

AFRICAN NETWORK  
FOR DEVELOPMENTAL DISABILITIES



EXTERNAL MID-TERM EVALUATION REPORT

Prepared by

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## **Acknowledgments**

This review is about ANDD, but largely about the cause for a better and inclusive society for people with developmental disabilities and children with disabilities. ANDD started about 6 years ago as a network of parents' organizations in Southern and Eastern African Countries. In its small way, it has expanded to include more countries in the region but above all, have made a case for people with developmental disabilities to be included- to be given a chance to express themselves.

I wish to extend my heartfelt thanks to all people particularly heads of the ANDD member organizations in various countries visited. Through you please extend my gratitude to the people I met and shared with me their story. Likewise, I wish to thank all those that responded to my assessment questionnaire especially from ACRIDEME, TAMH, and ZAPDD.

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To all of you mentioned and not mentioned who contributed to the success of this mission, I will always be grateful. This review would not have been accomplished without your input.

Basil Kandyomunda

## **List of Acronyms**

ACRIDEME	Associaçao dos Pais e Amigos da Crianca Deficiente Mental Mozambique
AFRODAD	African Network on Debt and Development
ANDD	African Network for Developmental Disabilities
AU	African Union
CAN	CBR African Network
COMESA	Common Market for Eastern and Sothern Africa.
CRDP	Convention on the Rights of People with Disabilities
CSOs	Civil Society Organisations
DCDD	Dutch Coalition on Disability and Development
DICAG	Disabled Children's Action Group, South-Africa
DPO	Disabled People's Organisations
ENAMRCY	Ethiopian National Association for the Mentally Retarded Children and Youth
EU	European Union
FEDOMA	Federation of Disabled People's Organisations in Malawi
HIV / AIDS	Human Immuno Virus / Acquired Immune Deficiency Syndrome
ICT	Information Communication Technology
II	Inclusion International
KAIH	Kenya Association of the Intellectually Handicapped
LSMHP	Lesotho Society of Mentally Handicapped Persons
MDGs	Millennium Development Goals
MOU	Memorandum of Association
MTEF	Medium Term Expenditure Framework
NACD	Namibia Association for Children with Disabilities
NFU	Norwegian Association for Developmental Disabilities
NGOs	Non-governmental Organisations
NORAD	Norwegian Agency for Development Cooperation
NUDIPU	National Union of Disabled People of Uganda
PCDSwa	Parents of Children with Disabilities in Swaziland
PEST	Political Economic Social and Technological
PMRG	Parent Mobilisation Resource Group
PODCAM	Parents of Disabled Children Association of Malawi
PRSP	Poverty Reduction Strategy Papers
SADC	Southern African Development Community
SAFOD	South African Federation of Organisations of Disabled People
SOPs	Standard Operating Procedures
SWAPs	Sector Wide Approaches
TAMH	Tanzania Association for Mentally Handicapped
UAMHIU	Uganda Association for the Mentally Handicapped and Inclusion Uganda
UN	United Nations
ZACALD	Zambia Association for Children and Adults with Learning Disabilities
ZAFOD	Zambian Federation of Organisations of Disabled People
ZAPDD	Zanzibar Association for Parents of Developmental Disabilities
ZPHCA	Zimbabwe Parents of Handicapped Children's Association

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## **E**xecutive Summary

The evaluation mission would like to start by making this observation. ANDD as a network whose mission is to strive for equality and promote inclusion persons with developmental disabilities at all levels, is within the time frame of its existence and the resources available achieving its strategic objectives and thus registering some positive impacts that can justify its existence, and hence continued support over the next years to enable it mature and realise its long term goals.

The African Network for Developmental Disabilities (ANDD) was formed in 2001, in Cape Town South Africa at a conference which was hosted by NFU with the long-term overarching development goal “to strive for equality in social development of persons with developmental disability, children with disabilities and parents thereby facilitating a standard of living enjoyed by all persons and promoting inclusion at all levels”.

This is the first external evaluation covering the period 2005 – 2008. The purpose and objectives of the mid-term evaluation was to: “review ANDD’s development as a network and assess the scope and impact of its interventions since 2005”. This report therefore presents the findings of the evaluation.

The mission finds ANDD interventions relevant as they are aligned to key development priorities of countries in the region and those of the development partners, namely; poverty reduction strategies, HIV/AIDS Strategic framework. Most of the member organisations are members of SADC and the East African community that have prioritised poverty reduction and combating HIV/AIDS. Most of the member countries also have disability issues addressed in their legal and policy frame works.

The mission also reveals that to a large extent, ANDD has been an effective forum that brings together parents’ organisations of persons with developmental disabilities but also bringing on board persons with disabilities to have their own voice. Of course there are a few areas the network has not yet managed to achieve its initial objectives such as participating influencing policy. But the mission finds that the decision to start developing manuals is a right step in the right direction so as to increase understanding and organisational learning in four thematic areas, namely; Inclusive Education, HIV/AIDS, Advocacy, and self advocacy.

Self-Advocacy training targeting persons with developmental disability is probably the most singular important and rewarding initiative as it allows the target group full participation but above all enables them to have their own say (voice). The impact it has had is overwhelming so far.

The ANDD interventions have had impact on the persons with developmental disabilities, their families, individual organisations but also on global policy and legal framework such as the development of the UN Convention on the Rights of Persons with disabilities. The Convention on the Rights of Persons with Disabilities (CRDP) with an input from the ANDD representative highlights the importance of participation but also potentials of persons with development disability if given an opportunity.

In terms of efficiency, ANDD has so far operated as a semi-formal network without standard operating procedures and other instruments which are a prerequisite in the case of a network of this nature. In the absence of a formal structure, the network’s activities and decision making have remained largely vested in NFU.

The mission finds that ANDD is funded 100% by NFU which funding is used to pay for coordination costs and programmes which mainly include annual conferences and training of self advocates. Whilst the mission finds intentions for the annual conferences noble, the mission contends that they are not yet yielding optimal returns. There is little or no networking that is happening beyond the conference.

As far as sustainability is concerned, ANDD is not institutionally sustainable because the network does not have a firm institutional governance structure. At programmatic level, the mission finds the trained self advocates as a beacon of hope for sustaining the long term benefits of ANDD. The other initiatives such as the development of manuals and others are commendable.

However, as far as ANDD's financial Sustainability is concerned the mission finds the network not financially sustainable. The network is still depending 100% on NFU for funding, which is not sustainable.

Based on the findings of this evaluation, the mission makes the following major recommendations:

- a) Complete the development of the ANDD as a matter of priority as a precursor for institutionalizing ANDD as a legal entity.
- b) Incorporate ANDD as a legal entity with the necessary governance and management structures including an Executive Board and Coordinator to manage the activities assigned to the secretariat.
- c) Establish a secretariat to help in streamlining the operations of the network with two of the main assigned roles being coordinating the activities of the network, an fundraising
- d) Support the completion of the manuals, so that they can start being used by the network to achieve the purpose for which they are being developed.
- e) Support capacity building for member organizations to make them stronger organizations in terms of advocacy and influencing national policies that affect persons with developmental disabilities.
- f) Develop a strategic plan to help ANDD make not only have a clear view of the direction it wants to take but also to help undertake a more comprehensive environmental scan, develop values as well as developing the necessary standard operating procedures, systems and procedures.
- g) Resolve the stand-off between ANDD and her Francophone members of Inclusion Africa and Indian Ocean. This in a way will pave way for the long term institutional stability and financial sustainability of ANDD.
- h) Let the network focus its agenda at influencing what is common to the number of countries mainly taking advantage of "collective voice". This could include the current issues but take them to power centres yonder, such as AU, UN, African Decade for Persons with Disability, SADC, SAFOD, COMESA, East Africa Community etc. Influence regional policies. Ensure that hot issues such as education that is inclusive for all is adopted by the respective countries.
- i) Increase networking beyond the annual conference. This could be also enhanced through setting up website to facilitate experience and knowledge sharing. Member organizations can then subscribe to it by uploading their stories / reports etc.
- j) Set aside resources that can go towards supporting common projects at the organizational level, such as training self advocates. Pass on skills to facilitators for training self advocates from each organization, give the organization funds, and let each organization train its self advocates and report to ANDD which in turn reports to NFU or whichever funder.

# 1

## BACKGROUND AND INTRODUCTION

### 1.1 *Introduction*

This external midterm evaluation of the development cooperation between African Network for Developmental Disabilities (ANDD) and the Norwegian Association for Persons with Developmental Disabilities (NFU) was commissioned with the aim reviewing ANDD's development as a network and assessing the scope and impact of its lobbying and advocacy work since 2005. The review was undertaken during the month of July and August 2008 by Basil Kandyomunda a development management consultant with a bias in disability programming. The findings in this report are a result of an intense field visit covering the three regions of Malawi and an array of interviews with key stakeholders. The report gives the background, objectives and methodology and the findings. It also provides a discussion of the emerging issues and recommendations covering relevance, effectiveness, impact, efficiency and sustainability aspects.

### 1.2 *Background*

#### 1.2.1 **NFU's international solidarity work**

NFU has since 1981 been involved in international solidarity work. The international projects have been in Asia, Central-America, the Caribbean, Eastern Europe, with a main emphasis on Sub-Saharan Africa. NFU is a member of the Atlas Alliance, an alliance for Norwegian DPOs involved in development work throughout the world. In addition to NFU's own strategy, NFU adheres to guidelines developed by the Atlas Alliance' and the Norwegian government.

NFU is an organisation of and for persons with developmental disabilities. Many members are either parents or close relatives of persons with developmental disabilities, or have a developmental disability herself/himself. It is in this respect that NFU is in partnership with similar organisations in other countries. The competence and experience NFU has as an advocacy organisation – or advocacy DPO, in Norway is one of the most important elements in the partnership with a sister organisation. Another equally important element is NFU's knowledge of how it is to either be a person with developmental disabilities, or how it is to live closely with a person with developmental disabilities.

