

# The African Report on Children with Disabilities



**Promising starts  
and persisting challenges**

**ACPF**



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and persisting challenges**

## The African Child Policy Forum (ACPF)

The African Child Policy Forum (ACPF) is an independent, not-for-profit, 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 to the realisation of their rights and wellbeing, and to 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; and it 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. Specifically, ACPF aims to contribute to improved knowledge on children in Africa; to monitor and report progress; to identify policy options; to provide a platform for dialogue; to collaborate with governments, intergovernmental organisations and civil society in the development and implementation of effective pro-child policies and programmes; and to promote a common voice for children in and out of Africa.



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# Acronyms

<b>ACPF</b>	<b>African Child Policy Forum</b>
<b>ACRWC</b>	<b>African Charter on the Rights and Welfare of the Child</b>
<b>CRC</b>	<b>UN Convention on the Rights of the Child</b>
<b>CRPD</b>	<b>Convention on the Rights of Persons with Disabilities</b>
<b>DISTAT</b>	<b>Disability Statistics Database (United Nations)</b>
<b>DPO</b>	<b>Disabled People’s Organisation</b>
<b>ICESCR</b>	<b>International Covenant on Economic, Social and Cultural Rights</b>
<b>IDP</b>	<b>Internally Displaced Person(s)</b>
<b>NGO</b>	<b>Non-governmental Organisation</b>
<b>NHRI(s)</b>	<b>National Human Rights Institution(s)</b>
<b>UN</b>	<b>United Nations</b>
<b>UNICEF</b>	<b>United Nations Children’s Fund</b>
<b>UNESCO</b>	<b>United Nations Educational, Scientific and Cultural Organization</b>
<b>WASH</b>	<b>Water, Sanitation and Hygiene</b>
<b>WB</b>	<b>World Bank Group</b>
<b>WHO</b>	<b>World Health Organization</b>
<b>ZAFOD</b>	<b>Zambian Federation of the Disabled</b>



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# Foreword

Persons with disabilities remain one of the most marginalised and excluded people in society. They face multiple physical barriers, discrimination and even deliberate abuse and violence. Many children with disabilities and their families are severely deprived of the basic resources and services that could enable them to develop to their full human potential. They are denied opportunities for education, socialisation and recognition. Most have very limited access to healthcare, clean drinking water, and sanitation, and nutritional deficiencies are widespread among children with disabilities. Only one in every ten children with disabilities gets access to education in Africa. The challenges facing children with disabilities are further complicated by the widespread negative attitudes and the stigma and discrimination they face in their daily lives: within their families and communities; at the level of service providing institutions; and in the law- and policy-making arenas.

This report is part of ongoing efforts to shed light on the realities that children with disabilities in Africa face. It is an important reference document for law and policy makers, service delivery institutions, civil society organisations, development partners, parents and community leaders. The report lays out a set of recommendations intended to contribute towards correcting the injustices, neglect and exclusion faced by so many children with disabilities. I believe that the issues revealed in this report will further re-orient society's thinking and its treatment of children with disabilities, from one of rejection and neglect to one of respect and inclusion. Indeed, the world is becoming less tolerant of exclusionary and discriminatory practices, including discrimination against persons with disabilities due to the increasing knowledge as well as growing awareness of universal human rights. Increased global commitment and accountability to the rights of persons with disabilities was made more recently by the adoption in 2006 of the UN Convention on the Rights of Persons with Disabilities and its Optional Protocol.

I urge all stakeholders, therefore, to commit themselves based on this and other similar evidence to take action. We need action that eliminates discrimination and ensures genuine inclusion; action that enables children with disabilities to enjoy a life full of dignity; action that eliminates all barriers and ensures equal opportunities and access to basic services; and lastly, action that promotes respect and recognises the contribution of children with disabilities to society.

A world that is exclusionary is lacking in social justice. Let us aim to build an Africa that embraces all its children and people with the ideals of equality, respect, dignity and social justice.

**Benyam Dawit Mezmur**

Chairperson, African Committee of Experts on the Rights and Welfare of the Child  
Vice-Chairperson, UN Committee on the Rights of the Child



# Preface

Africa has one of the largest populations of children with disabilities in the world. Disability on the continent has been fuelled by the affects of widespread armed conflict, including as result of uncleared mines, by poverty and a lack of adequate healthcare services. Many African children are born with some form of disability that could have been prevented by pre and postnatal healthcare services.

Children with disabilities in Africa comprise one of the most neglected groups, both socially and economically. The majority of these children and their families face enormous economic, political, and social barriers that have adverse impacts on their physical, social and intellectual development and wellbeing. As a consequence, the strengths and abilities of children with disabilities are invisible, their potential is consistently underestimated, and inadequate resources are allocated to social services for meaningful inclusion of children with disabilities.

Gaps in research evidence have hampered effective policy and legislative responses. In response to these gaps, ACPF embarked on a number of studies with the aim to better understand the situation, lives and experiences of children with disabilities in Africa. These studies, which were conducted between 2008 and 2014, examined the scale of disability in Africa, of the relationship between poverty and disability, access to services and the barriers that children with disabilities face.

The African Report on Children with Disabilities: Promising starts and persisting challenges represents a synthesis of the extensive research conducted by ACPF. It describes, including through the voices of children, and analyses the cultural, social, physical and other societal barriers preventing children with disabilities from realising their full human potential. The pan-African Report also describes the opportunities initiatives and good practices that exist, that indicate the progress, albeit insufficient, that has been made towards realising the rights for children with disabilities in Africa.

This report provides the evidence and analysis on children with disabilities in Africa. We present this Africa-wide report with great pleasure for use in law and policy formulation and implementation as well as for programme development as a contribution towards improving the lives of children with disabilities in Africa.

**H.E. Joaquim Chissano**

Chair, International Board of Trustees, ACPF  
President of Mozambique (1986-2005)



# Executive Summary

The overarching aim of ACPF's The African Report on Children with Disabilities: Promising starts and persisting challenges is to provide description, analysis and synthesis of the situation of children with disabilities across Africa, and to provide concrete recommendations for future policy and programme reform.

The report reviews the situation of children with disabilities from a pan-African perspective, and presents recommendations to promote inclusive and accessible laws, policies, and programmes for children with disabilities throughout Africa. The report is based on extensive research and evidence generated by ACPF and other institutions.

The lack of reliable and appropriately disaggregated data on children with disabilities is an impediment to the formulation of legal frameworks and their implementation. The lack of reliable data stems in part from a lack of standardised definitions of disability and a general lack of nationally representative data. Existing ambiguities in data are also a result of no distinction being made between degrees of severity of impairment.

In addition, data is affected by the fact that parental stigma exacerbates low birth registration of children with disabilities. For example, more than 79 per cent of children with visual impairments and 24 per cent of children with multiple disabilities are not registered in Ethiopia, while in Uganda, about 79 per cent of children with multiple disabilities and 58 per cent of children with intellectual impairments are not registered at birth.

More than one billion people, or 15 per cent of the world's population, have a

disability. The World Disability Report (WHO/World Bank, 2011) estimates that there are between 93 and 150 million disabled children aged under 14 years. The prevalence for moderate and severe disability in this age cohort in Africa is 6.4 per cent.

## Key Findings of the ARCwD

- Law and policies to promote and protect the rights of children with disabilities are not in place or are poorly monitored or implemented.
- Data and statistics on children with disabilities are not credible or reliable, are not appropriately disaggregated on the basis of disability, gender and age where needed, and do not accurately capture the number of children with disabilities or their needs.
- Children with disabilities and their families encounter stigma and discrimination.
- Multiple barriers create inaccessible infrastructure, information, and communication systems, thus impacting the realisation of rights for children with disabilities.
- Children with disabilities have limited access to early childhood development, education, health care, rehabilitation, and justice systems.
- Children with disabilities experience various forms of exploitation, violence and abuse.

Africa has a large population of children with disabilities. For example, an estimated 7.5 per cent of the total population in South Africa has a disability, and in Tanzania, children with disabilities account for about 4.5 per cent of the total child population.

Disability in Africa is largely attributable to war, poverty, and inadequate access to health and rehabilitation services. For example, it is estimated that 75 per cent of blindness in Africa can be prevented or cured. In Ethiopia, 60 per cent of children with visual impairments acquired them through preventable illnesses. In South Africa, the main contributors to childhood impairment and disability, in order of prevalence, are illness; pre- and peri-natal problems such as genetic disorders and birth trauma; injuries; accidents; and violence.

Children with disabilities face extreme forms of violence, stigma and discrimination based on misconceptions about the cause of disability that are rooted in cultural beliefs and traditions. The most frequently stated causes of disability in Africa include witchcraft; a curse or punishment from God; anger of ancestral spirits; bad omens; reincarnation; heredity; incestuous relationships; and the misdemeanours of the mother. These misperceptions not only lead to stigma, but also to a belief that children with disabilities should be demonised. As a result, children may be lashed in attempts to drive out “evil spirits” causing the disability, or may be neglected or even killed. Negative attitudes about children with disabilities within communities are reinforced at the household level and parents themselves often contribute to these children becoming invisible, virtually hidden from society.

However, ACPF studies have shown that societal attitudes towards children with disabilities are gradually improving in Africa and becoming more supportive. For example, the majority of households in the studies did not exclude their children with disabilities from family activities (66.7 per cent) or religious events (79.3 per cent). Within the family, 62.4 per cent treated the children with respect and did not hurt or abuse them because of their disability, and 41 per cent of children with disabilities reported they always get emotional support from family members when they feel sad, troubled or upset. 38 per cent of children were, however, still hurt or abused by members of their community.

Children with disabilities are twice as likely to become victims of violence when compared to non-disabled peers. Children with speech impairments were at five times greater risk of neglect and physical abuse than other children, and three times greater risk of sexual abuse. And the risk is between five and seven times higher than for those children with behavioural disorders than for children without disabilities.

A study in the eastern Africa region showed that 16 to 20 per cent of children with disabilities are victims of abuse. ACPF surveys revealed a high prevalence of sexual violence amongst children with disabilities, ranging from 1.9 counts per child per year in Senegal to 3.9 counts per child per year in Cameroon, far higher than for their non-disabled peers.

The factors exacerbating the vulnerability of children with disabilities to violence include their inability to report abuse or describe abusers because of language and communication barriers; their inability to flee or see their assailants approaching; their presence in residential care institutions; and their limited understanding of their rights. As revealed by a study in South Africa, children with intellectual disabilities are three to eight times more common in abused than in non-abused children.

Students with disabilities are also frequently physically abused as a means of disciplining them for behaviours that may be related to their disabilities. It is known that many children with disabilities display a variety of “problem” behaviours that are the product of complex interactions of a number of variables such as temperament, cognitive endowment, environmental hardship, learning history and experience of aggression.

Furthermore, prejudices about the incapacity of children with disabilities, coupled with their physical inaccessibility to courts and the failure to provide appropriate interpretation or other forms of support within the justice system, mean that they are unlikely to seek or gain justice. This leads to impunity for violent offenders.

In Africa, children with disabilities will continue to be perceived as a “burden to society” as long as their potential goes unrecognised by families, communities and authorities. Due to factors including negative attitudes, a lack of resources, poverty, and a lack of proper service standards, children with disabilities remain excluded from basic early childhood education, healthcare and rehabilitation services.

In Africa, fewer than 10 per cent of children with disabilities receive any form of education and only two per cent attend school. For example, 48 per cent of children with disabilities contacted in an ACPF study in Ethiopia had never been to school; the remaining 52 per cent had previously attended. Survey findings estimate that 76 per cent of children with disabilities in Sierra Leone are out of school; 67 per cent of children with disabilities aged between six and 14 are not attending any form of schooling in the Central African Republic; and in Senegal, 64 per cent of children with disabilities contacted in the ACPF survey did not attend school at all.

School drop-out is a significant problem among pupils with disabilities. Reasons for dropping out include the school refusing to keep the child on account of his or her disability, insufficient funds, and inaccessible facilities. For instance, 36.7 per cent of children surveyed in rural Senegal cited a school’s refusal to accept their child as the reason for the child not being in school, while six per cent cited the inability of teachers to teach children with disabilities. 18.4 per cent of children with disabilities surveyed in rural Ethiopia cited the long distances between their homes and their schools as the reason for not attending school. Lack of appropriate assistive devices also creates significant barriers that deny children with disabilities in Africa their right to an education.

Children with disabilities have a right to health, both in terms of meeting their basic needs and with regard to any specialised needs that they require as result of their disability. Disability itself is most often caused by preventable illnesses and a lack of access to prenatal or postnatal health services.

Children with disabilities are often denied access to adequate health care in Africa due to physical inaccessibility or challenges associated with travel to the facilities. In the cases of impoverished families in which children with disabilities are disproportionately impoverished, they may not be able to afford health service costs. This partly explains the higher rate of mortality among children with disabilities. While under-five mortality as a whole decreased in some countries to below 20 per cent, mortality among young children with disabilities has remained as high as 80 per cent.

There is also a serious shortage of early identification and rehabilitation services across Africa. Children with communication and sensory impairments are particularly disadvantaged, as they rarely receive the assistive devices and rehabilitation they require to develop to their full human potential. For example:

- In 2011, only 7.5 per cent of public hospitals in South Africa were able to provide some sort of infant hearing screening
- About 15 per cent of children with disabilities surveyed in Ethiopia live in an area where there no health services in their communities at all. Health services remained inaccessible for the majority of children with disabilities. The main reasons included expense (28 per cent) and a lack of accessible transport (12 per cent). NGOs provide the majority of health care services, including 87 per cent of CBR services; 65 per cent of specialised rehabilitation services; 88 per cent of occupational therapy; 84 per cent of speech therapy; 69 per cent of audiologist services; 62 per cent of ophthalmologist services; 81 per cent of counselling services; and 80 per cent of dietician services.
- In Senegal, a significant proportion of respondents said that they relied on religious healers (65.2 per cent) and traditional doctors (67.1 per cent). Leaving access aside, very few children even know of the existence of specialised services such as rehabilitation centres (16.9 per cent of children knew such centres existed); ophthalmologists (25.4 per cent); physical therapists (11.6 per cent); dieticians (7.8 per cent); orthopaedists (1.3 per cent); audiologists (1.1 per cent); and occupational therapists (0.9 per cent).
- 70 per cent of children with disabilities surveyed in Uganda said they relied on a religious faith healer; 54 per cent on a traditional healer; and 35 per cent on a community-based rehabilitation worker. Only 18.5 per cent reported having access to specialised rehabilitation services in their community.
- The 2006/7 National Department of Health Audit of Accessibility of Provincial Health Facilities to Persons with Disabilities in South Africa found that district hospitals were less accessible to people with disabilities than tertiary hospitals. Less than 10 percent of the 213 hospitals surveyed had a fully accessible toilet for persons with disabilities.

Children with disabilities have a right to adequate standards of living including housing and access to clean water and sanitation; yet only six per cent of Ethiopians and eight per cent of children with disabilities surveyed in Senegal reported having access to safe water sources. In Ethiopia 14 per cent of children with disabilities reported having no access to any toilet facility. 28 per cent had access to a communal pit latrine, and only seven per cent could access a flush toilet.

Children with disabilities continue to face significant barriers to access to water points, community, recreation and religious centres, and even their own homes. Most homes and neighbourhoods are not adapted to allow free mobility of children with disabilities. In Senegal, a survey of households having a child with a disability living with them showed that very few homes were so adapted, even with basic modifications like ramps (13.5 per cent); handrails (8.1 per cent); items related to toilet facilities (35.2 per cent); accessible furniture (16.2 per cent); and adjusted lighting fixtures (10.8 per cent). In Uganda, only 6.3 per cent of households having a child with a disability living with them said they had adapted their dwelling or accommodation to improve access for children with disabilities; 83.1 per cent had done nothing to adapt their dwellings, while 6.9 per cent were not aware of adaptation as an issue at all. Only 13 per cent of respondents in such households surveyed in Ethiopia stated that their houses had been physically adapted to assist their child with a disability.

Only two per cent of children with disabilities surveyed in Senegal reported that the doors of their houses were wide enough to allow free mobility, while only nine per cent of children with disabilities in Ethiopia reported access to appropriately modified toilets. Children with disabilities are, therefore, denied the equal opportunity to engage in their own families' activities as well as those of their communities.

Children with disabilities require support in terms of rehabilitation that helps improve their disability, or at least to manage it and limit its negative consequences. ACPF studies and others illustrated the huge unmet rehabilitation needs of children with disabilities in Africa. For example, in Senegal only 25.4 per cent of children with disabilities surveyed reported having access to ophthalmologists, while 11.6 per cent reported access to physiotherapists. Only 7.8 per cent of the children had access to dieticians, 1.3 per cent to speech therapists, 1.1 per cent to audiologists, and 0.9 per cent to occupational therapists. Less than 16 per cent of children surveyed in Ethiopia and 18.5 per cent of those in Uganda had access to specialised rehabilitation services such as occupational therapy, physiotherapy, speech therapy and audiology. Disability is highly correlated with poverty, and therefore families of children with disabilities are often heavily reliant on external assistance in order to meet their basic needs, as well as the additional costs associated with disability.

Social protection measures and other interventions that provide livelihood options are a priority for these families if their children are to be enabled to enjoy a life of dignity.

Due to disability-related stigma, discrimination and multiple other barriers, children with disabilities are often forced to work under exploitative and dangerous conditions. In many cases, they are forced to beg on the streets or undertake heavy domestic work. Their situation is often exacerbated by barriers to the justice system that prevent many from reporting abuse. Children with disabilities face significant challenges, not only in terms of physically accessing police stations and courts, but also in accessing the appropriate information and support, and being taken seriously during the justice process.

In response to the challenges above, many governments in Africa have put in place legislative and policy frameworks and programmes. The Convention on the Rights of Persons with Disabilities (CRPD) is serving as an important catalyst for disability law reform. There is, however, a significant amount of work needed to implement these instruments effectively. In addition to the relevant provisions contained in the African Charter on the Rights and Welfare of the Child (ACRWC), Africa is in the course of developing its own Protocol of the Rights of Older Persons and Persons with Disabilities, which is expected to further contextualise disability in Africa.

A number of good examples of legislation and policy exist throughout the continent. These include Constitutional provisions that protect the right to equality and non-discrimination of children with disabilities; legislative frameworks that facilitate access to the built environment and to information; and laws that entitle children with disabilities to free access to education and healthcare services, and to social assistance. Countries have either subsumed the issue of children with disabilities under broader child rights legislative and policy frameworks, or developed disability-specific legislation. Countries like Kenya, Zambia, Uganda, Sierra Leone, and Central African Republic have put in place laws that require public and private service providers to ensure access to public infrastructure and free healthcare services, and to allow access to assistive and mobility devices at reduced prices.

These good examples notwithstanding, a large number of countries' laws and policies still do not comply with international standards. There are also challenges associated with implementing relevant laws and policies. While some countries have created disability focal organisations for co-ordinating the implementation of inclusive programmes and interventions, these face capacity constraints that have undermined their effectiveness in monitoring and co-ordination, including in performing disability audits within government departments.

Furthermore, lack of synergy between policies, tendency to work in silos even within government, the disconnect between national and sub-national government levels, and the lack of adequate norms and standards for services have also been reported as implementation obstacles. Most such government bodies also fail to work in collaboration with DPOs, limiting their outreach and effectiveness.

# Priorities for Action

Based on the above analysis, the following recommendations are made with the intention of improving the situation of children with disabilities in Africa.

These recommendations imply a need for greater and accelerated collective action, particularly by African governments, regional bodies, NGOs, DPOs and development partners.

## 1 Put in place and implement appropriate legislation, policy and programmes in keeping with the CRPD

Ensure that:

- National laws and policies are harmonised with the CRPD, and that Sector Plans are developed in a manner consistent with the goals of the CRPD
- A national body, with a coordinator, is set up, comprised of multi-disciplinary and cross sectoral experts responsible for promoting and monitoring the implementation of disability inclusive policies and practices, including at sub-national level
- Specific, realistic, structured budgets are allocated for the effective implementation of disability-inclusive policies and practices and are closely monitored and evaluated
- The technical skills of those involved in service delivery programming, including those in the education and health sectors, are enhanced at national and sub-national levels
- Quality standards and indicators are developed for effective disability programming.

## 2 Develop and implement effective child protection measures for children with disabilities

Ensure that:

- Interventions are designed and implemented to address disability-based stigma and discrimination
- Preventative and remedial child protection services are made available, accessible and effective for children with disabilities
- Birth registration services are made freely available and accessible to children with disabilities, including through greater involvement of local community leaders, hospitals, churches and midwives
- Parenting and counselling interventions are designed and implemented for parents in order to enable them to address the special needs of their children with disabilities

Access to justice and legal services is ensured for children with disabilities, including by providing information in user-friendly formats and ensuring physical accessibility to justice facilities.

### **3 Ensure the provision of basic services in a disability-friendly manner**

Ensure that:

- Appropriate social protection measures are implemented for children with disabilities and their families in order to alleviate household poverty and improve standards of living
- Free or subsidised access is provided to preventive and curative healthcare and nutrition interventions
- Medical and rehabilitation practitioners (For example, audiologists, speech-language pathologists, dieticians, occupational therapists, etc.) of sufficient quality are made available in appropriate numbers
- Pregnant mothers are provided with screening services for disability-causing diseases and allowed appropriate medical follow-up
- Water and sanitation facilities are made accessible to children with physical and visual disabilities
- Early childhood development programmes are made available and accessible for children with disabilities, including through inter-sectoral co-ordination
- All teachers and school personnel are given adequate training to facilitate educational inclusion of children with disabilities
- School infrastructure and school accommodation are made accessible, and assistive devices are made available
- Centres with the necessary resources and expertise are created for assessing and supporting learners with disabilities, for making learning and teaching materials accessible, and for issuing assistive devices.

## 4 Improve physical accessibility of the built environment

Ensure that:

- Buildings and facilities are designed and constructed with users with disabilities and universal access in mind
- Families, communities and service providers are educated and provided with the skills to implement simple, inexpensive ways of adapting their homes for children with disabilities
- Assistive devices and rehabilitation services are made available free of charge or at affordable prices
- Tax exemptions on importations of assistive devices are put in place and local production of quality devices is encouraged
- Adequately trained rehabilitation experts of sufficient quality are made available in adequate numbers to provide mobility training and occupational therapy.

## 5 Build evidence and promote evidence-based advocacy and cross-learning

Ensure that:

- Government departments responsible for health, social development and education are mandated to include disaggregated data on children with disabilities in their information systems
- Advocacy efforts of national DPOs are strengthened, reinforced and supported to ensure that policies and laws are acted on, and that duty-bearers fulfil their obligations to children with disabilities and their families
- Good practices in inclusion and inclusive development are identified, and learning on these practices is catalysed in government, NGOs, communities and the private sector
- DPOs and other disability stakeholders advocate for inclusive development in their engagement with international donors and development assistance agencies, including for the inclusion of children with disabilities.

The disability landscape in Africa is indeed rapidly changing. For children with disabilities, the past has been undoubtedly characterised by exclusion, invisibility and isolation – yet there is a paradigm shift occurring within cultures and nations, and differences are increasingly perceived and even valued as opportunities. Within this unprecedented era of accountability, perhaps there is scope for more deliberate actions and measures for children with disabilities to realise their rights and enjoy a life free of stigma, abuse and exclusion.



# Chapter 1

## Introduction and report background

Africa is home to a large number of children with disabilities, although establishing accurate statistical estimates on the prevalence of disability in Africa remains a major challenge. Most disabilities in Africa result from preventable causes such as lack of access to basic healthcare services, war-related injuries and car accidents. Children with disabilities and their families continue to confront barriers that inhibit their full and equal enjoyment of human rights and fundamental freedoms. Discrimination and exclusion on the basis of disability persists and is a deeply entrenched phenomenon in all spheres of life – economic, political, religious, and cultural.

The aim of this The African Report on Children with Disabilities: Promising starts and persisting challenges is to provide an evidence base on children with disabilities in Africa, in order to inform policy and programme action. The report consolidates the extensive research work on children with disabilities undertaken by the African Child Policy Forum (ACPF) in Africa. It also draws on the work of other organisations and individual researchers to create a detailed picture of children with disabilities across the continent.

The inspiration for this report is the recognition by ACPF that children with disabilities are among the most neglected and least visible groups in Africa. Law and policy documents, sectoral development plans, poverty reduction programmes and data sets all neglect to account for children with disabilities. It is increasingly understood that gathering and disseminating evidence-based data on the situation of children with disabilities is an essential precondition to realising their human rights. Reliable and credible data drives law, policy, strategic plans, and effective services, and supports an environment that fosters human rights.

This report analyses the growing body of work on the situation of children with disabilities across Africa. It synthesises previous studies and reports of the ACPF as well as data from other sources and identifies emerging themes and provides key recommendations for future action.

Multiple sources were referenced in the preparation of this report, including existing statistical data sources, primary research findings, government policy and programme documents, NGO reports and general literature reviews. The report examines the situation of children with disabilities from a pan-African perspective, and takes into account the diversity of disability types, variations in levels of economic development, and varying socio-cultural contexts based on country-specific studies.

Should the reader wish to explore country-specific or thematic works in greater detail, reference may be made to the African Child Information Hub (<http://www.africanchild.info>).

## A note on the data source

This report is the result of a desk based analysis and synthesis of various sources on children with disabilities in Africa, which include the following:

### ACPF surveys and studies

- A pan-African overview of the challenges and opportunities facing children with disabilities in various sectors
- Surveys on the lives of children with disabilities in Ethiopia, Senegal, South Africa and Uganda
- Surveys on the education of children with disabilities in Central African Republic, Ethiopia, Sierra Leone, South Africa and Zambia
- A field study of the disability accessibility of five cities in Africa, namely Addis Ababa, Freetown, Johannesburg, Kampala and Lusaka
- An in-depth study of legislative, policy and programmatic good practices related to children with disabilities in Kenya, Liberia and Mozambique
- Field studies on violence against children with disabilities in Cameroon, Ethiopia, Senegal, Uganda and Zambia

### Other sources

- Review of major African and international publications on children with disabilities in Africa such as the African Disability Rights Year Book (Vol. I & II), World Disability Report, UNICEF's State of the World's Children Report 2013
- Declarations, Communiqués and Concluding Observations of the UNCRC and the ACERWC
- Annual and technical reports produced by DPOs
- Universal Periodic Reports
- State Party reports submitted to the UN Special Rapporteur on Disability
- Thematic reports by government ministries
- Annual and technical reports related to disability of UN agencies
- Reports by NGOs and INGOs on children with disabilities in Africa
- Journal articles and relevant theses and dissertations on children with disabilities

**Chapter 2** of the report begins with an overview of the situation of children with disabilities in Africa, and identifies barriers that impede the full realisation of their rights. In so doing, it draws on available qualitative and quantitative data in an effort to provide a comprehensive picture of the conditions facing children with disabilities throughout Africa.

Some of the themes are universal, insofar as children with disabilities around the world encounter common experiences of stigma and discrimination. Many, however, are unique to the African context, and identifying these is a first step in formulating a response to, and preventing human rights abuses of, children with disabilities throughout Africa.

**Chapters 3 and 4** provide important background information allowing a better understanding of both the cultural context within which children with disabilities live, and the regional and international law and policy framework that should inform national action on disability rights.

**Chapters 5 to 11** explore the extent of access to education, healthcare and rehabilitation services; the extent of violence and access to justice for children with disabilities.

**Chapter 12** provides an overview of the state of national monitoring and implementation mechanisms of disability strategies and programmes.

The report concludes with a comprehensive list of recommendations for policymakers and disability rights practitioners in the field; educators; healthcare and other service providers; and development partners.



# Chapter 2

## Children with disabilities in Africa

### 2.1 Defining disability

The definition of disability varies from one country to another, depending on the disability model upon which domestic legislation is based. Some definitions are still embedded in the biomedical model, wherein disability is identified with illness or impairment, with an emphasis placed on curing the disabled individual. This model attributes the causes of disability to medical conditions.<sup>1</sup>

Other definitions, especially those contained in most social welfare legislation, reflect the charity and economic dependency models, wherein disability is portrayed as a tragedy and persons with disabilities are considered as unproductive and burdens on society.

A more recent definition of disability that is becoming increasingly accepted, emerges from the social model of disability. This model views disability as a social construct, in that most of its effects are inflicted upon people by their social environment – for example, it is not the disability or the wheelchair that disables a person, but rather the stairs leading to a building. Definitions based on this model take the wider view that the ability of people with disabilities to engage in activities is dependent upon the extent of social intervention, and that activity limitations are not caused by impairments, but are rather a consequence of social organisation.<sup>2</sup>

The social model is an important framework for the following reasons:<sup>3</sup>

- Firstly, it provides a framework and language through which people with disabilities can describe their experiences
- Secondly, it allows naming and challenging discrimination, exclusion and inequality
- Thirdly, it offers a means by which the question of disability can be explained and understood in terms of wider socioeconomic conditions and relations
- Fourthly, it provides a basis for support and collective engagement of people with disabilities.

<sup>1</sup> <http://www.westerncape.gov.za/general-publication/disability-definitions-models-and-terminology>

<sup>2</sup> Tregaskis, C. (2002). Social Model Theory: The story so far. *Disability and Society* 17 (4). pp. 457-470.

<sup>3</sup> Barton, L. (2003). *Inclusive education and teacher education: A basis of hope or a discourse of delusion*. Pear Tree Press. Hertfordshire.

The social model forms the basis of the definition of disability adopted by the UN Convention on the Rights of Persons with Disabilities (CRPD) (Art.1), which defines persons with disabilities to include:

...those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. This report adopts this definition of disability and encourages others to do the same in their policy formulation and programme development endeavours.

## 2.2 The prevalence of disability among children in Africa

The prevalence of disability among children in Africa is very difficult to assess accurately, not only because of difficulties relating to standardised definitions, but also because of incomplete data collection and inaccurate statistical results. Available data tends to differ considerably from country to country due to divergent classifications, definitions, and thresholds in categorising disability. Ethiopia is an example of a country that has a high threshold for categorising a person as disabled, and therefore estimations do not necessarily represent the entire population of those who are disabled. Ethiopia estimates that 1.09 per cent of its population is disabled. However, that data excludes persons who are homeless, persons with temporary impairments, and persons with sensory impairments who are deemed to perform activities within the “normal” range.<sup>4</sup> Other estimates put the prevalence of disability in Ethiopia at 7.6 per cent.<sup>5</sup> In 1997, one report from Liberia noted that the national prevalence of disability was 16 per cent (prior to the armed conflict); but the 2008 Census reported the prevalence to be 3.1 per cent.<sup>6</sup>

The low percentage of persons with disabilities reported in most African countries is widely disparate from the findings of the 2011 World Report on Disability, which found that on average, 15 per cent of the world’s population has disabilities.<sup>7</sup> The underreporting of disability generally may be attributed to the ways in which data collection questions are framed – for example, when they are phrased ambiguously<sup>8</sup> or because of a lack of clarity of distinctions between the degrees of severity of impairment or methodologies used in assessments.

<sup>4</sup> ACPF (2011). The Lives of Children with Disabilities in Africa: A glimpse into a hidden world. Addis Ababa.

