

***The African Network on Evidence-to-Action in  
Disability  
(AfrINEAD)***



***Conference Report for the***

***AfrINEAD Symposium 2011:***

***Building Communities of Trust: Evidence-to-Action  
Disability Research***

***28 – 30 November 2011***

# *Elephant Hills Hotel, Victoria Falls, Zimbabwe*

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## Executive Summary From The Chairperson

January 2012

Dear colleagues and friends

The 3<sup>rd</sup> AfriNEAD Symposium has now passed, leaving us with a breath of fresh air lingering on our faces and the sweet taste of success in our mouths. The AfriNEAD family came together again for the third time with old familiar faces to act as steady pillars, and new eager faces to bring new life to the network.

At this juncture I would like to take a pause and extend gratitude to SAFOD and NUST who, despite their loss of a beloved leader, were brave enough to continue with the preparations to host this symposium. They continued to give us both the support and the action we needed during this trying time.

So, here we are, having shared our perceptions and realities regarding the issues that have delayed disability research evidence to be able to act as a facilitator in the realization of rights of disabled people.

The theme and the programme of this conference offered food for thought:- you do not build communities of trust unless you are serious and committed in the journey you have taken. Yes, as the AfriNEAD network membership, we are committed to our journey of using research evidence as a tool to realize the rights of disabled people. One of the things that gives us clarity on this journey is the understanding that people with disabilities are connected to each of us, and all of us, with a fine thread. When the gate-keeping mechanisms rob disabled people of essentials that give us all dignity, instead of pointing fingers, we all need to be resolute in taking action to challenge each other (as the global family) to travel the road less travelled and develop solutions that will turn the tide.

As we address poverty, politics, health and other issues that are highlighted in the UNCRPD we must also remember that we are all sexual beings. It was humbling to listen to some of our delegates within the conference who did not shy away from this topic and reminded us that when disabled women are undermined, ignored and abused sexually, we are all undermined, ignored and abused sexually – disabled women, as well as the abusers, are part of who we are. It was also humbling to hear the supportive feelings of the men at the conference about the book donated on this topic – sometimes we carry misconceptions within about us and we were proven wrong in such a beautifully positive way.

You will agree, Colleagues, that the papers that were delivered in this symposium were just the beginning and the network membership will need to continue its dialogue far beyond the AfriNEAD 2011 symposium. Our network has an avenue for continuing that dialogue.

Do immediately turn those papers into publications for our hungry African Journal for Disability, the AJOD. Prof Leslie Swartz, the Chief Editor of this journal, would love to hear from you regarding the status of your papers.

Please also give us permission to place your conference presentations on the AfriNEAD website. We would love for all this valuable information to be shared with others. If you do not want yours to be available online, or would like to make some changes first, please contact us at [info@afrinead.org](mailto:info@afrinead.org) urgently.

Three countries have bid to host the next symposium in 2014. Soon we will be hearing motivations from each country on why they should host the 4<sup>th</sup> AfriNEAD Symposium successfully. We hope by the end of April we can inform the AfriNEAD family where the 4<sup>th</sup> AfriNEAD symposium will be hosted in 2014.

We have managed to develop a warm, vibrant AfriNEAD family with this symposium – while this is good, we must just be careful not to become too cozy in our own little world so that we ignore our sister/brother networks out there that are also struggling like us. We must be proactive in thinking of ways to link the AfriNEAD network with these other disability development networks.

We would also appreciate your suggestions as to how to handle the resolutions/recommendations that we developed in our commissions at the conference. These are vital gems providing direction around which we can build the network and remain relevant. How should we implement these?

The relevance of AfriNEAD hinges around its commitment to use research evidence to break down the social practices that block disabled people from realizing their full potential.

Let us continue as a collective in being resolute in this quest.

