well as more subtle challenges, such as the politics of relationships between academic 'experts' and 'outsiders', and disabled people living in poverty. Given that most disabled people in the world live in poorer countries, it is important that disability research agendas be influenced by the experiences of disabled people in these countries. We need both qualitative data (introspective, experiential, discursive, as well as subjective) as well as the 'hard facts and figures' in order to facilitate change. For this to happen, training of researchers and activists who use research is crucial.

AfriNEAD has a critical contribution to make to this challenge. It has the potential to collectively address important issues and to draw on diversity to build a stronger evidence base for realizing the rights of persons with disabilities in Africa. However, it needs to remain a 'thinking organization' which fosters debate and keeps this debate close to the question of improving lives on the ground.

Where to from here?

Future AfriNEAD conferences will be held in different African countries and will be informed by the above issues. AfriNEAD needs to maintain the energy and vision generated thus far to take forward the UNCRPD principles and to close the 'know-do' gap. Its future success depends on two pillars: that of good quality,

rigorous research; and, sustaining relationships and partnerships within the context of *ubuntu*.

Given these twin imperatives, it is possible to foresee two potential threats to the process. On the one hand, an entirely technicist and outputs-based approach to research may well threaten the sense of common purpose and diverse contributions that currently exist within AfriNEAD. On the other hand, if there is too much focus on process and commonalities, AfriNEAD may become a self-referential group that misses the opportunity to take on the difficult challenges of providing good data that can move evidence into action. It remains to be seen how the AfriNEAD initiative evolves. However, by adopting a community-centred and African approach to what is often seen as an individualistic, technical and competitive challenge may create opportunities for all to learn and develop further.

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