#### 1.2.2 **The African Network for Developmental Disabilities**

The idea of networking started in 2001 in Johannesburg at an advocacy network held at Holiday Inn Garden Court, Johannesburg International Airport, South Africa. However, the Africa Network for Developmental Disabilities (ANDD) was finally formed in 2003, in Cape Town South Africa at a conference which was again hosted by NFU. The network was formed by ten parent organizations, from southern and eastern Africa. It was at this conference that the vision and mission of ANDD were concluded. Prior to the formation of the network NFU supported a Parent Mobilisation Resource Group (PMRG) which ran from 1994-1997 with six parents organisations (groups). The foundation of the African Network for Developmental Disabilities was a follow up of this project, which took the step further from focusing on only parents' mobilisation to strengthening of their organisations and equipping them with knowledge and skills in the realm of advocacy and policy influencing in favour of inclusive society. The network was thus created in order to be able to address issues regarding persons with developmental disability and to create pressure both at national, regional and international level for the development of inclusive policies for persons with developmental disability.

The member organisations are all advocacy organisations of and for disabled children and/or persons with developmental disability. Primarily they are mainly parents who are actively involved in the running of the organisation and advocacy work. Some of the organisations are national with local branches all over the country (ZAPDD, PODCAM, TAMH, ZPHCA, LSMHP, DICAG), while others are still more concentrated in the centre of the country (NACD, ACRIDEME and PCDSwa).

The long-term overarching development goal of ANDD is to strive for equality in social development of persons with developmental disability, children with disabilities and parents thereby facilitating a standard of living enjoyed by all persons and promoting inclusion at all levels.

To achieve this, the network aims to speak with one voice, to share human and material resources, build each others' capacity and development, and develop common advocacy tools and manuals to strengthen organisational competences nationally, regionally and internationally.

The four objectives of the network are:

- a) Strengthening of the network and member organisation (organisational development)
- b) Active participation of persons with developmental disability in national organisations and network
- c) Development of advocacy tools to address the issue of poverty and disability
- d) Inclusion of persons with developmental disability in regional HIV/AIDS programmes

One goal of the network has been to start up different common projects however the most important part of the network is still the exchange of information based on different national experiences. This is mainly done during an annual network meeting. In the long-term the aim of the network is to develop a common institutional learning so that the network speaks with one voice and be able to address issues together in regional and international forums.

### **1.3 Purpose and Objectives of the Evaluation**

The purpose of the mid-term evaluation was to "review ANDD's development as a network and assess the scope and impact of its interventions since 2005".

The objectives were to:

- assess the progress of ANDD's interventions in relation to the overall and immediate objectives of the network;

#### **Box 1: ANDD member organisations**

1. Disabled Children's Action Group (DICAG), South-Africa
2. Lesotho Society of Mentally Handicapped Persons (LSMHP)
3. Namibia Association for Children with Disabilities (NACD)
4. Associacao dos Pais e Amigos da Crianca Deficiente Mental (ACRIDEME), Mozambique
5. Parents of Children with Disabilities in Swaziland (PCDSwa)
6. Zambia Association for Children and Adults with Learning Disabilities (ZACALD)
7. Tanzania Association for Mentally Handicapped (TAMH)
8. Zanzibar Association for Parents of Developmental Disabilities (ZAPDD)
9. Parents of Disabled Children Association of Malawi (PODCAM)
10. Zimbabwe Parents of Handicapped Children's Association (ZPHCA)
11. Uganda Association for the Mentally Handicapped and Inclusion Uganda (UAMHIU)
12. Botswana Society of People with Disability
13. Kenya Association of the Intellectually Handicapped (KAIH)
14. Ethiopian National Association. Mentally Retarded Children and Youth (ENAMRCY)



- assess strategies for sustainability in order to assess ANDD's institutional viability regionally and internationally; and,
- give recommendations for NFU's role in the above

## **1.4 Approach and Methodology**

### **1.4.1 Process**

The evaluation mission armed with the revised terms of reference developed the methodology and the evaluation tools that would assist in enlisting the necessary information from the target partners. The field visits to ANDD members were carried out from 26<sup>th</sup> July to 30<sup>th</sup> August 2008. Field data collection was completed with phone interviews with officials from NFU, which were in turn followed by data synthesis, analysis and report generation.

### **1.3.2 Methodology**

#### Literature Review

A number of documents related to ANDD / NFU relationship and those that are relevant to the operational context were reviewed to give the mission an understanding of what ANDD with support from NFU has been doing and how it has been doing it. This was done selectively.

#### Meetings

A number of meetings were also organized to meet key informants (individuals) from the member organizations of ANDD. The meetings were meant to source for information on their assessment of the successes, achievements and challenges of ANDD. An interview checklist developed by the consultant (core evaluator) was used to guide the discussions with the ANDD members.

#### Field Visits to ANDD Members

The evaluation mission visited the following member organizations:

- Disabled Children's Action Group (DICAG), South-Africa
- Lesotho Society of Mentally Handicapped Persons (LSMHP)
- Namibia Association for Children with Disabilities (NACD)
- Parents of Children with Disabilities in Swaziland (PCDSwa)
- Zambia Association for Children and Adults with Learning Disabilities (ZACALD)
- Parents of Disabled Children Association of Malawi (PODCAM)
- Zimbabwe Parents of Handicapped Children's Association (ZPHCA)
- Uganda Association for the Mentally Handicapped and Inclusion Uganda (UAMHIU)
- Kenya Association of the Intellectually Handicapped (KAIH)

A total of 54 respondents were met from the 9 member organizations of ANDD, NFU, and a few other stakeholders. During the meetings, the objectives of the mission were explained and the member narrated the activities of the organizations, the achievements and challenges most especially the annual conferences and the self advocacy training project.

## **1.4 Process Limitations**

There is limited number of members in each organization that are informed about, and have been involved in ANDD activities [read conferences]. In most cases these are only two. This means that the mission had a limited catchment area for meaningful information.

Travelling in Africa is quite unreliable. This involves losing a lot of time in connections, fatigue, besides being expensive. Several times I was reunited with my suitcase 24 hours after arrival.

Lack of a strategic plan covering the 3 year period of evaluation or a project document detailing the expected outputs, activities and inputs including indicators means that the evaluation mission had to reconstruct proxies retrospectively to fit into the conventional evaluation parameters.

# 2

## FINDINGS

### 2.1 *Introduction*

This section discusses the findings of the review in terms of assessment of consistency and clarity of the program objectives and interventions; relevancy of interventions; compliance with the national strategic priorities; effectiveness and impact; efficiency and sustainability. The assessment is informed by the extensive review of documents and interviews and meetings with various stakeholders.

### 2.2 *Relevancy of ANDD Interventions*

To assess the relevancy of ANDD interventions, the mission had to interrogate the reasons why the network was formed. As already noted, ANDD was founded mainly to enable the members to address issues regarding persons with developmental disability but also to create pressure both at national, regional and international level for the development of inclusive policies for persons with developmental disabilities.

The 2007 ANDD Atlas Alliance Annual Report justifies the relevancy of ANDD interventions in terms of its alignment with poverty reduction strategies, HIV/AIDS Strategic framework, the African Decade for Persons with Disabilities and EU strategies on disability.

The countries within the network are most of them SADC members and East African Community. In both regional development blocks, poverty reduction is a priority. Disabled people are to a large extent mentioned among the most vulnerable groups that have to be targeted. SADC member states are addressing their poverty problems either through PRSPs and / or through other initiatives. However, families and persons with developmental disability are rarely singled out as a target group, and yet these are the most excluded.

On the other hand HIV/AIDS is also recognised as one of the biggest threats to development and hence each of the countries in the region has developed a strategy to address the scourge. In fact SADC has a multi-sectoral HIV/AIDS Strategic Framework and Programme of Action 2003-2007. The network's focus on HIV/AIDS is out of realisation that persons with developmental disability are largely excluded from information and treatment.

Furthermore, Education, Health/HIV/AIDS, Employment, and Capacity building, constitute the major focal projects being promoted by the African Decade of Persons with Disabilities among the African Countries but also targeted and given priority by the UN Convention on the Rights of Persons with Disabilities (CRPD).

In line with the African Decade of Persons with Disabilities the majority of the countries (Tanzania, Malawi, Namibia, Zambia, Uganda, and Kenya) have signed the UN Convention on the Rights of Persons with Disabilities and the majority also have their own domestic laws and policies aimed at providing for the issues and rights of persons with disabilities. Some of these countries such as South Africa and Uganda have elaborate provisions addressing disability issues in their Constitutions including political representation and participation of persons with disabilities in political governance and decision making.

On the other hand, the new EU-Africa Strategy finalised in December 2007 sets the priorities of a renewed EU-Africa relationship. The Strategy recognizes the importance of disability as a key development issue

and is therefore a major step forward for persons with disabilities. The adopted strategy pays particular attention to persons with disabilities in the fields of health and education as it gives recognition of the need for full access to health and education services for women, children and men with disabilities.

Basing on this discourse therefore, and in as far as poverty and disability are concerned, the mission finds the ANDD interventions relevant to the issues concerning persons with disabilities in general and persons with developmental disability in particular, but also being in conformity with the development priorities of the countries in the region and the development partners.

### 2.3 Effectiveness of ANDD Interventions

While opening the ANDD annual conference in Zimbabwe in 2007, the NFU President, Ms. Helene Holand listed 5 benefits that result from being a member of ANDD. These benefits are in conformity with the objectives of ANDD which include: a) strengthening of the network and member organisation; b) active participation of persons with developmental disability in national organisations and network; c) development of advocacy tools to address the issue of poverty and disability; and inclusion of persons with developmental disability in regional HIV/AIDS programmes.