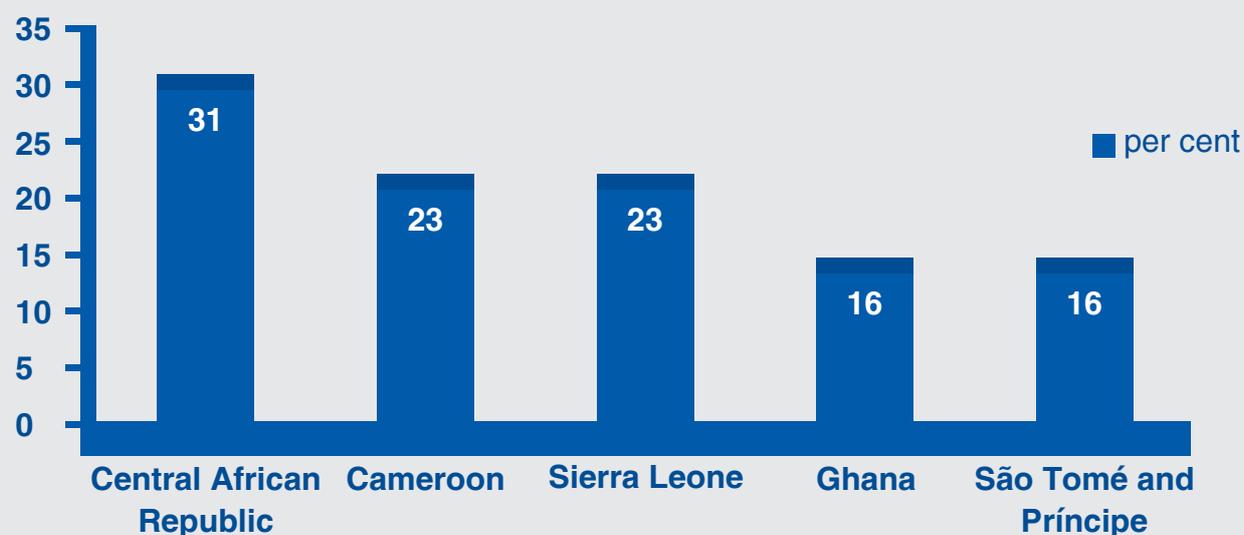
<sup>5</sup> Wakanè, D.B. (2011). The Role of Disability Rights Movements in the Ethiopian Development Agenda. Thesis. Stellenbosch University.

<sup>6</sup> Liberia Civil Society National Budget & Human Rights Forum (2012). Briefing Paper to Honorable Members of the National Legislature and Government of Liberia.

<sup>7</sup> World Health Organization & World Bank (2011). World Report on Disability.

<sup>8</sup> Lewis, I. (2009). Reaching the marginalized Education for Disabled People in Ethiopia and Rwanda. Background paper prepared for the Education for All Global Monitoring Report 2010.

**Figure 2.1** Percentage of disability among children 2-9 years of age in selected countries



**Source:** UNICEF & University of Wisconsin Achool of Medicine and Public Health (2008). *Monitoring Child Disability in Developing Countries-Result from the Multiple Indicator Cluster Surveys*. UNICEF. New York.

However, the limited data that is available shows that the prevalence of disability among children is very high. For instance a UNICEF survey showed that prevalence of disability among children aged 2-9 years is as high as 31 per cent in countries like Sierra Leone, 23 per cent in Cameroon and Central African Republic (Figure 2.1). The relatively low prevalence reported in other countries is likely to be the result of less robust data collection systems, stringent definitions of disability and a general lack of data itself (Box 2.1).

It is similarly difficult to access accurate data on the number of children with disabilities in most countries, not only because of divergent classifications, definitions, and thresholds in categorising disability, but also because of stigma on both familial and societal levels. Disability-based stigma, often rooted in long-held traditional beliefs, impacts on data collection, as parents may be reluctant to report that a child has a disability. Low birth registration rates among children with disabilities mean that children are not registered with health and rehabilitation services, schools and other social services. The segregation of children with disabilities into institutions, which is increasingly common in African countries, also hinders accurate data collection.<sup>9</sup> Children may also not be registered at birth or may not receive documentation of their disabilities because their families live in poverty or are illiterate. Furthermore, children of internally displaced families are less likely to have registration documentation.<sup>10</sup>

<sup>9</sup> UNICEF, Innocenti Research Centre (2007). *Promoting the Rights of Children with Disabilities*. Innocent Digest 13. <http://www.unicef-irc.org/publications/pdf/digest13-disability.pdf>

<sup>10</sup> Stein, M.A. & Lord, J.E. (2011). *Enabling Refugee and IDP Law and Policy: Implications of the UN Disability Convention on the Rights of Persons with Disabilities*. Faculty Publications. Paper 1461. <http://scholarship.law.wm.edu/facpubs/1461>

## Box 2.1 Reflections on the absence of reliable disability data

We don't have national data which talks about prevalence – the numbers of people with disabilities. There are...studies...but the government does not acknowledge them.

**Retta Getachew**

Ethiopian Centre for Disability and Development | Addis Ababa, Ethiopia

We know that in Uganda we do not have enough information or data about disability – we don't know the numbers. Some NGOs [provide data], but it is not authentic – it's not recognised by the authorities if only one NGO produces data.

**Dolorence Were**

Uganda Society for Disabled Children | Kampala, Uganda

In 2000 the census estimated that we have around 240,000 people with disabilities and in last year's census, after 10 years, it said we have around 350,000. But that's a serious underestimation. The population in 2000 was 9.4 million and last year...13 million. We did our own survey at ZAFOD and discovered that 13.4 per cent of Zambians had some disability, which is closer to the current estimate released by WHO World Disability Report [of] about 15 per cent.

**Wamundila Waliuya**

Zambia Federation of the Disabled (ZAFOD) | Lusaka, Zambia

Incomplete and incorrect data on the prevalence of children with disabilities creates a major barrier to positive change. African governments underestimate the number of children with disabilities, leading to a failure to prioritise the unique needs of children with disabilities and allocate sufficient funds for those needs.

African governments are making efforts to improve the quality of data on disability in order to comply with the mandates of Article 31 of the CRPD.<sup>11</sup> Additionally, in 2005 the United Nations Statistics Division launched a new effort for the systematic and regular collection of basic disability statistics.<sup>12</sup>

The following section describes in more detail the barriers to reliable data collection on disability prevalence: low birth registration rates; poverty; and stigma associated with disability in the African context.

<sup>11</sup> UNICEF, Innocenti Research Centre (2007). Promoting the Rights of Children with Disabilities. Innocenti Digest No. 13. Article 31 mandates the collection of disability data, disaggregated as appropriate as to age, gender and other factors. CRPD, Art. 31.

<sup>12</sup> UNICEF, Innocenti Research Centre (2007). Promoting the Rights of Children with Disabilities. Innocenti Digest No. 13. <http://www.unicef-irc.org/publications/pdf/digest13-disability.pdf>

## 2.3 Framing disability in the African context

Across the world, disability has traditionally been recognised as a medical, welfare, or even a charity issue. Both the medical and charity perspectives on disability have contributed towards reinforcing stigma and discrimination against persons with disabilities.

Stigma based on disability can have severe consequences for children with disabilities: stigma often causes parents to hide their children or keep them isolated from their communities. Negative perceptions have also served as the basis for the adoption of discriminatory and paternalistic policies and legal frameworks that have excluded children with disabilities from decision-making and have separated them into segregated schools and long-term care institutions.

Throughout Africa, addressing disability is often viewed as a matter of charity, with religious institutions or other organizations deemed appropriate to provide food or clothes for children with disabilities. In some African countries, disability is viewed strictly through a medical lens. The Constitution of Mozambique offers an example of how the medical model has been articulated in legal frameworks: Article 37 of the Constitution explicitly mentions that people with disabilities are entitled to enjoy all human rights contained in the Constitution – and yet the provision creates a clear exception that excludes persons with disabilities from exercising those rights which their disability ‘prevents’ them from exercising, and ‘exempts’ them from those duties that their disability precludes them from fulfilling. The provision states that:

...Disabled citizens shall enjoy fully the rights enshrined in the Constitution and shall be subject to the same duties, except those which their disability prevents them from exercising or fulfilling.<sup>13</sup>

Most disability in Africa results from preventable causes. The existing available evidence shows that in Africa:

- Illness-related infections account for 65 per cent of all cases of disability among children. Complications during birth and the birthing process, accidents and violence account for 17 per cent, 11 per cent, and 2 per cent of all cases of disability, respectively.<sup>14</sup>
- 75 per cent of blindness can be prevented or cured.<sup>15</sup>

<sup>13</sup> Mozambique Constitution, Art. 37. This exception, which embodies elements of the medical model of disability, cannot be regarded as a ‘best practice’.

<sup>14</sup> ACPF (2011). Violence against Children with Disabilities in Africa: Field studies from Cameroon, Ethiopia, Senegal, Uganda and Zambia. Addis Ababa.

<sup>15</sup> ACPF (2011). Children with Disabilities in Africa: Challenges and opportunities. Addis Ababa.

- 50 per cent of all cases of deafness and hearing impairments are avoidable through prevention, early diagnosis and management of meningitis, measles, mumps, chronic ear infections, malaria and tuberculosis (TB).<sup>16</sup>
- Asphyxia during birth leaves about 1 million children with learning difficulties and impairments such as cerebral palsy.<sup>17</sup>
- 70 per cent of cases of spina bifida – a disability that affects between 1,000 and 3,000 children per million in Africa – are preventable if pregnant women take folic acid supplements.<sup>18</sup>
- A significant percentage of disabilities could be prevented through breastfeeding and vitamin A supplementation. In Cameroon, Central African Republic and Ghana, a greater percentage of children (2-9 years of age) who were never-breastfed were found to be living with a disability than children who were breastfed.<sup>19</sup> In Ghana, Central African Republic and São Tomé and Príncipe, the prevalence of disability among children (2-9 years of age) was higher among those who did not receive vitamin A supplementation than those who received it.<sup>20</sup>
- In Ethiopia, for example, 60 per cent of children with visual impairments acquired them through illness.<sup>21</sup>
- River blindness (Onchocerciasis) is one of the leading illnesses causing blindness in Africa, affecting mainly rural villages with unsafe water sources. It is a major health problem in 27 African countries, putting approximately 100 million people at risk.<sup>22</sup>

<sup>16</sup> ACPF (2011). Children with Disabilities in Africa: Challenges and opportunities. Addis Ababa.

<sup>17</sup> ACPF (2011). Children with Disabilities in Africa: Challenges and opportunities. Addis Ababa.

<sup>18</sup> ACPF (2011). Children with Disabilities in Africa: Challenges and opportunities. Addis Ababa.

<sup>19</sup> UNICEF & University of Wisconsin School of Medicine and Public Health (2008). Monitoring Child Disability in Developing Countries-Results from the Multiple Indicator Cluster Surveys. UNICEF. New York.

<sup>20</sup> UNICEF & University of Wisconsin School of Medicine and Public Health (2008). Monitoring Child Disability in Developing Countries-Results from the Multiple Indicator Cluster Surveys. UNICEF. New York.

<sup>21</sup> ACPF (2011). Children with Disabilities in Ethiopia: The hidden reality. Addis Ababa.

<sup>22</sup> [http://www.cbmun.org.uk/pdf/River\\_Blindness\\_Factsheet.pdf](http://www.cbmun.org.uk/pdf/River_Blindness_Factsheet.pdf)

- In South Africa, the main contributors to childhood impairment and disability are illness; pre- and peri-natal problems such as genetic disorders and birth trauma, injuries, accidents, and violence.<sup>23</sup> Indeed, the South African Department for Social development estimated that up to 40 per cent of the causes of disability are preventable (DSD 2009).<sup>24</sup>
- 50 per cent of cases of disability among children surveyed in Senegal, 38 per cent in Ethiopia and 32 per cent in Uganda resulted from illness (Table 2.1).<sup>25</sup>

**Table 2.1** Causes of disability among children, by country

Cause and onset of disability	Ethiopia		Senegal		Uganda	
	Cause	per cent	Cause	per cent	Cause	per cent
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
<b>Total</b>	<b>470</b>	<b>100</b>	<b>456</b>	<b>100</b>	<b>517</b>	<b>100</b>

**Source:** ACPF (2011). *The Lives of Children with Disabilities in Africa: A glimpse into a hidden world*. Addis Ababa.

<sup>23</sup> Republic of South Africa, Department of Health (1999). *We also count! The extent of moderate and severe reported disability and the nature of the disability experience in South Africa*. Study conducted by the Community Agency for Social Enquiry (CASE).

<sup>24</sup> Republic of South Africa, Department of Social Development (2009). *Integrated national strategy on support services to children with disabilities*. DSD: Pretoria.

<sup>25</sup> ACPF (2011). *The Lives of Children with Disabilities in Africa: A glimpse into a hidden world*. Addis Ababa.

According to an ACPF survey in Ethiopia, disability-causing factors in Ethiopia, as in other countries, are highest during the prenatal and postnatal stages.<sup>26</sup> 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 care, and the absence of sufficient preventative services. Between 55-68.4 per cent of caregivers in the survey reported that their child acquired a disability before the age of five, and between 73-90.6 per cent of disabilities were caused by birth or childhood illness. Inadequate care for pregnant women and infants is a critical factor in disability prevention.<sup>27</sup>

War and conflict also account for a large number of disabilities in Africa. For example, deliberate amputations used as instruments of war during the civil war in Sierra Leone, and the high prevalence of unexploded mines in countries such as Angola and Mozambique, have left many with physical disabilities. Many children also become disabled as a result of their direct involvement in war as child combatants in countries such as Uganda, South Sudan, DR Congo (DRC) and the Central African Republic (CAR). According to estimates, there are over 100 thousand child soldiers in Africa.<sup>28</sup>

Given these facts, it is no coincidence that the CRC Committee, in General Comment No 9 (paragraphs 53, 54 & 55), clearly highlighted the importance of prevention by:

- Introducing prenatal and postnatal healthcare services for children and expecting mothers
- Providing public education and support for pregnant mothers who may be abusing substances
- Preventing dumping of hazardous materials
- Preventing road traffic accidents
- Clearing up unexploded landmines and keeping children away from suspected areas

## **2.4 Birth registration of children with disabilities**

Failure to register children with disabilities at birth is a major challenge throughout Africa. It is imperative that all children – with or without disabilities – are registered at birth and that they obtain a birth certificate in order to enjoy the full range of human rights. Gradually, across Africa, birth registration is no longer perceived merely as a proof of nationality but rather as a tool to access his or her rights.

<sup>26</sup> ACPF (2011). Children with Disabilities in Ethiopia: The hidden reality. Addis Ababa.

<sup>27</sup> ACPF (2011). Children with Disabilities in Ethiopia: The hidden reality. Addis Ababa.

<sup>28</sup> <http://en.kindernothilfe.org/Rubrik/Topics/Child+Soldiers/Facts+and+figures.html>

When children are not registered at birth, they cannot access all the rights to which citizens in a country are entitled. For example, if a child with a disability does not have a birth certificate he or she will not be allowed to enrol in school. The low birth registration rate of children with disabilities also leads to inaccurate data about the number of children with disabilities in a country. Inaccurate data significantly hinders the success of early childhood development and other interventions aimed at supporting children with disabilities and their families.

Many countries in Africa have low registration rates for children with disabilities. For example, only 28.5 per cent of children with disabilities in Ethiopia and 48.7 per cent of children with disabilities in Uganda<sup>29</sup> are registered at birth. Notably, the number of children with disabilities registered at birth in both countries may be even lower than the statistics suggest, because many caregivers surveyed were unaware of their child's registration status, and others declined to answer. The issue is particularly concerning in Uganda because the number of children with disabilities registered (48.7 per cent) is well below the national average of 62.0 per cent for birth registration of all children.<sup>30</sup> The majority of unregistered children with disabilities were born in rural areas, usually with the help of midwives: infants born with the assistance of a midwife rather than a medical doctor are easier to conceal, and less likely to have a birth registration.<sup>31</sup>

Children with multiple disabilities are even less likely to be registered compared with their peers with only one disability. For example, in Senegal only 40.9 per cent of children with multiple disabilities were registered at birth, which is striking in comparison to the birth registration rates for children with one disability (82.6 per cent for children with physical disabilities; 69.9 per cent for children with intellectual disabilities; 68.1 per cent for children with visual disabilities; and 67 per cent for children with auditory/hearing disabilities) (Table 2.2).<sup>32</sup> Stigma and the low expectations for survival for a child with multiple disabilities may be contributing factors to this.

<sup>29</sup> ACPF (2011). *The Lives of Children with Disabilities in Africa: A glimpse into a hidden world*. Addis Ababa.

<sup>30</sup> A 2000 survey indicated only 4 per cent of births were registered in Uganda. By 2005, birth registration increased to 62 per cent, but only 26 per cent of registered children received birth certificates. It is uncertain how many registered children with disabilities received birth certificates in 2005.

<sup>31</sup> ACPF (2011). *The Lives of Children with Disabilities in Africa: A glimpse into a hidden world*. Addis Ababa.

<sup>32</sup> UNESCO (2010). *Reaching the marginalized*. Oxford University Press. UNESCO.

**Table 2.2** Births registered by disability type

Disability Type	Ethiopia			Senegal			Uganda		
	Cause		per cent	Cause		per cent	Cause		per cent
	Sample	Registered		Sample	Registered		Sample	Registered	
Physical	138	36	25.1	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
<b>Total</b>	<b>497</b>	<b>133</b>	<b>27</b>	<b>421</b>	<b>299</b>	<b>71.0</b>	<b>513</b>	<b>223</b>	<b>44</b>

The cost of registration, including costs for travel and accommodation as well as the cost incurred in lost income as a result of the registration process, remain critical determinants of whether people register their children.<sup>33</sup> In Kenya, the Orphans and Vulnerable Children cash transfer programme succeeded in increasing birth registration by 12 per cent in comparison with the control group.<sup>34</sup>

The low level of birth registration of children with disabilities at birth is rightly recognised by CRC General Comment No 9:

Children with disabilities are disproportionately vulnerable to non-registration at birth. Without birth registration they are not recognized by law and become invisible in government statistics...Children with disabilities who are not registered at birth are at greater risk of neglect, institutionalization, and even death.<sup>35</sup>

In light of Article 7 of the CRC, General Comment No 9, under paragraph 3, recommends that States Parties:

...adopt all appropriate measures to ensure the registration of children with disabilities at birth. Such measures should include developing and implementing an effective system of birth registration, waiving registration fees, introducing mobile registration offices and, for children who are not yet registered, providing registration units in schools. [emphasis added]

<sup>33</sup> UNICEF (2005). Every Child’s Birth Right: Inequities and trends in birth registration, UNICEF. New York.

<sup>34</sup> Garcia, M. & Moore, C.M.T. (2012). The cash dividend. The rise of cash transfer programs in Sub-Saharan Africa. The World Bank. Washington DC.

<sup>35</sup> CRC GC 9 para. 34.

The CRPD reiterated this requirement in Art. 18(2):

Children with disabilities shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and, as far as possible, the right to know and be cared for by their parents.

In response to this, some countries have made notable improvements in birth registration for children with disabilities. Using technology and strengthening health systems, a number of countries are investing in innovative ways to strengthen birth registration to include children with disabilities (Box 2.2).

## Box 2.2 Targeted programming to promote birth registration

It has been found that many children with disabilities in Africa are not registered at birth. For example, in Ethiopia, as many as 79 per cent of children with visual impairments are not registered.<sup>36</sup> This leads to the exclusion of children with disabilities from health, education, and other services.

Against this background, it is significant that UNICEF has undertaken initiatives in a number of countries to increase birth registration rates. These have included integrating birth registration with health services (for example, in the Gambia and Mozambique);<sup>37</sup> establishing mobile registration units (for example, in Namibia);<sup>38</sup> and introducing new technologies such as registration by means of mobile phone texting, which has been adopted with good results in Uganda and Senegal.<sup>39</sup>

While these efforts are to the benefit of all children, they are specifically significant for ensuring the inclusion of children with disabilities, who have been disproportionately excluded from birth registration.

<sup>36</sup> ACPF (2011). Children with Disabilities in Africa: A glimpse into a hidden world. Addis Ababa.

<sup>37</sup> Muzzi, M. (2010). UNICEF Good Practices In Integrating Birth Registration Into Health Systems (2000-2009). Working Paper.

<sup>38</sup> Bloemen, S. (2009). Birth Registration Effort Aims To Protect Child Rights in Namibia [www.unicef.org/infobycountry/namibia\\_51570.html](http://www.unicef.org/infobycountry/namibia_51570.html)

<sup>39</sup> Anon (2012). Senegal: Texting for birth certificates. <http://www.irinnews.org/report/96066/senegal>

Anon (2011). Texting-for-birth-certificates; Uganda. Birth and death records will boost better planning. <http://allafrica.com/stories/201109220030.html>

## 2.5 Poverty and disability

Disability is a function of poverty.<sup>40</sup> According to the World Report on Disability, persons with disabilities experience higher rates of poverty than persons without disabilities.<sup>41</sup> People with disabilities are at risk of being discriminated against based on their perceived status, including their economic status. Therefore, the CRPD anticipated the “critical need to address the negative impact of poverty on persons with disabilities.”<sup>42</sup>

Across Africa, childhood disability is closely associated with poverty. Disability among children living in poverty often reflects the failure of the state to meet its obligation to provide maternal health services for women during pregnancy and basic health services for children in early childhood.<sup>43</sup> Children living in poverty are more likely to experience illness and infection, particularly in the vulnerable years of infancy and early childhood.

Poor people often live under relatively poorer sanitary conditions (lack of sewage systems, lack of access to clean water), which may compound their risks of being disabled. Similarly, children living in poor, urban slums are more likely to be exposed to the debilitating hazardous waste. In many African cities, urban slum dwellers come in contact with stockpiles of obsolete pesticides such as Polychlorinated Biphenyls (PCBs), dioxins, and Dichlorodiphenyltrichloroethane (DDT) and e-waste that contaminate soil and water, causing reproductive and developmental disorders and damaging the nervous systems<sup>44</sup> and causing impairments. Exposure to heavy metals, also common in urban waste dumpsites, poses serious threats, particularly to children and during foetal development.<sup>45</sup>

At the same time, disability can further entrench poverty by creating barriers to education and future employment opportunities for children with disabilities. Lack of community support may hinder families from working or taking on income-generating activities because of the need to care for a child with a disability<sup>46</sup> (Box 2.3).

<sup>40</sup> Lord, J.E. & Stein, M.A. (2008). The Domestic Incorporation of Human Rights Law and the United Nations Convention on the Rights of Persons with Disabilities. Faculty Publications. Paper 665. <http://scholarship.law.wm.edu/facpubs/665>

<sup>41</sup> World Health Organization & World Bank (2011). World Report on Disability. [http://www.who.int/disabilities/world\\_report/2011/report/en](http://www.who.int/disabilities/world_report/2011/report/en)

<sup>42</sup> CRPD: Preamble: The States Parties to the present Convention. <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx>

<sup>43</sup> UNESCO (2010). EFA global monitoring report 2010: Reaching the marginalized. Paris.

<sup>44</sup> Gordon, B. et al. (2004). Inheriting the World: The Atlas of children’s environmental health and the environment.

<sup>45</sup> Gordon, B. et al. (2004). Inheriting the World: The Atlas of children’s environmental health and the environment.

<sup>46</sup> UNICEF, Innocenti Research Centre (2007). Promoting the Rights of Children with Disabilities. Innocent Digest No. 13. <http://www.unicef-irc.org/publications/pdf/digest13-disability.pdf>

As both a cause and a consequence of disability, poverty serves as a major barrier to participation and inclusion. Children with disabilities are less likely to have access to adequate health care, medicines, and assistive devices. In addition, where services are available families may not have the resources to pay for assistive devices, medicine, or school fees, or for transport to and from school for their children.

### Box 2.3 Links between poverty and disability

- A review of 14 developing countries found that persons with disabilities are more likely to experience poverty than persons without disabilities.<sup>47</sup>
- Research indicates that people living in poverty are more likely to experience disability than those not living in poverty<sup>48</sup> A UNICEF study showed that children in the poorest 60 per cent of households are at increased risk of disability compared with children of the wealthiest 40 per cent of families.<sup>49</sup>
- A study in Malawi and Uganda found that households with members with disabilities have lower incomes than households that do not have members with disabilities.<sup>50</sup>

## 2.6 The new paradigm

The CRPD explicitly embraces a social model of understanding disability, by providing that:

“...disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others”

The social model of disability highlights the ways in which society creates barriers for persons with disabilities and impacts their enjoyment of human rights. For example, when a person who uses a wheelchair comes across a staircase, the result is a disability; in other words, the interaction between the individual’s physical impairment and the inaccessibility of the staircase is the disability. Conversely, when a building has a ramp,

<sup>47</sup> Mitra, S., Posarac, A. & Vick, B. (2011). Disability and Poverty in Developing Countries: A Snapshot from the World Health Survey. World Bank Publications.

<sup>48</sup> Groce, N., Kembhavi, G., Wirz, S., Lang, R., Trani, J.F. & Kett, M. (2011). Poverty and disability: A critical review of the literature in Low and Middle-Income Countries. Leonard Cheshire Disability and Inclusive Development Centre.

<sup>49</sup> UNICEF & University of Wisconsin School of Medicine and Public Health (2008). Monitoring Child Disability in Developing Countries: Results from the Multiple Indicator Cluster Surveys. UNICEF. New York.

<sup>50</sup> World Health Organization & World Bank (2011). World Report on Disability. [http://www.who.int/disabilities/world\\_report/2011/report/](http://www.who.int/disabilities/world_report/2011/report/)

persons who use wheelchairs can enter the building on an equal basis with others. This constitutes a paradigm shift in the understanding of how disability is defined that is reflected in some key legal documents (see Box 2.4).

### **Box 2.4** Uganda and Ethiopia: Shift to the social model of understanding disability

In its report to the CRPD Committee, the Government of Uganda provides a definition of disability and discusses the current trend toward the social model:

**22.** The Persons with Disabilities (PWD) Act 2006 defines disability as “a substantial functional limitation of daily life activities caused by physical, mental or sensory impairment and environmental barriers resulting in limited participation”.<sup>51</sup> By recognizing that disability is the result of the interaction between impairment and external barriers, the PWD Act aligns the legal definition of disability in the Ugandan law to that enshrined in the CRPD, implying a significant paradigm shift away from the medical/charitable models, to understanding disability as a social phenomenon.<sup>52</sup>

Similarly, the Government of Ethiopia redefined the definition of disability to include a social dimension:

**5.** The latest authority on the definition of disability in Ethiopia is the 2008 employment right legislation. Article 2 (1) of the proclamation reads as follows: “Person with disability” means an individual whose equal employment opportunity is reduced as a result of his physical, mental or sensory impairments in relation with social, economic and cultural discrimination (Employment Right Proclamation no. 568/2008, art. 2/1.)<sup>53</sup>

Societal attitudes towards children with disabilities are gradually improving in Africa and are becoming more supportive. For example, the majority of households in ACPF studies did not exclude their children with disabilities from family activities (66.7 per cent) or religious events (79.3 per cent). Within the family, 62.4 per cent treated the children with respect and did not hurt or abuse them because of their disability, and 41 per cent of children with disabilities reported they always get emotional support from family members when they feel sad, troubled or upset.<sup>54</sup>

<sup>51</sup> Persons with Disabilities Act. Art. 2: Interpretation.

<sup>52</sup> Uganda CRPD Report, para. 22.

<sup>53</sup> Ethiopia CRPD Report, para. 5.

<sup>54</sup> ACPF (2011). Children with Disabilities in Africa: A glimpse into a hidden world. Addis Ababa.

# Chapter 3

## Cultural and attitudinal barriers to Inclusion

### Introduction

In Africa, children with disabilities and their families face a longstanding history of stigma, discrimination, and exclusion from mainstream society (Box 3.1). As a result, they are routinely denied basic human rights and fundamental freedoms such as the rights to pursue an education, live with their families, enjoy recreational and sporting activities, and generally participate in the lives of their communities.<sup>55</sup> Participants in ACPF studies across Africa consistently reported experiencing stigma, prejudice and discrimination.<sup>56</sup>

Stigma, discrimination, and exclusion are deeply rooted in traditional African beliefs and attitudes surrounding disability.<sup>57</sup> Research indicates that in many countries disability is perceived as a curse from God.<sup>58</sup> Misperceived causes of disability in African communities include witchcraft; curse or punishment from God; anger of ancestral spirits; bad omens; reincarnation and heredity; incestuous relationships; and misconduct of their mothers.<sup>59</sup>

Negative attitudes towards disability are pervasive in all strata of African societies, from high-level authorities and policy-makers in government, to traditional chiefs and religious leaders, to the rural homes of African families. These negative attitudes have led to the deprivation of people with disabilities on multiple levels. For example, government authorities and policymakers in African countries tend to ignore the needs of citizens with disabilities and fail to ensure that relevant policies are adequately inclusive, enforced or budgeted for. Communities themselves, where traditional belief systems associate disability with divine retribution, magical curses, and demonic possession, can reinforce children's deprivation, even leading to them being deliberately neglected and shunned.

<sup>55</sup> World Report on Disability (2011).

<sup>56</sup> ACPF (2014). Access Denied: Voices of persons with disabilities from Africa. Addis Ababa. ; ACPF (2011). Educating Children with Disabilities: Towards a policy of inclusion. Addis Ababa.

<sup>57</sup> ACPF (2011). Educating Children with Disabilities: Towards a policy of inclusion. Addis Ababa. ; ACPF (2014). Access Denied: Voices of persons with disabilities from Africa. Addis Ababa.

<sup>58</sup> EveryChild, Enabling Reform. (n.d.).

<sup>59</sup> ACPF (2011). Educating Children with Disabilities: Towards a policy of inclusion. Addis Ababa.

### **Box 3.1** Understanding stigma and discrimination in the context of disability

**Stigma** may be defined as an attribute regarded as undesirable that a person or group possesses, and which results in a lowering of that person or group's status in the community. Stigma can result from an actual or perceived disability.

**Discrimination on the basis of disability** is defined in the CRPD as “any distinction, exclusion or restriction based on disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights. It includes all forms of disability discrimination, including denial of reasonable accommodation”.<sup>60</sup>

**Stigma and discrimination are connected.** Stigma can lead to prejudice and active discrimination against a person with a disability, a family member, or someone associated with a person with a disability.

### **3.1** Community perceptions about children with disabilities

Human rights studies conducted across Africa reveal that the denial of human rights as a result of stigmatising beliefs and attitudes is a common experience for children with disabilities and their families.<sup>61</sup> Stigma and discrimination based on disability increases the risk of violence and abuse in many African communities.<sup>62</sup> For example, the forced ingestion of harmful substances is considered a remedy for mental disabilities in some communities.<sup>63</sup> In Ghana, persons and children with psychosocial disabilities are exposed to abuse in prayer camps where they are chained to trees for lengthy periods, denied food, and exposed to the sun in supposed ‘healing’ processes.<sup>64</sup> In Sierra Leone, persons with epilepsy are ‘subjected to traditional treatments that are “tantamount to torture” – cuts, burning, inhaling or drinking potions’.<sup>65</sup> There are reports from some West African communities of persons with autism being expelled into the bush because they are considered ‘possessed’ and their behaviour is ‘demonic’.<sup>66</sup> In Tanzania there are widespread accounts of people and children with albinism being abducted and killed due to the ‘superstitious belief’ that utilizing their body parts ‘will lead to great wealth’.<sup>67</sup>

<sup>60</sup> CRPD Art. 2.

<sup>61</sup> ACPF (2011). Children with Disabilities in Africa: Challenges and opportunities. Addis Ababa.

