The lives of children with disabilities in Africa: A glimpse into a hidden world

The African Child
Policy Forum

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Nafisa Baboo

The African Child Policy Forum (ACPF)

ACPF is an independent, pan-African institution of policy research and dialogue on the African child.

ACPF was established with the conviction that putting children first on the public agenda is fundamental for the realisation of their rights and wellbeing and for bringing about lasting social and economic progress in Africa.

ACPF's work is rights based, inspired by universal values and informed by global experiences and knowledge. Its work is guided by the UN Convention on the Rights of the Child, the African Charter on the Rights and Welfare of the Child, and other relevant regional and international human rights instruments. ACPF aims to specifically contribute to improved knowledge on children in Africa; monitor and report progress; identify policy options; provide a platform for dialogue; collaborate with governments, inter-governmental organisations and civil society in the development and implementation of effective pro-child policies and programmes and also promote a common voice for children in and out of Africa.

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Acronyms

ACPF	The African Child Policy Forum
CBR	Community-Based Rehabilitation
CDG	Care Dependency Grant
CRC	Convention on the Rights of the Child
CRIN	Child Rights Information Network
CSA	Central Statistics Authority
CWD	Children with Disabilities
DISTAT	United Nations Disability Statistics Database
DPO	Disabled People's Organization
DSD	Department of Social Development (South Africa)
ECD	Early Childhood Development
ECDD	Ethiopian Centre for Disability and Development
EMIS	Education Management Information System
ENTSS	Senegal's National School of Specialist Social Workers
FDRE	Federal Democratic Republic of Ethiopia
FGD	Focus Group Discussion
HDI	Human Development Index
HRC	Human Rights Commission
INDS	Integrated National Disability Strategy
LCDRC	Leonard Cheshire Disability Research Centre
MDG(s)	Millennium Development Goal(s)
NCC	National Council for Children
NCD	National Council for Disability
NGO	Non-Governmental Organization
NUDIPU	National Union of Disabled Persons of Uganda
OT	Occupational Therapist/Cccupational Therapy
OSDP	Office of the Status of Disabled Persons
PASDEP	The National Plan for Accelerated and Sustained Development to End Poverty (Ethiopia)
PEIS	Project for Special and Integrated Education (Senegal)
RBC	Réadaptation à base communautaire
RSA	Republic of South Africa
SAHRC	South African Human Rights Commission
SNE	Special Needs Education
SPSS	Statistical Package for the Social Sciences
SSA	Statistics South Africa
UK	United Kingdom
UN	United Nations
UNCRC	United Nations Convention on the Rights of the Child
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNICEF	The United Nations Children's Fund
USD	United States Dollar
WHO	World Health Organization

Foreword

Today, millions of children in Africa live with the effects of disabilities, struggling with a myriad of challenges that can be attributed to the absence of an enabling environment.

Many children are left to be born with some forms of disability that could be prevented with a modest investment in basic healthcare services during pregnancy. Further, public programmes rarely consider the special needs of children with disabilities and, most importantly, fail to ensure their access to public goods and required services. Efforts aimed at meaningfully integrating children with disabilities into family and community life have been further frustrated by a litany of attitudinal and cultural barriers.

The majority of existing laws and policies on disability are not only out-dated, but also lack the necessary priority and are seldom implemented. This is so despite the ratification by many countries of relevant child rights treaties including the United Nations Convention on the Rights of the Child, the African Charter on the Rights of and Welfare of the Child and the United Nations Convention on the Rights of Persons with Disability.

Bringing such hidden realities to the limelight is a step in the right direction. This initiative by The African Child Policy Forum (ACPF) to document the lives of children with disabilities would greatly contribute to drawing public attention to the issue and to holding governments accountable. Notably, the report offers advice to governments in their efforts in formulating laws, policies and programmes for the benefit of children with disabilities and, by so doing, brings hope to these children.

I am proud to be associated with this compelling report and commend ACPF for giving us the glimpse of the hidden world within which our children with disabilities are living. In my view, this is a first step towards ensuring a meaningful improvement in the lives of African children with disabilities.

Let's always remember that children with disabilities are children first and foremost, and are hence entitled to the same rights in all aspects of their lives as other children. Thus, I urge all stakeholders to commit themselves to the task of translating words into action. What we need is action that eliminates discrimination and ensures genuine inclusion; action that enables the children with disabilities to be involved in decisions that affect their wellbeing; action that eliminates all barriers and ensures equal opportunities and access to basic services, such as health, education and protection; and lastly, action that promotes respect and recognition of the contribution of children with disabilities to society.

The onus is, therefore, on each and every one of us – if each one of us plays our part, it will not be far to see all children of Africa, regardless of their disability, enjoying their basic human rights to the fullest.

Dr Agnes Akosua Aidoo
Vice-Chair, UN Committee on the Rights of the Child

Preface

In Africa, children with disabilities are often deprived of resources, services and experiences that could have enabled them develop to their fullest. They are denied health care, education, socialisation and recognition. It is sad to note that parents of some of these children also victimise them. They treat their children with disabilities as unwanted objects. This lackadaisical attitude by parents is a point of concern as it affects the children's self-esteem, socialisation, performance in school and their aspirations for the future.

It is this dire situation of children with disabilities in Africa that led ACPF to initiate pioneering studies into the situation, lives and experiences of children with disabilities in Africa. Our studies have highlighted that the issues of children with disabilities still remain hidden and that these children never have a chance to realise their full potential. However, if given an opportunity and the right environment to pursue their dreams, children with disabilities can become meaningful contributors to our society.

This study explores the enabling conditions and barriers that prevent children with disabilities from claiming their rights and achieving their full potential. With respect to geographical scope and content, this study offers probably the widest and deepest study undertaken in Africa on children with disabilities since the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) came into force in 2008.

The countries participating in this study have all made a commitment to honour the UNCRPD. The findings and recommendations of this study shed light on ways in which to correct the injustices, neglect and exclusion that so many children with disabilities still face. We believe that the issues revealed in this report will further re-orient society's thinking and treatment of children with disabilities. Children with disabilities should be treated with dignity and respect.

David Mugawe
Executive Director

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Executive summary

The lives of children with disabilities in Africa: A glimpse into a hidden world is a multiple country study conducted by the African Child Policy Forum (ACPF). The study took place in Ethiopia, South Africa, Senegal and Uganda – all countries that have ratified the UN Convention on the Rights of Persons with Disabilities. In Ethiopia, Senegal and Uganda, approximately 1,339 children with disabilities and 1,473 primary caregivers were interviewed. In South Africa, a desk review was conducted of the situation for children with disabilities.

This project looked at various aspects of the realities facing children with disabilities in selected countries in Africa, including the following: a review of policies and legislation and their implementation; service delivery; the impact of poverty on wellbeing; health care, education and employment; knowledge, attitudes and practices; and social integration.

Findings suggested that while all four countries in the study have the necessary policies and legislation in place to protect the rights of children with disabilities, these are rarely implemented effectively. One reason for this is that monitoring bodies lack the capacity and technical expertise to fulfil their roles. Another part of the difficulty lies in the lack of reliable data on children with disabilities. Differing definitions of disability, combined with ineffective data collection, mean that statistics – where available – are seldom reliable. The problem is compounded by fear of stigmatisation, evidenced by the low birth registration of children with disabilities.

Poverty remains a major problem in safeguarding the wellbeing of children with disabilities: up to 88% of caregivers are unable to meet the basic needs of their children with disabilities. The most burdensome financial costs were connected with medical care and rehabilitation, assistive devices, and transportation. Despite the availability of free healthcare for the destitute, in some countries the cost and effort involved in negotiating administrative hurdles and paying for transport prevents many from taking advantage of it. However, community-based rehabilitation and other programmes have been effective in increasing access to education and assistive devices. Despite their material poverty and lack of financial support from outside sources, children themselves remain hopeful about their futures, their equal participation in society, and their ability to live full and independent lives.

While the study reveals a decline in misconceptions and superstitions about disability, some children and families still experience abuse and discrimination in their families and communities respectively. Physical accessibility of facilities also remains a problem, even in institutions for children with disabilities and family homes. Very few households surveyed made changes to their homes to improve access for a child with a disability, or even considered physical access to be an issue.

Healthcare is another area of concern. In the survey, 55–68% of caregivers reported that their child acquired their disability before the age of five. More than three-quarters of disabilities resulted from illness, and had been in place since birth. Illness was the leading preventable cause of disability, followed by accidents. Preventative healthcare and better care for pregnant women and infants would improve this situation.

In addition, the study revealed a serious shortage of rehabilitation and early childhood care and development services in the countries surveyed – services which could address the after-effects of illness and trauma. Children with communication and sensory impairments are particularly disadvantaged by this, as they rarely receive the assistive devices and rehabilitation they require in order to develop to their full potential.

The school enrolment figures for South Africa and Ethiopia are encouraging, but children with disabilities in Uganda and Senegal are still unacceptably excluded from the education system. One child with disabilities in five in Ethiopia and South Africa is excluded form education, as are about three in five in Uganda and Senegal.

The majority of children who were in school (67.7–74.6%) attended mainstream schools, regardless of the nature of their disability or their location. This indicates that an inclusive approach is more feasible in reality than the approaches laid out in the special needs education (SNE) strategy of Ethiopia and many other African countries, which revolve around opening special unit classes in mainstream schools in which children with a range of disabilities are lumped together. An inclusive education approach that promotes the transformation of the education system as a whole is therefore more viable, and would improve access for all children and the quality of the education system generally.

Access to quality education for children with disabilities remains a major concern across all four countries in the study. The failure of schools to be fully inclusive and accessible has denied many children their right to education. Approximately 45% of children and caregivers surveyed said school inaccessibility – in terms of infrastructure, location, negative attitudes towards children with disabilities, and unsupportive learning and teaching practices – prevented children with disabilities from attending school. Transforming schools into more resourceful and supportive places, through enhancing the skills of teachers, will improve learning outcomes for children with disabilities.

The issue of children with disabilities working under exploitative and dangerous conditions is another area of concern. Many children in the study felt they had to work to survive and support their families, including by running errands and doing chores for other households. In many cases, these children were below the legal working age, and worked in dangerous and exploitative environments and roles, such as begging. Although some children with disabilities of legal working age who were formally employed enjoyed their work and had friends at the workplace, there were still incidences of attacks and insults from fellow workers because of their disabilities. What is most worrying is that nearly one-third of working children reportedly worked under dangerous conditions. The high number of over-aged learners and the benefits of work expressed by those children who were employed, do, however, emphasise the importance of providing children with disabilities with relevant education and preparation for working life.

Societal and community attitudes to disability remain a problem for children with disabilities. Caregivers and community leaders reported that stigma is rife in many communities, and in some communities, services are nearly non-existent. Some caregivers felt stigmatised for having a child with a disability, and excluded from family and social events. In communities where there were active disabled people's organisations (DPOs) and non-governmental organisations (NGOs) working on disability, considerably more favourable attitudes were noted.

More positively, the study revealed that attitudes and practices at family level are largely supportive. Children participate in family life, and in many cases in family events. Sadly, however, children with disabilities are often prevented from attending school by their families, and nearly a third of such children felt they were the cause of fighting in the family. Despite this, the vast majority of caregivers and children received little or no emotional support in dealing with their stresses, and felt unable to approach family, or anyone in their neighbourhood, for support. Many felt a strong sense of inclusion as a result of the fact that fellow children recognised their abilities and worth.

About a third of children with disabilities were not aware of their key rights, and in general were less aware of their rights than their caregivers. The respondents from countries with lower access to basic services were less aware of their rights.

Children with disabilities will continue to be seen as a 'problem' as long as their potential goes unrecognised by those in positions of power. The onus is therefore on governments, service delivery organisations, communities and caregivers to create an enabling environment in which each and every child can fulfil their potential.

KEY ACTION POINTS

Policy, programming, service delivery and monitoring

- The UN Convention on the Rights of Persons with Disabilities (UNCRPD) must be incorporated into domestic legislation, and policies laid down by learning from best practice in developing countries.
- All sector plans and programmes must include children with disabilities, from conception to implementation, with appropriate budgets for human and material resources with which to enable access.
- The capacity and technical expertise of monitoring bodies promoting inclusive development must be enhanced.
- Community Based Rehabilitation (CBR) must be expanded, strengthened and used as a service delivery model for children with disabilities and their families.
- Disability service delivery performance indicators must be included in service delivery appraisals.
- "Quality Standards for Effective Disability Programming" must be developed.

Prevalence data and statistics

- A standard definition of disability and related methodology for population censuses must be used, to ensure comparability at regional and international levels.
- Government departments must collect data on disability, streamline data collection systems and methodologies, and harmonise geographical regions.
- A registry of children with disabilities must be created for each district.
- Birth registration must be free and accessible.

Poverty alleviation

- Programmes for the attainment of the MDGs must target children with disabilities and their families.
- Bureaucracy and administration requirements for accessing free services must be eased.
- Social assistance must be provided in the form of cash pay-outs or in-kind assistance for under-privileged caregivers of children with disabilities.
- In wealth creation programmes, priority must be given to families of children with disabilities.

Health, rehabilitation and early childhood development

- Free healthcare must be extended to pregnant mothers and children up to the age of seven.
- Mandatory screening for disability-causing diseases and impairments must be provided to pregnant mothers and children, in order to be able to provide appropriate medical care on time.
- Investment must take place in early childhood development and the inclusiveness of childcare facilities.
- Where available, a toll-free telephone help centre must be established to provide information and referral to relevant service providers.
- The skills of healthcare practitioners must be enhanced in order to make them more sensitive to disability, and to encourage a more social approach to treating children with disabilities.
- Access must be improved to appropriate assistive devices and rehabilitation services, in particular for those with communication and sensory impairments.
- Hospitals must provide transport and preferential treatment to children with disabilities coming for regular check-ups.
- A roll-out strategy and policy must be developed to improve access to assistive devices, encourage local production and maintenance of those devices, and prevent unequal provisioning to disability groups.
- Community health educators and mobile immunisation clinics must be established and used.

Education

- Education sector plans and whole school improvement approaches must be geared towards transforming mainstream schools to be inclusive, rather than opening more special unit classes.
- All in-service and pre-service teachers must be trained in inclusive practices, and mentorship and support must be provided at school level to deal with specific disabilities.
- Resource centres must be developed with expertise on assessment, making the curriculum accessible and providing assistive devices to support learners, teachers and parents.
- Reasonable accommodation must be made in education for children who are sick, or whose disabilities need adapted material and assessments.
- Vocational centres must be developed with an inclusive approach, and different routes to earning qualifications must be explored for over-aged learners with disabilities and children with intellectual disabilities.

Family and child well-being and standard of living

- Emotional support, counselling and education on positive child-rearing practices and dealing with stress must be provided to families of children with disabilities.
- Career counselling and emotional support must be provided to adolescents with disabilities, to help them deal with uncertainty about their future, and build and maintain a positive self-image.

Physical accessibility

- The principles of universal access must be applied to all buildings and facilities, through the use of appropriate accessibility guidelines and standard design requirements for buildings.
- Families and communities must be educated on simple, inexpensive ways to adapt their homes, facilities and everyday items to accommodate those with disabilities.

Rights, education and disability awareness

- Knowledge on rights, negotiating the system and channels of recourse and reporting violations must be improved.
- A national communication strategy must be launched to educate duty bearers (including health practitioners, school principals, teachers etc.) and the greater public on their obligation to honour the rights of children with disabilities, and on the benefits and requirements of inclusive education.
- Awareness of the rights of persons with disabilities and their inclusive development must be raised among children, using child-friendly methods.
- Caregivers and the public must be informed about the psychological harm caused by teasing, physical punishment and name-calling.
- Caregivers and the public must be informed about the availability and services of different medical and rehabilitation practitioners.

1. Introduction and study background

Disability is prevalent among children in Africa, but is seldom recognised and often deliberately hidden. Children with disabilities and their families constantly face social, political and economic barriers that adversely affect their development and prevent them from being included in society and enjoying their basic human rights to the fullest. Consequently, the strengths and abilities of children with disabilities go unnoticed, their potential is underestimated, and their needs are given low priority in the allocation of resources (UNICEF, 2007). As a result, the vast majority of these children receive no education, are absent in school data sets, and are invisible as far as national policy agendas are concerned.

Unfortunately, the barriers faced by children with disabilities result more from factors within their environment than from their disability itself. Some are considered curses to their families, and most are discriminated against and stigmatised at home, in schools, in institutions, and in the community.

Facts about Children with disabilities in developing countries

- Estimated 90% do not attend school (UNESCO)
- Children with disabilities have a 1.7% greater risk of being victim to violence than non-disabled children and girls with disabilities are more vulnerable (UNICEF).
- Students with disabilities are under-represented in higher education (OECD)
- 30% of street children have a disability (UNICEF)
- For every child killed in warfare, 3 are injured and permanently disabled
- 5 – 20% of working children suffer injuries or illness that permanently affect or disable them e.g loss of limbs, hearing, sight and burns (ILO, 2006).

As a leading, independent pan-African policy and advocacy centre on child rights and well-being, the African Child Policy Forum (ACPF) recognises children with disabilities as among the most neglected groups in the policy domain as well as the private sphere. These children are absent, or referred to only marginally, in public policy documents, sectoral development plans (for health, education and social sectors), and poverty reduction programmes. National Plans of Action for Children in African countries sometimes make reference to children with disabilities, but suggest little action to meet their needs (Ransom, 2008:1). This oversight consigns many children with disabilities to a fate of extreme poverty.

ACPF believes that presenting evidence-based facts on the situation of children with disabilities will draw attention to children with disabilities and achieve greater national commitment to improving their situation. Sound data provides the foundation for establishing sound policies, strategic plans, and effective services and support: knowledge has the potential to shape appropriate action in response.

The lives of Children with Disabilities in Africa: A glimpse in to a hidden world, is a multiple country study conducted in Ethiopia, South Africa, Senegal and Uganda. Primary data collection was undertaken in Ethiopia, Uganda and Senegal, where 1,339 children with disabilities and 1,473 primary caregivers[1] were interviewed, using structured questionnaires to solicit quantitative data on their life situation. In South Africa, on the other hand, a desk review was conducted of the realities of children with

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[1]   Numbers of caregivers and child respondents did not always correspond, because in some cases the child lived on the street, or in an institution where there might be one caregiver for several children with disabilities. Also, in cases where the child could not complete the interview, only the parent's responses were used.

disabilities in the country. This review was carried out based on the understanding that several studies documenting the realities of children with disabilities have already been conducted in South Africa. Respondents, including children with physical, visual, hearing and intellectual disabilities and their caregivers, were asked questions on many aspects of their daily life and their living situation (both the factual and the perceived). The quantitative survey questionnaires touched on the life of the child in the context of his/her family, neighbourhood and accessibility to basic services that should be enjoyed, as a right, by any child anywhere in the world. In order to get a broader and more realistic perspective, respondents were identified from both rural and urban settings, and both conventional (household) and unconventional (institutional or street) environments. Purposive sampling was necessary as a consequence of the unavailability of registers of persons with disabilities, which meant that children were identified primarily through non-governmental organisations (NGOs) and local government offices – increasing the likelihood[2] of the respondents being drawn exclusively from populations with access to basic services. Strict adherence to the sampling frame was not always possible, since finding the children proved challenging. To illustrate these difficulties with adherence, children in non-conventional settings either shared a caregiver, or did not have one; and in some cases, due to communication or attention difficulties – and despite employing strategies to mitigate the situation – the child was unable to complete the questionnaire, so only the responses of the caregiver were used. The following table shows the child respondents in the study by country, area of residence and disability type:

Table 1: Child respondents by country, area of residence and disability type

Disability type	Ethiopia				Senegal				Uganda			
	Rural		Urban		Rural		Urban		Rural		Urban	
	Cases	%	Cases	%	Cases	%	Cases	%	Cases	%	Cases	%
Physical	62	29.7	76	26.4	51	39.5	69	34.5	89	24.7	38	24.8
Visual	50	23.9	68	23.6	37	28.7	64	32.0	84	23.3	40	26.1
Auditory/hearing	62	29.7	71	24.7	26	20.2	25	12.5	82	22.8	35	22.9
Intellectual	30	14.4	66	22.9	12	9.3	38	19.0	84	23.3	34	22.2
Multiple	5	2.4	7	2.4	2	1.6	2	1.0	21	5.8	6	3.9
Total	209	100	288	100	129	100	200	100	360	100	153	100

The quantitative data gathered from respondents was supplemented using qualitative information collected from interviews with other stakeholders (community leaders, healthcare workers and teachers), focus group discussions with young people with disabilities, and through a new qualitative method named A *Day in the Life*. Each child who participated in a *Day in the Life* approach was given a disposable camera with which to document an average day in his/her life, before an interviewer interviewed him/her about the photos that they had taken.

