

Access Denied

Voices of persons with disabilities from Africa



ACPF

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THE AFRICAN CHILD POLICY FORUM (ACPF)

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. ACPF's work is guided by the UN Convention on the Rights of the Child, the African Charter on the Rights and Welfare of the Child, and other relevant regional and international human rights instruments. 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 Africa.



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ACRONYMS

ACPF	African Child Policy Forum
DFID	Department for International Development (UK)
DPO	Disabled Persons' Organisation
ECDD	Ethiopian Centre for Disability and Development
MDG(s)	Millennium Development Goal(s)
NGO	Non-governmental organisation
NUDIPU	National Union of Disabled Persons of Uganda
SRH	Sexual and Reproductive Health
STD/STI	Sexually Transmitted Disease / Sexually Transmitted Infection
UNCRPD	United Nations Convention on the Rights of People with Disabilities
UNICEF	The United Nations' Children's Fund
WHO	World Health Organization
ZAFOD	Zambia Federation of the Disabled

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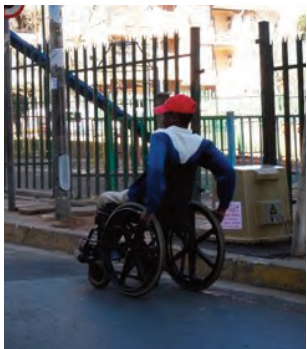
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Freetown Cityscape



Mother Melrose and some of the orphans (left)
Freetown, Sierra Leone



Inaccessible: a wheelchair-bound man using the road to avoid damaged pavement and pathway (right)
Johannesburg, South Africa



Kadijah and Elsie (seated) and classmate at REC Primary School
Freetown, Sierra Leone

FOREWORD

Persons with disabilities remain the most marginalised and excluded in society. They face multiple physical barriers, discrimination and often, face higher risks of abuse and violence. Many children with disabilities and their families are severely deprived of basic resources and services that enable them to develop to their full potential. They are denied of opportunities for education, social interaction and development.

The rights of children with disabilities are enshrined in a number of human rights instruments such as the CRC, the ACRWC and the CRPD. The CRC not only entitles children with disabilities to all human rights on an equal basis with other children, but also stresses the principle of the best interests of the child to apply to all actions concerning children, including those with disabilities. The ACRWC entitles children with disabilities the right to special measures of protection under conditions that ensure dignity and promote self-reliance and active participation in the community, while the African Women's Protocol accords special protection to girls with disabilities.

Accessibility is given significant emphasis in the CRPD where states parties are required to take appropriate measures to ensure that persons with disabilities get access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services, both in urban and in rural areas. ACPF's report *Access Denied*, not only strengthens this provision of the CRPD, but also complements the work of the Office of the UN Special Rapporteur on Disability by providing the evidence on the disability accessibility of the built environment in Africa.

Access Denied: Voices of persons with disabilities from Africa reflects and echoes the voices of people with disabilities and therefore through their experiences and opinions draws attention to the issue of accessibility in urban landscapes across Africa. Undoubtedly, accessibility of the built environment has been a major barrier to the social and physical inclusion and protection of persons with disabilities. While there are improvements in legislation and policies, the built environment still remains physically inaccessible for many persons with disabilities. Enforcement and implementation of these policies is wholly inadequate and remains constrained by a lack of resources, enforcement of construction standards, lack of awareness and underpinned that city authorities still do not consider the issue of disability as a high priority. As noted by the UNCRPD, African countries must make significant steps towards "universal design" which implies that buildings and services will be accessible to all, regardless of their status.

Access Denied: Voices of persons with disabilities from Africa is an important reference document for policy makers, service delivery institutions, civil society organisations, development partners, parents and community leaders. The recommendations in the report are based on the perspectives, ideas and concerns of those with disabilities themselves. This represents an opportunity to listen and act on their expressed opinions and priorities.

I am proud to be associated with this compelling report and believe that it is an important contribution towards ensuring a meaningful improvement in the lives of children with disabilities in Africa.

Mr Shuaib Chalklen

UN Special Rapporteur on Disability

PREFACE

Africa has one of the largest populations of children with disabilities in the world. Disability on the continent has been fuelled by widespread armed conflict and the legacy thereof, particularly in the form of un-cleared mines, and by household poverty allied with a lack of adequate healthcare services. Many children are born with some forms of disability that could be prevented with a modest investment in basic healthcare services during pregnancy.

Children with disabilities in Africa are among the most neglected groups in both social and economic domains. The majority of these children and their families face enormous economic, political, and social barriers that have an adverse impact on their physical, social and intellectual development and wellbeing. As a consequence, the strengths and abilities of children with disabilities go unnoticed, their potential is consistently underestimated, and their needs are given low priority in the allocation of resources. An interconnected set of factors explains this sorry state of affairs: limited political commitment, a genuine lack of resources, and lack of knowledge of current policy and legislative and programming options, to name but a few.

Despite the scale of the challenge, sufficient attention has not been accorded to the issue, either in research, policy and legislation, or in service programming. Gaps in researched evidence have also hampered effective policy and legislative responses. Aware of this gap, ACPF embarked upon

pioneering studies into the situation, lives and experiences of children with disabilities in Africa. The studies – conducted over the period 2009 to 2014 – looked at an array of issues, including the scale of disability among children in these countries, the level of poverty in households containing a disabled child, levels of access to services, the barriers that impede adequate access, etc.

This report analyses and summarises an assessment of the accessibility of five African cities, namely Addis Ababa, Freetown, Lusaka, Kampala and Johannesburg to persons with disabilities. Besides documenting the accessibility challenges faced by persons with disabilities, manifest in the way buildings, roads and public facilities are designed, constricted and fitted, the report also lauds progress and achievements made in that regard.

The report offers a set of recommendations that would help to break the barriers that stand in the way of the socioeconomic participation of persons with disabilities, not just in the study countries but also in other countries of a similar socioeconomic context. We present this Africa-wide report with great pleasure for use in law and policy formulation, programme development and advocacy by governments, civil society organisations and development partners in your respective domains.

Théophane Nikyèma
Executive Director, ACPF

KEY FINDINGS

- All of the study countries have signed and ratified the 2007 United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). This obliges each signatory to implement policies that will bring about full inclusion and integration for people with disabilities in every aspect of society.
- Respondents cite that lack of accurate data on people with disabilities, and/or flawed collection of such data, creates a major barrier to positive change. Governments underestimate numbers of citizens with disabilities, leading to (a) a failure to prioritise their needs over other perceived larger resource-needy groups; and (b) a lack of sufficient funds being applied to meet their needs. Lack of financial resources was a common thread through all key stakeholder interviews.
- Respondents report long traditions of stigma, prejudice and discrimination against people with disabilities. Negative attitudes pervade all strata of society, from the higher echelons of government and policymaking bodies, which for decades wilfully or unthinkingly ignored the needs of disabled citizens, down to grassroots community level, where traditional belief systems associating disability with divine retribution, magical curses and demonic possession are prevalent.
- Parental attitudes to disability are a major barrier to positive change. Some parents, particularly fathers, reject disabled children; many conceal children with disabilities in the home and deny them access to education, health and other social services. Disturbing stories are told of children being neglected until they die and, in Sierra Leone, of the ritual murder of babies with disabilities.
- Every country has responded to UNCRPD by introducing new policy measures in favour of children and adults with disabilities – ranging from discrete legislation on disability rights; amendments to existing legislation; policy guidelines; and inclusion of the needs of people with disabilities in strategic country papers and development plans.
- Respondents overwhelmingly report a major disconnect between policies on paper and the reality on the ground. A positive policy environment is not being matched by effective implementation.
- Respondents point to the failure of policymakers to recognise the diversity of disability types and to develop policies and interventions that meet the specific needs of people with different categories of disability. Some feel policymakers believe that ‘disability’ is synonymous with ‘physical impairment,’ and so inevitably focus their attentions on this aspect when developing policies.
- Built infrastructures in all study cities are significantly challenging for people with every kind of disability – physical, sensory and intellectual. Decades of failing to recognise or take account of the needs of people with disabilities have resulted in urban landscapes that are hostile and inaccessible to those with disabilities. Children and adults with disabilities are denied the personal freedoms – enjoyed by their able-bodied counterparts – to move without hindrance around their cities, and to access public and private facilities.

- Signs of improvement in the built infrastructure are, however, remarked upon in all study cities. New builds are incorporating some accessible features – although some respondents feel that corners are still being cut, and that sometimes the authorised, fully-accessible blueprints are not being adhered to when buildings are constructed.
- Older buildings remain largely inaccessible and present a huge challenge, logistically and financially, to those seeking to achieve a fully accessible environment.
- The parlous infrastructure of road networks and the inaccessibility of public transportation systems were almost universally derided by people with disabilities in all the study cities.
- In most of the study cities plans to improve transport networks and public transportation systems have been developed, but the challenge facing governments is vast, and only limited improvements have been made thus far.
- Public transport systems in the study cities remain extremely inaccessible for people with disabilities – reports are commonplace of people with wheelchairs being charged twice to travel on buses and people with disabilities being refused access to vehicles, or getting jostled and physically manhandled by able-bodied travellers.
- The reality on the ground for children and adults with disabilities seeking health services is very different to the aspirational model outlined in the UNCRPD. Many key facilities and services remain physically or practically inaccessible to people with disabilities; some service providers continue to display prejudicial attitudes; and many caregivers to children with disabilities find it difficult to find finances and to pay for services which should often be being delivered free of charge.
- Many children with disabilities in the study countries are denied opportunities to participate in education. In some of the study cities, as many as nine out of 10 children with disabilities of school age are denied any form of education. The barriers are various – ranging from physical inaccessibility of school buildings, absence of appropriate materials and lack of trained educators through to the attitudes of parents who fail to see the value of investing time and money in the education of their disabled child.
- Communication and accessing and sharing information can be restrictive for children and adults with every kind of disability. Problems can include libraries proving physically inaccessible to wheelchair and crutch users, a lack of Braille signage and materials, or the absence of trained sign language communicators who can convey information to the hearing impaired in cultural life and recreational, leisure and sporting activities. Most of the study cities demonstrated little in the way of effort to develop accessible facilities for people with disabilities to participate in sport, leisure and recreational activities on an equal basis with able-bodied people. Securing appropriate housing is a problem for people with disabilities in most of the study cities. Many are forced to resort to begging and may find themselves living on the streets, with obvious implications for their health and psychological wellbeing (especially for children with disabilities or the children of people with disabilities). Others