<sup>62</sup> ACPF (2011). Children with Disabilities in Africa: Challenges and opportunities. Addis Ababa.

<sup>63</sup> Lord, J.E. (2010). Shared understanding or consensus-masked disagreement? The anti-torture framework in the Convention on the Rights of Persons with Disabilities. *Loyola of Los Angeles International & Comparative Law Review* 78, No. 285, reviewing customary practices, including the forced ingestion of harmful substances to ‘heal’ persons with psycho-social disabilities, a practice observed during field work in Ethiopia.

Children with disabilities are generally perceived as incapable of becoming self-sufficient, unable to learn, and therefore undeserving of ‘opportunity’. There is a general tendency to think of children with disabilities as weak, hopeless, dependent, unable to learn and subjects of charity.<sup>68</sup>

Sometimes when I go out with my son, people consider us beggars, and just want to throw some coins. It is really upsetting and hurting.

**Parent of a child with a disability**

**Educating Children with Disabilities: Ethiopia**

In some cases, these negative attitudes result in parents keeping children in confinement as a result of their shame, as illustrated by a girl with a visual disability in Ethiopia:

...I was kept inside the house most of the time grinding grain. Growing up blind was hell, my hands were numb and swollen, and I was expected to do it all the time because I am blind and cannot do any other meaningful things.<sup>69</sup>

Different forms of disability-based stigma and discrimination are explained by the extent to which socio-legal norms about disability are applied. Undoubtedly, local contexts impact on perceptions of and attitudes towards children with disabilities. Moreover, attitudes

<sup>64</sup> Whitaker, R. (2001). *Mad in America: Bad science, bad medicine, and the enduring mistreatment of the mentally ill.* ; World Health Organization & Mental Health and Poverty Project (2010). *Mental health and development: Targeting people with mental health conditions as a vulnerable group.* ; (WHO/MH).  
[http://whqlibdoc.who.int/publications/2010/9789241563949\\_eng.pdf](http://whqlibdoc.who.int/publications/2010/9789241563949_eng.pdf) ; Human Rights Watch

(2012). *Ghana: People with Mental Disabilities Face Serious Abuse.*  
<http://www.hrw.org/news/2012/10/02/ghana-people-mental-disabilities-face-serious-abuse>

<sup>65</sup> New York Times. 29 August 2011. ‘Stigma is toughest foe in an epilepsy fight’.  
<http://www.nytimes.com/2011/08/30/health/30epilepsy.html?pagewanted=all> .

Bangura also reported that one of the association’s members survived drinking two liters of kerosene. Girls and young women are subjected to sexual assault as a purported ‘cure’, says Bangura.

<sup>66</sup> See No. 64 above.

<sup>67</sup> Albinism Foundation of East Africa. Petition: 13 December 2008.

[http://www.albinismfoundationea.com/index.php?option=com\\_content&task=view&id=6&Itemid=2](http://www.albinismfoundationea.com/index.php?option=com_content&task=view&id=6&Itemid=2)  
CNN. 2 March 2011. ‘Rights groups accuse Kenya of patient abuse’.

[http://articles.cnn.com/2011-03-02/world/kenya.health\\_1\\_human-rights-rights-groups-solitary-confinement?s=PM:WORLD](http://articles.cnn.com/2011-03-02/world/kenya.health_1_human-rights-rights-groups-solitary-confinement?s=PM:WORLD)

<sup>68</sup> Tirussew, T. (2005). *Disability in Ethiopia: Issues, Insights and Implications.* Addis Ababa University Printing Press. Addis Ababa.

<sup>69</sup> Cited in: Tirussew, T. (2005). *Disability In Ethiopia: Issues, Insights and Implications.* Addis Ababa University Printing Press. Addis Ababa.

and beliefs about disability vary based on the type of impairment. An understanding of these differences and complex interactions is important in order to address disability-based stigma and discrimination.

Stigma and discrimination are also perpetuated by parents themselves, especially in communities that reinforce exclusion of children with disabilities as a norm. However, ACPF studies have shown that societal attitudes towards disabled children are gradually improving and becoming more supportive in Africa. For example, the majority of households did not exclude their disabled children from family activities (66.7 per cent) or religious events (79.3 per cent). Within the family, 62.4 per cent treated the children with respect and did not hurt or abuse them because of their disability, but 38 per cent of children were hurt or abused by members of their community. Further, about half, or 41 per cent of children with disabilities reported they always get emotional support from family members when they feel sad, troubled or upset.

### **3.2 Parental attitudes towards children with disabilities**

Negative parental attitudes to disability pose a tremendous challenge to some children with disabilities in their own homes. Negative parental attitudes lead families to isolate, hide or essentially imprison children with disabilities in the family home. This, in turn, results in denying them access to education and social interaction compared to their siblings without disabilities.

The parents' attitude matters a lot – there will be children whose parents will not send them to school because of attitude – the stigma of having a child with a disability.

**Aychesh Molla,**

Ethiopian Center for Disability and Development | Addis Ababa, Ethiopia

Children with particular forms of disability, such as deafness, blindness or intellectual impairment, are often particularly vulnerable to prejudicial attitudes within the home.

If you look at these children in a home setting, the deaf blind child is very often marginalized. While others are eating good food, this child is left to be alone. I have seen cases of deaf blind children of up to 10, 14 years old, who still have not learned how to chew food because from their childhood their parents have resorted to just feeding the child with liquid or mashed material.

**Aloysius Kiribaki,**

Sense International Uganda | Kampala, Uganda

African tradition often blames the child's disability on the mother. When she is blamed, she is expected to assume all responsibility for the child's welfare. It is common for fathers to

reject responsibility for a child with disabilities because of this belief, leading to total abandonment or divorce.

The male parents are a problem. Once you have a child with a disability, that child belongs to the mother only. You, the father, did not take part in the creation of that child. Everything remains on the mother's side. The family on the father's side, they are also washing their hands of any responsibility and saying 'this is not our child'.

**Astrida Kunda,**

Zambia Association of Parents of Children with Disabilities | Lusaka, Zambia

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**

In cases where fathers do accept their child with a disability, they often experience societal discrimination.

It's difficult to hear from your peers that you are not a man because you fathered a disabled child.

**Dolorence Were**

Uganda Society for Disabled Children | Kampala, Uganda

In some African communities specific types of disabilities are regarded as curses or ill omens attributable to witchcraft or sorcery<sup>70</sup> (Table 2).

The perception that says that disability is a Godly curse still exists in the community... so, many children with disabilities are kept at home... If you go to rural communities in many parts of the country, children with disabilities are not taken into public, or to schools or any other social services.

**Teshome Deressa,**

Federation of Ethiopian National Associations of People with Disabilities  
Addis Ababa, Ethiopia

<sup>70</sup> Kisanji, J. (1995). Growing Up Disabled. In: Zinkin, P. & McConachie, H. (eds.). Disabled Children and Developing Countries. Mac Keith Press. London.

You'll meet groups of parents and they will tell you stories of demonizing children with disabilities. This is traditional and they think if you have a child with disability... that there is witchcraft around or you were promiscuous as a woman – you could have been a prostitute or doing prostitution while pregnant or it could have been a curse.

**Wamundila Waliuya,**

Zambian Federation of the Disabled (ZAFOD) | Lusaka, Zambia

Many parents hideaway children with disabilities in the home and deny them access to education, healthcare, rehabilitation, and other social services.<sup>71</sup> There are reports of children with disabilities being so severely neglected that it results in death. In Sierra Leone, the ritual murder of babies with disabilities is also reported.

I can categorically spell out here that there are harmful traditional practices that are being carried out against children with disabilities. For instance, children with multiple disabilities are murdered in the interior part of the country...these are ritual killings that they are doing...they will take the child into the middle of the bush, murder the child there and bury it deep in a grave.

The objective is to return the 'evil' child to the evil one – so they will put the perception into the minds of the people that the child, before he went back to the bush, he changed into a big snake and they will bring in this to make the whole process appear so fearful.

**Patrick James Taylor,**

Human Rights Commission | Freetown, Sierra Leone<sup>72</sup>

In some contexts, many children with disabilities are disowned by their parents, are not given a clan name, or are or are not permitted to inherit land.<sup>73</sup>

Some of the different types of stigma and the resultant discriminatory practices are summarised in Table 3.1.

<sup>71</sup> ACPF (2014). Access Denied: Voices of persons with disabilities from Africa. Addis Ababa.

<sup>72</sup> ACPF (2014). Access Denied: Voices of persons with disabilities from Africa. Addis Ababa.

<sup>73</sup> Terre des Hommes Nederland (2007). Hidden Shame: Violence against children with disabilities in East Africa.

**Table 3.1** Disability-related stigma and its discriminatory effects

<b>Witchcraft</b>	Subjected to harmful “treatments”, threats to life
<b>Possession by demons</b>	Subjected to harmful practices for “cure”, tied to trees, ritual killings
<b>Highly contagious</b>	Exclusion from community activities
<b>Possessing supernatural powers</b>	Violence, killed for body parts
<b>Cursed</b>	Isolation, hidden away at home, exclusion from school and community activities
<b>Punishment for sins of mother</b>	Mother and child shunned; abandonment by father
<b>Incompetent; unreliable</b>	Unable to serve as a witness in legal proceedings, including cases involving disability-based violence

Aware of the challenges presented by families that isolate their children, some countries have put in place legislation to criminalise acts of hiding and concealing children with disabilities. Examples include Section 35 of the Sierra Leone Persons with Disability Act 3 of 2011:

[A parent, guardian, next-of-kin or carer who]

- (a) Conceals a person with disability, or
- (b) fails to register a person with disability,

commits an offence and shall on conviction be liable to a fine not exceeding two million Leones<sup>74</sup> or to imprisonment for a term not exceeding one year or to both such fine and imprisonment.”

A similar provision is contained in section 45 of the Persons with Disabilities Act 14 of 2003 of Kenya:

- 1) No parent, guardian or next of kin shall conceal any person with a disability in such a manner as to deny such a person the opportunities and services available under this Act

<sup>74</sup> Equivalent to USD 455 at time of writing.

2) A person who contravenes subsection (1) is guilty of an offence and is liable on conviction to a fine not exceeding twenty thousand shillings.<sup>75</sup>

### 3.3 Gender-based stigma and discrimination

In Africa, there is a strong gender dimension to the stigma and discrimination experienced by children with disabilities. Girls and boys with disabilities experience different types of stigma and discrimination.

Disabled people have often been represented as without gender, as asexual creatures, as freaks of nature, monstrous, the ‘other’ to the social norm...yet the image of disability may be intensified by gender – for women a sense of intensified passivity and helplessness, for men a corrupted masculinity generated by enforced dependence.<sup>76</sup>

Girls with disabilities are often the least likely to be given the necessary support—for example, to enable them to access education, employment and appropriate general health care services. Girls are at higher risk of abuse and violence, which in turn can aggravate existing disabilities or create secondary disabilities such as psychosocial trauma. In some African countries there is a widespread belief that individuals with a sexually transmitted disease, such as HIV/AIDS, can rid themselves of the disease through sexual intercourse with a virgin; and so the assumption that girls with disabilities are asexual, and therefore virgins, places them at particular risk for “virgin rape.”<sup>77</sup>

Girls with disabilities are subjected to double discrimination, based both on their disability status and their gender. Gender bias results in lower literacy and education rates for women and girls with disabilities. Disability discrimination combined with gender discrimination results in a high proportion of women and girls with disabilities being denied access to school. UNESCO estimates that the literacy rate for persons with disabilities worldwide is only 3 per cent, while rates for women and girls with disabilities are about 1 per cent.<sup>78</sup> When treated unequally, girls cannot fully enjoy their other rights; a girl with a disability who receives an inferior education in relation to boys will be treated unequally throughout her work life.

<sup>75</sup> Equivalent to USD 224 at time of writing.

<sup>76</sup> Meekosha, H. (2004). Gender and Disability. Draft entry for the forthcoming Sage Encyclopaedia of Disability written in 2004.

<sup>77</sup> Groce, N. & Trasi, R. (2004). Rape of Individuals With Disability: AIDS and the Folk Belief of Virgin Cleansing. *The Lancet* 363. pp. 1663-1664.

<sup>78</sup> Groce, N. (2011). Women with Disabilities in the Developing World. *Journal of Disability Policy Studies*. pp. 177-93.

### 3.4 Positive traditional practices that reinforce inclusion of children with disabilities

In Africa, there are also a number of positive cultural values and practices that enable children with disabilities to be included within their communities and cared for and protected from ostracisation. These practices represent potential opportunities for policies and programmes to which can reinforce them to promote family-based and community-based protection of children with disabilities (Box 3.2).

#### Box 3.2 Positive African cultural values relating to children with disabilities

- In the Xhosa-speaking families in the Western Cape in South Africa, family and family love are seen as gifts from God.<sup>79</sup> Thus, parents and caregivers often express the importance of ‘love’ to their children, including children with disabilities<sup>80</sup>
- In the Tonga community of Zimbabwe, parents have no problem accepting a child with a disability and there is no evidence of Tonga families hiding their children with disabilities.
- In Botswana, the notion of Kagisano reinforces the obligations that societies have to the ‘lame’, the ‘halt’ and the mentally disabled. This also relates to the Tswana concept of Botho (respect for the humanity in all human beings), a concept incorporated into the country’s Vision 2016. Hence, this cultural norm is essentially about acceptance rather than rejection, inclusion rather than segregation of children with disabilities.
- The Zulu concept of Ubuntu, part of the Zulu phrase Umuntu ngumuntu ngabantu, literally means that “a person is a person through other people”. Ubuntu is a concept that upholds common humanity and oneness: humanity, you and me both, hence places an obligation on individuals to acknowledge the essential humanness of others.<sup>81</sup> It is a basic respect and compassion for others, including for those with disabilities. It can be interpreted as both a factual description and a rule of conduct or social ethic. It describes being human as “being-with-others”, and prescribes what “being-with-others” should be about.<sup>82</sup>
- Among the citizens of Benin, constables (law enforcement officers of a rural district) have been selected from those with obvious physical handicaps.<sup>84</sup>
- The Ga tribes of the Accra region in Ghana treat people with intellectual disabilities with awe. They believe that persons with intellectual disabilities are the reincarnation of a deity. Hence, they are always treated with great kindness, gentleness and patience.<sup>85</sup>

### 3.5 Tackling stigma and discrimination: Legislative and programmatic responses

Tackling stigma and discrimination based on disability requires deliberate action by government, DPOs, NGOs, and communities. Article 8 of the CRPD requires States Parties to raise awareness “throughout society, including at the family level, regarding persons with disabilities”, and “to foster respect for the rights and dignity of persons with disabilities”. A change in public and family attitudes requires significant and protracted investment in deliberate measures to redress pervasive stigma and discrimination.

There is improvement, albeit gradual, in terms of greater acceptance and inclusion of children with disabilities in Africa, especially in urban communities; this has been brought about largely as a result of efforts by DPOs and NGOs to raise public awareness of rights of persons with disabilities.

Furthermore, some countries have constitutional provisions that expressly protect children and adults with disabilities from discrimination. These countries include South Africa, Malawi, Zimbabwe, Eritrea, Kenya, Ghana, Namibia and Gambia (Table 3.2).

<sup>79</sup> Greeff, A.P. & Loubser, K. (2008). Spirituality as a resiliency quality in Xhosa-speaking families in South Africa. *Journal of Religion and Health*, 47(3). pp. 288-301.

<sup>80</sup> Chataika, T. & McKenzie, J. (2013). Considerations of an African childhood disability studies'. In: Curran, T. & Runswick-Cole, K. (eds). *Disabled Children's childhood studies: Critical approaches in a global context*.

<sup>81</sup> Hopkin, A.G. (2004). *Special Education in Botswana: Social inclusion or exclusion?* Pula: Botswana Journal of African Studies. Vol. 18 No. 1. Centre for Academic Development. Affiliated Institutions Unit. University of Botswana.

<sup>82</sup> Louw, D.J. (2004). *Ubuntu: An African Assessment of the Religious Other*  
<https://www.bu.edu/wcp/Papers/Afri/AfriLouw.htm>

<sup>83</sup> Amoako, J.B. (1977). *Integrating the disabled into the community*. University of Cape Coast. Ghana.

<sup>84</sup> Field, M. J. (1940). *Social organisation of the Ga people: The Crown Agents for the Colony*. London.

**Table 3.2** Constitutions expressly recognising disability as a protected ground of discrimination

Country	Constitutional provision	Content provision
South Africa	Sec 9(3)&(4)	<p>(3) The state may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, <b>disability</b>, religion, conscience, belief, culture, language and birth.</p> <p>(4) No person may unfairly discriminate directly or indirectly against anyone on one or more grounds in terms of subsection (3). National legislation must be enacted to prevent or prohibit unfair discrimination.</p>
Malawi	Sec 20 (1)	Discrimination of persons in any form is prohibited and all persons are, under any law, guaranteed equal and effective protection against discrimination on grounds of race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, <b>disability</b> , property, birth or other status or condition.
Zimbabwe	Sec 56(3)	Every person has the right not to be treated in an unfairly discriminatory manner on such grounds as their nationality, race, colour, tribe, place of birth, ethnic or social origin, language, class, religious belief, political affiliation, opinion, custom, culture, sex, gender, marital status, age, pregnancy, <b>disability</b> or economic or social status, or whether they were born in or out of wedlock.
Eritrea	Art 14(2)	No person may be discriminated against on account of race, ethnic origin, language, colour, gender, religion, <b>disability</b> , age, political view, or social or economic status or any other improper factors.
Kenya	Sec 27(4)	The State shall not discriminate directly or indirectly against any person on any ground, including race, sex, pregnancy, marital status, health status, ethnic or social origin, colour, age, <b>disability</b> , religion, conscience, belief, culture, dress, language or birth.

**Table 3.2** (Continued): **Constitutions expressly recognising disability as a protected ground of discrimination**

Country	Constitutional provision	Content provision
Uganda	Art 21(1)&(2)	<p>(1) All persons are equal before and under the law in all spheres of political, economic, social and cultural life and in every other respect and shall enjoy equal protection of the law.</p> <p>(2) Without prejudice to clause (1) of this article, a person shall not be discriminated against on the ground of sex, race, colour, ethnic origin, tribe, birth, creed or religion, social or economic standing, political opinion or <b>disability</b>.</p>
Gambia	Sec 31(2)	<p><b>Disabled persons</b> shall be entitled to protection against exploitation and to protection against discrimination, in particular as regards access to health services, education and employment</p>
Ghana	Sec 29(4)	<p><b>Disabled persons</b> shall be protected against all exploitation, all regulations and all treatment of a discriminatory, abusive or degrading nature</p>
Rwanda	Art 11	<p>All Rwandans are born and remain free and equal in rights and duties. Discrimination of whatever kind based on, inter alia, ethnic origin, tribe, clan, colour, sex, region, social origin, religion or faith, opinion, economic status, culture, language, social status, <b>physical or mental disability</b> or any other form of discrimination is prohibited and punishable by Law.</p>

A number of countries provide protection against inhuman treatment of persons with disabilities, including the use of degrading words. The Persons with Disabilities Act of Sierra Leone in Art. 33 (1) protects every child against torture or other cruel, inhuman or degrading treatment or punishment, including any “cultural practice which dehumanises or is injurious to the physical and mental welfare of the child”. The same Act, in its definition of discrimination, includes using words, gestures & caricatures that demean, scandalise or embarrass a person with disability. Art. 53(2) of Zambia’s draft Constitution prohibits:

...any law, practice, custom or tradition that undermines the dignity, welfare, interest or status of persons with disabilities.

DPOs and NGOs are engaged in protecting children with disabilities. For example, DPOs in Sierra Leone are working to counter the extreme prejudice associated with epilepsy through education and awareness-raising campaigns, as well as by ensuring access to inexpensive and often highly effective anti-seizure medications.<sup>85</sup> The South African Human Rights Commission has engaged in local training exercises and advocacy activities, and released public statements regarding disability equality.<sup>86</sup> Other DPOs and NGOs have exposed human rights abuses perpetuated against persons with disabilities, and have advocated for legal reform – for example, DPOs in Ghana, Kenya, South Africa, Tanzania and Uganda are working to repeal ‘mental health’ laws that permit forced medical treatment and involuntary confinement of persons with disabilities.<sup>87</sup>

The Government of Swaziland, together with partners, has made efforts to reduce discrimination within the education sector (Box 3.3).

### Box 3.3

#### Efforts to tackle disability-based stigma and discrimination in Swaziland

To combat negative attitudes towards persons with disabilities and to raise awareness of the need for inclusion, the Swaziland Ministry of Education introduced a national programme in which children composed songs and performed plays in schools and local communities. The Ministry also built ramps, made toilets accessible and designed accessible playgrounds for children with disabilities.<sup>88</sup>

<sup>85</sup> Inter Press Service News Agency (2011). The isolation of Epilepsy sufferers.

<sup>86</sup> South African Human Rights Commission. SAHRC statement to observe World Mental Health Day. 9 October 2011.

<http://www.sahrc.org.za/home/index.php?ipkArticleID=80>

Much of the SAHRC’s disability-related work has been conducted in conjunction with the Harvard Law School Project on Disability, which improves prospects for academic support of CRPD implementation and the continuing challenge to the adequacy of state-based efforts.

<sup>87</sup> Movement for Global Mental Health. <http://www.globalmentalhealth.org/home>

<sup>88</sup> Rieser, R. (2008). Implementing inclusive education: A commonwealth guide to implementing Article 24 of the UN Convention on the Rights of Persons with Disabilities. Commonwealth Secretariat.



# Chapter 4

## International and regional standards on the rights of children with disabilities

### 4.1 International conventions protecting the rights of children with disabilities

International human rights treaties and African regional human rights frameworks prescribe human rights protections that apply both directly and indirectly to children with disabilities. The two international human rights conventions most relevant to the protection of children with disabilities are the Convention on the Rights of the Child (CRC), adopted in 1989, and the Convention on the Rights of Persons with Disabilities (CRPD), adopted in 2006. Together, the two treaties lay out the legal foundation for the rights of children with disabilities. Both treaties embrace a perspective that understands human rights as endowing individuals with rights and responsibilities.

#### The Convention of the Rights of the Child

The CRC opened for signature on January 26, 1990. The CRC has been ratified by all African States with the exceptions of Somalia and South Sudan. Children's rights under the CRC are often characterised as covering four guiding principles:

- The right to survive
- The right to develop
- The right to be protected from harm
- The right to participate.

The CRC was the first legally binding instrument specifically to mention children with disabilities. Article 2 of the CRC explicitly prohibits discrimination against children with disabilities, and Article 23 specifically addresses children with disabilities.

Although the CRC includes this specific Article on children with disabilities, it is important to note that every right set forth in the CRC that refers to “the child” applies equally to children with disabilities.

The CRC marks an important shift in thinking towards a “rights-based approach,” holding governments legally accountable for failing to meet the needs of all children. The CRC creates a new vision of children as bearers of rights and responsibilities appropriate to their age, rather than viewing them as the property of their parents or the helpless recipients of charity. The CRC stresses the recognition of the child as a positive participant and social actor rather than a voiceless and powerless adult-in-waiting.<sup>89</sup>

<sup>89</sup> Lord, J.E. et al. (2012).

The CRC affirms that children with disabilities are entitled to the full range of human rights and fundamental freedoms of all human beings. The two instruments further recognise that:

- Children with disabilities are entitled to all human rights on an equal basis with other children
- The best interests of the child shall apply to all actions concerning children with disabilities
- Children with disabilities have the right to participate and state their views freely on an equal basis with other children, and disability and age-appropriate accommodations should be provided to facilitate such participation.

### **The Convention on the Rights of Persons with Disabilities (CRPD)**

On March 30, 2007, the first day that the CRPD was opened for signature, 16 African countries signed the treaty.<sup>90</sup> As of the writing of this report in mid 2014, 38 have ratified the treaty<sup>91</sup> and eight are signatory states.<sup>92</sup> Provisions in the CRPD support and in some cases strengthen the CRC framework, and thus CRC provisions must be read and understood in the light of the CRPD.

The CRPD's 25 preamble paragraphs and 50 articles provide a framework within which the rights of children with disabilities may be addressed in African country contexts. The aim of CRPD is not to create 'new' or 'special' rights for persons with disabilities, but instead to set out how existing human rights obligations apply specifically to children, youth and adults with disabilities.<sup>93</sup>

Article 3, General principles, makes important reference to children with disabilities and requires "respect for evolving capacities of children with disabilities and their right to preserve their identities."

<sup>90</sup> Algeria, Cape Verde, Republic of the Congo, Ethiopia, Gabon, Ghana, Kenya, Liberia, Morocco, Mozambique, Niger, Nigeria, Sierra Leone, South Africa, Sudan, Tunisia, Uganda and Tanzania.

<sup>91</sup> Algeria, Angola, Benin, Burkina Faso, Burundi, Cape Verde, Côte D'Ivoire, Djibouti, Egypt, Ethiopia, Gabon, Ghana, Guinea, Kenya, Lesotho, Liberia, Malawi, Mali, Mauritania, Mauritius, Morocco, Mozambique, Namibia, Niger, Nigeria, Rwanda, Senegal, Seychelles, Sierra Leone, South Africa, Sudan, Swaziland, Togo, Tunisia, Uganda, Tanzania, Zambia, and Zimbabwe.

<sup>92</sup> Cameroon, Central African Republic, Chad, Congo, Comoros, Guinea-Bissau, Libya, and Madagascar.

<sup>93</sup> Stein, M.A. & Lord, J. (2008). Prospects and practices for CRPD implementation in Africa. African Disability Rights Yearbook. Vol.1.

Article 4, General obligations, also includes children with disabilities in the general obligations that States must fulfil by stating that:

States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

The provision builds upon the CRC's principle of ensuring that children have the opportunity to state their views freely and to participate in matters that affect them. In addition, the CRPD articulates participation and inclusion as general principles in Article 3, which applies equally to children with disabilities.

Article 7, Children with disabilities, provides in-depth articulation of how all human rights apply to children with disabilities. Article 7 requires that:

- States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights on an equal basis with other children
- The best interests of the child are the primary consideration in matters affecting children with disabilities
- Children with disabilities have the right to express their views freely on all matters affecting them, given due weight to their age and maturity
- Children with disabilities are to be provided with disability- and age-appropriate assistance to help them realize their rights.

While Article 7 applies across the entire CRPD and requires that children with disabilities be taken into account in all aspects of CRPD implementation, there are other articles that raise specific issues of importance to children with disabilities and which add age-related considerations to certain obligations. For example, Article 6, Women with disabilities, underscores that girls with disabilities are often subjected to multiple forms of discrimination and requires States to take measures to tackle such discrimination. Article 8, Awareness-raising, emphasises the obligation of States to undertake awareness-raising in the context of the education system, including for early school-age children.

The CRPD establishes a system of monitoring and implementation (Articles 31-40) and includes final provisions that govern the treaty's operation (Articles 41-50). Some obstacles that inhibit disability rights implementation in the African context are addressed in the treaty implementation provisions.

The need to ensure that international cooperation programming is inclusive of persons with disabilities is set out in Article 32.

The framework for national level monitoring (Article 33) was facilitated by African national human rights institutions – in particular the South African Human Rights Commission – and several disability-specific African commissions participating in the CRPD negotiations.<sup>94</sup>

The Committee on the Rights of Persons with Disabilities (CRPD Committee) is tasked with monitoring implementation in States Parties through its oversight of the mandatory state reporting requirement and through the issuance of recommendations.

An Optional Protocol to the CRPD – a separate treaty linked to the CRPD – is comprised of eighteen articles. The Optional Protocol gives the Committee on the Rights of Persons with Disabilities competence to examine individual complaints and initiate inquiries with regard to alleged violations of the Convention by States Parties to the Protocol.

Based on the CRC and the CRPD, the following principles can be seen as the foundations for understanding the rights of children with disabilities (Box 4.1).

#### **Box 4.1** Conceptual foundations for understanding the rights of children with disabilities<sup>95</sup>

**Non-discrimination:** requires states to ensure that all children with disabilities within their jurisdiction enjoy human rights without discrimination of any kind. Reasonable accommodation must be provided and the failure to do so results in disability discrimination.

**Right to life, survival and development:** requires states to ensure the survival and development of children with disabilities to the maximum extent possible, including by undertaking positive measures.

**Adherence to the best interests of the child:** requires states to ensure that the central consideration in all decision making or actions concerning children with disabilities is in the best interests of the child.

**Participation and inclusion:** requires states to ensure that children with disabilities may express their views freely in all matters affecting them and that reasonable accommodations and other positive measures be taken to facilitate such participation. Inclusion entails providing the support needed to ensure that children with disabilities can access and enjoy their human rights.<sup>96</sup>

<sup>94</sup> The Working Group that developed the foundational text of the CRPD negotiations included delegations from seven African nations: Cameroon, Comoros, Mali, Morocco, Sierra Leone, South Africa, and Uganda.

<sup>95</sup> These four principles are overarching and apply in respect of any and all rights to be realised. They are derived from international human rights law and are reflected in the two most important human rights treaties pertaining to the rights of children with disabilities, namely the CRPD and the CRC.

<sup>96</sup> UNICEF (2002). Innocenti Digest. No. 13.

## 4.2 African framework protecting the rights of children with disabilities

The African Charter on Human and Peoples' Rights was adopted by the Organization of African Unity (OAU) in 1981. The Charter is the foundational instrument for the expression of human rights within the African context. While it only references children in one provision (Article 18(3) provides that States must “ensure ...the protection of the woman and child as stipulated in international declarations and conventions”), its provisions are applicable to all children, including children with disabilities.

The rights of children with disabilities in Africa are addressed by the African Charter on the Rights and Welfare of the Child (ACRWC) and the African Common Position on Children

### African framework protecting the rights of children with disabilities

Africa is the only continent with a region-specific child rights treaty. The ACRWC is an important regional framework for advancing the rights of children. It builds on the principles contained in the CRC and seeks to highlight issues of special importance in the African context.

Article 3 of the ACRWC prohibits discrimination against children. While it does not specify disability as a prohibited ground of discrimination, it is understood to apply equally to all children, including children with disabilities.

Article 13 of the ACRWC deals specifically with children with disabilities. It should be noted that the wording of the Article – handicapped children – reflects the time of its drafting and is clearly at odds with current terminology reflected in the CRPD and used by disability rights advocates.

Article 13 provides as follows:

- Children with physical or mental disabilities have the right to special measures of protection under conditions that ensure dignity and promote self-reliance and active participation in the community
- States must ensure, subject to available resources, special measures of assistance to ensure effective access to training, promotion for employment and recreational opportunities to achieve the fullest possible integration and development of the child
- States must use available resources to facilitate mobility for children with disabilities and their access to public highways, buildings and other places.

Although the rights specified in Article 13 are made contingent to the availability of resources, States parties to both instruments must move expeditiously towards the full realization of all rights and may not invoke the lack of resources as a basis for doing nothing.

## The Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa

The Protocol calls upon States Parties<sup>97</sup> to give special protection to women. Under Article 23, it requires States parties to:

- a) ensure the protection of women with disabilities and take specific measures commensurate with their physical, economic and social needs to facilitate their access to employment, professional and vocational training as well as their participation in decision-making;
- b) ensure the right of women with disabilities to freedom from violence, including sexual abuse, discrimination based on disability and the right to be treated with dignity.