Gubela Mji  
Chairperson  
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## **Main programme of events**

### **Monday 28 November 2011**

07:00 – 08:30 Registration

**Session 1: Official opening of the 3rd AfriNEAD Symposium**

**Chair: Prof Stanley Mpofu, NUST, Zimbabwe**

08:30 – 08:45 Welcome & House-keeping by Stanley Mpofu, Chairman, Local Organising Committee

08:45 - 09:00 Welcome by His Worship, the Mayor of Victoria Falls

09:00 - 09:10 Introduction of AfriNEAD Chairperson by Robert Mkozho, SAFOD Acting Director General

09:10 - 09:50 Remarks by Gubela Mji, AfriNEAD Chairperson

09:50 - 10:20 Official Opening by Vice Chancellor of NUST, Prof L.R. Ndlovu

10:20 - 10:30 Vote of Thanks by Felix Moyo, Director, Information and Public Relations, NUST

10:30 - 11:00 *TEA BREAK*

**Session 2: Roundtable Discussion: “Building Communities of Trust”**

**Chair: Rosewetter Mudarikwa (African Decade for People with Disabilities)**

11:00 – 12:30 Roundtable discussants:

Patrick Devlieger, Belgium

Jerome Slamant, University of Stellenbosch, RSA

Rachel Kachaje, DPI and DIWA, Malawi

Annie Malinga, SAFOD, Zimbabwe

Margie Schneider, University of Stellenbosch, RSA

12:30 - 13:00 Questions and general discussion

13:00 – 14:00 *LUNCH*

**Session 3: Research and Policy**

**Chair: Alex Kagona, Uganda**

14:00 - 15:00 Feedback from APODD project: Tsitsi Chataika and Margaret Wazakili (Centre for Rehabilitation Studies)

15:00 - 16:00 Roundtable Discussion: "Use of Research Evidence by Government in Policy Development & Implementation in the Realisation of Disability Rights"

Discussants:

Hon Moses Masemene (Lesotho)

Joshua T Malinga, MP (Zimbabwe); part-time University lecturer

Robert Mkozho, SAFOD (Zimbabwe)

Rosewetter Mudarikwa, African Decade of Persons with Disabilities

Mac MacLachlan, APODD, Centre of Global Health, Dublin (Ireland)

Gubela Mji, Centre for Rehabilitation Studies (South Africa)

16:00 – 16:30 TEA and COFFEE

16:30 – 17:00 Questions and general discussions

17:00 – 17:30 Official launch of the AfriNEAD Journal, the African Journal of Disability

**Session 4: Gala Dinner at Elephant Hills Intercontinental, sponsored by NUST  
Master of Ceremonies: Wabuhle Chimiza, NUST**

19:00 – 19:10 Welcome remarks by Prof L. R. Ndlovu, Vice Chancellor, NUST

19:10 – 19:20 Keynote remarks: Elliot Mujaji

19:20 – 19:30 Response from the Permanent Secretary of Labour and Social Services, Zimbabwe

19:30 – 21:00 Dinner and enjoy!

**Tuesday 29 November 2011:**

08:00–08:10 Brief outline of day's events (Chief Rapporteur)

**Session 1: “Research Evidence as a Tool to Realise the Rights of People with Disabilities”**

**Chair: Huib Cornielje, Netherlands**

08:10 –08:30 Taryn Young (University of Stellenbosch): Evidence-based Research Practice

08:30 –08:45 Frances Emily Owusu-Ansah (KNUST, Ghana): Indigenous Knowledge – Indigenous Research

08:45 –09:00 Ratie Mpofu: Knowledge Translation: The Key to Influencing Policy into Practice for Improved Quality of Life for People with Disabilities

09:00 –09:15 Leslie Swartz: SAFOD Research Programme

09:15 –09:30 Questions and discussion

09:30 –10:00 Book presentation and exhibition by various authors

Chair: Stanley Mpofu

*10:00 –10:30 TEA AND COFFEE: DELEGATES MOVE TO VENUES after tea*

*10:30 –17:00 COMMISSION PROCEEDINGS IN SEPARATE VENUES*

18:00 – 19:00 APODD meeting (by invitation only)

19:30 – 21:00 AfriNEAD CORE GROUP MEETING (by invitation only)

**Wednesday 30 November 2011**

08:30 – 08:40 Brief outline of the day’s proceedings (Chief Rapporteur)

**Session 1: Chair: Rachel Kachaje, DPI Deputy Chair**

08:40 - 09:00 SAFOD Silver Jubilee

09:00 - 09:20 Newton Phiri (ASNAPP): Land, water, food and sanitation

09:20 - 09:25 Questions and discussion

09:25 - 09:35 Marlene le Roux: The personal journey of making the book “*Look at me*”