- report encountering prejudicial attitudes from private sector landlords and communities that do not want people with disabilities living in their neighbourhoods.
- Most of the study countries have enacted legislation to protect the employment rights and opportunities of people with disabilities, yet discriminatory employment practices persist. Workplaces are often either inaccessible or incapable of meeting the special needs of employees with disabilities. Without gainful employment opportunities, many people with disabilities find themselves trapped in a cycle of poverty and deprivation, often resorting to street begging to survive.
 - Many respondents feel that disabled person's organisations (DPOs) in their countries are not sufficiently resourced or mobilised to advocate effectively for policy changes. Some feel that disability rights movements are too fragmented and self-interested to work collaboratively to a common cause.
 - Failure to mainstream disability is a major barrier to policy implementation. Lack of mainstreaming at ministerial level allows government departments to avoid their responsibility to include disability issues in their areas of activity. Failure to mainstream disability across the whole of civil society in the study countries is another concern. Respondents report that other civil society organisations representing, for example, the interests of children, women or people with HIV, consistently fail to take account of people with disabilities when planning and programming their activities.
 - Several respondents express concern that the 2000 Millennium Development Goals (MDGs), which govern international efforts to eradicate world poverty by 2015, do not make any express references to the needs of children or adults with disabilities. Respondents feel that this potentially deters international donors from supporting programmes for people with disabilities.

CHAPTER 1

1.2 INTRODUCTION

On 30 March, 2007, the UN Convention on the Rights of Persons with Disabilities (UNCRPD) was formally opened for signature by the United Nations. The Convention represented the culmination of 20 years of campaigning and negotiation by disabled people and their advocates and supporters, and was the first international human rights treaty of the new millennium.

The UNCRPD provides practical mechanisms to ensure that rights first identified in the 1948 Universal Declaration of Human Rights can be implemented by signatory countries to bring about equality of opportunity and participation in society for children and adults with disabilities, following decades of neglect and exclusion for this vulnerable group of people.

Countries, or ‘states parties’, agreeing with the UNCRPD provisions can elect either to sign the Convention, or to sign and ratify it. In signing, countries signify only that they agree with what the Convention says on human rights for disabled people. By signing *and* ratifying the treaty, however, countries agree to implement domestic changes in policy and legislation to bring about the Convention’s provisions in their own societies.

Since its introduction, 153 states parties have signed the UNCRPD, and 105 have

gone on to ratify it. Of the 54 nation states of the African continent, only eight have not signed the Convention. Twenty-two African states have both signed and ratified it, signalling a commitment to bring about real change in the lives and rights of their disabled citizens.

Despite this, even the most comprehensive and equitable framework of rights for people with disabilities will remain as hollow promises if the structures and mechanisms that enable them to participate equally and fully are not in place – a situation that is currently the case across much of the African continent. How relevant is the right to universal primary education, if schools remain physically inaccessible to wheelchair users, and teachers lack the training to communicate effectively with visually or hearing impaired students? How applicable is the right to equal employment opportunities if transport networks deny those living with disabilities the means to travel to the workplace on time? Or if the workplace itself is physically inaccessible? How can citizens with disabilities participate in society if its core institutions and civic amenities remain closed off to them?

Access is the lynchpin on which the rights, hopes and aspirations of people with disabilities across the African continent depend, without which they cannot participate fully in their societies. Unless, and until the states parties that signed and ratified the UN Convention act to implement its provisions

domestically – providing people with disabilities with the same unhindered access to the built environment, transport networks, education, information, health services, employment and all other amenities presently enjoyed by able-bodied citizens – those rights, hopes and aspirations will remain unattainable and unrealised.

Actions taken during this decade, both by African governments and by the international community, will provide a demonstration of the intent to end decades of discrimination and impoverishment for children with disabilities. This report, commissioned and produced by the African Child Policy Forum, provides a baseline against which such progress can be measured.

The report studies progress achieved since the passage of the UNCPRD in five African capital cities: Addis Ababa, in Ethiopia; Freetown, in Sierra Leone; Johannesburg, in South Africa; Kampala, in Uganda; and Lusaka, in Zambia. Each of these five study countries has signed and ratified the UNCPRD, and all have reached various stages in domesticating and implementing its provisions. Yet much remains to be done.

This report focuses on issues of accessibility – both in terms of the physical environment and of accessibility to critical services and information provision – particularly insofar as they relate to children with disabilities. It reviews the situation in each city through the words and experience of key stakeholders, and explores the barriers to access that persist, and the measures currently underway to eliminate them. The report also outlines a series of recommendations for priority actions if real change is to be achieved in the cities and countries under review.

1.2 OBJECTIVES OF RESEARCH

This research aimed to assess selected cities in Africa in light of their accessibility and friendliness to people with disabilities. The five sub-Saharan African countries chosen for this study were selected as broadly representative of the continuum of development in the region.

Circumstantial evidence suggests that the capital cities of any country are the places where the greatest development and investment in infrastructure is likely to take place, so the research aimed to reflect best-case scenarios for people with disabilities in each of the study countries. The exception here was Johannesburg, which is not the capital of South Africa, but which is nevertheless one of the country's largest and most developed cities.

All the countries selected for the study have signed and ratified the UNCPRD and are in the process of domesticating and implementing its measures. Ethiopia signed the convention on 30 March, 2007 and ratified on 7 July, 2010; Sierra Leone signed on 30 March, 2007 and ratified on 4 October, 2010; South Africa signed on 30 March, 2007 and ratified on 30 November, 2007; Uganda signed on 30 March, 2007 and ratified on 25 September, 2008; and Zambia signed on 9 May, 2008 and ratified on 1 February, 2010.

The study focussed on broad issues of accessibility, taking account of the differing needs of children and adults with a variety of disability types, including:

- Physical impairment
- Intellectual impairment
- Hearing impairment
- Visual impairment.

Areas subject to review and study included access to:

- The built environment and public spaces
- Transport networks
- Education
- Health services
- Other public services
- Information and communication technologies
- Recreation and play facilities
- Employment.

In addition, and given the critical importance of public perception and stigma in creating an enabling environment for positive change, consideration was given to establishing prevailing public attitudes towards people with disabilities in each of the study cities. A review was also undertaken of relevant policies and legislation currently in place relating to disability access.

The key objectives of the study were to:

- Provide an overview of how accessible each of the study cities currently is for children and adults with disabilities

- Identify any positive developments which have taken place since the study countries signed and ratified the UNCRPD
- Recommend priority actions that need to be taken to redress barriers that persist in the study cities and countries
- Trigger positive policy and administrative action at domestic and international level that will create accessible societies where children and adults with disabilities can participate on an equal basis with their able-bodied counterparts.

1.3 METHODOLOGY

Qualitative research was selected as the primary means of gathering information and knowledge about the study cities, in order to provide platforms for the broadest representation from across the spectrum of stakeholders involved in the accessibility debate. Almost 200 stakeholders were consulted during this primary research phase, using various interview methodologies.



Focus Group Session
Kampala, Uganda

Primary research was carried out in Johannesburg, Freetown, Kampala and Lusaka during August 2011; and in Addis Ababa during September 2011.

A series of face-to-face interviews with key stakeholders was undertaken in each study city, with participation of:

- Children and young people with disabilities
- Adults with disabilities
- Parents and guardians of children with disabilities
- Representatives from non-governmental organisations (NGOs)
- Representatives from disabled people's organisations (DPOs)
- Representatives from government ministries
- Representatives from health care service providers
- Representatives from education providers
- Representatives from local councils and planning authorities
- Representatives from policing authorities
- Representatives from architectural, civil engineering and construction organisations
- Representatives from commercial organisations.

Across all five study cities, a total of 83 key informant interviews were conducted.

In addition to key informant interviews, a series of focus group discussions were undertaken in each of the participating cities, involving:

- Children with disabilities
- Adults with disabilities
- Parents, guardians and carers of children with disabilities.

More than 75 children and adults participated in focus group discussions across the five study cities.

A total of 12 children and young adults with disabilities also provided 'day in the life' interviews to the researcher in four of the five study cities.

Secondary research was also undertaken, comprising a review of key legislative and policy instruments governing aspects of disability in each of the study cities and countries. Although by no means exhaustive, this research did provide an overview of progress in each country in terms of responding to the requirements of the UNCRPD, and helped to contextualise the responses of key informants.

In September and October of 2014 an update of the data, information and opinions collected in 2011/2012 was conducted. Disability organisations in the five countries were consulted and asked to provide evidence of new developments since the end of 2011. For this purpose questionnaires were distributed via e-mail to selected respondents in four of the study countries, while face-to-face interviews were conducted with those in Ethiopia. This data collection was supported by a brief desk review of recent developments in the five countries.

CHAPTER 2

2.1 THE STUDY CITIES

The five sub-Saharan countries selected for the study reflected different levels of economic and social development. The decision to focus on a city in each country was based on the fact that cities in most African countries are advanced than elsewhere in terms of disability-friendly infrastructure development. Studying cities, hence, indicates the maximum effort that a given country has made to enhance accessibility of persons with disabilities.

Addis Ababa, Ethiopia

Addis Ababa is Ethiopia's capital and the country's largest city by a wide margin. Its population, according to figures from the 2007 census carried out by the Central Statistical Agency of Ethiopia, is 2,112,737. It is the third highest city in the world, sited in some parts at an elevation of 3,000 metres above sea level.