### Overview of the African Common Position on Children

The second regional framework, the African Common Position on Children, consists of a Declaration and Plan of Action and makes reference to children with disabilities, but does so narrowly and contingently. The African Common Position emerged from the Pan-African Forum on the Future of Children held in Cairo, Egypt in 2001. The African Common Position articulates a number of priorities aimed at improving the quality of life of the child and taking appropriate measures to ensure that each child has a good start in life, and develops in an environment that allows them to fulfil their potential to accept peace, security and dignity. It calls for:

- The eradication of HIV/AIDS in order to ensure the rights of children to survival and development
- The achievement of the right to education to allow each child to realise his/her full potential
- Provision of legal protection outside situations of armed conflict and foreign occupation
- Protection of children against violence, lack of medical care, mistreatment and sexual exploitation
- The participation of youth and children.
- The 2007 Mid-Term Review of this framework addressed children with disabilities, but did so from a decidedly medical and non-rights oriented perspective. In the review, the report noted that:

<sup>97</sup> The Protocol was, up until September 2014, ratified by Angola, Benin, Burkina Faso, Cameroon, Cape Verde, Comoros, DR Congo, Djibouti, Gambia, Ghana, Guinea-Bissau, Libya, Lesotho, Liberia, Mali, Malawi, Mozambique, Mauritania, Namibia, Nigeria, Rwanda, Senegal, Seychelles, South Africa, Tanzania, Togo, Uganda, Zambia, Zimbabwe and Kenya.

## Overview of the African Common Position on Children

Unfortunately, there are thousands of children who do not possess all their mental, physical and psychological disabilities in Africa. Because of their health status, these children need special care. It further referred to children who:

...are blind, others are deaf and mute or have lost the use of their legs, hands or are mentally deficient.

It did, however note the need to address discrimination and stigmatisation.

## New African Decade of Persons with Disabilities and the AU Disability Architecture

In 2012, the African Union Conference of Ministers of Social Development, adopted the revised Continental Plan of Action of the African Decade of Persons with Disabilities (2010-2019) through which stakeholders recommitted themselves to the goals of the Decade: full participation, equality and empowerment of persons with disabilities.

The participants in the meeting also discussed specific measures to strengthen institutional arrangements for the implementation, monitoring and evaluation of the Plan of Action (para 19-20).

The implementation of the new Continental Plan of Action is expected to be realized through a newly-established African Union Disability Architecture. This new structure consists of three major elements:

- a)** a legal component, i.e., a new regional protocol on the rights of persons with disabilities;
- b)** a programmatic component, i.e., the Continental Plan of Action, which identifies key priority areas for action, expected outcomes, performance indicators and means of verification for each priority area and the key actors responsible for advancing the implementation of the Disability Architecture; and
- c)** the institutional component, including the African Union Commission, the African Commission on Human and Peoples' Rights, member States, regional economic communities and organizations of persons with disabilities.<sup>98</sup>

The UN Special Rapporteur on Disability, together with Governments, African Union agencies, African regional and sub-regional organisations of persons with disabilities,

<sup>98</sup> UN Economic and Social Council (2013). Commission for Social Development. Fifty-first session-Mainstreaming disability in the development agenda: towards 2015 and beyond. Report of the Secretary-General. para. 21.

academic institutional networks and development partners, organized a consultative meeting in Addis Ababa on 28 and 29 November 2012. The meeting saw the launch of the African Disability Forum, which aims to raise awareness further, strengthen the knowledge base and evidence-based research, support capacity-building and establish and support a partnership between multi-stakeholders within and beyond the African continent to promote the rights of persons with disabilities and a disability-inclusive development agenda in Africa and all over the world.<sup>99</sup>

### Overview of the African Common Position on Children

The Working Group on Older Persons and Persons with Disabilities developed the Draft Protocol “to provide an African context to rights of persons with disabilities”.<sup>100,101</sup> The CRC, the ACRWC and the CRPD are some of the international human rights instruments that guided the drafting of the Protocol.

Children with disabilities are referred to in Article 18 on the Right to Participate in Sports, Recreation and Culture, which states that all children with disabilities have the right to “participate in play within the learning environment”.<sup>102</sup> This statement asserts the right of all children with disabilities to be included in activities of play throughout their education, in order to allow them full and equal participation with other children.

Article 20 of the Draft Protocol provides more explicit and clear rights for children with disabilities. Within Article 20, there are clear parallels and connections drawn regarding the rights of children with disabilities as found in the CRPD, CRC, ACRWC, and African Charter on Human and Peoples’ Rights. All State Parties to the Draft Protocol are required to:

1. Recognise that children with disabilities have full enjoyment of human rights and fundamental freedoms on an equal basis with other children
2. Respect the evolving capacities of children with disabilities, and their right to preserve their identities and to enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child’s active participation in the community

<sup>99</sup> UN Economic and Social Council (2013). Commission for Social Development. Fifty-first session-Mainstreaming disability in the development agenda: towards 2015 and beyond. Report of the Secretary-General. para. 22.

<sup>100</sup> Protocol to the African Charter on Human and Peoples’ Rights on the Rights of Persons with Disabilities in Africa. Draft II. 14 Mar. 2014. <http://www.achpr.org/news/2014/04/d121>

<sup>101</sup> As of 14 March 2014, the Draft Protocol was in its second iteration as Draft II and the Working Group has requested all members of the African Charter to provide comments on how to improve it.

<sup>102</sup> Id. at Art. 18 (e).

3. Ensure that the best interests of the child are a primary consideration in all actions concerning children with disabilities
4. Ensure the rights of children with disabilities by taking policy, legislative and other measures.<sup>103</sup>

Article 20 further details the measures required to be taken by each State Party to protect the rights of children with disabilities through policy and legislative measures. Each of these measures must provide safeguards by protecting children with disabilities from sexual exploitation and abuse, abduction, trafficking, separation from their parents, violence within the family or institutional setting, and sterilization.<sup>104</sup> Moreover, these measures must allow children with disabilities full participation in society by providing them the right to express their views freely on all matters affecting them, providing them with assistance appropriate to their age and disability, giving them the ability to understand their rights, and providing access to recreational opportunities and training in a manner that will allow them to attain the highest possible level of social inclusion and cultural, individual, and moral development.<sup>105</sup>

Further, the Draft Protocol covers issues that are of close relevance to the African context, but did not receive traction in the CRPD, such as the protection of parents, guardians and caregivers from discrimination on the basis of their actual or apparent association with persons with disabilities (Art 3(3)); protection of persons with disabilities from harmful practices (Art 5); protection against use of traditional forms of justice to deny persons with disabilities access to appropriate and effective justice (Art 8(2)); promotion of community-based rehabilitation services (Art 9(e)).<sup>106</sup>

In general, the Draft Protocol takes a comprehensive approach to addressing the rights of children with disabilities. The rights listed within the Draft Protocol encompass all rights found within the major international human rights documents relating to the rights of children, and specifically children with disabilities.

Furthermore, the commitment to the protection and advancement of children with disabilities is illustrated by the African Committee of Experts on the Rights and Welfare of the Child (ACERWC) in their Strategy for the Promotion and Protection of Children with Disabilities in Africa (“the African Strategy”). The vision of the African Strategy is the creation of:

<sup>103</sup> Id. at Art. 20 (1)-(4).

<sup>104</sup> Id. at Art. 20 (4) (c), (e), (f), (g), (k), and (l).

<sup>105</sup> Id. at Art. 20 (4) (a), (b) and (i).

<sup>106</sup> Combrinck, H. & Mute, L.M. (2014). Developments regarding disability rights during 2013: The African Charter and African Commission on Human and Peoples Rights. African Disability Rights Yearbook. Vol. 2.

...an Africa fit for children with disabilities, where children with disabilities fully enjoy all their human rights and fundamental freedoms on an equal basis with others; their dignity is ensured; and where their self-reliance and active participation in the community is promoted.

In particular, the African Strategy states that its general principles follow both Article 4 of ACRWC and Article 3 of the CRPD.<sup>107</sup>

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<sup>107</sup> African Committee of Experts on the Rights and Welfare of the Child. Strategy for Promoting and Protecting the Rights of Children with Disabilities in Africa.

# Chapter 5

## Accessibility to the built environment and information

### Introduction

The inaccessibility of infrastructure, services and information constitutes one of the primary challenges faced by children with disabilities throughout Africa. Accessibility will be discussed with respect to different sectors and services, but the following section reviews the main access barriers encountered by children with disabilities in the built and urban environments.

ACPF studies showed that children with disabilities continue to face significant barriers to access to public spaces, community, recreation and religious centres, and even their own homes. Most buildings in Africa are largely inaccessible and present a huge challenge, and the newly built ones make only partial accommodations for the needs of persons of disabilities. Most buildings have stairs without ramps or handrails. Lifts are a rarity. At times ramps are constructed but are too steep for wheelchair users.<sup>108</sup> Lack of accessibility to public spaces has the potential to exclude or include people from socioeconomic and cultural participation and thereby produce and reinforce structural inequalities.<sup>109</sup>

The inaccessibility of so many places means that our rights to meet with friends and families in everyday activities are practically non-existent.

#### Young person with a disability | Cape Town<sup>110</sup>

“Going to a building with no lift and having to be carried is undignified and the most embarrassing thing ever”.

#### Young person with a disability | Cape Town<sup>111</sup>

Many buildings lack directional or informative signage, voice announcements or Braille buttons in elevators, visual alerting systems, sound buffering design features or reception station set-ups which allow for face-to-face or direct line communication with staff. Hence these buildings

<sup>108</sup> ACPF (2011). Children with Disabilities in Africa: Challenges and opportunities. Addis Ababa.

<sup>109</sup> Hamraie, A. (2013). Designing Collective Access: A Feminist Disability Theory of Universal Design. Disability Studies Quarterly. Vol. 33.  
<http://dsq-sds.org/article/view/3871/3411>

<sup>110</sup> Landsdown, G. (2002). Disabled Children in South Africa. Progress in implementing the Convention on the Rights of the Child.

<sup>111</sup> See No. 110 above.

are grossly inaccessible for both visually-impaired and hearing impaired people. Most workplaces, healthcare facilities, schools, hotels, banks and post offices and recreational centres are physically inaccessible, limiting the enjoyment of these services by persons with disabilities, even when some of these services are – in principle – offered free of charge. Bus stations, especially those that are over-crowded offer many obstacles for users of wheelchairs or crutches to negotiate. Noise pollution inhibits the movement of visually impaired people. It is commonplace in Africa for minibus conductors to call out bus destinations – oblivious to the fact there are also clients with hearing impairments.<sup>112</sup>

Pedestrian pathways and buildings serving the public lack inclusive design features such as level pathways of adequate width and curb ramps serving wheelchair users and all other pedestrians. Similarly, transit terminals seldom have well-located signs with high-contrast large print to assist deaf and visually impaired passengers; a low ticket counter for use by wheelchair users and short persons; and tactile warning strips at curbs and platform edges to assist blind persons.

Although not common, some African countries do have Constitutional provisions that require accessibility of public buildings and services to persons with disabilities (Table 5.1).

**Table 5.1** The Constitution of Republic of Zimbabwe

**Constitutional entrenchment of accessibility  
Zimbabwe Constitution: Section 22(4)**

The State must take appropriate measures to ensure that buildings and amenities to which the public has access are accessible to persons with disabilities

**Kenya Constitution: Section 54(1)(c)**

A person with any disability is entitled to reasonable access to all places, public transport and information

**Ghana Constitution: Section 29(6)**

As far as practicable, every place to which the public has access shall have appropriate facilities for disabled persons

Other countries have addressed the issue of accessibility through disability-specific legislation (Table 5.2).

<sup>112</sup> ACPF (2011). Children with Disabilities in Africa: Challenges and opportunities. Addis Ababa.

**Table 5.2** Examples of types of disability specific legislation

Country	Name of statute/policy	Essence of intervention
Malawi	Disability Act	<p><b>Sec 8(d):</b> Government to ensure the attainment of a barrier free environment that enables persons with disabilities to have access to public and private buildings and establishments and such other places in line with universal designs.</p> <p><b>Sec 8(e) :</b> Requires certification of architectural drawings for public and institutional buildings to comply with the standards of universal design.</p> <p><b>Section 8 generally:</b> Requires government to take appropriate measures to ensure that persons with disabilities have access to the physical environment, transportation, information and communications, including information and communication technologies and systems, and other facilities and services available or provided to the public.</p> <p>Obliges government to, among other things; ensure the development of a Malawi sign language as a national language for persons with hearing impairments and recognise it as an official language.</p>
Central African Republic	Law for the protection of persons with disabilities	<p><b>Article 23:</b> Spells out in detail the required design features, which include ramps, spacious entrances and corridors, and very specific requirements for the construction of bathrooms and toilets.</p> <p><b>Article 24:</b> Requires public buildings and all residential buildings to have appropriate public toilets and specially-made telephone booths, and equipment and other facilities specially adapted for persons with disabilities.</p>

**Table 5.2** (Continued): Examples of types of disability specific legislation

Country	Name of statute/policy	Essence of intervention
Lesotho	Buildings Control Act 1995	Specifies design of new buildings suitable for and accessible to people with disabilities.
Ethiopia	Building Proclamation No 624/2009	<p><b>Article 36:</b> Specifically addresses the accessibility of design and construction of public buildings for persons with physical disabilities.</p>
Zimbabwe	Disabled Persons Act	<p><b>Sec 8:</b> Strictly prohibits denying persons with disabilities access to public places, services, and other amenities.</p> <p><b>Sec 7:</b> Adjustment orders Under this section, if any premises to which members of the public are ordinarily admitted for a fee, or any places, services, or amenities that are ordinarily provided to the members of the public (including those that are state-owned) are discovered by the Board to have barriers or be inaccessible for disabled persons, the Board will require any such entity to rectify the inaccessibility. (The Board will issue an Adjustment Order).<sup>113</sup> The Board will also stipulate the period of time within which such remedial action must be accomplished.</p>

<sup>113</sup> Adjustment orders are discussed in more detail later in this report.

Table 5.2 (Continued) Examples of types of disability specific legislation

Country	Name of statute/policy	Essence of intervention
Central African Republic	2000 Loi Portant statut, Protection et Promotion de la Personne handicapée (Law for the protection and promotion of persons with disabilities)	<p><b>Title 1 (Article 3)</b> The State has the duty to ensure that persons with disabilities have access to appropriate leisure, sport activities and to public buildings.</p> <p><b>Title 2 (Chapter 3) (Article 22)</b> Requires architectural designs to envisage specialised facilities for accommodating the needs of persons with disabilities of limited mobility and the needs of wheelchair users.</p>
Uganda	Persons with Disabilities Act	<p><b>Sec 19: Access to premises</b> Requires all organs in a public or private institution to provide: (a) Suitable exits for persons with disabilities; (b) Universal standards for designs of public toilets</p> <p><b>Sec 20: Duty to provide access to buildings</b> Requires any person who constructs a building which will be available for the public to ensure that persons with disabilities have access through, amongst others, provision of accessible elevator, ramps, Safe and well-dimensioned staircases for the comfort of persons with mobility problems</p> <p><b>Sec 22: Access to public transport facilities</b> Requires any person providing public transport services to provide access to transport for disabled persons</p>

**Table 5.2** (Continued): Examples of types of disability specific legislation

Country	Name of statute/policy	Essence of intervention
Uganda	Persons with Disabilities Act	<p><b>Sec 23: Access for visually impaired road users</b>                      Obliges the Government to make public roads and highways accessible to persons with disabilities by (i) equipping pedestrian crossings with traffic control signals controlled by a pedestrian push-button system; (ii) providing pedestrian traffic lights with clearly audible signals; and (iii) use of alarms or bells to signal approaching traffic, among other things</p> <p><b>Sec 29: Access to public facilities</b>                      Requires any person operating a service or public facility to make the service or facility readily accessible to and usable by all persons including persons with disabilities.</p>
Tanzania	Persons with Disabilities Act	<p><b>Sec 35: Access to public buildings</b>                      Obliges the state to ensure that every public building and other buildings which provide services to the public are accessible to all persons with disabilities</p> <p>Mandates the government to prepare regulations prescribing accessibility of public buildings for the purpose of giving guidance to public and private bodies</p> <p><b>Sec 36: Accessibility to services provided by public bodies</b>                      Requires the Head of every public body which is providing a service to (i) ensure that the provision of access to the service by disabled persons and non-disabled persons is integrated; and (ii) ensure the availability of persons with appropriate expertise and skills to give advice to the body on means of ensuring that the service provided by the body is accessible to disabled persons</p>

**Table 5.2** (Continued): Examples of types of disability specific legislation

Country	Name of statute/policy	Essence of intervention
Tanzania	Persons with Disabilities Act	<p><b>Sec 37: Accessible public services</b> Requires a Head of a public body to ensure that a service that is provided by such public body is also accessible to disabled persons</p> <p><b>Sec 39: Accessibility to heritage and tourism sites</b> Requires the state to ensure that the whole or part of a heritage site or tourism facility or activity to which the public has access is accessible to disabled persons.</p>
Ghana	Persons with Disabilities Act <sup>114</sup>	<p><b>Sec 7: Access to public services</b> Requires a person who provides a service to the public to put in place the necessary facilities that make the service available and accessible to a disabled person</p> <p><b>Sec 6: Access to public places</b> Requires the owner or occupier of a place to which the public has access to provide appropriate facilities that make the place accessible to and available for use by a disabled person.</p>
Kenya	Persons with Disabilities Act	<p><b>Sec 21: Accessibility and mobility</b> Guarantees disabled persons the right to a barrier-free and disability-friendly environment to enable them to have access to buildings, roads and other social amenities, and assistive devices and other equipment to promote their mobility</p>

<sup>114</sup> Act 715 of 2006.

**Table 5.2** (Continued): Examples of types of disability specific legislation

Country	Name of statute/policy	Essence of intervention
Kenya	Persons with Disabilities Act	<p><b>Sec 21: Accessibility and mobility</b> Guarantees disabled persons the right to a barrier-free and disability-friendly environment to enable them to have access to buildings, roads and other social amenities, and assistive devices and other equipment to promote their mobility</p> <p><b>Sec 22: Accessible buildings</b> Requires a proprietor of a public building to adapt it to suit persons with disabilities in such manner as may be specified by the National Council for Persons with Disabilities. (The provision expects all proprietors of public buildings to comply with this obligation within a period of five years.)</p> <p><b>Sec 23: Accessible public services vehicles</b> Requires an operator of a public service vehicle to adapt it to suit disabled persons in such manner as may be specified by the National Council for Persons with Disabilities (The provision expects all operators of public service vehicles to comply with this obligation within a period of two years).</p>
Sierra Leone	Persons with Disabilities Act	<p><b>Section 24 (1):</b> Entitles persons with disabilities to a barrier free environment to enable them to have access to buildings, roads and other social amenities and assistive devices and other equipment to assist their mobility. Section 24(2) requires a proprietor of a public building to adapt it to suit persons with disability in such a manner as may be specified by the Commission.<sup>115</sup></p>

<sup>115</sup> The Persons with Disability Act (2011). Supplement to the Sierra Leone Gazette. Vol. CXLII No. 22. Dated 5 May 2011.

In South Africa, strategic litigation has been used successfully to ensure enforcement of the law as it relates to the rights of children with disabilities, as illustrated in Box 5.1.

### **Box 5.1** Litigation case for access to school in Mpumalanga Province, South Africa

#### **Lettie Hazel Oortman v St Thomas Aquinas Private School & Bernard Langton<sup>116</sup>**

##### **Facts:**

The St. Thomas Aquinas private school had refused to re-admit a former learner with disability on the basis of her physical disability. The student, who was a wheelchair user, had withdrawn from the school due to accessibility challenges in the school environment.

##### **Court's finding (Witbank Equality Court in Mpumalanga Province):**

The Equality Court found that the refusal to re-admit the student with a disability constituted unfair discrimination on the basis of disability contrary to the Constitution and the Equality Act (Promotion of Equality and Prohibition of Unfair Discrimination Act).

##### **Court order:**

The Court ordered the private schooling institution to take reasonable steps to remove all obstacles so that the learner should have wheelchair access to classrooms and other facilities.

In 2012, ACPF conducted a comprehensive assessment of accessibility in five African capital cities: Addis Ababa, in Ethiopia; Freetown, in Sierra Leone; Johannesburg, in South Africa; Kampala, in Uganda; and Lusaka, in Zambia.<sup>117</sup> The findings, documented in a publication entitled *Access Denied: Voices of persons with disabilities from Africa* (ACPF, November 2014), illustrate how inaccessibility is perpetuated in most African cities despite rapid rates of urban development. It also illustrates the diverse types of inaccessibility to the built environment that people and children with disabilities might encounter in cities.

First, inaccessibility is perpetuated by the failure to consider accessibility needs for persons with disabilities from the design stage of new buildings. As a result, new buildings in urban settings throughout Africa are still not accessible. According to one first-person report:

<sup>116</sup> Case No. 1 of 2010. Witbank Equality Court. ; South African Human Rights Commission (2011). Annual international report. pp 56-57.

<sup>117</sup> ACPF (2014). *Access Denied: Voices of persons with disabilities from Africa*. Addis Ababa.

The physical and social environment in general is not conducive for people with disabilities in the city. So any construction, or any service or school or the roads, beginning from the design, does not consider people with disabilities, and so there are a lot of problems around physical accessibility. It's a big obstacle to mobility for people with disabilities in this country.

**Teshome Deressa,**  
Federation of Ethiopian National Associations of Persons  
with Disabilities | Addis Ababa, Ethiopia

Furthermore, many older buildings remain inaccessible, although there has been some positive work to upgrade older buildings. For example:

I'm accessing the International Hospital in Kampala. I don't know whether it's because it's a hospital or because it was built by a foreign investor – but it is in some ways accessible. There is a ramp from the entrance up to the third floor. Of course, after you reach the third floor you have to use the stairs. But at least you can access the first floor, second floor and third floor by wheelchair.

**Disabled youth focus group member** | Kampala, Uganda

All of the major hotels and restaurants in Kampala are trying to make an effort to incorporate the ramps, the elevators and the toilets. They are making the effort to make themselves more accessible.

**Disabled youth focus group member** | Kampala, Uganda

Another accessibility issue across Africa is a lack of directional or informative signage such as voice commands or Braille buttons in elevators, visual alerting systems, sound buffering design features, and reception stations that allow for face-to-face or direct-line communication with staff. Inaccessible signage creates barriers for people who are blind or visually impaired and people who are deaf or hearing impaired. One example in the ACPF assessment tells of trouble in finding the correct floor in a building without accessible signage:

When we are accessing buildings and we want to go up the elevator there is no sound on the elevator to tell us what floor we are on, neither is there Braille on the buttons for us to choose a floor to go to. So, those are some of the problems we are facing in the city. We want provisions of this kind in public places.

**Keshi Chisambi,**  
Zambia National Federation of the Blind | Lusaka, Zambia

Braille signage and voice synthesisers for the visually impaired have become more readily available in Johannesburg, South Africa;<sup>118</sup> in addition, Johannesburg has notable accessibility provisions in the built environment for people with physical or mobility disabilities.<sup>119</sup>

<sup>118</sup> ACPF (2014). Access Denied: Voices of persons with disabilities from Africa. Addis Ababa.

<sup>119</sup> ACPF (2014). Access Denied: Voices of persons with disabilities from Africa. Addis Ababa.

These features include exterior ramps and evenly paved surfaces; wider, wheelchair accessible corridors and doors; accessible toilets with appropriate signage; lowered counters to allow wheelchair users visibility and interaction with service providers; and handrails.

Accessibility features have greatest impact when installed in locations frequently visited by the public. For example, one of the largest malls in the city of Lusaka in Zambia incorporates a wide range of accessibility features including regularly spaced ramps up from road level onto pavements; ramps between floors; elevators with Braille buttons (though not audio floor announcements); ample disabled parking bays placed close to mall entrances; and accessible toilet facilities on every floor.<sup>120</sup>

Despite some evident improvements, cities across Africa generally have limited access for children and people with disabilities. Much progress is still needed, since not only are many old buildings still awaiting upgrades, but many new buildings also continue to be erected without complying with universal design and building standards.

There's a new building [in Freetown] and it's a building for disabled people – it's something like a disabled help centre and it actually has loads and loads of stairs. When I actually saw that I called up the organisation responsible for building it and said – 'come on, you guys have made a building for disabled people with stairs. How are they supposed to get up into it?' They couldn't account for it.

**Leslie Clarkson,**  
Consulting Engineer | Freetown, Sierra Leone

Disabled People's Organisations (DPOs) are advocating for accessibility in many African countries. For instance, DPOs in Zambia, Ethiopia, South Africa, and Uganda are collectively requesting authorities to incorporate disability friendly design into new buildings and carry out adaptations to existing infrastructure, with varying degrees of success. In Uganda, for example:

We are hoping that if we do a lot of lobbying and shouting some of the things we want to see done will be done. But people who are responsible for the structure of the city, still have the attitude problem, they still do not really know what to do.

**Connie Kekihimbo,**  
Cheshire Home for Rehabilitation Services | Kampala, Uganda

The Zambia Federation of the Disabled (ZAFOD) has been systematically conducting accessibility audits of key structures in Lusaka, by sector.

In 2008 we chose old public buildings owned by the state – so we looked at police stations, post offices, civic centres and old learning institutions. Because they were old they were 95 per cent inaccessible. After [carrying out audits],

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<sup>120</sup> ACPF (2014). Access Denied: Voices of persons with disabilities from Africa. Addis Ababa.

we give them reports with advice [on how] to adjust [to achieve accessible standards]. We give them three months to comply, and then six months - and then we sued them. We've got 16 different cases - including the attorney general - in court now for being inaccessible.

Last year, our theme was around new learning institutions, tourism and banking – so we did hotels, resort centres and banks. The banks are making adjustments, the University of Zambia is making adjustments, hotels are making adjustments – because of the first group whom we sued. And they have the money to make adjustments – so Barclays Bank is putting in ramps and lowering one of its counters for people with disabilities, for example.

**Wamundila Waliuya**  
ZAFOD | Lusaka, Zambia

ZAFOD and other DPOs in Zambia have engaged in raising awareness on accessibility standards with key public and private institutions. Similar efforts are being made by DPOs in other study cities. In Addis Ababa, for example, DPOs and NGOs are increasingly engaging with architectural practices and civil engineering companies to increase awareness of accessibility issues.

We have done seminars with architects, civil engineers and planners – so this is the hope that we have that in the future buildings will be accessible. Most of the architects and civil engineers don't know the standards for accessibility – [they] do not have the knowledge about universal design. So in our training we reflected universal design and all of them became interested to know about it. So we hope that when they are designing in future they will incorporate universal design and promote the benefits of having buildings with accessible features.

**Aychesh Molla**  
Ethiopian Centre for Disability and Development | Addis Ababa, Ethiopia

In Liberia, DPOs have worked with the government to develop regulations on access to public infrastructure for persons with disabilities. Yet the enforcement of these regulations remains unsatisfactory.

Accessibility is also an issue for displaced people. Africa is home to 22 per cent of the global refugee population. Of the six countries that host almost half the world's Internally Displaced People (IDPs), three are in Africa: Democratic Republic of Congo (over 2 million people); Somalia (over 1.5 million); and Sudan (1 million).<sup>121</sup> Some of those living in camps in these countries are disabled, many as a result of the conflicts that they have fled. Accessibility remains a challenge for those

<sup>121</sup> Doctors without Borders Fact sheet (n.d.): 43 million people uprooted by war.

who are disabled and displaced. There have been some recent efforts, however, to ensure that this problem is addressed (Box 5.2).

### **Box 5.2** Special focus: accessibility in displaced persons camps

Inaccessibility is a problem in refugee and camps for internally displaced persons (IDPs). The physical layout and infrastructure of camps for displaced persons present many accessibility barriers to persons with physical disabilities. They are difficult to traverse for wheelchair and crutch users, and for people whose brain injuries compromise their balance.

For example, the refugee settlement areas in Dadaab, Kenya, are located in a sandy river delta that presents considerable mobility challenges for many persons with disabilities. To address this issue, one humanitarian assistance organisation with expertise in designing and distributing assistive devices introduced specially designed wheelchairs with tires that could navigate the terrain. Too often, however, humanitarian staff lack the expertise to address these constraints.

With regard to ensuring accessibility to information, there are some encouraging examples of legislative action across Africa. The Persons with Disabilities Act of Tanzania and the Persons with Disabilities Act of Uganda offer very good examples. The Acts contains provisions that guarantee the right of access to information, including through televisions and telephones (Boxes 5.3-5.4).

### **Box 5.3** Section 38, Persons with Disabilities Act of Tanzania

- (1) Where a public body communicates with one or more persons, the head of the body shall ensure that-
  - (a) if the communication is an oral one, and the person with disability has a hearing impairment and so requests; or
  - (b) if the communication is a written one, and the person or persons aforesaid have a visual impairment and so requests, as far as practicable, the contents of the communication shall be communicated in a form that is accessible to the person concerned.
  
- (2) Where a public body communicates in electronic form with one or more persons, the head of the body shall, as far as practicable, ensure that the contents of the communication are accessible to persons with visual impairment to whom adaptive technology is available.
  
- (3) The head of a public body shall, as far as practicable, ensure that, information published by the body, which contains information relevant to persons with intellectual disabilities, is in a clear language, legible and easily understood by such persons.

### **Box 5.3** (Continued): Section 38, Persons with Disabilities Act of Tanzania

#### **Section 55(1), Persons with Disabilities Act of Tanzania**

All television stations shall provide a sign language inset or subtitles in all newscasts, educational programmes and other programmes covering national events

#### **Section 56**

All persons providing public telephones services shall, as far as possible, install and maintain telephone devices or units for persons with hearing disabilities and tactile marks on telephone sets to enable persons with visual disabilities to communicate through the telephone system.

### **Box 5.4** Section 21(1), Persons with Disabilities Act of Uganda

**(1)** It shall be the duty of the responsible Government authority to promote the rights of persons with disabilities to access information through:

- (a)** The development and use of sign language, tactile, sign language interpreters, in all public institutions and at public functions
- (b)** Brailing of public information, such as Government documents, government newspapers and other publication

#### **Section 21(2)(a),**

**(2)** Any person who owns a:

- (a)** Television station shall provide sign language inset or subtitles in at least one major news cast program each day and in all special programs of national significance.

#### **Section 21(2)(b), Persons with Disabilities Act of Uganda**

**(2)** Any person who owns a:

- (b)** Telephone company shall provide special telephone devices for the hearing-impaired

The implementation of these legislative frameworks remains a persistent challenge, however, as most of these laws and policies are not translated into meaningful budgets, programmes and changes in capacity of the necessary systems. Very few countries have allocated budgets for ensuring the implementation of these provisions and many lack a government coordination focal point with sufficient capacity (see Chapter 12 for a detailed discussion of implementation mechanisms).

# Chapter 6

## Access to education

### 6.1 The current situation in Africa

In Africa, fewer than 10 per cent of children with disabilities receive any form of education and only 2 per cent attend school.<sup>122</sup> People with disabilities are generally less likely than their non-disabled peers to be literate, and often have very little or no education.<sup>123</sup> Lack of access to the physical environment and to information, lack of communication, lack of trained teachers within schools and negative attitudes all create barriers preventing children with disabilities from accessing their right to education. Many parents, teachers, school administrators, and policymakers have the false perception that children with disabilities cannot be educated, despite the existence of policy frameworks, educational materials, trained educators, special teacher training, and – in some countries – model schools.

