

ASSESSING

DISABLED PEOPLES' ORGANISATIONS IN AFRICA WITH A CHILD RIGHTS LENS

Towards greater mainstreaming of
children with disabilities within the DPO agenda



ACPF

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LIST OF ABBREVIATIONS AND ACRONYMS

ACHPR	African Charter on Human and Peoples' Rights
ACPF	African Child Policy Forum
ACRWC	African Charter on the Rights and Welfare of the Child
ADF	African Disability Forum
AFUB	African Union of the Blind
APAPE	Association des Parents et Amis des Personnes Encéphalopathies
APEE	Association des Parents et Amis d'Enfants Encéphalopathies
AU	African Union
AYWDN	African Youth with Disabilities Network
CDT	Critical Disability Theory
CEMAC	Communauté Economique et Monétaire de l'Afrique Centrale
CEN-SAD	Communauté des Etats Sahélo-Sahariens (Economic Community of Sahelo-Saharan Countries).
CERD	The Committee on the Elimination of Racial Discrimination
COMBHEN	Comité de Bourses pour Handicapés et Enfants Nécessiteux
CPoA	Continental Plan of Action for the African Decade of Persons with Disabilities
CRC	Convention on the Rights of the Child
CRPD	Convention on the Rights of Persons with Disabilities
CSO	Civil Society Organisation
DIWA	Disabled Women in Africa
DIWODE	Disabled Women in Development
DPI	Disabled Peoples' International
DPOs	Disabled Peoples Organisations
ECOWAS	Economic Community of West African States
ELECAM	Elections Cameroon
FAMOD	Associations of Disabled People in Mozambique
FARIPH	Fonds d'Appui à la Réadaptation et à l'Intégration des Personnes Handicapées
FEMANPH	Fédération Mauritanienne des Associations Nationales de Personnes Handicapées
FETAPH	Fédération Togolaise des Associations des Personnes Handicapées
FOAPH	Fédération Ouest des Associations des Personnes Handicapées
ICCPR	International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic Social and Cultural Rights
IDAL	Intellectual Disability Association of Lesotho
JICA	Japan International Cooperation Agency
LNAPD	Lesotho National Association of the Physically Disabled

MDGs	Millennium Development Goals
NCHRF	National Commission for Human Rights and Freedoms
NFPDN	National Federation of People with Disabilities in Namibia
NGO	Non-governmental Organisation
NUOD	National Union of Organisations of the Disabled
OTDDPH	Organisation Tunisienne de Défense des Droits des Personnes Handicapées
OFAB	Organisation des Femmes Aveugles du Bénin
OPEHN	Organisation pour le Parrainage des Enfants Handicapés au Niger (OPEHN MurnaYara)
PAFOD	Pan African Federation of the Disabled
PANUSP	Pan African Network of Users and Survivors of Psychiatry
PODCAM	Parents of Disabled Children Association of Malawi
SADC	Southern African Development Community
SDGs	Sustainable Development Goals
SHAP	Self Help Association of Paraplegics
TAS	Tanzania Albinism Society
THT	Personnes Handicapées Twuzuzanye
UDHR	Universal Declaration on Human Rights
UNAPHAC	Union Nationale des Associations et Institutions de et pour Personnes Handicapées
UNICEF	United Nations Children's Fund
VIHEMAV	Visual Hearing Impairment Membership Association
VSO	Voluntary Service Overseas
XAF	Central African CFA franc (CFA stands for "Communauté Financière d'Afrique" - African Financial Community), the currency of six independent states in central Africa.

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FOREWORD

Disabled People Organisations (DPOs) across the globe and indeed in Africa have much to celebrate for building strong constituency of people who are associated with disability and bring publicity to social, cultural, economic and political rights of people with disability. With their authentic voice, they fought to bring about change in understanding and attitude that disability needs to be seen from the context of human right not of a charity. Thus became a major part of the disability movement.

Yet, there remain huge challenges, particularly in Africa where persons with disabilities are still subject to deprivation in many dimensions of their lives more so than the non-disabled. The situation of the most vulnerable group, children with disabilities is even at dire state.

In 2014, African Child Policy Forum (ACPF) launched the first-ever report – *The African Report on Children with Disabilities: Promising Starts and Persisting Challenges* – on children with disabilities. One of the critical issues that was brought out by this report was the importance of empowering persons with disabilities and their representative organisations, primarily DPOs, to effectively advance the cause of disability rights. The report also revealed that DPOs' essential role of advocating for the rights of all persons with disabilities including children is seriously undermined by capacity deficit.

We believe this synthesis report presents an Africa-wide capacity assessment of DPOs not just in terms of what has gone wrong with DPOs currently but also in terms of offering important insights into how governments, CSOs, development partners and donors can go about supporting DPOs who are key elements in advancing the rights and wellbeing of persons with disabilities.

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EXECUTIVE SUMMARY

The situation of persons with disabilities generally in Africa is characterised by extreme levels of poverty, low levels of education and illiteracy, and low esteem. These factors present particular challenges to persons with disabilities and organisations promoting and protecting their interests as well as their capacity and effectiveness to influence policy makers and other development actors on disability issues.¹ And in this scheme of things, children with disabilities are the most affected.

Disabled People's Organisations (DPOs) are organisations by or for persons with disabilities, irrespective of the type of disability although some may have more focused mandates or expertise with respect to specific disabilities. There are quite a good number of these organisations across Africa helping to improve the quality of life of persons with disabilities and pushing legal and policy reforms to enhance their rights and promote their effective integration into society as full members. In short, by their very existence, DPOs channel the core message in current disability theory, reminding society that persons with disabilities are not or should no longer be seen as objects of ridicule, exclusion, and discrimination. Persons with disabilities are no longer to be secluded to the fringes of society as a group of unfortunate and pitiable people afflicted by nature, who need to be 'rehabilitated' or 'cured' and are therefore at the mercy of the 'charity' of others (society). Persons with disabilities are integral 'subjects' of society with rights, prerogatives and obligations and not 'objects', and who simply need society's support to enjoy their rights and fulfil their obligations, thus making their own contribution to society in their own way; albeit small.

DPOs' mission is for the effective inclusion of persons with disabilities in their communities as full members and, in the process, become active participants. Yet, DPOs often feel treated as 'clients' rather than the primary constituency to legitimise outside intervention in disability matters. Generally, DPOs in Africa operate within favourable legal contexts for the promotion of the rights of persons with disabilities. All the countries surveyed (with the exception of Cameroon) are parties to the CRPD and have put in place follow-up mechanisms in which DPOs are involved. DPOs in Central, West and Northern Africa, for example, have put in place national monitoring mechanisms in accordance with the CRPD wherein DPOs are involved.

This synthesised report gathers from the two regional assessment reports, which form its basis that, while there are several DPOs across Africa doing quite a praiseworthy work on the ground,

¹ Ncube, *infra*.

they are equally facing several challenges in different degrees which have been hampering their work and output. DPOs in Africa continue to face enormous difficulties in promoting the rights of persons with disabilities and the different operational gaps such as poor advocacy, leadership, networking amongst DPOs, lack of information sharing between DPOs at all levels and knowledgeability of disability standards, low levels of involvement in legal and policy initiatives concerning them, institutional deficiencies and inadequate funding, etc. DPOs across Africa are weak in designing coherent and articulate mission and visions statements on the one hand and mission and visions statements that align with their actions on the ground on the other hand, excepting those of the Northern African sub region. This mix-up is essentially due to weak intellectual resources and knowledgeability in and access to disability standards and theories.

While on average DPOs have been involved in law and policy making processes in Central, West and North Africa, in East and Southern Africa, it is below average. Central and North African DPOs have been minimally involved in legal and policy formulation, implementation and, follow-up and evaluation processes, to ensure that the interests of persons with disabilities are taken into consideration across the board in development programmes. Meanwhile, DPOs in West Africa provide strong support to policy formulation, action plans and development programs. For example, national coalitions here are and remain the direct interlocutors of governments, which involve them in policy formulation. Such disparities in levels involvement amongst DPOs at their respective national levels do not enable them to engage sufficiently when they cooperate or engage and communicate with other DPOs within sub regional and regional networks. Experience sharing is therefore one-sided and the learning/empowerment process can only favour the less experienced side.

The poor articulation of vision, mission and mandate statements and/or the low levels of DPOs involvement explains a major problem. DPOs neither have adequate knowledge of disability standards, nor of current disability theories, chiefly represented by the social model and the critical disability theory. The poor articulation of vision, mission and mandate statements is compounded by low levels of child-oriented agendas/activities. Half of the DPOs surveyed in East and Southern Africa intimated that they were implementing a particular project or activity related to children with disabilities and their parents/care takers/guardians but only few mention children in their vision/mission statements. All DPOs surveyed in Central and North Africa make reference to children in their respective vision/mission statements, except in West Africa where only 4 of eleven so do. In Central Africa, beyond merely referencing children all six DPOs conduct advocacy

to promote the rights of children with disabilities especially the right to education however, in West and North Africa have largely contributed to legal and policy reforms relating to protection and promotion of the rights of persons with disabilities especially children.

The findings in this synthesis show that the levels of institutional capacity for the majority of the DPOs at all levels – continental, sub-regional, and national – are significantly low in terms of leadership and governance, resource mobilisation, project management, monitoring and evaluation, even advocacy and lobbying, just to mention a few areas. The situation would therefore pose a threat when it comes to advocating and to influencing the formulation and implementation of rights and policies, focusing particularly on the rights of children with disabilities.

The institutional and operational inadequacies relate to lack of office space equipment and generally and other logistic problems, while operational relates to lack of competent human resources, adequate funding, weak competence and functioning strategies such as poor advocacy skills and governance issues. However, in the Central African sub region, for example, DPOs have engaged capacity building of their members and the professionalization of their administration as well as engaging more and more persons with disabilities and their families.

The issue of funding is particularly important because DPOs can neither employ competent staff or equip their services nor meaningfully assist persons with disabilities with support of services or carry out other activities such as advocacy in the absence of good financial backing. While it is true that some DPOs in Central, West and North Africa have good funding levels to carry out their activities, others operate on the fringes of extreme poverty. The case of the l'Association pour l'Information et la Défense des Droits des Jeunes Sourds du Congo (Brazzaville) with a budget of just a little over US \$ 2000 is telling of the latter situation. In some countries, funding from external donors has dried up. As a palliative to funding problems, some DPOs have received government funding as in Chad, Cameroon, Congo and Mauritania. Meanwhile, others have been able to put in place good practices to close the funding gap by creating income generation activities such as SHAP in South Africa which sells items produced by persons with disabilities in its factory. SHAP seeks funding from the community for capital projects and in support of its always partially self-funded service programs. Some DPOs have put in support funds for children with disabilities as in Niger and Benin.

In terms of the financial, technical and institutional accountability structures and auditing systems,

the situations vary disproportionately from one DPO to another. Auditing systems, in particular, appeared to exist and practiced in DPOs that already have a strong financial base (funding) whereas those with weak financial base also have weak accountability structures especially in East and Southern Africa. In Central, West and Northern Africa, while most DPOs have administrative and financial management procedures, only very few do practice auditing.

The successes of DPOs in advocacy are impressive although, generally, DPOs lack the requisite skills here and need to be boosted. The main reason is lack of qualified or competent human resources. But DPOs have generally registered several successes in advocacy here. In Niger, for example, as a result of advocacy by DPOs, the Department of Education has registered, in the last two years (2013-15), a budget line for the purchase of specialised teaching materials to improve the quality of learning for children with disabilities. Meanwhile IDAL has developed an advocacy tool called Speaking in One Voice that helps members to advocate for needed services.

Cooperation amongst DPOs and between DPOs and other CSOs in the area of disability at all levels in Africa is generally weak. However, contrary to registered limited cooperation with the civil society, government and other actors in East and Southern Africa, DPOs in West, Central and North Africa have shown proof of concrete cooperation here. Benin is a good example where such cooperation with CSOs is emphasised. In Benin, several NGOs have been responsible for various inclusive holiday activities for children with disabilities such as the 'inclusive holidays' by the organization *Le Cercle des Oliviers*.

National cooperation and inter-regional cooperation is weak in Central Africa and North Africa. Meanwhile, in the Southern African region, there is evidence that the cooperation enjoyed by the different national disability movements under SAFOD has contributed immensely to experience sharing, confidence building and mutual support, while opening and utilising avenues for close cooperation between DPOs.² Although DPOs are severely constrained by weak capacity to mobilise and unify themselves across Africa, it is hoped that this is currently changing under the banner of ADF, which has been a significant boost or opportunity for all Africa sub-regional and national DPOs. ADF has successfully filled the gap left by PAFOD in this regard. ADF has now taken the enormous responsibility of unifying and amplifying the voice of Africans with disabilities, their families and their organisations in advocating for their rights and inclusion in all aspects of development and society at Pan African, sub-regional and national levels. But it remains that DPOs

² Ncube J. (2005). 'Capacity Building of Disabled People's Organisations in Mozambique'. Disability Knowledge and Research, pp. 12/13

at the national level should have competent operational capacities in return to be able to effectively and efficiently network amongst themselves at national levels, and between national levels and regional levels. This would ensure the sharing of summed up experiences and concerns from national levels to sub regional levels and from there to the continental level. In this way, the voices of persons with disabilities, the families and DPOs for reform in Africa, would be legitimate and stronger. Hence, DPOs will feel treated as the primary constituency than clients, to legitimise insider intervention in disability matters.

A lot therefore needs to be done to ensure that African DPOs do not only remain strategically focused, but also that they are able to formulate, understand, articulate and re-align their own missions, visions and mandates with the needs of persons with disabilities and work that they actually do on the ground.

Recommendations

Strengthening the technical and organizational capacities of DPOs

- DPOs should be supported through capacity building programmes and self-empowerment to ensure that they are not only strategically focused but also able to understand, articulate and re-align their own mission, vision and mandates with conventional disability standards and the work that they actually do on the ground.
- The financial, technical and institutional accountability structures and auditing systems should be strengthened as they are core in donor placement decisions.
- DPOs should be empowered through regular training of their members to work closely with communities and private sector stakeholders, individuals and organisations
- ACPF/ADF need to work towards building strategic partnerships with training institutions (including universities) to offer capacity building initiatives for targeted DPOs' representatives at both pan-African, regional and national levels in the area of leadership and governance, advocacy and lobbying, and project management.
- ACPF should develop programmes that are focused on building the capacity of pan-African, sub-regional and national DPOs in generating more disability data/research at all levels which would inform legal and policy reforms, further disability programming in the area of children with disabilities, notably, disability standards, complaint mechanisms /procedures for the protection of the rights of persons with disabilities as well as leadership and

governance, advocacy, and project management. Here, ACPF/ADF should work towards building strategic partnerships with training institutions (including universities) to offer capacity building initiatives for targeted DPOs.

- ACPF/ADF should engage the African Committee of experts to consider the possibility of drafting a General Comment on children with disabilities.
- Umbrella DPOs should be supported to develop advocacy plans for inclusive public policies for persons with disabilities including children with disabilities and accompany these DPOs in the implementation of the plans.
- A strategy to strengthen the organisational, institutional and technical capacities of umbrella DPOs at the regional level so that they can in turn transfer skills amongst their member associations should be developed.
- AU member states which are not yet parties to the CRPD should be lobbied to do so in order that its provisions take effect within their national legal orders in terms of having states parties respect their international law obligations under the CRPD, and of availability of remedies to persons with disabilities seeking redress for alleged violations by their states. This would also create a uniform legal platform for and legitimacy of DPOs and CSOs' actions

Cooperation between DPOs at all levels

- Cooperation and information/experience sharing among African DPOs at all levels should be promoted and, where possible, enhance scaling up or replication of good practices demonstrated by some DPOs in all aspects of disability programming, including those impacting positively on children with disabilities.

Role of states in legal, policy and other measures

- States have a number of responsibilities to ensure that persons with disabilities' rights are promoted through awareness raising, collection of statistics, policy making and planning, ombudsperson, national committees and personnel training.
- In order that the work of DPOs gains credibility, national frameworks should ensure equal protection, affirmative actions, an integration policy particularly in relation to education and professional training, health care and social security and shaping remedies for violations of the rights of persons with disabilities.

