# THE FIRST STELLENBOSCH SYMPOSIUM ON EVIDENCE-TO-ACTION IN DISABILITY 2007

Medical Research Council Conference Venue, Tygerberg, Cape Town

# EXECUTIVE SUMMARY FROM THE CHAIRPERSON: SSEAD 07

Dear friends and colleagues

Once again, thank you for your overwhelming response to this symposium. The conference has now passed and we are still delighted at the extent of participation we enjoyed.

In lobbying support from the Faculty of Health Sciences for funding for AFRINEAD, we were advised to hold the symposium to gauge the extent of support for such a network. Your overwhelming response to attend the symposium, the obvious need for a forum for ongoing debate around disability issues, and the determination with which opportunities to continue this debate was pursued by delegates both in and out of the formal conference space, has endorsed our vision of a network to act as a vehicle to facilitate the realisation of rights for people with disabilities in Africa.

We were again reminded of how this conference was for all of us. The programme took its own twists and turns and was revised according to the needs of the audience as they presented themselves. Thank you for your patience and acceptance of these changes.

Now that the two days are concluded, we need to go back and reflect on how the conference originated. It was identified that people with disabilities in South Africa 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 supportive research evidence base. Real change and social development are still required to realise a truly inclusive society.

In other African countries too, a need exists to concentrate on development of inclusive policies that will enable disabled people to access equal human rights in their respective societies by unlocking their potential to contribute.

The Centre for Rehabilitation Studies at Stellenbosch University’s Health Sciences Faculty, therefore began developing a plan to facilitate the translation of existing and new research in the disability arena into meaningful evidence-based advocacy, practice, products and policy in a coherent and consistent fashion, in order to realise equal opportunities and human rights for people with disabilities.

The conference speakers reiterated the current urgency for action to maximise the momentum given by the recent UN Convention on the Rights of Persons with Disabilities (UNCRPD). Making the shift towards “emancipatory research” which will support advocacy, influence the development agenda and achieve real service delivery commitments from governments will be

crucial. To achieve this there is a need to build and sustain mutually beneficial partnerships between disabled people’s organisations (DPO’s) and researchers so that research results are more specifically targeted to influence attitudinal barriers, policy and practice. Researchers will need to coin further questions around issues related to the media portrayal of disability, exclusion from mainstream society, inaccuracies in communications about people with disabilities, as well as the growing frustration with the level of hesitation in all aspects of the research-action cycle. Perhaps we will need to “just do it’ at times and research the results!

This sense of urgency supports our proposal for a pan-African network, the **African Network on Evidence-to-Action in Disability (AfriNEAD)** which was presented to you at the SSEAD 07 symposium. This multi-sectoral network is a genuine attempt to develop meaningful, strategic partnerships with disabled people, business, civil society, academic programme developers and researchers as well as policy-makers, service providers and international donor organisations.

The proposed network will seek to have representatives from as many African countries as possible and, within each country, it will seek to have representatives of as broad a range of stakeholders as is possible. An interim International Advisory Working Group has been established and will provide strategic and practical advice regarding the projects and activities that AfriNEAD undertakes. Substantive products which will arise from AfriNEAD are detailed in the attached AFRINEAD document.

So, here we are, after the conference excitement has died down, left with the challenges of what needs to happen to realize this vision. A handful of delegates met on 28 November and 29 November 2007 and 2 working groups were established to look at developing the AFRINEAD as a programme and the DABGC as a product of AFRINEAD.

There was also a need expressed for Stellenbosch University to commit to what it has started by championing the programme, a need for an office and dedicated staff members to coordinate operations at this stage. All these things will require funding.

We are appealing to all members to see this as a collective venture and to help us explore avenues for funding the network by giving us suggestions on how and where to go about looking for such funding.

We also appeal to you to initiate and manage your own regional SSEAD- related activities between now and SSEAD 2009. In this way the debates can be further honed before we all meet again. Stellenbosch University is willing to host the next biannual conference if members are agreeable.

Otherwise there is little left for me to say but to wish you everything of the best for 2008.

Warm regards

Gubela Mji

Head: Centre for Rehabilitation Studies Stellenbosch University

# THE FIRST STELLENBOSCH SYMPOSIUM ON EVIDENCE-TO-ACTION IN DISABILITY

**27- 28 NOVEMBER 2007 CONFERENCE REPORT**

## Introduction:

The Centre for Rehabilitation Studies at the Faculty of Health Sciences at Stellenbosch University identified a need for existing and new research in the disability field to be translated into real change to impact the quality of lives of people with disabilities throughout Africa. The symposium aimed to address how this can be achieved and what key factors are required to facilitate this process.

The vision was to facilitate a multi-dimensional, intersectoral, interactive forum for debate around the focussed topic of Evidence-to-Action. Significant effort was made to invite people from as many different sectors as possible and as many African countries as possible to fully represent the spectrum of stakeholders in the pan-African disability arena.