We therefore assess achievements of these objectives to a large extent in terms of realisation of these benefits highlighted by the NFU president.

**Box 2: Benefits of membership to ANDD**

- Learning about what other organizations are doing for purposes of replicating best practices, building capacity and presenting opportunities for exchange of skills, knowledge and experiences
- Establishing links with other organizations and raising awareness together on issues of disabilities regionally. This will promote mobilization of parents.
- Parents are in a better position to advocate government on service provision for persons with disabilities as well as lobbying regional; bodies that will make local lobbying effective
- Promotion of the participation of the disabled children and young adults through youth forums on disability and self advocacy
- Improving organizational sustainability through exposure to national and international partners.

*-Extracted from ANDD 2007 Report*

#### 2.3.1 Annual Conferences

The network was created to enable parents organisations in Southern and East African Countries to address issues regarding persons with developmental disability and to create pressure both at national, regional and international level for the development of inclusive policies for persons with developmental disability. In order to achieve this, the network aims to speak with one voice, to share human and material resources, build each others' capacity and development, and develop common advocacy tools and manuals to strengthen organisational competences nationally, regionally and internationally. So far the most important part of the

**Box 3: ANDD Annual Conferences & Host**

2001	South Africa	NFU
2002	-	
2003	South Africa	DICAG
2004	Tanzania	TAMH
2005	Zambia	ZACALD
2006	Malawi	PODCAM
2007	Zimbabwe	ZPHCA

network has been the exchange of information based on different national experiences which is mainly done during an annual network meetings / conferences.

This means that the annual meetings / conferences have been used to create opportunities for member organisations to meet and share experiences, individual organisational achievements with regard to their interventions in the areas of furthering common and shared objectives. In some of the annual meetings, efforts have also been made to address organisational development issues such as developing / reviewing ANDD constitution, and in more recent meetings attempting at developing manuals on a number of thematic areas such as HIV/AIDS, Advocacy, Inclusive Education; and Self Advocacy. The mission revealed that so far 6 annual conferences have been organised (see box 3 above).

The mission finds that indeed, the annual meetings / conferences have to a large extent been used for the purpose of sharing experiences and lessons. However, as a network, the mission finds it strange that this sharing has not continued in between the conferences. There was largely little communication between the network members in between the conferences. Most members met confessed this to be a weakness. Even during this year since the last conference in Zimbabwe where members were organised into different thematic groups with specific assignments, there was still very little communication going on in pursuit of the assignments. This therefore leads us to ask why if the sharing of experiences and learning was an expressed and felt need of the member organisations why then do they take advantage of the network to satisfy that need. Some of the answers were: "We lack the means to communicate"; we in Africa are lazy when it comes to sharing information"; "we lack some central place (hub) to help us share the information"; "once home we forget that we need to share information, each one of s get back to doing their things the way they have done it always".

Evolving a culture of information sharing is a challenge in Africa. In fact in a number of countries, there was no evidence of the attending members organising feedback sessions for their membership or executive committee members to reflect on the issues and adopt some in their programmatic agendas. In some situations, some participants were finding the annual conferences mere boring talk shows barely adding value to their organisations.

***"We spend a week talking with barely anything tangible in terms of improving our organisations, not even networking, since some of the members feel they know too much and intimidate others.."*** a member observed.

#### **Box 4: Way Forward on HIV /AIDS during the 2005 Conference**

All member organizations agreed to embark on the following:

- Training of people with developmental disability
- Targeted awareness campaign on issues of HIV/AIDS
- Care and support for people with disabilities developmental
- Not to hide their children who are disabled but to be open about it.
- Teach persons with disabilities on how to defend themselves from possible defilers.
- Track on how the money meant for HIV/AIDS issues is used in the different countries and how to access the same funds
- Team up with other NGO's involved in matters of HIV/AIDS in each respected country
- To first sensitised parent member organizations themselves on issues of HIV/AIDS.

The mission therefore concludes that the annual conferences were being used by the participants as an occasion for a free travel holiday (tourism) and not really for the benefit of the member organisation.

### 2.3.2 Including PDDs and HIV/AIDS programmes

One of the developmental objectives of ANDD is about inclusion of persons with developmental disability in regional HIV/AIDS programmes. To achieve this, it was felt there was need to increase organisational learning about the subject of HIV/AIDS and then get persons with developmental disabilities and children with disabilities to get involved in the mainstream HIV/AIDS programmes in their countries and in the region. The mission revealed that ANDD had the most extensive discussion on the issue of HIV/AIDS in the Zambia Annual ANDD conference 2005. The members discussed the challenges of HIV/AIDS and possible solutions and even developed a way forward on the issue.

In terms of increasing the organisational learning and interventions on HIV/AIDS, so far different members were making attempts at individual level to start addressing the issue for their membership and especially children with disabilities. Generally, the mission was impressed with the efforts in each member organisations in this area of focus. The majority of the member organisations were collaborating with the National HIV/AIDS focused organisations. For instance, at the time of the review mission in Kenya, there was a training session for peer educators funded by Handicap International, Kenya going on for young people with developmental disabilities concerning issues of reproductive health, HIV /AIDS and sexuality.

In Lesotho, DPOs including LSMHP are working with the National AIDS Commission to increase the understanding of persons with persons with disabilities about HIV/AIDS. The National AIDS Commission has also developed HIV/AIDS IEC materials in Braille, and DPOs are represented in the development of HIV/AIDS strategic plans.

#### Box 5: Disability on the PRSP agenda

PRSPs (Poverty Reduction Strategy Papers) are a key government policy instrument for poverty reduction and are seen as the operational framework for implementing the Millennium Development Goals (MDGs). PRSPs have put poverty reduction at the centre of development planning. There is an increase in the number of PRSPs in which disability is mentioned, but this is only partial progress. Disabled persons still remain largely invisible in PRSPs. The result is an incomplete policy agenda: in 67% of the PRSPs, disability is only mentioned as a social protection measure. PRSP measures to economically integrate disabled people are rare.

It is at the level of disability policies that PRSPs face their greatest challenge: PRSP programs need to be translated into annual government budgets but there is a strong risk that the initial policy commitment will evaporate. Data show that in only approximately one third of the planned interventions in social protection, education and health are targets and budgets allocated. There are three key constraints hindering the participation of disabled people in poverty alleviation: they are economically excluded from pro-poor growth, there is social exclusion from education and health and they have a weak political voice. The weak political voice of disabled people (organisations) is a concern. Associations representing disabled people are consulted in only a few cases, in 29% of PRSPs, and in the follow-ups, like the policy discussions of PRSPs, they are rarely involved at all.

Evidence from the PRSPs studied shows that when DPOs participate in PRSP consultation, the social focus of disability policy on social protection measures decreases and the economic focus increases, and the problem is analysed more in terms of a list of human potential. DPOs should be involved not only in the preparation of PRSPs, but also during the policy discussions. Capacity building may be required: training in advocacy (for example, how to formulate economic argument for disability policy), and financial support.

*This text is based on the contribution of René Bonnel, World Bank, to the DCDD symposium.*

However, although other networks such as SAFOD and national umbrella organisations such as FEDOMA, NUDIPU, ZAFOD and others were already involved in inclusion of persons with developmental disability in regional HIV/AIDS programmes, ANDD was not yet strategically playing at that level.

In terms of development of training manuals as a shared activity, during the ANDD conference in Victoria Falls, Zimbabwe in 2007, a thematic group on developing a Training Manual on HIV/AIDS was constituted but by the time of this mission there was no evidence of making progress beyond what had been achieved during the workshop.

### **2.3.3 Advocacy on Poverty and Disability**

Advocacy is a key and central issue in ANDD development agenda. In fact ANDD is said to be a network of advocacy organisation with a focus on developmental disabilities. One of the strategic objectives of ANDD is to develop advocacy tools to address the issue of poverty and disability.

There are two main observations to make here. First, the member organisations of ANDD claim to be advocacy organisations. However, a discussion with these organisations reveals the majority are not very competent in advocacy as area in general, and engaging in PRSPs in particular which requires another set of competences, mainly in policy analysis. Most of the personnel interacted with seemed not to have the necessary level of economic literacy<sup>1</sup> to enable them participate and influence PRSPs to address challenges of disability as a development concern.

It is also important to note that the development objective of ANDD is to develop advocacy tools to address the issue of poverty and disability and not necessarily to effectively engage in PRSPs. The discussion of Poverty and Disability during the 2005 Conference, revealed the members' translation of poverty and disability in terms of lack of access to specific services such as education, health care and such issues rather than analysing the complex mix of poverty and disability as cause and effect relationship which analysis can lead to appreciating the need for tackling the issue at both macro- and micro-levels.

At the Victoria Falls Conference in 2007, there was an effort to start developing advocacy tools. A thematic group to develop Advocacy Training materials was also constituted, but likewise nothing much had been achieved by the time of the review.

### **2.3.4 Self-Advocacy Training**

Finally, active participation of persons with developmental disability in national organisations and network is one of the key objectives of ANDD. So far, training and self representation of self advocates in the Regional and International Conferences such as the UN Ad hoc Committee on the Rights of Persons with Disabilities is probably the most successful and tangible intervention ANDD has achieved.

The mission revealed NFU and ANDD have been involved in self advocacy work in the region since 2005 with a pilot project in Zambia. At the 2005 Annual Conference organized in Zambia, the participants were

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<sup>1</sup> Economic literacy is here used to refer to a set of competences needed to understand and engage in macro- and micro-economic policy discussions and debates on the Brettonwoods Institutions tools used in engaging borrowing nations, how economic policies are generated at the national level, the role of national central banks, inflation, PRSPs, SWAPs, MTEFs etc. Without basic working knowledge in these issues renders meaningful participation of CSOs marginal.

also given an exposition by NFU President on what Self Advocacy entails and the role of support persons. The President supported by other NFU officials also conducted a fully-fledged training in Lesotho after which LSMHP integrated it in her strategic plan. It is now a core element of LSMHP country programme.