Institutional arrangements

- National disability councils with the status *ombudspersons* should be created. They would investigate the activities of disability service providers on the basis of the report of the audit teams and report to the ministry in charge of persons with disabilities, and where necessary initiate proceedings against defaulting parties.
- Audit teams comprising persons with special training in the standards in disability issues should be set up in countries at national level. Their annual reports are forwarded to a national *ombudsperson* on disability which reports in turn to the relevant ministry in charge of disability and can equally trigger the appropriate remedial mechanism.

Funding strategies to alleviate financial difficulties

- The development of partnership and strategies for the mobilisation of funding is crucial. Also, the creation and institutionalisation of national support funds for DPOs by national governments as well as encouraging income generating activities by DPOs themselves will help alleviate over reliance on goodwill funding and subrogate donor funding which may dry up at any time.

Other inclusion measures

- Children with disabilities should be consulted, involved in decision-making and given greater control over their lives; existing good practices should be publicised in relevant formats and shared, and appropriate training materials devised.
- Inclusion is the core of the disability agenda. Inclusion is not just about integrating persons or children with disability in their communities; it is the other way round as well – including parents, families of children with disabilities themselves in DPO operational architecture. This will enhance the functioning and the outcome of their activities.

1. INTRODUCTION

Background

*Disability is not a 'brave struggle' or 'courage in the face of adversity....
disability is an art. It's an ingenious way to live'.*

Neil Marcus.

It is undeniable that throughout their history, persons with disabilities, as a group, have been ignored, mistreated, stigmatized, hidden and even cursed. Sometimes when made visible, they have been subjects of exhibitions and objects of ridicule. At other times, they have been placed in institutions or prisons while involuntary sterilisation of women and girls is undertaken as an acceptable treatment³ contrary to international human rights law. Persons with disabilities have been denied the right to vote, locked away in remote institutions where they have been excluded from society and subjected to neglect and abuse. History is replete with numerous incidents of assault, rape, and even killing of people simply because were considered disabled. As a group, persons with disabilities also are less wealthy, less independent, less educated, and less likely to reach their full potential than other disadvantaged groups. Indeed, persons with disabilities are commonly depicted as suffering subjects, characterized by the devastating changes and crises for both themselves and their families⁴and society. Disability is caused by many factors, including malnutrition and disease, environmental hazards, traffic and industrial accidents, and civil conflict and war, and the number of persons with disabilities continues to increase.

Children with disabilities are one of the most marginalized and excluded groups in society. They face discrimination, lack of adequate policies and legislation and are effectively barred from realising their rights to healthcare, education, and even survival. In fact, legislation, policies and attitudes that fail to recognise the legal capacity of children with disabilities are factors that aggravate their discrimination and exclusion of society and increase their vulnerability to violence, abuse and exploitation.⁵ Yet, children with disabilities have the same social needs, interests and rights as any other child. However, largely due to stigma and discrimination, children with

³ History of Disability Rights Movement in Australia. At: <http://www.pwd.org.au/student-section/history-of-disability-rights-movement-in-australia.html> (accessed on 04 January 2016)

⁴ Hiranandani, V 'Towards a Critical Theory of Disability in Social Work', *Critical Social Work* (2005) Vol. 6, No. 1 (unnumbered treatise)

⁵ UNICEF, 'Child protection from violence, exploitation and abuse : Children with disabilities' At: http://www.unicef.org/protection/57929_58537.html (accessed on 12 January 2016)

disabilities are often denied opportunities for participation and integration. Their disabilities also place them at a higher risk of physical abuse, and often exclude them from receiving proper nutrition or humanitarian assistance in emergencies. Stigma, ignorance, neglect, superstition and communication barriers for children with disabilities are among the social factors that explain their discrimination and isolation from society.⁶ This situation of child disability is worsened by the fact that children are already a vulnerable group of persons by their very nature.

The attitude of governments has not been helpful either. Governments have been slow despite the existence of international, regional and sometimes national legal, policy and institutional frameworks, to ensure the promotion and protection of the rights of persons with disabilities generally. A child with disability is more at risk of not having a life at all than a child without disability who is already plagued by vulnerability. The promotion of awareness of the disability rights of child is therefore crucial especially in the African context where children are the victims of society's marginalisation. However, attitudes are changing and initiatives are being undertaken to change the *scenario*.

The defunct Millennium Development Goals (MDGs) were not for the most part disability friendly. As a result, persons with disabilities, who constitute 15% of the global population and are commonly amongst the poorest of the poor, have not fully benefited from many development and humanitarian response programmes under the MDGs. However, the new Sustainable Development Goals (SDGs, 2015-2030), which have succeeded the MDGs are disability friendly as disability is referenced in various parts thereof. This is specifically so in parts relating to education, growth and employment, inequality, accessibility of human settlements, as well as data collection and monitoring (Goals 4, 8 10 11 and 17). Goal 4, for instance, on inclusive and equitable quality education and promotion of life-long learning opportunities for all, focuses on eliminating gender disparities in education and ensuring equal access to all levels of education and vocational training for the vulnerable, including persons with disabilities. In addition, the proposal calls for building and upgrading education facilities that are child, disability and gender sensitive and also provide safe, non-violent, inclusive and effective learning environments for all. Closely following is Goal 10, which strives to reduce inequality within and among countries by empowering and promoting the social, economic and political inclusion of all, including persons with disabilities.

⁶ Ibid.

Persons with disabilities are also specifically mentioned in the 2030 Agenda for Sustainable Development and on 22nd September 2015, a meeting of experts from across 24 UN Member States entitled 'The Importance of Disability Indicators for Measuring the Implementation of the SDGs for Persons with Disabilities' introduced five disability indicators that were endorsed by the UN. Additional indicators were further proposed to match all targets referencing persons with disabilities with an indicator.

Furthermore, The African Union (AU), African governments and NGOs have taken steps to address the disability challenge in Africa. In 1988, the African Rehabilitation Institute (ARI) was established in Harare. This Specialised Agency of the AU reports to the political organs of the AU on disability issues and coordinates all matters relating to disability in Africa. Pressures exerted by DPOs contributed to the proclamation of the African Decade of Disabled Persons (2000-2009) at the [O]AU Assembly of Heads of State and Government, meeting at Lomé, Togo, in July 2000. The aim of the Decade is to promote awareness and commitment to full participation, equality and empowerment of persons with disabilities in Africa. Responsibility for organising the Decade was given to ARI, together with the Pan African Federation of Disabled Persons (PAFOD) , the African Union of the Blind (AFUB) and other regional organisations of persons with disabilities.

In February 2002, then OAU organized at Addis Ababa, in collaboration with regional organisations of persons with disabilities, the Pan-African Conference on the Africa Decade of Disabled Persons to consider a 'Plan of Action for the Decade'.⁷ The Action Plan calls upon [O]AU member States and Governments to study the situation of persons with disabilities with a view to formulating measures favouring equalization of opportunities, full participation and their independence in society. **The first AU** Conference of Ministers of Social Development which convened in Namibia in 2012 extended the Africa Decade of Persons with Disabilities for the period 2010-2019.

The unprecedented recognition that persons with disabilities are receiving at both the AU and UN therefore presents a big opportunity for persons with disabilities and their DPOs in Africa, whence the need for strengthening them.

Context and Justification

According to UN statistics, there are currently over 600 million persons with disabilities

⁷ The Secretariat of the African Decade of Persons with Disabilities (SADPD) office opened in Cape Town in 2004.

throughout the world of whom 400 million live in developing countries and 80 million in Africa.⁸ A World Health Organisation source maintains that about forty per cent of Africa's population consists of persons with disabilities, including 10-15 per cent of school-age children. Estimates suggest that there are at least 93 million children with disabilities in the world or 1 in 20 of those aged 14 or younger – live with a moderate or severe disability of some kind⁹.

The vast majority of Africans with disabilities are excluded from schools and opportunities for work, virtually guaranteeing that they live as the poorest of the poor. School enrolment for children with disabilities is estimated at no more than 5-10 per cent and as many as 70-80 per cent of working age persons with disabilities are unemployed.¹⁰ The social stigma associated with disability results in banishment, marginalisation and isolation, often leading to begging as the sole means of survival.

While the overall mission of ACPF is to contribute towards the realisation of the rights of the African child, ACPF is particularly noted for being a pioneer on the promotion of the rights and the inclusion of children with disabilities on the continent. This synthesis report marks a major step in this direction which complements ACPF's earlier work on disability as well as on-going efforts within the African Union (AU) disability architecture and the African Disability Forum.

This study comes at a time when the UN, AU, national governments and persons with disabilities themselves have begun to take cognisance of the fact society needs to change its attitude towards persons with disabilities. For one, DPOs have now realised that they have been passengers in the bus for too long as passive participants in their own affairs which society is not really willing to handle. Indeed, up until the late 1970's, the views of persons with disabilities were largely filtered through the voices of disability service providers, professionals working in the area of disability and family members, including at the international level.¹¹

At the time, the key international disability organisation, *Rehabilitation International*, had a policy that persons with disabilities could attend its periodic international conference as observers, but

8 African studies Centre, 'Disability in Africa', Leiden. Online at: <http://www.ascleiden.nl/content/webdossiers/disability-africa> (accessed on 03 January 2016)

9 UNESCO, The State of the World's Children 2013: Children with Disabilities. On line at: <http://www.uis.unesco.org/Library/Documents/state-world-children-2013-children-with-disabilities-en.pdf> (accessed on 29 December 2015)

10 African studies Centre, op. cit.

11 'Disabled People's Organisations. At: <http://www.pwd.org.au/student-section/disabled-people-s-organisations-dpos.htm>. (accessed on 30 December 2015)

were not permitted to speak. Persons with disabilities strongly protested against this policy at the 1980 conference of Rehabilitation International, held in Winnipeg, Canada where a decision was made to establish a new International organisation of and for persons with disabilities. The organisation founded was *Disabled Peoples International*, which now has members in over 160 countries throughout the world.

Subsequently, since the International Year of Disabled Persons in 1981, persons with disabilities have organised themselves into their own organisations (DPOs) all over the world. DPOs are organisations controlled by a majority of persons with disabilities (51%) at the board and membership levels. The role of these organisations includes providing a voice of their own, identifying needs, expressing views on priorities, evaluating services and advocating change and public awareness. DPOs believe that persons with disabilities are their own best spokespersons and their role has been and is fundamental for the human rights movement of persons with disabilities.

The formulation and implementation of public policies and programs, and the planning, delivery and evaluation of specialised and general services require a contribution from representatives of the disability community - DPOs. The United Nations Convention on the Rights of Persons with Disabilities (CRPD) requires states and other organisations, participation, consultation and integration of persons with disabilities in all decisions that may affect them. The slogan 'nothing about us without us' sums up the importance of the need to ensure and support the growth and development of strong African DPOs at all levels especially local, national, regional.

There are generally about three kinds of DPOs, some being more inclusive in terms of the different types of disabilities than others which are disability or group/gender specific. These are:3

- Diagnostic-focused (such DPOs represent a medical diagnostic group – e.g. people living with cerebral palsy).
- Population-specific (such DPOs represent a population group – e.g. women with disability).
- Cross-disability (such DPOs represent the interests of persons with all kinds of disability).

The introduction of 1981 as the International Year of Disabled Persons and the institution of a world disability day celebrated on December 3 each year (now in its 3rd edition in 2015), are milestones towards raising awareness amongst persons with disabilities through DPOs and stakeholders such as development NGOs, governments, public and private employers, and the

public at large, on the place of disability in general and persons with disabilities in particular in our societies. Also, the creation of the continental platform to animate conversations around their rights, the ADF, one of whose prime objectives is to '[a]dvocate for the inclusion of disability issues and persons with disabilities in all development programs and projects in Africa',¹² are milestones towards recognising and enhancing the space of persons with disabilities as full and responsible community members with all attendant rights and obligations. By setting this goal, the ADF acknowledges that the lack of inclusion policies and practices constitutes a substantial challenge for all Africans with disabilities. As a matter of fact, the ADF stands as a new and remarkable advocacy platform to further widen the chances of cooperation in the field of disability, and to advance the rights and inclusion of persons with disabilities in Africa;¹³ especially so for children with disabilities.

Broadly speaking, therefore, this synthesized report brings together the general situation of persons with disabilities and their representative organisations (DPOs) on the continent, identifies available opportunities, which DPOs at all levels (national, sub-regional and pan-African) can leverage in order to advance the disability agenda in Africa, and highlights good practice stories; and stresses the need for more focus on disability research.

This report will enable ACPF to have a precise identification of DPOs for capacity building and other relevant actors to be incorporated in the various phases of policy development and monitoring processes for children with disabilities, according to their structuring levels and action lines. It has catalogued DPOs' key structural challenges, advocacy issues, organisational strengths and opportunities as well as good practices. It has brought together critical findings from the two regional assessment reports, which may be useful in informing the programmatic interventions relating to children with disabilities planned by ACPF and ADF as well other players.

Methodology

This synthesis report is carved from two regional reports which cover all five regions of Africa (Eastern, Southern, Central, Western and Northern Africa): a regional assessment report covering the Eastern and Southern African regions; and another covering the Western Central and North

12 See Perini, F. (28 November 2014) 'African disability forum: a new opportunity for Africans with disabilities', Global Observatory for Inclusion. Online at: <http://www.globi-observatory.org/african-disability-forum-new-opportunity-africans-with-disabilities/> (accessed on 29 December 2015)

13 Ibid.

African regions. These two reports are the result of an ACPF-led Africa-wide capacity assessment of DPOs, which aims to contribute to further strengthening the implementation of relevant policies for children with disabilities, specifically through enhancing the capacities of DPOs in terms of their capacity to undertake research, advocacy and support the implementation of policies. Both assessment findings were validated at a continental multi-stakeholder workshop on the protection rights of children with disabilities in Niamey, Niger on November 26-27, 2015.

Reporting Structure

This synthesized report presents the findings of the two regional assessment reports in the following manner: a general introduction, four core sections assessing the operational capacities of DPOs in fostering the realisation of the rights of children with disabilities, and conclusions and recommendation. The general introduction paints the background and situates the context and justification for the exercise and other methodological parameters.

The first section addresses gaps in knowledge on current disability theory and practice which involves the extent to which DPOs are knowledgeable with/access disability standards and current disability theories.

The second section examines the capacity of DPOs in pursuing their operational mandates. Issues assessed here concern human resources and financial and infrastructural issues.

Section three assesses how DPOs have been mainstreaming issues of children with disabilities within their respective agendas from the standpoint of the extent of their awareness of child rights standards including those related to children and their skills in child rights programming and child rights advocacy.

The fourth and last section examines the networking abilities between in-country DPOs and regional and continental DPOs on the one hand, and networking between DPOs and civil society organisation working on disability on the other.

Each section has sub thematic issues and a case and good practice(s) is required for each theme.

The report ends with summary of the conclusions and recommendations and priorities for action, informing potential capacity assessment interventions at all levels: continental, regional relevance and some country-specific focuses.

2. ANALYTICAL SYNTHESIS OF FINDINGS OF THE REGIONAL ASSESSMENTS

The key findings of the capacity assessment in the two reports forming the basis of this synthesis followed the five thematic categories used in the research protocol, namely: governance, leadership and accountability; institutional arrangements (structures and functions); institutional capacity and resources; and knowledge and competencies.

2.1 Gaps in Knowledge on Current Disability Theory and Practice

2.1.1 The situation

Gaps between DPOs' knowledge of disability theory and the practice could be gleaned by first of all identifying what the disability standards are at all levels. This will enable a clear mapping of the degree of awareness of the standards and access thereto by the DPOs. It would also determine the extent of their knowledge on emerging disability theories, since these theories inform the standards.

Whether a DPO is knowledgeable or not on current disability standards or theories, largely depends on the way they define their own objectives, vision and mission (operational mandate) statements. If this is missed, it is clear indication that disability standards and theories are not fully known and this automatically results in gaps between theory and DPO's capacity of action on the ground.