The topography of Addis Ababa varies, ranging from rugged, steep landscapes to the gentler rolling hills to the south of the city.

The city has seen a construction boom in recent years, with a number of multi-story buildings, hotels, shopping malls and most recently a comprehensive city train system being built, that are particularly relevant in the context of this accessibility study.

Public transport facilities principally take the form of minibuses, larger city buses and taxis. The city has a ring road, which

commenced construction in 1998 and was conceived as part of a plan to relieve inner city congestion and enhance development in the suburban areas. At the time of writing, a bill was under consideration which will further develop Addis Ababa's road and transport networks in the coming years.

Freetown, Sierra Leone

"The geographical location of Freetown itself is a problem – you look at it, it's on a hilltop. That tells you the roads will definitely be rugged."

Alpha Kamara, Leonard Cheshire Disability - Freetown, Sierra Leone

Freetown is Sierra Leone's capital city. A 2004 official census estimated its population at 772,873, although the actual population is now likely to be well in excess of one million, due to recent rapid population growth and migration into the city from rural areas.

The city is located on a rocky coastal peninsula and has a natural deep-water harbour. The topography is hilly and steep in places, making it somewhat inhospitable to physically impaired people.

The East End of Freetown is the most populous and the poorest of the city's three geographical areas. It is also the area where the vast majority of Freetown's disabled population dwells. Central Freetown, which includes the city's central business district, features Freetown's tallest buildings, although the city is generally quite low-rise.



Freetown
Street Scene

Johannesburg, South Africa

Johannesburg is South Africa's largest city by population, with 7,151,477 living in the Greater Johannesburg Metropolitan Area according to a 2007 Community Survey. It is the provincial capital of Gauteng, South Africa's wealthiest province, though – unlike the other cities featured in this study – it is not the national capital.

Topographically, the north and west of the city is built on undulating hills, whilst the eastern areas are flatter.

Johannesburg is one of Africa's richest cities, has a well-developed infrastructure, and possesses a central business district characterised by many of the continent's tallest and most imposing buildings.

Johannesburg's transport network is geared more towards private motorists,

and the city lacks a well-developed public transport system. Travellers without private transport means often rely on local minibuses to get around the city.

Kampala, Uganda

"Kampala is not for the disabled. It is built on hills, which is very uncomfortable for wheelchair users. It is a curse to be on these hills."

Adult disabled focus group member - Kampala, Uganda

Kampala is the largest city in Uganda and the country's capital. In 2011 the Ugandan Bureau of Statistics estimated the population of Kampala as 1,659,600. Traditionally the city is supposed to be sited on seven hills – although there are, in fact, several more – and the city's topography reflects this. As in most of the

other cities featured in the report, major new construction projects are currently underway, including numerous malls and office buildings, many of which are high-rise.

Public transport facilities include minibuses, taxi cabs and the ubiquitous *boda boda* motorcycle taxis.

Lusaka, Zambia

Located in the southern part of Zambia's central plateau at an elevation of 1300m, Lusaka is the capital of Zambia and the country's largest city. Its population, based on a 2010 census, is estimated at 1,700,000. The city forms the smallest of the country's nine provinces, but the second most populous.

CHAPTER 3

KEY FINDINGS

3.1 DISABILITY STATISTICS

Respondents in every country studied cited a lack of accurate data or flawed data collection creates a major barrier to positive change, because governments invariably underestimate the numbers of citizens with disabilities in their respective countries. This in turn leads to a failure to prioritise the needs of people with disabilities over other, supposedly larger, resource-needy groups.

In Johannesburg, for example, evidence from two successive censuses showed an unlikely decline in the number of people with disabilities in the city over a five year period. A total of 141,664 people with disabilities in Johannesburg were recorded in the 1996 census, falling to 114,270 in 2001. It has been suggested that this was because different definitions of what constitutes 'disability' were used in the two population censuses.

Respondents in other countries cited the huge shortfall between 'official' numbers of people with disabilities claimed by country governments and global estimates produced by the World Health Organisation (WHO) in its World Disability Report (2011)¹. The WHO report concluded that 15% of any given population was living with a disability of one form or another.

"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. Even the

WHO [data] – they [the government] don't accept because it is an estimate. The only document is [from] the Central Statistical Authority, the government body responsible to count the number of people. That figure shows less than one million people with disabilities [when, out of a country population of 77 million people, the WHO estimate would suggest that more than 11 million are disabled] – which shows the government that we don't have a huge population of people with disabilities – so there are other tasks they must prioritise"

Reta 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... We know that in Uganda we do not have enough information or data about disability – we don't know the numbers. Some NGOs do it, 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

NGOs and DPOs in Zambia also dispute official government figures, claiming that they woefully underestimate the size of the disabled population in the country.

¹ http://www.who.int/disabilities/world_report/2011/report/en/index.html

“I feel that people who are making policies don’t have adequate information to see that there’s a need here – they need statistics – they need numbers. People believe in numbers – and if there is no information flowing from the ground.....they are not going to see the need to do anything about it.”

Precedence Gertrude Kapulisa, Community Based Interventions Association - Lusaka, Zambia

“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 our census discovered that 13.4% of Zambians had some disability, which is closer to the current [estimate] released by WHO World Disability Report about 15%.”

Wamundila Waliuya, Zambia Federation of the Disabled (ZAFOD)– Lusaka, Zambia

Obtaining accurate statistical data on the numbers of children with disabilities in the study countries is even more fraught with difficulties. Stigma means that families will often fail to register the birth of a child with a disability, or conceal the child’s existence by keeping him or her in the family home, hidden away from the wider community.

“Here, traditionally, people look at a disabled person as a curse, as a misfit, as somebody not worth being near others, and because that belief has come a long way it is still within the people.”

Aloysius Kiribaki, Sense International Uganda - Kampala, Uganda

Article 31 of the UNCRPD requires states parties to:

...collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention.

Clearly, ensuring that accurate data is collected on the total numbers of people with disabilities is a pre-requisite to understanding and meeting the needs of the various disabled communities in each of the study countries.

3.2 ATTITUDES TO DISABILITY

“People with disabilities should have awareness that they are equal with their non-disabled peers. And in order to convey this, we young people with disabilities should try our best to raise awareness among non-disabled persons.”

Youth Focus Group participant - Addis Ababa, Ethiopia

A change in the lives and fortunes of children and adults living in the study cities and countries can only fully be achieved if public will acknowledges and accepts the need for change, and supports the implementation of policies and allocation of resources necessary to bring it about.

The challenge of bringing about attitudinal change is complex and formidable, as each of the study societies has a long, regrettable tradition of stigma, prejudice and discrimination against people with disabilities that must be overcome. Such attitudes have pervaded all strata of society, from the higher echelons of government and

policymaking bodies – which for decades wilfully or unthinkingly ignored the needs of disabled citizens – down to the grassroots community level, where traditional belief systems associated disability with divine retribution, magical curses and demonic possession.

Examples of institutional or societal prejudice were offered by key informants in every city taking part in the study.

“People look at us like we’re beggars. We are trying to change this attitude – but the person with a disability who cannot sustain him or herself – they look at him or her as a beggar.”

Disabled adult focus group participant - Kampala, Uganda

“Generally [Uganda] is very good when it comes to meeting the needs of children – there are some very good actors in society that really advocate for children’s issues, but for many years they haven’t known how to deal with issues around children with disabilities. The majority talk about street children, children in conflict, but the issues of the disabled child has never been addressed.....so this means that children with disabilities are missing out.”

Connie Kekihimbo, Director Cheshire Home for Rehabilitation Services - Kampala, Uganda

“Among the vulnerable groups who are within my purview the issues of people with disabilities are quite alarming. Economically they are known to be the poorest of the poor. They are known to be the forgotten ones, and when you look at our agenda for change – when you look at the country’s development programmes

– you will see that their issues are not taken into consideration.”

Patrick James Taylor, Human Rights Commission - Freetown, Sierra Leone

Ignorance, prejudicial attitudes and even overt bullying were widely cited by young people with disabilities and their parents in all study cities.

“I feel very uncomfortable getting on a public bus [with my disabled child] because everyone will want to look at her, stare at her. And if they are sitting near her they will want to move because they don’t want to be near her. So, I would rather walk if I possibly can.”

Focus group participant, parent of child with a disability - Lusaka, Zambia

“I feel that people use insults deliberately to hurt me, because their insults are based on our disabilities. Once when people tried to insult me I drank something toxic in order to kill myself. Since other people [saw] my reaction to that kind of insult, people have now stopped ridiculing me.”

Young peoples’ focus group participant - Addis Ababa, Ethiopia

“You’ll meet groups of parents and they will tell you stories of demonising 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

Despite the persistence of prejudicial attitudes in most of the cities, many respondents were keen to acknowledge that the situation was slowly improving in their urban communities, thanks largely to efforts by DPOs and NGOs to change public opinion through sensitisation programmes. There was almost universal agreement, however, that progressive attitudes were not filtering down into rural communities at anything like the same rate, mainly due to lack of resources to mount nationwide campaigns.

“[We have] been working on raising public awareness for many years, but the scope of the campaign has been limited to some parts of the country. For example, it has been moving in Addis and other larger cities. But it has not gone down to the public at grassroots level... And so 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. But there is a slight change, especially in cities – but in the rural areas still there exists that negative perception.”

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

“The attitude is just like in the past – it’s still negative. Because many of the hearing people up until now, they just cannot understand us [the hearing impaired]. Like, for example, in the past if you were signing with other deaf people, the hearing people were getting scared but as of now I can say that the attitudes are changing – they are starting to understand us. But we

do need more awareness raising for sign language.”

James Kapembwa, Zambia National Association of the Deaf - Lusaka, Zambia

Several respondents felt that government-backed national sensitisation and awareness programmes were the only way of tackling the issue of negative public attitudes.

“For me, the huge challenge we have is perception and attitudes. There is a need for more sensitisation on disability related issues...and people need to arrive at the understanding that disability is not inability – that people who are disabled can still produce, can still contribute. It’s going to take political will which has been demonstrated by government. It is also going to take massive advocacy and sensitisation.”