Since 2005, the majority of the countries have benefited from the training of self-advocates conducted by NFU and in 2008 by Mr. James Mung'omba and Quincy Mawiya under a project co-sponsored by Inclusion International. Apart from Lesotho and Zimbabwe where training self advocates is already part of their development programme funded by NFU, in other countries, the training sessions were on ad hoc basis organized and carried out by the duo with very little integration into the organizational programmes. So far a total of 86 self advocates have been trained in 8 countries in 2008. Table 1 below shows the breakdown of the trained self advocates by country.

**Table 1: Trained Self Advocates by Country**

Country	Name of Organisation	No. of trained	Funder
Uganda	Uganda Association for Mentally Handicapped	10	NFU
Namibia	Namibian Association for Children with Disabilities	15	NFU
Swaziland	Parent for Children with Disabilities in Swaziland	9	II
South Africa	Disabled Children's Action Group	15	II
Kenya	Kenya Association for Intellectually Handicapped	10	NFU
Zanzibar	Zanzibar Association for the People with Developmental Disabilities	9	II
Tanzania	Tanzania Association for Mentally Handicapped	9	II
Malawi	Parent of Disabled Children Association in Malawi	9	II
Zambia	Zambia Association for Children with Learning Disabilities	27	NFU
Lesotho	Lesotho Society for the Mentally Handicapped	57	NFU
Zimbabwe	Zimbabwe Parents of Handicapped Children Association	59	NFU
<b>Total trained</b>		<b>229</b>	

The number of trained of self advocates altogether totals 229. This includes the number of self advocates trained through workshops organised and facilitated by Quincy and James as well as those undertaken by ZPCHA and LSMHP as part of their programs.

Besides, the training, the self advocates have been given an opportunity to participate in key important international and regional forums. For instance, Quincy who was identified and seconded by NFU and Inclusion International to represent fellow young people with developmental disabilities effectively represented ANDD at the last two UN Ad hoc meetings on the Convention on the Rights of Persons with Disabilities. Quincy is also serving on the Board of Inclusion International. *See case story of Quincy on the next page.*



## The Story of Quincy Mwiya



Quincy is a single man, aged 30 year; he comes from Africa and lives in Zambia. He is a person with an Intellectual disability and a Council member of the Inclusion International. In the council, he represents the region called Inclusion Africa and Indian Ocean. Quincy is also a self advocate member of Africa Network for developmental Disability (ANDD) He is also an active member of a national organization in Zambia called Zambia association for Children and Adults with Learning Disabilities (ZACALD).

With the help from ZACALD, ANDD, NFU, Inclusion International and UN-DESA, Quincy was able to attend the UN 7<sup>th</sup> and 8<sup>th</sup> AD HOC Session on the rights of persons with disabilities and was an instrument in that process as a self advocate, particularly for Africa. This experience exposed Quincy to levels where he now feels confident to talk about human rights for persons with disabilities.

At birth Quincy appeared to have had no disability at all, but between the ages of four to six years, the mother had started noticing certain signs of disability in the child. At the age of seven, Quincy was enrolled in grade one in the mainstream of education. During that time, it was evident that Quincy had an intellectual disability and could not match with the rest of pupils in that class. As the result of his condition, Quincy was put in a special class that accommodated only persons with disability who they referred to as mentally retarded. Quincy was prompted to prematurely leave school because the other students thought that he could not learn. However, he felt much offended because he knew how important education was for him. When he left school, he continued living with his family.

Quincy was fortunate enough, the government had introduced skills training courses that included persons with special needs especially persons with intellectually disabilities, his application was accepted at Livingstone Trades Centre and he successfully completed his course in Home Management.

Quincy got a contract job for one year with a large hotel in Zambia, he then got another one with an NGO called ZAEPD as a Restaurant Manager. This meant that, he had to leave home and live in another town where his services were needed.

He is a living example that having a disability does not prevent them from living in the community. Quincy's dream is to see that people with intellectual disabilities are also part of the solution to many problems that they face and that they should fight for their rights at all levels. To do that, he is planning to embark on self advocacy training program for people with intellectual disabilities in the region.

- Extracted from: [www.inclusion-international.org](http://www.inclusion-international.org)

## 2.4 Impact of ANDD Interventions

The impact of a development intervention is normally assessed at the goal and purpose levels of the intervention (project). In the case of ANDD, the long term goal is “to strive for equality in social development of persons with developmental disability, children with disabilities and parents thereby facilitating a standard of living enjoyed by all persons and promoting inclusion at all levels”. The mission therefore decided to assess the impact by tracing the aspects of equalisation of opportunities for persons with developmental disabilities, children with disabilities and parents, and policy level.

### 2.4.1 Individual Level

At the individual level, the mission was interested in assessing the level of participation of persons with developmental disabilities / children with disabilities in community affairs and development work in general; increase in self-esteem; ability to speak for one-self; and the appreciation and respect for the individual's contribution.

At the individual level, ANDD has trained a number of self advocates who are already participating in policy influencing activities in their respective countries. The trained self advocates met by the mission were found to have boosted self-esteem, were articulate in terms of what they want and how they want to be treated. They are able to challenge anybody who is threatening their rights. They know their limitations but they have their own life goals of leading independent lives as much as possible.

When interacting with Mortonique, Codlyne and Jessy, three young people with various disabilities who had attended the self advocacy training in Cape town, the three exuded a high level of confidence in a way they expressed what they wanted in their lives and how they wanted society to treat them including being enabled to access employment after their school.



In Namibia, Melany (pictured left) and Jeffrey, two self advocates that had benefited from the training when challenged to mention the benefits from the training, they listed that they realized their worth as human beings who needed to be respected. Asked what more training Melany confidently said that they needed to be trained about “love issues” – issues about sexuality and sexual reproductive health. Asked about what she wanted to be, Melany said she wanted to become a model while demonstrating for the team.

Independent living is the ultimate goal of every human being. This is also the goal of self advocacy training as categorically stated by Mohammed, a self advocate from Tanzania “we also have rights to live independently [sic]; get married and have children like anyone else” (Self Advocacy Training Project Report, [www.inclusion-international.org/](http://www.inclusion-international.org/))

The example of Quincy Mwiya (see page 11 above) resonates high in the world. Quincy Mwiya was selected by NFU to represent ANDD and participate in the UN Ad hoc Committee meetings on the Convention of the Rights of Persons with Disabilities.

## **2.4.2 Organisational Level**

At organizational level, many member organizations of ANDD have improved in terms of programming focus, albeit still weak in organizational development. For instance there is evidence of these organizations repositioning themselves as advocacy organizations and those in bilateral partnership with NFU have become better capacitated and organized parents' organizations, more democratic and transparent. It is also gratifying to note that almost all members are changing their strategies to include and allow people with developmental disabilities more participation. The self advocacy training is a key element in their strategic programs that will ultimately translate into this participation.

However, the assessment reveals that the member organizations still have a long way to become democratic and sustainable institutions. Some of the members are only national in name and not in character and membership development. Some are actually not even truly parents' advocacy organisations, but rather largely schools or centres. Nevertheless, the mission revealed that there is a will on the part of the member organizations to change and become better and more effective advocacy organizations.

## **2.4.3 Policy Level**

At the macro-policy level, many countries in the region have developed poverty reduction strategy papers (PRSPs) in which CSOs are active participants. In a number of countries such as Uganda, Malawi, Zambia and a few others, the DPOs especially through their national umbrella organizations have been active participants in the development and revisions of the PRSPs. However, the majority of the ANDD members have not been active participants. There are two reasons for this. The organizations lack the necessary competences to engage at that level. The other reason is that the majority of the ANDD member organisations are too small with very few staff<sup>2</sup> to be able to effectively participate. Generally, DPOs do not have capacity to employ high flyer economists and other highly economic literate personnel that can effectively engage with the policy makers at the macro-and sectoral policy decision making levels.

However, even where CSOs have been active participants in the development of PRSPs, they are excluded at the high level of approval and other decision making points. After passing the PRSPs, the CSO participation in implementation especially at sectoral levels is diminished as very few have capacity to engage in SWAP and MTEF negotiations.

## **2.5 Efficiency**

ANDD has so far operated as a semi-formal network without standard operating procedures and other instruments that make up a formal network. In the absence of a secretariat, the functions of a secretariat have remained shared between the host organization and NFU, which is the main funding partner. This means that major financial decisions are taken by NFU, with lesser input from the host organisation.

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<sup>2</sup> Some of the member organizations like PODswa, ZACALD, KAIH and NACD do not employ full time contract staff. A few like DICAG employ one staff. It is very difficult for such organizations to set time aside to participate in intensive PRSP processes.

So far, once a host organisation is elected at the annual conference, NFU enters into a Memorandum of Association (MoU) which spells out terms and conditions governing the relationship between the host organization as grant recipient and NFU as the funding agency. The host organization is then required to open a separate bank account into which NFU transfers some resources to use for specific activities but largely those connected with organising the annual conference and coordination. At the end of the year (which is basically end of the term of the hosting period, the books of accounts are audited and the audit report submitted to NFU. So far, the audit reports seen by the mission showed proper use of the resources.

The mission finds that ANDD is funded 100% by NORAD through NFU. The funding is used to pay for coordination costs (host organisation) and NFU management costs (Norway) and programmes which mainly include annual conferences and training for self advocates. This means that ANDD as an outfit is not yet raising her own funds from any other source. The funding from Inclusion International for self advocates is directly sent to James Mung'omba (II Regional Coordinator?), hence comes to ANDD (not necessarily in cash transfers) but rather managed directly by II through their agent.