The research design, therefore, used both qualitative and quantitative data collection methods, so as to document as comprehensively as possible the situation faced by the research respondents. All respondents were fully informed of research objectives and outputs, and all quantitative and qualitative interviewers were thoroughly trained in appropriate, respectful and non-biased interview techniques. Primary data analysis was conducted using SPSS (Statistical Package for the Social Sciences), and thematic analysis was conducted for the qualitative data. Relevant secondary data was thoroughly reviewed and analysed in this study to contrast with the findings.

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2   National Survey evidence, however, suggests that the vast majority of children with disabilities are not in school; anecdotal evidence suggests many do not have access to community-based rehabilitation (CBR) (CSA 2008). Unfortunately, due to the necessary respondent identification process, the population without access to CBR services was under-sampled.

This report presents an analysis and summary of the four country reports, highlighting common themes. While the report is very comprehensive, for readability purposes and sharpening the messages, we have deliberately left some of the details in the country reports. Should the reader require additional detailed information, it is recommended that he or she should refer to individual country reports. Electronic versions of the reports are available at the African Child Information Hub (www.africanchild.info).

All the countries that participated in the study are signatories to the UNCRPD. As a result, they all have to monitor and report on progress made towards honouring the rights of children with disabilities as enshrined in the Convention. This report therefore uses the UNCRPD as a framework to present the study findings.

This report first gives an overview of the situation of children with disabilities in Africa, and existing barriers to realising their rights. Thereafter, the situations for children with disabilities in Ethiopia, Senegal, South Africa and Uganda respectively are reviewed in more detail by describing policy and legislation in those countries, and examining existing mechanisms to ensure service delivery for children with disabilities. The findings from the primary data collected are then discussed and compared with human development indicators, and with progress reportedly being made towards achieving the rights to an adequate standard of living; health, habilitation and rehabilitation; education; and social inclusion. The report concludes with a comprehensive list of recommendations for policymakers and practitioners in the field.

2. Children with disabilities in Africa

2.1. Poverty and disability

> *Poverty is not simply the consequence of a lack of resources. Some people are unable to access existing resources because of who they are, what they believe or where they live. Such discrimination is a form of exclusion and a cause of poverty.*
>
> *(Yeo, 2001)*

Poverty and disability go hand in hand as illustrated in Figure 1, poverty is both a cause and consequence of disability Because of social and economic marginalisation, children with disabilities are more likely to be poor than their non-disabled counterparts; and people living in poverty are more likely to become disabled than those who are not living in poverty (Eyben, Rosalind & Fergusen, 2000).

Figure 1: The cycle of poverty and disability
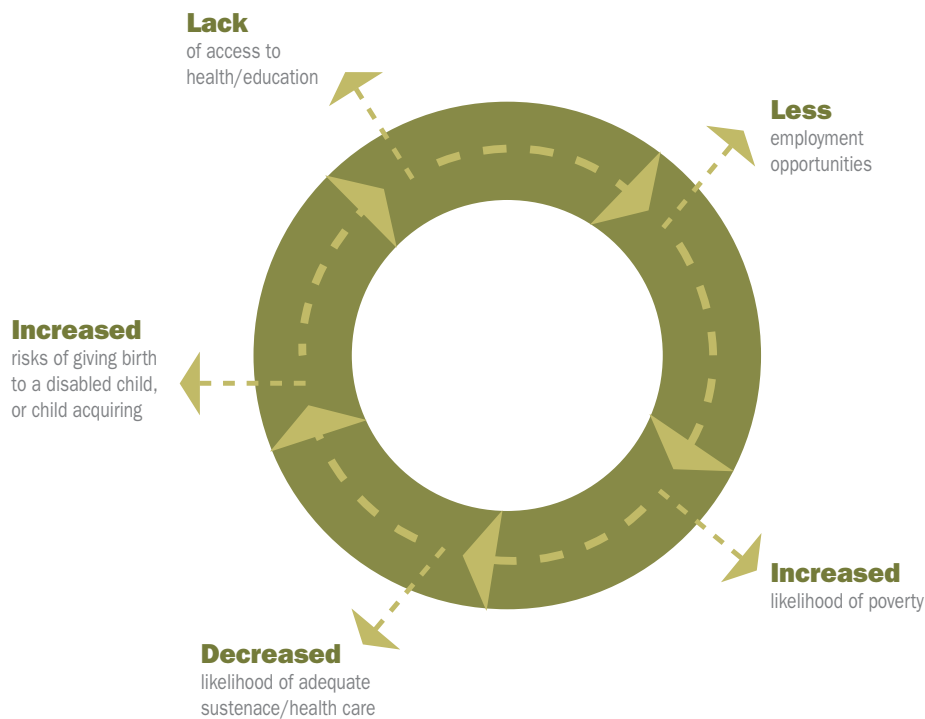
A study by NUDIPU (the National Union of Disabled Persons of Uganda, the umbrella organisation in Uganda for persons with disabilities) indicated that 72% of persons with disability in the Northern Region – Uganda's poorest – lived in a state of chronic poverty. Given the relationship between poverty and disability, the international community has begun to realise that achieving the Millennium Development Goal to cut poverty in half by 2015 is impossible, unless it addresses the needs of its poorest minority persons with disabilities. Fast Track initiatives and other programmes designed to alleviate poverty should therefore consider people's varying abilities and other diversities if they are to be effective in ending the cycle of poverty and promoting the universal enjoyment of human rights.

2.2. Changing views on disability

Persons with disabilities have long been seen as inferior, deficient and in need of special care and charity. The charity/welfare and medical perspectives on disability are reinforced by well-meaning individuals, health professionals and religious organisations. This perspective, mixed with deep-seated negative cultural beliefs associated with punishment, evil and witchcraft, alloted persons with disabilities and their families to second-class citizenship, marginalising them in their communities. Persons with disabilities were consequently denied their basic human rights and excluded from education, health and socio-economic life.

Activism against these negative views gave rise to the social model of disability. The social model acknowledges that barriers to participation in society and its institutions are in the environment rather than in the individual, and that such barriers can and must be prevented, reduced or eliminated. In addition to poverty, environmental barriers include inadequate or inaccessible policies and regulations, public buildings, transportation, and recreational facilities. They may also be attitudinal, including superstition, and underestimation of the abilities or potential of people with disabilities, resulting in under-expectation, under-achievement and low priority in the allocation of resources (UNICEF, 2007). Persons with disabilities are therefore 'disabled' by prejudice, stigma, discrimination and the failure of society to adapt to accommodate their needs.

The social model was strengthened by the 'human rights approach', which stresses the basic fact that persons with disabilities are inherently human, and should naturally be afforded the rights, services and opportunities afforded to every human being. The UN Convention on the Rights of Persons with Disabilities is firmly rooted in this approach, and requires governments to step up their actions to ensure the protection, participation and full enjoyment of rights by this previously marginalised group.

2.3. International and regional instruments protecting the rights of children with disabilities

Legislation is the first step in chiselling away the barriers faced by children with disabilities and their families. In this area, the efforts of many years of activism and lobbying by persons with disabilities, their families and civil society organisations have paid off to a certain extent. Some countries have reformed their legislation and policy to attend better to the needs of children with disabilities, and a number of international conventions and commitments include disability, the most pertinent of these being the United Nations Convention on the Rights of the Child (UNCRC) and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). All four countries in this study have ratified the UNCRC and UNCRPD, with South Africa and Uganda also adhering to the Optional Protocol (discussed in greater detail below).

Article 23 of the UNCRC acknowledges explicitly the right of children with disabilities to a full and decent life, including the right to full participation within their communities and the right to special care where needed. The obligation of states to honour these rights is, however, weakened by the Article, which makes this subject to the availability of resources. The UNCRC also endorses special or segregated service delivery, as opposed to inclusive development whereby services for children with disabilities form part of ordinary service provisioning. In contrast, the UNCRPD embraces the principle of inclusion, addressing all the facets of life of people with disabilities, both adults and children.

Article 7 of the UNCRPD focuses specifically on children with disabilities, stipulating that:

> *States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children. (UNCRPD, 2006).*

Article 7 also asserts that children with disabilities must be included in decisions made about them, and that their best interests should always be the first and foremost consideration in these decisions.

The steps to be taken by states in specific areas are spelt out in the various Articles, along with the required monitoring and reporting procedures needed to promote accountability. Signing of the optional protocol to the UNCRPD is an additional accountability measure that allows individuals whose rights have been violated to bring complaints to a Committee on the Rights of Persons with Disabilities, which then undertakes an enquiry and makes recommendations to the state. It is also the duty of civil society and international agencies to ensure that children with disabilities are deliberately and automatically attended to in the design and delivery of development programmes – i.e. in the objectives, targets, resource allocation and monitoring indicators. With this in mind, the ACPF *The lives of children with disabilities in Africa: Glimpses into a hidden world* study touches on several areas covered by the UNCRPD, in order to gauge the extent to which the rights of children with disabilities are being met from the perspective of children and their caregivers.

At a regional level, the two principal instruments protecting the rights of African children are the African Charter on the Rights and Welfare of the Child (ACRWC), which entered into force in 1999, and the plan of action to create an 'Africa Fit for Children', The African Common Position Declaration and Action Plan (2001). Both have the same limitations as the UNCRC, in that they fail to recognise the inherent rights that children with disabilities enjoy by virtue of the fact that they are children; and they are weak on obliging states to take action. Article 13 of the ACRWC, on 'handicapped children,' takes a special needs approach as opposed to a rights-based approach, speaking of 'special measures' to be taken 'subject to available resources'. This, along with the passing reference made in the Action Plan in the African Common Position on Children, lessens the responsibility of African governments to meet the rights of children with disabilities. In contrast, the Continental Plan of Action for the African Decade of Persons with Disabilities (1999 – 2009), which was extended for a second decade, is the only disability-specific legal instrument that demands that governments mainstream disability issues into policies and programmes across all sectors.

2.4. Challenges in gauging the prevalence of disability

A vital first step towards realising the rights of children with disabilities is gathering credible, accurate and up-to-date prevalence data on the age, gender and geographical spread of childhood disability in a country. Unfortunately, such prevalence data is hard to come by, largely because of the varying definitions used to define disability, and the methodologies used in gathering disability statistics for household surveys, population censuses, and population registration. A fear of stigmatisation and the promise of social benefits lead to under- and over-reporting respectively; and, furthermore, chronic illnesses and diseases are often undiagnosed and the resultant impairments unrecognised, particularly in areas where there is poor health and rehabilitation coverage. These difficulties are compounded by poor or absent routine data collection systems for the number of children with disabilities receiving services (e.g. the number of children with disabilities enrolled at special or mainstream schools across the country), and the difficulties of bringing statistical data together from various departments when the definitions used to classify this data are not consistent across sectors or geographical boundaries.

The lack of reliable, comparable prevalence rates for children with disabilities is a major challenge to the development of targeted and appropriate preventative and rehabilitative services, and has a strong negative impact on the rights of disabled children. In the absence of such data, we have asked children with disabilities and their caregivers to explain the extent and magnitude of the challenges they face in accessing essential services and achieving social integration. Knowing this information, and including strategies to overcome disparity and discrimination in poverty eradication and other development agendas, is crucial.

3. Overview of countries

3.1. Prevalence and socio-economic data

The countries participating in this study are diverse: they are at different stages of socio-economic development and at different levels in the attainment of human rights for children with disabilities, and they provide a wealth of perspectives to draw on and learn from. The table below shows their performance in key development areas, and provides information with which to contextualise the study findings. Statistics on disability are particularly unreliable, and caution should be observed when comparing data on disability across countries.

The table below shows prevalence statistics on disability as reported in census results. Data on prevalence among children is taken from the UN statistical database on disability, from the UN Statistics Division (UN DISTAT). Many of the figures are disputed, and there are discrepancies across census years for the same countries.

Table 2: Development indicators in four African countries

Development Indicators	Ethiopia	South Africa	Senegal	Uganda
Total population	80.7 mil	48.7 mil	12.2 mil	32 mil
Under 15 years (%)	43%	30%	43%	49%
Disability prevalence as per most recent census data	1.09%	5%	1.4%	7%
Estimated no. of persons with disabilities (UN DISTAT)	3.8%	0.5%	1.2%	1.3%
Estimated no. of children with disabilities (UN DISTAT)	1.8%	0.2 %	0.4%	0.7%
Infant mortality rate (per 1,000 live births)	55	50	56	65
School enrolment, primary (% net)	71.4	85.8	71.9	94.6
Combined gross enrolment ratio in education (%)	49	76.8	41.2	62.3
Population not using improved water source (%)	58	7	23	36
Population living below US $1.25 a day (%) 2000 – 2007	39	26.2	33.5	51.5
Population living below the national poverty line 2000-2006	44.2	50% (est)[3]	33.4	37.7
Human Development Index (HDI) ranking[4]	171	129[5]	166	157
Human Poverty Index (HPI-1) Rank (2007)	130	85	124	91

Source: http://unstats.un.org/unsd/demographic/sconcerns/disability/disab2.asp

All four countries in the study reported census data for disability prevalence well below the WHO estimate of 10% of the world population –further evidence of the unreliability of statistics on the prevalence of disability. In Ethiopia, the prevalence of disability is estimated to be 1.09%, but data excludes the homeless, persons with temporary disabilities, and those with sight or hearing impairments who are able to perform activities within 'normal range'. Furthermore, the ambiguous census question 'Is there member of household who is physically or mentally disabled?' could have resulted in under-reporting (Lewis, 2009).

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3   Retrieved from https://www.cia.gov/library/publications/the-world-factbook/fields/2046.html

4   The HDI is the UNDP's broad wellbeing indicator, taking into account monetary and non-monetary wellbeing, including healthcare, education and purchasing power of 182 countries.

5   South Africa's high HDI ranking and the fact that the country is the 24th biggest economy in the world mean that statistics provide an unfair reflection of the poverty and poor service delivery experienced by the black majority. Closing the gap between the rich and poor and promoting equity across the board is an ongoing challenge for the post-apartheid regime, and disability is often sidelined as a result.

Statistics on the prevalence of disability in Senegal are scanty. Census data from 1988 provided by UN DISTAT indicates that children aged 0-14 make up 27% of the total number of persons with disabilities. However, the total prevalence indicated in both the 1988 census and the country report is well below the WHO estimated population prevalence. The prevalence amongst children falls equally short of the United Nations estimate of one in ten children (Ransom, 2008), and of the UNICEF estimate of a 20 to 50% prevalence of disability among children aged 0-9 living in Africa.

Interestingly, Uganda's national prevalence for disability was adjusted upwards to 7%, because the disability fraternity disputed the lower figure provided by the National Demographic Survey in 2005/2006. Data from a 1991 census indicated that the prevalence was 1.2%; this represents a significant discrepancy between what is being observed by the NGOs in the field and what is being recorded and reported in census figures.

In South Africa there are similar discrepancies. Close to 30% of the total population of persons with disabilities are children aged 0-17 years (250,804), with the majority presenting physical disabilities (79,884), followed by impairments of hearing (62,958), vision (36,554) and speech (18,682). The most recent findings of Statistics South Africa (SSA), in 2005, stated that about 5% of children aged 0-19 have a reported disability, making a total of approximately 496,000 children. Further, the SSA study found that visual, physical and hearing impairments account for 80% of disabilities. Overall, there is a serious lack of age- and gender-specific prevalence data on childhood impairment and disability in South Africa, including risk and associated factors.

3.2. National legislation and policies

> *"Legislation alone cannot guarantee that human rights are realised; rather, it simply provides a framework of directives with which to begin a process of exploration and redress". (McClain-Nhlapo et al, 2006: 101)*

The UNCRPD has generated great optimism and renewed efforts to ensure that the rights of persons with disabilities are domesticated into national laws, and that effective strategies aimed at realising the rights of children with disabilities are properly planned for, implemented and monitored. The countries under study all boast examples of national policies, laws and strategies in education, health and social protection that promote the advancement and equalisation of opportunities for children with disabilities.

Uganda

The Ugandan Constitution and Local Government Act (1997) demands that persons with disabilities are represented in parliament and local government structures, through a quota system that allows them to be well represented. An electoral college comprised of the district structures of NUDIPU (the national disability organisation) elects five MPs representing persons with disabilities from Uganda's four regions (Central, East, West, North), and one woman representing women with disabilities. This has increased the visibility of disability as a development issue at the political level, and helped with the establishment of the National Council for Disability (NCD) in 2003. The Act also provides for the establishment of District, Municipal and Sub-County Councils all over the country. The primary function of the NCD is to communicate to the government and its implementing bodies the needs, problems, concerns, potentials and abilities of persons with disabilities.

The National Council for Children (NCC), established in 1996 by an Act of Parliament, performs a similar function, but in relation to children. Its main role is to advise and promote policy and programmes regarding the survival, development and protection of children in Uganda, and to ensure proper planning and coordination of all child-based programmes in the country. Even though the NCC

Act does not specifically mention children with disabilities, it must coordinate and provide direction to all persons involved in child-based activities in Uganda, in order to minimise duplication of effort and wastage of resources. This involves maximising multi-sectoral and integrated approaches to meeting The needs of children and solving the problems they face.

> **Key functions of the Uganda National Council for Disability**
>
> - Monitoring and evaluating the extent to which government, NGOs and the private sector include and meet the needs of persons with disabilities.
> - Acting as a coordinating body between government departments, other service providers and persons with disabilities.
> - Providing guidance to organisations working with persons with disabilities.
> - Conducting research.
> - Investigating and acting on rights violations and non-compliance with laws and policies by government and non-governmental organisations.

The National Policy on Disability 2006, recently passed by the Ugandan Parliament, provides a framework for empowerment and participation of persons with disabilities in the development process. This includes promoting and improving user-friendly, accessible services to children with disabilities and their caregivers by mobilising and using resources efficiently. It also includes building the capacity of service providers, persons with disabilities and caregivers for the effective prevention and management of disabilities.

South Africa

The South African government adopted the White Paper on an Integrated National Disability Strategy (INDS) in 1997. This is based on the social model of disability: the understanding that most barriers and difficulties for disabled people are caused not by their impairments, but rather by the barriers that exclude these people from society. The INDS identifies a number of sectors experiencing particularly high levels of exclusion. These include:

- Children with disabilities, particularly black disabled children.
- Those with severe intellectual or mental disabilities.
- Adults and children with disabilities living in remote rural areas.

The vision of the INDS is 'a society for all' which encompasses human diversity and the development of all human potential. It therefore prescribes the integration of disability issues in all government strategies, planning and programmes, through integrated and co-ordinated management systems. Central to this is the involvement of disabled people in the transformation process, and recognition of the need for capacity building and widespread public education.