Statistics on access to education for the continent and for individual countries in Africa are concerning. According to UNESCO, fewer than 10 per cent of children with disabilities in Africa receive primary education. An estimated 76 per cent of children with disabilities in Sierra Leone are out of school. Of the 30 million school-aged children in Ethiopia, less than 1 per cent of children with disabilities have access to education. In Central African Republic, 67 per cent of children with disabilities aged 6-14 are not attending any form of schooling. In Malawi, Tanzania and Burkina Faso, children with disabilities are two or three times more likely to be out of school than children without disabilities. In Uganda, in 2008, children with disabilities represented only 0.023 per cent of the general primary school population.<sup>124</sup>

These low percentages of children accessing education are due to multiple barriers that exist that limit the implementation of inclusive education. These barriers include lack of implementation guidance; a lack of reliable data on the number of children with disabilities that impacts on planning; inadequate identification and assessment of children; teacher shortages; lack of teachers trained in inclusive education; lack of educational resources; issues pertaining to access to buildings and information; long distances to school; and stigma.

School drop-out is a significant problem among students with disabilities. Reasons for dropping out include the school refusing to keep the child on account of his or her disability, inaccessible facilities, and insufficient funds.

<sup>122</sup> ACPF (2011). *Educating Children with Disabilities in Africa: Towards a policy of inclusion*. Addis ababa.

<sup>123</sup> World Conference on Education for All Meeting Basic Learning Needs. Jomtien, Thailand. Mar. 5-9, 1990. World Declaration on Education for All, pmb. Mar. 9, 1990.

[http://www.unesco.org/education/pdf/JOMTIE\\_E.PDF](http://www.unesco.org/education/pdf/JOMTIE_E.PDF)

<sup>124</sup> Uganda Bureau of Statistics (2012). *Statistics abstract*.

For example, 36.7 per cent of children surveyed in rural Senegal cited a school's refusal to accept their child as the reason for the child not being in school, while 6 per cent cited the inability of teachers to teach children with disabilities.<sup>125</sup> 18.4 per cent of children with disabilities surveyed in rural Ethiopia cited the long distances between their homes and their schools as the reason for not going to school.<sup>126</sup>

Children with cognitive and sensory disabilities face additional stigma and barriers to education; those with multiple disabilities or intellectual disabilities are most affected. In Ethiopia and Uganda, 44-57 per cent 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 per cent of children with intellectual disability and 95.5 per cent of children with multiple disabilities were not in school, followed by children with visual impairments (69.5 per cent).<sup>127</sup>

## 6.2 The right to education

Without access to education, children with disabilities are likely to experience long-term difficulties in finding meaningful employment, staying healthy, and meaningfully accessing civic and political participation. The right to education has long been recognised in international human rights law. Article 26 of the Universal Declaration of Human Rights (UDHR) provides that everyone has the right to education.<sup>128</sup>

The CRC affirms the right to education for children in Articles 28 and 29.<sup>129</sup> The CRPD further outlines the right to education in Article 24, which clearly applies it to persons with disabilities, stipulating that:

...States Parties recognize the right of persons with disabilities to education.<sup>130</sup>

Furthermore, Article 24 employs the concept of inclusive education for the first time in international law:

**1.** ...With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and lifelong learning...

**2(b)** Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live.

<sup>125</sup> ACPF (2011). Children with Disabilities in Senegal: The hidden reality. Addis Ababa.

<sup>126</sup> ACPF (2011). Children with Disabilities in Ethiopia: The hidden reality. Addis Ababa.

<sup>127</sup> ACPF (2011). Educating Children with Disabilities in Africa: Towards a policy of inclusion. Addis Ababa.

<sup>128</sup> UDHR, Art. 26.

<sup>129</sup> UNCRC, Art. 28 & Art. 29.

<sup>130</sup> CRPD, Art. 24(1).

The concept of inclusive education outlined in the CRPD is new in international law and therefore represents a new standard for countries to implement. The CRPD requires States Parties to implement inclusive education systems that ensure reasonable accommodation for children with disabilities. Inclusive education enables the education of children with disabilities in general education programmes, alongside children without disabilities.

Article 24 of the CRPD requires States Parties to ensure that “persons with disabilities are not excluded from the general education system on the basis of disability.”<sup>131</sup> This means that States Parties cannot prohibit children with disabilities in law or practice from attending general schools because of their disability. It also means that States Parties must ensure that persons with disabilities do not face barriers in general education settings that amount to exclusion based on disability.

Furthermore, Article 24 also requires States Parties to ensure that “[p]ersons with disabilities receive the support required, within the general education system, to facilitate their effective education.”<sup>132</sup> To this end, Article 24 calls on States Parties to ensure “[r]easonable accommodation of the individual’s requirements is provided.”<sup>133</sup> “Reasonable accommodation” is defined in Article 2 of the CRPD as:

....necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.

Despite the large number of children with disabilities in Africa, these children are absent from, or referred to only marginally in, many public law and policy documents pertaining to education and social development plans. There has been some progress in this regard, however, not least on the legislative front. Some countries – such as South Africa, Kenya and Burundi – have Constitutional provisions to ensure the right to education of children with disabilities. In many countries, this right is ensured through children’s acts. These include the Children’s Act 8 of 2001 of Kenya; the Child Rights Act 7 of 2007 of Sierra Leone; the Children’s Act 38 of 2005 of South Africa and the Children’s Statute No 6 of 1996 of Uganda. The most common approach to addressing the right to education is, however, through education/schools Acts (examples include: South African Schools Act 84 of 1996; Education Act 12 of 1987 of Zimbabwe; and Loi Portant Orientation de l’Education 97.014 of 1997 of the Central African Republic.

A number of countries have also put in place education sector plans or special needs education strategies to address the educational needs of children with disabilities, with some defining specific targets in terms of educational provision and budget allocations.

<sup>131</sup> CRPD, Art. 24(1).

<sup>132</sup> CRPD, Art. 24(2)(d).

<sup>133</sup> CRPD, Art. 24(2)(c).

For example, in 2004, Mauritius, through its National Policy for Children and a National Plan of Action, promised to ensure universal access to good quality education for all children with disabilities in the country by 2015. In 2005, the country more than quadrupled its budget for the education of children with disabilities.

In countries such as South Africa, there have been commendable efforts to use strategic litigation to push for the enforcement of the education rights of children with disabilities (Box 6.1).

## Box 6.1

### Western Cape Forum for Intellectual Disability v. the Government of the Republic of South Africa<sup>134</sup>

#### Facts:

A provincial education policy and practice differentiated between children with ‘severe or profound’ intellectual disabilities and other children. While other children with disabilities attended (the few available) special schools that received considerable state funding, the children with ‘intellectual disabilities’ were sent to childcare homes to learn, but government funding for these homes was very low and many of the children could not access education. This resulted in the effective exclusion of children with this category of disability from access to state funding, from state schools, and, broadly, from attaining education. The children with disabilities claimed violations of rights to education, dignity and equality, among others.

#### Court’s finding (Western Cape High Court):

The Court found that the rights of children with disabilities to equality, protection against discrimination on the basis of disability, and education, among other rights, had been violated. The Court found that every child with disability is capable of learning, and that the state should provide funding for the children.

#### Court’s order:

The Court ordered the state to develop a programme that would ensure the education of the children with disabilities. The Court found that the state had to spread its funding towards the education of all categories of children, including the children with disabilities on whose behalf this case was brought.

<sup>134</sup> 2011 JDR 0375 (WCC).

### 6.3 Types of education services for children with disabilities

Different modes of education provision have been used in Africa. Three types of educational arrangements for children with disabilities exist globally:

- The one-track system, or inclusive education (serving all pupils in one system).
- The dual track system (serving pupils with special educational needs in one system and all others in another, main, system).
- The multi-track system or integration (serving various groups in different, parallel systems).

The most predominant type of education services is the dual track system, wherein education for children with disabilities is provided in special classes and units. These can also be classified in three types:

- First, there are those located on ordinary school premises, with very little interaction, social or otherwise, with the rest of the school. Special education staff may be involved in all the non-classroom activities of the school. Sometimes the special unit is a 'school-within-a-school,' with independence.
- In the second type of special unit, there is social interaction between children with and without disabilities in all non-classroom activities.
- In the third type, special classes teach special needs children separately, but those who attain skill levels equivalent to those needed in mainstream classes are accordingly transferred to the latter, or attend some lessons in them.

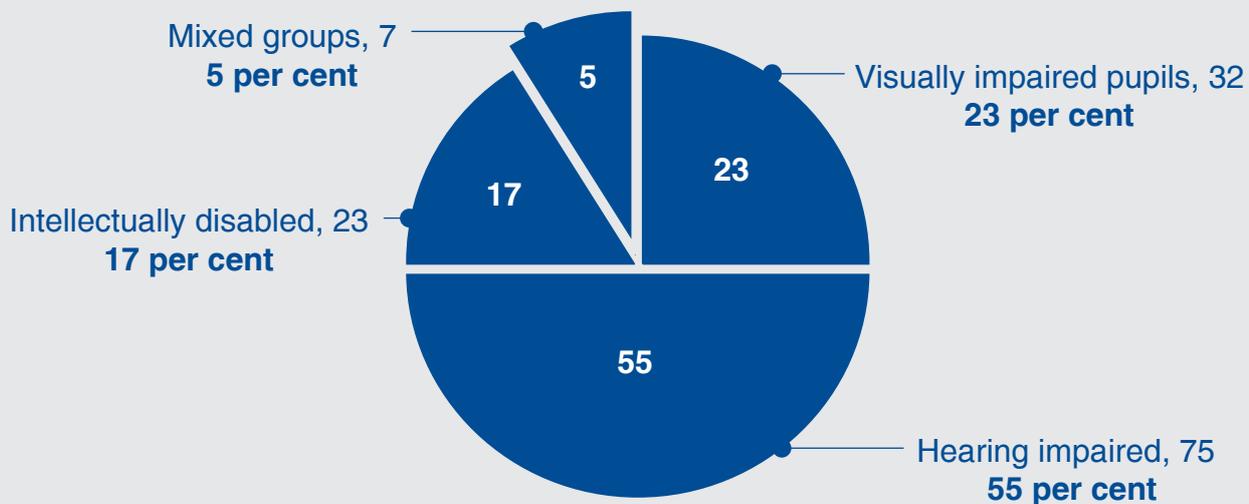
Resource centres are another important tool: these may be special education units at ordinary schools that provide assistance to special needs children in a resource room while children attend ordinary classes in the same schools. The special education staff at such centres prepare materials required by children with special education needs, and perform necessary repairs on their equipment.

Special schools and units are available for children with hearing, visual, mental, or physical disabilities. However, students with psychosocial disabilities, autism, multiple disabilities, and with specific learning and communication disabilities are not included.<sup>135</sup>

In Ethiopia, pupils with hearing impairments account for about 55 per cent of children with disabilities attending special schools within mainstream schools, while children with intellectual disabilities are the least represented (Figure 6.1).

<sup>135</sup> Njoka et al.: supra note at 30.

**Figure 6.1** Children with disabilities attending special schools in Ethiopia by disability type



**Source:** ACPF (2011). *Educating Children with Disabilities in Africa: Towards a policy of inclusion*. Ethiopia. Addis Ababa.

Some of the greatest life lessons learnt in school are not taught in the classroom but in the playground, where children have the opportunity to acquire important social skills (Box 6.2).

**Box 6.2** The right to play and mainstream schools

Facilities accessible to all children in school are essential. Of the children sampled, 61 per cent in Ethiopia, 82.3 per cent in Senegal and 75 per cent in Uganda were able to access their school’s playground. Accessing the playground was 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 per cent played with friends without disabilities, and 50 per cent played with friends with disabilities). In Senegal, only 43 per cent of children with disabilities played with non-disabled peers during break, while in Ethiopia the figure was significantly higher at 65 per cent – possibly again as an outcome of community based rehabilitation interventions. A key informant from Addis Ababa, a teacher in an inclusive school, praised the children with disabilities in his classes, saying they socialised well with the students without disabilities.

At times, the exclusion of children with disabilities from playgrounds may be due to legitimate health considerations; however, as is the case with other activities, a better option would be to present all children with a variety of indoor and outdoor play options.

In most situations, children with physical disabilities attend regular schools despite the fact that most of these schools do not meet accessibility standards and often the school infrastructure is totally inaccessible. Children with physical disabilities and visual impairments often rely on their peers in order to move from one location to another within schools.

Efforts are, however, being made to realise inclusive education, as illustrated in the examples of good practice outlined in Box 6.3 and Box 6.4.

### **Box 6.3** Building an inclusive education and training system in South Africa

Following a long consultative process, the Republic of South Africa prepared a comprehensive plan for inclusive education entitled Education White Paper 6, special needs Education: Building an inclusive Education and Training system. The White Paper outlines what an inclusive education and training system is and how to create it. It also provides the framework for establishing such a system, details of a funding strategy, and the key steps that need to be taken. South Africa is now implementing the inclusive education strategy.

While inclusive education for children with disabilities is an important new strategy in South Africa, traditional special education approaches also remain important in order to meet the particular educational needs of some children with disabilities. Existing Special Education Centres function as support and resource centres to strengthen the inclusive education system.

In many situations where structural access is largely assured for children with disabilities, the quality of education still remains inadequate.<sup>136</sup>

Therefore, both human rights and educational considerations need to be considered in order to ensure access to subject matter content needed to reach required levels of achievement. The way the curriculum is organised, managed, and delivered – including the medium of instruction, the learning materials and equipment used, and the manner in which learning is assessed – may all facilitate or impede such access.

South Africa offers one of the most advanced and detailed policies in Africa for ensuring access to curriculum content for children with disabilities. South Africa's Department of Education has produced a guideline for full service/inclusive schools.<sup>137</sup> The guideline envisages ensuring inclusion by:

<sup>136</sup> Sage, D.D. & Burrello, L.C. (1986). Policy and management in special education. Prentice-Hall. Englewood Cliffs.

<sup>137</sup> DoBE (2010). Guidelines for Full-service/Inclusive Schools. Department of Basic Education. Pretoria.

...making provisions for individualised support measures that could include for example facilitating the learning of Braille, using alternative script, communicating through augmentative and alternative modes, means and formats of communication, the introduction of orientation and mobility skills, and facilitating peer support and mentoring, facilitating the learning of sign language and the promotion of the linguistic identity of the deaf community.

The guideline<sup>138</sup> details further accessibility requirements in the following passage:

When a school includes deaf children, it makes use of South African Sign Language interpreter and trained educators and offers deaf children the chance to work with native signers. It also offers hearing children the chance to study sign language as part of the curriculum.

Schools are also required under the guideline to procure portable ramps or fitted seats for learners with mobility impairments, and to make arrangements with drivers to supervise the travelling arrangements of disabled learners.

#### **Box 6.4** Ensuring curricular accessibility in Uganda

Since 2008, the Ministry of Education in Uganda has prioritised the adaptation of the curriculum in order to take into consideration the learning needs of children with disabilities. The curriculum has been adapted with special features for sign language users and for those with visual impairments. A dedicated position was established at the National Curriculum Development Centre for an expert in special needs education to guide the development of an accessible curriculum. A similar position was established at the Uganda National Examination Board (UNEB) to guide the development of assessment methods that take into consideration the learning potentials and challenges of learners with disabilities.

Inclusive education is taking root in Africa, albeit slowly. The value of an inclusive education is evident in the words of one child from Malawi:

I walk a kilometre to Mbavi Primary School every morning with my friend Amadu. According to my mother, I became blind when I was 2 years old after getting measles. I live at home with my mother – she doesn't work and gets support from her family. I'm very happy going to school. I used to sit at home and wait for my friends to return from school – now I go to school with them. My classmates don't think my blindness is anything special. They make me feel normal.

**James Kanoute**  
Age 14 | Malawi<sup>139</sup>

<sup>138</sup> DoBE (2010). Guidelines for Full-service/Inclusive Schools. Department of Basic Education. Pretoria.

<sup>139</sup> Sightsavers International (2005). From: Seeing a Future.

Implementing inclusive education creates demonstrably positive effects, such as in the life of Joseline, a young woman in Uganda:

Generally I feel very happy, especially about going to school, since this will make me an important and independent person in future.

**Joseline Mbabazi**

Day in the life | Uganda<sup>140</sup>

## 6.4 Teacher training for inclusion

Most current teacher training programmes in many African countries follow a two-track approach whereby training for special education and general education are undertaken separately. The separation between general and special education reinforces the misperception that children with disabilities have educational requirements that cannot be met by general classroom teachers. The emphasis on ‘special education’ as a field for specialists hinders other teachers from educating children with disabilities and hampers potential progression towards integration and inclusive education. This separation also affects teachers, as demonstrated by the following example from Zambia.

Teachers who do not teach children with disabilities call us bad names – they call us ‘deaf teachers’ or ‘teachers of the deaf’. They don’t even want to associate with us. They transfer to us the stigmatising tendency they give towards children with disabilities. They think that we are useless teachers. When it comes to talk to them, they don’t even think that it worth speaking to us or listening to us...some of them do not understand. They look at me as somebody who put himself in very painful work.

**A special needs teacher**

Mumbwa Secondary School | Lusaka<sup>141</sup>

An incremental integration that aims to prepare teachers for both general education and special education will facilitate progress towards inclusive education for children with disabilities in Africa. Within this context, the principle to follow would be that “good teaching practice is good for every child, regardless of levels of ability”.<sup>142</sup>

Burkina Faso has made efforts to train teachers for inclusive education (Box 6.5).

<sup>140</sup> ACPF (2011). Children with Disabilities in Uganda: The hidden reality. Addis Ababa.

<sup>141</sup> ACPF (2011). Children with Disabilities on Africa: Challenges and opportunities. Addis Ababa.

<sup>142</sup> ACPF (2011). Educating Children with Disabilities in Africa: Towards a policy of Inclusion. Addis Ababa.

### **Box 6.5** Teacher training for inclusion in Burkina Faso

Access and staying in school are major problems facing children with disabilities in Burkina Faso – a country that already has low enrolment rates – with only 56 per cent of children in school (2005). Inclusive education, whereby all children with special needs receive their education in ordinary schools, is a relatively new phenomenon for the country.

The training of teachers is therefore one of the major priority strategies within a programme called Promoting inclusive education for children with disabilities in Burkina Faso, which has been implemented by Handicap International in 36 schools in the region of Tanghin-Dassouri. In partnership with the Ministry of Education and Literacy, 165 teachers and 49 education inspectors and counsellors were training in the concepts and practices of inclusive education. In addition, 31 teachers were trained under this programme in the use of sign language. As a result, in the region of Tanghin-Dassouri, the number of pupils with disabilities increased from 54 in 2003 to 228 in 2005.

To conclude, there is a general consensus across countries that – regardless of genetic makeup or physical or intellectual differences – children have the right to learning environments that enable them to develop a wide range of abilities. The creation of human societies that value persons with disabilities individually, and which find valued roles for them, must remain the aspiration for countries in Africa.

While most African countries have ratified the relevant human rights treaties that uphold the right to education of children with disabilities, and despite some attempts to integrate these instruments into national laws, policies and education plans, implementation of legislative and policy provisions has been very slow and inconsistent. A large number of children with disabilities still remain excluded from education services. Those who do have access struggle with significant physical accessibility challenges. Furthermore, professional capacity remains severely limited; specially trained teachers are in short supply, and existing teachers in mainstream education lack the necessary skills to educate children with disabilities.

# Chapter 7

## Access to health

### Introduction

Good health is a precondition for the enjoyment of rights essential to the development and wellbeing of children, including participation in education, play, and family life. The World Report on Disability noted that persons with disabilities experience substantially poorer health outcomes than their counterparts without disabilities.<sup>143</sup> In some countries where under-five mortality as a whole has decreased to below 20 per cent, mortality among young children with disabilities is as high as 80 per cent.<sup>144</sup>

A child born deaf may not require ongoing health care for a primary health condition associated with his or her deafness. A child that experiences spinal cord injury may have health care needs at the outset of the injury, but later on may only require services to maintain health and prevent the onset of secondary conditions such as pressure sores. Children with chronic conditions, such as certain types of epilepsy, may require ongoing medical services relating to their primary health condition. Some children with disabilities may be more vulnerable to communicable illnesses, such as influenza, a condition independent of the primary health condition. In other words, a disability can be both cause and effect of health problems in children, or may be present in a child with good health.

### 7.1 Current status of access to health in Africa for children with disabilities

In many African countries, access to health and rehabilitation services for children with disabilities is limited to urban areas, if it is available at all. The public health care system is usually responsible for providing medical care and rehabilitation services, including assistive devices, to children with disabilities. In many cases, children with disabilities have very limited access to the health system in their communities or to specialised rehabilitation services outside of their communities'.<sup>145</sup>

<sup>143</sup> World Report on Disability (2011).

<sup>144</sup> UK Department for international Development (2000). Disability, Poverty and Development. DFID. London.

<sup>145</sup> ACPF (2009). Missing Voices: Children with disabilities in Africa. Addis Ababa.

For example,

- In 2011, about 7.5 per cent of public hospitals in South Africa were able to provide some sort of infant hearing screening, a cause for concern, given the fact that 85 per cent of the South African population rely on the public health system for health care.<sup>146</sup>
- About 15 per cent of children with disabilities surveyed in Ethiopia live in an area where there no health services in their communities at all. Health services remained inaccessible for the majority of children with disabilities. The main reasons cited for this include: too expensive (28 per cent); and a lack of accessible transport (12 per cent).
- Only 18.5 per cent of children with disabilities surveyed in Senegal reported having access to specialised rehabilitation services in their community.<sup>147</sup>
- NGOs provide the majority of health care services, including 87 per cent of CBR services; 65 per cent of specialised rehabilitation services; 88 per cent of occupational therapy; 84 per cent of speech therapy; 69 per cent of audiologist services; 62 per cent of ophthalmologist services; 81 per cent of counselling services; and 80 per cent of dietician services.<sup>148</sup>

Governments have a responsibility to ensure the physical, mental and social wellbeing of children with disabilities as part of their human rights obligations.<sup>149</sup> While it is commonly accepted that there are many social determinants of health for children with disabilities, disability is often viewed narrowly in Africa as a health issue requiring medical intervention and cure.

The current situation for children with disabilities in terms of access to health services in Africa does not meet the standards and provisions stipulated in the CRPD. Many key facilities and services remain physically or practically inaccessible to children with disabilities; some service providers continue to display prejudicial attitudes; and many caregivers for children with disabilities find it difficult to pay for services that should be provided free of charge.<sup>150</sup>

This often leads most families of children with disabilities resorting to low fee, traditional healers.

<sup>146</sup> ACPF (2011). Children with Disabilities in South Africa: The hidden reality. Addis Ababa.

<sup>147</sup> ACPF (2011). Children with Disabilities in Senegal: The hidden reality. Addis Ababa.

<sup>148</sup> ACPF (2011). Children with Disabilities in Ethiopia: The hidden reality. Addis Ababa.

<sup>149</sup> In order to understand what is meant by the “right to health” for children with disabilities, it is important to understand how health is defined in the context of human rights. In the Preamble to its Constitution, the World Health Organization (WHO) defines health in the following broad terms: “Health is a state of complete physical, mental, and social wellbeing and not merely the absence of disease or infirmity”.

<sup>150</sup> ACPF (2011). The Lives of Children with Disabilities in Africa: A glimpse into a hidden world. Addis Ababa.

For example,

- In Senegal, a significant proportion of the respondents said that they rely on religious healers (65.2 per cent) and traditional doctors (67.1 per cent) as well.<sup>151</sup>
- 70 per cent of children with disabilities surveyed in Uganda said that they rely on a religious faith healer; 54 per cent on a traditional healer; and 35 per cent on a community-based rehabilitation worker.<sup>152</sup>

The physical inaccessibility of healthcare facilities is one of the primary barriers. This is further complicated by lack of accessible, convenient and affordable transport to and from facilities. Even where physical accessibility is assured, communication and informational barriers hamper adequate diagnosis and treatment.

Many of these barriers are likely to have particular impact on disabled children and their families, as they face additional challenges with transport (for example, having to travel with assistive devices) and can be particularly affected by long waiting periods (for example, a child with cerebral palsy would find it difficult to spend many hours waiting for medication). The National Department of Health Audit of Accessibility of Provincial Health Facilities to Persons with Disabilities undertaken in 2006/07 in South Africa found that district hospitals were less accessible to people with disabilities than tertiary hospitals. Less than 10 per cent of the 213 hospitals had a fully accessible toilet for persons with disabilities.<sup>153</sup>

## 7.2 The right to the highest attainable standard of health

The right to health is recognised in international human rights law. Article 24 of the CRC specifically recognises the right of the child to the enjoyment of the highest attainable standard of health, and to facilities for the treatment of illness and rehabilitation of health, and Article 23 reaffirms the right of children with disabilities to health. States Parties are required to adopt measures to ensure that no child is deprived of his or her right of access to such health care services.<sup>154</sup>

<sup>151</sup> ACPF (2011). Children with Disabilities in Senegal: The hidden reality. Addis Ababa.

<sup>152</sup> ACPF (2011). Children with Disabilities in Uganda: The hidden reality. Addis Ababa.

<sup>153</sup> Department of Women, Children and Persons with Disabilities (South Africa), Department of Social Development & UNICEF (2012). Children with disabilities in South Africa: A situation Analysis 2001-2011.

<sup>154</sup> CRC, Art. 24.

The International Covenant on Economic, Social and Cultural Rights (ICESCR) likewise affirms the right to health for all persons. General Comment 5 of the ICESCR on disability and General Comment 14 on health were adopted by the Committee on Economic, Social and Cultural Rights, and together elaborate a framework for ensuring the right of persons with disabilities to health. Together, ICESCR General Comments 5 and 14 clarify that persons with disabilities have the right to access health care services on the basis of equality and non-discrimination in relation to all aspects of the right to health.

Article 25 of the CRPD reinforces and further develops the right to the highest attainable standard of health for children and adults with disabilities. Article 25 sets out state obligations, including:

- The right to sexual and reproductive health services
- Access to population-based public health programmes
- Services provided as close as possible to people's communities
- Provision of disability-specific health services, including prevention of further disabilities
- Autonomy and independence in healthcare decisions, on the basis of free and informed consent
- Non-discrimination in access to health insurance and life insurance
- Prohibition against the denial of care, including food and fluids, on the basis of disability.

The ACRWC reaffirms the right to health in Article 14, providing that children “have the right to enjoy the best attainable state of physical, mental and spiritual health”. It further requires states to take measures in order to:

- Reduce infant and child mortality rates
- Ensure the provision of necessary medical assistance and health care to all children, especially in primary health care
- Ensure the provision of adequate nutrition and safe drinking water
- Combat disease and malnutrition within the framework of primary health care through the application of appropriate technology.<sup>155</sup>

<sup>155</sup> ACRWC, Art. 14.

### 7.3 The right to the highest attainable standard of health in national legislation

A number of countries in Africa have put in place legislative frameworks to facilitate access to healthcare of persons with disabilities. In some countries, the right to health is addressed through multiple pieces of legislation. South Africa addresses the right to healthcare of persons with disabilities through, among other instruments, its Free Healthcare Policy, its White Paper for the Transformation of Health Services, the National Health Act and the Mental Health Act (Box 7.1).

#### Box 7.1 Cross-sectoral legislation to address the right to health: South Africa

- White paper for the transformation of health services in South Africa
- National Health Act
- Mental Health Care Act
- Child and adolescent mental health policy guidelines
- Rehabilitation policy
- Free healthcare policy
- Guidelines for provision of assistive devices

Many existing legislative frameworks entitle persons with disabilities to free healthcare services and/or discounts for such services. For example, the 2011 Persons with Disabilities Act of Sierra Leone (Sec. 17(1)) entitles every person with disability to free medical services in public health institutions. Section 20(e) of the 2003 Kenyan Persons with Disabilities Act requires the government to provide essential health services to persons with disabilities at an affordable cost.

Similarly, the decree of implementation of the 2000 Loi Portant Statut, Protection et Promotion de la Personne Handicapée (Central African Republic) gives persons with disabilities automatic entitlement to discounts when buying orthopaedic equipment, accessing medical and hospital services, and undergoing laboratory and radiological tests and surgical interventions.

Zambia offers a very comprehensive entitlement to healthcare for persons with disabilities through the Persons with Disabilities Act of 2012. Section 27 requires the Minister responsible for health to take appropriate measures to ensure access for persons with disabilities to health services that are also gender sensitive, and to health-related rehabilitation. It also provides that he or she shall in particular prescribe measures to:

- a) Provide persons with disabilities with the same range, quality and standard of free or affordable healthcare and programmes as provided to other persons, including in the area of reproductive health and population-based public health programmes
- b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimise and prevent further disabilities, including among children and older persons
- c) Provide health services as close as possible to people's own communities, including rural areas
- d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, among others, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities and the promulgation of ethical standards for public and private healthcare
- e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance, where such insurance is permitted by law, which shall be provided in a fair and reasonable manner.

Through Burkina Faso's Zatu 86-5 of January 1986, related to the adoption of social measures in favour of persons with disabilities, the Ministry of Health entitles persons with disabilities to the right to enjoy fee and tariff reductions in public health, transport and recreation facilities.

Although not a widespread practice, strategic litigation has been used to highlight the healthcare barriers facing persons with disabilities in Africa, and to promote the right to health (Box 7.2).

## Box 7.2

### Non-discriminatory access to healthcare for children with mental disabilities

#### Purohit and Moore v. The Gambia

In a complaint to the African Commission on Human and Peoples' Rights on behalf of mental health patients detained in a unit, Gambian legislation governing mental health (the Lunatics Detention Act of 1917) was challenged. The complaint alleged that the Act contained no guidelines for making a determination and diagnosis of mental disability; included no safeguards during diagnosis, certification, or detention of a person; and lacked requirements for consent to treatment, independent examination of hospital conditions, and provision for legal aid or compensation in the case of a rights violation.

## Box 7.2 (Continued): Non-discriminatory health care access for children with mental disabilities

The Commission held, among other things, that The Gambia failed to comply with requirements of the African Charter on Human and Peoples' Rights, and particularly Articles 16 (best attainable standard of physical and mental health) and 18(4) (right to special measures for disabled persons with regards to moral and physical needs).

Furthermore, the Commission held that States Parties were required to take concrete and targeted steps to ensure the right to health.<sup>156</sup>

## 7.4 Access to healthcare services

While relatively strong legislative and policy frameworks exist to regulate the right to health of persons with disabilities, implementation and enforcement is weak. In the majority of countries in Africa, healthcare facilities are not physically accessible, and many do not offer disability-friendly communication interfaces. For example, numerous hospitals and health centres in Addis Ababa, Ethiopia, including the largest public hospital in the city, are inaccessible to persons with physical disabilities.

The challenge is really serious for wheelchair users. In health centres, especially government health centres, the challenge is often from the gate to the building. Starting with the entrance, the road is rough, so the wheelchair user cannot easily even access the building.

### Retta Getachew

Ethiopian Centre for Disability and Development | Addis Ababa, Ethiopia

In Uganda, a similar situation is reported:

When you look at the hospitals and health centres, these places are not accessible at all. Whenever you find a service, it's upstairs – and the wheelchairs cannot reach the place. How do you expect someone in a wheelchair to climb those steps?

### An adult with a disability

Focus group participant | Kampala, Uganda

In countries where free healthcare<sup>157</sup> is made available for children with disabilities, such as South Africa, access to these benefits is made difficult by other factors, such as cost of transport and inaccessibility of the healthcare facilities.

<sup>156</sup> Purohit and Moore v. The Gambia, Communication 241/2001 (2003). AHRLR 96 (ACHPR 2003).