In terms of value for money, the programmatic budget has so far been spent on conferences which is basically the main activity aimed at promoting the objective for networking, sharing experiences and learning between the membership. Whilst the mission finds intentions for the annual conferences noble, it is important to put it into context. True the conferences have promoted sharing of information among the member organisations, but if this is the sole objective, then it could be done through other options such as e-mail, exchange visits and many others.

The mission also considers the frequency of the conferences rather too short. The conferences should probably be convened once every two years. During the time between the conferences other projects can be undertaken, especially those aimed at capacitating members of ANDD to become better organisations, such as facilitating exchange visits, and other small but innovative projects for promoting sharing of information and experiences.

## **2.6 Sustainability**

### **2.6.1 Unpacking Sustainability**

The sustainability of a network like ANDD is dependent on a number of inter-related elements. These include:

- ANDD's reading of, internalization of and responsiveness to changes in needs, interests and priorities - the changes arise from shifts in the broader social, political and economic environment;
- the need to develop a diverse range of organisational forms (e.g. alliances) to meet needs and interests in a strategic and ethical manner;
- the importance of building strong relationships with central and local government, the private sector, the media and the beneficiaries;
- the availability of appropriate support and resources;
- the need to attract, develop and retain appropriate human and financial resources; and
- the importance of creating an enabling environment and fiscal framework.

This mission therefore examines the sustainability of ANDD at several levels; namely:

- a) Institutional sustainability which refers to the ability of ANDD, to continue its operations after leadership transition.

- b) Programmatic sustainability which refers to the ability of ANDD to constantly shift interventions to keep in line with the changing needs of beneficiaries within a given programme.
- c) Financial sustainability which refers to the ability of ANDD to finance its operations – ANDD is totally dependent on NFU / NORAD funding.

### **2.6.2 Institutional Sustainability**

As a network, there have been attempts to draw a constitution and other instruments that should guide not only the day-to-day operations but also the transfer of power, although this has not yet been completed and adopted by the membership. ANDD is to a large extent still a semi-formal network whose institutional sustainability cannot be guaranteed. The network does not have a basic institutional governance structure. Although the host organization assumes that responsibility of a secretariat, the mission revealed that the host organizations do not properly fit into that role. Besides a secretariat that transits yearly makes it fragile and ineffective. The institutional memory is therefore non-existent. All in all, it is plausible to conclude that without a secretariat and an Executive Committee (Board) to aid decision making.

Institutionalizing the network through creation of an Executive Board and a secretariat is therefore imperative and one such element that can guarantee the network's long term institutional sustainability.

### **2.6.3 Programmatic Sustainability**

Between 2005 and 2008, ANDD has besides the traditional activity of conducting annual conferences added on the training of self advocates. The trained self advocates are probably the most sustainable element of the program so far. The trained self advocates met gave the evaluation team the needed reassurance that even if ANDD wound her business today, the energized self-advocates would remain icons in their society able to articulate their demands.

The representation of self advocates and ANDD in general at the meetings of UN Ad hoc Committee on the Rights of Persons with Disabilities and at Inclusion International conferences has left indelible ink.

The other sustainable elements in terms of benefits include: the development of manuals and the sharing of experiences arising out of the conferences. Once completed, the manuals will become a strong guide and reference in the day to day programming of the member and other organizations for developmental disabilities. On the other hand, sharing of information at the conferences is challenging member organization into soul searching into how they can improve and become better organizations.

At the organisational level, however, there are not yet systematic and structured initiatives aimed at supporting the member organisations, to make them (organizations) stronger, more democratic and capable of influencing development policy in favor of persons with development disabilities, children with disabilities and their parents. It is therefore recommended that ANDD should focus at supporting capacity building initiatives for her member organizations.

### **2.6.4 Financial Sustainability**

As already described above, ANDD is a semi-formal network that has so far managed to operate as an NFU project. Unlike many other networks which open up several income streams with various donors as well as subscriptions / contributions from members, ANDD is basically and solely dependent on funding from NFU / NORAD funding. As an NFU project, NFU prepares the project funding documents, reporting and decision making in general. This is because ANDD has largely remained operating without a

secretariat, an operational constitution and the attendant standard operating procedures (SOPs). This means that in its semi-formal outfit, ANDD is not a legal entity which can fundraise and manage donor resources. Indeed any attempts to fundraise have raised questions about her identity and operational boundaries. The mission therefore would like to state here that ANDD in its present organizational and operational status is not financially sustainable.

To ensure financial sustainability there are a number of measures that need to be taken:

- Complete the development and adoption of the Inclusion Africa constitution, which most likely would give ANDD a basis for being the springboard for organizing Inclusion Africa and relating with other II global fraternity
- Finalize the discussion and resolve the differences between the two blocks of Inclusion Africa (Anglophone Vs Francophone). Incidentally Inclusion International should be part of resolution of his impasse.
- Establish a secretariat and recruit staff (preferably small, one or two) with a mandate to fundraise
- Incorporate and register ANDD as a legal entity within the country hosting the secretariat with clear mandate that it is a regional body. Other networks such as SAFOD, AFRODAD, CBR African Network (CAN) etc, can provide examples for guidance.
- Once ANDD has a legal status, with a secretariat, develop a strategic plan, and embark on rigorous fundraising for definite projects based or derived from the strategic plan. This would also enable it to fundraise as a legal entity.
- Build capacity of member organizations in fundraising and resource mobilization. Strong and well resourced member organizations will naturally contribute to and sustain ANDD collective initiatives.

## **3** EMERGING ISSUES AND RECOMMENDATIONS

### **3.1** *Introduction*

In this section we discuss the emerging issues from the assessment of ANDD mainly focusing the network as a development network. The discussion covers programmatic issues, organizational development issues (including the physical issues of the network, structures and procedures, identity, relationships, values, operational environment issues and roles of stakeholders) as well as sustainability issues.

### **3.2** *Programmatic issues*

The mission observes that the network has not had a strategic plan to guide its short and long-term planning. The planning and reporting have been basically been dictated by NFU as a directly managed project. In terms of programming, the mission therefore highlights the following issues which ANDD needs to work on.

#### **3.2.1** *Strategic Planning*

Being a project, NFU has been preparing long-term and annual work plans and budgets for ANDD for submission to Atlas Alliance and NORAD funding. Therefore, it is important to note here that ANDD has been operating without a strategic plan. Strategic planning is an important tool in the life of an organisation. Strategic planning gives the organisation clarity about what it actually wants to achieve and how to go about achieving it. In fact it is often said that without a plan, the only way an organisation gets where it is

going is by accident. Strategic planning allows for all other planning (that is; budgets, staffing, fundraising) to be coordinated. A strategic plan defines where the organization is going or where it is supposed to go.

The mission also revealed that the member organizations and not even the host organization are involved in the process of preparing these annual plans, budgeting and the reporting. This can be considered a bad practice.

The mission therefore makes the following recommendation:

- As part of the process of institutionalization of ANDD to make it a stronger and independent network, NFU should support ANDD to develop a strategic plan defining a clear vision and mission for the network and strategic direction in terms of what the network wants to take on and accomplish during the next 5 years and strategies that will take it there. This should be done in a participatory manner. The strategic plan should define clearly the roles for each stakeholder.

### **3.2.2 Regional Annual Conferences**

One of the most visible activities for the network has been organising annual conferences since 2001 with the exception of 2002. These conferences are regarded as a means of sharing experiences, knowledge and information in general. Information sharing is supposed to be a need arising out of each individual organisation for purposes of self improvement. Indeed, the mission found evidence of sharing information during the conferences. But sharing of information beyond the conferences was found a missing element. Therefore this tells us that if annual conferences were to stop then there would be no more information sharing. In the modern ICT era, where the majority of membership have access to internet / e-mail services, it is expected that members would be exchanging information more regularly.

Furthermore, the mission found that the membership was not involved and proactive in contributing to the development of the agenda for the conference. The members did not consider it very important in spite of them knowing that is it part of their role.

The information exchanged during the conference through the oral or written reports was considered by some members interviewed boring, monotonous and repetitive and in some instances the content suspect or recycled, thus not adding value to growth of the member organisations. In fact some members considered it “creatively packaged reports to satisfy NFU and the other members”, one member observed. Some members once out of the conference conveniently cut off communication lines until the next conference.

It was also observed that it is always the same faces attending the conferences with a few changes. These are mainly the Executive Directors and the Chairpersons. In terms of learning therefore, the mission found that beyond these two, there was little known about ANDD by other members of the organisations. The exception may be ZACALD and ZPHCA where the mission met with more than 4 members and all of them significantly informed about ANDD. The two can serve as a case of good practice.

Lastly, the mission would like to observe that the value out of annual conferences attended by the same faces who barely report back to their organisations was generally very difficult to justify.

The mission would therefore like to recommend the following:

- a) Scale down on the frequency of the conferences (may be one every two years) where members should sufficiently prepare and make them more engaging and profitable.
- b) Alternatively, if they have to remain annual, change the packaging to make them more profitable and justifiable, by introducing capacity building content on the agenda. Some experts can be hired to tackle some common areas of interests and needs such as, training in fundraising and resource mobilisation, disability mainstreaming / programming, developing advocacy content probably feeding into some development programs say on poverty reduction, HIV/AIDS and many others. The conferences can also be used as writing workshops provided the right and competent facilitators are identified to facilitate the relevant sessions. This should occupy at least ½ of the duration of the one week conference.
- c) In case of option (a) above being adopted, during the years when there is no conference, other information exchange initiatives such as exchange visits, supporting exchange through internet and e-mails, electronic and printed newsletters and other initiatives should be explored and encouraged. This initiative would be funded with the potential savings from the-would be conference funding.

### **3.2.3 Self-advocacy training**

As already noted in previous sections, the self advocacy training is the most beneficial activity that has direct benefits to the young people with developmental disabilities. The training has been facilitated by James Mung'omba and Quincy Mwiya from Zambia. Most of the training sessions have been conducted in 2008 targeting 9-15 participants in each country. There is need to note few issues here.