Following ratification of the UNCRPD, the Office of the Status of Disabled Persons (OSDP) in South Africa published the National Disability Policy Framework and its accompanying Guidelines (OSDP, 2008). The OSDP's intention is to provide a local interpretation of the UNCRPD, and to outline practical steps towards creating an inclusive society. The Framework aims to ensure that all disability programmes

and objectives are mainstreamed into government line function planning, implementation and budget allocations, and to promote an inter-sectoral approach. The Policy Guidelines (OSDP, 2008:20) identify a number of cross-cutting issues according to which all stakeholders will be monitored. These are:

Access to communication & information. **Prevention.** **Public education and awareness.** **Reasonable accommodation.** **Universal access.**	**Monitoring and evaluation.** **Budgeting.** **HIV and AIDS.** **Mainstreaming.** **Safety and security.** **Human resource development.**

The Guidelines contain detailed policy objectives and targets for the period 2008-2019 for each of these cross-cutting issues, and specify the lead institutions responsible for implementation. At grassroots level, the Disability Policy Framework for Local Government 2009-2014 (RSA, 2009) provides the policy framework to address the needs of persons with disabilities within the local government sector. This framework seeks to provide an enabling environment for municipalities, provincial and local government departments, and other role-players in the local government sphere. It also proposes implementation structures and mechanisms for co-ordination of disability services, and for monitoring.

Senegal

In Senegal it has taken nearly a decade of lobbying to obtain laws on social care for persons with disabilities approved by parliament with the same conviction as in Uganda and South Africa. The process was set in motion by the Interdepartmental Board in 2001, but was only approved in May 2010.

Article 17 of the Constitution of Senegal stipulates that state and local public offices have a duty to ensure the health and welfare of the family, especially the disabled and the elderly.

The government of Senegal has initiated a number of programmes to facilitate the integration of persons with disabilities into the economic and social arena. These measures place particular emphasis on the inclusive dimension, and include the PEIS (project for special and integrated education). This national programme began in 2006 with RBC (réadaptation à base communautaire– community based rehabilitation),and has an annual budget of more than 350 million CFA.

Ethiopia

In Ethiopia, there are a number of legal and policy instruments that promote the principles of non-discrimination. The primary legal instrument is the Constitution of the Federal Democratic Republic of Ethiopia (1995). Article 41(5) of the Constitution states that the government *shall, within available means, allocate resources to provide rehabilitation and assistance to the physically and mentally disabled" (FDRE Constitution, 1995: 41(5)).*

This article is outdated and stems from charity model thinking; however, under Article 9(4) of the Constitution, all international agreements ratified by the Ethiopian government automatically become part of the law of the land; as a result, the state is obliged to ensure the rights of persons with disabilities as prescribed in the UNCRPD.

The sub-articles of the *Developmental Social Welfare Policy* (1997) talk about inclusion, participation (in political, economic and social activities) and independence of persons with disabilities, including children. It is stated in these sub-articles that efforts should be made to include these people in

education, employment and health. The strategies prescribed for this include creating an accessible physical environment, promoting positive attitudes towards disability, and assisting action groups and NGOs working on the issue.

Similarly, the National Programme of Action for Rehabilitation of Persons with Disabilities (1999) intends to put in place measures to prevent disability, empower those with disabilities, and promote equity and participation in society of persons with disabilities.

The National Plan for Accelerated and Sustained Development to End Poverty (PASDEP) guided the national poverty-reduction programmes for 2006-2010, and includes persons with disabilities and their families in its safety net programmes. The Ethiopian building proclamation (proc. No. 624/2009) makes it mandatory for public buildings to be physically accessible for persons with disabilities.

The Ministry of Labour and Social Affairs (MoLSA) is the main governmental organ at federal level, responsible for the provision of social and vocational rehabilitation of people with disabilities. Operating within MoLSA is the Department of Rehabilitation Affairs, which coordinates disability issues at the federal level. This department mainly deals with employment and social issues. Within each of Ethiopia's eleven regional states, there is a regional council, each with a Bureau for Labour and Social Affairs (BoLSA). BoLSAs handle all social matters, including disability-related issues, under the policy framework established by MoLSA. These structures are meant to plan, facilitate, implement and monitor programmes aimed at realising the rights of persons with disabilities.

Accountability measures

Despite all the legal provisions in force, the attainment of the rights of children with disabilities remains a major concern. All of the countries in this report have monitoring mechanisms in place, but the bodies responsible for these mechanisms lack the technical expertise and human resource capacity to fulfil their role. Moreover, the effectiveness of these mechanisms in helping realise the rights of children with disabilities in the deep rural villages of Ethiopia, Senegal, South Africa and Uganda is arguable. For example, if the school in a local village refuses to enrol a child who has cerebral palsy because they do not know how to "handle such children" or because their school is not "physically accessible"–seemingly plausible reasons – what options of recourse are available to parents? In fact, how can parents and children demand their rights if they are not aware of them, or if they do not know where to report violations?

Is Keeping quiet the only option?

The South African Human Rights Commission (SAHRC) has the mandate to receive complaints from citizens whose rights have been violated, and to take appropriate legal action on their behalf. However, McLain-Nhlapo (2006:102) note that the Commission has received surprisingly few complaints relating to the violation of rights on the basis of disability, and so the Commission's ability to hold government, organisations and individuals accountable and make recommendations to improve legislation and practice is restricted. Although it does not disaggregate figures for disability, the Annual Report of the SAHRC for the period April 2009-March 2010 indicates that there were 233 complaints of human rights violations relating to children during that time, and 244 relating to education.

Little has been done to date to challenge the violations of the rights of disabled children using available channels, such as Human Rights Commissions. The levels of efficiency, power, accessibility to complainants, impartiality and knowledge on disability of Human Rights Commissions (HRC) make them dubious protectors of human rights. In addition, HRCs are usually located in capital cities, and are therefore relatively unknown to most people. For these reasons, multiple means of reporting violations and progress towards achieving the rights of children with disabilities are necessary.

3.3. Barriers to honouring the rights of children with disabilities

Children with disabilities continue to experience discrimination at all levels of society. They are excluded from mainstream services that are relatively more resourced, less costly and within reach. These services are not accessible due to physical structures, communication barriers, negative attitudes and inexperienced service providers. (Department of Social Development, RSA, 2009:11)

Despite the progress made in terms of legislative and policy reform, the realities for children with disabilities have not changed much, even in relatively progressive and economically stronger countries like South Africa. And although the constitutions of most countries prohibit discrimination on the basis of disability, this does not mean that such discrimination does not happen.

Why are children with disabilities not assured of the rights articulated in their constitutions? Why are they not benefiting from the legislation and policies of the government departments that should give effect to these rights? Some theories are presented in Figure 2.

Figure 2: Reasons for the inadequate implementation of legislation concerning children with disabilities

Policies and legislation	• Lack of co-ordination of services between government departments (which tend to work in silos) and between government and NGOs (Nkeli & Associat, 2008; DSD, 2009) • Lack of budgeting for services for children with disabilities (Wildeman & Nomdo, 2007)
Design of monitoring and evaluation	• Poor alignment of programmes of action to policies • Few sanctions or punitive measures when disability issues are not handled in accordance with legislation or policy (SIDA, 2003) • Lack of standardised and harmonised tools to monitor the implementation of policies with proper benchmarks
Service delivery	• Inadequate data collection systems required for tracking access and real progress • No systems to identify children with disabilities at birth and track their progress through early childhood to school-going age and beyond
Society and community	• Negative attitudes towards disability, prejudice and misconceptions about disability issues (Nkeli & associates, 2008;26)
Children with disabilities	• Impairment debilitating due to lack of resources and support • Poor social integration and confidence • Low educational attainment

4. Realities of children living with disabilities

4.1 The right to adequate standard of living and social protection

4.1.1 The context

Poverty increases the prevalence of disability, because it limits access to information, adequate healthcare, proper nutrition, safe water, clean sanitation and hygiene. Families living in poverty are far more prone to disability-causing illnesses. Article 28 of UNCRPD, on adequate standards of living and social protection, demands that governments recognise and honour the right of children with disabilities to proper housing, food, clothing and better living conditions, by assisting with disability-related expenses and by providing social protection.

4.1.2 Housing, water and sanitation

Sanitation is an essential component of an adequate standard of living, but is particularly pertinent for children with disabilities, whether at home or at school. Clean toilet facilities are essential for children with physical disabilities such as cerebral palsy and spina bifida, due to their increased susceptibility to urinary tract infections. Unsafe sanitary facilities also facilitate the spread of waterborne diseases that may cause disabilities, malnutrition, stunting and malaria. Malaria – which is exacerbated by poor water management, hygiene and housing – can cause all forms of disability, and more than 90% of an estimated 300-500 million cases in Africa occur in children below 5 years of age (WHO, 2005).

> Bethel wakes up at 6:30 each morning. She makes her bed and gets ready for church. She has a physical disability, caused by contracting polio as a young child, and finds it hard to use the toilet, as it is so low to the ground. She doesn't complain about this to her caregivers, who are members of her extended family, as she doesn't think they can afford to build one that is accessible for her.
>
> **Day in the Life Study, Ethiopia**

The survey findings, although in line with national figures, are worrying in light of the risk of disease and injury that unhygienic and inaccessible toilet facilities pose to children with disabilities. Fewer than seven percent of households across the countries surveyed have access to flushing toilets. The situation is particularly dismal in Ethiopia, where 43.4% of households use unsafe sanitary facilities. Many use communal pit latrines, which in most cases are extremely unhygienic; or they have no access to toilet facilities at all, and use bushes to perform their ablutions. The situation in Senegal and Uganda is slightly better, with only 20.2% and 16.9% of people respectively using unhygienic and unsafe sanitary facilities.

Table 3: Access to sanitary facilities

| Type of toilet facility	Ethiopia		Senegal		Uganda	
	Cases	%	Cases	%	Cases	%
Flush toilet	33	7.0	27	6.0	25	4.7
Pit latrine (private)	232	49.6	315	72.6	411	77.8
Pit latrine (communal)	132	28.2	66	15.2	49	9.3
None	70	15.0	22	5.0	40	7.6
Other	1	0.2	5	1.2	3	0.6
Total	468	100	434	100	528	100

Clean drinking water is vital to everyone's health, but more so for children who have existing medical challenges and weak immune systems. Contracting diarrhoea can have serious effects, causing long absences from school. Gains made towards Millennium Development Goal (MDG) No. 7 (ensuring environmental sustainability) are noticeable, since the majority of households surveyed had access to clean drinking water; but, sadly, many families are still forced to use unsafe water. Approximately six per cent of Ethiopians, nine per cent of Senegalese and 22% of Ugandans surveyed used unsafe water from unprotected wells, springs, ponds, rivers, rain water and streams. Those living in rural areas were most reliant on these sources, increasing vulnerability to disability-causing diseases, such as trachoma, which can lead to blindness.

4.1.3 Physical accessibility

Physical accessibility of a home can help or hinder a child's participation in family and household activities, self-care, and development. Items for cooking and cleaning may be out of reach for a physically disabled child. A child using a wheelchair or a blind child may find it hard to move around the rough terrain of a compound, negotiate clutter, or enter through doors. Poor lighting may make it difficult for a sign language user or hearing-impaired child to see hand-signs or read lips.

In spite of the importance of physical accessibility, very few of the households surveyed made changes to their homes to improve access for their children, or even considered physical access to be an issue. About six per cent of caregivers in Uganda, ten per cent of caregivers in Senegal and 13% of caregivers in Ethiopia stated that their houses had been physically adapted to assist the child with a disability under their care. Homes in rural areas were particularly likely to neglect this issue. Small, inexpensive adaptations to many of the homes would have improved the day-to-day function of the child with a disability living there.

Figure 3: Adaptations made to homes/institutions
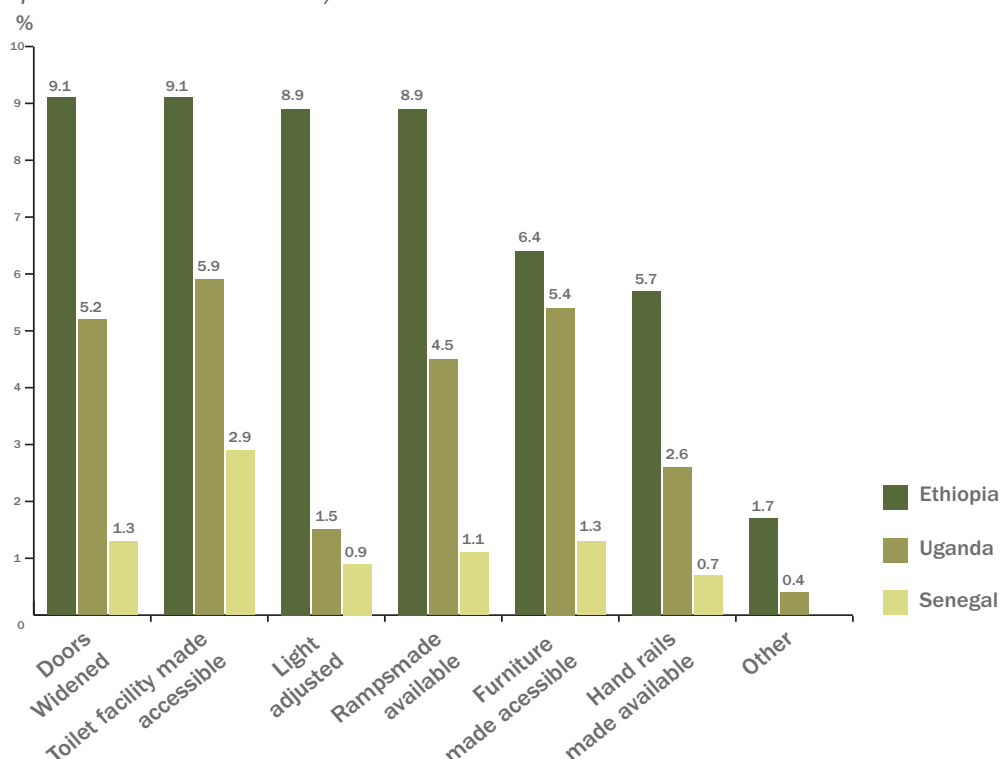
The majority of the adaptations made to homes or institutions were paid for by members of the households themselves, or by the institution in question, but a small number were paid for by other people outside of the family unit, such as members of the community and NGOs. Despite the fact that Article 9 of the UNCRPD obligates states to ensure physical accessibility of buildings, governments across the survey were insignificant contributors.

Despite awareness raising on the issue and legislation demanding that public buildings be made accessible, accessibility needs to be given more priority and attention in terms of allocation of government funds and encouragement of sponsorship from the wider community. Families also need to be educated on how to make their homes accessible, and on the benefits of accessibility for their child with a disability, so that the efforts made can be seen as an investment in the welfare of their child.

Table 4: Sponsorship of accommodations

Sponsors of accommodations	Ethiopia		Senegal		Uganda	
	Cases	%	Cases	%	Cases	%
Members of the household/institution	43	67.2	38	92.7	21	47.7
Members of the community	5	7.8	-	-	4	9.1
Community or NGO	3	4.7	-	-	10	22.7
Organisation	10	15.6	-	-	3	6.8
Government	2	3.1	1	2.4	5	11.4
Other	1	1.6	2	4.9	1	2.3
Total	64	100	41	100	44	100

4.1.4 Household income

The sources of income for the majority of households surveyed are the informal and agricultural sectors. These sources of income are generally inconsistent or seasonal, or both, leaving many families vulnerable to poverty and unable to meet their needs for food, shelter or clothing. It is therefore not surprising that high numbers of caregivers (77% in Ethiopia, 58.7% in Uganda and 88 % in Senegal) reported that caring for a child with a disability burdened them financially to a point where they were unable to meet their monthly household expenses. The most burdensome financial costs were medical care and rehabilitation, assistive devices, and transportation.

The majority of children lived with their families and were cared for by their biological mother or father. Overall, women are primarily responsible for caring for children with disabilities. Their commitment is strong in the face of much adversity.

The stigma of having a child with a disability, and the responsibility of caring for the child, also prevented caregivers from working, or hampered their earning potential. In Ethiopia, 26% of parents had to work reduced hours, and 20% could not work at all, because they had to care for their child. Similarly, at least one in ten caregivers in Senegal and Uganda had to work reduced hours or could not work at all because of the demands of caring. Families of children with intellectual disability are more disadvantaged: more caregivers of children with intellectual disability felt unable to work as a result of having to care for their children than did caregivers of children with other types of disabilities. Poor access to childcare and the refusal of schools to admit children with intellectual disability left their parents with no other option: for example, in Ethiopia, 44% of children with intellectual disability surveyed were not in school, and 27% of parents of children with intellectual disabilities reported that they could not work because they needed to stay home to care for their child. This finding supports an earlier study by Inclusion International (2009:59) that noted that parents of children with disabilities were less likely to be able to participate in the labour market because of poor access to childcare for their children. As a result, their vulnerability to poverty is increased.

Table 5: Effects of having a child with a disability on the household income/expenditure

Reasons for decreased income or increased expenditure of households with a disabled child	Ethiopia		Senegal		Uganda	
	Cases	%	Cases	%	Cases	%
Cost of assistive devices	140	32.2	216	50.7	161	37.9
Medical care or rehabilitation expenses	127	29.3	138	32.6	157	36.9
Members of the household work reduced hours to look after the child with a disability	111	25.5	75	17.2	59	13.8
Responsibility of caring for the child prevents members of the household from working	88	20.2	25	5.7	52	12
Transport costs	83	19	68	16.4	107	25.1
Stigma prevents the child with a disability from engaging in a part time job	55	12.6	17	3.9	59	13.9
Stigma against the household prevents other members of the household from working	45	10.3	21	4.8	44	10.5
Expenses associated with sport and recreational activities	34	7.9	102	25.5	37	8.7
Absence of paying helper/caregiver	26	6	48	11.4	54	12.5
School fees are higher because of the child's disability	23	5.3	60	14.9	57	13.6
Other reasons	20	8.3	5	3.2	9	5.1

The added cost associated with schooling a disabled child was a heavy load for many caregivers. For example, in Ethiopia, 43% of caregivers who felt burdened by higher school fees were the caregivers of children with hearing difficulties. This may be due to the additional expense of employing an interpreter, or of transport to school.

Unfortunately, the vast majority of caregivers receive little to no financial aid from outside the family to lighten their financial load. In Uganda as many as 97.4% received no financial support, because it is not customary in Uganda to expect financial support from outside the family. In Ethiopia, fewer than 10% of caregivers reported receiving financial support from the government, while in Senegal and Uganda, only 3.4% and 1.9% of families respectively reportedly received government aid. The lack of tangible support offered in Uganda is particularly disappointing in light of the country's extremely progressive legislation and vibrant NGO community.

> "Karamoja is characterized by poverty, violence, cattle rustling, lack of health services and educational services, and chronic food shortage, which means that the children in Karamoja are more prone to disabilities. But there are no NGOs in our area to help us and our children with disabilities."
>
> *FGD, Parents, Nakapriprit, Uganda*

The costliness of raising a child with a disability is recognised in Article 28 of the UNCRPD, which demands that governments honour the right of children with disabilities to proper housing, food, clothing and better living conditions, by assisting with disability-related expenses and by providing social protection.

Many children with disabilities are also compelled to work or beg for money, goods and favours in order to contribute to the welfare of the household. Between 17% and 23% of children surveyed in Ethiopia, Senegal and Uganda worked to support their families. All children worked in the informal sector in exploitative situations (dangerous, poorly paid and without appropriate support), especially those involved in begging, running errands or carrying out domestic chores for other households. Although the proportions of underaged working children that were revealed by the study (Ethiopia 3.7%, Senegal, 7.7% and Uganda 5.6%) were significantly lower than the country estimates, they nonetheless highlight negligence on the part of the countries' respective governments in protecting all vulnerable children from exploitation, as obligated by the UNCRC.