<sup>157</sup> Free healthcare is broadly defined by the Department of Health to “include all inpatient and outpatient hospital services such as diagnosis and treatment, specialised services, rehabilitation and provision of assistive devices”. Department of Health (2003).

### **Box 7.3** Free healthcare versus access in South Africa

In South Africa, healthcare 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 per cent of facilities are wheelchair-accessible, and only 28 per cent have specific toilet facilities for disable people.

**Source:** ACPF (2011). *Children with Disabilities in South Africa: The hidden reality*. Addis Ababa.

In addition to physical barriers, there are often information and communication barriers for children with different types of disabilities. For example, many healthcare facilities do not provide sign language interpreters to children who are deaf.

Health providers are complaining that they don't understand our sign language – you also find that a deaf person sometimes hasn't been to school and doesn't know how to read. So it can be very dangerous – you might even receive some wrong medications because of bad communication. So that's why we need people who understand sign language.

**James Kapembwa**

Zambia National Association of the Deaf | Lusaka, Zambia

This challenge is duly recognised by some countries' legislative frameworks. Uganda's Persons with Disabilities Act (Section 7(3)) requires the Government to ensure that (a) sign language is introduced into the curriculum for medical personnel; (b) interpreters are included in hospital organisational structure; (c) labels on drugs are pre-brailled.

The stigma and negative attitudes prevalent in many African countries lead to additional barriers to accessing health services for children with disabilities. In many countries, children with disabilities encounter prejudicial or negative attitudes from health care professionals and do not fully benefit from health services.

When I go to the clinic where we are given medication then the nurses themselves get surprised – “how come this child looks like this?” they say.

They are not very supportive – they start to ask questions instead of attending to you. On the part of the doctors, they are very helpful and attentive, but the nurses are the ones who get surprised and say all sorts of things.

**Focus Group participant**

Mother to a child with a disability | Lusaka, Zambia<sup>158</sup>

Very often, children, adolescents, and adults with disabilities are unable to access sexual and reproductive health services. They are therefore likely to be excluded from sex education and HIV/AIDS outreach efforts due to stigma and discrimination, including the common and wholly false assumptions that persons with disabilities are not sexually active, are unlikely to use drugs or alcohol, and/or are at less risk of violence or rape than their peers without disabilities.

Persons with disabilities are more vulnerable to infection if they do not have ready access to the information, education, and services necessary to ensure good sexual and reproductive health and prevention of infection. Poverty exposes girls with disabilities to sexual exploitation, and research suggests that a large percentage of all persons with disabilities will experience sexual assault or abuse during their lifetime. Children with intellectual disabilities and children with disabilities living in institutional settings experience elevated risks of sexual violence and abuse. Vulnerability also decreases the likelihood of being able to negotiate safe sex. Physical barriers to centres for HIV prevention, voluntary counselling and testing (VCT), treatment, and care limit access for persons with mobility impairments. Likewise, transport may be unavailable or inaccessible to persons with disabilities. And communication barriers limit access to certain HIV/AIDS messaging, such as radio programming, for persons who are deaf.

The issue of preserving patient confidentiality represents another major concern for children and youth with disabilities, especially in the field of sexual and reproductive health service delivery. For example, children who are blind may require assistance filling out personal medical forms, and often healthcare provider reading questions aloud in crowded rooms without considering the issue of privacy. The issue is further highlighted by a first person account from Uganda:

Recently I was at a health centre and [into] the facility came a gentleman in a wheelchair, but he could not reach where the doctor was. He tried to be in the line, but other people were passing by. Then the service provider came [and asked] ‘What is the problem?’ And the man had sexually transmitted diseases [STDs]. How do you start telling almost everyone, “I’m having STDs”? It was really hurtful and the reason was that the wheelchair could not enter where the medical person was. And these are government health centres, these are government hospitals.

**A person with a disability**

Focus group participant | Kampala, Uganda

<sup>158</sup> See Chapter 9 for more information about violence against children with disabilities.

Despite the clear challenges in accessing health services faced throughout Africa by children with disabilities, there are some positive developments in some African cities, provided through both public and privately funded interventions (Box 7.4).

#### **Box 7.4** Initial steps towards creating disability-friendly healthcare services: A case from Ethiopia

A specialist HIV/AIDS testing centre in the grounds of Addis Ababa's Zewditu Hospital, for example, is fully accessible and recently managed to secure funding for a small team of counsellors trained in sign language. Addis Ababa also has a private hospital that is completely accessible, with a central, wheelchair-friendly circular ramp spiralling up all of its inner floors, accessible toilets, and space set aside to introduce an accessible elevator in the future. Unfortunately, because it is a private, fee-paying hospital, many potential beneficiaries of its accessible features are not able to afford services, especially given that persons with disabilities and families of children with disabilities are among the city's poorest residents and do not receive appropriate financial support to pay for services.

In Kenya, the Ministry of Health (MOH) is working to mainstream disability issues into the general health care system. The MOH:

...has trained health workers on early identification and management of disability. Disability has also been mainstreamed into the health professional curriculum while there are continuous professional development courses which are done periodically to sensitize health workers.<sup>159</sup>

In Uganda, the government has introduced a National Minimum Health Care Package (NMHCP) that prioritises services that are cost effective, targets diseases that impose a high burden, and focuses on the poor and disadvantaged (women, children and persons with disabilities).<sup>160</sup> Uganda also has put in place a system for identifying children with disabilities early and assisting them. Under the system, primary healthcare providers and community-based rehabilitation and educational personnel identify children with disabilities and are responsible for sensitising, counselling and training parents, teachers and local administration staff in how to meet their needs.<sup>161</sup>

<sup>159</sup> Kenya report to CRPD Committee.

<sup>160</sup> ACPF (2011). Children with Disabilities in Uganda: The hidden reality. Addis Ababa.

<sup>161</sup> Ransom, B. In: ACPF (2009). Missing Voices: Children with disabilities in Africa. Addis Ababa.

A few African countries – for example, Mozambique, South Africa, Uganda, Tanzania, Zambia and Zimbabwe – have demonstrated good practice in collaborating with DPOs.<sup>162</sup> For example, national disability and HIV organisations in Tanzania and Mozambique worked in collaboration with Rehabilitation International to develop educational materials as a component of HIV/AIDS education and outreach.<sup>163</sup> In spite of these positive engagements between governments and DPOs and NGOs, however, it is important to underscore the fact that combating HIV/AIDS remains a state obligation and greater efforts are urgently needed on the part of governments throughout Africa to ensure children and youth with disabilities are included in HIV/AIDS education and prevention, as well as care and support programmes.

In some countries there are laws that allow the sterilisation of women with disabilities – mostly women with epilepsy, intellectual or psychiatric disabilities – thereby denying their right to have, and raise their own children. This is mainly done, with or without their consent, through surgery that inhibits reproduction.<sup>164</sup> This is unjustifiable, given the recent availability of effective long-term, reversible contraceptive devices.<sup>165</sup>

While many countries have put in place adequate legislation to ensure access to healthcare services for persons with disabilities, due to attitudinal, budgetary and other capacity constraints, implementation and enforcement of these legislative and policy frameworks has been inadequate. Physical accessibility of healthcare facilities, including their distance from communities, and communication and information barriers that compromise effective diagnosis and treatment, pose serious challenges in accessing healthcare. For example, in many countries systems for the early identification of childhood impairments do not exist or are inadequate. Furthermore, despite legislative provisions to ensure free access to health

<sup>162</sup> The World Bank (2010). HIV/AIDS & Disability: Three Country Studies - South Africa, Uganda, and Zambia' The International Bank for Reconstruction and Development World Bank. AIDS Campaign Team for Africa (ACT Africa).  
<http://siteresources.worldbank.org/EXTAFRREGTOPHIVAIDS/Resources/Conference-Edition-HIV-AIDS-Disability.pdf>

<sup>163</sup> Rehabilitation International et al. (2007). HIV/AIDS Awareness and Disability Rights Training Manual. [http://www.aidslex.org/site\\_documents/DB-0045E.pdf](http://www.aidslex.org/site_documents/DB-0045E.pdf)  
Combating AIDS-related stigma and violence against women and girls with disabilities was the life work and legacy of disability rights advocate G. Charowa, founder of the Disabled Women Support Organisation of Zimbabwe. NEWS: 'Disability advocate, Gladys Charowa, dies'. We Can Do. 21 April 2008.  
<http://wecando.wordpress.com/2008/04/21/news-disability-advocate-gladys-charowa-dies/>

<sup>164</sup> Marks, G. (1996). Coming out as gendered adults: gender, sexuality and disability. In: Christensen, C. & Rizvi, F. (eds.). Disability and the Dilemmas of Education and Justice. Open University Press. Buckingham. pp.119-130.

<sup>165</sup> Brantinger, E. (1995). Sterilization of people with mental disabilities: Issues, perspectives and cases. Greenwood Publishing Inc. Westport.

services for all children, other factors – such as the prohibitive cost of accessible transport – mean that disabled children continue to have limited access to healthcare.

The reproductive health of adolescents with disabilities has also been grossly neglected for a number of reasons, including lack of tailored services; lack of appropriate educational material; parental anxieties about raising issues of sexuality with disabled children; social isolation of adolescents with disabilities that compounds their difficulties with access to information and services; and, not least, the widespread attitude that persons with disabilities are asexual and hence do not need awareness of their reproductive and sexual rights.

# Chapter 8

## Access to habilitation and rehabilitation

### Introduction

“Habilitation” refers to a process aimed at helping children who acquire a disability at birth or early in life to gain skills, abilities, and knowledge. “Rehabilitation” refers to regaining skills, abilities, or knowledge that may have been lost or compromised as a result of acquiring a disability or due to a change in one’s disability or circumstances.

Habilitation and rehabilitation are essential components in ensuring that children with disabilities are able to lead full, meaningful lives and access all of their human rights. Without effective access to adequate habilitation and rehabilitation services, children with disabilities may not be able to work, go to school, or participate in cultural, sports, or leisure activities.

The goals of habilitation and rehabilitation as defined in Article 26 of the CRPD are to:

...enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social, and vocational ability, and full inclusion and participation in all aspects of life.<sup>166</sup>

Habilitation and rehabilitation are often linked with health-related issues and consequently addressed along with policies related to the right to health. In reality, however, rehabilitation is much more complex and far-reaching. While health-related rehabilitation can be a vital aspect of strategies to achieve these goals, many other elements are equally important, including those related to employment, education, or simply life skills. The common approach of classifying habilitation and rehabilitation as health issues reinforces the medical model of disability and does not adequately consider how the various facets of rehabilitation promote social inclusion, not just medical interventions. One example of this can be found in the Government of Mauritius’ report to the CRPD Committee, which lumps Articles 25 and 26 into one section of the report and focuses only on health-related rehabilitation.<sup>167</sup> In order to distinguish clearly in the African context between access to health for children with disabilities and access to habilitation and rehabilitation, this report has divided the topics into two distinct chapters.

### 8.1 National legal frameworks

The right to rehabilitation is addressed in various international instruments. Article 23 of the CRC calls on States Parties to ensure “effective access” of children with disabilities to:

...education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child’s

<sup>166</sup> CRPD, Art 26.

<sup>167</sup> Mauritius report to CRPD Committee.

achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development.

The CRPD is the first instrument to mention both habilitation and rehabilitation: Article 26 calls on States to:

...organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services.

The CRPD stresses that habilitation and rehabilitation should be multi-disciplinary and individualised to take into account the needs and strengths of the person, and that services should be available to people as close to their own communities as possible, including in rural areas. It recognises the need for ongoing training of habilitation and rehabilitation professionals and the important role that assistive technologies and devices play in habilitation and rehabilitation processes.<sup>168</sup>

## 8.2 The status of rehabilitation in Africa

In Africa, there is a significant lack of skilled personnel in the habilitation and rehabilitation sector. Less than 16 per cent of children with disabilities surveyed in Ethiopia and 18.5 per cent of children in Uganda had access to specialised rehabilitation services such as occupational therapy, physiotherapy, speech therapy, or audiology. In 2008, South Africa – a relatively well-off country – had one physiotherapist for every 45,000 people, and one occupational therapist for every 53,000.<sup>169</sup>

The issue is further exacerbated by the fact that many children with disabilities and their families and/or caregivers often do not know about such services, or about how to access them when they do exist in their communities.

Children with disabilities require support in terms of rehabilitation that helps improve their disability, or at least to manage it and limit its negative consequences. ACPF studies and others illustrated the huge unmet rehabilitation needs of children with disabilities in Africa.

For example, in Senegal only 25.4 per cent of children with disabilities surveyed reported having access to ophthalmologists, while 11.6 per cent reported access to physiotherapists. Only 7.8 per cent of the children had access to dieticians,

<sup>168</sup> The CRPD also mentions rehabilitation in the articles on work, health, and freedom from exploitation, violence, and abuse, though no specifics are offered as to what rehabilitation entails in those contexts.

<sup>169</sup> ACPF (2011). *The Lives of Children with Disabilities in Africa: A glimpse into a hidden world*. Addis Ababa.

1.3 per cent to speech therapists, 1.1 per cent to audiologists, and 0.9 per cent to occupational therapists. Less than 16 per cent of children surveyed in Ethiopia and 18.5 per cent of those surveyed in Uganda had access to specialised rehabilitation services such as occupational therapy, physiotherapy, speech therapy and audiology.<sup>170</sup>

In Tanzania, many persons with disabilities reported that they did not access services because they were unaware of any rehabilitation services available in their community.<sup>171</sup> In some countries, initiatives are underway to raise greater awareness of the existence of rehabilitation services for children with disabilities (Box 8.1).

### **Box 8.1** Raising awareness about rehabilitation services in South Africa: The Sponge Project

The Sponge Project was set up in recognition of the fact that persons with disabilities and parents of children with disabilities (especially those living in rural parts of South Africa), often find it difficult to get information about rehabilitation services that are 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 persons with disabilities 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; the reply is by SMS and contains the contact details of local organisations. The Project holds a database that currently contains over 3000 contacts. An electronic newsletter is sent out to everyone on the database to improve their awareness of disability issues and inform them of available resources.

Additionally, there is a shortage of rehabilitation and early childhood development (ECD) services and trained professionals throughout Africa. The lack of specialists such as audiologists, physiotherapists and occupational therapists, combined with insufficient ECD services, constitutes a significant impediment to ensuring adequate and quality habilitation and rehabilitation services for children with disabilities. Data from Uganda and South Africa shows:

<sup>170</sup> ACPF (2011). The Lives of Children with Disabilities in Africa: A glimpse into a hidden world. Addis Ababa.

<sup>171</sup> LMG November Workshop Report.

<sup>172</sup> ACPF (2011). Children with Disabilities in South Africa: The hidden reality. Addis Ababa.

- Between 0.4 per cent and 18 per cent of children with disabilities surveyed in Uganda reported having access to ECD services. The lack of specialists such as audiologists, physiotherapists and occupational therapists, allied with insufficient CBR programmes, were the main reasons for poor access.<sup>173</sup>
- In the rural districts of Ehlanzeni, Nkangala and Gert Sibande in the Mpumalanga province, South Africa, only 42 per cent of the children with disabilities identified were receiving rehabilitation and only 33 per cent had the assistive devices they required. Some 59 per cent reported that the caregiver did not know how to apply for an assistive device.<sup>174</sup>

## **Box 8.2** Training for habilitation and rehabilitation in Ethiopia

In its report to the CRPD Committee, the Government of Ethiopia acknowledged the crucial need for trainings and noted:

94. Training of professionals and staff working in the habilitation and rehabilitation service is of crucial importance both to extend the coverage and increase the quality of the service. At present, we observe a wide gap of, and high demand for trained manpower in the fields of prosthetics, orthotics, physiotherapy and occupational therapy.

95. Considering the need for more trained manpower, the government has taken measures to ensure availability and deployment of professionals. Over the last two years, 97 students have been admitted to universities in the fields of physiotherapy, orthopaedics and prosthetics. 69 of these students are receiving training at diploma level while the remaining are prospect graduates in degree programmes. Upon completing their training, the graduate is placed in relevant areas in the respective regions to support rehabilitation services.

<sup>173</sup> ACPF (2011). Children with Disabilities in Uganda: The hidden reality. Addis Ababa.

<sup>174</sup> Department of Women, Children and Persons with Disabilities (South Africa), Department of Social Development & UNICEF (2012). Children with disabilities in South Africa: A situation Analysis 2001-2011.

### 8.3 Access to devices and technologies

Assistive devices have the potential to enhance the function and participation of most children with disabilities, but very few children with disabilities have access to assistive devices. For example, less than 5 per cent of children with disabilities in Uganda have appropriate assistive devices. Notably, such devices are more available to children with physical and visual disabilities, while children with hearing, speech and intellectual impairments are largely neglected. Access to assistive devices is also equally limited in countries such as Senegal, Ethiopia and South Africa (Box 8.3).

A major challenge is the fact that assistive devices are currently, for the most part, imported into Africa and therefore prohibitively expensive and related consumables and maintenance services are not readily available or affordable. For example, a ream of imported Braille paper in Zambia costs about ten times more than an ordinary ream of paper.<sup>175</sup> In Ethiopia, the average cost of crutches is about USD 8, while a wheel chair costs USD 224 – which is unaffordable for the average Ethiopian family.

In an effort to curb the high cost of assistive devices, some African countries have provided relevant tax breaks or tax incentives. For example, in Kenya, assistive devices are imported duty free:<sup>176</sup> Section 35 (3) of the Kenyan Persons with Disabilities Act 2003 exempts from import duty, value added tax, demurrage charges, port charges and any other government levy which would in any way increase their cost to the disadvantage of persons with disabilities materials, articles and equipment, including motor vehicles, that are modified or designed for the use of persons with disabilities. Similarly, Section 33(1) of the Persons with Disabilities Act of Sierra Leone exempts materials, articles, equipment and motor vehicles that are modified or designed for the use of persons with disabilities from import duty, goods and services tax, demurrage charges, port charges and any other levy which would in any way increase their cost to the disadvantage of persons with disability.

Similarly, the Government of Ethiopia adopted legislation:

....to ensure availability and supply of rehabilitation tools and equipment for use by persons with disabilities. The custom tariff regulation guarantees exemption from custom tariffs. Pursuant to the regulation, those organizations that import items for the purpose of rehabilitation and habilitation of persons with disabilities pay no custom duty on such appliances as ICT equipment and devices, Braille materials, wheelchairs and other mobility devices, hearing aids, etc.<sup>177</sup>

<sup>175</sup> At time of writing a ream of Braille paper costs Kwacha 300,000 (equivalent to USD 64) while an ordinary ream is about Kwacha 30,000 (equivalent to USD 6.4).

<sup>176</sup> Kenya CRPD report. para. 207.

<sup>177</sup> Ethiopia CRPD report. para. 92.

### Box 8.3

#### Assistive devices for persons with hearing and visual impairments 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.

**Source:** ACPF (2011). *The Lives of Children with Disabilities in Africa: A glimpse into a hidden world*. Addis Ababa.

It is clear that rehabilitation services remain a hugely neglected area in Africa. The few existing services remain fragmented and uncoordinated due to the low priority given them and the lack of an effective system to coordinate medical, vocational, and psychosocial and education components. There is a general lack of awareness of the existence of rehabilitation services for children with disabilities, due partly to inadequate public sensitisation efforts, and a dire shortage of rehabilitation personnel such as physiotherapists and occupational therapists. The provision of assistive and adaptive devices has also been a huge change, partly due to the fact that most such devices are imported from abroad and are unaffordable for average households in Africa.

# Chapter 9

## Access to an adequate standard of living

### Introduction

The right to an adequate standard of living is a fundamental human right. Children with disabilities in Africa have the right to accessible housing, clean water, proper sanitation systems, good hygiene, nutritious food, and social protection. Families living in poverty are far more prone to disability-causing illnesses, and poverty limits access to basic needs. This chapter will focus on access to an adequate standard of living for children with disabilities, with a particular emphasis on housing, water and sanitation, and social protection.

### 9.2 The situation in Africa

#### Access to water and sanitation

Clean drinking water is vital to health, especially for those with additional health challenges, including children with disabilities. Many children with disabilities in Africa and their families lack access to safe drinking water. For example, approximately six per cent of Ethiopians, nine per cent of Senegalese and 22 per cent of Ugandans surveyed used unsafe water from unprotected wells, springs, ponds, rivers, rainwater and streams. Those living in rural areas were most reliant on these sources, which increase vulnerability to disability-causing diseases such as trachoma, which can lead to blindness. In some countries, specific measures are being taken to ensure that children with disabilities and their families have access to clean water (Box 9.1).

#### Box 9.1 Burkina Faso: Access to drinking water for people with disabilities

Since 2001, the Dakupa organisation has worked to ensure that families with disabilities not only have access to clean water sources, but can also use these facilities independently.<sup>178</sup> In collaboration with Water Aid, Dakupa began to implement a WASH project in several urban municipalities.

Access ramps and handrails, along with suitable wheelchair-accessible standpipes, were put in place, allowing children and adults to access clean water without assistance.

<sup>178</sup> Handicap International (2010). Rights in Action: Good practices for inclusive local governance in Western Africa.

<http://www.makingitwork-crpd.org/miw-initiatives/west-africa/regional-project/>

Sanitation is also an essential component of an adequate standard of living. 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 many

forms of disability, and more than 90 per cent of an estimated 300-500 million malaria cases in Africa occur in children under five.<sup>179</sup>

Research findings, although in line with national figures, are worrying in light of the risk to disease and injury that unhygienic and inaccessible toilet facilities pose to children with disabilities.

**Table 9.1** Percentage use of types of toilet facilities by country

Type of toilet facility	Ethiopia		Senegal		Uganda	
	Cause	per cent	Cause	per cent	Cause	per cent
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
<b>Total</b>	<b>468</b>	<b>100</b>	<b>434</b>	<b>100</b>	<b>528</b>	<b>100</b>

**Source:** ACPF (2011). *The Lives of Children with Disabilities in Africa: A glimpse into a hidden world*. Addis Ababa.

Fewer than seven per cent of households across the continent have access to flushed toilets. The situation is particularly dismal in Ethiopia, where 43.4 per cent of households use unsafe sanitary facilities. Many use communal pit latrines, which in most cases are extremely unhygienic; others have no access to toilet facilities and use the bushes for ablutions (Table 9.2). The situation in Senegal and Uganda is slightly better, with only 20.2 per cent and 16.9 per cent respectively using unhygienic and unsafe sanitary facilities.

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**

<sup>179</sup> ACPF (2011). *The Lives of Children with Disabilities in Africa: A glimpse into a hidden World*. Addis Ababa.

Inadequate sanitation is even worse in primary and secondary schools, where toilets are inaccessible to many children with disabilities due to steps, narrow doorways, low toilets and lack of space in which to turn around. Inaccessibility of sanitation facilities is even more complicated for girls with disabilities as Rousso explains:

...the inaccessibility of toilets and the unsanitary nature of many bathrooms, coupled with the nature of certain disabilities, can create situations where a girl has to be helped go to the toilet. The emphasis on modesty and privacy shared by many cultures, and a restricted degree of openness concerning some biological processes, such as menstruation, make the provision of intimate help in toileting and sanitation highly problematic, as well an intense safety concern.<sup>180</sup>

The same author goes on to point out:

The absence of provisions at school enabling the girl to manage her period in a safe way can intensify...parental fears and further discourage school attendance. A girl's need for help with such personal tasks may reinforce negative stereotypes about her ability to function as a pupil, and also increases staff anxieties about issues of sexuality.<sup>181</sup>

### Access to housing

The accessibility of a home can help or hinder the participation of a child with a disability in family and relevant household activities. Consequently, this can hinder their development and their long-term ability to care for themselves. For example, a child using a wheelchair or a child who is blind may find it difficult to move outside and inside the house. Poor lighting may make it difficult for a sign language user to see hand-signs, or for a hearing-impaired child to read lips. Cooking and cleaning equipment may be out of reach for a child with a physical disability.

In spite of the importance of physical accessibility, very few households surveyed by ACPF made changes to their homes to improve access for their child with a disability, or even recognised that physical access was a challenge for their children. Most homes and neighbourhoods are not adapted to allow free mobility of children with disabilities. In Senegal, a survey of households having a child with a disability living with them showed that very few homes were so adapted, even with basic modifications like ramps (13.5 per cent); handrails (8.1 per cent); items related to toilet facilities (35.2 per cent); accessible furniture (16.2 per cent); and adjusted lighting fixtures (10.8 per cent).<sup>182</sup> In Uganda, only 6.3 per cent of households having a child with a

<sup>180</sup> Rousso, H. (2003). *Education for All: A Gender and Disability Perspective*. UNESCO.

<sup>181</sup> See No. 180 above.

<sup>182</sup> ACPF (2011). *Children with Disabilities in Senegal: The hidden reality*. Addis Ababa.

disability living with them said they had adapted their dwelling or accommodation to improve access for children with disabilities; 83.1 per cent had done nothing to adapt their dwellings, while 6.9 per cent were not aware of adaptation as an issue at all.<sup>183</sup> Only 13 per cent of respondents in such households surveyed in Ethiopia stated that their houses had been physically adapted to assist their child with a disability.<sup>184</sup> Only 2 per cent of children with disabilities surveyed in Senegal reported that the doors of their houses were wide enough to allow free mobility, while only 9 per cent of children with disabilities in Ethiopia reported access to appropriately modified toilets. Children with disabilities are, therefore, denied the equal opportunity to engage in their own families' activities as well as those of their communities.

<sup>183</sup> ACPF (2011). Children with Disabilities in Uganda: The hidden reality. Addis Ababa.

<sup>184</sup> ACPF (2011). The Lives of Children with Disabilities in Africa: A glimpse into a hidden World. Addis Ababa.

# Chapter 10

## Freedom from violence and exploitation

### 10.1 The situation in Africa

Violence against children with disabilities is widespread and often disability itself is caused by intentional violence committed during conflict (Box 10.1). Other factors that contribute to violence against children with disabilities in Africa include:

- Dependence on caregivers for mobility and basic daily needs
- Children with disabilities may be isolated and hidden within the home or institution
- Lack of voice within the home, community, and government
- The fact that complaints about violence and abuse are ignored, disbelieved or misunderstood
- The fact that some parents and caregivers may abuse children with disabilities because of their own financial, emotional and physical stress.

#### Box 10.1 Targeted programming to promote birth registration

“Some elders shout at us when we approach them for help. It is even worse when you have a physical disability, because you may be considered insane by others.”

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

An 8-year-old Bintu Koroma describes the day rebels came to her house in Sierra Leone and demanded money her mother did not have:

“They led us to the cotton tree, where we sat together with others who had been captured. I was the first one they called. They grabbed my left hand, put it on the root of the tree and chopped it off. I was four years old.”

**ACPF (2009). Missing Voices:**  
Children with disabilities in Africa. Addis Ababa. pp. 40-41.

Children with disabilities throughout Africa are at acute risk of violence and abuse on account of stigma, negative traditional beliefs, and lack of knowledge about the causes of

disability.<sup>185</sup> Violence against children with disabilities occurs in multiple forms and includes physical, psychological, and sexual abuse.

Children with disabilities are at particular risk of violence in many different environments and situations. In Africa, children with disabilities are two-to-five times more likely to be abused than their non-disabled peers, while those with intellectual disabilities are three to eight times more likely to be abused. In South Africa, it has been found that children with physical disabilities are three to four times more likely to be abused than able-bodied children<sup>186</sup> and children with intellectual disabilities are three to eight times more common in abused than in non-abused children.<sup>187</sup>

Another study shows that children with speech and language difficulties were at five times greater risk of neglect and physical abuse than other children, and three times greater risk of sexual abuse. And for those children with behavioural disorders, the risk is between five and seven times higher than for children without disabilities.<sup>188</sup>

This may be due to a number of factors. Many children with disabilities in Africa live in isolation: parents hide them, either because of the stigma and shame associated with having a child with a disability, or for the safety and protection of the child. Violence can and does also occur in the home, perpetrated by family members, and in schools. In school, children with disabilities are targeted by classmates and physically, psychologically, and sexually abused far more than children without disabilities.<sup>189</sup> The abuse often goes unnoticed or unreported due to the lack of access to effective complaint mechanisms.

Children with disabilities may not be able to resist or avoid physical or psychological abuse because of their physical or mental disability. The vulnerability of children with disabilities to violence is aggravated by their inability to escape potential perpetrators, the difficulty they may have discerning the intentions of assailants, and an inability to communicate incidents of violence to law enforcement bodies.

<sup>185</sup> ACPF (2009). *Missing Voices: Children with disabilities in Africa*. Addis Ababa.

<sup>186</sup> Lamprecht, L. (2003). *Sexuality in children with intellectual disabilities*. Presented at a workshop of the South African Association for Scientific Study of Mental Handicap. Johannesburg General Hospital.

<sup>187</sup> Dhai, A. (2003). *Ethical & societal issues in the care and management of the intellectually disabled child as they grow up*. Presented at a workshop of the South African Association for Scientific Study of Mental Handicap. Johannesburg General Hospital.

<sup>188</sup> Save the Children Fund (2011). *Out from the shadows: Sexual violence against children with disabilities*. London.

<sup>189</sup> ACPF (2010). *CRC General Comment 9. Studies in Ethiopia, Senegal, Uganda, Zambia, and Cameroon found that children with disabilities are likely to have experienced at least one instance of psychological violence, such as being bullied, ridiculed, shunned, or verbally assaulted*.

The following factors contribute to higher levels of violence and abuse against children with disabilities in Africa when compared to children without disabilities:

- Children with disabilities may be unable to report abuse because of language and communication barriers
- Children with disabilities are especially vulnerable to bullying and intimidation because of stigma, prejudice, and misconceptions of disability
- Children with disabilities in foster/kinship care or institutions are particularly at risk of abuse
- Children with disabilities may feel that the abuse is their fault, and can even become desensitised to abuse
- Children with disabilities are less likely to know about and understand their rights<sup>190</sup>
- Children with disabilities in refugee and IDP camps are at a higher risk of violence.

## 10.2 The right to freedom from violence and exploitation

The Convention on the Rights of the Child (CRC) recognises the right of the child to be free from torture. The CRC specifically calls for the protection of children from:

...all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse.

It further recognises State obligations regarding sexual exploitation and abuse, economic exploitation, and promoting recovery of child victims.

The Convention on the Rights of Persons with Disabilities (CRPD) specifically outlines a framework for protecting the rights of children with disabilities from violence and abuse. The standards set out in the CRPD complement and further develop standards of child protection reflected in the CRC and other human rights instruments.

The CRPD addresses violence and abuse in two specific provisions: Article 15, Freedom from torture or cruel, inhuman or degrading treatment or punishment; and Article 16, Freedom from exploitation, violence and abuse. Together, the provisions state:

<sup>190</sup> Child Protection Toolkit (2014). Scottish Government Ministerial Working Group.

- The right of persons with disabilities to be free from torture, as well as cruel, inhuman, or degrading treatment or punishment
- The right of persons with disabilities to be free from subjection to medical or scientific experimentation unless they have provided informed consent
- The right of persons with disabilities to be free from all forms of exploitation and abuse.

Article 16 of the CRPD provides that States Parties should take all appropriate measures to prevent all forms of economic exploitation of persons with disabilities. This includes legislative measures to protect children with disabilities from child labour in the informal sector (Box 10.2).