According to the benefiting organisations the majority had very little information about the funding of their training sessions. It was pre-determined with very little flexibility on how the sessions could be organised. The host organisations only had to select the participants and identify the training venue. Even the training content was also pre-determined by the resource persons (James Mun'gomba and Quincy Mwiya).

The training was considered by the participating organisations as the case of "giving a fish to a hungry man". A number of organisations felt that they should have been allowed to nominate some potential facilitators who would in future conduct such training in their organisations the way LSMHP and ZPCHA are doing.

In spite of these short comings, the self advocacy training remains the most directly beneficial intervention that targets people with developmental disabilities. The training is causing positive change in the lives of young people with developmental disabilities.

We therefore make the following recommendations:

- NFU, II and ANDD membership should streamline this training and get it more coordinated. The ANDD member organisations as beneficiaries of this training project should be given more information regarding the funding and its management. There is need for transparency.
- Provide more funding to increase the number of young people with disabilities. The target should be reaching every trainable young person with developmental disabilities. In fact this should be the flagship project for ANDD.



- Identify key role models among the trained self advocates in each country so that they can eventually lead their fellow young people with developmental disabilities to start their own organisations or take active leadership roles in their current parents' organisations.
- Invest more resources in the development of the self advocacy training manual so that it can be used in the subsequent training sessions. A team of resource persons (experts) should be identified and facilitated to finalise the preparation of this manual in a professional manner.
- Create a reserve of self advocacy trainers by identifying at least two resource persons from each member organisation and train them as facilitators of self advocacy training.

### 3.2.4 Capacity Building

The mission revealed that the membership of ANDD is composed of generally young parents' associations (the majority less than 15 years), and weak but quite promising in terms of representing young people with developmental disabilities and children with disabilities in general. The member organisations with partnership agreements with NFU such as ZPCHA, PODCAM and LSMHP were strong on the ground with country wide branches and operational regional structures. There are also member organisations even if not funded by NFU which are dynamic and quite promising in terms of forging partnerships with other potential funders such as KAIH. Some members such as ZACALD though duly registered and recognised in their countries, do not have any funding and have a dwindling membership - hardly 100 members country wide.

Apart from the members funded by NFU and probably another handful, the majority do not even have full time contract staff. They depend on volunteers. The lucky ones have an office but depend on volunteers to manage them. All this goes to show that the ANDD membership is composed of emerging organisations which still have many organisational development challenges to grapple with.

This therefore means ANDD member organisations still need to be capacitated to become strong organisations in order to pursue and achieve the ANDD stated development goal of striving "*for equality in social development of persons with developmental disability, children with disabilities and parents thereby facilitating a standard of living enjoyed by all persons and promoting inclusion at all levels*".

These organisations should be considered as strategic partners by NFU and Inclusion International and thus helped to transform into strong and effective DPOs.

It is against this background therefore that the mission recommends to NFU and ANDD to:

- Initiate a capacity building project along lines of the self advocacy training but targeting Organisational Capacity Building for the members as a group. Some of the elements of this project would be done collectively while others would be specific to each individual organisation. In this regard, the capacity building includes a number of components such as: organisation management, issues of membership development, strategic planning, fundraising and resource mobilisation, leadership and management skills and communication skills.
- Capacity building support should also aim at enabling the beneficiary organisations to broaden and increase networking with mainstream players and among different disability structures.
- The mission also recommends that NFU includes capacity building this in its next 3-year funding plan for ANDD, besides approaching other potential funding partners to support this initiative.

### 3.2.5 HIV/AIDS

At the Zambia Conference the members expressed candidly the challenges they had in their organizations regarding HIV/AIDS, notable among them included:

- HIV/AIDS focused NGOs were not adequately addressing issues affecting disabled children/youth with regard to HIV/AIDS
- Orphaned disabled children in most cases are not considered as vulnerable children and as a result; do not receive any tangible help that is usually given to their fellow non-disabled children/youth.
- Children and youth with developmental disability are sexually abused.
- Young girls with disabilities were considered to be more vulnerable to HIV/AIDS.
- Parents were not giving HIV/AIDS issues priority attention as they do to income generating

The mission found some efforts by each of the organizations visited trying to understand and put HIV/AIDS as one of their priority issues on their organizational agenda. Some organizations were already part of coalitions on HIV/AIDS, a number were participating in meetings etc. However, the children / young people with development disabilities were not yet effectively participating in peer education activities aimed at increasing knowledge about the problem and how to protect themselves against the scourge.

It is therefore recommended that:

- Sexual and reproductive health and rights be included on the menu for self advocacy training programme
- Some self advocates in each country be selected and given training as peer educators and counsellors. KAIH who have already started on this intervention can serve as a case of good practice.
- The development of the manual on HIV / AIDS should be expeditiously completed and tested for use as soon as possible.
- Experts in HIV/AIDS training peer education and counselling should be involved in the process to give the manual a professional touch.
- In addition a generic project should be prepared with the help of an expert to work as a template for the member organisation to use to apply for funding to the HIV/AIDS funding initiatives in their different countries.
- Self advocates should also be active participants as they can provide a good basis for the issues to include in the manual
- A writing workshop for completing the manual should be organised to write these manuals.

## 3.3 *Organisational Development Issues*

### 3.3.1 Coordination of ANDD

In 2006 Conference, the issue of Secretariat / Coordinator was raised and no concrete conclusion was reached apart from postponing the decision to the future ANDD conference. However a few concerns (see **box 6**) were raised that needed to be addressed. Unfortunately in 2007 at Victoria Falls Conference, the issue was not discussed.

The more subtle issues underlying these questions are:

- Which country should host the secretariat?

- What will be the mandate (ToR) of the secretariat?
- How will the Coordinator and other employees of the secretariat be recruited?
- Who will oversee the activities of the secretariat?
- Will the creation of the secretariat jeopardize the chances for the host organisation?

**Box 6: Decision on the Need for the ANDD Coordinator**

There was a proposal of employing a full time employee for the ANDD Coordinator and members were requested to discuss in their groups if they felt of a need or not to employ one.

After heavy discussions it was suggested that the issue should be postponed to the next ANDD meeting until the questions related to the matter can be answered i.e.

- Who pays for the placement of the Coordinator
- Where will the person be placed
- Do we really need the service of this person
- Can we sustain the post if NFU might cease to support

In terms of answering whether ANDD needs a Secretariat and by association a Coordinator, the mission's recommendation is an emphatic yes. ANDD should have a secretariat to enable it run as legal entity which can then enable it to engage in resource mobilisation to support the aspirations of her membership. The legal registration of ANDD and subsequent operation as an independent regional network should not be seen to contradict the ideals and vision of Inclusion Africa and Inclusion International. Rather a strong ANDD means a strong Inclusion Africa in terms of meeting its objectives. Having made this general recommendation, we proceed to address the key concerns raised above.

Host Country for the Secretariat

Centrality is always one huge factor in considerations for network secretariats. Yes, but centrality should only be in terms of technological access. The Secretariat should be seen in the light of being a service centre from where issues can be flagged onto members but also receive issues and information for onward dissemination. In this case therefore, centrality should not be in terms of geography. However, the Secretariat should be located at least in Africa in a country that has a member organisation.

The most preferable scenario would have been where a member country has good offices with a room or two to sublet for the purpose. However, this host organisation should be well established with functional departments from which services such as accounts, communication (internet), front office management services and many others can be outsourced. The host country for the secretariat should also be pro-disability in terms of CSO laws and policies, as the network would have to be registered and incorporated under the relevant laws in such a country. In the event that none of the current member organisations qualifies, the search can be extended to other disability agencies with adequate office space, such as the African Decade Secretariat, or any other.

Mandate and Roles of the Secretariat

The roles of the secretariat are generally generic in nature, and should among others include:

- The Secretariat represents the Executive / Co-coordinating Committee of the network
- It co-ordinates the work of the Network;
- It secures and provides the information necessary for the Network's members and makes decision regarding other communication matters;

- It organizes working meetings, discussions, conferences and other events in the frame of the functioning of the Network;
- It implements other decisions and directives taken by the Executive Board / Coordinating Committee;
- The secretariat is accountable to the Board.

#### Executive Board / Coordinating Committee of ANDD

The Executive or Coordinating Committee should be elected from amongst the members in accordance with the relevant articles of the ANDD constitution if any. The Board once elected plays the following roles:

- Representation and management of the Network
- Plays an oversight role over the Secretariat
- Takes decisions on behalf of the membership (general assembly)
- Recruits senior staff of the Secretariat (should there be need)

#### Coordinator

Once the decision has been taken to recruit a coordinator, the Board should be guided by the labour laws of the country especially with regard to recruitment of expatriate staff. This is because the position of the Coordinator of the secretariat should be open to any qualifying candidates from member countries. In this case therefore the employment laws of the country chosen to host the secretariat do matter.

The Coordinator should possess the following qualities:

- A relational networker, who has the humility to actively listen to others,
- A consensus builder, able to resolve conflict and facilitate joint action
- A mobiliser;
- A manager and planner;
- A Strategic thinker
- A persuasive and active advocate;

In addition the Coordinator should have the following basic competences:

- Leadership skills
- Fundraising and Resource Mobilisation skills
- Knowledge in disability programming
- Good communication skills;
- Strong strategic, analytical and research skills
- Partnering & networking skills: builds and sustains relationships with key constituents, etc

#### Role of Coordinator (Job specifications)

- Coordinate the activities and be overall in charge of day to day operations of the secretariat
- Facilitate wide range of capacity building activities, especially training and exposure visits, for the members
- Facilitate regular and constructive dialogue between ANDD and other civil society organizations and other development partners interested in disability issues
- Lead fundraising initiatives for the network
- Document and disseminate best practices of ANDD among the partners through various means, including electronic and print

### How will the Secretariat be sustained?

Within the current funding in the short term, a simple budget to sustain the establishment of the secretariat, initially with a coordinator can be created. One of the mandates for the coordinator would then be to fundraise for projects which are aimed at enhancing the objectives of the network such as capacity building, development of manuals, training self advocates and many others. Within three years, the secretariat should potentially be self-sustaining in meeting its costs.