The two regional assessment reports show that, with the exception of the North African DPOs which have coherent and clear visions, missions, and areas of action, all DPOs surveyed in Central/West Africa and East/Southern Africa, generally mix up issues.

It is worth noting that despite the relative youthfulness of some of the North African DPOs (such as the *FEMANPH* (officially recognised in 2004) Mauritanie, the *Collectif pour la Promotion des Droits des Personnes Situation de Handicap* (2005) Morocco and *OTDDPH* (2012) Tunisia,) their respective objectives, mission and vision statements are coherent (and human rights-based).

In the Central African Region, two of the six surveyed organisations mix up vision, mission, scope of action, goal and objective. For the other four organisations, there is generally coherence and relevance of their goals, missions and visions, which are human rights based. But an analysis of

their objectives shows confusion between ground DPOs and umbrella DPOs whose actions are rather oriented towards advocacy and capacity building of member organisations.

In the East and Southern African regions, several DPOs are not strategically focused and unable to formulate, articulate and align their own missions, visions and mandates with the work that they actually do on the ground. For example, the Parents of Disabled Children Association of Malawi (PODCAM) indicates its mission as follows:

PODCAM works to ensure that parents are championing the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.

PODCAM is an advocacy and lobbying organisation that empowers parents of children with disabilities, conducts civic education, and mitigates abuse of children with disabilities and their parents.

PODCAM is an association of parents with children with disabilities in Malawi. It empowers parents of children with disabilities, conducts civic education, and mitigates the impact of abuse among children with disabilities

These three statements hardly delineate which one is the mission statement, and assuming all three sentences are meant to be it, the statement smacks lack of strategic focus as an organisation. Even the phraseologies do not follow conventional standards of a mission statement.

In some cases, a number of DPOs could hardly differentiate between the 'vision statement' and the 'organisational mandate'. For example, the Epilepsy South Africa provided the following as their vision statement:

To provide integrated services that are equitable, accessible, sustainable and people-centred with and for persons with epilepsy and other disabilities and all affected by epilepsy, to promote social justice.

Although the two regional assessment reports do not specifically inform on the state of DPOs knowledgeability on disability standards, for the above considerations it is evidence that African DPOs are on the average, weak as to acquainting themselves on those very standards which justify their existence and inform their actions for the benefit of persons with disabilities.

2.1.2 Recap of disability standards

Disability standards, whether international, regional or national, are generally based on human rights principles contained in relevant human rights instruments. Disability standards comprise

both normative rules and justiciability mechanisms. Disability standards could be reduced to two broad overlapping concepts: *rights* and *inclusion and participation*. They overlap in the sense that inclusion and participation are aspects of human rights, and are particularly central in the effectiveness of children's rights. This is a rights-based approach to disability standards. The purpose is to promote ethical, respectful and safe service delivery which meets, if not exceeds, legislative requirements and achieves positive outcomes for persons with disabilities.

The *rights* standard promotes individual rights and service delivery responsibility. It emphasises the importance of:

- access to disability services
- dignity and respect;
- non-discrimination;
- having a say in decision making and choice
- taking part in the community (participation and inclusion)
- valued status (doing things the community thinks are important equality of opportunity;
- freedom of expression;
- freedom from exploitation, abuse, harm, neglect and violence;
- the role of families, friends, carers and advocates in the safeguarding rights; and
- comprehensive systems to prevent or promptly respond to any breaches of rights - availability of and access to complaint procedures

Participation and inclusion is all about promoting the connection of persons with disabilities with their families, friends and chosen communities. It also requires that services work together with individuals to enable their genuine participation and inclusion.

This participation and inclusion standard recognises the role services can play in enabling the inclusion and participation of persons with disabilities and their valued contribution in the community. In meeting the standard, services will actively support and encourage persons with disabilities to connect with family and friends and to feel included in their chosen communities. This standard emphasises the role of family, friends, carers, advocates and other organisations in promoting participation and inclusion.

The human rights based-approach informs the global, regional and national standards. These standards are contained on normative rules and mechanisms to enforce them.

2.1.2.1 The disability framework

Disability rights instruments

At the global level, disability standards are essentially covered by UN instruments. There are eight core UN Conventions which have a bearing on the rights of persons with disabilities. However, the chief instruments which have a direct bearing to child disabilities are the CRPD, the Convention on the Rights of the Child (CRC)¹⁴.

The CRC is concerned with protecting children generally, as well as children with disabilities. Article 2 states that the rights set forth in the Convention must be applied ‘...without discrimination of any kind, irrespective of disability’.

The CRC is the chief child rights instrument but the CRPD is the chief disability rights instrument. The CRPD expressly recognises in the preamble, the right of children with disabilities to the full enjoyment of all human rights and fundamental freedoms on an equal basis with other children, and recalls states obligations to this end under the CRC. It especially recognises that women and girls with disabilities are often at greater risk.¹⁵ The CRPD is discussed further in this report. Suffice to note here that it should be read in conjunction with other relevant human rights instruments.

At the regional level, African regional human rights disability framework comprises two main instruments: the African Charter on Human and Peoples' Rights (ACHPR) and the African Charter on the Rights and Welfare of the Child (ACRWC), and their monitoring mechanisms.

The ACHPR contains a list of the prerogatives and obligations, and also organs for the protection and defence of those values. Article 18 (4) of the Charter provides that persons with disabilities have the right to special measures of protection in keeping with their physical or moral needs.

The ACRWC specifically makes reference to children with disabilities in Article 13. This article provides special measures of protection to these children in relation to their mental and physical needs under conditions which guarantee their dignity, and principles which promote their self-

14 The others are: International Covenant on Civil and Political Rights (ICCPR); International Covenant on Economic, Social and Cultural Rights (ICESCR); Convention on All Forms of Discrimination against Women (CEDAW); Convention Against Torture and other Cruel, Inhuman and Degrading Treatment or Punishment (CAT); and International Labour Organisation (ILO) conventions.

15 These are elaborated under articles 3 (General Principles), 4 (General Obligations) and 7 proper. There are other Articles in the Convention on the Rights of Persons with Disabilities that specifically mention young disabled people (Arts 8, 16, 23-30). Articles 31 – 50 state how adults and governments must work together to promote and protect all the rights in this Convention.

reliance, active participation in community life and access to services and public premises. Article 13 should normally be read in line with articles 11 (on education) and article 14 (on health) of the same Charter. Most of the provisions of the ACRWC are modelled on the articles of the CRC.

National disability rights frameworks derive their force and propriety from international and regional/sub regional standards. The main instruments are national constitutions and other specific national disability laws.¹⁶ National courts may look at international and regional human rights norms in deciding how to interpret and develop national law.

Enforcement mechanisms

At the global level, the CRC Committee and the CRPD Committee are the monitoring bodies under their respective treaties. Of more importance here is the latter committee, the CRPD Committee. It comprises disability rights experts who examine how well governments are protecting the rights of persons with disabilities, including young persons with disabilities. All States parties are obliged to submit regular reports to the Committee on how the rights under the CRPD are being implemented. The Optional Protocol to the CRPD gives the CRPD the competence to examine individual complaints with regards to alleged violations of the Convention by States parties to the Protocol. Like all other treaty monitoring bodies, the CRPD Committee will only receive complaints after exhaustion of local remedies by the complainant.

At the African regional level, there are mechanisms under the ACHPR and ACRWC. Under the ACHPR there are two parallel mechanisms: the African Commission on Human and Peoples' Rights and the African Court on Human and Peoples' Rights, which complements the mandate of the Commission. Individuals or groups can submit written communications to the African Commission alleging violation of the provisions of the Charter by a state.¹⁷ Advocates can also bring any issues relating to human rights violations to the monitoring arm of the African Commission. The decisions of the latter are non-binding.

Under the ACRWC the African Committee of Experts is the monitoring body mandated to receive

¹⁶ Some of the possible constitutional provisions that affect the rights of disabled persons are: right to non-discrimination; right to equal treatment in specified spheres, such as employment or the court system or in all spheres of life; right to freedom from violence; other civil and political rights available to people including, for example, the right to free speech, to privacy etc.; other economic and social rights available to all people, including for example, the right to health care, housing and education.

¹⁷ But as in the case of the international mechanisms, there must be exhaustion of local remedies first although there are exceptional situations where this rule will not be observed.

reports and investigate violations with regards to rights protected by the Charter. The Committee has not yet issued a General Comment on children and disabilities or any Communication on disability. However, the Committee has a promotional mandate.¹⁸

At the national level, the main medium for enforcing the rights of persons with disabilities are the national courts, particularly, constitutional courts or councils etc. A successful rights claim before national mechanisms may have wider impact and lead to the reform of legislation or policies found to violate the rights of persons with disabilities. The right of a constitutional court or the highest court of the land to declare certain laws unconstitutional is termed the power of *judicial review*. This is a useful weapon in the event of discriminatory laws against persons with disabilities.

2.1.3 Degree of awareness by DPOs of national, regional, continental and global disability standards

The two assessment studies show that DPOs are not generally well versed with disability standards. Although national or regional DPOs may be having a well-defined mandate and objectives supported by a clear mission and vision, it may still lack adequate knowledge and understanding of existing national, regional, continental and global disability standards. Before assessing these issues, it is necessary to first of all determine the consideration of children in DPOs' mandates. Again, this will determine the extent to which DPOs consider children with disabilities.

The evidence shows that DPOs in West and North Africa have largely contributed to legal and policy reforms relating to protection and promotion of the rights of persons with disabilities especially children. This is proof somehow that these DPOs have the requisite knowledge of existing disability standards in order to make insightful contributions. This capacity is rather weak in East and Southern African DPOs.

Overall, because DPOs in Africa have limited knowledge on disability standards, they can hardly effectively participate in law and policy reform process. This is aggravated sometimes by low literacy levels. Those that are not knowledgeable enough cannot really foster the disability. For example, although a majority DPOs in East and Southern Africa, are able to explain in one way or

18 Wakefield, L. (2013). 'Making Progress: The African Committee of Experts on the Rights and Welfare of the Child and the Rights of Children with disabilities' *African Disability Rights Yearbook* 1 PULP, p. 373

another how their organisational mandate is aligned to the CRPD as well as their own national legislative and policy frameworks, they can hardly link their organisational mandate with the Continental Plan of Action for the African Decade of Persons with Disabilities 2010–2019 (CPoA).

Evidence of the situations of DPOs in East and southern African indirectly indicate that they are not really conversant with disability standards. There is poor rating by DPOs themselves of the levels of their involvement in mainstream development programmes (either government-led or NGO-facilitated), which may be as a result of lack or low levels of awareness of disability standards.

The main challenges that the national DPOs in East and Southern Africa face is associated with access to the knowledge resources including unfavourable societal stereotypes and communication challenges – i.e. failure to get first-hand information. Consequently, they suffer poor orientation on disability needs assessment. This hinders them from carrying out effective advocacy. In Rwanda, for example, the spread of persons with disabilities reflects that of the wider population – there is a higher percentage of persons living with disabilities in rural areas than urban ones. Furthermore 50% of persons with disabilities are not informed on their rights and are illiterate, a situation which prevents them from participating in government development programs.

However, overall, DPOs in the East and Southern Africa improve on their knowledge gap through learning and building links and partnerships with other DPOs out of the region. These links invariably promote learning and sharing of ideas and experiences based on disability standards.

Box 1. Case and good practice on acquiring knowledge on disability standards

A number of DPOs in the East and Southern regions have been bridging the knowledge gap in disability standards over the last two years, by participating in the following disability-related courses: Research and Survey, United Nations Convention on the Rights of Persons with Disabilities (CRPD); and Disability in general. The main sources of DPOs' knowledge come from the work they do including attending workshops organised by organisations with similar programmes; collaboration with other civil society organisations, DPOs, Government ministries and regional and international organisations. In terms of promoting learning and exchange within and across similar organisations in the continent, in East and Southern Africa, most national DPOs are affiliated to continental and sub-regional organisations like SAFOD, Disabled Peoples' International (DPI) and ADF. They also partner with international human rights NGOs such as the Japan International Cooperation Agency (JICA).

In Central Africa, there is low capacity in all six DPOs support for the formulation of development policies, plans and programs taking into account the inclusion of children with disabilities and their

families. Even the four DPOs that claim to have participated in the analysis of public policy, jam box analysis, identification of needs, reporting and proposal. For example, the Platform Cameroun describes these actions on these saying:

‘Our work with the government on our inclusion in public policies is the collection of field data. Through our member organisations, we know the situations of persons with disabilities and we honestly transmit them so that appropriate action be taken.’

Although five of the six organisations in Central Africa claim to have expertise in the protection of the rights of children with disabilities. Meanwhile, DPOs in Gabon and Congo cannot provide precise information on specific laws or policies protecting and promoting disability rights currently in their countries, unlike in Cameroon (where a disability law (law no. 2010/002 of 13 April 2010 on the Protection and Promotion of the Disabled) and the Social Inclusion Policy, exist.

DPOs in West Africa and Northern Africa have shown a strong ability to support policy formulation, action plans and development programs. For example, national coalitions are and remain the direct interlocutors of governments, and the latter has involved them in policy formulation. The table below recapitulates this for each DPO in West Africa.

Table 1: DPOs engagement in policy influencing

N°	DPOs	Involvement in the formulation
1	FETAPH/Togo	Child Protection Policy
2	FESAPH/ Senegal	Social Protection Policy
3	FNPH/Niger	National Social Protection Policy Economic and Social Development Plan
4	FEMAPH/Mali	Development of a national program
5	GFD/Ghana	Preparation of Ghana’s national development plans
6	NUOD/Liberia	Child protection Law
7	FEBAPH/Burkina Faso	Law on the promotion and protection of persons with disabilities

DPOs in the North have expertise in relation to supporting the formulation of public policies that take into account the needs of children with disabilities. All six (three national DPOs and three national DPO federations) DPOs have participated in developing legislation, action plans or protection programs and promoting the rights of persons with disabilities in general and children with disabilities in particular, either directly or indirectly through other member associations as

seen in. All three national DPOs surveyed in North Africa are involved in monitoring the implementation of the CRPD within the mechanisms put in place by their governments. In Morocco and Mauritania, DPOs have become a source of expertise for the government and other partners in protecting and promoting the rights of persons with disabilities. This is clear proof that, if they are able to achieve these results, it is because they have adequate knowledge of disability standards.

2.1.4 Accessibility of DPOs to existing disability standards in disability-friendly formats

DPOs need to have access to existing disability standards and this has to be done through various means and formats, depending on the type and degree of disability. This entails access to supports and services. Thus for example, in educational settings or training sessions, for example, persons with hearing impairment may need speech-reading, assistive listening devices, and good environmental acoustics in indoor settings. Persons with hearing impairments use sign languages and deaf blind use Braille. People who are blind or have low vision require instruction in Braille, equipment to produce Braille materials, and access to library services that provide Braille, audio and large-print materials, screen readers, and magnification equipment. Persons with intellectual impairments need information presented in clear and simple language. But where the impairment is severe, there is need for health workers who have the communication skills to communicate effectively with such persons.

Article 19 of the CRPD is the core international human rights provision here which portrays the standards of access but also the difficulty in understanding what these standards entail. Article 19 requires states parties to recognise equal rights of persons with disabilities in the community. The article equates the right to liberty with the right of persons with disabilities to live in and be part of the community¹⁹ - community living. *Community living or independent living* means that communities should ensure that persons with disabilities are able to live in the community as equal citizens with the necessary support and services they need to participate in everyday life, and contribute as full citizens in society.²⁰ This means that they should be provided with services,

19 Kayess, R & P French 'Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities' (2008) *Human Rights Law Review* 1.

20 European Coalition for Community Living, (November 2008). 'Creating successful campaigns for community living: A advocacy for disability organisations and service providers' At: <http://www.community-living.info/documents/EECL-Manual-final-WEB.pdf>. (accessed on 29 December 2015) See generally, Kamundia, E. (2013). 'Choice, Support and Inclusion,: Implementing Article 19 of the Convention on the Rights of Persons with

skills (through specialised and adapted training) and conditions adapted to their respective situations which will enable them have equal access participate effectively. Therefore independent living means having a choice and control over assistance and /or equipment needed to go about daily life and having equal access in specialised disability formats to housing, special access to buildings, transport and mobility, health, employment and education, and specialised learning/training programmes and tools²¹. In Lesotho, for example, IDAL provides life skills to children/youth with intellectual disability and other children with disabilities, as well as early childhood intervention strategies. Also, FENMANPH in Mauritania provides specialised educational facilities to children with certain forms of disabilities. It owns and runs an autonomous centre for the training and education of children with sensory problems. It also takes care of children with intellectual deficiencies in specialises centres.