## The Conference Programme:

The conference programme was originally planned as detailed in the conference booklet. The organisers were aware of the tight scheduling but were very keen to include as many voices as possible from as many sectors as possible in this important debate. Several challenges and the enthusiastic extent of audience participation necessitated various changes to the programme. The actual programme as it happened is detailed below. It is recommended that future organisers review the length of the conference so as to be inclusive of all sectors involved.

## Key note addresses:

Mary Robinson highlighted the critical timing of this conference in relation to the recent publication of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and the resulting focus of the international community on disability issues.

AK Dube motivated for a shift towards more equally balanced partnerships between researchers and disabled persons to facilitate “emancipatory research” in order to support advocacy, influence the development agenda and achieve real service delivery commitments from governments. In this way disabled people would gain greater or major control over both the process and the resources of the research and thus encourage the production of relevant and effective research.

Arne H. Eide outlined the current dire lack of quality, usable disability-related evidence in the pan-African context and reiterated the need for research of a high quality which is targeted to relevant areas to be able to withstand the lack of political will and attitudinal barriers encountered in processing the evidence into policy and action. He also highlighted the need for appropriate resources and support to achieve action from research findings. He detailed some of the existing research findings for the Southern African region.

Alexander Phiri urged DPO’s and researchers to build and sustain mutually beneficial partnerships so that research results are better targeted to influence policy and practice. He proposed a paradigm shift around the way that researchers and DPO’s have traditionally interacted and encouraged researchers to assist in building capacity and confidence in DPO’s to facilitate people with disabilities into a more directive role. In this way DPO or user-led research, which is jointly produced by professional researchers and disabled people, can become more authentic and responsive to the needs of the target groups.

Leslie Swartz outlined factors which limit the production of good research partnerships and therefore findings and encouraged delegates to find ways in which research and activism can work together to get things to change. He encouraged delegates too to work out how research can be used as PART of an argument to change policy, and to be aware of the value of different roles (for example “outsider”, “objective” researcher, versus “insider” activist) in creating a “theatre of evidence” which will tell as good a story as possible and be convincing. We have to work together strategically to engage with the mainstream for maximal effect and impact.

Mzolisi ka Toni reiterated the need for the disabled sector collaboration with researchers in order to generate relevant research.

Malcolm MacLachlan urged delegates to create and pursue opportunities and together with Gubela Mji proposed a network (the “African Network on Evidence-to-Action in Disability”: AfriNEAD) as a mechanism for collective positioning, resourcing and operating to maximise efforts in advancing the cause of disabled people in and around Africa. This proposed network is an initiative of the Centre for Rehabilitation Studies at Stellenbosch University, the African Decade of Persons with Disabilities, and the Centre for Global Health, Trinity College, Dublin, and provides an opportunity for bringing together stakeholders and disability- related research and development initiatives on a regional basis. The opportunities for learnerships and capacity building for research participation, and the need for dissemination of research findings in accessible formats for various target groups were discussed.

The idea of a network was supported by Mary Robinson who said that “networks offer the opportunity for the net impact of peoples’ actions to be greater than the sum of their individual efforts. Networks offer a mechanism not just of information gathering and sharing but also for the inclusion, participation and empowerment of people with disabilities themselves.”

## Other speakers:

Other speakers highlighted the ongoing need for deeper understanding and internalization of the issues of disability by researchers, DPO’s, business and the wider public to facilitate changes in attitudes to people with all kinds of disabilities. The role of the media in influencing these attitudes, the work being done by the Department of Communications in SA, the willingness of the South African government at national and provincial levels to support programmes for people with disabilities were also presented. Again the need for meaningful political, educational and international commitment and will to address real change was raised.

Paper presentations and posters addressed ways in which evidence is already influencing practice and lessons learned from these experiences; different ways of gathering, collating and storing good research so that it can be effectively used for advocacy and influence; what evidence currently exists; and what is still needed.

Issues arising from paper presentations included the need for broader education and familiarisation with the ICF model by research partners in order to focus more on social inclusion than on the medical model, the need for monitoring and evaluation of provisions made and prevention of abuse of provision by service users, the need for governments to progress in creating and acting on appropriate rehabilitation policy.

Discussions also raised the lack of translation of research into service strategies and the subsequent need to find information on disability that will guide policy development and service foci, with subsequent monitoring of implementation.

Delegates urged each other to move beyond where we are now and to become ACTION-orientated instead of continually debating at a theoretical level only.

Day 2:

Questions arose around the representation, especially of African countries, at further events post-SSEAD and in the AFRINEAD network, and their possible roles in the future. There is a need to identify continental DPO leaders who can represent and network with other DPO’s in their region. Specific regions will need to be clearly defined.