Table 6: Number and percentage of children with disabilities working by country and age group

Age group	Ethiopia (n=462)		Senegal (n=297)		Uganda (n=476)	
	Cases	%	Cases	%	Cases	%
9 – 13 years	17	3.7	23	7.7	17	5.6
14 – 17 years	63	13.6	45	15.2	46	9.7
Total	80	17.3	68	22.9	63	13.2

Social assistance to families of children with disabilities

In response to the financial strain on caregivers of children with disabilities, the Social Assistance Act of South Africa (RSA, 2004) provides social assistance in the form of the Care Dependency Grant (CDG), a non-contributory monthly cash transfer of approximately US $144 per month to caregivers of children with disabilities who receive permanent care. To qualify, the child is required to undergo a medical assessment and the parent must pass an income or means test.

The majority of the children working for a living enjoy their work, in spite of it taking them away from their schoolwork. Contributing to the family wellbeing helped them feel a sense of responsibility, independence and worth. Although only a few who worked were forced to do so by other people, circumstances of poverty compelled the majority of children to work in order to support their households (this was the case for 58.2% of respondents in Ethiopia, 86.1% in Senegal, and 65.9% in Uganda). Interestingly, Senegal, where the highest proportion of children were compelled to work out of poverty, also had the lowest percentage of children enrolled in school at the time of the survey – a statistic that reinforces the link between poverty and educational achievement.

Table 7: How working children feel about their work

	Ethiopia		Senegal		Uganda	
Reasons for working	**Cases**	**%**	**Cases**	**%**	**Cases**	**%**
The money I make is low	66	84.6	56	83.6	42	50.6
I have to work to survive	63	80.8	7	15.2	19	22.4
The money I make comes now and then	55	71.4	17	27.9	41	50.6
It helps me feel accepted	56	70.9	64	90.1	63	74.1
It helps me be independent	52	65.8	71	95.9	59	70.2
I would rather have more time for school than earn money in this way	47	60.3	40	62.5	42	50.6
It helps me learn skills I need for the future	47	59.5	46	67.6	62	72.9
It helps me support others in the household	46	58.2	62	86.1	56	65.9
I spend the money I earned the way I want	37	48.1	62	87.3	48	56.5
I would rather have more time with family and friends than earn money in this way	33	42.3	44	65.7	23	27.7
My working conditions are dangerous	24	30.8	21	30.9	25	29.1
I am forced to work by other people	10	12.7	2	2.8	8	9.4

In light of the above, and in the absence of social protection, efforts directed towards improving the socioeconomic welfare of the family must take a more sustainable approach in these countries. Families must be encouraged to partake in wealth creation schemes, such as microloans, and the capacity of children with disabilities must be strengthened so that they are sufficiently skilled to join the workforce or become entrepreneurs.

4.2 The right to health, habilitation and rehabilitation

4.2.1 The context

Article 25 on health and Article 26 on habilitation and rehabilitation reinforce the duty of states to provide quality health care services, information and skills, including early intervention and assistive devices, that promote the development and self-reliance of children with disabilities. Fulfilling this obligation requires the government to promote training programmes for rehabilitation personnel, and to provide appropriate assistive devices.

The absence of timely and effective health care and rehabilitation causes impairments and permanent disabilities. The economical and physical inaccessibility of health care facilities, and prejudices and lack of expertise on the part of health service providers, further exacerbate the problem. Children with disabilities are often unable to access badly-needed healthcare services with the potential to stop debilitating healthcare conditions from becoming more complicated.

The health policies of the countries in the survey acknowledge the unique needs of persons with disabilities, but meeting these needs against the backdrop of an overburdened healthcare system with often-inaccessible infrastructure and geographical location and a shortage of qualified staff, equipment and medication is extremely challenging. Many children with disabilities, and their families, face additional challenges with transport, since many public transport vehicles (e.g. minibus taxis) are reluctant to transport a commuter with a wheelchair, and often charge extra to do so. Long waiting periods resulting from staff shortages are difficult to bear, especially for a parent accompanying – for example – a restless child with autism.

4.2.2 Cause and onset of disability

The leading causes of disability in Africa are preventable diseases, war, accidents, and inadequate prenatal and neonatal health care services (UN, 2006). These causes can be linked to poverty, via malnutrition, inadequate preventable and curative health services, and diseases resulting from poor access to water and sanitation services.

> " Some children become disabled due to the negligence of parents. For instance, some parents don't take their children for immunisation against the known tropical diseases hence disability."
>
> *FGD with Parents, Katana Cell, Lomu Parish, Nakapriprit, Uganda*

Illness is reported to be the leading preventable cause of disability (37.9% in Ethiopia, 41% in Senegal and 49.7% in Uganda), followed by accidents, another preventable cause. In South Africa, incidences of disability caused by epidemics, natural disasters, pollution and trauma, most of which are preventable, are estimated to be up to 40% of total cases (DSD, 2009).

Disease is a function of poverty

- 85% of visual impairment and 75% of blindness (the vast majority occurring in developing countries) can be prevented or cured (WHO, 2009).

- 50% of all cases of hearing impairments are avoidable through prevention, early diagnosis and management of diseases such as meningitis, measles, mumps, chronic ear infections, malaria and tuberculosis.

- Fewer than 1 in 40 people in developing countries who need hearing aids have one (WHO, 2010).

- Asphyxia (lack of oxygen) during birth, often resulting from the absence of a skilled health professionals, leaves an estimated 1 million children with impairments such as cerebral palsy and learning difficulties (UNICEF 2008).

- Maternal iodine deficiency leads to 18 million babies being born with mental disabilities, and deficiency in vitamin A leaves about 350,000 children in developing countries blind (Micronutrient Initiative et al. 2009, cited in UNESCO 2010:181).

- Exposing pregnant mothers to hazardous pesticides, solvents and organic pollutants places their children at risk of a birth defect or disability.

- 9 out of 10 people with epilepsy in Africa do not get the medication and treatment they require, often resulting in increased stigma, intellectual disability, psychosocial problems and physical injury (WHO 2005).

- 1-3 per 1000 children in Africa are born with spina bifida, yet 70% of cases are preventable if folic acid supplements are taken by women before pregnancy and during the first trimester (Spina Bifida Association of America, 2009).

In Ethiopia, 60% of children with visual disability acquired it through illness. River blindness (onchocerciasis) is one of the leading illnesses causing blindness in Africa, affecting mainly rural villages with unsafe water sources[6]. It is a major health problem in 27 African countries, with approximately 100 million people at risk.

Disabling factors in Ethiopia, like other countries, are strong at the prenatal, perinatal and postnatal stages (Tirussew 2006). These include factors relating to the health of prospective mothers, the child delivery options available to them, childhood infectious diseases, poor nutrition, harmful traditional practices (HTPs), lack of proper child management, and the absence of sufficient preventative services or awareness. 55–68.4% of caregivers in the survey reported that their child acquired a disability before the age of five, and 73–90.6% of disabilities were caused by birth or childhood illness. Better care for pregnant women and infants would improve this situation. In rural areas, educating and collaborating with traditional midwives is essential.

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6 http://www.cbmuk.org.uk/pdf/River_Blindness_Factsheet.pdf

Table 8: Causes and onset of disability

Causes and onset of disability	Ethiopia		Senegal		Uganda	
	Cases	%	Cases	%	Cases	%
From birth	165	35.1	226	49.6	165	31.9
Illness	178	37.9	187	41.0	257	49.7
Accident	46	9.8	24	5.3	28	5.4
Violence	3	0.6	1	0.2	1	0.2
Hereditary	1	0.2	4	0.9	5	1.0
Unknown	67	14.3	12	2.6	50	9.7
Other	10	2.1	2	0.4	11	2.1
Total	470	100	456	100	517	100

Preventing childhood disease in South Africa and Uganda

The Department of Health in South Africa has introduced a 10-point plan to improve the quality of healthcare for mothers and babies, which includes a strong community outreach programme. It has also introduced the Expanded Programme of Immunisation (EPI) to prevent vaccine-preventable diseases, with new vaccines to prevent the most common forms of pneumonia and diarrhoea. Recently, the government announced a campaign to get 15 million people (one in three of the population) tested for HIV, and is currently rolling out one of the largest antiretroviral (ARV) programmes in the world.

Uganda has introduced the National Minimum Health Care Package (NMHCP), which prioritises services that are cost effective, targets diseases that are a high burden, and focuses on the poor and disadvantaged (women, children and persons with disabilities). The disability management policies (the District Rehabilitation Package) set out minimum levels for staffing services, equipment and supplies, and provide management and support to enable districts to develop their own strategic plans. The policies are intended to streamline, strengthen and extend medical rehabilitation services to all districts, in line with decentralisation of services. Unfortunately, as qualified health professionals are reluctant to settle in rural areas, many posts are unfilled.

More positively, efforts to increase awareness about the true causes of disability and to dispel related superstitious beliefs seem to have paid off, since fewer than 2% of respondents attributed the cause of disability to a curse from God, punishment for sin and evil spirits. It should, however, be seen as a matter of concern that a small but significant proportion of primary caregivers (14.3% in Ethiopia, 4.6% in Senegal and 9.7% in Uganda) were not aware of the cause of their child's disability. Depending on the nature of the disability, knowing the cause can help with treatment, and can also prevent disabilities from spreading among a family or community. This is particularly pertinent in the context of sexually transmitted diseases in mothers, such as syphilis and genital herpes, that cause children to be born with deformities, intellectual disability and neurological damage.

4.2.3 Free accessible healthcare

Over 73% of respondents across the surveyed countries had access to or used regular health care services in their community from time to time. Those who did not use regular health care services were unable to because they could not afford it (43% Ethiopia, 27.3% Senegal, 50% Uganda), or because reaching the clinic was problematic. Although the affordability of health care should not deter people from accessing health services (as they are free to the poorest), administrative requirements pose a great barrier.

> …there are services which can benefit children with disabilities, such as psychosocial support, education, nutritional services, surgery and many others. However, some of these services, such as surgery, are not accessible, and all are too expensive and not affordable [for] parents of children with disabilities.
>
> *Community Leader, Jinja, Uganda*

Street children with disabilities in Ethiopia participating in a focus group discussion (FGD) stressed that they knew their right to free primary healthcare, but were unable to provide the permanent residency identification needed by officials in order to register them so that they could enjoy that right, and had no other proof of their destitute status. They criticizsed the fact that no-one had facilitated this process for them, or given them information on how to access healthcare and education.

Free health care in South Africa

In South Africa, health care is free to pregnant mothers and children with disabilities, but the following problems are costing children with disabilities their right to health:

- A lack of accessible, convenient and affordable transport to and from health care facilities.

- A lack of appropriate training for staff in identifying a disability and making relevant referrals.

- Inaccessible facilities: only 24% of facilities are wheelchair-accessible, and only 28% have specific toilet facilities for disabled people.

Table 9: Reported availability of healthcare services in the community

Healthcare services	Ethiopia		Senegal		Uganda	
	Cases	%	Cases	%	Cases	%
Regular health services	391	83.4	334	73.4	462	85.7
Religious/faith healer	217	47.4	298	65.2	373	69.6
Traditional health care provider	112	24.8	296	67.1	288	53.9
Community-based rehabilitation	197	42.1	35	7.7	188	35.0
Specialised rehabilitation services	72	15.4	77	16.9	100	18.6
Physiotherapists	87	18.8	53	11.6	92	17.1
Occupational therapist (OT)	51	11.0	4	.9	57	10.6
Speech-therapists	75	16.2	6	1.3	27	5.0
Audiologists	36	7.8	5	1.1	46	8.5
Optometrist/ophthalmologist	75	16.3	115	25.4	93	17.3
Counsellors	143	31.0	94	20.7	133	24.7
Dieticians	42	9.2	35	7.8	45	8.3

Community Based Rehabilitation (CBR) was adopted by all the countries in the ACPF survey as a service delivery model for persons with disabilities. This model mitigates the problems of inaccessibility, and its integrated approach has facilitated the successful inclusion of many children in school who were previously excluded from the education system. Despite its benefits, access to CBR was extremely poor across the countries surveyed, with as low as 7.7% of respondents in Senegal having access.

The roll-out of CBR is, however, extremely challenging, as it requires the co-ordination of services provided by various government departments. For example, in South Africa, CBR provision has been fragmented, due to the lack of an effective system to co-ordinate medical, vocational, psychosocial and education components, which are the responsibilities of different government departments.

Worryingly, over 80% of children surveyed had no access to specialised rehabilitation services such as occupational therapy, physiotherapy, speech therapy, audiology etc. Many caregivers did not know about specialised rehabilitation services and their benefits, or whether they existed in the community. Poor knowledge and availability of specialist rehabilitation services and CBR make it virtually impossible for caregivers or children with disabilities to demand or receive early intervention, and denying these children the right to habilitation and rehabilitation deprives them of the opportunity to reach their full potential.

4.2.4 Service delivery issues

Public health facilities and staff are currently stretched to breaking point in many African countries, and curative and HIV services often take priority over rehabilitation (Singh, 2008). Bringing the issue of comprehensive health care services for children with disabilities to the attention of policy makers, and making it a priority on their agenda, is imperative in order to realise the rights of children with disabilities.

Sadly, in developing countries where the disability situation is critical, the estimated average physiotherapist-to-population ratio is 1:550,000 (Twible & Henley, 2000), while speech therapists, occupational therapists and audiologists' services are even scarcer. In 2008[7], only 67% of registered physiotherapists and 25% of registered occupational therapists in South Africa were working in the public sector –well below what is required. In this survey, the situation was shown to be equally

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7   www.hst.org.za/healthstats

dismal. Fewer than 2% of children in Senegal and Uganda could use occupational therapists, speech therapists or audiologists, yet over two-thirds of these children had communication problems. The ability to communicate is essential for interacting with peers, learning and claiming one's rights, but it is often neglected in rehabilitation service provisioning.

The Sponge Project: knowledge is power

The Sponge Project was set up in South Africa in response to the recognition that disabled people, and parents of children with disabilities (especially those living in rural parts of South Africa), often find it difficult to obtain information about the rehabilitation services available to them from government departments and NGOs in their area. The Project is a privately funded initiative that offers a free SMS information service to enable disabled people and their families to locate their nearest rehabilitation resource. Those needing information must SMS their name, town, disability and the service needed to a central number; they then receive a reply by SMS, with the contact details of local organizations. The Project holds a database that currently has over 3,000 contacts on it. An electronic newsletter is sent out to everyone on the database, in order to improve their awareness of disability issues and inform them of available resources.

A large number of caregivers still use traditional and faith healers. Educating faith and traditional healers about disability, early intervention and rehabilitation, and then enrolling them as rehabilitation workers and in referral centres, would be a useful collaboration towards realising access to quality healthcare for children with disabilities.

In Ethiopia, specialised health care services, and in particular rehabilitation, were predominantly offered by NGOs. For example, NGOs provided 87% of CBR services, 65% of specialised rehabilitation services, and 88% of occupational therapist services. The majority of users of government services in Ethiopia reported low benefits. In contrast, many of those using NGO-provided services reported big improvements, and expressed satisfaction with CBR programmes and speech and occupational therapies offered by NGOs.

Access to quality health is not only limited by poor coverage of health care services and the high cost of care, but also by the inadequacy and deterioration of health infrastructure, poor technical facilities and human resource problems (poor skills and staff shortages). The treatment approach doctors use, and their morale, also contribute to quality of care, which invariably affects how clients benefit. A key informant from Adama, Ethiopia, stated that in his personal experience, the condition of children with medical diagnoses often deteriorated, as they were either not taught, or not reminded of, best practice in caring for and minimising their own impairments. Similarly, a high number of child respondents were unaware of how they acquired their disability. This is discouraging, since knowing the cause of your disability is an important first step in developing acceptance and participating actively in rehabilitation and health care.

A more progressive treatment approach is needed, whereby children with disabilities are actively involved in their own treatment and rehabilitation. They can then take ownership of their health and wellbeing from an early age.

Service delivery in the health sector tends to focus on a medical model of disability, whereas it

should operate within a human rights model, with a more comprehensive and integrated approach. Such an approach would involve a greater appreciation for the child's context and potential. Enquiring about the child's family dynamics and focussing on their strengths and abilities would help health practitioners to design suitable intervention programmes. Compliance with these programmes will increase significantly when all involved, including the child, carers and teachers, are educated fully about the child's condition, and enrolled in designing and implementing the intervention programme. For example, children with epilepsy who understand their condition, what triggers a seizure, and the repercussions of repeated seizures, are more likely to take their medication regularly. Explaining the condition and treatment to the teacher and family will dispel fears and alert them of what to do when the child has a seizure. Also, when everyone is aware of when the drugs should be taken, they can remind the child to do so.

Figure 4: Bonny Kulaba took this picture of the health centre he attends ('Day in the Life', Uganda)

4.2.5 Early Childhood Development (ECD)

Early Childhood Development (ECD) is critical for children with disabilities, as it is a means of access to early identification and, where necessary, referral. It also provides opportunities for better social, physical and emotional development. This notwithstanding, an overwhelming majority of children surveyed did not attend a pre-school, crèche or play centre before the age of five.

> ECD and stimulation within an inclusive environment is the cornerstone for the development of an integrated and equitable society
>
> *(OSDP, 2008:36).*

Similarly, in South Africa, an analysis of the profile of CDG beneficiaries with disabilities found that only 24% of children aged 0-6 years attended a crèche or child minding group (De Koker, 2006). Regrettably, ECD services in Ethiopia, Senegal and Uganda are scanty, with an urban bias.

The neglect of Early Childhood Development (ECD) has serious repercussions in later years. Children with disabilities who receive early intervention in their formative years can minimise or prevent disabling effects of an impairment or condition. For example, doing simple physical exercises with children who have cerebral palsy as early as possible in the lives of those children can prevent their muscles from contracting further, and improve their movement.

Children with Down Syndrome who receive regular stimulation in their early years are more likely to advance in their later life, falling into the mild-moderate categories of intellectual disability, than those who do not.

Where early childhood development does occur, it often happens within informal community settings, with mothers of disabled children running stimulation programmes. Although this is better than nothing at all, it is felt that children with disabilities should instead be accommodated in mainstream ECD, and in centres that have access to specialised rehabilitation staff.

4.2.6 Assistive devices

Provision of assistive devices is part of rehabilitation, and key in enabling disabled people to participate equally in society. The majority of children surveyed have disabilities that curtail their functioning to the extent that they need someone else to help them, an assistive device, or both, in order to function. However, access to such devices is limited, with no more than five per cent of children surveyed in Uganda having access to assistive devices of any form. Shockingly, less than one per cent of hearing impaired children in Uganda had a hearing aid, and the majority of those with mobility problems who had access to crutches, wheelchairs, orthopaedic shoes and walkers were those living in urban areas.

> We pay for orthopaedic services but the equipment given is outdated and they do not provide proper rehabilitation therapy.
>
> *FGD with Parents in Dakar, Senegal*

Assistive devices for hearing and visually impaired go under the wheel

Regrettably, the provision of assistive devices has often been unequal, with children with mobility impairments taking priority. This is the case in Uganda, where the Ministry of health, along with some CSOs, have established orthopaedic workshops for manufacturing and maintaining assistive devices in regional referral hospitals. The workshops are unable to meet the need for mobility aids, due to a lack of personnel and raw materials, and other aids are rarely produced. The situation is similar in Senegal, where rehabilitation services and mobility aids for people with physical disabilities are provided, but little is offered for the visually and hearing impaired. In South Africa, the government issued directives in 2003 to mitigate unequal provisioning of assistive devices amongst different disability types.

Similarly, children with hearing or visual impairments living in rural areas rarely have hearing aids or corrective lenses, magnifiers or Braille. In Ethiopia, however, the majority of children interviewed had access to assistive devices, because they were identified through CBR programmes. Those using an assistive device or getting assistance from a person reported that they no longer had a problem, or that the assistance they received improved their functioning significantly.