### Hosting the ANDD annual Conferences

The hosting of the ANDD annual conference should continue rotating amongst the member countries depending on ability and of course any other considerations that the members are privy to.

## **3.3.2 Structures and Procedures**

Being a semi-formal network, ANDD has not yet developed effective systems and procedures in form Standard Operating Procedures (SOPs) that are needed to guide decision making in program implementation, monitoring and evaluation, data collection, reporting, and documentation.

In the absence of such therefore, for the day to day management of the ANDD work, it is currently being managed as an NFU project and hence decisions regarding the project must be guided by NFU systems and procedures, which to a large extent are based on NORAD and Atlas Alliance requirements. This is understandable in as long as ANDD is still in transition to develop its own identity.

- For that matter, it is recommended that besides, completing the development of the network constitution, there is need to embark on developing some key standard systems and procedures needed to guide the transformation phase from the current loose network to institutionalized network.
- As already recommended above, in the case for establishing a secretariat and coordinator, it is recommended that for purposes of developing clear systems and procedures, ANDD should start with recruiting a “Starter Coordinator” whose terms of reference would include:
  - Starting up the Coordination Offices (Secretariat)
  - Developing the necessary systems and procedures, policy manuals, and SOPs
  - Assist in the process of recruiting the substantive Coordinator
  - Induct / coach the Coordinator for about three months before finally handing over full responsibility.
- An alternative is to outsource the services of a starter coordinator from a competent private firm / organization.

## **3.3.3 Relationships and Networking**

As a preamble to this section, we need to define what networks are within the realm of civil society organizations (CSOs). In their separate works, Miller, 2005 and Church 2003, hold the view that civil society networks have become a major player in global development. Over the last decade, donors have placed greater emphasis on civil society voice in encouraging pro-poor development through their inputs in policy formulation processes and then holding government to account and implementation. Civil Society Organisation (CSO) networks have been the prime organisational form for articulating the voice.

Indeed, ANDD was created in order to address issues regarding persons with developmental disability and to create pressure both at national, regional and international level for the development of inclusive policies for persons with developmental disability. Essentially the idea was floated by NFU (which is largely

regarded as a donor within the ANDD fraternity) in consideration of the work it was already supporting with a number of Parents Organisations in the region. Essentially this means that the network members are supposed to share strategies, information, and where possible other resources in their pursuit of issues for persons with developmental disabilities.

The mission has revealed that the annual conferences have created a huge opportunity for member organisations to get to know each other better but also of recent started even development of manuals on key thematic areas such as poverty reduction, HIV / AIDS, Inclusive education and many others. All this is commendable. However, the mission also revealed the following challenges mentioned by the members.

In spite of these opportunities for networking, the members were not yet cherishing the value of networking and sharing information and other opportunities. Many were instead looking at the network for opportunities of accessing funding and not the essence and substance of networking benefits..

Furthermore, there is a feeling that the network has a general fault line, dividing the membership between two categories:

- a) The blue eyed lucky members who have (or have had) direct partnerships with NFU and therefore are stronger, more vocal and confident and are in direct consort with NFU officials during the annual conferences. Some of these organisations it was alleged try to undermine their weaker sister organisations.
- b) The other category comprises of weaker and newer members who are in most cases mesmerised by their elder sisters. These are the ones who feel out of place on some occasions. The language used by their elder sisters was sometimes considered derisive and condescending. They feel psychologically bullied.

This kind of relationship is not pro- and cannot encourage the building of a sustainable network and true friendship.

At the next level, ANDD as a network of disability focused organizations, is operating in an environment where there are other players such as national disability umbrella organizations, SAFOD, the African Decade, and of course other Civil Society Organisation networks that are interested in the promotion of social justice, human rights and many others. Although not based on solid evidence, some member organizations visited suspected that ANDD was not yet effectively cultivating sustainable relationship with other networks, be it at national level, regional, continental or global level.

At the national level, there still remain unresolved differences between ANDD members (largely organizations of parents of children with disabilities) and the other DPOs but most especially the national disability umbrella organizations.

At the regional level some members felt that ANDD and SAFOD are not yet harnessing the potential synergies.

At the continental level, ANDD whose membership is constituted by Anglophone members of Inclusion International in Africa from Southern and Eastern Africa seems to be having “irreconcilable” differences with the Francophone brothers who incidentally are also members of Inclusion Africa and Indian Ocean). This therefore is threatening the existence of Inclusion Africa and Indian Ocean as a viable chapter for Inclusion International.

At the international level, ANDD is actually doing very well courtesy of NFU and Inclusion International support for instance to participate in the UN Ad hoc Committee on the Convention of Persons with Disabilities, and the Inclusion International Conferences. The decision to use self advocates as flag bearers for ANDD has given it a lot of credence as a true platform for promoting self representation and equalization of opportunities for persons with developmental disabilities.

The mission therefore recommends the following:

- At the inter-organisational level, ANDD conferences should be used to promote team building and genuine sharing. Team building exercises should therefore be conducted to help in strengthening the relationship and closing the gap between the members.
- At the national level, ANDD should support the member organization to engage in constructive dialogue with the national disability umbrella organisation as well as other sister organizations.
- At the regional level, ANDD should equally engage in constructive dialogue with the regional bodies such as AU, SADC, East African Community and other bodies on key and strategic regional policies such as PRSPs, HIV/AIDS, educational policies and many other such issues. Once the issues of concern become obvious, alliances will be needed to do effective advocacy.
- At the continental level, Inclusion International needs to come out clear and assist the two warring factions of Inclusion Africa and the Indian Ocean to resolve the differences between them.

### **3.3.4 Leadership and Management**

#### *Increasing participation in Leadership of the network*

As already noted ANDD is still running as a semi-formal network, essentially as a NFU project. To nurture and make it progress into the future and fulfil her mandate, ANDD needs to institutionalise so as to start engaging in strategic partnership frameworks on her own merit. It is therefore important to institute an Executive / Coordinating Board to take over the role of decision maker with regard to the affairs of the network. NFU should remain only a strategic partner, who can besides remaining a link with NORAD it can also link ANDD to more potential Scandinavian and European funding agencies.

#### *Increasing participation in network activities*

Currently, it was observed that it was almost the same officials (especially the Executive Directors) from the organizations attending the annual conferences, year in year out. At the organizational level, there are no sufficient mechanisms to cascade the learning.

- The mission therefore recommends that participation in the annual meetings should be freed to allow participation of other technical staff depending on the focus / theme of the year. For instance, if the conference is going to concentrate on advocacy, then Advocacy Officers are the most suitable candidates to attend. Alternatively a separate arrangement can be made for the other technical people in the member organizations to meet and network.

#### *Increasing participation of Self-Advocates in the network*

The case of Quincy has vindicated the benefits of exposure and participation of self-advocates in the affairs of the network. Quincy has justified why people with developmental disabilities can shine if allowed to participate at any level.

- Based on this successful case, it is therefore recommended, that self-advocates should be given more and clearer roles in the leadership and management of not only the member organisations but also the network.
- More self advocates should also be promoted to shine along with Quincy at an international level. Create more role models within each country.

### Role of Inclusion International in ANDD

There is no doubt, Inclusion International is a stakeholder in ANDD since the member organizations of ANDD to a large extent also double as members of Inclusion International. The interests of Inclusion International besides the participation in the ANDD annual conferences, is also now manifested in the support for self-advocacy training. However, that is also where questions emerge from. In the absence of a leadership structure for ANDD, Inclusion International (II) has been working with James Mung'omba and Quincy Mwiya to manage the training project. According to the members, these two are interpreted as appointed as pseudo coordinators of ANDD / Inclusion International affairs. The members noted that they have not been involved in this decision thus increasing suspicions against the two in spite of the commendable job they are doing.

The mission therefore recommends the following:

- At the next conference, an interim Board of ANDD should be constituted to prepare ANDD institutionalizing its legal entity (in the event a decision is not taken to have a full substantive board).
- Subsequently, Memoranda of Understanding (MoUs) between ANDD and other partners like NFU, Inclusion International and others be developed and signed. These MoUs should spell out the interests of each partner and how they intend to cooperate.

### **3.3.5 ANDD Vision, Mission and Values**

ANDD has an implied vision of an inclusive society for all and one could say the mission of striving for equality in social development of persons with developmental disability and children with disabilities. As already noted these are implied. However, what are missing are the values and principles. Organisational values underpin the culture of an organisation, so are critical to an organisation achieving its strategic goals. And the culture has such an impact that it can make or break any organisation's success. Indeed, Collins and Porras (1994) note that core values are "the organisation's essential and enduring tenets: timeless, guiding principles requiring no external justification, with intrinsic value to the organisation's members. Organisations decide for themselves what values they hold as core, without compromise".

It is against this background that we ask whether ANDD has any such guiding principles. If ANDD is a network composed of member organisations, what are the acceptable minimum standards that should govern the behaviour of these member organisations within the network?

So far membership to ANDD family is by invitation on the basis of one country one member. The character and behavior of the invited member is not often subjected to serious scrutiny before invitation. There are also no mechanisms for expelling any member organization that might be found out to be engaged in activities that are contrary to the ideals of the network.