Priscilla Nyaruoye, Ugandan Human Rights Commission - Kampala, Uganda

“First of all I think we need to educate our people that being disabled does not minimise your opportunity to enjoy what a normal person enjoys. Education has to play a very important role in Sierra Leone.”

Dr William L Farmer, Ministry of Lands, Country Planning and the Environment - Freetown, Sierra Leone

An even greater challenge is posed for some children with disabilities, a challenge existing right at the heart of their homes. Negative parental attitudes to disability can result in children being isolated, hidden or literally imprisoned within the family home; denied access to education and nutrition freely offered to their able-bodied siblings; and even, in

some reported worst case scenarios, being abandoned or physically harmed by parents who cannot cope with the perceived shame of their existence.

“The parents’ attitude also matters a lot – whether they send their children to school or not. There are children like me – I am not severely disabled – I can manage stairs – but there will be children like me 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.

“It so happens that many parents with deaf blind children have already signed off on their child. That is, they feel what can they ever get from this child? So, even if you are telling them, please – this child is capable of learning.....their minds are already set, that this child is useless. If you look at these children in a home setting the deaf blind child is very often marginalised. 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 – like potatoes or porridge. So these other foods – they have plenty of foods here, like bananas, fruit – this child has never tasted.”

Aloysius Kiribaki, Sense International Uganda - Kampala, Uganda

One reliable key informant in Freetown recounted stories of ritual killings of new born children with severe disabilities in rural communities.

“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.

“It is very difficult for them to admit but some of the traditional leaders say...that [villagers] are doing it out of ignorance because when you go to the ordinary person down there he or she will not say they are killing them... ...they will take the child into the middle of the bush, murder the child there and bury it deep in a grave. Then they will come back to the community and say – ‘oh, this child was evil, it was good that it was returned’.

“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. So that is just one big challenge people with disabilities are facing in terms of our culture and tradition.”

Patrick James Taylor, Human Rights Commission - Freetown, Sierra Leone

In all the study countries, it is mothers who bear the burden and blame of having given birth to a disabled child. Men often do not accept any responsibility for fathering a child with a disability, and women are frequently abandoned or divorced.

"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

"When I found out my child had TB [resulting in a disabling spinal tumour] I told my husband about it and he was very upset with me. There hasn't been peace in our marriage – it almost ended – but we are still together, although he is not very helpful. We still fight over our child. The family too – his family, say that they don't have a disabled child in the family so how could this have happened? I've actually thought about committing suicide and taking the child as well. It is very tough for me."

Focus Group participant - mother of a child with disability - Lusaka, Zambia

A parent support group in Zambia reported that 85% of its membership was female, citing fathers' abandonment of their families and subsequent absenteeism as the principal reason for this disparity.

"The male parents are a problem. Once you have a child with a disability, that child belongs to the woman 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

As is the case with generating public awareness, it is NGOs and DPOs that are taking on the burden of working with families to change attitudes.

"Our very first objective is creating awareness, because we know that attitudes do not change easily. We work at that all the time. We do not carry out a clinic without talking to the parents. We go on radio and also encourage parents themselves to talk – especially parents that have a positive attitude. We encourage others to phone in when it's a radio talk show. But sometimes you are merely preaching to the converted, and not truly reaching those parents who are hiding their child because he or she is disabled, or those parents who are abandoning their disabled child - those we will probably never get to call."

"There are positive examples – recently we were told the story of a family where the husband separated from his wife because there was a disabled child born into the family. The mother struggled along with the child, which was bedridden with cerebral palsy. But when the mother started talking on the radio and the father heard, he came back. He said that listening to her touched him to the point that he had shed tears and he asked to be reunited with his family."

Dolorence Were, Uganda Society for Disabled Children – Kampala, Uganda

Article 8 of the UNCPRD places squarely on the states parties that have signed and ratified the Convention the burden of responsibility for raising 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'. Clearly, a great deal of work and investment of resources will be required to bring about changes in public and family awareness that will create an enabling environment in which children with disabilities can flourish.

ORPHANS IN THE STORM

Freetown, Sierra Leone

The baby sleeps soundly, swaddled in a makeshift nest of blankets, oblivious to the laughter and chatter of the 15 or more children at play around him and the sounds of a heavy tropical rainstorm raging outside.

He was discovered when just a few days old, abandoned in a Freetown marketplace. Fortunately, the market traders knew exactly where to bring him. Despite being malnourished and suffering from a bout of malaria, he has been nursed back to health and is thriving under the careful ministrations of Melrose Kamara, who runs an orphanage from her own home in the eastern suburbs of the city.



Mother Melrose and some of the orphans

The baby boy is the youngest and latest addition to the unique family at the Manenheim Orphanage. The only thing he shares in common with his 37 'brothers and sisters' is that all were born with some form of disability and subsequently abandoned by their families.

"I started the orphanage after the war – the majority of these children were abandoned by their families, thrown in the street," says Melrose. "They were begging. So, I take care of them and hope that they will be able to become somebody in the future."

The new baby boy was born with two club feet, and the other orphans have a range of physical and intellectual disabilities which would challenge even the skills of a team of professional health care workers. Yet, as a disabled wheelchair user herself, Mother Melrose has a unique insight into what it takes to nurture and help her charges to realise their full potential.

"I try hard to enable them to be educated, because when a disabled child is educated, he or she can become somebody of prosperity," she says. "But if they are completely abandoned with no challenge for them, that is why they go astray and will end up street begging."

Melrose receives no support from the government, relying instead on small grants from NGOs and individual philanthropists. "The first organisation to come in was Defence for Children International," she says, "They came in, they saw the situation of these children, and they had sympathy. The government of Sierra Leone does not impress me, because if they were interested they would come and see. If there was love they would do it. They don't have love. How they treat us, is that we are disabled,[therefore] we are not useful. But I'm telling them that we are useful."

"The first organisation to come in was Defence for Children International," she says. "They came in, they saw the situation of these children, and they had sympathy. "The government of Sierra Leone does not impress me, because if they were interested they would come and see. If there was love they would do it. They don't have love. Because we are disabled, they believe we are not useful. But I'm telling them that we are useful."

Melrose is clear about what the fate of her charges would be if she were not around to take on the challenge. "If this home was not in this country, some of these children would have gone astray, some would have died." She cradles the baby boy in her arms. Newly awakened, he stares transfixed at the rivulets of raindrops running down the window at her side.

"If this home was not in this country, some of these children would have gone astray, some would have died." She cradles the baby boy in her arms. Newly awakened, he stares transfixed at the rivulets of raindrops running down the window at her side. "Just look at the example of this child – if this home was not around, where would they have taken him to? I have taken on this challenge. I teach these children to take care of themselves. I teach them to feed themselves, to clean the place. They launder their own clothes. So, if they have to leave tomorrow, they can at least take care of themselves."

DAY IN THE LIFE

Carole, Kampala, Uganda

Carole is 16 years old and physically disabled as a result of Osteomyelitis. "When I wake up in the morning, I pray first. And then, I wash my face, I brush my teeth. "I have been staying with my cousin since 2009, because my Mum was working when I had this accident, then she had to come and take care of me at the hospital. When she went back, she was discharged from her job. So she had no job. Until she finds a new job there is no place for me because she cannot support us both, so that is how I came to stay with my cousin's family. I would rather be with my Mum. When she finds a job, she can find a house and I can stay with her again. My Mum has three children and we are all staying with different relatives right now. "There are some chores I can do, like mop the floor. But not well, because my legs are weak. Osteomyelitis [a bone infection] has weakened my bones, so I cannot do much. Sometimes I feel pain. But, you know, when you are not living with your parents you have to try to help out. Sometimes I cook, sometimes I wash utensils. And the day just goes like that. "I was studying, but now I no longer am. I was attending a secondary school. But my father died so my studies were not good. And then I got this disability, and so I come to Katelemwa [Cheshire Home for Rehabilitation Services]. They are treating me, so things are just not going on very well right now with my studies. I don't move around much at all. I just stay near my cousin's place most of the time."

3.3 THE POLICY ENVIRONMENT

The UNCRPD establishes clear mechanisms by which ratifying states parties can bring about the changes in their countries that are required to achieve full participation and inclusion of people with disabilities.

Article 33 of the UNCRPD requires states parties to establish one or more focal points within government to be responsible for matters relating to implementation of the Convention's provisions. This article also requires states parties to establish an independent framework to promote, protect and monitor implementation.

Article 34 establishes regulations governing the formation of a Committee on the Rights of Persons with Disabilities, currently comprising 18 members drawn from the various states parties to the Convention.

Article 35 requires states parties to report on progress towards implementation of the Convention within two years of its ratification, followed by additional reports every four years for consideration by the Committee. Following these reports, the Committee, under Article 36, shall then make such recommendations and suggestions as it considers appropriate.

One of the core tasks facing states parties after ratification involves the domestication of the Convention's principles, to effect the changes within societies that are necessary in order to achieve equality of opportunity for people with disabilities. Each of countries reviewed in this research project has embarked upon this process, though some have made more progress than others.

Some of the study countries had previously enacted laws and policies

relating to disability rights, which now need to be reviewed and adapted in line with the Convention; others had little or no existing legal provisions on the issues, so are enacting new laws on disability rights and including provisions on disability in other relevant instruments, such as transport, health or housing bills.

In Ethiopia, through a short proclamation (law) passed in 2010 (number 676), the government ratified the Convention and brought its measures into constitutional effect – a step considered a huge achievement by commentators, given the previous lack of any specific disability legislation in the country.

“Under Article 9 of the Constitution, the Convention gets status of being part of the country’s law, which is a great thing, because we never had a comprehensive disability law or any proclamation.”