### **Box 10.2** Comprehensive protection from violence through the CRPD

**Article 16 of the CRPD** requires states to adopt measures to prevent torture and abuse. The measures must:

- Protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including gender-related abuse
- Prevent all forms of exploitation, violence and abuse and ensure, for instance, the availability of appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers, including information and education on how to avoid, recognize and report instances of exploitation, violence and abuse
- Ensure that protection services are age-, gender- and disability-sensitive
- Ensure the effective monitoring of all facilities and programmes designed to serve persons with disabilities
- Ensure victim services to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse in an environment that respects the rights and dignity of victims, their age and gender
- Adopt laws and policies to ensure that exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted.

## Box 10.2 (Continued): Comprehensive protection from violence through the CRPD

### The CRPD Committee on Freedom from Exploitation, Violence and Abuse

In the CRPD Committee's Concluding Observations on the Report of Tunisia, the Committee stated the following:

The Committee expresses concern at the situation of violence that women and children with disabilities might face.

The Committee encourages the State party to include women and girls with disabilities in the National Strategy for the prevention of violence in the family and society, and to adopt comprehensive measures for them to have access to immediate protection, shelter and legal aid. It requests the State party to conduct awareness campaigns and develop educational programmes on the greater vulnerability of women<sup>191</sup>

## 10.3 The African legal framework

Within the African human rights system, the African Charter on the Rights and Welfare of the Child (ACRWC) requires states to enact measures to protect children from all forms of torture and inhuman or degrading treatment. Article 16 of the ACRWC mandates measures to protect children from mental or physical abuse, injury, neglect or maltreatment, including sexual abuse, and demands protection of children from inducement, coercion or encouragement to engage in any sexual activity.

## Box 10.3 Article 23 on Special Protection of Women with Disabilities

The States Parties undertake to:

- a) ensure the protection of women with disabilities and take specific measures commensurate with their physical, economic and social needs to facilitate their access to employment, professional and vocational training as well as their participation in decision-making;
- b) ensure the right of women with disabilities to freedom from violence, including sexual abuse, discrimination based on disability and the right to be treated with dignity.

<sup>191</sup> Committee on the Rights of Persons with Disabilities, Fifth Session (2011). Concluding Observations Consideration of the Report of the Government of Tunisia. para. 26 & 27. <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Session5.aspx>

The UNCRC (Article 23 and its general comment No. 13) and the ACRWC (Article 13) both contain provisions that protect the rights of children with disabilities. Other provisions of these instruments that relate to child protection equally apply to children with disabilities.

The Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa gives special protection to girls with disabilities (Box 10.3).

## 10.4 Nature and extent of violence against children with disabilities in Africa

### Sexual violence and abuse

Sexual violence and abuse is a widespread phenomenon among children with disabilities, particularly girls, although boys with disabilities also experience it. Most instances of abuse go unreported and remain unaddressed. Often, sexual abuse of children with disabilities happens within the home or in institutions perceived to be safe for children.

According to ACPF research, sexual violence inflicted on children with disabilities is high in many countries, ranging from 1.9 counts of sexual violence per child in Senegal to 3.9 counts per child in Cameroon. Types of sexual violence included rape (52 per cent), forced prostitution (30 per cent), and indecent touching (43 per cent).

Girls with disabilities are often subjected to sexual abuse in the home of their employer, especially where the head of the family is an unmarried man or where there are young men in the house (Box 10.4). One girl from Ethiopia noted:

I was working as a maid in the house of an unmarried man when he molested me and dishonoured me of my virginity. I couldn't do anything other than stop working there.<sup>192</sup>

Sexual abuse goes unreported because of the mistaken belief that children with disabilities are asexual and cannot understand their own bodies.

"I tried to fight him, but I do not have strong feet [due to polio]. He raped me until...

I was not able to attend school since then. The exam is going on and I am missing it. I [was] ranked first in my class in the first term...I am very annoyed and frustrated."

**A12-year-old girl with polio**  
Kono district, Sierra Leone<sup>193</sup>

<sup>192</sup> ACPF (2014), The African Report on Violence against Children, Addis Ababa

<sup>193</sup> ACPF (2010). National Study on School-Related Gender-Based Violence in Sierra Leone,

### Box 10.4 Sexual violence and abuse against girls with visual impairments in Ethiopia

Girls with visual impairments are highly vulnerable to sexual abuse, especially in situations where they live in rented houses without an accompanying person.<sup>194</sup> Reports noted situations where visually impaired girls were gang-raped after being led into the wrong place by offenders posing as helpers.<sup>195</sup>

In one Ethiopian boarding school for the visibly impaired, once children graduate from Grade 6, they leave the boarding school and rent a house using a monthly subsistence stipend provided by the school.

In these houses, potential abusers exploit the visual impairments of the girls. As most of the houses are cheaply built, they do not have adequate security.

Another report told of a situation where girls with hearing and speech impairments were seized by assailants and – given their inability to scream – were abused.<sup>196</sup>

**Source:** ACPF (2011). *Educating children with disabilities: Ethiopia*. Addis Ababa.

Sexual violence, exploitation, and abuse have long-lasting harmful effects on children with disabilities. When sexual abuse of a child with a disability occurs in isolated settings, it is unlikely the child will receive the services necessary to recover from such a traumatic event. It is more likely that such traumatic experiences will increase disability-related functional limitations or create secondary disabilities.

In Africa, programmes and services that address sexual violence and abuse in the community, particularly those targeting women and girls, very often do not reach out to children with disabilities. Disability advocates are working to address these gaps and to ensure that programmes and services are inclusive and accommodating to all. Violence prevention advocacy is an important component of ensuring the right of children with disabilities to be free from violence and to lead self-determined lives.

<sup>194</sup> ACPF (2011). *Educating children with disabilities: Ethiopia*. Addis Ababa.

<sup>195</sup> Tirussew, T. (2005). *Disability in Ethiopia: Issues, Insights and Implications*. Addis Ababa: Addis Ababa University Printing Press, p.182.

<sup>196</sup> ACPF (2011). *Educating children with disabilities: Ethiopia*. Addis Ababa

## Violence in the home

Children with disabilities are more likely than siblings without disabilities to experience violence at home.<sup>197</sup> The main cause of such violence is the stigma associated with disability, often due to the lack of knowledge about the cause of disability (Box 10.5).

### Box 10.5 Violence against children with disabilities in the home

In societies where there is stigma against those with disability, some parents become violent towards a child with a disability because of the shame the child has brought to the family, or resort to violence because of a lack of social support. A 2009 ACPF report entitled *Missing voices: Children with disabilities in Africa* identifies the following forms of violence in the home:

**Infanticide and “mercy” killings:** Children with disabilities may be killed immediately after birth or at some point after birth. These killings are associated with the belief that the child is evil and will bring misfortune to the family and community, or that the child is suffering and is better off dead than alive. The decision to kill a child with disability is either taken independently by the family or at the advice of medical doctors or religious leaders. The communities concerned rarely prosecute such cases. Regrettably, in some communities girls with disabilities are more likely to be subjected to “mercy” killings than boys with disabilities.

**Physical, emotional, verbal and sexual abuse within the household:** Children with and without disabilities are subjected to violence in the household. However, where there is a child with disability such violence significantly increases. For example, a child who is deaf may not be able to communicate abuse with anyone outside the family. Furthermore, even if someone is able to understand what the child says, frequently they do not believe the child.

**Neglect as a form of violence:** Children with disabilities may receive less food, medical care or other assistance than their siblings without disabilities. Such neglect can lead to aggravation of impairments or secondary disability, and seriously jeopardise health and wellbeing.

**Social isolation as violence:** Sometimes a child with a disability is not allowed to leave the home or a room within the home. There are cases of children with disabilities being shackled in windowless rooms, for weeks, months, even years, often with little or no interaction with family members. In many cases, next-door neighbours are unaware of the child’s existence.

<sup>197</sup> ACPF (2010). *Breaking the Silence: Violence against children with disabilities in Africa*. Addis Ababa.

**Box 10.5 (Continued): Violence against children with disabilities in the home**

**Abuse by support staff within the home:** Parents often rely upon helpers and caregivers drawn from family members, friends, neighbours and paid staff. Physical, sexual, verbal and emotional abuse may be perpetrated by caregivers in the home without the parents' knowledge.

**Barriers to intervention:** Social service and child advocacy agencies may be aware that a child with a disability is a victim of violence or neglect, but may nonetheless choose to keep the child in the household because there are no other alternative placements, or because they may be unaware that such abuse is unacceptable.<sup>198</sup>

**Violence in schools and educational settings**

In many African countries, children with disabilities spend most of their lives in institutional settings such as community schools, special schools, or hospitals. Children with disabilities are at great risk of violence while in transit to these schools or institutions. Schools for children with disabilities are often far from home, forcing the child with disabilities to travel long distances. Reports indicate that children with disabilities experience a wide range of violence en route to school, including beatings, being spat upon, and verbal harassment and abuse.

Once in school, teachers and peers frequently bully, beat, and verbally abuse children with disabilities. While all children with disabilities are likely to be victimised in school, children with intellectual disabilities face an enhanced risk. Violence in school often goes unreported because very few schools have the mechanisms in place to allow students, parents and caregivers to complain. Furthermore, parents often do not report abuse in educational settings due to the low number of schools that admit children with disabilities and the fear that they will not be able to place their child in a different school.

In many African countries, children with specific types of disabilities, and particularly children who are blind, deaf or intellectually impaired, are educated in residential schools, and face increased risk of physical violence and sexual abuse.

One major concern with regard to violence in educational settings is that some children with disabilities are being disciplined for reasons directly related to their disability. For instance, a child with a disability should not be disciplined for being unable to hear, unable to walk, or unable to control certain emotional outbursts. A student with a hearing impairment, for instance, should not be punished for failing to comply with spoken instructions. A student who is blind should not be punished for knocking over something in a walking path.

<sup>198</sup> ACPF (2009). Missing Voices: Children with disabilities in Africa. Addis Ababa.

In situations where a child's impairment cannot be easily detected, apparent behavioural patterns such as not paying attention, poor learning performance, or hyperactivity in the classroom – which are otherwise linked to the child's disability – may be wrongly identified as misbehaviour.<sup>199</sup>

In fact, many children with disabilities display a variety of “problem” behaviours that are the product of a complex interaction of such variables as temperament, cognitive endowment, environmental privation, learning history and previous experience of aggression. Children with severe intellectual disabilities are also reported to display behaviours of non-compliance, persistent screaming, over activity and eating inedible objects.<sup>200</sup>

Children with learning disabilities, including those with intellectual disabilities and information processing and cognitive disorders, as well as attention deficit hyperactivity, exhibit aggressive and disruptive behaviour to avoid distress and control a difficult situation. They may also exhibit self-injurious behaviour that may be related to poor self-esteem. In both instances, aggressive and self-injurious behaviours might be triggered by previous experiences of aggression or by health-related triggers such as the exacerbation of epilepsy. At times, especially in the case of children with autism, the behavioural problem might be triggered by a change in routine or to some aspect of familiar surroundings, such as when furniture is moved.<sup>201</sup>

### Violence in institutions

Children with disabilities are at a high risk of violence in institutional settings such as social care homes, orphanages, juvenile detention facilities or hospitals. Children with disabilities in Africa's institutions are at such a risk because they are cut off from the community and largely hidden from public view, and the institutions are rarely monitored. Sexual violence against children with disabilities is of particularly grave concern, and is prevalent in such institutional settings throughout Africa.

Far too many children with disabilities remain in institutions for their entire lives. Children with disabilities living in institutions are routinely subjected to physical violence and verbal and emotional abuse by staff, visitors and fellow residents. Institutions are often inhumane environments, overcrowded and understaffed. Many children with disabilities in such environments are neglected to death.

<sup>199</sup> UNESCO (2006). Positive discipline in the inclusive, learning-friendly classroom: A guide for teachers and teacher educators. Embracing diversity: Toolkit for creating inclusive, learning-friendly environments. UNESCO. Bangkok.

<sup>200</sup> Emerson, E. & Einfeld, S.L. (2011). Challenging behaviour. Cambridge University Press. Cambridge.

<sup>201</sup> O'Brien, G. (2000). Learning disability. In: Gillberg, C. & O'Brien, G. (eds.). Developmental Disability and Behaviour. The Lavenham Press Ltd. Lavenham.

Orphanages and social care homes are problematically on the rise in Africa, particularly in sub-Saharan African countries greatly impacted by HIV/AIDS.<sup>202</sup> Children who have lost their parents due to AIDS may themselves have disabling illnesses, but are also at a high risk of acquiring newly disabling conditions when they are housed in congregate settings with sub-standard care and limited stimulation.<sup>203</sup> Moreover, instances of abuse against persons with disabilities in institutional settings – and particularly individuals with mental and intellectual disabilities – are coming increasingly to light and must be addressed by law and policymakers.

### Violence in the community and workplace

Children with disabilities are at increased risk of violence in the community because they may be physically or emotionally vulnerable. Children with disabilities are vulnerable because police and legal systems for protection are unresponsive to many children with disabilities. As discussed in Chapter 9, children with disabilities are vulnerable to violence and abuse in the community due to the following factors:

- Easy victimisation
- Lack of consequences for abusers
- Lack of knowledge about disability within the legal system.<sup>204</sup>

While it is known that many children with disabilities are in the workplace, little information on these children exists because most find work in the informal sector, particularly in workshops. Documentation of violence against children with disabilities in the workplace is therefore limited. In African countries, begging on the streets is the most common type of work undertaken by children with disabilities. These children are routinely exploited by others to generate income through begging; some are put on the streets to beg by their own families or by other adults. There are anecdotal reports of some children with disabilities being subject to physical abuse and injury in order to make them appear more “pathetic” and worthy of pity and charity.<sup>205</sup>

In Africa, most children with disabilities work in the informal sector under difficult conditions, instead of attending school. About 17 per cent of children with disabilities in Ethiopia (of which 32 per cent were under age by law) and 12.4 per cent in Uganda work in this informal sector and are forced to beg, run errands, or provide cleaning services without pay or protection.<sup>206</sup>

<sup>202</sup> Sloth-Nielsen, J. & Mezmur, B.D. (2008). HIV/AIDS and children’s rights in law and policy. In: Sloth-Nielsen, J. (ed.). *Children’s rights in Africa: A legal perspective*, South Africa. pp. 279-280.

<sup>203</sup> Hutchinson, D. & Tennyson, C. (1986). *Transition to adulthood: A curriculum framework for students with severe physical disability*.  
The exclusion of children with disabilities from social interaction has been shown to stifle both mental and physical wellbeing.

<sup>204</sup> See Chapter 9 for further discussion of this issue.

<sup>205</sup> ACPF (2009). *Missing Voices: Children with disabilities in Africa*. Addis Ababa.

<sup>206</sup> ACPF (2011). *Children with Disabilities in Africa: Challenges and opportunities*, Addis Ababa. pp. 31.

Almost all of these children with disabilities reported that they felt compelled to work to survive, regardless of the exploitative, dangerous conditions.<sup>207</sup>

In conclusion, children with disabilities are often subjected to mental and physical violence and sexual abuse in the home and in institutions, school settings and residential care, and are also particularly vulnerable to neglect and negligent treatment and exploitation. Girls with disabilities are especially vulnerable to sexual abuse, especially in situations where they live in rented houses without an accompanying person. The characteristic dependency of disabled children on carers often results in a deep level of trust, which can be abused; and parents experiencing high levels of stress and frustration caring for a child who requires extra assistance that is difficult to provide may be more likely to inflict violence on that child.

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<sup>207</sup> Andvig J.C. et al. (2011). Issues in Child Labour in Africa Region Human Development. Working Paper Series.

# Chapter 11

## Access to justice for children with disabilities

### Introduction

“Access to justice” is a broad concept, encompassing people’s effective access to the systems, procedures, information, and locations used in the administration of justice. People who feel wronged or mistreated usually turn to their country’s justice system. People may also be called upon to participate in the justice system as, for example, witnesses or jurors in a trial. The ability to access justice is of critical importance in the enjoyment of all other human rights. For example, a child with a disability who has been the victim of a crime may wish to report the crime to the police and press charges against the offender. However, if he or she is denied physical access to the police station, clear communication with the police, or access to information that is readily understood, then that child may not be able to exercise his or her rights as a victim.

### 11.1 The situation in Africa

Many children with disabilities throughout Africa have been denied fair and equal treatment before courts, tribunals, traditional and informal justice mechanisms, and other bodies that make up the justice system in their countries because they have faced barriers to accessing the justice system.<sup>208</sup>

Prejudices about the incapacity of children with disabilities, coupled with the failure to provide them with appropriate interpretation or other forms of support mean that they are unlikely to effectively seek or gain justice. This leads to, to a much greater extent, the impunity of offenders.<sup>209</sup> In particular, children with speech impairments may not be able to communicate about the incident, cannot name the offender or adequately describe the situation, resulting in no prosecution or punishment being made.<sup>210</sup> The existing evidence suggests that, often, charges of violence presented by individuals with a disability are dismissed by police or judges who are unfamiliar with disability – with the assumption that a ‘misunderstanding’ has occurred, or that “individuals with disability are easily confused”.<sup>211</sup> A study by the Disabled Children’s Action Group (DICAG) in South Africa found that, in a sample of 36 cases of abuse against children with disabilities that came to trial, 14 were withdrawn. There were 8 acquittals, and 14 convictions. The prime reason given for this high rate of withdrawal and low rate of conviction was that ‘witnesses were seen as being incompetent’, when in reality, it is the language used in

<sup>208</sup> ACPF (2009). *Missing Voices: Children with disabilities in Africa*. Addis Ababa.

<sup>209</sup> Leibowitz, T. (2014). *Living in the community, access to justice: Having the Right Makes a Difference*. In: Sabatello, M. & Schultz, M. (eds). *Human Rights and Disability Advocacy*. University of Pennsylvania.

<sup>210</sup> Doe, T. (1955). *Access to justice and children with disabilities*. In: The Roeher Institute (ed.). *As if children matter: Perspectives and children, rights and disability*. The Roeher Institute.

<sup>211</sup> Disabled Children’s Action Group (DICAG). Cited in ACPF (2011). *The realities of children with disabilities in South Africa*.

court proceedings that is too complex and not understood by many of the victims.<sup>212</sup> Therefore, disabled children are often deliberately targeted by sexual offenders because they are often able to get away without punishment.

A similar challenge is faced by children with disabilities who come in contact with the justice system as offenders. Studies in many contexts show that children with disabilities, especially those with learning, mental and intellectual disabilities, are over-represented in the criminal justice system. This is a function of a number of factors. These children are often coerced, deceived or even forced into carrying out the offence. Furthermore, their offence may have been as a result of a behaviour related to their disability. In these circumstances children are often misunderstood – by family members, friends, the police, lawyers, prosecutors, or judges – as a result of their communication and intellectual challenges.<sup>213</sup>

In prison, the situation of children with disabilities may be even worse. The inaccessibility of information, lack of appropriate communication mediums such as Braille machines or hearing aids, and limited verbal and comprehension skills often limit the capacity of children with disabilities to interact with their environment and hence to know what is going on around them or what is expected of them. The challenges encountered by these children in access to justice are largely attributable to the lack of procedures within the justice system for the identification of children with disabilities; lack of specialist support and service provision, and availability of appropriate interventions.<sup>214</sup> In custody, children with intellectual, behavioural and learning disabilities are also more likely than other prisoners to be subject to disciplinary procedures and to spend time in segregation.<sup>215</sup>

## 11.2 Legal standards

The CRPD expands on the provisions of previous legal instruments and provides extensive protection to children with disabilities in the context of accessing justice and pursuing legal remedies for violations of disability rights. Article 13 specifically addresses access to justice: it guarantees access to justice at all levels and in relation to all types of roles in the justice system, including those of lawyers, witnesses, and complainants. Notably, Article 13 requires age-appropriate accommodations to facilitate access to justice for children with disabilities.

In order to give full effect to the rights of children with disabilities, justice procedures and mechanisms must be accessible. States Parties must introduce measures that accommodate persons with disabilities in the justice system, and must be proactive in planning for accessibility.

<sup>212</sup> Disabled Children's Action Group (DICAG). Cited in ACPF (2011). The realities of children with disabilities in South Africa.

<sup>213</sup> Talbot, J. (2010). *Seen and Heard: Supporting vulnerable children in the youth justice system*. Prison Reform Trust. London.

<sup>214</sup> Owen, F. et al. (2008). Human rights for children and youth with developmental disabilities. In: O'Neill, T. & Zinga, D. (eds). *Children's Rights: Multidisciplinary approaches to participation and protection*. University of Toronto.

<sup>215</sup> Talbot, J. (2010). *Seen and Heard: Supporting vulnerable children in the youth justice system*. Prison Reform Trust. London.

Many countries protect the right of access to justice through their constitutional provisions, and many others have put in place legislation and guidelines to standardise and ensure access to justice by all. While some countries ensure this right through their Children’s Act, such as South Africa, others do so through disability legislation such as Zambia and Ghana. For instance, the Zambia Persons with Disabilities Act (sec 8 & 9)<sup>216</sup> and the Persons with Disability Act 715 of 2006 of Ghana (sections 5 & 40(1)) contain explicit provisions ensuring the right of access to justice by persons with disabilities. The Persons with Disability Act 715 of 2006 of Ghana (section 5) states that:

Where a person with disability is a party in judicial proceedings, the adjudicating body shall take into account the condition of the person with disability and provide appropriate facilities that enable the person with disability to participate effectively in the proceedings.

Section 40 (1) of the Act requires that law enforcement agencies take into consideration the disability of a person on arrest, detention, trial or confinement of the person and provide for that person accordingly. It also requires (under sec 40(2)) that institutions for the training of law enforcement personnel to have as part of their curricula, the study of disability and disability related issues.<sup>217</sup>

### 11.3 Barriers to accessing justice

The barriers that children with disabilities encounter in the justice system can be divided into the following categories, each of which requires different types of interventions (Box 11.1 for details):

- Legal barriers
- Attitudinal barriers
- Information barriers
- Physical barriers.

#### Box 11.1 Barriers to access to Justice

- Physical barriers to police stations, courthouses, jails, prisons, and other public buildings;
- Lack of accessible transportation to police stations, courthouses, and other public buildings;
- Legislation, regulations, policies, or practices expressly barring people with disabilities from being witnesses, jurors, judges, or lawyers;

<sup>216</sup> Government of Zambia (2012). The Persons with Disability Act of 2012.

<sup>217</sup> Government of Ghana (2006). The Persons with Disability Act 715 of 2006.

### **Box 11.1** (Continued): **Barriers to access to Justice**

- Lack of accessible information about how the justice system works and what a disabled person's rights and responsibilities are within the justice system;
- Lack of accommodations to facilitate communication by people with disabilities, especially blind, deaf and deafblind people, people with intellectual disabilities, and people with learning disabilities;
- Attitudes about the ability of people with disabilities to participate meaningfully in the administration of justice; for example, the belief that people with psychosocial disabilities cannot be reliable witnesses;
- Lack of training for police and other officials to understand the specific needs of people with disabilities in accessing justice and how to provide necessary accommodations.

**Source:** <http://www1.umn.edu/humanrts/edumat/hreduseries/TB6/html/CH12.html>

#### **Legal barriers**

In some countries, legislation, regulations, policies, or practices bar people with disabilities from being witnesses, jurors, judges, or lawyers. For instance, the Criminal codes, Criminal Procedure Codes and Evidence Acts of many countries contain provisions that restrict access justice of persons with certain types of disabilities.<sup>218</sup>

Identifying the legal barriers preventing children with disabilities from accessing justice is a multi-dimensional process. Reviews of the legislative framework to identify legal barriers should be comprehensive and must address discriminatory legislation, regulations and policies or practices barring children with disabilities from participating in judicial proceedings. In addition, analysis of civil and criminal law and court procedure is relevant, in order to assess the variety of barriers that may exist for children with disabilities within civil and criminal court processes. During reviews and reforms of judicial, legal, and regulatory frameworks (codes, laws, Constitutions, etc.), DPOs must be consulted and must have the opportunity to provide meaningful input. International standards on disability should serve as the touchstone for such reviews (Box 11.4).

#### **Attitudinal barriers**

Negative attitudes and misconceptions can cause law enforcement officers to fail to take children with disabilities seriously when those children report a violation. Furthermore,

<sup>218</sup> Mute, L. (2012). Moving from the Norm to Practice: Towards Ensuring Legal Capacity for Persons with Disabilities in Kenya. *The Equal Rights Review*, Vol. 9.

the lack of awareness about disability issues leads to many children with disabilities not receiving reasonable accommodation to allow them to communicate with law enforcement officers or other legal professionals. Some examples exist of efforts to redress this (Box 11.2).

### **Box 11.2** Training for justice sector professionals in Ethiopia and Kenya

In its report to the CRPD Committee, the government of Ethiopia included the following information about training for professionals working in the justice sector:

**65.** Part of the effort to ensure access to justice is training of personnel working in the field; some effort has been made to organize trainings in collaboration with DPOs and NGOs. In 2011, about 30 of Addis Ababa's regular and traffic police officers were given training on treating persons with disabilities in the police investigation process and managing disability on the roads and streets. The training was focused more on sexual offences against women with disabilities.

In its report to the CRPD Committee, the government of Kenya noted training of law enforcement personnel:

**118.** In Kenya, the National Disability Policy calls upon the development of programs to train service providers and personnel on disability related specialized areas. The Government is training law enforcement agencies on handling children with disabilities.<sup>219</sup>

### **Information and communication barriers**

Communication barriers prevent children with disabilities and their families from understanding where and how to access justice mechanisms and prevent them from effectively communicating, thereby hindering their ability to claim their rights (Box 11.3). At the same time, lack of information about disability and disability rights among individuals working within the justice sector exacerbates problems of access. In most cases people with various disabilities are not accommodated in judicial proceedings because of the unavailability of court materials in alternative formats, the inaccessibility of court websites for persons who use assistive technology and the lack of listening systems in courtrooms.

In one case in Madagascar, a survivor with a learning disability had to tell his story 14 times to different people, and still found it difficult to be understood. Because his story changed slightly over time, the perpetrator was released.<sup>220</sup>

<sup>219</sup> Kenya CRPD. para.118.

<sup>220</sup> Save the Children Fund (2011). Out from the shadows: Sexual violence against children with disabilities. London.

## **Box 11.3** Communication barriers and acquittals of abusers

### **A case from Madagascar**

At the age of 23, when she heard that another girl from her school for children with a hearing impairment had reported a teacher for rape, Mara filed a complaint against the same school where she had been sexually abused when she was 15. Surprisingly, the cases were heard together, through a sign language interpreter employed by the same school. Although both named their attackers, one of whom admitted to rape, both cases were dismissed.

The court found that, “Contradictory statements have been revealed during the proceedings, all the more so as the victims are handicapped, being deaf and dumb. In spite of the efforts made by the interpreter called to the hearing to translate the gestures of these handicapped girls, misunderstandings have come to light on several occasions during the proceedings. So, as it appears from what has preceded that there is no irrefutable evidence, the Court cannot find the defendants guilty.”

### **A case from Burundi**

Because her family could not afford to support her, at the age of 12 Francine – who is paralysed in one leg and has difficulty walking – was sent to work as a house maid and nanny. One day when the children’s mother was out, the father raped her and threatened to kill her if she told anyone.

However, she was so badly injured and in such pain that she told some women neighbours who referred her to the Association for the Protection and Promotion of Women’s Rights, where she stayed for several days and received medical care. Through Lawyers without Borders, the case was reported to the police and the alleged rapist arrested. However, although a medical certificate proved rape, and although Francine had the support of her neighbours, the court held that they could not prove the involvement of the accused and he was acquitted.

**Source:** Save the Children Fund (2011). *Out from the shadows: Sexual violence against children with disabilities*. London.

Support is crucial for DPOs working to improve access to justice and enable persons with disabilities to acquire the skills and knowledge necessary to use the justice system effectively. Information awareness about disability rights should also be part of the mandate of human rights institutions such as Ombudsmen’s offices and national human rights commissions, all of which should include persons with disabilities in their work.

Section 118 of Uganda’s Evidence Act provides an example of legislation that aims to break down information barriers and which “allows witnesses with speaking disabilities to give their testimony in writing or in signs.”<sup>221</sup> Similarly, section 126 (1) of the Evidence Act (Cap, 80) of Kenya allows a witness with hearing impairments to give evidence “in any other manner in which he can make it intelligible” including by writing or signing so long as this is done in open court. This is significant as it considers signing or writing as oral evidence (section 126(2)). Section 135 of the Act confers as privileged communications between interpreters and their clients.<sup>222</sup> Furthermore, section 31 of the Sexual Offences Act (No. 3) of 2006 of Kenya introduces a range of support measures and safeguards to ensure that a victim of sexual abuse with disability, such as one with a mental disability, to communicate effectively with the court.<sup>223</sup>

The following case from Zambia illustrates how access to information and communication can make the difference between justice served and justice denied (Box 11.4).

#### **Box 11.4** Advocacy to support access to justice: Zambia

In Zambia, a DPO coalition advocated against the detention of a boy with hearing impairments accused of murdering his mother. The boy was not provided with an interpreter or access to legal representation. After several months, he was given assistance and exonerated from what was deemed a false accusation. In response, the Zambian Federation of Disabled Persons designed and implemented an access to justice project to address systemic barriers faced by persons with disabilities seeking justice in the Zambian court system.<sup>224</sup>

#### **Physical barriers**

Courts, tribunals, government offices, national human rights institutions (NHRIs) and legal assistance organisations must be fully accessible. Many children with disabilities cannot access the justice system as courts and police stations often have physical barriers that prevent access for children with disabilities. Courts housed in old structures across Africa present numerous barriers for persons with mobility impairments, such as stairs, narrow doorways, and inaccessible restrooms.

According to one judge in Zanzibar, “[court] Infrastructures are not designed for such children. There is no adequate translator for mute persons and the deaf.”<sup>225</sup> A similar observation made about courts in Uganda:

<sup>221</sup> Uganda CRPD. para. 112.

<sup>222</sup> Evidence Act (Cap, 80) of Kenya.

<sup>223</sup> Sexual Offences Act (No. 3) of 2006 of Kenya.

<sup>224</sup> ZAFOD (2006). Advocacy and Influence. Zambia Federation of the Disabled (ZAFOD). [http://www.safod.org/about%20safod/Countries/zambia\\_web.htm#Advocacy\\_and\\_Influence](http://www.safod.org/about%20safod/Countries/zambia_web.htm#Advocacy_and_Influence)

<sup>225</sup> Save the Children Fund (2011). Out from the shadows: Sexual violence against children with disabilities. London

Most of the taller buildings in Kampala, if they have lifts, they are not functioning. So, you may have to get off and then crawl. This even applies to the police – all the police stations in Kampala are not accessible, and similarly the courts of law. So if you have a case to report then you have to stay out, because you cannot access the judge, because these places are inaccessible.

### Spokesperson

Disabled Youth and Parents Association | Kampala, Uganda

The lack of proper transportation services to travel to a police station, courthouse, or other place where justice is administered coupled with lack of money for transportation also poses a major challenge accessing justice by children with disabilities. This has, in many cases, led to acquittals of offenders.<sup>226</sup>

Although there are still many physical accessibility challenges affecting justice systems throughout Africa (see Box 11.5), notable improvements are underway. For example, in Kenya:

...[t]he judiciary is in the process of putting in place age-related accommodations to ensure effective participation of children and young persons with disabilities. Courts are currently being adapted to suit the accessibility challenges of persons with disabilities including children with disabilities. To this end, the newly constructed Milimani Court in Nairobi has been made disability friendly.<sup>227</sup>

## Box 11.5 Challenges to full realisation

In its report to the CRPD Committee, the Government of Uganda provided a useful breakdown of the challenges to providing access to justice for persons with disabilities. Although the following list of challenges is from Uganda, many of the challenges are applicable across Africa.