Yet, this has not been the case everywhere as children with disabilities are sometimes totally deprived of all education as a result of the total absence of disability friendly leaning tools. The East and Southern African assessment report, for example, states in this regard:²²

[T]he percentage of youth with disabilities aged 11-20 not enrolled in formal education was seven times higher than children without disabilities in the same age group. The situation is even more serious for children with intellectual disability than other types of disabilities.

Also, the North African assessment states that members of FEMANPH *are not pleased with the head office of their organisation because it is inaccessible in terms of adaptability to their conditions.*

The article 19 rights are primarily socioeconomic and therefore subject to progressive realisation.²³ Meanwhile, Article 19(c) on access to mainstream services is said to be more of a civil and political right to non-discrimination in relation to accessing goods and services, including the duty to make reasonable accommodations, legislative measures which are required with

Disabilities in Kenya'. *African Disability Rights Yearbook 2013*, PULP, pp. 50 & 56.

21 See Office for Disability Issues, 'Independent Living: A Cross-Government Strategy About Independent Living for Disabled People' (February 2008), p. 28

22 Referring to a joint Living Conditions Study conducted in 2009-2010 by the Lesotho National Federation of Organisations of the Disabled (LNFOD), the Southern Africa Federation of the Disabled (SAFOD) and the Foundation for Scientific and Industrial Research (SINTEF).

23 See Kamundia, Elizabeth, 'Choice, Support and Inclusion, Implementing Article 19 of the Convention on the Rights of Persons with Disabilities in Kenya'. *African Disability Rights Yearbook 2013*, PULP, p. 57. This contention of progressiveness is also contained in article 13(3) of the ACRWC.

immediate effect, but which in practice (such as making premises accessible) may take time to be realised.²⁴

Whatever the scope of the standards under article 19, the problem facing not only children with disabilities in Africa but all persons with disabilities in Africa as in other developing parts of the world is the unavailability of required support and services to enable independence and enable full participation in society. Intellectual disability (ID) is one of the most overlooked disabilities in terms of service provision in the entire Africa. Some of the factors contributing to this problem include the fact that teachers have not been educated about special needs children. Meanwhile, curricula discourage underperforming students from progressing beyond primary education and there is lack of schools willing to include students with intellectual disability. The unfortunate result therefore is that many children and youths with intellectual disability lack the basic life skills to survive on a day-to-day.

Article 13 of the ACRWC provides that ‘every child who is physically or mentally disabled has the right to special measures of protection in keeping with his or her physical or moral needs. This is a broad protective framework and is linked to promoting the independence and participation of children with disabilities in their communities. However, just as article 19 CRPD, article 13 (2) & (3) place on states duties, which are subjected to progressive realisation. Article 13 therefore leaves an open ended obligation on states parties to comply with its provisions but at the same time is not prescriptive in terms of the necessary achievements which states must make. However, Wakefield has rightly remarked that ‘though treaties cannot provide prescriptions of necessary achievements, it is left within the mandate of the relevant treaty body to provide guidance in this regard’.²⁵ The African Committee of Experts can therefore bring such guidance in General Comment.

In terms of the progressive realisation of support services (disability friendly formats) to enable persons with disabilities access disability standards, it can be deduced from one of the recommendations of the Central and West African assessment report, for example, that DPOs in these regions do not experience progressive realisation. In fact, the recommendation states that

24 Joint Committee on Human Rights ‘Implementing of the Right of Disabled People to Independent Living’ (23rd Report, Session 2010-2012) 18. At: <http://www.publications.parliament.uk/pa/jtselect/jtrights/257/257.pdf> (accessed on 29 December 2015)

25 Wakefield op. cit., p. 371

states in these regions should ‘progressively implement the CRPD in strict compliance with its spirit.’

Experience has shown that required support services are often unavailable and even when they are, they do not necessarily or automatically lead to the integration and participation persons with disabilities in society in general. Societal barriers such as negative attitudes, prejudices and discrimination, inaccessible public premises and transport services, and the general lack of knowledge regarding the capabilities of persons with disabilities and their contributions, still largely affect them.

The capacity of DPOs in Africa to access disability standards is largely restrained by low levels of education where reading and writing even in the adapted format becomes a challenge because some never had the opportunity to access education or training in the disability friendly formats, which in some cases was unavailable in the first place.

It should be remarked that DPOs in Africa generally lack actual knowledge of disability theories. Even if some have indirectly carved their activities in the line of these theories; it is mainly as a matter of coincidence than a conscious act based on knowledge of the theories. As DPOs, there are some minimum things they should be doing in furtherance of the disability cause, and of course, they at least know the disability standards to a certain degree. Besides, some respondents of the East and Southern African survey indicate another serious reason for lack of knowledge of disability standards, namely, that, *‘individual members [of DPOs] ... are self-centered and cannot impart knowledge and information sharing with other members.’*

However, there are good examples of access to disability standards in disability friendly formats from the Central and Northern African sub regions.

Box 2: Access to disability standards in disability formats in Cameroon and Benin, (by CSOs) and Mauritania
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Case study 1: <i>In all ten regions of Cameroon, there are at least two schools for children with special needs. These schools are established and run by leaders with disabilities for the majority and some by charitable institutions benefiting from external grants. Such private (non DPO) initiatives apart, there are two public institutions in Cameroon that ensure the educational integration of children with disabilities. The first is the Rehabilitation Institute for the Blind (RIB), created only for the training of blind children in Braille writing. The second institution is the l'Ecole Inclusive du Centre National de Réhabilitation des Personnes Handicapées, which receives all children in an inclusive education system for children with special needs of any kind of disability. DPOs have also been instrumental in the creation of institutions adapted for the training and follow-up of children with different disabilities (visual impaired, hearing</i>

Box 2: Access to disability standards in disability formats in Cameroon and Benin, (by CSOs) and Mauritania

impaired, speech impaired, mental deficiency, and autism). However, government action in education of children with special needs is inadequate.

Case study 2: *In Benin, the NGO, ASSINOES runs ‘the inclusive school’ program for children with hearing impairment and children with hearing ability. The program consists in teaching children with hearing impairment and kindergarten children with hearing ability together until high school using both French language and language signs. This has enabled several Beninese youngsters to have a mastery of the sign language and thus created a pool of language teachers for children with hearing impairment. Also, it has enabled some persons with hearing impairment who have studied right up to the university to be supported by their mates who learnt/understand and practice the sign language.*

Case study 3: *In Mauritania, FEMANPH’s actions within the national action plan revolve on providing every child with multiple disabilities monthly cash transfers to strengthen their resilience, reducing opportunistic costs related to disability, supporting children with intellectual disability in specialised centres, and creating an independent administrative centre for specialised training and education of children with sensory disability. While it is true that the above actions benefit children with disabilities, it is also true that they are based on a charity and do not promote the inclusion of those children.*

2.1.5 Knowledge on emerging disability theories

From both assessment reports, there is a sense that DPOs have very little knowledge of existing disability standards as well as emerging disability theories which inform those standards. Notwithstanding, emphasis on non-discrimination and the inclusion/participation of persons with disabilities are central in the emerging disability theories such as the *social model* and *critical disability theory*, away from the traditional approaches based on exclusion chiefly represented by the *medical/individual theory*, which is today highly contested and driven into desuetude.

2.1.5.1 Overview of main emerging disability theories

According to the *medical/individual* model, a person with a disability is considered as sick and in need of treatment, rehabilitation, cure, or charity in order to be fit in society, if at all. Disability is seen as tragic or pitiable. This model of disability locates the ‘problem’ within the individual rather than in society. It places responsibility on the person with disability to change or to be ‘rehabilitated’ or ‘cured’ in order to fit into society, since it locates the problem in the individual as ‘stemming from the functional limitations or psychological losses which are assumed to arise from disability.’²⁶ As a result of viewing disability through a medical lens, societies have erected large institutions to protect and exclude persons with disabilities from society.

26 Kanter, A. ‘The Law: What’s Disability Studies Got to do With It Or an Introduction to Disability Legal Studies’.42 *Columbia Human Rights Law Review* 403, p. 53

In fact, article 19 CRPD specifically enjoins states parties to recognise the equal participation and to facilitate the full inclusion of persons with disabilities in the community. Inclusiveness particularly can reduce the vulnerability of children with disabilities to discrimination, exclusion and abuse.²⁷Theories such as the *social model*, the *minority model*, the *feminist theory* and the *critical disability theory* (CDT), deviate from exclusion and the traditional approach to disability as they question impairment as necessarily an individual issue; a personal tragedy. In short, contrary to the traditional disability theories, current disability theories embody values based on viewing the person with a disability not as a victim of pathological defect or deficiency that must be remedied (eliminated, treated or cured),²⁸ but as a full member of the community who can be supported to participate therein.

Most especially, the social model and the minority theory contrast sharply from the medical theory. The social model sees disability as a social construct and part of the human experience. It offers a strategy of barrier removal, and education to remove prejudice, with the goal of inclusion of persons with disabilities. Unlike the minority group model, though, the social model of disability focuses less on the relationship between the group of persons with disabilities and other groups; it focuses more on disability as a relationship between persons with impairments and a discriminatory society. The social model places the responsibility squarely on society (and not on the individual with a disability) to remove the physical and attitudinal barriers which persons with various disabilities face, and which prevent them from exercising their rights and fully integrate into society. The minority model supports this rights-based view of disability. It views persons with disabilities as victims of indignities, discrimination, and exclusion from society in much the same way as are other marginalized groups of people based on race, gender, or sexual orientation.²⁹ It 'involves processes which challenge views of persons with disabilities as incapable, powerless and passive; and *it establishes persons with disabilities as the experts on disability*.'³⁰

The assessment reports show that some DPOs especially those in the West and Northern Africa, in consonance with the social theory, are moving away from considering impairment as a source of

27 Hiranandani,V. (2005). Towards a Critical Theory of Disability in Social Work, *Critical Social Work*, Volume 6, No. 1. At: <http://www1.uwindsor.ca/criticalsocialwork/towards-a-critical-theory-of-disability-in-social-work> (07 January 2016)

28 Kanter op. cit., p. 410

29 Ibid., p. 422

30 Shakespeare, T. (1996) 'Disability, Identity and Difference', in *Exploring the Divide* 94, 102 (Colin Barnes & Geoff Mercer (Eds). Online at: <http://www.leeds.ac.uk/disability-studies/archiveuk/Shakespeare/Chap6.pdf>. (accessed on 29 December 2015)

exclusion and oppression or a factor diminishing the right of persons with disabilities to fully participate and contribute to communities through full integration into the economic, political, social, cultural, educational mainstream of society. Thus, it has been seen that DPOs in West and Northern Africa have particularly been able to participate and influence legal and policy reform affecting persons with disabilities.³¹ Yet, the absence of adequate knowledge of both the disability standards and the theories by a majority of DPOs does not really propel the disability agenda forward.

The Feminist theory offers an analytical framework that can take into account the personal and social realities of disability and elucidate how experiences of disability and the social oppression of persons with disabilities interact with sexism, racism, nationalism, and class oppression. Women are generally discriminated against and excluded as the weaker sex in most African societies and disability is just an aggravating circumstance in this regard. A feminist analysis of disability is important because more than half of persons with disabilities are women³² and because the feminist movement has questioned the most deep-seated issues about cultural representations of the body.³³

The evidence from the assessment reports shows that there are traces of the Feminist analyses in the DPO landscape in Africa. The evidence shows that, to some extent, women with disabilities are against culturally and traditionally imposed constructs of sexism and at the forefront of having their voices heard and their rights realised. They are not only involved in DPOs as members but equally own and run their own DPOs or participate in the management of other non-exclusively women DPOs.

Whilst the mission and organisational mandates/objectives of most East and Southern African DPOs make mention of the participation of women and girls with disabilities (LNAPD in Lesotho or SAFOD), others are entirely women DPOs advocating for the rights/participation of women and girls with disabilities in development leading to equal enjoyment of rights in society. This is the case, for example, of DIWODE (Malawi) and DIWA in Southern Africa, (just as the Organisation des

31 See section 2.1.3 of this report (notably Table 1) above.

32 Wendell, S. (1996). *The rejected body: Feminist philosophical reflections on disability*. New York: Routledge. Also, Asch, A., & Fine, M. (1988). 'Shared dreams: A left perspective on disability rights and reproductive rights'. In M. Fine & A. Asch (Eds.), *Women with disabilities: Essays in Psychology, Culture and Politics* (pp. 297-305). Philadelphia: Temple University Press.

33 Hiranandaniop. *cit.*

Femmes Aveugles (OFAB) (Benin) in West Africa.). Apart from the women-based DPOs, the proportion of women representation in the other non-exclusively women based DPOs is not clear in Eastern and Southern Africa. In Central, West and North Africa, there is clear indication of the proportion of female representation in DPOs especially in managerial positions. The regional assessment report shows that in Central Africa, the representation of women in DPOs is commendable. Women are represented in the executive bureaus of three of the six organizations surveyed: 16 women out of 30 members in the executive bureau of the l'Association pour l'Information et la Défense des Droits des Jeunes Sourds du Congo; 3 women out of 7 members of the Steering Committee of the Fédération Gabonaise; and 2 women out of the 5 members in the executive management of the Platform Cameroun. This proportion of representation is very low in the management committee of COMBHEN and in the executive bureau of UNAPHT Chad with just one woman out of the 7 members in both bureaus respectively. In West Africa, the representation of women is fair. Women have taken up interest in DPOs as they hold positions in the executive bureaus of all the 23 DPOs surveyed although only 3 of the DPOs are managed by women. In North Africa, the situation is rather grim. There is a low involvement of women in executive bureaus or management committees. The best involvement of women is registered in the executive bureau of OTDDPH (Tunisia), where they represent 1/3 of the members. Meanwhile, FEMANPH has only two women of a total 9 members and one woman out of 11 members in the Collectif Marocain.

It should be noted that the critical disability theory (CDT), for one, enhances the social model philosophy. It holds that law plays an important role in protecting persons with disabilities. Accordingly, critical legal theorists have characterized the law as a set of rules used by the powerful to oppress the powerless but identify the potential positive role of law in the struggle for the emancipation of persons with disabilities. CDT welcomes and values diversity and adjusts the concept of equality to accommodate diversity. CDT provides a conceptual framework to understand the relationship between impairment, disability and society and to inject disability interests into all policy arenas. *CDT privileges the voices of persons with disabilities and relies on their voices* to challenge the negative attitudes toward disability commonly expressed by able bodied people often through language dynamics.

The assessment reports show that most of the DPOs in East and Southern Africa mention enhancement of the voices of persons with disabilities in their mission and organisational

mandates/objectives but this is not seen practically in their activities. Implicitly, they cannot have their voices properly heard because they lack the requisite knowledge and skills (particularly advocacy) to effectively convey their messages. The East and Southern Africa assessment report particularly carves out the problem of low literacy levels amongst DPOs as affecting their output. It states for example that:

‘The low levels of education and illiteracy tend to have an ensuing consequence on their capabilities to effectively run their DPOs, or manage specific projects and activities’.

Nonetheless, both the CRC and CRPD are in line with modern disability theories as they challenge the ‘charitable’ approaches that regard children with disabilities as passive recipients of care and protection. These instruments demand recognition of each child as a full member of her/his family, community and society. This entails a focus not on traditional notions of ‘rescuing’ the child, but on investment in removing the physical, cultural, economic, communication, mobility and attitudinal barriers that impede the realisation of the child’s rights – including the right to active involvement in the making of decisions that affect children’s daily lives.