09:35 - 09:55 Rosemary Garland-Thomson: Gender, disability and sexuality

09:55 - 10:00 Questions and discussion

10:00 - 10:30 *TEA BREAK*

***Session 2: Feedback from commissions***

***Chair: Nondwe Mlenzana, University of the Western Cape, South Africa***

10:30 – 10:40 Introduction and Housekeeping

10:40 – 10:50 Feedback from: Children and youth with disabilities

10:50 – 11:00 Questions and discussion

11:00 – 11:10 Feedback from: Development Process in Africa: Poverty, Politics and Indigenous Knowledge Systems

11:10 – 11:20 Questions and discussion

11:20 – 11:30 Feedback from: Education: early to tertiary

11:30 – 11:40 Questions and discussion

11:40 – 11:50 Feedback from: Economic Empowerment: skills training, development, and employment

11:50 – 12:00 Questions and discussion

12:00 – 12:10 Feedback from: Health, HIV/AIDS and Community-Based Rehabilitation

12:10 - 12:20 Questions and discussion

12:20 – 13:30 *LUNCH*

***Session 3: Feedback from commissions***

***Chair: Margaret Wazakili, University of Stellenbosch, South Africa***

13:30-13:40 Feedback from Commission: Holistic wellness: spirituality, sport, recreation and tourism

13:40-13:50 Questions and discussion



13:50-14:00 Feedback from Commission: Research evidence and utilization

14:00-14:10 Questions and discussion

14:10-14:30 Further questions and discussion

14:30-15:00 *TEA and COFFEE*

**Session 4: Chair: Antonio Bila, SAFOD Research Programme**

15:00 – 15:15 Presentation of SRP certificates: Leslie Swartz

15:15 – 15:45 Summary of the key issues from the Symposium: Robert Mkozho, Acting DG, SAFOD and SRP members

15:45 –16:30 Response from network members and the way forward

16:30 –17:15 Closing remarks: Jerome Slammat, representative of the Stellenbosch Vice Chancellor

17:30 - 18:00 Closing ceremony by Stanley Mpofu, LOC Chairperson

**18:30 – 20:00 AfriNEAD Bi-Annual General Meeting**

**POST-SYMPOSIUM EVENTS:**

**Thursday 1 December 2011:**

09:00 – 13:00 Research Writing Workshop: Theresa Lorenzo and Patrick Devlieger

09:00 - EquitAble Project Workshop (by invitation only)

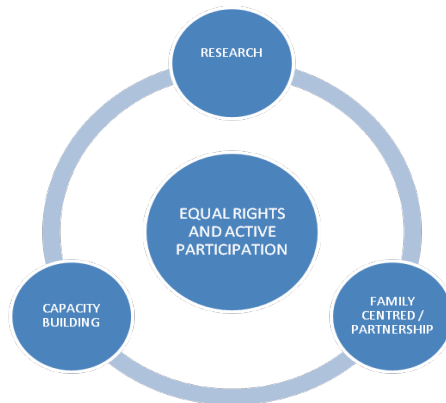
## **AfriNEAD Symposium 2011: Recommendations and resolutions**

We, the delegates of the AfriNEAD Symposium 2011, comprising representatives of governments, academic institutions, researchers, disabled people's organisations, civil society and non-governmental organisations, and business, and representing African countries as well as other Northern countries, met and deliberated on the following 7 key areas:

- A. Children and youth with disabilities
- B. Education: early to tertiary
- C. Economic empowerment
- D. Development process in Africa: Poverty, politics and indigenous knowledge systems
- E. Health, HIV/AIDS and community-based rehabilitation
- F. Holistic wellness: sport, recreation, sexuality and spirituality
- G. Research evidence and utilisation

and make the following recommendations:

### **A. COMMISSION FOR CHILDREN AND YOUTH WITH DISABILITIES**



Research:

- ▶ A needs assessment must be done
- ▶ Informed consent from children must be obtained
- ▶ Self-representivity of children is key

Family-centred/ partnership:

- ▶ Two-way relationship between parents and service providers, researchers
- ▶ Focus on knowledge sharing between all stakeholders

- ▶ Shared decision-making
- ▶ Shared learning experience
- ▶ Respect and recognition of roles and knowledge