117. The prevailing challenges include:

- Limited access to and understanding of the disability policy and the CRPD by some critical stakeholders like police and court officials.
- Limited skills and communication options between persons with disabilities and different service providers has robbed many persons with disabilities of redress.

<sup>226</sup> Terre des Hommes Nederland (2007). Hidden Shame: Violence against children with disabilities in East Africa.

<sup>227</sup> Kenya CRPD. para. 134.

<sup>228</sup> Uganda CRPD. para. 117.

**Box 11.5 (Continued): Challenges to full realisation**

- Most persons with disabilities like many poor Ugandans cannot access justice due to lack of legal representation.
- Government is resource-constrained to provide free legal representation to Ugandans who cannot afford to pay for the services. Nevertheless, lawyers are also expected to provide free legal services to a specific number of marginalized groups each year.

## Government Plans for full realisation

118. Government will take steps to ensure that law enforcers – local councilors, police and prison staff – understand and implement the CRPD. This will be through the use of mass media and focused education meetings.

**Capacity constraints**

The justice system, like any other government functionaries in Africa, faces capacity constraints. Nearly every justice system in Africa is understaffed and suffers from severe shortage of communication and transport infrastructure. Most justice systems also have inadequate capacity in evidence handling and forensic investigations. The understaffing has often resulted in a backlog of cases.<sup>229</sup> Although some training programmes have been implemented within justice systems, the lack of adequate focus on human rights has meant that the police and the judiciary know little about human rights as they pertain to disabilities. In many courtiers there is lack of interest on the part of the police to investigate complaints of sexual violence against children with disabilities, leading to key gaps in evidence. Corruption and years of incompetent handling of cases has led to public frustration towards and lack of trust in the justice system. This exposes them to further violence (Box 11.6.)

little about human rights as they pertain to disabilities.<sup>230</sup> In many courtiers there is lack of interest on the part of the police to investigate complaints of sexual violence against children with disabilities, leading to key gaps in evidence.<sup>231</sup> Corruption and years of incompetent handling of cases has led to public frustration towards and lack of trust in the justice system.<sup>232</sup> This exposes them to further violence (Box 11.6).

<sup>229</sup> Terre des Hommes Nederland (2007). Hidden Shame: Violence against children with disabilities in East Africa.

<sup>230</sup> Robins, S. (2009). Addressing the challenges of law enforcement in Africa: Policing in Sierra Leone, Tanzania and Zambia. Policy Brief No. 16.

<sup>231</sup> Save the Children Fund (2011). Out from the shadows: Sexual violence against children with disabilities. London.

<sup>232</sup> See No. 230 above.

## Box 11.6 Lack of justice increases risk of violence

Children with disabilities are at increased risk of violence in the community because police and legal systems for protection are unresponsive to or are not well aware of the needs of many children with disabilities. The failure of the justice system in many African countries to include children with disabilities leads to the following:

- **Easy victimisation** Children with disabilities are often victims of violence because they are easy targets, physically unable to flee or protect themselves from attack. Children who are blind or deaf, or who have intellectual disabilities, may not be able to report what has happened to them or to describe their attackers. Furthermore, their need to communicate with law enforcement officers is often not accommodated.
- **Lack of consequences for abusers** In many countries police and the criminal justice system are inaccessible to, or fail to respond to complaints by, children with disabilities.
- **Lack of knowledge about disability within the legal system** Children with disabilities are rarely believed when they seek help. Charges by children with disabilities of violence or rape are usually dismissed by police or judges who are unfamiliar with disability, or who assume that a child or youth with disability is not capable of telling “right” from “wrong”. Even when police, lawyers, and judges recognise that children with disabilities are subject to violence or rape, it is often assumed that they will not make good witnesses on their own behalf, and they are discouraged from pressing charges.

“In a township in Gauteng, South Africa I came across three teenage sisters in a special school for the intellectually disabled. All three had been repeatedly sexually abused by a neighbour who had HIV/AIDS. When the girls told their mother, she beat them for lying. When this was reported to the police, [the police] turned a blind eye. Upon my last visit to the school, one sister had died (from HIV/AIDS related illnesses) and the other two looked sick and malnourished.”

### Hear our Voices:

Global Report by Inclusion International (2006)

Access to justice for children with disabilities is multifaceted and must accommodate both disability - and age - related dimensions. For a child with a disability who is the victim of a crime to seek a remedy effectively, law enforcement facilities, personnel, and procedures must be made accessible to them and must be ready to take them seriously. If a police station is physically inaccessible, a child who uses a wheelchair will have difficulty reporting a crime. Construction of courthouses, police stations, and other justice sector facilities must be done in a manner that makes them physically accessible to children with disabilities.

<sup>233</sup> ACPF (2009). Missing Voices: Children with disabilities in Africa. Addis Ababa.

# Chapter 12

## National implementation and monitoring mechanisms

### Introduction

The Convention on the Rights of Persons with Disabilities (CRPD) requires implementation measures as well as national and international monitoring mechanisms to be put in place. These measures are essential elements in ensuring the rights of children with disabilities are protected, respected, and fulfilled.

- At the national level, Article 33 of the CRPD on national implementation and monitoring identifies three mechanisms for the implementation and monitoring of the Convention:
- First, States must establish national focal points within government for Convention implementation matters
- Second, States must establish or designate an independent monitoring system
- Third, States must ensure the participation of civil society, in particular persons with disabilities and their representative organisations.

All three mechanisms of national level monitoring must incorporate a child rights dimension.

An effective national level monitoring framework requires States to ensure that the rights of children with disabilities are effectively incorporated into each and every element of monitoring, consistent with CRPD Article 6. National human rights institutions, as well as DPOs, child rights, human rights and other civil society organisations, are expected to fulfil their respective roles in monitoring. This tri-partite structure provides an essential role for all stakeholders.

The first step in monitoring the implementation of inclusive policies and programmes is the development of national action plans and strategies, tailored to a country's specific national context. Based on the principle of inclusive development, these national plans contribute towards closing the gap between legislation and practice, and allow for the formulation of targeted actions in the sectors of education, health, social protection, housing; i.e. the integration of disability across all sectors (CRPD, para 9). Many countries have formulated these national plans of action, for example, Ethiopia's National Plan of Action for Inclusion of Persons with Disabilities 2010-2020; Rwanda's National (disability) Programme 2010-2019; and Tanzania's National Disability Mainstreaming Strategy 2010-2015; the National Plan of Action for Children in South Africa 2012-2017 which also includes a comprehensive chapter on children with disabilities (Box 12.1).

## **Box 12.1** The National Plan of Action for Children in South Africa 2012-2017

### **Objectives:**

- To create an enabling environment where children with disabilities can function optimally.
- To ensure that all parents/caregivers of children with disabilities receive knowledge, skills and support on how to stimulate, support and enhance their children's abilities and rights.
- To ensure that data collected in the country includes childhood impairment and disability and is age and gender specific (disaggregated).
- To ensure that all public facilities are accessible for children with disabilities and children with disabilities are mobile in their communities.
- To ensure that children with disabilities have access to information on their rights, services and policies that affect them as children, in a manner that they can understand and engage with.
- To ensure that children with disabilities have equal opportunities to participate in matters affecting them and are able to express their views freely.
- To ensure that all children with disabilities have access to educational and learning/development opportunities.
- To ensure the implementation of early screening of all children for the early identification and intervention to address preventable disabilities.
- To ensure that all early learning and development programmes are inclusive of children with disabilities.

### **E. Responsible Lead and Supporting Departments**

**Lead Department:** Department for Women, Children and People with Disabilities

**Supporting Departments:** Department of Social Development, Department of Health, Treasury Department, Department of Co-operative Governance and Traditional Affairs, Department of Justice and Constitutional Development, South African Police Service, Department of Home Affairs, Department of Correctional Services.

Once a comprehensive national plan of action or strategy is developed, national governments are expected, as outlined under Article 33 of the CRPD, to establish three mechanisms that are relevant for the implementation and monitoring of the national plan of action. First, States must establish national focal points within government for coordinating the follow-up of CRPD. Second, States must establish an independent monitoring system. Third, States must ensure the participation of civil society in these mechanisms, in particular by persons with disabilities and their representative organizations. All three mechanisms of national level monitoring of the Convention must incorporate a child-rights dimension. An effective national level monitoring framework requires States to ensure that the rights of children with disabilities are effectively incorporated into each and every element of monitoring, consistent with CRPD Article 6. National human rights institutions as well as DPOs, child rights, human rights and other civil society organisations are expected to fulfil their respective roles in monitoring.

### 12.1 National focal points and coordination mechanisms

The effective implementation of national plans of action and strategies depends on the political will of governments to establish and run effective national co-ordination mechanisms. These coordination mechanisms are mandated to monitor and evaluate the implementation of disability-related laws or policies, to make recommendations on existing services, incorporate disability dimensions to improve equal access for persons with disabilities. The designated disability focal point should ensure monitoring systems are in place and that children with disabilities and their representative organisations are consulted in implementing the national plan of action. They are also tasked with ensuring coordination and cooperation between ministries and agencies, civil society and other stakeholders.<sup>234</sup> This implies that disability is cross-cutting and requires the implementation of a coherent and cohesive framework of disability rights protection. Coordination mechanisms aim to facilitate inter-ministerial coordination. Coordination mechanisms also serve to integrate disability across government beyond the ministry where the disability focal point is located.<sup>235</sup>

In many African countries, the disability focal point is situated within a ministry of social affairs or the ministry of health. Several challenges arise in relation to this approach. Where disability coordination is effected from a ministry of health, there is the risk that disability rights issues will reflect a medical model of disability as opposed to a more holistic, social model perspective. In countries with focal points situated in the ministry of social affairs, the challenge is the

<sup>234</sup> UN Economic and Social Council (2013). Commission for Social Development. Fifty-first session-Mainstreaming disability in the development agenda: Towards 2015 and beyond. Report of the Secretary-General. para. 12.

<sup>235</sup> UN Economic and Social Council (2013). Commission for Social Development. Fifty-first session-Mainstreaming disability in the development agenda: Towards 2015 and beyond. Report of the Secretary-General. para 12.

limited influence that ministries have in relation to others. Where a designated coordination mechanism is housed within an under-resourced and weak ministry, the effectiveness of its coordination will be compromised.

Challenges arise in countries where no coordination mechanism is created. For example, disability-inclusive efforts within a ministry of education to educate children with disabilities may be disconnected from efforts in a ministry of labour to address employment opportunities for youth with disabilities, resulting in uncoordinated action. The failure to coordinate all efforts with the ministry of education also leads to further segregation and exclusion for children with disabilities in education systems.

...a year ago, there was no proclamation which forces other government organisations to consider...disability...because the Ministry of Labour and Social Affairs is the line ministry responsible for disability issues. And when you went to the Ministry of Health, or Education, and raised disability issues, they would tell you to go there. But now... this proclamation [outlines] every government organisation's duties and responsibilities and every governmental organisation is responsible to consider the issue of disability.

**Betelhem Abebe**

Ethiopian National Disability Action Network | Addis Ababa, Ethiopia

Another approach is to situate the coordination function in a disability-specific ministry or department. In Malawi, for example, there is a dedicated Ministry of Persons with Disabilities. The Ministry monitors the CRPD, carries out awareness-raising programmes, drafts and enacts policies on the promotion of disability rights, and coordinates across ministries.<sup>236</sup>

Both government focal points and coordination mechanisms should be regarded as essential strategies to ensure effective monitoring and implementation of the rights of children with disabilities. Such an approach recognizes the cross-cutting nature of disability as well as the cross-cutting nature of ensuring that disability monitoring and implementation is sensitive to child-specific issues and priorities.

The effective implementation of national plans of action and strategies is determined by the positioning of the focal points and co-ordination mechanisms within the overall government structures as well as the scope of their mandate (Table12.1).

<sup>236</sup> UNICEF Malawi. [http://www.unicef.org/malawi/media\\_12762.html](http://www.unicef.org/malawi/media_12762.html)

**Table 12.1** Selected examples of national disability organisations that enforce, coordinate, and monitor the implementation of the rights of persons with disabilities in addition to involving DPOs

Country and name of body	Rights enforcement and promotion	Monitoring and evaluation of implementation	Coordinating implementation	Involving DPOs
<p><b>Uganda:</b> National Council for Disability</p>	<p>1. Carries out surveys and investigations into violations of rights of people with disabilities and non-compliance with laws or policies on disability</p> <p>2. Promotes development of programmes and projects designed to improve lives of people with disabilities</p>	<p>Monitors and evaluates the extent to which Government, NGOs and the private sector include the needs of people with disabilities in planning and service delivery</p>	<p>Acts as a co-ordinating body between Government departments and other service providers and people with disabilities</p>	<p>Identifies and gives guidelines to DPOs</p>
<p><b>Ghana:</b> National Council on Persons with Disability</p>	<p>Promotes studies and research on issues of disability; provides education and information to the public on issues of disability</p>	<p>Monitors and evaluates disability policies and programmes</p>	<p>Coordinates disability activities</p>	<p>Coordinates activities of DPOs, international organisations and NGOs that deal with disability</p>

**Table 12.1** (Continued): Selected examples of national disability organisations that enforce, coordinate, and monitor the implementation of the rights of persons with disabilities in addition to involving DPOs

Country and name of body	Rights enforcement and promotion	Monitoring and evaluation of implementation	Coordinating implementation	Involving DPOs
<p><b>Zimbabwe:</b> National Disability Board</p>	<p>1. Issues adjustment orders to enforce accessibility for people with disabilities</p> <p>2. Conducts inquiries, including public inquiries, into any matter relating welfare and rehabilitation of people with disabilities</p>	<p>Reviews and evaluates measures for welfare and rehabilitation of people with disabilities</p>	<p>Coordinates services provided in Zimbabwe for the welfare and rehabilitation of people with disabilities</p>	<p>Provides all institutions and organisations concerned with the welfare and rehabilitation of people with disabilities, including those managed by the state and local authorities, with access to information and technical assistance</p>
<p><b>Kenya:</b> National Council for Persons with Disabilities</p>	<p>1. Conducts inquiries into any matter relating to the welfare and rehabilitation of persons with disabilities</p>	<p>Reports to the Minister on welfare and rehabilitation of persons with disabilities; advises on relative priorities to be given to the implementation of related measures</p>	<p>Coordinates services provided in Kenya for the welfare and rehabilitation of persons with disabilities</p>	<p>Provides access to available information and technical assistance to all institutions and organisations concerned with the welfare and rehabilitation</p>

**Table 12.1** (Continued): Selected examples of national disability organisations that enforce, coordinate, and monitor the implementation of the rights of persons with disabilities in addition to involving DPOs

Country and name of body	Rights enforcement and promotion	Monitoring and evaluation of implementation	Coordinating implementation	Involving DPOs
<b>Kenya:</b> National Council for Persons with Disabilities	2. Issues adjustment orders that enforce accessibility for people with disabilities			of persons with disabilities, including those managed by government
<b>Zambia:</b> Agency for Persons with Disabilities	Promotes public awareness on prevention of disabilities and the care of people with disabilities; promotes research into general rehabilitation programmes for people with disabilities	Co-ordinates rehabilitation and welfare services provided to persons with disabilities by ministries and voluntary associations	Monitors and supervises the provision of services to persons with disabilities	Cooperates with ministries and other organisations in the provision of preventive, educational, training, employment, rehabilitation and other welfare services for persons with disabilities.

However, implementation of national plans of action has been hampered, in many countries, by a number of factors, including:<sup>2</sup>

- Failure to establish a disability unit
- Lack of adequate staff to co-ordinate and monitor policies
- Lack of adequate budget for co-ordination and monitoring, leading to ineffective co-ordination and inefficiency
- Lack of a provincial strategy for implementing national plans of action, in decentralised, federal structures
- Failure to undertake disability audits within government departments
- Limited engagement with civil society.

Another study in South Africa identified other implementation barriers: lack of synergy between policies, tendency to work in silos even within government, the disconnect between national and sub national government levels in implementing disability programmes, and the lack of adequate norms and standards for services.<sup>238</sup>

## 12.2 Independent monitoring mechanisms

The CRPD specifically provides for a national level independent monitoring mechanism. This mechanism must be independent of government and must provide an additional check on CRPD implementation. Article 33(2) requires the designation or establishment of one or more independent mechanisms, as appropriate, to promote, protect and monitor implementation of the CRPD. Notably, to comply with Article 33(2), states must ensure that the national level mechanism is in line with the Paris Principles endorsed by the UN Commission on Human Rights and the UN General Assembly in 1993. The Paris Principles outline the responsibilities, composition and working methods of national human rights institutions (NHRIs): under these principles, NHRIs must be independent entities free from governmental interference, and must have sufficient funds to choose staff and determine internal priorities.<sup>239</sup>

<sup>237</sup> Landsdown, G. (2002). Disabled Children in South Africa Progress in implementing the Convention on the Rights of the Child.

<sup>238</sup> Department of Women, Children and Persons with Disabilities (South Africa), Department of Social Development & UNICEF (2012). Children with disabilities in South Africa: A situation Analysis 2001-2011.

<sup>239</sup> Principle 2B. Composition and guarantees of independence and pluralism. Paris Principles.

In Africa, recent practice suggests that NHRIs are taking on the role of monitoring the implementation of the CRPD. For example:

- In 2012, the Malawian Human Rights Commission conducted a monitoring exercise of mental health facilities throughout Malawi
- In Kenya, the Kenya National Commission on Human Rights (KNCHR) undertook ongoing implementation and monitoring responsibilities with regard to addressing the challenges of effectuating CRPD Article 12 on legal capacity, establishing a committee to draft a policy paper that will be used to increase the government's understanding of Article 12
- Togo's National Commission of Human Rights is competent to receive complaints (including from child victims) regarding the violation of the rights of the child, after which such complaints may be forwarded to the children's court
- Nigeria's Human Rights Commission has appointed a Special Rapporteur on Child Rights, who has the mandate to monitor and collect data on violations of children's rights.

Therefore, a critical component of monitoring the rights of children with disabilities under the CRPD is to ensure that the independent monitoring mechanism(s) takes into account disability rights, and that the independent monitoring framework ensures the participation of children with disabilities and organisations representing them, such as DPOs or child rights organisations. An increasing number of countries in Africa where NHRIs are in place specifically include the rights of children with disabilities within the remits of those institutions, as per Article 33(2) of the CRPD; these potentially serve as examples of good practice for other African countries.

### **12.3** Engagement of children in civil society monitoring

Under both the CRPD and the CRC, children with disabilities in Africa have the right to participate in, and express their views on, matters that may affect them. The child's right to participate extends to all levels at which monitoring occurs, from national and international policy-making down to community decision-making. A child-friendly approach to disability rights requires putting girls and boys from all backgrounds and with all types of disability, including intellectual and psychosocial disability, at the centre of disability rights policy, programming and monitoring.

Article 6 of the CRPD recognises children with disabilities as rights-holders and members of society, and Article 33(3) holds governments accountable for ensuring their participation in the monitoring process, both as individuals and as parts of their representative organizations.

It is essential for DPOs and child rights organisations documenting disability rights to ensure that they are proactive in their engagement with NHRIs. In assessing gaps between legal and policy provisions and the reality of everyday lives, NHRIs should consult with children with disabilities to understand their lived experience and views. For example, the South African Human Rights Commission, an independent NHRI, monitors implementation of the CRPD and convenes twice a year to give civil society an opportunity to share experiences and challenges regarding the implementation of the CRPD with the Commission. It also engages regularly with DPOs and child rights organisations (Box 12.2).

### **Box 12.2** Monitoring the CRPD in Zambia with all stakeholders

The Zambian Federation of the Disabled (ZAFOD) is heavily involved in monitoring the implementation of CRPD in Zambia, and in ensuring that government meets its commitments. An independent ZAFOD unit, funded by and collaborating with the European Union (EU), is working to sensitise key stakeholders about the requirements of CRPD, and involve them in reviewing existing legislation and making recommendations for amendments.

It's been like a twin track approach, where we carry out sensitisation on the CRPD and also consultations on the laws that we want to review. Because law review is a long process, and we cannot review all the laws, we came up with five priority laws that we feel have a direct impact on people with disabilities. And these are the Persons with Disabilities Act itself, the Education Act, the Employment Act, the Urban and Town Planning Bill and also the Mental Health Act.

**Milika Sakala**

ZAFOD / EU Monitoring Unit | Lusaka, Zambia

Interviews with child advocates with disabilities and their representative organisations can ensure appropriate law, policy, and programming inclusive of children with disabilities. Furthermore, children and their representative organisations are best suited to provide information about what is really happening to children with disabilities in a country.

We have to pressure these people. They will say 'we will do this and we will do that' and nothing will happen. But if we, the disabled, will continue pressuring them that these things should be implemented, then I think it will be done.

**Mariama Jallah**

Polio Women's and Girls' Development Association | Freetown, Sierra Leone

When laws and policies are made, we don't want them just to be brought in and then put undercover.

No. We want them to be seen to be implemented. Because most of the time, you make policies and then just keep them there. We want to see them being implemented.

**James Kapembwa**

Zambia National Association of the Deaf | Lusaka, Zambia

It is crucial that persons with disabilities be heard; and such monitoring of individual experiences should be as inclusive as possible. Strategies must be adopted to ensure that all persons with disabilities, no matter the type of disability or the person's age, gender or socioeconomic or ethnic background, have an opportunity to participate. To address the complex realities facing children with disabilities, the scope of monitoring must be broad, encompassing the full spectrum of human rights – civil, cultural, economic, political and social – and addressing matters that impact disability rights in both the public and private spheres.

Special responsibilities arise for all actors involved in monitoring the situation of children with disabilities, including those in civil society. In all cases, the free and informed consent of interviewees should be ensured. Monitors should maintain the privacy and safety of interviewees and the confidentiality of information. Depending on the situation, interviews might take place without family members, caregivers or other people present, in a location where the interview cannot be overheard: family members, caregivers or other people may be responsible for the human rights violations experienced by the interviewee (For example, by perpetrating physical or psychological abuse, or preventing the person with a disability from leaving the home). It is important to ensure that the interviewee can speak freely and without fear of reprisal. At the same time, approaches of monitors must in all cases put the protection of the child with a disability as their top priority, above any monitoring objective.

Finally, laws and policies can be put in place to empower and protect children with disabilities, but to ensure laws and policies have meaning it is important to train children with disabilities and their families about their rights. Equality and inclusion will not be achieved for persons with disabilities until the capacity of children with disabilities to make decisions is ensured, opportunities to make those decisions are provided, and those choices are respected. Advocates play essential roles in empowering both children and adults to realise child rights. The importance of human rights education for children with disabilities cannot be overstated.

Children with disabilities and their representative organisations – whether DPOs, child rights organisations or other civil society organisations – have both the right and the duty to engage proactively in national level monitoring and implementation exercises to advance disability rights.

To conclude, while entrenching the rights of children with disabilities in legislation and policy is crucially important, monitoring the improvement of their quality of life is a task of equal significance. Monitoring the implementation of laws and policies requires adequately resourced and inclusive co-ordination bodies that provide a platform that includes all stakeholders, including children with disabilities themselves.



# Chapter 13

## Conclusions and recommendations

### 13.1 Conclusions

Despite the challenge of limited data, it is known that many children in Africa have disabilities. Inconsistent definitions of disability and the lack of disaggregated data on disability have hampered genuine efforts to formulate informed policies and programmes. Most disabilities result from preventable causes, such as lack of access to basic nutrients, birth attendance services and poor road safety.

Unlike other African children, children with disabilities are often subject to abuse and discrimination and excluded from family life, their neighbourhoods, peer interactions, school life and integration into the larger community.

Many children with disabilities in Africa lack access to quality education, due to factors including the failure of schools to be accessible and inclusive. Accessibility in African schools includes not only issues pertaining to infrastructure, location, and negative attitudes towards children with disabilities, but also the unsupportive learning and teaching practices that deny children with disabilities their right to education.

Access to healthcare is a major area of concern, as more than three-quarters of disabling conditions are acquired after birth- for instance, due to illness, which is the leading preventable cause of disability. Implementation of effective preventative healthcare measures and a focus on providing quality pre-natal and infant care remain areas of gross neglect.

#### Key Findings

- Law and policies to promote and protect the rights of children with disabilities are not in place or are poorly monitored or implemented.
- Data and statistics on children with disabilities are not credible or reliable, are not appropriately disaggregated on the basis of disability, gender and age where needed, and do not accurately capture the number of children with disabilities or their needs.
- Children with disabilities and their families encounter stigma and discrimination. Children with disabilities and their families encounter stigma and discrimination.
- Multiple barriers create inaccessible infrastructure, information, and communication systems, thus impacting the realisation of rights for children with disabilities.
- Children with disabilities have limited access to early childhood development, education, health care, rehabilitation, and justice systems.
- Children with disabilities experience various forms of exploitation, violence and abuse.

In addition, there is a serious shortage of rehabilitation services and early childhood identification and intervention to address the after-effects of illness and trauma. Children with communication and sensory impairments are particularly disadvantaged, as they rarely receive the assistive devices and rehabilitation they require to develop to their full potential in education and in society.

The very low level of awareness on the part of law- and policy makers and service providers has resulted in the inaccessibility of the built environment, which is a serious impediment to accessing the existing services.

A majority of children with disabilities in Africa lack access to early childhood services, which is also a reflection of an overall lack of early childhood services, and which impacts on the possibility for early intervention. Where early intervention services are lacking, the opportunity to improve the cognitive, emotional and social skills of young children is lost, exposing children to further delays or secondary complications.

The findings of this report illustrate that these children and their families still experience exclusion, abuse, harassment, and discrimination within their families and within their communities.

A significant amount of work must be done in order for children with disabilities to enjoy their fundamental human rights and freedoms fully within African societies. At the same time, however, there is increasing evidence of progress across the continent, as governments, DPOs, child rights organisations, human rights organisations, national human rights institutions and researchers take steps towards advancing the rights of children with disabilities.

Ratification of the CRPD, in conjunction with reform of domestic laws and policies, constitutes an important step in addressing the rights of children with disabilities. Nevertheless, more supportive legislation is required to develop specific enabling environments that protect children with disabilities and seek to remove barriers to access. This requires governments to address disability stigma and discrimination, institutional barriers, and exclusionary practices at all levels of society in order to eliminate challenges to inclusion. In particular, DPOs and other civil society organisations must continue their work to shift attitudinal norms away from the prevailing medical and charity perspectives of disability and towards a holistic, rights-based approach to disability issues. This effort will also require DPOs and civil society organisations to monitor governments and hold them to account for violations of the rights of children with disabilities.

Families of children with disabilities continue to rely heavily on the services and assistance offered by governments, religious organisation and NGOs. A rights-based approach to disability implies that these families and their children need to be empowered and supported with livelihood options that allow them to be self-sufficient and meet not only their basic needs, but also the special needs of the children with disabilities.

A lack of accurate prevalence data and low birth registration rates for children with disabilities result in inadequate planning by governments; but African countries together have a strong and increasingly numerous community of scholars and research institutions working on expanding disability rights research and data collection, and much of their work focuses on children with disabilities. These factors, along with models of good practice developed by DPOs and other civil society organisations, are critical elements in the effort to transform attitudes, laws, policies, programmes and services, and realise the rights of African children with disabilities.

## 13.2 Priorities for action

### 1 Put in place and implement appropriate legislation, policy and programmes in keeping with the CRPD

Ensure that:

- National laws and policies are harmonised with the CRPD, and that Sector Plans are developed in a manner consistent with the goals of the CRPD
- A national body, with a coordinator, is set up, comprised of multi-disciplinary and cross sectoral experts responsible for promoting and monitoring the implementation of disability inclusive policies and practices, including at sub-national level
- Specific, realistic, structured budgets are allocated for the effective implementation of disability-inclusive policies and practices and are closely monitored and evaluated
- The technical skills of those involved in service delivery programming, including those in the education and health sectors, are enhanced at national and sub-national levels
- Quality standards and indicators are developed for effective disability programming.

### 2 Develop and implement effective child protection measures for children with disabilities

Ensure that:

- Interventions are designed and implemented to address disability-based stigma and discrimination
- Preventative and remedial child protection services are made available, accessible and effective for children with disabilities
- Birth registration services are made freely available and accessible to children with disabilities, including through greater involvement of local community leaders, hospitals, churches and midwives
- Parenting and counselling interventions are designed and implemented for parents in order to enable them to address the special needs of their children with disabilities

Access to justice and legal services is ensured for children with disabilities, including by providing information in user-friendly formats and ensuring physical accessibility to justice facilities.

### **3 Ensure the provision of basic services in a disability-friendly manner**

Ensure that:

- Appropriate social protection measures are implemented for children with disabilities and their families in order to alleviate household poverty and improve standards of living
- Free or subsidised access is provided to preventive and curative healthcare and nutrition interventions
- Medical and rehabilitation practitioners (For example, audiologists, speech-language pathologists, dieticians, occupational therapists, etc.) of sufficient quality are made available in appropriate numbers
- Pregnant mothers are provided with screening services for disability-causing diseases and allowed appropriate medical follow-up
- Water and sanitation facilities are made accessible to children with physical and visual disabilities
- Early childhood development programmes are made available and accessible for children with disabilities, including through inter-sectoral co-ordination
- All teachers and school personnel are given adequate training to facilitate educational inclusion of children with disabilities
- School infrastructure and school accommodation are made accessible, and assistive devices are made available
- Centres with the necessary resources and expertise are created for assessing and supporting learners with disabilities, for making learning and teaching materials accessible, and for issuing assistive devices.

## **4 Improve physical accessibility of the built environment**

Ensure that:

- Buildings and facilities are designed and constructed with users with disabilities and universal access in mind
- Families, communities and service providers are educated and provided with the skills to implement simple, inexpensive ways of adapting their homes for children with disabilities
- Assistive devices and rehabilitation services are made available free of charge or at affordable prices
- Tax exemptions on importations of assistive devices are put in place and local production of quality devices is encouraged
- Adequately trained rehabilitation experts of sufficient quality are made available in adequate numbers to provide mobility training and occupational therapy.

## **5 Build evidence and promote evidence-based advocacy and cross-learning**

Ensure that:

- Government departments responsible for health, social development and education are mandated to include disaggregated data on children with disabilities in their information systems
- Advocacy efforts of national DPOs are strengthened, reinforced and supported to ensure that policies and laws are acted on, and that duty-bearers fulfil their obligations to children with disabilities and their families
- Good practices in inclusion and inclusive development are identified, and learning on these practices is catalysed in government, NGOs, communities and the private sector
- DPOs and other disability stakeholders advocate for inclusive development in their engagement with international donors and development assistance agencies, including for the inclusion of children with disabilities.

To conclude, children with disabilities in Africa have the same rights as other children. By promoting, respecting, protecting and fulfilling the rights of children with disabilities, we build a better community and society that upholds social justice and human dignity

The disability landscape in Africa is indeed rapidly changing. For children with disabilities, the past has been undoubtedly characterised by exclusion, invisibility and isolation – yet there is a paradigm shift occurring within cultures and nations, and differences are increasingly perceived and even valued as opportunities. Within this unprecedented era of accountability, perhaps there is scope for more deliberate actions and measures for children with disabilities to realise their rights and enjoy a life free of stigma, abuse and exclusion.