Betelhem Abebe, Ethiopian National Disability Network - Addis Ababa, Ethiopia

Disability is now being referred to routinely in a variety of proclamations, and the government is in the process of establishing its own independent monitoring body – a step that respondents broadly welcomed, although most still had reservations about whether the policies would be implemented fully on the ground.

“We have a number of policies and legislations that talk about ensuring access for people with disabilities – but why aren’t these implemented on the ground to improve the lives of children with disabilities?”

Youth focus group participant - Addis Ababa, Ethiopia

“Now it’s after the Convention, there are a number of policy instruments. After the Convention, now the government is in the process of establishing a National Council for Disability – the Council will be responsible to make sure that the provisions of the Convention are actually implemented... We do have the policies; we have the commitments on paper. The challenge is implementation. That’s a key issue here.”

Reta Getachew, Ethiopian Centre for Disability and Development – Addis Ababa, Ethiopia

“What you see from the government side, because of the new policy environment, they have changed institutional recognition of people with disabilities. For example, the Construction and Urban Development Minister has developed a new construction law which very much considers the issue of disability. If they control the buildings of the future so that they can be disability inclusive – that’s a big start.”

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

Before a year ago, there was no proclamation which forces other government organisations to consider the issue of disability as their own thing to deal with 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 – or any of them – and raised disability issues, they would tell you to go there. But now there is this proclamation which puts every government organisation’s duties and responsibilities and every governmental

organisation is responsible to consider the issue of disability. So, I think now the government is making disability a priority."

Betelhem Abebe, Ethiopian National Disability Network - Addis Ababa, Ethiopia

One huge advance, cited by numerous respondents, is the fact that disability issues have been referred to expressly, for the very first time, in Ethiopia's latest five-year Growth and Development Plan.

"Ethiopia has its third development plan. The previous two didn't have a single word on disability. But currently this new five year Growth and Development Plan puts disability as a cross cutting issue, which is a big thing. And all the government policies, all the regulations and plans will be driven from this plan – so it's a great thing, and it shows that the Government is giving priority to issues of disability."

Betelhem Abebe, Ethiopian National Disability Network - Addis Ababa, Ethiopia

"The Federation has also been advocating for the inclusion of issues of people with disabilities in the national poverty reduction strategies of the country. This is a national development plan and for so many years the issues of people with disabilities had not been included in them. So, we have been advocating for this issue, and the government has listened and finally issues of people with disabilities has become one of the cross cutting issues in the latest development agenda of the country."

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

Respondents felt that the new positive policy environment in Ethiopia was partly the result of a new international focus on issues of disability, but equally the result of the strengthened role of the disability movement in the country.

"The disability movement in Ethiopia is becoming stronger and stronger. It was not at this stage when you go back 10 years, or even five. It's getting stronger. When you come to the DPOs, it is they who are the main stakeholders – they are more willing to speak up than the others."

Betelhem Abebe, Ethiopian National Disability Network - Addis Ababa, Ethiopia

Ethiopia also has a National Plan of Action of Persons with Disabilities (2012-2021) (revised in 2012) aiming at an inclusive society. It calls, among others, for extensive rehabilitation services, equal opportunities in education, skills training and work, and also for full participation on all levels in society for people with disabilities.

The role of DPOs and NGOs in contributing to an improved policy environment is also acknowledged by respondents in Kampala, though some expressed concerns about their capacity to respond effectively.

"I'd say we have a reasonably large number of DPOs active here. We have up to 15 national DPOs based on their relative disablements. We have an organisation of the blind, the deaf, the physically disabled, epilepsy, mental health and even a few organisations of parents of children with learning disabilities. But we also have other organisations which are not necessarily DPOs, but which

almost behave as if they were DPOs themselves. These include service providers for people with disabilities, like Katelemwa Cheshire Home, for example. “Then there is also the national umbrella NUDIPU (The National Union of Disabled Persons of Uganda). Certain issues are better advanced from a common front. One of the things we have tried to do is support NUDIPU to support the disability fraternity to develop a joint disability advocacy agenda.”

Joseph Walugembe, Action on disability in Uganda – Kampala, Uganda

“Even the leaders who are representing people with disabilities, who you would think are in the know – actually they are not. Even here in Kampala, in the local government, we have what we call the planning cycle. Usually very few people with disabilities are aware when the cycle starts and ends – so if they don’t insert their needs, they lose out. So, a lot of work needs to be done in the area of policy, advocacy.”

Spokesperson for Disabled Youth and Parents Association - Kampala, Uganda

As in Ethiopia, there is concern in Uganda about the ‘disconnect’ between the policy framework and implementation.

“Uganda was one of the first countries in Africa to support people with disabilities. It has the political will to support them. However, in terms of what has been done for them practically, it’s still very, very little. We have a good framework – the instruments are there. They always include us. But a lot has been at ‘recognition’ level – in terms of things

that are of actual benefit to people with disabilities, it is very little.”

Connie Kekihimbo, Director Cheshire Home for Rehabilitation Services - Kampala, Uganda

Uganda’s core legislation on disability, an act of 2006, amended in 2013, pre-dated the UNCRPD. The challenge now is to adapt that legislation in line with the Convention.

“The UNCRPD is of course at a very high level. Uganda has ratified as a country but we cannot claim to have implemented the UN Convention – we’ve got to domesticate it. Luckily enough we have the Disability Act of 2006, which was passed before the UNCRPD – that is being amended at the moment. “People have compared the two documents and felt that there is a lot more in the UNCRPD than in the act – and ours was also done a bit hurriedly – so now they would like it amended and guidelines will be developed. The UN Convention is more elaborate but it’s not at a level that is friendly to Uganda as a country – it has to be simplified, but yet if we do more on the act there will be a meeting point somewhere in the middle.”

Dolorence Were, Uganda Society for Disabled Children – Kampala, Uganda

One key respondent, however, felt that the Government of Uganda’s positive response to the UNCRPD has been motivated by wider political considerations.

“I think our leadership is a leadership which can read the signs of the times and wants to make use of it to benefit

a certain class rather than the people whose welfare it is aimed at. Uganda is good at reading the international scene – what counts most now? I think, if we passed a law like this, we can be rated high. So you go, you pass a law and you are rated high – you are very good. But now go down to the implementation and that's where the challenge is.

**Aloysius Kiribaki, Sense International
Uganda– Kampala, Uganda**

This act, I think the people who wrote it, first quickly read the draft of the UN Convention. They came down here and drafted the act and it came out as a very good law. But unfortunately, up to this day, it has never been fully implemented.”

**Aloysius Kiribaki, Sense International
Uganda – Kampala, Uganda**

Kiribaki points to a lack of genuine commitment to bring about progressive changes to the rights and welfare of people with disabilities, citing as evidence the fact that the realisation of Uganda's commitment to present its first report on progress to the UN is now well overdue.

“Uganda ratified the UN Convention in 2008, but up to today they have not yet presented a report to the UN Committee. They are required to do so within two years, so last year they were supposed to have done this. This is August 2011 and they still haven't done so. The reason is very simple – they wanted to run very fast and be seen to be in tune with the UN Convention.

“Policy wise, our country is very good. Actually we could be the leading country in Africa in terms of having very good policies, but let it come to implementation. Implementation is a problem. There are no specific guidelines to show the implementers how to do things.”

**Aloysius Kiribaki, Sense International
Uganda– Kampala, Uganda**

Sierra Leone passed The Persons with Disabilities Act in 2010 and it was enacted in 2011. Implementation of the Act has begun. The country is now making preparations to establish a National Commission for Persons with Disabilities with its head quarters in Freetown and having three regional branch offices. The Commission, not yet operational, aims to facilitate and advocate for the implementation of the Act through collaboration with the Ministry of Social Welfare, Gender and Children's Affairs and other relevant ministries. . Concerns were expressed by some respondents, however, that little effort is being made to generate awareness of the act and its provisions among potential beneficiaries and those who represent them.

“The provisions of the act provide a lot of facilities, a lot of freedoms. A lot of the provisions there to a great extent open doors for disabled people to access services. But the point is – these people with disabilities – do they also have enough education about this act? Are they fully aware of the provisions of this act? Are the heads of the DPOs fully capacitated to interpret this act?”

**Alpha Kamara, Leonard Cheshire
Disability – Freetown, Sierra Leone**

Respondents felt that the act would only be implemented if DPOs and individuals living with disabilities placed pressure on the authorities.

"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."

"Even the ratification [of UNCRPD] – we did a series of workshops and sensitisations, that's how we got it ratified. So, I think the same thing will be done for implementation. We won't just sit down like that. We have to give them the pressure to implement what has been signed."

Mariama Jallah, Polio Women's and Girls' Development Association, Freetown, Sierra Leone

"The Disability Bill was passed and is now an act and we have to push for implementation because there are a lot of things that need to be done. The population of the nation needs to be educated somehow as to how, where and what to do to improve the lives of blind people."

Ahmed Sankey Dian-Tury, Sierra Leone Association of the Blind – Freetown, Sierra Leone

Others are more optimistic about the situation and the capabilities of DPOs to advocate for implementation.

"The disability issue before this time, you know, used to be an isolated issue. It is now becoming not an isolated issue, but a developmental issue. And then, having actors and

stakeholders who are very much interested in the area of advocating for the rights of people with disabilities and supporting them to advocate for their rights and inclusion, I think will make a difference. When the [national council] has been formed, it will then be the responsibility of the [DPOs], for them to put their hands on deck and see how well they can influence policymakers to ensure that whatever needs to be is implemented. For me, I'm very much optimistic about it."

Issa Turay, Handicap International - Freetown, Sierra Leone

Representatives of government ministries, perhaps not surprisingly, share this optimism and are keen to point out how the disability rights agenda is moving forward in Sierra Leone. They tend, however, to focus more on enabling measures than on practical implementations, which perhaps echoes and reinforces the reservations expressed by some civil society.

"... we have embarked on a plan to make sure that every plot of land is accessible. So we are now engaging the developers to make sure they do this. We are developing a national lands policy – a draft copy has come out and is now being looked at by other professionals, and a workshop will soon be called to validate that document."