2.1.5.2 Experience of DPOs

Generally, the assessment reports reveal that DPOs that they have a limited degree of knowledge on the emerging disability theories. It has been mentioned that the current disability theories place the burden of disability on the wider community than on the individual with a disability as well as involving the individual with a disability as part and parcel of the integration process in the community. This is all about inclusion and integration.

In the East and Southern African regions, it has been seen that generally, DPOs have not actively been involved in law and policy making processes concerning persons with disabilities in their countries, hence the level of their involvement was on average rated as poor. This leaves behind a limited space for DPOs to advocate for the voices and privileges of persons with disabilities thereby not enabling them exercise rights or to participate and contribute fully in their own way in society.

The Forum of Associations of Disabled People in Mozambique (FAMOD) in Southern African region notes on its part that:

There is little collaboration between policy makers and persons with disabilities.

Persons with disabilities are not involved in decisions on matters that affect their lives. With the growth of the disability movement and pressure on the government, the situation is changing as persons with disabilities are sometimes consulted and involved in some policy making processes. However, the situation is still very bad.

In Central Africa, there is evidence of action by non-state actors notably the private sector. In Cameroon, there are two public institutions which ensure the educational integration of children with disabilities mentioned before (RIB and the *Ecole Inclusive du Centre National de Réhabilitation des Personnes Handicapées* (Inclusive School of the National Centre for Rehabilitation of Persons with Disabilities)).

Box 3: Good practice: inclusion and participation following the social model of disability in Cameroon and West/Northern Africa

Knowledge acquisition through training programmes on emerging disability theories, notably the social model and the critical disability theory (CDT) is relevant in building the operational capacity of DPOs in view of their mandates. The duration and level of training inputs need to be correctly balanced to permit the DPOs not to rely heavily on the mentors of the training for practical support. To be effective, mentors need to be good facilitators themselves so as to give the organisation space to practice and gain confidence.

Training manuals and literature are relevant to help them as practical guide to DPOs in their activities. The core issue in current disability theories is inclusion which involves supporting persons with disabilities to handle their disabilities instead of relying solely on care givers, medical personnel and other service providers.

Case studies: Inclusion and Participation following the social model of disability in West/North and Southern Africa.

DPOs in West Africa and Northern Africa have shown a strong ability to support policy formulation, action plans and development programs. In West Africa, national coalitions are and remain the direct interlocutors of governments, and the latter have involved them in policy formulation. In North Africa, the OTDDPH in Tunisia participated in the development of personalised social support programs and the inclusive school. Meanwhile, the AnaïsHanane association for the protection of children with disabilities, members of the Moroccan group participated in developing the National Action Plan for Children – NAPC (Plan d’Action National pour l’Enfant - PANE, 2006-2015), and FEMANPH in the drawing of Ordinance 043 -2006 of November 23, 2006. These last two organisations participated in the analysis of the degree of incorporation of public policies. The FEMANPH and the Ministry of Social Affairs, Childhood and the Family in Mauritania work together in an equally represented Joint Committee on analysing the degree of disability inclusion in national public policies.

In Rwanda, for example, the Troupe des Personnes Handicapées Twuzuzanye (THT) has taken up the challenge of inclusion in their own way. They have chosen theatre as a technique/tool for advocacy, contributing to its vision of a society where persons with disabilities are recognised as talented, capable and equal and where no Rwandan sees disability as inability. THT uses theatre and the power of culture to advocate for the realisation of the rights and social inclusion of persons with disability, including children with disabilities.

2.2 Capacity

The effective functioning of any organisation depends on its resources: human, financial, material and time. All these resources are interrelated and need to be put together for the functioning and realisation of organisational objectives. The internal institutional capacity need to be directly

linked to the use which the DPOs put such resources in the service of its members. That is why with the changing nature and complexity involved in dealing with disability issues, capacity building is necessary to enable DPOs provide the much needed resources to enable the efficient and effective operation of these organisations. Despite the importance of these resources, the DPOs surveyed in the regional assessments appear to be facing serious capacity problems in Africa.

2.2.1 Human resources

DPOs need the appropriate human resources (skills) to build a good team, strategic planning and for good governance. Both persons with disabilities and those without disabilities work with and for DPOs and most of the time, they lack the necessary know-how in dealing with disability issues because most of them offer volunteer services and may not be trained. This creates a gap that manifests itself in several ways within the organisation.

2.2.1.1 Inadequate skilled man/woman power

DPOs in Africa generally lack the necessary human resource capacity to deal with disability related issues, which is further compounded by the lack of capacity building. Most DPOs are usually heavily understaffed to the extent that even the skilled and unskilled staffs put together hardly carry out programs effectively.

Among various reasons evoked for the poor functioning of DPOs in East and South Africa sub regions, the lack of adequate skilled man power for program and service delivery came out very strong. SAFOD, for example, has three full-time male staff members (Director General, Programs Manager and Office Clerk) and one female staff member (Finance Officer). The number of both skilled and non-skilled staff members to effectively carry out programs and activities of the organisation is inadequate. The ideal number, it was intimated, would have been 10 (with 8 managing each of the eight core program areas of SAFOD).

However, national DPOs of East and Southern Africa dispose of some man/woman power resources especially in policy advocacy and lobbying, disability leadership, project management, critical research, a mastery of international human rights standards and monitoring mechanisms among others.

Pan-African DPOs employ both skilled and unskilled staffs who are not apt to effectively execute

the programs and activities of the affiliated NGOs. Being the bigger organisations, the Pan African DPOs are not supposed to face problems of human resource but rather set the standards for the national DPOs to emulate. In Cameroon the situation is somehow appealing as special teachers are being trained and integrated in the two centres that exist in the country – the RIB and the *Centre National de Rehabilitation des Personnes Handicapées*.

In North Africa, the DPOs surveyed make use of skilled labour and volunteers when need arises. The problem of human resources did not come up in West Africa but it is not clear whether it is because it does not exist.

Box 4: Good practice: Overturning the human resource deficit

DPO must have sufficient skilled man/woman power. This entails competent and non-routine skills that involve understanding disability and disability standards, having advocacy, creativity, problem-solving, communication and teamwork skills which enhance resilience in different disability situations in the community. It is therefore essential to be able to anticipate skills needs and to align personnel training with actual needs on the ground.

Where, for example, specialist rehabilitation personnel are in short supply, develop standards in training for different types and levels of rehabilitation personnel and establish strategies to build training capacity in accord with national rehabilitation plans.

In the central African sub-region, the case is different. Six DPOs actually hire qualified human resources to accomplish their mission and objectives and where there is need, they let people volunteer their services. Some of these volunteers however lack the basic skills and need capacity building exercises to boost their skills.

2.2.1.2 Limited skills in advocacy and organizational development, project/programme

The assessment studies reveal that DPOs lack the capacity and skills to advocate for law and policy changes. Of course, this limitation invariably flows from the lack of competent staff. Yet, advocacy can influence policy makers to consult with and include the concerns of persons with disabilities when making public policies. One of the roles of DPOs is to put pressure for the enforcement of laws and policies that respect and protect the rights of persons with disabilities. Thus, they need to understand disability issues, the law and the application of the law. Because this is not done, persons with disabilities face different forms of discrimination because their needs and rights are not mainstreamed into the development agenda of many countries.

Policy advocacy and lobbying, and disability leadership for East and Southern African countries is fairly good based on the opinion of respondents during the regional surveys. Meanwhile project management skills of the various DPOs are good meaning that projects and programs are effectively planned, executed, monitored and evaluated. Averagely, the East and Southern African

sub-regional DPOs have more skills in law and policy advocacy, project management, critical research, human rights standards, organisational development, contrary to the sub regional organisations of West, North and Centre Africa.

In terms of the financial, technical and institutional accountability structures and auditing systems, the situations vary disproportionately from one DPO to another in the East and Southern African sub regions. In the sub region, auditing systems, in particular, appear to exist and practiced in DPOs that already had a strong financial base (funding) whereas, those with weak financial base also had weak accountability structures.

In French speaking Africa, in addition to the lapses in advocacy mechanisms, DPOs here also lack appropriate mechanisms for financial control both internally and externally (internal and external audit systems). Among the countries of the central African sub region for example, only one organisation has a procedure manual for administrative and financial management. In Central Africa weak resource mobilisation strategy plaguing all DPOs surveyed is compounded by weak control mechanisms for internal and external financial management systems. Although three of six organisations surveyed claim to have such a mechanism, none of them could produce an audit report. Moreover, only one organisation has a manual for administrative and financial management procedures. Similarly, in West Africa, seven DPOs do not have administrative and financial management procedures manuals. DPOs in the region also show a low capacity in administrative and financial management. Out of the 23 DPOs surveyed, only three could produce an audit report.

Meanwhile, in the Northern sub region, all three DPOs surveyed confirmed they have internal control mechanisms as well as administrative and financial procedures manuals. However, only the Collectif pour la Promotion des Droits des Personnes en Situation de Handicap could produce an audit report. Averagely, therefore, the Northern DPOs have functioning monitoring financial management mechanisms.

Regarding research on disability in Africa, not very much has been done particularly in relation to children with disabilities. The absence of research data has a negative impact on the plans and programs put in place to intervene in disability issues. Research on disability in the south has not been able to mitigate discriminations against and the exclusion of persons with disabilities in

Africa.³⁴ SAFOD, has tried to influence policy and strengthen activities tailored towards persons with disabilities in South Africa, the results did not have the desired impact thus raising the need for more comprehensive research.

The CRPD is the first international human rights treaty which addresses information and communication technologies (ICT) by establishing an obligation to the State Parties to take appropriate measures ‘to ensure persons with disabilities access, on an equal basis with others, (...) to information and communications, including information and communications technologies and systems’³⁵ Hence, the UN recognised the fact that accessible technology can be used by persons with disabilities to overcome certain barriers in order to live independently and enhance their participation in the society. Studies show that investment in new technologies might reduce the cost of the assistance for persons with disabilities.

The low levels of education and illiteracy tend to have an ensuing consequence on their capabilities to effectively run their DPOs, or manage specific projects and activities. As can be seen in the findings above, even for some of the DPOs that have in place strategic plans to guide their programs, they are not able to really implement and internalize the strategic plan due to low levels of institutional capacity to do so.

Box 5: Good practices: DPOs efforts to develop key skill sets

To be successful, DPOs require certain skill sets ranging from a deeper understanding of disability rights to operational skills in administration and management, from research competencies to advocacy and lobbying skills.

Law and policy Advocacy is action to create positive change and the best advocates for disability rights are self-advocates - persons with disabilities themselves. DPOs should do advocacy themselves. They should adopt a rights-based approach. This approach can transform the needs of persons with disabilities into rights they can claim and advocate. Legal/policy change would be influencing the passing of new law/policy or amending or repealing a law/policy.

Disability specific projects/programmes or components thereof, should aim to empower persons with disabilities in particular. This is called the ‘twin track approach’. The program/project should have an overall objective. For example, the overall objective of the PSS (Pastoral Social Services) programme of direct child assistance by Hope for Life Association, Bethany Project in Ghana is to help mobilize persons with disabilities and community members so as to contribute towards addressing their health, rehabilitation, education and social inclusion needs within the mainstream society.

Financial management consists in allocating a budget for a proposed project, monitoring that the existing budget is

³⁴ McKenzie, J, Gubela M, S ‘With or without us? An audit of disability research in the southern African region’, *African Journal of Disability*, Vol 3, No 2 (2014)

³⁵ Article 9

Box 5: Good practices: DPOs efforts to develop key skill sets

sufficient to complete all the activities planned and also reporting on the financial story of the project. The successful way of managing finances is to be transparent and accountable. Accounts books and audit reports should be kept in order and ready for inspection at all the times.

DPO research: *Interesting areas for DPO research include: research on disability standards and relevant disability instruments and theories; gathering data on the degree of the impact of child disability.; research on organization structures, roles, capacities, funding sources and sustainability of DPOs in different regions; research on the relationship and communication between service providers, persons with disabilities and their organisations,; research on the extent to which DPOs influence policy.*

Communication and information management. *It is needed to make decisions and for to gain (or lose) visibility and credibility. Above all, it is necessary for needs assessment and funding process. It is essential for after-action analysis, evaluation, and lessons learned.*

Case Studies: Advocacy

Case 1: *In Cote d'Ivoire children with hearing and visual impairments were integrated into four colleges of the Yopougon municipality thanks to advocacy carried out by DPOs; and till today these are the only schools open to children with hearing and visual impairments. Still in Cote d'Ivoire, DPO have been able to advocate and open the doors of the Université Felix Houphouet Boigny, where voluntary interpreters have been put in place by an NGO – 'Society without Barriers', who support children with hearing and speech impairments by the use of sign language. Also, as a result of advocacy, DPOs have succeeded in the integration of children with hearing and visual impairment in 4 schools in the municipality of Yopougon, which remains the only one accessible to deaf and blind child.*

Case 2: *The Tanzania Albinism Society (TAS) has raised public awareness on albinism. Thanks to its advocacy efforts, Tanzania's national albinism day was established in 2006. TAS also influenced UN General Assembly to proclaim an albinism Day. The organization is proud of this and says: 'The organization has contributed in increased public understanding on albinism.... It established the national albinism day in 2006, advocate for the day to be international and by involving others through networking the General Assembly passed June 13 as the International Albinism Awareness Day. The agenda was initiated from our organization.'*

2.2.2 Infrastructural and financial constraints

Financial resources as well as infrastructure are vital elements in the life of any organisation, especially for organisations dealing with disabilities. Accessibility to these resources is important to achieve full inclusion and participation of persons with disabilities in society and a lack of access impacts negatively on the activities of DPOs.

2.2.2.1 Inaccessibility of office space, equipment and information

Where ever persons with disabilities find themselves, they need to freely access the space; equipment and information useful to them, without which they will never be fully included. Access to information particularly creates opportunities for everyone in society and people use information to make important decisions about their lives. Office space and equipment including

computers, telephones, internet connections, websites and email etc. are some of the utilities that enhance DPOs' work, physical identification, visibility and credibility. All the DPOs surveyed had problems of availability and access to some of these utilities in varying degrees.

The studies revealed that the institutional capacity of some DPOs in Southern and East Africa is very low. The assessment report of this sub region revealed that it was very difficult to get hold of respondents because most of the DPOs did not have offices, and this implies the lack of other working equipment and access to information. Though some DPOs had office space, they lacked access to basic facilities and equipment like internet, websites, official email contacts, computers, telephones and printers. Thus contacting these DPOs by email during the study was almost impossible.

DPOs in Central Africa, lack adequate equipment and office space as well. Persons with disabilities lack of access to these resources in all diagnosed DPOs in the region. In infrastructure, five of the organisations out of six in the region have head offices although accessibility is poor.

North African DPOs are no better in terms of equipment. The three organisations have adequate equipment to carry out their mission, including internet connection. However, there is accessibility to equipment in varying degrees. For example, FEMANPH is not satisfactorily accessible to members.

In West Africa, all the DPOs and Federations surveyed have minimum functioning material and office space. They all have telephone contacts and 13 of them have direct email access in their offices, while the 10 others use cyber café services or their smart phones to access information. Meanwhile, Some DPOs in Central and North Africa have office space and internet facilities.

Box 6: Creating office space: Good examples from the East and Southern Africa

Case study 1

The Self Help Association of Paraplegics (SHAP) is one of the DPOs in South Africa whose good practices have significantly impacted the lives of persons with disabilities and their families. SHAP was launched in 1981 by a group of unemployed paraplegics in the Soweto Township of Johannesburg, and is currently one of the active members of the Disabled Peoples South Africa (DPSA). They successfully fundraised for sponsorships for a building, equipment cash. The building was completed in 1983, covering 600 square meters of potential production space, offices, and ablutions.