Providing quality rehabilitation services – which includes the provision of suitable assistive devices, therapies and training to children and caregivers – is essential for optimising the functioning of children with disabilities. The challenge is that assistive devices are currently mainly imported, and prohibitively expensive. Consumables and maintenance services are also not readily available and affordable. Even in a country as affluent as South Africa, the promise to deliver on free health care, including rehabilitation and assistive devices for children with disabilities, is far from being achieved.

CBR: A government-DPO partnership

In South Africa, a strategy to roll out CBR nationally has yet to be developed. There have been several CBR projects in different parts of the country, one of which was based on a partnership between the provincial Department of Health in Mpumalanga and Disabled People South Africa. The focus was on the provision of support to DPOs, with identification and referral of children and adults with impairments to relevant services. There was also provision of information relating to disability, and disabled consultants were trained in peer counselling as well as in the facilitation of access to assistive devices in order to enhance social rehabilitation and integration.

4.3 The right to education

4.3.1. The context

Article 24 of the UNCRPD on education obliges states parties to ensure that educational systems are appropriate to children with disabilities, enabling those children to develop their potential and become equally involved in society. The Article stresses the importance of removing barriers that exclude children with disabilities from free compulsory education, and promotes inclusive education at all levels. It also states that children who are deaf, blind and deaf-blind must be educated in settings that maximise their social and academic development.

> If we are given an opportunity to go to school, we can become doctors, nurses, or even ministers. But we need books, pens and food to be able to go to school.
>
> *FGD with Parents in Dakar, Senegal*

The inclusion of disability in education policies and campaigns to achieve the MDGs, among other interventions, has contributed to the increased enrolment in school of children with disabilities. However, there is still a long way to go to achieve 'education for all,' and meet the obligations set out in Article 24 of the UNCRPD. Over 90% of children with disabilities in Africa are being denied the right to primary education (UNESCO, 2006). Children with

disabilities are also more likely to drop out of school and are less likely to achieve positive learning outcomes than their peers without disabilities. Poverty, negative attitudes, unskilled teachers, inaccessible infrastructure and location are the main barriers to honouring the education rights of children with disabilities.

The inadequate number of teachers being trained in inclusive education and special needs education (SNE), as well as the lack of appropriate resources to facilitate inclusive learning (Braille or audio materials, classroom assistants etc.), pose further barriers to meeting the obligation of inclusive education set out in the UNCRPD.

4.3.2. School attendance

Of the children surveyed, 73.8% in Ethiopia, 57.2% in Uganda, and a staggeringly low 32.1% in Senegal were in school. The most recent data from South Africa is promising in comparison, with an estimated 77.5% of children with disabilities aged 7-15 years attending school[8]. Apart from Ethiopia, the enrolment rates for children with disabilities in the study countries fall well below these countries' overall primary school enrolment rates. For example, Uganda has a primary school enrolment rate of 94.6%, but only 57.2% of children surveyed were in school. Similarly in Senegal, the primary school enrolment rate is 71.9%, but only 32.1% of surveyed children were in school[9].

Figure 5: Children with disabilities attending school
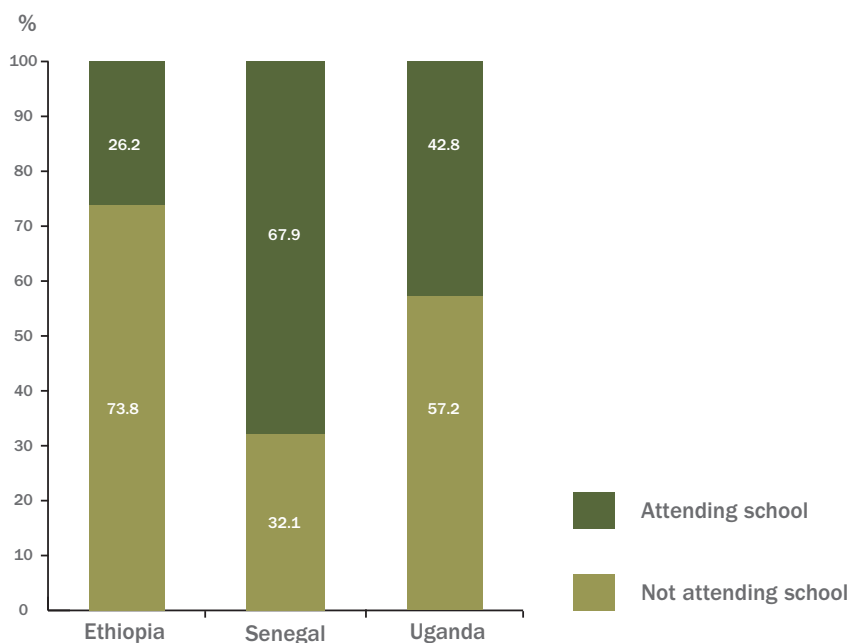
This high enrolment rate for children with disabilities in Ethiopia can, however, probably be attributed to the surveyed children being linked to CBR services.

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8   Data from the Community Survey conducted by Statistics South Africa in 2007, cited in Fleisch et al., 2008:43

9   Primary school enrollment rates were used rather than the combined gross enrollment rate because the vast majority of surveyed children receiving education were in primary school. The enrolment rates for primary school are: Ethiopia 71.4%; South Africa 85.8%; Senegal 71.9%; Uganda 94.6% (UNDP, 2007)

Figure 6: Bonny Kulaba took this picture to show how he sits in class (Day in the Life, Uganda)

Most children with disabilities surveyed in Senegal knew that education can lead to better life chances[10]. Sadly, only three in 10 children with disabilities went to school, and over 70% of out-of-school children with disabilities had never been inside a classroom, while the remaining 30% dropped out of school.

An estimated one in five children with disabilities in Ethiopia and South Africa, and about 2-3 in five children with disabilities in Uganda and Senegal, were excluded from education. Additionally, the numbers of children with disabilities who are out of school in the surveyed countries are likely to be understated in this report, since the majority of respondents were contacted through organisations offering support to persons with disabilities. These organisations have limited reach, however, particularly in rural areas where disability is more prevalent.

Rural contexts

In Uganda, over 70% of the children with disabilities who were out of school came from rural areas, where people often adhere strongly to traditional practices, and where stigma towards disability is rife. The case of Karamoja (Uganda), a rural town with a myriad of social problems, illustrates the challenges of providing education to children with disabilities: the population is seasonally on the move, and professionals are reluctant to work there due to the unavailability of basic infrastructure. This situation is further exacerbated because elders oppose formal education, seeing it as a colonialist threat to their cultural existence. In locations like Karamoja, involving the elders and gaining their support is essential to the success of any formal education initiative like inclusive education; otherwise, alternative ways of educating children with disabilities are required.

Specific disabilities

Children with cognitive and sensory disabilities face additional stigma and barriers to education. Children with multiple and intellectual disabilities seem most likely to be excluded from school. In Ethiopia and Uganda, 44–57% of children with either intellectual or multiple disabilities were not in school; those next most likely to be absent were children with hearing or visual impairments. In Senegal, an alarming 86.5% of children with intellectual disability and 95.5% of children with multiple disabilities were not in school, a rate followed by that of children with visual impairment (69.5%).

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10 67.4% of children surveyed believe that going to school promotes good skills and 65.9% believed it opens opportunities to work.

Across the countries surveyed, more children with physical disabilities were in school than were children from any other disability group. This is not surprising, for various reasons. For instance, the physical inaccessibility of school buildings can often be overcome with the help of peers, and teaching a child with a physical disability is usually perceived to be less demanding for teachers, requiring no changes to their traditional lecture-style approach. Teaching a child with any other impairment is usually more costly (or is perceived to be so): additional teaching resources – such as material in accessible formats (Braille, large print), interpreters and/or class assistants – are often required. Teachers also may feel they need to put in more time and effort in order to design appropriate lessons and learning material for children with other impairments, and this may feel impossible for them, in part because they are not trained for, or used to, the concept of adapting materials and approaches to suit the individual needs of all their learners.

Table 10: Children attending school by disability type and grade repetition

Country	Disability type	Repeated a grade		No repeated grade		Don't know		Total	
		Cases	%	Cases	%	Cases	%	Cases	%
Ethiopia	Physical	20	19.2	76	73.1	8	7.7	104	100
	Visual	14	16.0	73	82.0	2	2.0	89	100
	Hearing	30	28.0	77	71.0	1	1.0	108	100
	Intellectual	32	52.5	28	45.9	1	1.6	61	100
	Multiple	3	37.5	5	62.5	-	-	8	100

Country	Disability type	Repeated a grade		No repeated grade		Don't know		Total	
		Cases	%	Cases	%	Cases	%	Cases	%
Senegal	Physical	41	56.2	32	43.8	-	-	73	100
	Visual	17	39.5	26	60.5	-	-	43	100
	Hearing	13	48.0	14	52.0	-	-	27	100
	Intellectual	18	69.3	8	30.7	-	-	26	100
	Albinism		0.0	1	100	-	-	1	100
	Multiple	1	50.0	1	50.0	-	-	2	100
Uganda	Physical	61	64.0	34	36.0	-	-	95	100
	Visual	52	60.5	32	37,2	2	2.3	86	100
	Hearing	47	57.3	34	41.5	1	1.2	82	100
	Intellectual	43	72.9	11	18.6	5	8.5	59	100
	Multiple	6	50.0	6	50.0	-	-	12	100

Table 11: Type of school attended by residential area

Country	Type of school attended	Type of residence				Total	
		Rural		Urban			
		Cases	%	Cases	%	Cases	%
Ethiopia	Regular pre-school	4	2.9	8	3.9	12	3.5
	Regular primary school	94	69.1	137	66.8	231	67.7
	Regular secondary school	7	5.1	13	6.3	20	5.9
	Special school (any level)	21	15.4	27	13.2	48	14.1
	Special class (remedial)	9	6.6	18	8.8	27	7.9
	Other	1	0.7	2	1.0	3	0.9
Total		136	100	205	100	341	100
Senegal	Regular pre-school	3	3.8			3	2.0
	Regular primary school	50	64.1	47	65.3	97	64.7
	Regular secondary school	16	20.5	11	15.3	27	18.0
	Special school (any level)	3	3.8	8	11.1	11	7.3
	Special class (remedial)			2	2.8	2	1.3
	Vocational training centre	1	1.3	1	1.4	2	1.3
	Other	5	6.4	3	4.2	8	5.3
Total		78	100	72	100	150	100
Uganda	Regular pre-school	9	4.1	8	8.6	17	5.5
	Regular primary school	163	74.8	69	74.2	232	74.6
	Regular secondary school	22	10.1	4	4.3	26	8.4
	Special school (any level)	20	9.2	7	7.5	27	8.7
	Special class (remedial)	1	0.5	2	2.2	3	1.0
	Vocational training centre	3	1.4	3	3.2	6	1.9
Total		218	100	93	100	311	100

Role of parents

Approximately 10% of parents of children with disabilities who never attended school did not want their child to go to school. A teacher in Adama, Ethiopia, reportedly approached the families of children with disabilities to ask why their children were not in school. She was told that the parents feared social stigma, and that some even believed their children with disabilities were "useless" or "hopeless" (key informant, Adama). Another key informant from Addis Ababa, a teacher in an inclusive school, stressed his personal experience of children with disabilities wanting to attend school, but being forbidden to do so by their families, who feared insults or abuse directed at themselves or at their children. This demonstrates that parents need to be encouraged to accept their child's disability, and to take responsibility to ensure that their children reach their full potential.

Understanding that, with the right support, all children can learn, regardless of disability, and that their rates of learning might differ, is an important first step towards empowering parents to demand their children's rights. Parents need to be informed about the benefits and requirements of inclusive education, so that they can better advocate for the education system and schools to accommodate children who are 'different'. The importance of involving parents is illustrated by the example of advocacy campaigns on inclusive education in South Africa, which were criticized for not specifically targeting parents of children with disabilities in the initial stages (Wildman & Nomdo, 2007). As a result, many South African parents and families of children with disabilities are still not aware of their rights in relation to access to education and education support.

> ### Progress towards inclusive education in South Africa
>
> Advocacy programmes were carried out in South Africa in designated pilot schools and districts, and a large-scale media campaign was launched, with 13 episodes on inclusive education broadcast on prime-time TV, reaching, on average, 1 million viewers per episode. A countrywide seminar series was arranged to inform people about the UNCRPD, and a DVD on best practice in inclusive schools was produced. A website (www.thutong.doe.gov.za/inclusiveeducation) also serves as a learning space where relevant policies, guidelines, research, training material and best practices are shared (Department of Education, 2008, 2009).

Health issues

A significant number of children with disabilities involved in the survey never attended school, or dropped out of school for health reasons. The highest numbers in this category were in countries with significantly inferior health systems. More than a third of children reported that they missed two or more weeks of school due to illness. It is not uncommon for children with disabilities to fall ill and be absent from school for long periods of time: some may be particularly vulnerable to infections, while others may have to undergo surgery to improve their function. Schools need to be flexible, understanding and helpful, by allowing learners who are recovering from illness to learn from home, and/or to return to school on a flexible or part-time basis. Schools could, for instance, ask a classmate to take schoolwork to the child at home, offer catch-up classes, or extend the time allowed for disabled children to complete the grade.

Non-attendance and school drop-out

In Uganda, a country applauded for its efforts to provide free primary and secondary school education, children with disabilities appear to have been neglected. The majority of children who reported having dropped out did so because their families could not afford school fees (22.9%). Unfortunately, but

perhaps not surprisingly, this affected more girls than boys. In Uganda, affirmative action to ensure the ability of persons with disabilities to access education from primary up to tertiary level has had some benefits and positive impact in terms of enrolment (for instance, more students are being enrolled in public universities), but clearly family poverty is still preventing children with disabilities from capitalising on this affirmative action.

About 3 in 5 surveyed children in preschool or primary school were over-aged, either because they had repeated grades or because they started school later than the prescribed age. The majority of children in this category were those with intellectual disabilities. This finding indicates the increased efforts needed to ensure that children with disabilities, especially those with intellectual and multiple disabilities, have better access to appropriate opportunities to learn and to acquire skills. Many respondents shared the view that centres focusing on vocational training with an inclusive approach would constitute one way to achieve this.

A significant number of children with disabilities in Ethiopia reportedly dropped out because the school would not allow them to progress further, because of their disability. Many schools – both inclusive schools and special schools – in Ethiopia do not allow children to continue their education beyond Grade 5. This ultimately deprives them of the chance to acquire a trade/skill to support their livelihood, as vocational training courses require at least a Grade 10 qualification. In the survey, no children with disabilities were receiving training in vocational centres in Ethiopia and Senegal, while only six were enrolled in Uganda.

The majority of children surveyed who worked to earn a living enjoyed it, and felt that the skills they learnt would benefit them in the future. This supports the importance of offering learning programmes where the link between school and work is more obvious, such as those offered in vocational centres. It is also a more viable option for children who are less academically inclined, and who need to earn an income while they learn. These children could possibly work towards attaining a qualification in a trade (motor mechanics, hairdressing or catering etc.) by learning theory, and doing practical work in a regulated environment.

School accessibility

In Ethiopia, physical inaccessibility in schools accounted for the majority of children who never attended or who dropped out of school (who, in turn, made up 33% of all children surveyed). Conversely, the majority of schools attended by children with disabilities had accessible toilets (60% in Ethiopia, 84% in Senegal and 78% in Uganda), suggesting that increased physical accessibility of schools in turn improves access to education for children with disabilities. A key informant from Addis Ababa (a teacher in an inclusive school) criticized the new government schools currently being built in the city for having five stairs at the entrance and no ramp, contravening the building standards set out in the Ethiopian SNE strategy and UNCRPD.

Of the children with disabilities currently enrolled in school, 26% in Ethiopia, 52.3% in Senegal and 62.6% in Uganda had had to repeat at least one grade. The high level of grade repetition and the number of children with disabilities not attending school for reasons other than poor physical access indicate that even schools that attempt to improve physical accessibility are very often not ensuring that the wider learning environment is welcoming and accessible for children with disabilities. Physical accessibility alone does not ensure that children with disabilities have equal opportunities regarding their learning outcomes; the culture created within the school also plays a huge part in this.

Vocational training and rehabilitation centres in Uganda

The Ugandan government established vocational rehabilitation centres and sheltered workshops for persons with disabilities in the late 1960s and early 1970s in order to provide vocational rehabilitation and resettlement services. Unfortunately, most of these have ceased to provide meaningful services, and only five are still operational. The skills offered at the training institutions include carpentry and joinery, leather craft, tailoring, handcraft and nursery teaching. In a bid to promote entry into the open labour market, the Ministry of Gender, Labour and Social Development in Uganda, through the employment services, also gives guidance on employment opportunities for people with disabilities who are trained in the Vocational Rehabilitation Centres. Vocational rehabilitation measures are generally offered to persons with physical, hearing and visual disabilities. Children with intellectual disabilities, however, seem be poorly catered for within this framework.

This failure of schools to be fully inclusive and accessible in every way has denied many children with disabilities their right to education. Approximately 45% of children and caregivers surveyed said school inaccessibility – in terms of infrastructure, location, negative attitudes towards children with disabilities, and unsupportive learning and teaching practices – prevented children with disabilities from attending school. In Senegal, which had the survey's lowest school enrolment rate for children with disabilities, 28.1% of schools reportedly refused to admit a child with a disability. This highlights the importance of supporting school principals to understand that educating a child with a disability is their obligation. It also reminds us that such an obligation can only be met through transforming schools into more resourceful and supportive places, and through enhancing the skills of teachers.

Raising teacher capacity

Many people consulted during the survey felt that teachers were not adequately trained to meet the needs of children with disabilities. A teacher from Bahir Dartown (Ethiopia), working at an inclusive school, felt that the demand for SNE training was far greater than the supply, and said that many children with disabilities in the locality attended schools in which no teachers had received SNE training. Consequently, teachers were not capable of providing appropriate and effective learning opportunities for all their students. Teachers in Ethiopia revealed that, despite having had SNE training, they felt badly equipped to teach children with intellectual disabilities[11] .Other teachers were unaware of the presence of hearing impaired children in their classes, or, if they were aware, were not knowledgeable about how to assist them. The crisis of inadequately trained teachers is further evidenced by the high number of children who reported dropping out of school because their teachers felt incapable of teaching them. In Senegal, as many as 19.5% of children with disabilities who dropped out stated this reason, a clear reminder that inclusive education philosophies and practices must be integrated into pre-service and in-service teacher education if we are to overcome these exclusion problems. Such training of teachers, coupled with ongoing mentoring and support, will ensure that teachers have the skills and confidence to alleviate barriers to learning and to adapt the classroom environment, material and lessons so that they successfully include children with disabilities.

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11 Obtained from a focus group discussion with teachers.