Delegates are encouraged to establish links with each other, to perhaps meet annually to discuss localised issues of importance and to come with resolutions, experiences and papers from their countries/ regions to the next SSEAD conference in 2009. Delegates for 2009 are also encouraged to elect representatives to the AFRINEAD Advisory Working Group for the next 2-year period. This will ensure that all regions are represented.

Other concerns were raised about the relationship between AFRINEAD and the African Decade. Terms of reference need to be defined to guide the

relationship between these organisations to avoid duplication of roles and clashes of funding and other interests. AFRINEAD is an initiative of the Centre for Rehabilitation Studies and will be hosted by the University of Stellenbosch for the foreseeable future. Currently the African Decade has a Memorandum of Understanding with AFRINEAD to assist in creating links with other African countries to increase the representation of the entire continent and to ensure maximal impact across Africa. These delegates of SSEAD will hopefully go back to their countries and regions and engender further support for the network in their own right.

These remain matters for debate and further discussion. Members are encouraged to contribute their opinions and ideas and to suggest resolutions to these issues.

# KEY RESOLUTIONS:

* There is a continual gravitation to the same issues in the disability debate, with little progress being made in changing the quality of lives of people with disabilities.
* Research is still largely impairment-focussed. There needs to be a shift to more action-focussed research to realise the rights of people with disabilities in Africa. There is also a need to address the existing structures of government, research institutions, etc.
* There is a need to aim for universal access in all areas.
* There is an urgent need for effective partnerships between civil society, DPO’s, researchers, business and governments. The AFRINEAD network was proposed as a strategy to facilitate this.
* There is a need to change focus on what is the purpose of research?
* Throughout the conference there was a sense of building consensus, and clarifying issues, so that we can be ready for action at the 2nd SSEAD. A lot of people were asking questions, and reaffirming their understanding of each other rather than reaching specific resolutions.
* The hope is that the AfriNEAD network will continue this process and continue to provide a platform for debate as there are still many questions without answers at this stage.
* There is a need to move the argument forward to ACTION.

## Network Members’ Contributions:

Network members and SSEAD delegates are encouraged to submit constructive suggestions on changes to the programme, format or other arrangements for future conferences to AFRINEAD@sun.ac.za

# ACTUAL CONFERENCE PROGRAMME:

## Tuesday the 27th of November 2007

07:30 – 08:45 Registration

08:45 – 09:30 Welcome and opening remarks (Gubela Mji, Prof Volmink, Prof Botman)

09:30 – 10:10 Evidence to Action for Disability (A.K. Dube) 10:10 – 10:40 Life Stories (Vincent Daniels, Marlene le Roux) 10:40 – 10:50 Outline of the day’s events

10:50 – 11:15 TEA and COFFEE

11:15 – 12:00 What Constitutes Good Research Evidence? (Alexander Phiri)

12:00 – 13:20 Information and Communication Technology and Disability (Petronella Linders & Hina Patel)

13:20 – 14:20 LUNCH and Poster Viewing 14:20 – 15:30 Open Paper Presentations 15:30 - 15:50 INTERVAL TO MOVE VENUES

15:50 - 16:50 Plenary open session for questions to the keynote speakers

16:50 - 17:10 Summary and Integration (Gubela Mji)

19:30 SYMPOSIUM DINNER (Gubela Mji / Mary Robinson / Prof Botman/ A.K. Dube)

## Wednesday the 28th of November 2007

08:30 – 08:40 Outline of day’s events

08:40 – 09:00 Message from the Office on the Status of Disabled Persons (Zaid ?????)

09:00 – 09:30 Message from the Directorate: Social Dialogue and Human Rights, Department of the Premier of the Western Cape (Marie Hendricks)

09:30 – 10:20 What Evidence is There? (Prof Arne Eide / Prof Leslie Swartz)

10:20 – 10:50 TEA and COFFEE

10:50 – 12:10 Open Paper Presentations

12:10 – 12:30 INTERVAL TO CHANGE VENUES

12:30 – 13:00 What evidence is needed? (Mike Ka Toni)

13:00 – 13:20 Integration of poster presentations into symposium 13:20 – 13:40 Evidence in Action vs Evidence to Action: An example of

“Just doing it” (A. Fortuin, S. Hill, M. Cozett) 13:40 – 14:30 LUNCH and Poster Viewing

14:30 – 15:30 Panel Discussion: Barriers and Facilitators to Realizing Evidence-to-Action in Disability (Prof Rati Mpofu (Chair), Rachel Kachaje, Dr Pam McLaren, Siphokazi Gcaza, Dr Nora Groce, Theresa Lorenzo)

15:30 – 16:00 Networking Evidence-to-Action (Malcolm Mac Lachlan) 16:00 – 16:30 Introduction to the African Network on Evidence-to-Action

in Disability (AfriNEAD) (Gubela Mji) 16:30 – 17:10 Plenary open question session 17:10 – 17:30 Conference Conclusion