- The mission therefore recommends that ANDD should develop a statement of values and a standard code of conduct document which should guide the member organizations on how to



conduct their business. Each member should be made to sign. This can be done at the time of developing a strategic plan too. Examples of Codes of Conduct / Ethics can be obtained on: [www.ngoforum.or.ug](http://www.ngoforum.or.ug), [www.wango.org/codeofehics.aspx](http://www.wango.org/codeofehics.aspx), [www.ingoaccountabilitycharter.org/](http://www.ingoaccountabilitycharter.org/)

### 3.3.6 ANDD Identity and Membership Issues

Identity is the summation of what makes an organisation uniquely itself. The organisational identity is embodied in its origins and values, core skills and knowledge, and practices. Origins spell out the vision and purpose for which the organisation was established, core skills and knowledge refer to the expertise that sets the network aside from other organisations. ANDD's foundation and it seems its long term institutional sustainability is closely linked to Inclusion International membership. However, as an African Network for Developmental Disabilities, the network needs to develop its own identity.

There are some issues that are unique to the member organizations in Southern and Eastern African region but also cutting across the organizations that make them different from other organizations. These need to be dug out and highlighted as the strings that hold the network together.

#### Membership Requirements

So far every member seems to know who should be a member of ANDD but the detailed criteria, seems not to be written in some form of document which is handed over to any organization invited to the network.

The mission recommends that the criteria<sup>3</sup> for membership to ANDD should among others include:

- a) It must be a voluntary non-governmental organization of parents and friends of persons with intellectual disability or an organization of people with intellectual disability themselves operating at a national level,
- b) It must be concerned with all phases of the welfare of persons with intellectual disability and the promotion of a wide range of services, not limited in scope to a single or special service interest.
- c) In case more than one organization exist in one country and both meet the above two criteria and are interested in seeking membership to ANDD, the two or more organizations should be allowed membership but only as one composite national society with equal fractional votes assigned to the constituent organizations.
- d) Once admitted, the organization should agree to meet all obligations of full membership including the payments of such subscriptions as are lawfully determined by the General Assembly.
- e) The organization must be duly incorporated in the defined region (Southern and Eastern African region),
- f) The organization should have a national membership character in the country of incorporation,
- g) The organization should have well developed and distinguishable democratic governance structures which allow the membership especially persons with developmental disabilities to participate.

And as already noted above, there should be a fully developed "Code of Conduct Statement" which the member seeking membership should sign thus binding the member to subscribe to those ideals.

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<sup>3</sup> Criteria a - d are borrowed from Inclusion International.

### **3.3.7 Operational Environment**

The members of ANDD are operating in their different countries. Each of these countries spells out different social, cultural, economic, and political challenges. For instance, some of these countries have restricted space for CSO operations many of course are poor with high HIV/AIDS incidence rates etc. This in a way defines the operational environment. What we need to emphasize here, though, is that this external environment is constantly changing. There are two things to note here: a) the operational environment has not been given adequate time to scan it for purposes of identifying what it (operational environment) offers to ANDD. It is also not yet being used as a basis for effective strategizing and programming. b) the changing environment also basically means changing expectations, needs, trends, demands and this means that the members and the network itself should also be constantly responding to these changes.

- The mission therefore recommends that as soon as it sorts out legal identity issues and gets a secretariat and governing board, the next immediate thing should be for ANDD to undertake a comprehensive strategic planning activity. This will allow the network to do a more comprehensive environmental scan (PEST Analysis) and then draw appropriate strategic directions in response to the demands dictated by the operational environment.

### **3.4 Sustainability of ANDD**

The issue of ANDD sustainability was exhaustively discussed in section 2.6 above. But there are two major issues that need to be addressed. ANDD needs to position its own institutional development within the framework of Inclusion International. This will give it visibility and a bigger array of partnership possibilities with other Inclusion chapters such as Inclusion Europe.

The second issue is that of financial sustainability. In this case, section 2.6.4 has given detailed recommendations on how to increase financial sustainability possibilities for ANDD. But again this starts with first sorting out the issues of assuring the institutional development issues.

## **4 CONCLUSION**

The evaluation mission would like to end by ANDD as a network whose mission is to strive for equality and promote inclusion persons with developmental disabilities at all levels, is within the time frame of its existence and the resources available achieving its strategic objectives and thus registering some positive impacts that can justify its existence, and hence continued support over the next years to enable it mature and realise its long term goals.

On the basis of the programmes and activities proposed to full its mandate, that is, networking and influencing policies to make them more inclusive, as well as capacitating the members ANDD has achieved at different levels, with training of self advocates and creating opportunities for networking (conferences) being shining examples of success.

The network remains relevant as an outfit for promoting the rights of persons with development disabilities through North-South as well as South-South cooperation but also tackling issues that affect the disabled people and DPOs.

However, the mission has identified a number of challenges which need to be addressed to make ANDD become more effective and achieve greater impact.

The mission notes that for the long term sustainability, ANDD needs to institutionalise and create structures to take the lead role in decision making, planning, fundraising and above all strategic thinking.

Focusing on capacity building for the individual member organisations to make them better and effective democratic advocacy organisations is also one of the important recommendations.

## ***Bibliography***

1. Collins J.C. & Porras J.I. (1994) Built To Last Harper Collins, USA
2. Inclusion International, (2008), Self Advocacy Training Project Report, [www.inclusion-international.org/](http://www.inclusion-international.org/)
3. ANDD, 2005, Report of 4<sup>th</sup> Conference, LUSAKA ZAMBIA, 21<sup>th</sup> – 25<sup>th</sup> Sept 2005
4. ANDD, 2006, Report of the 5<sup>th</sup> Conference, Lilongwe, 18<sup>th</sup> -26<sup>th</sup> Sept, Malawi
5. ANDD, 2006, Report of the 6<sup>th</sup> Conference, Victoria Falls, 17<sup>th</sup> – 21<sup>st</sup> September, Zimbabwe
6. NFU, ANDD 3-Year Long Term Plan 2007-2009
7. DCDD, 2004, Disability, Self- Organisation and Aid Finding an Empowering Mix, Symposium Report, The Hague, 15th November 2004

### ***Annex 1: List of Participants***

<b>Name of Participant</b>	<b>Sex</b>	<b>Position</b>	<b>Organisation</b>
<b>South Africa</b>			
1. Sandra Ambrose	F	National Coordinator	DICAG
2. Mbusi	M	Chairperson	DICAG
3. Nozulwana Nomaxabiso	F	In charge Day Care Centre	DICAG
4. Mortinque Carlse	F	Self Advocate	DICAG
5. Jessy	M	Self Advocate	DICAG
6. Codlyne Joubert	F	Self Advocate	DICAG
<b>Kenya</b>			
7. Fatuma Wangare	F	Secretary General	KAIH
8. Ceclia Kahahia	F	National Treasurer	KAIH
9. Peter Owaga	M	National Financial Officer	KAIH
10. Doris Jerop	F	Officer, Handicap International, Kenya	
<b>Malawi</b>			
11. Musa Salif	M	Chairperson	PODCAM
12. Suluma	M	Member (former Chairperson)	PODCAM
13. MacTonnick Phiri	M	Vice Chairperson	PODCAM
14. Mirriam Namanja	F	Executive Director	PODCAM
15. Enock Mithi	M	Program Officer	PODCAM
16. Mussa Chiwawula	M	Executive Director	FEDOMA
17. Steven Msowoya	M	Executive Director	MACOHA
<b>Namibia</b>			
18. Pamela Somses	F	National Coordinator	NACD
19. Ingrid Haraes	F	Regional Coordinator	NACD
20. Maria Kakishi	F	Vice Chairperson	NACD
21. Marcella Katire	F	Vice Secretary	NACD
22. Meriem Thomas	F	Organiser	NACD
23. Jeffrey	M	Self Advocate	NACD
24. Melany	F	Self Advocate	NACD
<b>Lesotho</b>			
25. Kgomoco Motsamai	F	National Coordinator	LSMHP
26. Hlalefang Konka	M	Chairperson	LSMHP
<b>Zambia</b>			
27. John Mukopola	M	Chairperson	ZACALD
28. Charles Chimwasu	M	Treasurer	ZACALD
29. Simon Nguluwe	M	General Secretary	ZACALD
30. Mary Mkuyamba	F	Committee Member	ZACALD
31. Barbra Phiri	F	Executive Director	ZACALD
32. James Mung'omba	M	Self Advocacy Trainer / II Regional Coordinator	
<b>Zimbabwe</b>			
33. Elizabeth Chidi	F	NEC Member	ZPHCA
34. Raxere Mutsau		Child Program Facilitator	ZPHCA

35. Ronald Mazango	M	National Treasurer	ZPHCA
36. Kudzanai Chigerwe	M	Finance and Admin Officer	ZPHCA
37. Emelda Nkani	F	Receptionist	ZPHCA
38. Teckler Muchirahondo	F	Admin. Secretary	ZPHCA
39. Andrew Chawaguta	M	Office Orderly	ZPHCA
40. Casper Boiodo	M	National Coordinator	ZPHCA
41. Chipso Mushininga	F	National President	ZPHCA
Swaziland			
42. Grace Bhembe	F	Secretary General	PCDSwa
43. Bennet	M	Councillor, Manzini Town	
<b>Uganda</b>			
44. Bertha Kawoya	F		
<b>Zanzibar</b>			
45. Mpaji Ali Maalim		Written Response	ZAPDD
46. Juma Salim Ali		Written Response	ZAPDD
<b>Tanzania</b>			
47. xx		Written Response	TAMH (NEC Member)
<b>Mozambique</b>			
48. Arsenio Benjamin Machebene		Vice Secretary General	ACRIDEME
<b>Others</b>			
49. Helene Holand	F	President	NFU
50. Manuela Rorfeldt	F	Program Officer	NFU
51. Bettina Thorvik	F	Former Program Officer	
52. Lilian Mariga	F	Regional Consultant	NFU
53. Geir Ambro	M	Development Advisor	Atlas Alliance