Table 12: Reasons for never attending school

Reasons for never attending school	Ethiopia		Senegal		Uganda	
	Cases	%	Cases	%	Cases	%
The people with whom the child lives do not want the child to attend school	5	9.4	13	13.5	20	23.3
The child is not interested in school	6	11.3	3	3.1	11	12.8
The household could not afford the fees to send the child to school	3	5.7	7	7.3	7	8.1
No school nearby	6	11.3	6	6.3	5	5.8
The nearby school was not accessible	9	17	2	2.1	6	7
No transport available	4	7.5	2	2.1	3	3.5
The school would not let the child go because of her/his disability	1	1.9	25	26	10	11.6
The child was ill/sick	3	5.7	19	19.8	9	10.5
The child thinks he/she could not learn	3	5.7	5	5.2	6	7
The child has to work to support themselves/ the family	–	–	1	1	–	–
The teachers felt they are unable to teach the child	–	–	5	5.2	5	5.8
Other (specify)	13	24.5	8	8.3	4	4.7
Total	53	100	96	100	86	100

Table 13: Reasons for dropping out of school

Reasons for dropping out	Ethiopia		Senegal		Uganda	
	Cases		Cases	%	Cases	%
The people with whom the child lives do not want the child to attend school	2	4.3	4	8.5	8	10.3
The child was not interested in school	3	6.5	6	12.8	8	10.3
The household could not afford the school fees	3	6.5	2	4.3	11	14.1
There was no school nearby	3	6.5	1	2.1	4	5.1
The nearby school was not accessible	7	15.2	1	2.1	2	2.6
The school would not let the child continue because of his/her disability	5	10.9	4	8.5	7	9
The teachers felt that they were unable to teach the child	2	4.3	6	12.8	10	12.8
The child was ill/sick	5	10.9	16	34	17	21.8
The child thinks they could not learn	5	10.9	3	6.4	1	1.3
The child got discouraged because they felt weak in their lessons	1	2.2	1	2.1	–	–
The child got discouraged by the attitudes of others to them	1	2.2	–	–	3	3.8
The child failed and quit	3	6.5	–	–	3	3.8
The child has to work to support themselves/ the family	–	–	1	2.1	1	1.3

Reasons for dropping out	Ethiopia		Senegal		Uganda	
	Cases		Cases	%	Cases	%
The child was head of the household	_	_	1	2.1	_	_
There was no transport available	_	_	_	_	2	2.6
The child does not think being in school will help in the future	_	_	_	_	1	1.3
Other (specify)	6	13	3	6.4	_	_
Total	**46**	**100**	**47**	**100**	**78**	**100**

Teacher training challenges

Despite the fact that over 5,000 teachers in South Africa have been trained in inclusive education and in how to adapt their teaching techniques and material to accommodate learners with disabilities, problems persist in schools. According to research conducted by Sisonke Consortium, the training focused on raising awareness (as opposed to specific skills) and has not been sustained and supported at district level (Department of Education, 2008). The following examples of deficiencies were noted by the Department of Education (2009):

- In some schools for the deaf, teachers cannot use sign language.

- A large number of teachers in special schools have been trained to teach mainstream learners and do not have the skills to differentiate students' differing needs and adapt the regular curriculum for children experiencing barriers to learning.

- In many instances, district officials are reluctant to support teachers in special schools, as they fear that the knowledge of those teachers is greater than their own.

- Many special school staff have not been trained in the National Curriculum used in regular schools, and have expressed the need for more support from district officials. These teachers need mastery of the mainstream curriculum before being trained on differentiation and adaptation for learners with various disabilities (Dept of Education, 2008).

Inclusion as the way forward

The majority of surveyed children in school (67.7% – 74.6%), regardless of the nature of their disability or location, were being educated in mainstream schools. This clearly suggests that spending resources on making mainstream schools more inclusive is a worthy investment for increasing the educational opportunities of children with disabilities and their non-disabled peers. It also indicates that an inclusive approach is more feasible than approaches laid out in the SNE strategy of Ethiopia and many other African countries, which revolve around opening special unit classes in mainstream schools in which children with a range of disabilities are lumped together.

Inclusive education = quality education to end exclusion

The Salamanca Statement and Framework for Action (1994), endorsed by 92 countries and 25 international organisations, acknowledges diversity and proclaims that every child has unique characteristics, interests, abilities and learning needs. It also asserts in Article 2 that educational systems that acknowledge and respond to diversity

> …are the most effective means of combating discriminatory attitudes, creating welcoming communities, building an inclusive society and achieving education for all; moreover, they provide an effective education for the majority of children and improve the efficiency and ultimately the cost effectiveness of the entire education system.

This perspective was more recently reinforced at the 48th UNESCO International Conference on Education (ICE) in Geneva – entitled *Inclusive education: the way of the future* – which called on member states to:

> …adopt an inclusive education approach in the design, implementation, monitoring and assessment of education policies, as a way to further accelerate the attainment of Education for All (EFA) goals as well as to contribute to building more inclusive societies. (UNESCO, 2008)

4.3.3. Education support and reasonable accommodations

Children who receive the educational support they need are more likely to have positive outcomes to their education and to have an enjoyable school life. The vast majority of children with disabilities in the survey reported that they needed help with their schoolwork. Of those who needed help with their homework, the majority (37% in Uganda and 29% in Ethiopia) were helped by a parent, while 33% of children with disabilities in Senegal were helped by a sibling or other child in the household. Parents in Senegal, where the enrolment rate for children with disabilities is lowest, were least active in helping their child with schoolwork. Only 15.8% of Senegalese children with disabilities reported that their parents helped them with schoolwork, while over 60% were helped by a sibling. Enrolling parents, siblings and other children in supporting the learning of children experiencing barriers to learning is vital for their success.

In relation to the support received in the classroom, a reassuring majority of children in the study who were linked to CBR services felt that their school had adapted both its learning and play environments in various ways to facilitate their needs. In Ethiopia and Uganda, about 70% felt that their teachers had adapted their teaching style to ensure that it was easy for them to learn and understand. Approximately half the surveyed children in Senegal were dissatisfied with the way their teacher taught. Poor quality teaching places many children at risk of dropping out or underachieving.
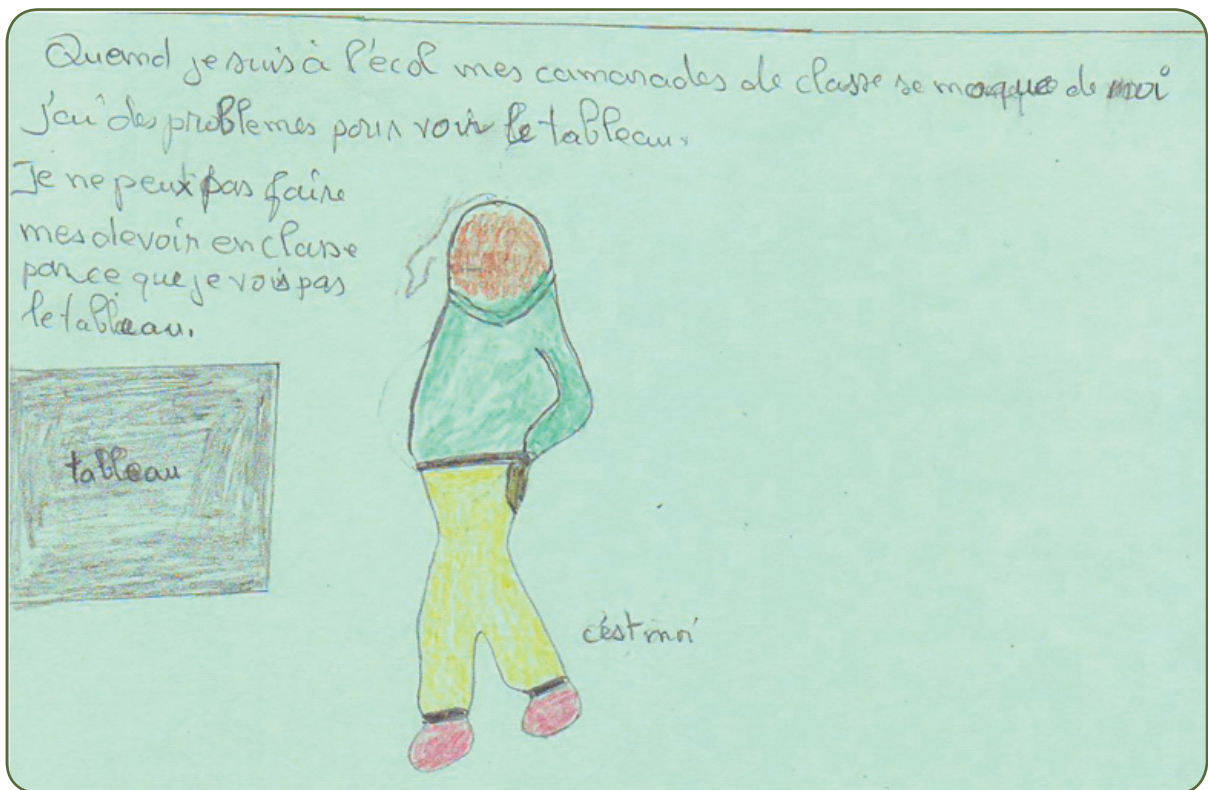
The words say: "I cannot do my class work because I cannot see the board".

In the surveyed countries, as many as two-thirds of children reported that they get extra time to complete class work and exams; however, no further questions were asked in relation to this issue to determine whether those who did not receive extra time had actively been denied it, or had not actually required it.

Bringing support into the classroom and using children as a resource to support each other is increasingly common. About two-thirds of surveyed children received assistance either from another child or from a classroom assistant. It is hard to tell if the assistance children receive from peers is orchestrated, or if it is just a natural consequence of them not receiving adequate support from their teacher.

> What makes it easy to learn in the classroom is the solidarity that exists between students.
>
> *A school going child from Dakar, Senegal*

The probability that children with disabilities will require some form of adaptation to teaching and learning materials is high, but such inclusive teaching practices are underused. Such adapted materials could include enlarging a worksheet or placing tactile markers on a ruler to help a child with visual impairment to understand measurement. Teachers reportedly failed to adapt learning and teaching materials for 69.6% of children in Senegal and 48% of children in Uganda.

Physical changes in a classroom can help to include more learners. For example, seating a child with poor eyesight closer to the writing-board is a simple yet effective strategy that can often make a big difference to the child's learning progress. Among those surveyed, 70% of children in Senegal, 55% in Uganda and 60% in Ethiopia reported that the classroom had been physically changed to enable them to learn better. The adaptations they reported included seating them at the front of the class, providing additional space and changing the lighting.

It was also reported that teachers neglected to use audio and visual aids such as flow charts and sound recorders: only 11-18% of child respondents reported that their teachers used such media. Despite these shortcomings, over two-thirds of children surveyed felt supported by their teachers.

Access to appropriate assistive devices is particularly problematic. In Uganda, for example, only 12% of the children requiring assistive devices to aid their communication (e.g. communication boards and voice output devices) received these devices; only 10.7% requiring Braille, audio-recording or enlarged print received it; and only 31% of hearing impaired children requiring sign language had access to it in the classroom. In Ethiopia, the proportion of children with access to assistive devices was significantly higher, but these results must be seen within context: the majority of respondents were enrolled in CBR programmes.

Why are so few children with disabilities in school?

"Several factors explain the fact that some children with disabilities are not in school. We can cite, among others, parents' ignorance of the existence of specialized structures such as rehabilitation centres and special schools; and the social pressures that lead some parents to lock their children in homes to escape the gaze of the community… but also [we can cite] poverty and the absence of civil documents due to the fact that some parents do not report their disabled children at birth".

Rehabilitation Centre Manager

4.4 The right to social inclusion

4.4.1 The context

Children with disabilities and their families face a range of barriers that prevent them from fully participation in their communities. The UNCRPD intends to eliminate these barriers, and promote social inclusc for persons with disabilities. Every article in the UNCRPD touches on this, but the most pertinent is Article 5, on equity and non-discrimination. This Article prohibits all forms of discrimination within the home, school, community and political domain. It covers practices that are not openly unfair, but would disadvantage the child with a disability; and it insists that changes that are not excessive and overburdening, insisting instead that reasonable accommodations be made to enable the child to take part in society on an equal footing.

An important step to achieving social inclusion is assessing how we view children with disabilities, and focussing on the most obvious factors. Children with disabilities are first and foremost *children*. They laugh, misbehave, play and take risks, like all children. Sadly, the overemphasis on their 'special needs', 'impairments', and 'vulnerability' is possibly the greatest barrier to their social inclusion.

Adults tend to overemphasise this difference, while children are more inclined to focus on similarities – a valuable lesson to be learned. The stories of the children with disabilities reveal how 'ordinary' their lives are: many partake in the same day-to-day activities as their non-disabled peers. This can be an indication that negative attitudes towards disability are reducing among the younger generations, while the remnants of old stigmas and prejudices remain a barrier.

4.4.2 Social identity and birth registration

The child shall be registered immediately after birth and therefore it is entitled to a name, the right to acquire a nationality and, as far as possible, the right to know his parents and be cared for by them.

UNCRC, Article 7

Societal attitudes are arguably the greatest barrier to social inclusion and access to services. The negative attitudes and discrimination that people with disabilities face are almost always a function of how a given society conceives the cause of disability (Ransom, 2009).Disability is sometimes believed to be caused by evil, witchcraft, demonic intervention, or a curse from God as the result of sinful behaviour. Such mediaeval, tragically negative perspectives of people with disabilities are supported by the media and biblical and cultural stories and beliefs, reinforcing damaging stereotypes (Rieser, 2008).Mothers of disabled children are often accused of wrong doing, even, in many instances, leading to their abandonment by their husbands, or to their being shunned by families and communities. Such negative attitudes result in children with disabilities being hidden from public view and excluded from health, education and other services (Richler, 2008). The hidden nature of disability is perhaps seen in the huge number of children with disabilities who are not registered at birth. Shockingly, only 28.5% of children with disabilities in Ethiopia, and 48.7% in Uganda, are registered. These figures may in actuality be even lower, since many caregivers surveyed did not know if the child with disabilities under their care was registered, and others declined to answer the question. This is particularly disconcerting for Uganda, because the number of children with disabilities registered in that country is well below the national average registration rate for all children of 62%[12].

It is highly likely that the efforts made in the past decade by governments and international NGOs to improve compliance with birth registration laws have failed to target families of children with disabilities. In Senegal, the percentages of children whose births are registered are considerably higher than in the other surveyed countries since, unlike in Ethiopia and Uganda, parents are not charged administration fees. Other barriers exist to registration as well: for example, travelling to the nearest official office to register a child can be a costly exercise for poor families with other competing essential expenses such as food and clothing.

Those children with disabilities who are not registered mostly reside in rural areas where children are born to midwives, so concealing them from the authorities is easy. Of those children who were not registered in Uganda and Senegal, the majority were children with multiple disabilities. Stigma, and low expectations concerning the possibility of the child's survival into adulthood, may have prompted this neglect. In Ethiopia, the high incidence of blindness acquired congenitally and through illness in infancy results in many blind children being abandoned: this may account for the low percentage (16.1%) of visually impaired children who are registered.

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12 A survey completed in 2000 indicated that only 4% of births in Uganda were registered. By 2005, this had improved to 62%, but with only 26% having birth certificates.

Table 14: Births not registered by country and residential environment

Type of residence	Ethiopia			Senegal			Uganda		
	Sample	Cases	%	Sample	Cases	%	Sample	Cases	%
Rural	209	142	68	129	58	45	360	129	36
Urban	288	150	52	200	38	19	153	48	31
Total	497	292	60	329	96	29	513	177	34.5

Table 15: Births registered by disability type

Disability type	Ethiopia			Senegal			Uganda		
	Cases			Cases			Cases		
	Sample	Registered	%	Sample	Registered	%	Sample	Registered	%
Physical	138	36	26.1	121	100	82.6	127	61	48.0
Visual	118	19	16.1	94	64	68.1	124	52	42.0
Auditory/hearing	133	34	25.7	91	61	67.0	117	51	44.0
Intellectual	96	38	40.0	93	65	69.9	118	57	48.3
Multiple	12	6	50.0	22	9	40.9	27	2	7.4
Total	497	133	27	421	299	71.0	513	223	44

Birth registration has long been neglected, especially in countries where there is conflict, or where administrative systems are poor. The UNCRC (Article 7), UNCRPD (Article 18) and national legislation in many countries all demand that all births be registered: a fully registered birth and the accompanying birth certificate help a child secure the right to his or her origins and to a nationality, and also safeguard the right education and health.

The issue of birth registration must be addressed urgently. Inaccurate data caused by inadequate registration coverage significantly hinders the ability of policy makers, healthcare workers and other agents to identify, monitor and improve disease prevention programmes, early childhood development initiatives and other interventions aimed at supporting children with disabilities and their families. A first step to addressing the issue would be making birth registration free. In South Africa, the entitlement to social protection has encouraged parents to register their children's births.

4.4.3 Participation in home and family life

Inclusion begins in the family, and in full involvement in family activities. Article 23 of UNCRPD, on respect for and the family, insists that governments ensure that children with disabilities have a loving, fulfilling and secure family life, by providing information, support and services to families with disabled children as early as possible. Governments are also obliged to take action to prevent concealment, abandonment, neglect, segregation and separation of children with disabilities from their families.
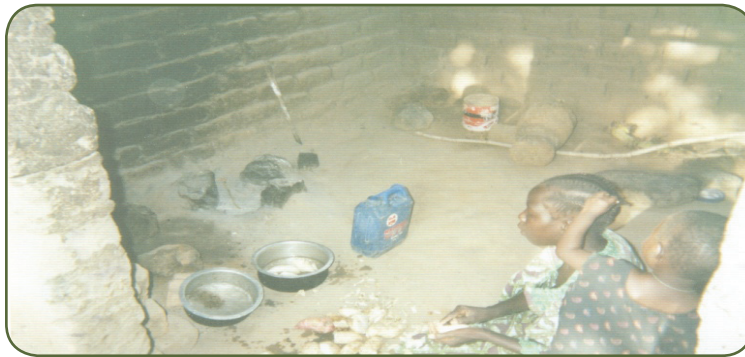
> "On a typical day I participate in doing household chores like any other member of the family. I participate in almost every activity in the home, ranging from cooking, to fetching water, cleaning household utensils, and even a bit of playing with my siblings.
>
> *Rukia, Day in the Life, Uganda*

Figure 9: Rukia's sister plaiting her hair (Day in the Life, Uganda)

Contributing to the household

In Africa, children are traditionally expected to contribute to the upkeep of the household through daily chores. In cases where, 'out of the best interest of the child', he or she must be removed from the parents, a suitable home within the immediate family or community must be sought.

In doing household chores, children also learn important life skills (Larson, 2004). Such chores generally include fetching firewood and water, cleaning the home, doing laundry, cooking, and taking care of siblings. The extent of children's involvement in such work is, however, a concern. Children with disabilities are sometimes forced to work excessively, and disproportionately in relation to other children in the household, in order to justify their lodging, food and other expenses (Groce, 2004).

> *"...I help my mother and brothers in household chores, like fetching water, cleaning utensils. I also play a bit with my brothers. I also like watching TV, especially football... I go to bed at 9:00pm and sometimes 10:00pm. I do not need help while going to bed. I like eating... I and my three brothers share a bedroom which we have nicknamed "Big Brother House". I like my brothers although we fight sometimes. But that is normal and we remain friends. I also like my uncle's children. They are my friends".*
>
> *Bonny, Day in the Life, Uganda*

The majority of children with disabilities in the survey said they participated in household chores, and the chores were generally gender specific. Girls were more likely to work more than four hours a day than boys, and also more likely to work most days or every day. Children with hearing disabilities were notably more involved in household chores than children with any other disability.

Among children with most disability types, girls typically engaged in play activities that were more social and involved a great deal of communication. It is surmised that proficiency in household chores may be a way for the child to elevate their social standing within the family, since the lack of educational opportunities prevents them from showing accomplishment in school.

The children surveyed who were involved in household chores were happy to contribute to the upkeep of the household, feeling that it affirmed them as meaningful members of their families. For example, two visually impaired teenagers from Uganda and Senegal, Rukia and Ndoya, felt proud of the contributions they made in their families, from which they derived a sense of worth and belonging.

Figure 10: Rukia washing clothes with her sister (Day in the Life, Uganda)

> " I learn my lessons quickly to enjoy most of the daylight. Sometimes my mother sends me to the corner store to buy condiments for lunch. It is a nice opportunity for me to get out of the house a little. In the morning I prepare to feed the sheep. I cut the cardboard paper that I mix with animal feed and I put water and then I leave it all to rest. This activity is important for me because it allows participation in family tasks. I feel useful and it does not require much physical effort "
>
> **Rukia, Day in the Life, Uganda**

Although the majority of children with disabilities were happy to do household chores, a concerning proportion – one in five children – felt that their chores prevented them from attending to their schoolwork and from socialising with friends. Additionally, more than half of the children surveyed who were engaged in paid work said they would prefer more time for schoolwork (French, 2006). This is of particular concern because children with disabilities often need to put more time and effort into schoolwork in order to stay on par with their non-disabled peers.