Capacity-building:

- ▶ Capacity-building needs to be done across all levels:
  - Parents
  - Service providers
  - Children/youth
  - Community
- ▶ Parents experiences should be valued
- ▶ Using different child-centred or age-appropriate methods
- ▶ Sexuality issues need to be skilfully and sensitively managed > need training

## **B. COMMISSION FOR DEVELOPMENT PROCESS IN AFRICA: POLITICS, POVERTY AND INDIGENOUS KNOWLEDGE**

The key issues highlighted in this commission were:

Traditional leaders:

- The disparities between tribal authority versus “modern” governments was noted.
- Traditional leaders must be convinced that some of the cultural aspects they continue to hold dear are just myths.
- There is a need for specifically designed advocacy programs targeting traditional leaders in rural areas to combat culture-based violent discrimination against disabled people.
- Differences in meanings and understandings of disability need to be interrogated.

Access to health:

- Health service providers need to understand the barriers that people with disabilities face if service delivery is to be equitable and inclusive.
- The landscape and terrain was particularly a barrier for disabled persons who had no transport to the hospital.
- People with disability should demand their health rights as enshrined in different statutes.

Issues of poverty, and access are relevant for everyone in society but PWDs are more likely to be excluded:

- Value of understanding the perspectives and perceptions of indigenous communities was highlighted.

- Increased access to livelihood activities/economic empowerment – there is a need for more research.
- There is a close relationship between the environment and the QOL of PWDs. Therefore different contexts/environments therefore require different solutions.
- There is enough evidence to say there is a significant correlation between poverty and disability

Development of tools for collaboration to facilitate implementation/services:

- Need for multi-sectoral collaboration
- Extend the research networks to universities of other African countries
- AfriNEAD to have a page in the new African Journal on Disability (AJOD)
- DPOs to link with the law fraternity to look at policies/legal frameworks/rights abuses
- Work with research institutes, national bureau of statistics to make disability visible in monitoring of national development plans, MDGs etc
- Service providers and disability organisations to form a network

Development of inclusive policies and practises

- Inclusion of PWDs on policy development processes
- Lot of gaps analysed – more should be done to research successful policies and practises
- Awareness campaigns about policies and rights
- Give technical support and social/cultural awareness to government officials
- Issues of disability are a human rights issues

### **C. COMMISSION ON EDUCATION: EARLY TO TERTIARY**

#### **Key issues**

1. Educator training (teachers and lecturers) – emphasis on curriculum adaptation and inclusive assessment, policy awareness, and paradigm shift from Early Childhood Education to higher/life-long learning.
2. Inclusion of disability issues in the curriculum across disciplines in higher education – training all future professionals, policy-makers and researchers in disability issues so that they can include disability at all levels, including the classroom
3. Responsive research – defining a research agenda according to needs and best practice, children's and families' experiences, policy-led (implementation of policy), reliable database (Knowledge Management Systems) – education is the gateway to success.

## **Strategies**

- Following up on issues of discrimination and be able to explore ways of taking legal actions (e.g. the Australian example).
- Advocacy and lobbying - working with policymakers, DPO's and other relevant stakeholders
- Writing 4 papers based on the above 3 key issues.

### **D. COMMISSION ON ECONOMIC EMPOWERMENT**

- Urgent need for a paradigm shift from the traditional career guidance to career construction in the way disabled people perceive lifelong career choices by utilising the concept of Hephapreneurship.
- Need to decentralise the provision, design, repair and maintenance of assistive devices and empowering disabled people to be the custodians of this process through support from government and other stakeholders.
- Need for African governments to domesticate the UN Convention on the Rights of People with Disabilities to ensure the right to equal access to transportation, information and services and facilities through the engagement of professionals and experts in the development of legislation, access guidelines and operationalising policy in making the environment accessible for all.

### **E. COMMISSION ON HEALTH, HIV/AIDS, AND COMMUNITY-BASED REHABILITATION**

- To build a critical mass within the mainstream of society on disability issues incl. mainstream human rights organisations e.g. Amnesty International Human Rights Watch.
- To investigate the mismatch between policies and implementation; and to use this evidence with core quantitative data to advocate government.
- To motivate and lobby governments to adopt Community Based Rehabilitation as part of National Rehabilitation Policy.