Dr William L Farmer, Ministry of Lands, Country Planning and the Environment - Freetown, Sierra Leone

"We were very much involved in developing the Act itself - we were very much as a Ministry involved in that. In fact we are part of a steering group – a task force that was set up to

develop the act. And also, His Excellency's pronouncement on the free healthcare to pregnant women, lactating mothers and children under 5, we know that someday it would be extended to other groups."

**Sidie Yahya Tunis, Head of Information,
Ministry of Health - Freetown, Sierra Leone**

Zambia passed the Persons with Disabilities Act in 1996, enacted long before the UNCRPD process was completed. The country has also put together a National Policy on Disability and National Disability Mainstreaming Plan.

The challenge now is to align the provisions of the UNCRPD and those of the Act with other pieces of legislation so that they address disability rights in a comprehensive manner.

"In Zambia we already have an act, but that was done some time back and before the ratification of UNCRPD. So there's a need to look at that act so that it can be amended in line with the Convention. Also we need to take a look at other legislation in the light of the Convention and if it doesn't work, then something should be done. Because, you know, legislation is power."

**Francis Chilufya – Zambia Agency for
People with Disabilities – Lusaka, Zambia**

"[UNCRPD] is something that has been cherished by most people with disabilities in the country. It's seen as an opportunity to ensure that issues that are of concern are covered by legislation – and that once domestication has taken place, then it will be easier to identify any field where government is not doing as

they should. The DPOs of people with disabilities have organised themselves into certain forums in order to monitor what government is doing about UNCRPD."

**Francis Chilufya, Zambia Agency for
People with Disabilities – Lusaka, Zambia**

As in the other countries, the sense of having policies on paper and no implementation on the ground means that the need is strong in Zambia for DPOs and NGOs to apply pressure on government.

"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**

"We hope that when [UNCRPD] is domesticated, that people with disabilities will be respected, their rights will be upheld – they are going to participate in every activity in the Zambian environment."

What we want is to have an enabling environment – an environment that will be inclusive of all children. So, when you go to school, the teachers are aware that there is this programme for children with disabilities. When you go to the hospital, the nurses are able to handle that child without a lot of barriers. There should be policies, laws which improve the lives of people with disabilities. That is our vision. We want to see children with disabilities

living in an all-inclusive society where they will freely interact with other children without facing a lot of discrimination.

“We advocate for involvement but at times it will reach to a certain level, and then you are not consulted anymore. You just find that this policy has been formulated. But what we are advocating for is full inclusion, full involvement at each and every level of policy and decision making.”

Astrida Kunda, Zambia Association of Parents of Children with Disabilities – Lusaka, Zambia

The Zambian Federation of the Disabled (ZAFOD) is heavily involved in monitoring the implementation of UNCRPD in the country and ensuring that government meets its commitments. An independent unit, funded by and collaborating with the European Union (EU), is working to sensitise key stakeholders about the requirements of UNCRPD, and to 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 UNCRPD 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 Persons with Disabilities Act itself, the Education Act, the Employment Act, the Urban and Town Planning Bill and also the Mental Health Act.”

“We have been going around having consultations with people, to get their

opinions about what they feel should change in our domestic laws. In our consultations we discovered that most of the people are not actually aware of the UN Convention so that is why we decided to change the approach so that instead of just consultations, we start with sensitisation.”

Milika Sakala, ZAFOD / EU Monitoring Unit – Lusaka, Zambia

South Africa probably has the most extensive range of legislative measures and policies governing disability of all the study countries. A range of progressive legislation and policies aims to ensure that people with disabilities have access to services and facilities. As a city, Johannesburg has also developed and adopted laws and policies that guide the city in the provision of an accessible environment.

The South African Constitution (1996), as the supreme law of the country, represents the government’s commitment to breaking away from the country’s past by protecting the rights of all South African citizens, including children and adults with disabilities. Some of the rights itemised in the Bill of Rights included in the Constitution make specific reference to people with disabilities. These include the right to equality, which states that “the state may not unfairly discriminate against anyone on one or more grounds including disability”. Clause 28 of the Bill of Rights gives all children special rights, including to basic nutrition, shelter, basic health and social services and the right to be protected from maltreatment, neglect, abuse or degradation. The Constitution also states that everyone has the right to basic education.

South Africa is expected to launch two policy documents soon, namely: the National Disability Rights Policy and the Social Inclusion Policy. The first policy aims at guiding the government in promoting a more inclusive society including involving people with disabilities in decision-making processes, and the second policy focuses on education.

The Disability Framework for Local Government (2009-14) guides local government in the implementation of the Integrated National Disability Strategy and other government policies on disability. Its objective is to support integrating disability into all policies, plans, budgets, programmes and activities of local government. A City of Johannesburg Disability Policy of 2009 seeks to ensure that the city's residents and visitors with impairments are able to access all council facilities and services as well as services rendered by municipally-owned entities.

Despite the existence of such progressive laws and policies, awareness among respondents in Johannesburg is very limited. The city official, architect, community activist and some DPOs who took part in interviews are aware of some of the key legislation and policy. Very few parents of children with disabilities are aware of the Constitution, and none are aware of other legislation and policies. Such limited knowledge may deprive them of critical information they need in order to lobby for their children's right to an accessible environment. Limited knowledge among city officials and staff also contributes to poor policy implementation.

There is a general perception that the laws, policies and structures have only very minimal accessibility impact on the lives of people on the ground, especially access to facilities directly used by children with disabilities.

All of the five study countries have responded to UNCRPD by creating, or starting work on creating, an enabling policy environment for both children and adults with disabilities. The challenge for all, however, remains transforming the policy into practical measures on the ground.

3.4 ACCESS TO THE BUILT ENVIRONMENT

"In the past no attention was paid to accessibility – why do you think that is? Do you think things will change now there is a law? No. Not unless the people with disabilities fight for their rights."

Leslie Clarkson, Consulting Engineer - Freetown, Sierra Leone

Article 9 of the UNCRPD provides a number of measures that states parties to the Convention are required to implement in order to bring about physical accessibility of the environment, in order to 'enable persons with disabilities to live independently and participate fully in all aspects of life'.

These measures include developing a set of minimum standards governing accessibility of public buildings, spaces and services; ensuring that private entities take account of the needs of people with disabilities; and providing sensitisation training of stakeholders on accessibility issues.

The Persons with Disabilities Act of Uganda is one of the most progressive when it comes to accessibility. Section 20 of the Act requires any person, who constructs, a building to which the public is invited, to ensure that persons with disabilities have access through

1. Provision of -

- a) Accessible and easy-to-find building entrances, connected by accessible pathways to accessible indoor or outdoor parking areas, local public transit stops and accessible elevators;
- b) Safe and accessible urinal, bathrooms for the diverse disabilities;
- c) Safe and well-dimensioned staircases for the comfort of persons with mobility problems;
- d) Ramps wherever stairs obstruct the free passage of pedestrians, mainly wheel chair users and people with mobility problems;

- e) Adequate railing around hazardous areas, stairs, ramps, accessible roofs, mezzanines, galleries, balconies and raised platforms;
- f) Well-dimensioned elevators, ('in the case of multi-storied buildings) that persons with disabilities can use conveniently.

2. An accessible elevator should-

- a) serve all floors normally reached by the public;
- b) Have embossed numerals on the floor selector buttons to be easily identifiable by touch;
- c) Signal arrival at each floor to alert sightless and hearing impaired passengers simultaneously

3. Where it is difficult or unfeasible to install a ramp or an elevator to an existing building, the owner of the building shall provide platform lifts to provide accessibility



Accessible wheelchair access ramp in shopping mall

Kampala, Uganda

Further, the building Control Act passed by parliament in 2013 has a clear focus on accessibility to the built environment by people with special needs. The Act also has an annex that gives detailed accessibility guidelines. Action on Disability & Development International in Uganda recently reported, however, that unfortunately there seem to be no or hardly any positive developments in this area.

The Ethiopian Building Proclamation No. 624/2009 requires that public buildings have a means of access suitable for use by physically impaired persons, including those who are obliged to use wheelchairs and those who are able to walk but unable to negotiate steps. It also requires that an adequate number of such facilities shall be made suitable for use by physically impaired persons and shall be assessable to them (FDRE 2009).

Of the five study cities, Johannesburg probably demonstrates the most advanced development in terms of achieving

comprehensive standards of accessibility across its urban infrastructure – perhaps unsurprisingly, given South Africa's economic dominance in the region. Numerous respondents in other study cities – particularly those working in the fields of architecture and civil engineering – cited South Africa as a regional model for accessible urban environments to which their cities and societies aspire. Yet even Johannesburg has not yet completed its journey towards full accessibility.

There was general agreement among respondents in Johannesburg that the city is attempting to make public buildings, such as government offices, clinics, libraries and police stations, physically accessible. This was especially so with new buildings and recently refurbished buildings. There was further consensus that the city is beginning to take account, not just of the accessibility requirements of the physically impaired, but also of the needs of other disabled people, in the design and construction of buildings.



Accessibility lift at front entrance to municipality offices

Johannesburg, South Africa

Examples of accessibility improvements noted by respondents in Johannesburg include exterior ramps and evenly paved surfaces; wider, wheelchair accessible corridors and doors; accessible toilets with appropriate signage; lowered counters for wheelchair users' visibility and interaction with service providers; and handrails, Braille signage and voice synthesisers for the visually impaired. Furthermore, the National Institute for the Deaf, for example, reports on their efforts to provide wheel chair ramps, hand rails, disability-friendly toilets, visual key locks on toilets, strobe lights, flashing door bells and digital notice boards.

Despite these welcome improvements, however, the general consensus was that much remains to be done. Not only are many old buildings still awaiting upgrade, but even some new buildings continue to be erected without complying with universal design and building standards.