One of five children with disabilities surveyed also reported that the chores they did were strenuous, and caused them pain. This finding is of grave concern, because it suggests that these children were at risk of deteriorating their condition, or – at worst – acquiring further disability. For example, children who contracted a visual impairment through river blindness, often have glaucoma; lifting heavy objects with this condition may put them at risk of increasing their intraocular pressure, causing their vision to deteriorate further.

4.4.4 Interaction and play

Play is an important part of socialising and development. The ability to play depends on several factors, including attitudes towards disability, the child's physical limitations, the accessibility of the surroundings, and the type and degree of parental control exercised over the child.

In school

Some of the greatest life lessons learnt in school are not taught in the classroom, but in the playground, where children interact freely with each other. Facilities accessible to all children in school are therefore essential. Of the children sampled, 61% in Ethiopia, 82.3% in Senegal and 75% in Uganda were able to access the school's playground. Accessing the playground was, however, difficult for visually impaired children.

When asked about their interactions with their peers, approximately two-thirds of respondents in Ethiopia felt that they had other children to play with always or sometimes (65% played with friends without disabilities, and 50% played with friends with disabilities). In Senegal, only 43% of children with disabilities played with non-disabled peers during break, while in Ethiopia the figure was significantly higher (65%) – possibly again as an outcome of CBR interventions. A key informant from Addis Ababa, who is a teacher in an inclusive school, praised the children with disabilities in his classes, saying they socialised well with the students without disabilities.

The box below tells the 'Day in the Life' story of a young disabled boy in an urban area of Ethiopia. Despite his disability, he feels included and valued among friends and family. It is interesting to note that his sport teacher believes he is unable to participate in sport activities, effectively creating a barrier to his participation that would not otherwise exist. This fact illustrates how important it is for teachers and families of children with disabilities to learn to listen to the children themselves: if the children feel able to participate in a given activity (at school or otherwise), they should be allowed, and provided with the appropriate means, to do so. Placing restrictions on their participation emphases their perceived inabilities, and subsequently may hinder their interaction and social standing with peers.

Day in the life of Yasser, a boy living in a city in Ethiopia

I wake up at 6 am on weekdays. I put on my clothes and wash my face to eat my breakfast, with help from my mother and sister. I find it difficult to use the toilet, because I can't sit comfortably, due to the problems with my leg muscles. Some days I do sports exercises in the mornings, which makes me happy. Today, I am frustrated because my sister failed to make breakfast on time, and I was late to school on a day I have exams.

I go to school with friends from my neighbourhood, and I am the highest achieving student in the school. I have received numerous awards. I have never felt discrimination from my friends, and I get good care and support from my teachers. The sports teacher does not let me take part in sports periods, which makes me sad. I am also sad when people see disability as a curse from God. All people should be evaluated on the basis of their merit, rather than physical appearance.

After school, I eat lunch and rest for a few minutes, before helping my mother make Akenbalo (a mud and thatch made cover used for baking), the family's main livelihood source. I am proud to help my family, and I feel that I deserve to eat because I work.

After I finish helping my mother, I watch a movie with my friends, before studying. I like to read, especially psychological and philosophical books, but I cannot afford these books often.

I go to sleep at about 9pm, in the bed I share with my mother.

The extent of inclusion varies depending on the child's disability. A SNE trained teacher in Bahir Dar stated that children with visual disabilities appeared to have no problem playing with non-disabled children; however, he did find that children with hearing impairments were entirely alienated due to communication barriers, and that intellectually disabled children were often bullied because of the stigma surrounding their conditions.

A child's impairment may hamper their ability to initiate play and interactions. Some children with disabilities may require the support of a friend to interact with others. For example, for a visually impaired child, eye contact and gestures are difficult to read, so a friend may need to alert the visually impaired child that a group of children are signalling for him or her to join them in playing a game. Approximately two in three of the children with disabilities surveyed reported that they had difficulty communicating, posing another huge barrier to interacting with peers. Sensitising non-disabled children about exclusion in a way to which they can relate, while informing them about the challenges that children with disabilities may experience, could encourage them to problem-solve around ways to adapt a game, or to interact better with one another.

Schools are the hubs of our communities, and should reflect the societies we are striving to build. The evidence related to play highlights the need for teachers to ensure that they create a supportive and open learning environment where diversity is embraced and accepted.

Figure: 11 Bonny Kulaba took this picture to show his friends at school

Community

Parents sheltering or concealing their children from others in the community is a phenomenon on the decline. Over two-thirds of children with disabilities in Uganda and Ethiopia were allowed to play with other children in the community, or invited children over to their homes to play. However, a considerable proportion of children in Ethiopia (23%) didn't feel that they had time for fun, possibly due to school and/or work commitments. This issue needs further examination, given the inherent importance of play in early childhood development and a child's emotional wellbeing.

The affirmation and acceptance of peers within the community helps build self-esteem. The story outlined below of Dagnachew, a boy with a physical disability, shows that he engages in the same activities as other boys in his village, and enjoyed the company of his friends and family. More importantly, when he felt that his disability was hindering him, his non-disabled friends lifted his spirits by reminding him of his abilities.

Day in the life of Dagnachew, a boy from a rural village, in Ethiopia

I am up at 7am. I get dressed, wash my face and use the toilet without any help from my family. My mother prepares my breakfast whilst I fetch water from the river, before going to school. I live with my mother and sister, who I love and want to help.

I go to school with friends from my neighbourhood, who support and encourage me. I study and come home for lunch. I spend the afternoon in the fields herding my family's cattle, which I enjoy because my friends are there too, and we play football and other games. I get upset, and sometimes I cry, because I am only allowed to play as a goalkeeper, because of my mobility challenges. My friends tell me I am the best goalkeeper and this makes me feel better, because they care and support me. On the way home, I collect firewood for my mother.

I study at night from 7 pm until 9 pm. My mother prepares my supper and makes my sleeping place ready. I wash my leg and pray to God with my mother for healing, before going to sleep on the ground.

Inaccessible transport and facilities hinder participation in community activities. The physical and logistical difficulties of moving about the community to a friend's home, a place of worship, or a shop, and the difficulty of carrying out self-care activities, were the hardest for children with disabilities in Senegal. These children very rarely received assistance with these tasks (only 22–37.5% of children requiring assistance received it), which made integrating themselves into the community more challenging. Children in South Africa, Ethiopia and Uganda experienced the same problem.

A lack of accessible transport and facilities constitutes a breach of Articles 19 and 30 of the UNCRPD, which assert the right of children to participate equally in the community. This includes taking part in cultural, sport and recreational activities, and covers the obligation of the state to ensure that the facilities and material required are accessible.

In the family

Although the majority of children part took in family activities, a significant number were always or sometimes excluded from family events (45% in Ethiopia and 31% in Uganda) and religious events (40% in Ethiopia and 18.4% in Uganda) as a result of their disability. A further 45% in Ethiopia and 21% in Uganda were reported to be always or sometimes excluded from family time because of their disabilities. In Ethiopia, the majority of children were always or sometimes excluded from important household decisions. It is to be noted, however, that children in most African communities are not given space to participate in decision-making, and they usually only participate when their labour is required.

Sadly, in Ethiopia 27% of children felt that their disability was the cause of fighting within the family. This statistic highlights the need for psychosocial and emotional support for children with disabilities, and their families. Unfortunately, caregivers of children with disabilities reported that they could not even depend on religious organisations – the most common source of this type of support – for help.

4.4.5 Support

Well-being and positive outcomes in education are strongly influenced by the support a child receives from the family. This survey revealed mixed results in terms of the support that children felt they received from their caregivers. A considerable number of children felt unsupported in the family and greater community.

> The family members at times neglect children with disabilities to the extent of not providing necessities like clothes, beddings…Sometimes our own brothers, sisters and peers in the community call us abusive names leading to stigmatisation.
>
> *FGD Ngeta Girls School, Lira, Uganda*

Based on the respondents who reported to have received support 'always' and 'sometimes', results were generally positive on the household front; but in Ethiopia, 20% of children never got support in achieving their goals, or had no one to turn to for emotional support. One in five children in Ethiopia, and about a third of children surveyed in Uganda, reported that they never got help from the people they lived with in doing difficult activities, while 16% of children reported that they never had anyone in their household to turn to for emotional support when they felt sad, troubled, upset or in need of advice. This is a very disconcerting finding, since the adolescent years are particularly challenging for children with disabilities (Groce, 2004). A safe and supportive family environment can help children with disabilities work through their uncertainty about their future, and help them to develop a positive self-image.

> The family members at times neglect children with disabilities to the extent of not providing necessities like clothes, beddings…Sometimes our own brothers, sisters and peers in the community call us abusive names leading to stigmatisation.
>
> *FGD Ngeta Girls School, Lira, Uganda*

To compensate for the lack of emotional and financial support from a family, street children with disabilities were found to have formed their own family units with other children on the streets, sharing food, money and clothes, and consoling each other in times of distress.

In Africa, children are often regarded as a source of future wealth: parents believe that investing in their children's education and wellbeing will payoff when these children become economically active adults. Parents contacted in Uganda, however, were less positive with less than half of them having trust in their child's ability to be financially independent and with only 44% of them being confident that their children will eventually support them financially (44% Uganda). Similarly, in Ethiopia, a large majority of children (66%) believed that the family did not spend more money on them because of their disabilities. In light of the stigma, challenges and lack of opportunities faced by children with disabilities, and of this way of perceiving a child's future 'worth,' it can be understood how it is difficult for parents of these children, who live in poverty, to justify the use of their resources on their children.

Poverty is the pervasive factor here, since the study found parents were generally positive about their child's abilities[13]; and, moreover, the vast majority of the child respondents had aspirations of well-paid and respected positions, and believed in their capacity both to have a family of their own, and to support their caregivers.

As long as their potential and abilities go unrecognised by those in leadership, children with disabilities will continue to be seen as a 'problem'.

Table 16: Sources of emotional support

Sources of emotional support	Ethiopia		Senegal		Uganda	
	Cases	%	Cases	%	Cases	%
Family	184	42.3	209	44.9	100	18.6
Neighbours	81	18.6	162	34.8	99	18.4
Friends who are not neighbours	79	18.2	96	20.6	86	16.0
Religious organisation/people	48	11.1	24	5.2	104	19.4
Community leaders	27	6.3	17	3.7	57	10.6
Politicians	42	9.7	1	0.2	43	8.0
Government officials/civil servants	76	17.7	6	1.3	43	8.0
Charitable organisations/NGOs	59	17.6	4	0.9	29	5.4
From any other source	2	1.4	2	0.4	6	1.1

Table 17: Sources of financial support

Sources of financial support	Ethiopia		Senegal		Uganda	
	Cases	%	Cases	%	Cases	%
Family	49	11.3	18	3.9	58	10.8
Neighbours	18	4.1	12	2.6	4	0.7
Friends who are not neighbours	18	4.1	8	1.7	8	1.5
Religious organisation/people	20	4.6	6	1.3	4	0.7
Community leaders	7	1.6	2	0.4	4	0.7
Politicians	12	2.8	4	0.9	2	0.4
Government officials/civil servants	42	9.8	16	3.4	10	1.9
Charitable organisations/NGOs	33	9.8	18	3.9	29	5.4
From any other source	4	2.7	4	0.9	3	0.6

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13 In Uganda, for example,73% of parents interviewed believed that their children could lead independent lives, and 77% believed that their children were as smart as non-disabled children

Support in the community

It was pointed out by Hillary Clinton in 1996 that 'it takes a village to raise a child': a timeless reminder that children will only thrive if their families thrive, and if society cares enough to provide for them. Sadly, 'villagers' often abandon their responsibility when a child has a disability. 60 per cent of children in Ethiopia felt they could not approach anyone in their neighbourhood for emotional support; 75% felt that seeking financial support was impossible; and 58% felt they could not ask for physical support with activities that were difficult for them. In Uganda, children surveyed preferred to approach the church for counselling and emotional support, rather than elders in the community: they felt that the elders disregarded their issues and considered disabled children to be a trivial concern and a waste of time, because of their disability. The views expressed in focus group discussions by children and caregivers showed that intolerance and negative attitudes are rife in many communities.

> *Some elders shout at us when we approach them for help, it is even worst when you have a physical disability because you may be considered insane by others.*

> *14 year old pupil, FGD, Jinja, Uganda*

Caregivers also complained that they seldom received support from others in the community to care for their child. The vast majority of caregivers across the surveyed countries reported that they received no emotional or financial support from any source: only one in ten caregivers received a financial contribution from an NGO or charitable organisation in Ethiopia and Uganda. Caregivers in Senegal were particularly disadvantaged and received minimal support from outside sources.

> " The community, in reality, does not support parents with children with disabilities. When I ask someone to take care of Zeina, the latter always finds an excuse to refuse. I am no longer able to tend to my affairs because I devote all my time to her. It is very difficult, and it's heavy. "
>
> **Mother of a child with a disability, Senegal**

Caregivers were grateful to schools that accepted their children with disabilities as students, as it lightened their load by giving them a break from their caregiver duties. These feelings were shared by a number of parents, who agreed with a statement to that effect made by a mother from Senegal in a focus group discussion.

4.4.6 Violence and abuse

Sadly, many children suffer abuse at the hands of their families. More than a third of children surveyed in Uganda reported that they were either verbally or physically abused by family members as a consequence of their disability. In Ethiopia, more children were victims of verbal abuse (28%) than physical (18%). In Uganda a disturbingly high number of children[14] (54.6%) reported abuse. More education is needed around positive child-rearing practices that focus on building the self-esteem of children with disabilities. Parents also need support in dealing with the stresses of raising a child with a disability. Simultaneously, parents, children and the greater community need to be made aware of the psychological harm caused by teasing, physical punishment and name-calling.

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14 The figure is based on those who were sometimes (38.3%) and always (16.3%) abused.

We feel unhappy when we are discriminated against, both in our families and in the community. And worst, when we are called abusive names such as atowang [blind person], angwalo odole [lame person], apoa [mad person]…Ababang is very common among the community members we live with.

FGD, Children with Disabilities, Ngeta Girls' school, Lira, Uganda

Information on what constitutes abuse, and where to report it, must be disseminated, and authorities dealing with these cases must be trained on how to handle them appropriately.

The survey also revealed that between 3% and 6% of caregivers of children with disabilities themselves experienced exclusion from family events and/or physical or verbal abuse from their family or community. In Senegal the situation appears to be worse, particularly in rural areas, where children with disabilities are abandoned at birth or within the months afterwards, because mothers fear ridicule from their families. The quotations in the bubbles on this page bear testimony to the hardship faced by mothers in particular.

My husband left me four months after the birth of my child with a disability. I was repudiated and excluded (thrown out) with my child. Even worse, my own parents rejected me because they had been against the marriage.

Mother of a child with a disability, Senegal

> " My husband abandoned me and then divorced me three months after our child was born with an innate disability. He was influenced by his family who told him that I had brought bad luck into the family, that I had changed their lineage and that I was a sopi kët –cursed, a carrier of bad luck. "
>
> **Mother of a child with a disability, Senegal**

A considerable proportion of Ugandan children with disabilities in the study – 38 per cent – reported episodes of attacks and insults from fellow workers related to their disability. The study also revealed that many workers with disabilities – a proportion as high as 64% in Uganda – are not given equal treatment and opportunities for advancement. Over a third of children with disabilities working also reported that their work environment was dangerous. These findings highlight the need for employers to foster a climate where diversity is appreciated, and to put in place policy measures protecting workers with disabilities. More awareness-raising about creating accessible and suitable working conditions for persons with disabilities is also needed.

The quantitative and qualitative tools used in this survey provided conflicting evidence regarding community participation, and it is apparent that some children live in more inclusive communities than others. Through focus group discussions and interviews with community leaders, it became clear that there were major differences in attitude towards children with disabilities, depending on whether there was an active disability-inclusive NGO or DPO in the locality. In those communities with NGO support, positive attitudinal change was witnessed by community leaders throughout their communities. An FGD conducted with street children with disabilities in Hawassa (Ethiopia), an area in which several disability NGOs and DPOs are active, revealed that donations from the community and psychological assistance were easily available. In contrast, a community leader interviewed in Mekele, Ethiopia, an area that does not have a large disability network, stated that in his community disability is still regarded as a curse, and anyone who gives birth to a disabled child is automatically discarded from the community.

Similarly, in Uganda, parents and children – especially those living in rural communities where stigma is highly prevalent– complained about the limited emotional support offered by government, NGOs and DPOs.

> *The community see disabled children as cursed, non-performers in decision making, dependants, and a burden to the community. They (children with disabilities) don't have any specific role they can play in the community.*
>
> *Community Leader, Jinja, Uganda*

Another perspective was shared by a community leader in Adama, Ethiopia, who believed the negligence by the government in educating children with disabilities was compounded by a lack of concern of the community towards them. Through community education, this leader hoped that community members might be empowered to approach the government and insist on fairer treatment of children with disabilities in policy-making and budgeting. Challenging community stigma and negative attitudes is crucial in diminishing prejudice against children with disabilities, and in ensuring their equal access to services and opportunities.

4.5. Awareness of rights

Justice for all?

A study by the Disabled Children's Action Group (DICAG) in South Africa found that, in a sample of 36 cases of abuse of children with disabilities that came to trial, 14 were withdrawn, with eight acquittals and 14 convictions. The prime reason given for the high number of withdrawals and acquittals was that 'witnesses were seen as being incompetent'. In many cases, however, the language used in court proceedings was in fact too complex, and incomprehensible to many of the victims.

Old stigmas die hard, so a concerted effort must be made to raise awareness about the rights of persons with disabilities. Article 8 of the UNCRPD obliges states to inform children with disabilities, their families and the broader public about the rights of children with disabilities.

All forms of media must be used to promote a better understanding of disability, and to dispel negative beliefs. Broadcasting positive images and stories can elevate the standing of persons with disability in society and encourage positive feelings towards them.

The majority of children with disabilities and caregiver respondents in the survey were aware of their key rights - the rights to free education, the best possible healthcare, equal opportunities and protection against violence and abuse. But, in light of the tragic implications of not knowing these rights, the levels of awareness among caregivers and children with disabilities are far from ideal. In Senegal and Uganda, where considerably fewer children with disabilities accessed education, one in four caregivers and one in three children were not aware of the right to free primary education.