Case study 2

Some DPOs are beginning to leverage on the power of technology by recognizing meetings held through tele/video conferencing or what is termed as Voice Over Internet Protocol (e.g. Skype) particularly where is not financially feasible for members to physically meet face-to-face. This is one of the good practices that need to be encouraged and sustained in all the Pan-African DPOs such as SAFOD. SAFOD relies on its internet savvy researchers

with high technical experience in evaluation of a variety of web content.

Case study 3

In Mozambique, the national umbrella organization FAMOD shares offices with its partners, to facilitate their work in the field in relation to geographic proximity. It enjoys access to offices, furniture, transport, fax, email and photocopying, electricity, and security services.

2.2.2.2 Accessibility of public and private spaces and facilities

Existing standards provide that persons with disabilities have access to public facilities and services and calls on the state to make this possible in order to guarantee their full participation in society. Article 13 of the ACRWC is squarely in line here, the two sub regional assessments do not bring out this element but the theory is self-edifying of the fact it is not given sufficient attention.

Everybody has a right to live as normal a life as possible. Many persons with disabilities already have a difficult life so it is a matter of fairness and respect for them to have access to public and private premises and facilities. As mentioned before people, with disabilities have the same rights as others, including the right to fully participate in community life including attending religious services, dining in public restaurants, shopping, enjoying community park facilities, and the like.

However; access to public and private facilities remains problematic for persons with disabilities despite the efforts made by governments in creating conducive environment for participation. This is however not the case as most infrastructures in most of the sub regions in Africa lack facilities like ramps and lifts which facilitate movement for those with disabilities. For those having some physical disability, a few steps may constitute a serious barrier. In other words, physical features can present serious challenges for persons with disabilities because their needs were not considered in the designing of those features.

There is a link between lack of access and exclusion in the sense that employment opportunities, for example, become meaningless in the absence of public transport that is easily accessible to persons with disabilities. Though physical accessibility to public space and facilities is one of the reasons of guaranteeing the rights of persons with disabilities, both regional assessment studies reveal that no considerable attention has been paid to physical accessibility, depriving various categories of persons with disabilities from enjoying their rights and having access to public buildings; services and other places because of various kinds of disabilities. To add, they also lack equal opportunities to healthcare, job opportunities, and other necessary services due to the stereotypes communities have about persons with disabilities.

To sum it all, different categories of disability should be considered when designing buildings; infrastructure or information technologies so that everyone can have equal opportunity and access to the services offered.

Box 7: Making transportation and premises accessible—Good Practices

Good Practices

Accessibility to public and private space means that parking spaces for persons with disabilities are close to entrances; ensuring that public transportation is accessible to people who use wheelchairs; floor spaces and hallways are free of equipment and other equipment to facilitate movement for those with visual impairment; well-placed ramps; doors that are wide enough to open so that persons with disabilities can get into buildings, other assistive technologies used increase, maintain, or improve the functional capabilities of individuals with disabilities such as crutches, magnifiers, ocular devices, talking books etc. On the other hand; accessibility to services means that once persons with disabilities are already in public facilities like hospitals staff and health care professionals can use sign language or have access to someone who can use sign language; counter and service windows should be low enough for everyone to reach including those who are on wheelchairs.

Case study: *In Nigeria, most public buildings are not accessible to persons with disabilities. Only very few tertiary institutions and government offices have ramps, lifts with sound and floors with brail numbering. The National Human Rights Commission has provided ramps and lifts with sound and brailed floor numbering in its head office at Abuja, Nigeria.*

2.2.2.3 Budgetary constraints

The lack of effective financing for support is a major problem in all the sub regions covered by the study, and it is an obstacle to the proper functioning of national DPOs, even their survival is threatened. In the study it was revealed by the National Federation of Persons with Disabilities in Namibia (NFPDN), that DPOs are beginning to face difficulties in raising awareness, lobbying and advocating because donors withdrew their funding in Namibia. To add, representatives of DPO work as volunteers since the organisations are struggling to meet up with running costs. Membership contributions, fundraisers, income generating activities and donor based project proposal are the main sources of finance for DPOs.

The Pan African DPOs are also affected by the international “donor fatigue” which is seriously affecting the performance of these organisations. Despite financing their activities through membership contributions, this has not been enough to remedy the budgetary constraints they face.

While some DPOs are sourced by the state, others mobilise funding from both internal and external sources. Others raise funds through income generating activities of persons with disabilities. This latter technique is salutary as it permits and even avoids situations where donor

fatigue dries up funding. In Lesotho, for example, some DPOs empower persons with disabilities and their families economically by getting them involved in income generating activities. By so doing, persons with disabilities and their families become financially independent and will depend less on the financial assistance and grants which might be offered by DPOs or expected from DPOs but are not forthcoming.

The East and southern African regional assessment found that while the majority of DPOs did not have both a resource mobilization strategy or plan and the monitoring and evaluation framework, about 25 percent of them indicated, nonetheless, that they had the strategic plan. In fact, one of the respondents representing the Troupe des Personnes Handicapees Twuzuzanye (THT) in Rwanda explained that the strategic plan helps to prioritize THT projects and helps to identify potential funding partners which meet THT's most pressing needs. Amongst other things, therefore, the plan enables funding partners to appreciate how their programmes fit into the wider aims of THT.

DPOs in Central and West Africa do not have to deal with tight budgets. In Central Africa, DPOs and DPO Federations have not been facing budgetary problems like those in East Africa between 2013 and 2015. The Fédération Nationale des Associations de et pour Personnes Handicapées du Gabon could gather more financial resources in central African suregion (XAF 197.938.000), followed by COMBHEN of Chad with XAF 183.667.960. Plateforme Cameroon was able to raise XAF 61.700.000 and l'Association pour l'Information et la Défense des Droits des Jeunes Sourds du Congoonly XAF 1.350.000. The Fédération Nationale des Associations de et pour Personnes Handicapées du Gabon disclosed that it receives government's subsidy. DPOs in Chad and Cameroon also receive government subsidy to support disability projects.

In North Africa, l'OTDDPH was able to self-raise US\$421 000 000 in five years, contrary to FEMANPH which is almost entirely funded by government subsidy: 92 per cent. FEMANPH is the only organisation receiving government subsidy in the region.

In West Africa, Some DPOs have been able to mobilise resources both internally and externally. For instance; FETAPH mobilised XAF 137 502 341 and APAPE mobilised XAF 63 445 650 within the last five years (2010-2015). These funds are poorly managed due to the lack of efficient administrative and management skills. As such programs and projects are poorly executed.

Box 8: Self remediation of budgetary constraints

Good Practices

Rationalisation can reduce budgetary constraints, for example, through shedding off programmes, reducing operational areas and, where necessary, reducing staff. Also more efficient resource management should be used to reduce expenditure of scarce resources. DPOs may also identify alternative funding sources such as mobilisation of local resources through consultancies in their areas of predilection to generate income – income generating activity.

Case study: *The SHAP in South Africa has been able to raise its own financial resources through income generation activities. SHAP has a factory which employs persons with disabilities to do packaging and assembly work, manufacture of protective clothing and other sewing products, and repairing sophisticated mechanical and electronic devices, such as cameras and calculators. All administrative and supervisory positions are held by people with disabilities. Today SHAP only seeks funding from the community for capital projects and in support of its always partially self-funded service programs.*

2.3 Mainstreaming Issues of Children with Disabilities within the DPO Agenda

2.3.1 Limited awareness on child rights standards

Children, especially those with disabilities constantly experience barriers in the enjoyment of their human rights, and are often given low priority. As mentioned earlier, DPOs need to understand disability standards, the law and its application. Though there are standards that could make the situation better for children with disabilities, there is a serious awareness gap.

It has been mentioned that the state of awareness of disability standards amongst DPOs in Africa is generally poor as the regional reports show. There is also a general tendency that DPOs themselves marginalise children (and girls) as a more vulnerable sub set within the larger vulnerable group of persons with disabilities. The practice of inclusion should normally begin within DPOs themselves, taking cognisance of the fact that amongst persons with disabilities, there are more vulnerable groups like children and girls who should be projected in advocacy, action plans and other programmes.

In Central Africa, beyond merely referencing children in their mission, vision or mandate statements, all six DPOs conduct advocacy to promote the rights of children with disabilities especially the right to education. They have within them, specifically associations operating in the field of protection of rights of children with disabilities. Two of the six organisations claim to have plans or specific action program to protect and promote the rights of children with disabilities. However, only *Plateforme Cameroun* could provide direction as to its actions mainly oriented towards advocacy programmes to improve the education of children with disabilities. Two

national DPOs consider children in their mission, vision or mandates accounting for 33 % of DPOs (six) surveyed in the region.

In the West African sub region, the analysis show minimal consideration of the needs of certain categories of children with disabilities, including those with severe disabilities. Four national DPOs out the eleven (representing 36.36%) take into account children with disabilities in their mission, vision and mandate. They represent 17.39 % of all the DPOs surveyed in the sub region. In general, the actions of DPOs in the region are limited to education, training and rehabilitation. As a result of lack of means, the prevention of disability seems to be ignored. However, in response to this problem of taking into account the needs of children with disabilities, associations of or for persons with disabilities have joined the associative movement of persons with disabilities in West Africa. This is the case of APAPE in Togo, OPEHN MurnaYara in Niger and APEE in Burkina Faso. Again, the analyses show inadequate consideration of the needs of certain categories of children with disabilities, including those with severe disabilities.

In the North African sub region, on the contrary, three out of three national DPOs (100%) of the total of 6 surveyed (50%) in the sub region have a mandate for children with disabilities in their respective visions, mission. Two of the DPOs, have specific plans or programs of action to protect and promote the rights of children with disabilities. However, only FEMANPH highlights actions included in the national action plan articulated around children:

- providing every child with multiple disabilities monthly cash transfers to strengthen their resilience, reduce opportunistic costs related to disability;
- support for children with intellectual disability in specialized centres;
- creation of an independent administrative centre for specialized of training and education of children with sensory disability.

This is a good practice. But while it is true that the above actions benefit children with disabilities somehow, it is also true that they are based on a charity and do not promote the inclusion of these children.

Only very few DPOs surveyed in the Eastern and Southern African sub regions direct their mandates to children as well. Half of the DPOs consulted indicated that they were implementing a particular project or activity related to children with disabilities and their parents/care takers/guardians. Yet, very few of them (7 out of a total of about 27) include children in either

their vision and mission statements and or organisational mandates. For example, IDAL in Lesotho includes children in its mission and vision statements, while ECD Ethiopia does in its vision and mandate statements. But a more radical approach is taken by PODCAM Malawi which is specifically a child oriented DPO. Here the mission, vision and mandate are all focused on children. The Zimbabwe Down Syndrome Association takes the same approach.

DPOs in East and Southern Africa tried to justify the fact that their organisational mandates respect the provisions of the CRPD and their national laws and policies. However, some could not link their mandates to the Continental Plan of Action for the African Decade of Persons with Disabilities 2010– 2019 (CPoA).

The fact that a majority of the DPOs have non-children focused mandates, does not augur well for children with disabilities as their activities may not be oriented to meet the special needs of children, including girls, who, without even having disability, are already vulnerable and discriminated against in most communities.

Box 9: Good practice on DPO realisation of child disability rights/standards

A good practice consists in considering all the rights in the CRPD, CRC, and ACRWC in relation to children with disabilities, and they should be considered when examining the implementation of all the rights in the Convention. DPOs, must take a holistic approach to disability. DPOs must master the framework of principles for monitoring law, policy and practice in respect of children with disabilities. Actions, including advocacy and lobbying must be taken at every level - international, regional, national, local and community - to effectively promote the rights of children with disabilities.

Case study 1: *DPOs in West Africa have been instrumental in advocating the elaboration of policies for the protection of the rights of children with disabilities. For instance, FETAPH of Togo participated in the elaboration of the national policy for the protection of children, including children with disabilities. NUOD of Liberia on its part participated in the elaboration of a law on the protection of children. These and many more cases prove that DPOs have been able to advocate for the rights of children to be streamlined in national policies.*

Case study 2: *In Cameroon, the national Platform has successfully advocated for the creation of institutions that cater for children with disabilities – the blind, dumb, deaf, the mentally and those suffering from autism.*

2.3.2 Inadequate skills in child rights programming and child rights advocacy

In dealing with children with disabilities, a rights-based approach is required in programming such that children are recognized as social actors. Here too, the role of adults is very important in child rights advocacy.

The survey findings show that the levels of institutional capacity for the majority of the DPOs at all

levels – continental, sub-regional, and national – are significantly low in terms of advocacy and lobbying, amongst other areas. The situation poses a threat to influencing the formulation and implementation of rights and policies focusing particularly on the rights of children with disabilities. This is reminiscent of the situation in East and Southern Africa.

However, some DPOs of the East and Southern African sub regions reveal that they are implementing programmes related to children with disabilities and their parents though some did not specifically point to the said programmes. For instance; the mandate of SAFOD reflects the protection of the rights of children with disabilities but so far it does not have particular programmes related to children with disabilities.

Box 10: Child rights programming/advocacy good practices

A good practice of skills by a DPO to child rights programming would involve using principles and standards of children's human rights such as children's best interests and the promotion of their survival and development with the overall goal of improving the position of children. Similarly, all decisions about children must always consider their opinions and make efforts to avoid missing out often excluded or marginalised groups such as persons with disabilities. Meanwhile, the child rights-based approach considers that children are entitled to rights, which are interdependent and interrelated. They have legally entitled claims and entitlements and action is mandatory³⁶.

Advocacy is a programming tool that ensures that duty bearers are held accountable. It comprises standing up for children and helping to inform communities and decision makers about children's rights. It should encourage children (with disabilities) to actively take part in the decision-making processes that affect their lives and, if possible, speak up for themselves

Case study

The Intellectual Disability Association of Lesotho (IDAL) was founded in 1992 by parents of children with Intellectual disabilities. It aims to represent and protect the rights of children with disabilities including severe or multiple disability and individuals of all ages with intellectual disability through the empowerment of parents and youth. IDAL operates in 21 branches in 8 districts of the country with a membership of 2,000 individuals.

IDAL advocacy work is on the four key areas of education, health, protection and employment. In all these key areas, IDAL uses a community-based approach to provide parents, carers and individuals with the support, training and knowledge needed to live and engage in their own community.

While the national movement of persons with disabilities in Lesotho has successfully lobbied the government to open its schools to children with disabilities, IDAL has moved a step further in developing interventions that help to achieve dissemination and sustainability and has also provided high quality empowerment, support and training to parents in rural areas, strongly encouraged partnerships between parents and teachers at local level and has played a leading role in the training and support of teachers at all levels.

IDAL has developed an advocacy tool called Speaking in One Voice that helps members to advocate for needed services. In addition, IDAL has also employed Early Childhood Intervention strategies to support families during the critical early years of their children. Families who have children ages from birth to three years with diagnosed disabilities, developmental delays or substantial risk of significant delays receive resources and support that assist

36 Save the Children, (2005) 'Child Rights Programming: How to Apply Rights-Based Approaches to Programming A Handbook for International Save the Children Alliance Members'. Lima: Peru, pp. 26 et seq. At: <http://images.savethechildren.it/f/download/Policies/ch/child-rights-handbook.pdf> (accessed on 11 January 2016)

Box 10: Child rights programming/advocacy good practices
<i>them in maximizing their child's development while respecting the diversity of families and communities.</i>

Some DPOs have been ingenious in advocacy skills, employing non-conventional methods. An example is THT.