Decades of failing to recognise or take account of the needs of people with disabilities have inevitably resulted in urban landscapes that are hostile and inaccessible. People with disabilities are being denied the personal freedoms

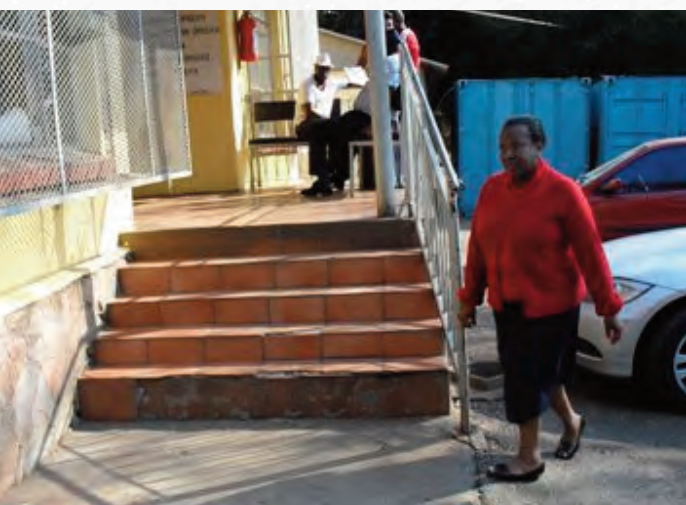
enjoyed by their able-bodied counterparts to move freely around their cities, to access public and private buildings, and to participate fully in their societies.

Currently, the built infrastructures in all the study cities prove to be hugely challenging for people with every kind of disability – physical, sensory and intellectual.

Accessibility to buildings in outlying residential areas is reportedly worse than in the Central Business District. In some instances where the city has attempted to make improvements, the perception is that it tends to focus on wheelchair users and ignores the needs of people with other impairments.

Some respondents report that even in instances where a building has adhered to accessibility standards, the area around the building itself is often inaccessible. For example, the area around Park Station (the central railway station) in the Central Business District in Johannesburg is cluttered by road works, broken pavements and hawkers selling on the streets, making the station itself effectively inaccessible for people with disabilities.

Respondents also report that some buildings have no accessible toilet facilities, one example being the Johannesburg Magistrates Court. In some instances there may be one accessible toilet in a multi-storied building. There is minimal regard for deaf and hearing impaired people inside some buildings. For example, there may be no directional or informative signage, no visual alerting systems, sound buffering design features or reception station set-ups which allow for face-to-face or direct line communication with staff.



Inaccessible entrance to municipality offices
Johannesburg, South Africa

DPO spokespersons generally expressed views that city officials in Johannesburg frequently ignored professional advice and at times totally disregarded notions of universal accessibility. Others reported the general lack of an integrated approach in dealing with accessibility issues.

After Johannesburg, the city of Lusaka has probably made the greatest progress in recent years, when compared to the other study cities, in terms of adapting its infrastructure to the needs of people with disabilities. This finding is based on direct observation, as numerous buildings old and new appeared to have incorporated ramps and other accessible features into their design or during retrofitting, improving access at least for the

physically disabled. The *Zambian Persons with Disabilities Act* of 2012 provides for accessible buildings and inspections of buildings.

“In the recent past, issues to do with accessibility for people with disabilities weren’t really considered. But today, the buildings that are being erected are actually incorporating designs which [are] accessible. For example, in the past, most of the buildings never had ramps, so those in wheelchairs could not reach the upper stories. Whereas today, there are improvements in terms of accessibility and ramps are generally being incorporated.”

Chipuso Kavimbi, Engineering Institute of Zambia – Lusaka, Zambia



Accessible pavement surface in city centre street
Lusaka, Zambia

Manda Hill, Lusaka's largest shopping mall and a relatively recent build, is one modern addition that appears to be appropriate in terms of design and accessibility. The mall incorporates a wide range of accessibility features, including regularly spaced ramps up from road level onto the pavements; ramps between floors; elevators with Braille buttons (though not audio floor announcements); ample disabled parking bays placed close to the mall entrances; and fully accessible toilet facilities on every floor.

"Although there are a lot of positive steps that have been made - you can say that the new developments now are considering issues of disability. It's actually [a] requirement now, but we need I think to move in dealing with the issues of disability on a broader perspective. Maybe on a broader frame than just maybe, for instance, having one development consider issues of disability, [whilst in] other parts [of the city] – there is nothing."

Maxwell Zulu, Department of Physical Planning and Housing, Ministry of Local Government – Lusaka, Zambia



Accessible parking bays at mall
Lusaka, Zambia

Several key informants, however – including official representatives from ministerial level – are apparently less than satisfied with the progress that has been made in Lusaka to date and willing to concede that more needs to be done.

"I think we have a long way to go in terms of the way that the city is at the moment and in terms of tackling issues of disability. I don't think we have a lot which we have achieved in terms of tackling accessibility for people with disabilities. In terms of building infrastructure, we have done not much."

"Lusaka hasn't really been doing that well, especially when it comes to the old buildings. An example [is] the building where we are right now [Lusaka's City Council Headquarters]. Seriously speaking, if you look at it, it's got a lot of major lapses in terms of design for people with disabilities. So, if you look at the old buildings, I don't think we have been doing well, but if you [consider] the new buildings we have been doing better, especially in the last 10 or so years, because that aspect has been well catered for."

Michael K Kabungo, City Planning Department, Lusaka City Council – Lusaka, Zambia



Inaccessible ministry building,
Lusaka, Zambia

“We are still a long way from realising the expectations of people with disabilities. Some attempt is being made. There is interest in the authorities that are charged with the responsibility to see that in the area of construction issues of accessibility are taken into account. The work is not yet properly co-ordinated but there is interest amongst, say, the ministry that is responsible for that kind of work and the local authorities and the National Council for Construction. So that needs to be co-ordinated properly.”

“There are a lot of buildings that were put up a long time ago, and they have not yet been worked on in order to make them accessible. On some of them, something has been done – some have fixed lifts to make it a little easier, some have lifts with some form of audio service for the visually impaired – but there is quite a lot of work to be done. We are a long way off.”

Francis Chilufya, Zambia Agency for People with Disabilities – Lusaka, Zambia

As in Johannesburg, progress on making older buildings accessible is patchy and

uncoordinated. For every respondent who reports on elevators with accessible features for the visually impaired, another will point to buildings that do not cater for their needs.

“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

Leslie Clarkson, Consulting Engineer - Freetown, Sierra Leone

Recently introduced policy on planning regulations and the work of inspectorates are improving adherence to accessibility standards in Lusaka, particularly on new builds.

“Initially there was not deliberate policy, except for schools. Normally, for schools, that was an issue that was

normally considered – accessibility for children who were differently abled. Early this year, the Ministry of Local Government issued a directive to all local authorities with instructions that this should be extended to all building proposals that are coming through. Now it is government policy that the issue of accessibility should be considered in the design of buildings that are coming up.

“Fortunately now most of the developers are realising that including facilities for the disabled is not an extra cost on themselves but it works to their advantage, because then they get a lot more people getting access to their businesses. We get issues of including these features in private developments as well as public buildings.”

Michael K Kabungo, City Planning Department, Lusaka City Council – Lusaka, Zambia

One reason for Lusaka’s relatively successful progress compared to some of the other study cities in achieving greater accessibility was the willingness of DPOs to challenge decisions and hold the authorities to account for implementing legislation.

The Zambian Federation of the Disabled (ZAFOD) has been particularly active in this regard, and is even prepared to resort to legal action to enforce compliance with laws.

“Around access, we began doing some accessibility audits in 2008. We have a checklist that we developed but we are using standards from UN Enabling and South Africa and we localise the checklist to fit our situation. It looks at the physical environment of the premises, it looks

at the stairs and ramps, it looks at the doors, at the painting, the windows, the sound – everything – the passages, the emergency areas – on particular buildings.

“We have been doing these on a thematic basis. For example, 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% inaccessible. After [carrying out audits], 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

One Lusaka bank has even introduced an audio automated telling machine for the visually impaired, and the intention is that this will encourage other banking institutions to take similar initiatives.

ZAFOD and other DPOs in Zambia also engage in sensitisation programmes with

key public and private institutions to create awareness of accessibility standards and promote changes in attitudes to people with disabilities, all of which helps to create an enabling environment for change. Similar efforts are being made by DPOs in the 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.

Addis Ababa has had a similarly chequered response to making its city infrastructure accessible for people with disabilities, with examples of good and bad practice clearly evident to the observer.

“I think Addis Ababa is far better than it used to be. At least you can see some ramps when buildings are being put up. This is a big development. Considering where we need to go, though, it is not as we would expect. There are big challenges. Especially the public buildings – when you go to health stations, when you want to go to the schools, they are still not accessible.”

Betelhem Abebe, Ethiopian National Disability Network - Addis Ababa, Ethiopia

Some commentators are more pessimistic about the current state of infrastructure development in the city.

“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, do 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 People with Disabilities –Addis Ababa, Ethiopia

“The challenges are that most of the buildings have stairs without ramps or handrails. Toilets are really inaccessible – especially the toilets of hotels. Most of the buildings don’t have lifts. And even those with a lift – the lift doesn’t start on the ground floor – it starts from the first floor. When we asked why, they told us it was just to minimise the electric consumption.”

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



Accessible entrance to private hospital facility
Addis Ababa, Ethiopia

“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

Over the past few years, the Ethiopian Centre for Disability and Development said it observed small but clear

improvements as regards accessibility of some public buildings, such as university facilities.

In some of the cities, recent legislative and policy developments in the area of building and construction have been welcomed by many respondents.

The Ethiopian Centre for Disability and Development has recruited one architectural champion who is generating awareness within the entire architecture profession. Not only did consultant Amanual Tesfaye produce the first thesis on accessibility in Ethiopia he also lectures at a college training the next generation of Ethiopian architects and uses that platform to promote awareness. He believes that historical ignorance on the part of his profession, coupled with reluctance on the part of building owners and developers to invest in accessibility measures is a major barrier to change.