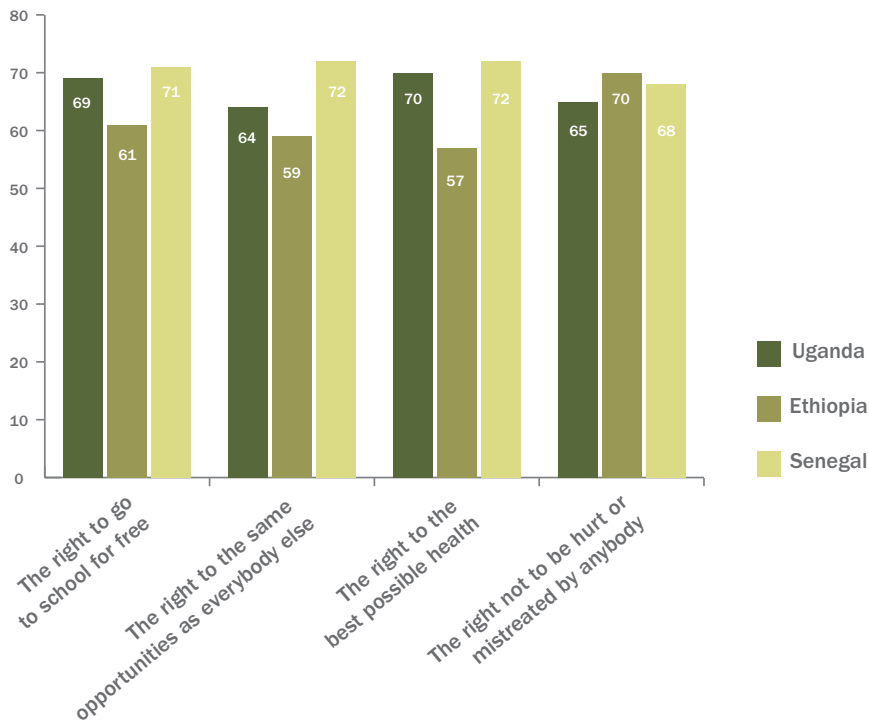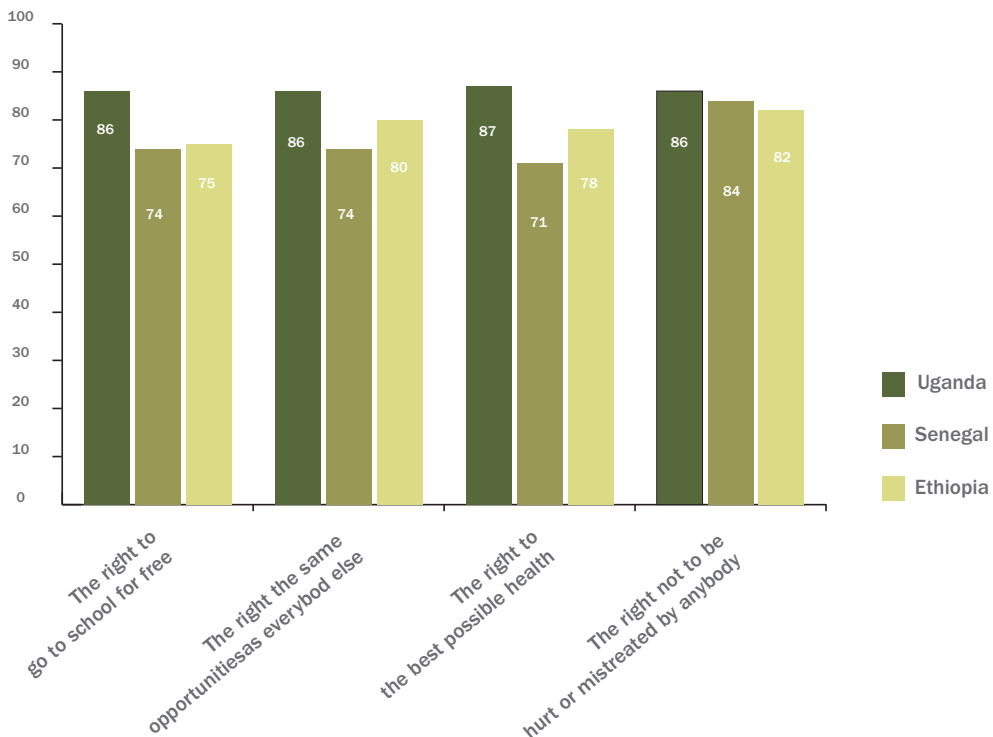*Figure 13: Caregivers awareness of rights of their children*

Figure 14: Children's awareness of their rights

Children were less aware of their rights than caregivers were of the children's rights. About a third of children with disabilities were not aware of their key rights. The levels of awareness of rights among children with disabilities in Senegal was particularly low.

More awareness-raising needs to take place, particularly with children. To this end, child-friendly methods of teaching, such as drama, story-telling, cartoons and music, can serve as useful media. Also, existing mechanisms and facilities where children and youth gather (e.g. youth, church and cultural clubs) should be encouraged to be inclusive, and to discuss the rights and issues faced by children with disabilities. It should be stressed that children with disabilities are inherently children first and foremost, and are hence entitled to the same rights as other children; and that in an effort to be fair and to promote equal opportunities for children with disabilities, they are allowed 'reasonable accommodations'.

Street children with disabilities who participated in the FGD in Ethiopia stated that the government made them feel like "second rate citizens", implying that they felt they were not entitled to any rights. Special efforts must, therefore, be made to inform this most vulnerable of vulnerable groups in the child population.

The majority of respondents in this survey were linked to CBR services and NGOs working on disability, and hence had better-than-average awareness of their rights. For the general population, though, the proportions of caregivers and children with disabilities unaware of their rights are likely to be far greater. The information gained through key informants and FGDs supported this theory, portraying a less positive picture: all the key informants stressed the fact that the community (including themselves) were generally unaware of disability policies: the study therefore suggests that this is an area on which policy makers should work.

> *The community does not have the [means of] inquiry to know about newly adopted government policies. Similarly, the policy makers do not exert… effort to introduce the newly promulgated policies to the community.*
>
> *Key informant, Adama, Ethiopia*

In spite of increasing awareness of the rights of children with disabilities, and sensitisation on disability among household members and children with disabilities themselves, negative and non-supportive attitudes still present a serious challenge to social integration and participation.

5. Conclusion and recommendations

5.1 Conclusion

The findings of the ACPF study show that enormous improvements are still needed in order to ensure the full and equal inclusion of children with disabilities in African societies, but that positive moves forward have been made in key areas in recent years, including in education, health, and community participation. Many of these achievements can be attributed to the efforts of stakeholders such as governments, civil society, and non-governmental organisations working on disability.

The most notable advancements can be credited to CBR programmes. The high numbers of child respondents in Ethiopia with access to education, rehabilitation and assistive devices were the result of child respondents being linked to Community Based Rehabilitation Services offered by NGOs. Furthermore, communities with active CBR services and DPOs were considerably more positive towards children with disabilities and their families.

Unfortunately, a significant number of children with disabilities and their families still experience exclusion, abuse, harassment and discrimination within their families and the greater community. Although there has been a significant decline in disability-related misconceptions and superstitions, more work needs to be done to ensure that all children with disabilities, their caregivers and the greater community are aware of the rights of children with disabilities.

Ethiopia, Senegal, South Africa and Uganda have all made a commitment to realising the rights of children with disabilities, as set out in the UN Convention on the Rights of Persons with Disabilities and the Convention on the Rights of the Child. All four countries have instituted progressive legislation and policies aimed at ensuring that the rights of children are upheld. However, removing barriers to access for disabled children requires more than a supportive legislative context: it requires the transformation of institutions, practices, facilities and environments at every level of society. Serious political commitment will ensure that duty-bearers make the shift in thinking away from the welfare approach to a respect for rights, and that they strengthen their commitment to realising the rights of children with disabilities.

Civil society must hold governments accountable using all available monitoring mechanisms. Violations of the rights enshrined in the UNCRPD must be reported to the relevant committee for those countries that have ratified the Optional Protocol to the Convention (e.g. Uganda and South Africa), and shadow reports based on sound research must verify claims of government progress reported to the international community.

Empowerment of children with disabilities depends heavily on the services and assistance offered by governments, considering that the majority of households are unable to meet their basic needs, let alone the special needs of the children with disabilities under their care. The lack of accurate prevalence data and low birth registration make planning for service delivery extremely difficult.

Fortunately, the countries studied (South Africa in particular) have sufficient resources at their disposal to support children with disabilities. These include training manuals, resource materials for parents and educators, and guidelines to promote integrated service delivery. These countries also have a vast pool of academics and research institutions from which to draw skills in research and analysis. These factors, combined with models of good practice developed by NGOs, represent critical resources with the potential to inform service conceptualisation and planning as well as monitoring and evaluation.

The challenge remains to retain the vision of "an Africa fit for all children", and to work collaboratively in order to keep this a priority, such that it does not remain a theoretical concept, rather but results in qualitative improvements to the lives of children with disabilities.

5.2 Recommendations

The recommendations that follow are to all countries, were derived from the analysis of this study and the suggestions made in the course of research by parents, caregivers and other stakeholders.

Domesticate UNCRPD into legislation and policies

- Identify and remedy domestic laws and policies in contradiction with the UNCRPD, and ensure that Sector Plans address disability in a manner consistent with the goals of the UNCRPD.

- Human Rights Commissions must be more actively engaged in monitoring the implementation of the UNCRPD.

Promote inclusive programmes and service delivery

- Inclusive services require the adoption of the principles of universal access. This means that children with disabilities and their families must be anticipated, welcomed and accommodated when conceptualising, planning and implementing all programmes targeted at children; and that these programmes must have appropriate budgets for human and material resources.

- Programmes and budgets for improving the situation of children with disabilities must be specific, realistic, structured, monitored, and evaluated, so as to ensure effective service delivery and the progressive implementation of disability-inclusive policies and practices.

- A strong national body promoting the inclusion of disability, with branches at provincial and local government level, must be strengthened or established to function as a 'watchdog' and to provide technical guidance to both state and non-state service delivery agents.

- Agencies working with children and in the field of child rights must set up task forces to oversee the inclusion of children with disabilities in all programmes, from planning through execution to the evaluation phase. Targets for children with disabilities must be indicated and monitored.

- Information on disability, the rights of children with disability, and how to claim those rights or report violations thereof, must be disseminated in accessible child-friendly formats. For example, reports, laws/policies and awareness-raising material must be printed in Braille or large print for the visually impaired, and simple text and pictures as well as sign language could be used for children who are hearing impaired or cognitively challenged.

Generate reliable prevalence data and improve birth registration

- A standard definition and methodology must be agreed upon for population censuses, in order to produce reliable and comparable data that accurately reflects the situation of children with disabilities.

- Government departments responsible for portfolios such as health, social development and education must include data on children with disabilities in their information systems. For example, the Education Management Information System (EMIS) must include information specific to children with disabilities, such as information on access to assistive devices and accessible materials.

- Birth registration must be free and accessible. Local community leaders, hospitals, churches and midwives should be employed to help with birth registration, to mitigate the related expenses.

- A database and registry of children with disabilities should be created in every locality by harmonising the geographical regions and statistical data collection systems across government departments.

Enhance human capacity and technical support

- The knowledge and technical skills related to disability of those involved in service delivery programming at national, provincial and local government levels, and those at service delivery points, needs to be enhanced. Relevant training programmes with ongoing live support (e.g. regular site visits, call centres and resource centres) and virtual support (websites with online material, mobile phone technology, etc...) would be most effective in reaching people in both rural and urban areas.

- Disability service delivery performance indicators must be included in central and local government performance assessments to promote service delivery.

- "Quality Standards for Effective Disability Programming" must be developed to guide state and non-state actors in effective planning and delivery of inclusive services.

Step up disease prevention and maternal care

- Disease prevention efforts should be stepped up through training and employing local community members to serve as community health educators.

- Mobile immunisation clinics should be increased and linked up with HIV testing centres to include testing services.

- Free health care should be extended to pregnant mothers and infants up to the age of seven.

- Pregnant mothers must undergo mandatory screening for disability-causing diseases and conditions that may affect unborn children, in order to ensure that appropriate medical care is provided on time.

Early intervention services and Early Childhood Development (ECD) to minimise disabling effects of impairments

- Awareness must be increased among mothers and the general public about the early detection of disabilities (particularly "invisible disabilities" such as hearing loss).

- All children must be screened for language problems, learning difficulties, neurological disorders and other impairments from birth (e.g. hearing screening can be done immediately after birth).

- Local childcare facilities must be encouraged, and given the capacity, to admit young children with disabilities, in order to allow mothers sufficient free time to earn a living. This capacity building should focus on all disabilities, with particular emphasis on children with intellectual and multiple disabilities.

- Early childhood development strategies and programmes must be enhanced to cater for children with disabilities.

- Institutions – both governmental and non-governmental – working on water and sanitation should be sensitised about disability-causing diseases and the importance of building better facilities that are accessible to children with physical and visual challenges.

- A toll-free mobile phone help-desk centre should be established with the function of providing information, referring caregivers to the relevant service provider or a resource person (e.g. parent with similar challenges) in their locality, and alerting the authorities to children with disabilities who need assistance.

Expand community-based rehabilitation (CBR) to promote access to education, health and social integration

- Governments must use CBR as an approach to planning and delivering interventions for children with disabilities, as CBR tends to be more holistic and effective[15].

- An interdepartmental policy framework for CBR, with clear mandates and clarification of the roles of different stakeholders, must be developed.

- A body comprised of multi-disciplinary and cross-sectoral experts must be established within the ministry responsible for social development in order to implement and co-ordinate CBR services.

Strengthen healthcare service delivery

- Qualitative improvements are needed to the public health system, particularly at primary level.

- Children with disabilities must be given preferential treatment when coming for regular check-ups at state hospitals, to lessen the difficulties of waiting for long periods of time with a child who is difficult to manage.

- Caregivers of children with disabilities and the greater public must be educated on the scope of practice of different medical and rehabilitation practitioners (e.g. audiologists, speech-language pathologists, dieticians, occupational therapists, etc.). This will help them to advocate better for support for their children with disabilities.

- A strategy must be developed for securing and retaining medical staff where they are needed. This may involve offering greater incentives to health specialists posted to rural areas.

- In-service and pre-service sensitisation and training on disability has to be given to health practitioners, and these practitioners should be encouraged to take a more social and holistic approach to the management of patients with disabilities.

- Better collaboration must be encouraged between different stakeholders in interventions – including parents, NGOs, therapists, teachers and health personnel.

- A formal body must be established for traditional health practitioners, which will include traditional healers, faith healers and midwives. This body will help to regulate practices, and will encourage sharing of information and expertise among traditional and medical practitioners.

- Midwives must be educated on effective birthing techniques, identifying mothers and babies at risk of disability, early intervention, and encouraging mothers to register their children and support their development.

Improve access to assistive devices and specialised rehabilitation

- Rehabilitation services must be improved to include speech therapists and audiologists, since communication impairments are high among children with disabilities, and are rarely addressed.

- African universities must offer training in all rehabilitation fields. Training sufficient numbers of individuals to meet the population requirements, and making community service mandatory, will help address immediate demand.

- Assistive devices, where possible, need to be produced locally to reduce cost and maintenance challenges.

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15 CBR guidelines are available from http://www.who.int/disabilities/cbr/en/

- A roll-out strategy and policy for assistive devices needs to be developed, to prevent unequal provisioning among disability groups.

Develop an inclusive education system

- Resources must be geared towards making mainstream schools inclusive, since the majority of children with disabilities reside in such schools and this will ultimately increase educational opportunities for children with disabilities and their non-disabled peers. The necessary awareness raising, human resource development, material resources (e.g. audio recorders, computers and assistive devices) and infrastructural accommodations must be budgeted for accordingly.

- These interventions must be monitored and adjusted as required to ensure proper expenditure, usage and quality assurance.

- An aggressive campaign to get children with disabilities enrolled in school needs to be launched, while simultaneously promoting understanding about inclusive education and the right to quality education for ALL children.

- Parents of children with disabilities need to be informed about the benefits and requirements of inclusive education, so that they can advocate better for the education system and schools to accommodate children who are 'different'.

- The whole school improvement approach must be geared towards transforming schools to be inclusive. The *Index for Inclusion*[16] can be used to evaluate and improve on cultures and practices in schools.

- All new and old schools must be made physically accessible, and inspected. Standard designs for schools, meeting physical accessibility requirements, must be issued and adhered to.

- Schools need to apply 'reasonable' accommodations to cater for children with disabilities. For example:

  - *They need to be flexible, understanding and helpful, allowing learners who are recovering from illness to learn from home, and/or allowing them to return to school on a flexible or part-time basis. They could, for instance, ask classmates to take schoolwork to the child at home, offer catch-up classes, or extend the time allowed to complete grades.*

  - *Learning material must be made available in accessible formats – for example, material in Braille or large print, or tactile and audio material for learners who are visually impaired or have learning difficulties.*

  - *The option of provision of extra time for exams, and alternative forms of assessment (such using a reader and scribe during testing, demonstration, etc.) must be available to learners with disabilities who require such interventions.*

Improve teacher training and support

- Teachers must be encouraged to work from the premise that all children have different learning styles and issues that could hinder their learning, and lessons should be tailored accordingly.

- Training for in-service and pre-service teachers must include:

  - *Disability awareness.*

  - *Minimisation of barriers to learning (including attitudinal barriers).*

  - *The use of assistive devices.*

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16 The inclusion index is available in English and other languages from www.eenet.org.uk

- *Making the curriculum accessible to children with different disabilities and learning barriers.*

- *Developing individual learning programmes with goals relevant to children's developmental milestones, which focus on children's abilities and interests, and which set out to build children's self-reliance.*

- *Adapting teaching material, the classroom environment and strategies to meet individual needs.*

- Teacher training must be coupled with ongoing mentoring and support, to ensure that teachers have the skills and confidence to alleviate barriers to learning.

- Hubs must be developed that have resources and expertise in assessing and supporting learners with disabilities, making accessible learning and teaching material, and issuing assistive devices; or special schools must be strengthened to assume this role.

Provide relevant education leading to employment and marketable skills

- The entry requirements for vocational learning centres must be made less stringent.

- More centres focusing on vocational training (in motor mechanics, child care, catering, plumbing etc.) must be established, with an inclusive approach aiming to provide over-aged learners with disabilities, and those with learning difficulties, with opportunities to acquire marketable skills.

- Partnerships between business and education must be forged, to open up to children with disabilities the option of working as apprentices in a trade, while gaining qualifications.

Eliminate exploitation and promote safe employment

- Stricter adherence to employment laws must be ensured by governments, to prevent the exploitation of children with disabilities, and to increase the likelihood of their participation in education.

- Organisations combating child labour must include children with disabilities in their interventions.

- Informal and formal employment sectors must be sensitised about disability, and urged to develop and implement comprehensive human resource policies that improve working conditions and eliminate discrimination of children with disabilities.

Improve physical accessibility

- Buildings and facilities must be designed and built with users with disabilities in mind (in accordance with the principles of universal access).

- Families and communities must be educated on simple, inexpensive ways to adapt their homes, facilities and everyday items, using readily available material and equipment[17], in order to make these facilities easier for children with disabilities to use, and to improve their function.

- A civil society 'watchdog' on building accessibility must be established, comprising architects, engineers, DPOs and NGOs working in disability, academics, and other committed parties.

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17 *Disabled Village Children* is one of many publications by the Hesperian Foundation. It provides examples of equipment adaptations for children with disabilities, and can be downloaded for free from http://www.hesperian.org/publications_download.php.

Provide psychosocial support to families and children with disabilities

- Counselling on positive child-rearing practices and dealing with the stresses of raising a child with a disability should be provided, to promote harmony in households.

- Adolescents with disabilities should be provided with career counselling and emotional support to help them deal with their uncertainty about the future, and to help them to develop a positive self-image.

- Parents, children and the greater community need to be made aware of the psychological harm caused by teasing, physical punishment and name-calling.

- Information on what constitutes abuse, and where to report it, must be disseminated. Authorities dealing with these cases must be trained to handle them appropriately.

- Formal mechanisms that harness the expertise of mothers and caregivers of children with disabilities in the community – such as voluntary class assistantships, mother-to-mother support groups, and information sharing sessions – should be established.

Provide financial assistance and easy access to free services

- Fast Track initiatives, and other programmes designed to alleviate poverty, must include children with disabilities and their families. Social assistance, in the form of cash payouts or in-kind transfers, should be made to poor families in order to alleviate the financial burden of caring for a child with a disability, and to help pay for disability-related expenses.

- Families of children with disabilities must be encouraged to join, and be given priority in, microloan and other wealth creation schemes.

- The administration requirements for obtaining free health and education services need to be reduced, in order to make it easier for destitute families to benefit.

Improve knowledge on rights, systems and channels of recourse

- National communication strategies aimed at promoting positive attitudes should be launched, and should be targeted at stakeholders and the greater public.

- Duty-bearers – namely teachers, health professionals and civil servants – must be educated on policies and strategies for promoting the rights and well-being of children with disabilities, and on their own responsibilities in this regard.

- Communication tools used to disseminate information on policies and programmes affecting children should portray images of children with disabilities, and should refer to them explicitly.

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