### **F. COMMISSION ON HOLISTIC WELLNESS: SPIRITUALITY, SPORT AND RECREATION**

#### **Key issues:**

- Accessibility
  - Public transport (human movement, mobility)
  - Education
  - Equipment
  - Material
  - Support services
  - Service deliveries

- Information
- Social support net works
- Appropriate assistive devices e.g. wheelchair, prosthesis, orthosis, hearing aids etc.
- Sports facilities
- Coaches
- Disability is not necessarily a hindrance, it can teach society (acceptance), coping skills.

**Action Plans:**

- Adaptation
- Networking and collaboration
- Public education on disability issues
- Develop human resources
- Promote formation of structures

**Resolutions:**

- Understand the context – take into consideration indigenous knowledge systems
  - Historical
  - Time
  - Social
    - Traditions
    - Cultures beliefs
    - Myths
  - Economic
  - Local and global issues/views

**G. COMMISSION ON RESEARCH EVIDENCE AND UTILISATION**

- Evidence based practice requires a match between research, participation and feedback from the community for effective intervention and or practice.
- There is the need to recognize and value alternative forms of gathering information to complement rigorous scientific methodologies. There is a plethora of rich information that needs to be collected and structure for recognition in academic circles to inform policy and identified gaps.
- Once research is put into action – there needs to be ongoing monitoring and evaluation to ensure that practice remains linked to evidence and appropriate to culture setting for continued effective outcomes.

## *AfriNEAD Biannual General Meeting: 30 November 2011*

### *Elephant Hills Hotel, Victoria Falls, Zimbabwe*

**PRESENT:** All 2011 conference delegates were invited. No attendance list was kept.

**AGENDA:**

1. Welcome
2. Mission and vision statements
3. AfriNEAD country focal person
4. Links with other networks
5. Future conferences
6. Membership
7. Core group members
8. AJOD
9. "Resolutions"
10. Matters arising

**1) Welcome:**

Ms Gubela Mji welcomed all attendees and gave some history of design of the AfriNEAD Symposia.

Discussion from the delegates suggested:

- having up to a maximum of 3 commissions running concurrently
- Change the design of organising commissions

Gubela thanked SAFOD and NUST for successfully hosting the symposium.

The challenge for AfriNEAD members now is to develop a way forward with the 3 specific recommendations from each commission. Recommendations should be linked to the UNCRPD.

SAFOD and AfriNEAD committed to partner and see how to implement these recommendations. Ms Mji encouraged DPOs to see how they can work together to see implementation happen. She also encouraged delegates to form partnerships with other countries to strengthen the outputs and reach of the network.

She requested that the African Decade be a closer stakeholder in the implementation phase> take recommendations to AU Office on Disability.

Delegates should come ready to report progress at next symposium.

The AfriNEAD Core Group met last night and the following issues are for feedback and discussion:

**2) Vision and mission statements:**

The following statements were decided upon after some discussion:

*AfriNEAD's **mission** is to be a dynamic network where there is open exchange of ideas and evidence to advance the realisation of equal rights for persons with disabilities and to promote action for social inclusion and participation.*

*AfriNEAD's **vision** is to facilitate evidence-to-action, enabling ability.*

**Slogan:** "Evidence-to-action: enabling ability."

These were endorsed by the floor.

**3) AfriNEAD Country Focal Person:**

There is a need to identify key persons who will report on status of disability in their own countries, as well as market AfriNEAD in countries not represented.

ROLE of focal person was discussed and the following were suggested:

- Do research on disability status
- Produce snapshot summary
- Identify research initiatives for future

The idea of identifying a focal person was endorsed.

The core group was tasked to draw up roles and responsibilities and to implement.

Possibilities of working groups where feasible for support was discussed.

**4) Links with other networks:**

Noted that it will be important to link with other networks eg ADPD and CAN

**5) Future conferences:**

The AfriNEAD Symposium is to be hosted every 3 years in future due to the logistical challenges and demands of organising and hosting and capacity constraints.

3 countries have expressed interest in hosting the next conference: Namibia; Ghana; Malawi

Countries are to bid for hosting: Core group to draw up criteria for bid process.

Need to decide on host country in advance so that every next host plays observance role prior to hosting.