Box 11: Successful use of non-conventional advocacy skills
Case Study 1: <i>In Rwanda, THT is one of the very few DPOs– and indeed in Africa – that celebrates culture in its advocacy strategies as reflected in article 30(2) of CRPD: to enable persons with disabilities to have the opportunity to develop and utilize their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of society. THT has created four new troops in four districts which are committed to perform to advocate for the rights of persons with disabilities through theatre and they are trained on script-writing and role-playing.</i> <i>THT is made up of five groups and each group has its task in order to fulfil the objectives and missions of the organisation. For example, Group one is composed by 18 persons with disabilities who are skilled in performing Drama and it is responsible for advocacy and sensitisation on issues affecting persons with disabilities through drama. Under the support of VSO, this group has managed to deliver the message of inclusive education and sensitisation of persons with disabilities to enhance their participation in the formulation, implementation and monitoring of the country's policies on education for all.</i> Case Study 2: <i>In Niger, as a result of advocacy by DPOs, the Department of Education has registered, in the last two years , a budget line for the purchase of specialized teaching materials to improve the quality of learning for children with disabilities</i>

2.4 Networking between in-Country DPOs and, Regional and Continental DPOs

Partnerships, networking and collaboration are crucial assets for organisations dealing with disability issues. These tools provide a platform where DPOs come together at all levels to brainstorm, share experiences and best practices and together map out the way forward in dealing with the various challenges they face. The multi-faceted nature of disability; requires that DPOs work together with government, regional and sub-regional organisations and CSO to plan for and address the needs of persons with disabilities.

2.4.1 Limited coordination and cooperation between in-country DPOs

It is always necessary for organisations with similar objectives to work in collaboration so as to achieve sustainable results. There is lack of concrete evidence that cooperation exists between national DPOs, although national DPO networks exist especially in Central and West Africa. Some national DPOs therefore do not cooperate with others although their missions, visions and mandate statements mention cooperation with most DPOs as in East and Southern Africa. The absence of cooperation according to some DPOs in East and Southern Africa is due to lack of

funds, resources and networking skills.

Weak or inexistent coordination and cooperation between national DPOs limits knowledge/experience sharing and the threshold of action in very many areas which could have been enriched from experience sharing from the cooperation and coordination such as in: lobbying, advocacy, techniques of fund raising, knowledgeability in disability standards – in short capacity building generally, is lost.

This notwithstanding, countries in the Central and West African sub-regions have national networks that coordinate the activities of in-country DPOs. In the Central African sub region for instance, six national DPO networks were surveyed and all are registered.³⁷ Together, these six networks of DPOs represent 218 DPOs (95 in Cameroon, 65 in Congo, 20 in Gabon and 38 in Chad). This grand total indicates that there is some degree of established collaboration between national DPOs in the sub region.

In North Africa, three DPOs are within networks of DPOs in their respective countries. They are: FEMANPH; the Collectif pour la Promotion des Droits des Personnes en Situation de Handicap and OTDDPH. However, there is no unity of action between DPOs in Tunisia and Morocco as well as in the whole Maghreb.

Box 12: In-country DPO cooperation

Good Practice

The need for broader networking. DPOs are themselves encouraged to seek and find useful networks from which they could derive value. These would include the national NGO forum, among others. The mentoring opportunity cited by NGOs would considerably be enhanced by broader knowledge about which of the key actors is where, and doing what.

Case study: *In West Africa, both national DPO associations and federations are in national partnerships or local networks. There is improved in-country DPO networking in the sub region, with the establishment of the: Fédération Ouest des Associations des Personnes Handicapées (FOAPH) which is an umbrella grouping of all national DPOs in the sub- region.*

2.4.2 Lack of Cooperation between national DPOs and Regional DPOs

The lack of effective collaboration between national and regional DPOs promotes unnecessary duplication; waste and confusion amongst DPO partners. National – regional cooperation provides

³⁷ They are: the National Platform of Organisations for the Promotion of Disabled Persons (Plateforme); the Union Nationale des Associations et Institutions pour les Personnes Handicapées (UNAPHAC) of Cameroon; l'Association pour l'Information et la Défense des Droits des Jeunes Sourds du Congo; the Fédération Nationale des Associations de et pour Personnes Handicapées du Gabon; the National Union of Associations of Disabled People and COMBHEN of Chad.

an advanced and expert platform for DPOs to collaborate in designing and executing programs for persons with disabilities. Networking and collaboration here eases lobbying and leadership because through sharing best practices, lessons are learnt, and through this, DPOs can effectively influence policy and pursue collective action.

DPOs in the East and Southern African sub-regions are affiliated to continental and sub-regional organisations like SAFOD, ADF, Disabled Peoples' International (DPI), and work in partnership with foreign governmental technical support cooperation agencies like the Japan International Cooperation Agency. According to the Visual Hearing Impairment Membership Association (VIHEMA – Deaf Blind Malawi), networking with continental and sub-regional DPOs *'has been a major challenge except in cases where we have been invited to attend forums at such level.'*

The ADF is made up of Pan-African, sub-regional and national DPOs and tries to strengthen the capacity of these DPOs to effectively promote the rights of persons, especially children with disabilities in Africa.

In Central, West and North Africa, there is a glaring absence of sub-regional and Pan-African Federations. The gaps and difficulties in dealing with issues of disability in these sub regions can be partly due to the absence of a potential coordinating body.

In North Africa, there is hardly any cooperation between national DPOs, lest between them and regional DPOs. For example, as mentioned earlier, there is no unity of action between DPOs in Tunisia and Morocco as well as in the whole Maghreb. There are strives towards DPO cooperation but they are undeveloped. For example, all three national DPOs are part of OMPH, the Maghreb Coalition of National Disability Organisations, which is not yet formalized and the newly created African Forum for Handicapped Persons.

Box 13: National and regional DPOs cooperation in West and Southern Africa

In West Africa persons with disabilities enjoy freedom of association with all benefits attached thereto. Despite the few challenges in cooperating with regional DPOs and other international bodies, DPOs in West Africa enjoy credibility before their partners in executing their programs by benefitting from technical and financial assistance. For instance; FNPH at the time of the regional assessment was executing two programs financed by the European Union and CBM Australia respectively. FOAPH is also credible; facilitating its partnership with Disability International, CBM and the European Union.

The Southern Africa Federation of the Disabled (SAFOD) and the Eastern Africa Federation of the Disabled, the two regional DPOs of the east and southern Africa sub regions, have ten national DPOs each affiliated to them. This shows that in these sub regions, there is some minimum cooperation and networking between national and regional DPOs.

2.4.3 Lack of networking between DPOs and civil society organisations working on disability

The civil society is a powerful force in advocating for policy change in any domain. Thus the role of the civil society in promoting the rights of persons with disabilities is indispensable. CSOs can also help strengthen the capacity of DPOs in lobbying and advocacy matters.

In all the sub regions, it can be noticed that there is scanty cooperation between DPOs and the civil society. Some DPOs in East and Southern Africa have created space in their respective mandates for collaboration with the civil society but nothing is mentioned about the realisation of this cooperation. The African Youth with Disabilities Network (AYWDN), the Pan African Network of Users and Survivors of Psychiatry (PANUSP) and the Disabled Women in Africa (DIWA), all have provisions in their mandates to build partnerships with the government, CSOs and other stakeholders.

Generally, in East and Southern Africa, national DPOs are affiliated to continental and sub-regional organisations like SAFOD, DPI, ADF, and have partnership with Human Rights International NGOs such as JICA. But no specific DPO is identified with this partnership in terms of networking.

Contrary to the limited cooperation with the civil society, government and other actors in East and Southern Africa, DPOs in West, Central and North Africa have shown proof of concrete cooperation here. Benin is a good example where such cooperation with CSOs is pronounced. In Benin, several NGOs have been responsible for various inclusive activities for children with disabilities such as the program 'inclusive holidays' by the *Le Cercle des Oliviers*, consisting of programming holiday activities: holiday classes, games, cultural activities for the both persons with disabilities and persons without disabilities together. This activity does not only help to generate awareness early enough, but it also sets the basis for an inclusive society.

In North Africa, FEMANPH is the only DPO which has integrated other CSO networks on disability.

Box 14: Networking between DPOs and CSOs on disability

Case study 1: *In Cameroon, DPOs collaborate with government and other civil society organisations to bring durable solutions to the challenges faced by persons with disabilities. Examples are the collaborations with the National Commission for Human Rights and Freedoms (NCHRF) and Elections Cameroon (ELECAM). These DPOs are equally supported by the United Nations System, Sightsavers and other organisations.*

Case study 2: *DPOs in Morocco and Mauritania work in collaboration with the government and CSOs to ensure the implementation of the CRPD; through actions carried out by government. The Moroccan Union for the Promotion of the Rights of Disabled Persons and the Mauritanian Federation for the National Associations of Disabled Persons provide their governments and other partners with expertise in the domain of protecting and promoting the rights of persons with disabilities*

The Moroccan network particularly collaborates with the National Human Rights Council and other government agencies such as the Agency for Social Development, the National Democratic Institute and the International Foundation of the Electoral System; to realise the rights of persons with disabilities. To add, this network has been benefiting from the assistance

Case study 3: *In Benin, a support fund, the Fonds d'Appui à la Réadaptation et à l'Intégration des Personnes Handicapées (FARIPH): Amongst other things, this support fund is responsible for setting up an inclusive dialogue in the Cotonou municipality: This setting brings together representatives of local CSOs and local DPOs with the objective of practising inclusion of persons with disabilities, taking in account their specific needs. This initiative is sustained by the NGO International Handicap.*

3. CONCLUSIONS AND RECOMMENDATIONS

3.1 Conclusions

This synthesised report has identified the organisational capacities, challenges of and opportunities for DPOs in Africa and how they can be involved in and contribute to the formulation and implementation of policies and legislation regarding children with disabilities and to suggest ways of empowering them in promoting the rights and inclusion of these. No doubt therefore that the CRPD requires states parties and other organisations to ensure the effective, participation, consultation and integration of persons with disabilities in all decisions that may affect them to ensure their full inclusion and participation and contribution in their communities in their own way. Quite a good number of issues spring from the analyses.

DPOs in Africa operate within favourable legal contexts for the promotion of the rights of persons with disabilities since all the countries surveyed (with the exception of Cameroon) are parties to the CRPD and have put in place follow-up mechanisms in which DPOs are involved. But they do not seem to be taking advantage of this situation to foster the rights of persons with disabilities.

The two regional assessment reports have highlighted various challenges faced by DPOs in promoting the rights of persons with disabilities and the different operational gaps such as poor advocacy, leadership, networking amongst DPOs, lack of information sharing between DPOs at all levels and knowledgeability of disability standards, low levels of involvement in legal and policy initiatives concerning them, institutional deficiencies and inadequate funding etc.

Several DPOs are not strategically focused as they are unable to articulate clear missions, visions and mandates which align with the work that they actually do on the ground. In some cases, there is difficulty in differentiating between the vision statement and the organisational mandate. This is problematic and reveals at least two major shortcomings: weak knowledgeability of disability standards, inadequate human resources; and incoherent and unsustainable activities.

DPOs face quite a great deal of challenges in terms of institutional and operational inadequacies. The institutional relates to lack of office space equipment and generally and other logistic problems, while operational relates to lack of adequate funding, weak competence and functioning strategies such as poor advocacy skills and governance issues. Just like the national DPOs, Pan-Africa DPOs too also have capacity needs which require external support in leadership

management and governance; project development and management; fundraising and resource mobilisation; financial management; monitoring and evaluation; media and advocacy; and research and documentation. For example, as regards media and advocacy/communication, it is currently hard to find any information about the ADF on its own website, but google search would generate information from other sites.

The integration of persons with disabilities depends on the availability of specialised support and services to persons with different forms of disabilities to enable them reach their full potential. Integration often requires adaptations and modifications of premises buildings and structures, accessible transportation services, availability of educational material in Braille, the interpretation of sign language etc. However, experience has shown that the existence of special disability services does not necessarily or automatically lead to the integration and participation of persons with disabilities including children. As a matter of fact, attitudinal, physical and other barriers (such as negative attitudes, prejudices and discrimination as well as the inaccessibility of public places and transport services, and the general lack of knowledge regarding the capabilities and contributions of persons with disabilities), must be overcome to ensure the full and harmonious integration of persons with disabilities and children in society.

DPOs only averagely take in consideration children with disabilities in their agendas/activities, yet in the context of this assessment, this is crucial. Half of the DPOs surveyed in East and Southern Africa intimated that they were implementing a particular project or activity related to children with disabilities and their parents/care takers/guardians but only few mention children in their vision/mission statements. All DPOs surveyed in Central and North Africa make reference to children in their respective vision/mission statements, except in West Africa where only 4 of eleven so do. In Central Africa, beyond merely referencing children, all six DPOs conduct advocacy to promote the rights of children with disabilities especially the right to education. However, West and North Africa have largely contributed to legal and policy reforms relating to the protection and promotion of the rights of persons with disabilities especially children.

The average consideration of children in DPO agendas/activities can be explained by the low levels of knowledgeability of disability standards and accessibility thereof, as well as unfamiliarity of the conceptual framework of these standards. For example, DPOs in Gabon and Congo could not identify any relevant existing laws or policies relating to the protection and promotion of the rights

of persons with disabilities in their respective countries excepting the DPOs of Cameroon. Again this is reminiscent of the lack of knowledge and access to disability standards. For example, the activities of almost all DPOs in central, west and northern regions are focused on the promotion and protection of the rights of persons with disabilities in general. This is particularly observable in the case of umbrella DPOs at the national level who rather have broad projects and programs. In West Africa, the specific protection of the rights of children with disabilities is more of the concern of national associations who are members of national federations such as the NGO Murna Yara in Niger, APEE in Burkina and APAPE in Togo that is specialized in the hold and the sponsorship of children with disabilities.

The regional assessment reports reveal globally that there is poor networking between DPOs and at all levels and between the levels. Networking seems to be better in West Africa followed by east and southern Africa, and least in North Africa. This situation does not enable them to share experiences on best practices emanating from amongst their own, and improve on their mandates and their actions on the ground. This cannot enable them engage with other civil society organisations which may be willing and available to help to support and empower them. Thus, communication and networking and sharing of experience between the DPOs at the national level, sub-regional, regional and international are underdeveloped and poor across Africa. Yet, communication and networking are essential for DPOs experience sharing amongst themselves to acquire new skills and strategies; it is a medium of self-empowerment.

The ability of DPOs to carry out their activities is further weakened by their weak financial base and poor strategies to attract funding for their activities. The DPOs across Africa evidenced uneven sources of funding and funding levels to the extent that some, especially those receiving funding from the state (which is almost automatic), stand in a better position than those who depend on donor funding which based on strong governance prowess (justification, results and accountability) in order to get (more) funding. Un-renown or DPOs with weak funding attraction acumen cannot receive substantial funding for their activities while renowned DPOs with stronger strategies can. For example, OTDDPH in Tunisia, registered a record highs of US\$ 421.000.000 in five years while the *Association pour l'Information et la Défense des Droits des Jeunes Sourds*, Congo (Brazzaville) could only raise a little over US\$ 2000 (XAF 1.350.000) in two years. On its part, SAFOD established that the biggest challenge that DPOs face in South Africa is lack of funding, coupled with the lack of capacity in fundraising and resource mobilisation.

Funding problems are worsened by poor financial management techniques. Most DPOs in Africa have administrative and financial management producers in place but only very few practice auditing which is not good for attracting donor funding particularly.

While it has been said that research on disability generally in Africa is slim, although arguable, it is undisputed in the area of children with disabilities and DPOs.

The assessments show generally that DPOs have been actively involved in policy reform most especially, and in some cases as in North Africa they have been associated in legal and policy reform as well. This has been largely due to the fact that they have clearly defined mandates and missions as they are knowledgeable enough on disability standards and can therefore make insightful contributions. It is worth noting that despite the relative youthfulness of some, such as the FEMANPH (officially recognised in 2004), the *Collectif pour la Promotion des Droits des Personnes Situation de Handicap* (2005) in Morocco and OTDDPH (2012), there is relevance and consistency in their objectives, missions and visions oriented toward a human rights-based approach and this has helped them to make meaningful policy contributions on issues of durability.

The low levels of education and literacy tend to have an ensuing consequence on the performance of DPOs to manage specific projects or carry out their activities. It can be seen from the findings above that even for some of the DPOs that have in place strategic plans to guide their programs, they are not able to really implement and internalize the plans due to low levels of institutional capacity to do so. The findings show that the levels of institutional capacity for the majority of the DPOs at all levels – continental, sub-regional, and national – are significantly low in terms of leadership and governance, resource mobilisation, project management, monitoring and evaluation, even advocacy and lobbying, just to mention a few areas. This situation poses a threat when it comes to advocating and to influencing the formulation and implementation of rights and policies in Eastern and Southern Africa, focusing particularly on the rights of children with disabilities.

DPOs face challenges in developing a synergy between their actions and those of other CSOs in their countries or sub regions. This is the case of the Moroccan *Collectif pour la Promotion des Droits des Personnes Situation de Handicap* and the Tunisian OTDDPH in the North African sub region. In fact, there is lack of unity of action amongst DPOs in Tunisia and Morocco and the whole

Maghreb. The formalisation of the Maghreb coalition remains a priority in the sub region to facilitate contact between disability organisations in the sub region and other DPOs of Africa, and to influence decisions and agendas policies in their region.

In the Southern African region, there is evidence that the cooperation enjoyed by the different national disability movements under SAFOD has contributed immensely to experience sharing, confidence building and mutual support, while opening and utilising avenues for close cooperation between DPOs.³⁸

The Central African sub region has a high concentration of national DPO networks. Six national DPO networks were surveyed and all are registered. These six national networks of DPOs all together represent 218 DPOs (95 in Cameroon, 65 in Congo (Brazzaville), 20 in Gabon and 38 in Chad). The number of DPOs in the 6 networks indicates that there is established collaboration between the national DPOs but it is not certain whether this is transposed to the (sub) regional level i.e. whether there is effective collaboration between the national networks and the (sub) regional networks.

The facts and analyses in this report show that persons with disabilities through DPOs in Africa have been mustering huge efforts to ensure the promotion and fulfilment of the rights and preservation of the dignity of persons with disabilities including children to ensure their full integration. Although, there are registered successes and good practices almost across the entire board, much still has to be done to empower DPOs to reach their full potential and achieve more meaningful results particularly for children with disabilities through more focused and properly defined operational mandates and actions.

³⁸ Ncube op, cit., pp. 12/3

3.2 Recommendations

The situation of DPOs in Africa is not completely gloomy. At continental, sub-regional, and national levels, opportunities exist that can help turn round the situation positively. DPOs need to leverage on existing opportunities. However, for this to happen, DPOs need to be well-coordinated and empowered in specific areas at all levels through concrete and prompt supportive actions and accompanying measures.

1. Strengthening the technical and organisational capacities of DPOs

DPOs should be supported through capacity building programs and self-empowerment measures to ensure that they are not only strategically focused. Capacity building runs across all the challenges faced by DPOs from institutional to organisational shortcomings and advocacy deficiencies.

However, the understanding of capacity building should be cleared first. In Mozambique, for example, DPOs are very clear about what they want from capacity building. They consider capacity building as a tool for strengthening them to be effective in their work and to achieve concrete results for their members. Consequently, they understand capacity building as creating 'legs with which to walk'.³⁹ That said, capacity building could be divided into three main strands.

First, DPOs should be technically empowered/supported to take a leading role in the implementation processes of relevant international or regional human rights instruments. This would enable them to assimilate disability standards in the first place and undertake focused and informed actions in the interest of children with disabilities, engage productive lobbying and advocacy strategies, as well as, where necessary, seek remedial solutions in times of violations or non-realisation of the rights of persons with disabilities. For this to happen, the following should occur:⁴⁰

- DPOs should have good knowledge of the standards and implementation processes of international and regional human rights instruments and provisions relating to disability;
- They should receive relevant education and training to develop their research and advocacy skills not only to play a role in implementing international and regional human

³⁹ Ncube op. cit., p. 4

⁴⁰ See *African Disability Rights Yearbook*, Country Reports: Eritrea, Vol , 2015. PULP, P. 177.

rights instruments but also to advocate and lobby for required reforms on the protection of the rights of persons with disabilities.

- DPOs should have adequate human and financial resources, technical and other supports to undertake their activities - Their capacities on budget analysis and advocacy for disability- sensitive budgets should be strengthened.
- DPOs representing various persons with different types of disabilities within the disability community, should forge to have one voice for the community as a whole, instead of creating unnecessary competition and conflicts amongst them.
- DPOs should strengthen their organisational structures and create relations with other DPOs in advocating for the rights of persons with disabilities.

Second, any well thought-out process of capacity building should aim at increasing the skills of DPOs to plan, implement, monitor and evaluate their work. This is already happening amongst DPOs in North Africa. They are gradually empowered through capacity building of members, professionalism in their administration and the increasing engagement of persons with disabilities and their families. Thus, high priority areas for capacity building of members of DPOs here are as follows:

- Human Rights Standards in (including the CRPD), monitoring mechanisms and structures related to the rights of persons with disabilities;
- Articulation of coherent mission, vision and operational mandate statements properly aligned with conventional disability standards to inform the work DPOs do or should do on the ground. DPOs cannot produce any meaningful results, if they do not understand or miss their respective focuses from the outset. This is a priority area for immediate action and support;
- Governance, leadership and organisational development;
- Financial, technical and institutional accountability structures and auditing systems. DPOs are very weak here and this is a disincentive for private funding;
- Partnership development and mobilisation of financial resources strategy. The resource mobilisation (fundraising) skills of some DPOs such as the Association pour l'Information et la Défense des Droits des Jeunes Sourds, Congo (Brazzaville) which could only raise a

little over US\$ 2000 (XAF 1.350.000) in two years should be strengthened, else they cannot meet the set goals within their operational mandates, lest network and share experiences within other DPOs at all levels;

- Analysis of inclusive public policies taking into account the needs of persons with disabilities in general and children with disabilities in particular;
- Development of monitoring and evaluation tools for the inclusion of public policies;
- Involvement of DPOs, in reporting processes before relevant treaty monitoring bodies. DPOs and other NGOs have a role to play especially in reporting processes before report submissions, during examination by treaty bodies and following the examination of the report through monitoring and evaluation.
- Lobbying and advocacy skills. As a matter fact, capacity building is more about building advocacy skills.

Third, DPOs should be empowered through regular training of their members to work closely with communities and private sector stakeholders, individuals and organisations to:

- develop real opportunities for people/children with disability in the community;
- raise the presence, participation and contribution of people/children with disability;
- promote the achievements and contributions of persons with disabilities;
- lobby and advocate for the institution of disability insurance scheme by national governments.

However, the acquisition of skills and empowerment through capacity building alone is not enough. Technical support should be accompanied with resourcing DPOs not only financially, but also, in terms of competent human resources.

2. Stakeholders' contributions in lobbying, capacity building programmes and research

- a. ACPF/ADF should engage the African Committee of experts to consider the possibility of drafting a General Comment on children with disabilities.
- b. ACPF/ADF and other stakeholders should engage with the African Committee of Experts to encourage African governments to develop a culture of consulting, involving children in decision-making and children be given greater control over their lives.

- c. ACPF should foster research to show statistics and empirical evidence on the magnitude and impact child disability. This would promote awareness and challenge the widespread existence of superstition, stigma and denial of access to education in relation to children with disabilities as well as the cost effectiveness argument against the inclusion package – i.e. balancing the cost of providing support service against the output of persons with disabilities.
- d. ACPF should develop programmes that are focused on building the capacity of Pan-African, sub-regional and national DPOs in generating more disability data/research at all levels which would inform legal and policy reforms, further disability programming in the area of children with disabilities, notably, disability standards, complaint mechanisms/procedures for the protection of the rights of persons with disabilities as well as leadership and governance, advocacy, and project management. ACPF/ADF should work towards building strategic partnerships with training institutions (including universities) to offer capacity building initiatives for targeted DPOs. Such training initiatives should prioritize particularly the youth with disabilities (boys and girls equally) who are expected to fill the gap that will have been left by the current leaderships.
- e. Where capacity-building trainings are to be deployed, over-reliance on foreign experts (outside Africa) should not be encouraged at the expense using local capacity (within Africa) so that such initiatives are really tailored to prevailing situations and experiences on the ground within the African context. Training materials should be produced for subsequent use by DPOs in their sub regional and national networks to ensure sustainability of acquired skills from training sessions. Governments should be encouraged to make these materials available at the community level in appropriate forms for children and persons with disabilities. Existing good practices should be publicised and shared.
- f. ACPF/ADF should collaborate with national, sub-regional and Pan-African DPOs in lobbying Governments to ensure that all sector plans and national programs are involving persons with disabilities, from conception to implementation, with appropriate budgets for human and material resources with which to enable access. For this to happen the reinvigoration of regional networks or national federations through training in leadership and mobilisation is also crucial and should be supported by all relevant stakeholders.

- g. ACPF should develop and implement a strategy to strengthen the organisational, institutional and technical capacities of umbrella DPOs at the (sub) regional level so that they can in turn transfer skills amongst their member associations. Strengthening technical capacity should make provision for post training follow-up, develop inclusive analysis tools and the monitoring and evaluation of public policies, as well as project and development programs.
- h. Umbrella DPOs should be supported to develop advocacy plans for inclusive public policies for persons with disabilities including children with disabilities and accompany these DPOs in the implementation of the plans. They should also spearhead cooperation/networking between national DPOs and between national and sub-regional/regional DPOs. They should involve national DPOs in the networks of other CSOs.
- i. AU members states which are not yet parties to the CRPD such as Cameroon, should be lobbied to do so in order that its provisions take effect within their national legal orders in terms of having states parties respect their international law obligations under the CRPD, and of availability of remedies to persons with disabilities seeking redress for alleged violations by their states. This would also create a uniform legal platform for and legitimacy of DPOs and CSOs' actions. This would, in turn, enhance cohesion between them at all levels of national, sub regional, regional and international networking and cooperation.

3. Cooperation between DPOs at all levels

- a. Cooperation and information/experience sharing among African DPOs at all levels should be promoted and, where possible, enhance scaling up or replication of good practices demonstrated by some DPOs in all aspects of disability programming, including those impacting positively on children with disabilities. DPOs can fully take advantage of experiences from their peers in advocacy, institutional development and governance, funding etc. Regional platforms, forums, seminars ('best practice seminars') or symposiums designed to enhance learning and exchange of experiences of DPOs, need to be created while exchange visits among African DPOs need to be also encouraged at both sub-regional and national levels and, where possible, financially supported.

- b. DPOs should be supported to strengthen internal cohesion and national networks, as well as strengthen cooperation ties between national networks and (sub) regional networks. The probity area here is North Africa where in-country and sub-regional networking is extremely weak. This should also be the case of the Central African sub-region which has a high concentration of national DPOs within national networks as seen (95 in Cameroon, 65 in Congo, 20 in Gabon and 38 in Chad). This would enable national networks to work in synergy with (sub) regional networks in order to establish strong and competent (sub) regional movement of the civil society to lobby states and national, regional and sub-regional institutions (such as the AU, SADC ECOWAS, CEMAC, CEN SAD) for the ratification or implementation of the CRPD or on other issues to push the DPO agenda at the continental level, as the case may be.
- c. Greater co-operation between DPOs and community based rehabilitation programmes (CBR) can help empowering DPOs take control of inclusion measures. The CBR is an expression of the social approach to disability wherein the persons with disabilities should be active participants rather than passive participants in measures concerning them. In a number of countries, CBR have been started by organisations of persons with disabilities. In other countries, CBR initiatives have helped persons with disabilities begin to organise and take united action. Whichever is retained, persons with disabilities need to take a more active and leading role in the CBR programmes. They should therefore not be considered as 'objects' of rehabilitation steered from above (top down) through the chain to the target (person with disability), but 'subjects' who actually propel their own process of rehabilitation together with the professionals, where necessary – bottom up. The goal of the alternative or reverse bottom-up approach is to empower persons with disabilities. The active participation of DPOs in launching and leading CBR initiatives DPOs should therefore be encouraged and supported. Funding agencies and organisations should give preferential funding to CBR programmes which are started or run by groups with disabilities, or which maintain a certain quota of persons with disabilities at all levels, including technical and decision-making posts.⁴¹ However funders should ensure that programmes include a plan and timetable for training persons with disabilities to move into such posts.⁴²

⁴¹ Werner op. cit.

⁴² Ibid.

4. Role of states in legal, policy and other measures

- a. States have a number of responsibilities to ensure that persons with disabilities' rights are promoted through awareness raising, collection of statistics, policy making and planning, ombudsperson, national committees and personnel training.
- b. In order that the work of DPOs gains credibility, national legal frameworks should ensure equal protection, affirmative actions, an integration policy particularly in relation to education and professional training, health care and social security and shaping remedies for violations of the rights of persons with disabilities (due process of law, locus standi, national appeal procedures etc.).
- c. States should facilitate the creation of National disability councils with the status ombudspersons. These independent mechanisms are appropriate, to promote, protect and monitor implementation of CRPD and report to the mandated ministry. They would also investigate the activities of disability service providers on the basis the report of the audit teams and report to the ministry in charge of persons with disabilities, and where necessary initiate proceedings against defaulting parties. They would oversee the smooth functioning of national DPOs, their networks, and between them and regional/international DPOs. The national council should be capable of identifying DPOs crucial institutional and resources needs and table them before the relevant national authorities or donors.
- d. Audit teams comprising persons with special training in the standards in disability issues should be set up in countries at national level to assist DPOs to check annually whether national disability services are complying with the standards and prepare annual reports to this effect. The reports are then forwarded to a national ombudsperson on disability for follow-up and proper action.

5. Other funding strategies

- a. The development of partnership and strategies for the mobilisation of funding is crucial. The DPOs in all regions are weak in financial resource mobilisation even if some are individually well-funded. Funding problems could be also alleviated by the creation and institutionalisation of national support funds for DPOs by national governments as in Benin

and Niger. Also, DPOs should be encouraged to carry out income generation activities (as is the case with SHAP in South Africa) to help alleviate over reliance on goodwill funding.

These would pre-empt and subrogate donor funding which may dry up at any time.

6. Other Inclusion measures

- a. Inclusion is the core of the disability agenda. Inclusion is a *right* and not a 'privilege'. Inclusive education needed to be introduced as part of a strategy for promoting an inclusive society. Children with disabilities should be consulted, involved in decision-making and given greater control over their lives. Existing good practices should be publicised in relevant formats and shared, and appropriate training materials devised.
- b. Inclusion is not just about integrating persons or children with disability in their communities; it is the other way round as well – including parents, families of children with disabilities themselves in DPO operational architecture. This will enhance the functioning and the outcome of their activities. Parents and families of children with disabilities are often shunned by DPOs, yet, they are capable of bringing more insight on the child's disability which may provide knowledge to other parents improve care and inclusion techniques to DPOs in specific cases of disability. For example, persons with disabilities and family members can come together, exchange information and experiences, and provide assistance and advice to one another. For example, a mother who has cared for her child with cerebral palsy for many years, and has learned many skills and *tricks* in caring for her, can provide valuable advice to the mother of a new-born with cerebral palsy.⁴³ A respondent representing the Zimbabwe Down Syndrome Association, for example, explained that he was not happy or satisfied when it comes to inclusion in the executive committees, because the parents are not considered 'Disabled' which leaves parents of children with disabilities out of decision making levels. Of the six DPOs in Central Africa reviewed only the bureau of the Plateforme Cameroun recorded the participation of either children with disabilities or parents of children with disabilities.
- c. Each disability has its specificities. Hence, the attitudes and knowledge of people working in DPOs should be participatory and non-discriminatory. Society has several stereotypes about persons with

43 Werner,D. 'Strengthening the Role of Disabled People in Community Based Rehabilitation Programmes'. At: <http://english.aifo.it/disability/documents/innovations/2werner.pdf> (accessed on 03 January 2016)

disabilities, and this requires that those who work in national DPOs and sub- regional networks should be efficiently trained to work in a way that meets the international standards available for the protection of the rights of persons with disabilities. For example; those involved need to undergo appropriate training to gain the relevant knowledge needed to deal with or care for persons with disabilities. Even in cases where persons with disabilities themselves are part of the teams of DPOs, it is equally necessary to build their capacity and confidence so that they can successfully work to meet the objectives of these organisations, especially in meeting the needs of children with disabilities.

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