CAN and AfriNEAD to meet and discuss their relationship and timing of their respective conferences.

**6) Membership:**

Need to have a membership fee with different membership structures for AfriNEAD to be sustainable into the future.

Membership money will be needed to fund the operational costs of the secretariat of AfriNEAD.

Will need to have criteria as to who is a member and who is part of future AGMs.

Voting rights of members to be described.

Network needs a constitution.

AfriNEAD is to be registered as an NPO to facilitate funding.

**7) Core Group members**

The current core group is to remain operational until next symposium. Prof Mpofu has been co-opted.

**8) African Journal Of Disability:**

Need to utilise AJOD for advancing the cause of the network.

Review of papers in progress but others are welcome.

Writers need to return reviewed papers.

Leslie Swartz is to take on building capacity of writers.

**9) Recommendations**

Change wording for future conferences from “resolutions” to “recommendations”.

10) No further matters were arising.

The meeting was closed by G. Mji.

## *Drawing threads from AfriNEAD 2011:*

### *Impressions, reactions and some recommendations*

We, a group of 7 delegates, did a quick piece of research. The aim was to get impressions, reactions, learning points and recommendations from participants. Our methodology was a snap poll – we all approached a few people at random and did short interviews to obtain information on their impressions, reactions, learning points and recommendations. We analysed these into major themes and this is what we are presenting.

Here are the results of our little survey presented in 3 sections:

1. Processes around the symposium
2. Learning points and major topic themes that have come out of the conference
3. Recommendations

#### *1. Processes of the AfriNEAD symposium*

These are the comments made by a number of participants:

- An important point made was that the staff were great and the meals served on time.
- The long tea and lunch times are really good as it gives us time to network
- The way the symposium is organized is new and creative –
- It gives a good platform for new ideas and for discussion
- Presentations were sometimes very technical and difficult to understand. We need to have presentations that are more accessible.
- There were too many commissions running at the same time. These should be spread out so we can go from one to another. And so that we can attend more than one commission
- Use of different types of presentations is good – powerpoint, written, round tables, and so on.
- High credibility for people with disabilities as we can share platforms and join hands with researchers.
- There is still some confusion between roles of work of DPOs, government, civil society and research. This creates mistrust. We must clarify these roles. The same person can do both roles but we must make these clear.
- We all interacted well – we listened and we talked - that is trust being built!

#### *2. Learning points and major topic themes*

- There have been lots of new and diverse ideas
- There is a gap between policy and implementation

- People learnt new things and about what is happening in different countries
- The experience of disability in rural areas is an important theme that came out in plenary and a couple of sessions.
- Indigenous knowledge research and academic research must work in collaboration and not be in conflict.
- Many of the presentations looked at disability holistically and not just about rehabilitation, economic, etc.
- Research can start at the grassroots level and must come back with dissemination of results also at the grassroots level.
- Look at different models and choose one that makes sense for us in AfriNEAD as empowering
- Problems experienced by disabled people are often experienced by other non-disabled people – our problems are common ones. Disability makes these worse but not different.
- We must look at abilities and not disabilities
- Democracy and human rights must be addressed in an African context; for example, why are African governments not ratifying the UN Convention?
- There needs to be more awareness-raising around children and youth with disabilities. We must not only include children but involve them as well.
- Academics and parents of disabled children have their own perspectives – they must work together for the benefit of the child. We must document parents' experiences.
- With statistics – we must compare the new and the old and understand the background of the statistics.
- We say there are negative attitudes but we must give more information to change these attitudes – what are the reasons for the bad attitudes, such as ignorance, and so on.

### ***3. Recommendations for the next symposium***

- Prepare guidelines on how to prepare presentations to make them more accessible. Making messages short and simple and not presenting too much detail, especially technical detail. Possibly we can think of asking people to prepare some notes with presentations.
- Give guidance on recommended terminology.
- Spread out the commissions over two days.
- Gates to university must be opened for disabled people.
- Building of kinship and family of AfriNEAD must continue.
- We need to have more information on finding and accessing existing research.
- Information must be shared continuously to build better policies.
- People with disabilities must be included in all development.
- Need political will.

- Need capacity building in using print and electronic media.
- Include people with disabilities as research partners.