Inaccessible stairways leading to upper floor of
Zewditu Hospital
Addis Ababa, Ethiopia

"....many architects also do not consider these things [accessibility]. Some don't have the knowledge, and even if they do have the knowledge, they don't want to practice it. "The trouble is that there is so much corruption that the kind of building commissioned and the kind of building built are often very different. Even though you put a ramp in the design, that ramp will not be there when the construction happens. Even if you put an accessible toilet – it's not there... .When it is funded by private people, they want to profit out of it. I think most of the owners think that it is going to cost them money [to make premises accessible] – that's the challenge that we are facing."

Amanual Tesfaye, Consulting Architect - Addis Ababa, Ethiopia

According to Tesfaye and other commentators, one issue uniquely reported on only in Addis Ababa, and which has compounded the problems of building inaccessibility for many decades, has been the practice of radically changing building use over time.

"The previous government had been changing buildings' use a lot – so the high school becomes a high court, and a residential house becomes a museum. Imagine the implications – you cannot push a person's private house to be accessible, but then if it changes to a public building like a museum....then you have to do something about it. But this has not been done. Before this government, we had almost no construction was just only transformation, with private buildings becoming public buildings."

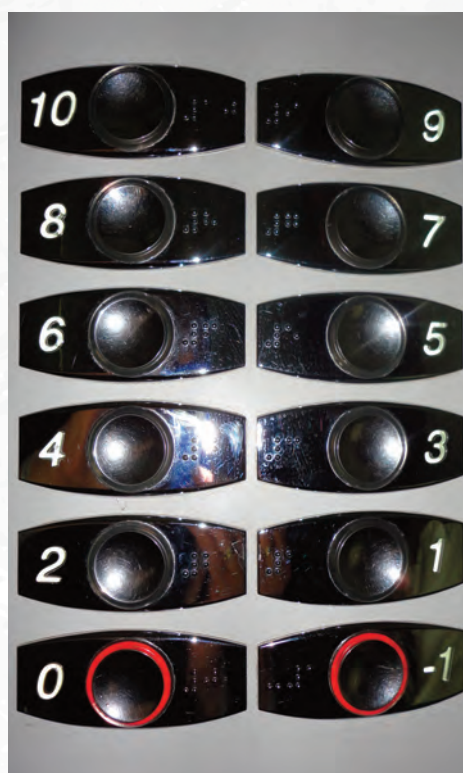
Amanual Tesfaye, Consulting Architect - Addis Ababa, Ethiopia

Recent legislative developments are welcomed by many respondents. These have included a new building proclamation and new regulations governing construction practice. Also Ethiopia's latest five year national growth and transformation plan has referenced the needs of people with disabilities for the very first time.

"With regard to...proclamations, we do have the Building Proclamation, which clearly indicates that any buildings when constructed should be accessible to people with disabilities, so that proclamation mandates building owners to build accessible buildings."

"Secondly, there is the growth and transformation plan of Ethiopia – this is a five year plan. And on this plan with regard to construction, it asks that building owners should build in consideration of people with disabilities."

Gebre Teshome, Ethiopian National Association of the Blind - Addis Ababa, Ethiopia



Accessible lift with Braille buttons

Bedesta Building
Addis Ababa,
Ethiopia

"The law is here and sooner or later it is going to be enforced. There are so many stakeholders, so many participants pushing for this to be taken very seriously."

Amanual Tesfaye, Consulting Architect - Addis Ababa, Ethiopia

In terms of infrastructure accessibility Kampala is similar to Addis Ababa. Its older buildings have very limited accessible features, whilst newer buildings' accessibility standards are inconsistent.

"Kampala is a relatively old city – a city that was initially developed before much thought was being given to this whole issue of accessibility in terms of design. And so most of the infrastructure to which you would expect children to have primary need to access - like schools, like hospitals, like play facilities - was all constructed without having any disability perspective. So that makes much of Kampala's infrastructure inaccessible."

Joseph Walugembe, Action on Disability in Uganda – Kampala, Uganda

"Organisations are becoming more aware of the need that everyone has to access buildings and services. Some places are accessible, for example, public places like banks, and hospitals and some NGOs. But other aspects of accessibility are very bad, so like me, if you are using a wheelchair, it is really difficult."

"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

Even where accessible features are incorporated into new design and builds, some respondents report that the features are not appropriate for use by people with disabilities.

"There are so many mushrooming buildings in this city. If really the policy was in place, people such as these would not be building such buildings without accessibility for people with disabilities. Those who construct the ramps, they don't consult the users – so you have ramps like this [indicates steep inclination]. I don't know what we can do – it's a very big, big challenge".

Disabled adult focus group participant - Kampala, Uganda

"If architects and builders are able to construct stairs properly, why do they fail to construct a ramp properly? They construct a ramp which is very steep. Those buildings where they have tried to construct ramps – they are too steep. They are unfriendly. You cannot ride properly with a wheelchair. So, I think we need to do something – like, at their training schools and institutes that train architects, so that they know how to construct a proper ramp."

Disabled adult focus group participant - Kampala, Uganda

Some disabled respondents noted that environmental inaccessibility results in an additional burden their already overstretched financial capacity.

“Another big concern is the markets. The majority of people with disabilities are illiterate so they have very little money. You’ll find that markets are not designed to accommodate people with disabilities, either as part of the business or as customers. So you find you cannot shop, and end up depending on the people who sell vegetables at the roadside, which in most cases are not fresh. They are more expensive, too - and you have no choice. All over Kampala there is no single market that is accessible. There is no single accessible toilet in any of these places. The only places that are fairly accessible are the shopping malls. And how many people with disabilities can afford that?”

Disabled adult focus group member – Kampala, Uganda

Some representative of DPOs or NGOs appeared to feel that their lobbying and representations to ministries and institutions responsible for making buildings more accessible were failing to get through.

“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. For example, they are aware that when new schools are built, they should be accessible to all – they should have ramps for access – but when the contractor is

awarded the business, making savings and cuts is the first thing they do – so they remove ramps or make the width of doors narrower – so children with disabilities will not be able to access the schools. And the good schools in the city are in tall buildings, with no lifts – so they are pretty much inaccessible. So, whilst the city is still being restructured and reorganised the people in charge of the process are not very mindful of the needs of people with disabilities.”

Connie Kekihimbo Katalemwa, Cheshire Home for Rehabilitation Services - Kampala, Uganda

Some respondents were, however, able to point to examples of buildings, both in the public and private domains, where efforts to improve accessibility had been taken.

“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 first floor, second floor and third floor by wheelchair.”

Disabled youth focus group member - Kampala, Uganda

“The parliament is fairly accessible. I was there for about five months. There are ramps on either side – on the south wing and north wing of the building. There are lifts – quite big – so the wheelchair can get in and you

can even manoeuvre within it. It's the only place I can think of which is accessible."

Disabled adult 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

There was almost universal consensus among DPO and NGO spokespeople across the study cities about the need for better enforcement of building regulations and policy. Most felt that there was a major disconnect between policy and practice in their cities. Others stated that profit was often a motivator for both good and bad practices, insofar as some developers would include accessibility measures merely to attract the business of people with disabilities, whilst others would cut accessible design features to save money.

"Private investors seem almost to be above the law. They do not follow guidelines. I will often meet government officials who will lament how powerless they are to intervene where it is a private investor."

Joseph Walugembe, Action on Disability in Uganda – Kampala, Uganda

"We are seeing constructions going up – no ramps, no lifts – nothing. And we are shouting, but nothing can be done. Because first of all, the person doing

the construction is thinking how much they can make out of it.

"A few of the corporate people are beginning to respond – like banks, a few hotels – which is positive. But it's because they are missing out on money. They realise that some people with disabilities have money to hold conferences, for example – so they will make their hotels accessible in part to make money from such conferences."

Connie Kekihimbo Katelemwa, Cheshire Home for Rehabilitation Services - Kampala, Uganda

"Yes. We have a policy. Engineers have their binding rules and all blueprints should include [accessibility features]. We have the documents, but the practice is never followed. It's an issue of corruption really because if you bid and you are awarded that contract you should follow everything and somebody supervising should be able to see that everything is in place as it continues, but it is never done."

Dolores Were, Uganda Society for Disabled Children – Kampala, Uganda

Of the five cities included in the study, Freetown in Sierra Leone has probably made the least progress in terms of creating an accessible infrastructure for people with disabilities.

"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



Inaccessible entrance to police station

Freetown, Sierra Leone

"The geographical location of Freetown itself is a problem – you look at it, it's on a hilltop. Even the buildings do not provide for access with the use of ramps or other facilities which the disabled might use.

"Government ministries themselves still have architectural barriers and these barriers inhibit access to these centres. Houses – you see stairs and stairs and stairs – they do not provide access."

Alpha Kamara, Leonard Cheshire Disability - Freetown, Sierra Leone

In Sierra Leone, DPOs and NGOs are attempting to mobilise and influence change collectively, but in Sierra Leone these movements are relatively weak and uncoordinated. Nevertheless, individual agencies are having some impact.

"The element of accessibility has been a very key component of all our various projects. We have focussed on physical accessibility – where we tried to work with various communities. We worked at national and local level to see how structures could be made accessible to children with disabilities, especially when it comes to getting to school.

"We have been awareness raising through our community sensitisation programme, targeting school authorities to encourage them to ensure that they do not have structures within their school settings which cause difficulties in accessibility for children with disabilities."

Issa Turay, Handicap International - Freetown, Sierra Leone

Recent legislation passed in Sierra Leone contains provisions about building accessibility, at least for publicly owned buildings, and regulations governing standards and inspections of new builds are also in place. But the difference between policy and practice can still be stark.

"Very recently the government of Sierra Leone has enacted a policy on disabilities. There are a few articles in this that provide for access to government facilities but at this point they have still not streamed down to community level."

Alpha Kamara, Leonard Cheshire Disability - Freetown, Sierra Leone

"You get plans drawn up by an architect – and then you take that plan to the Ministry of Lands. They are



Freetown
Street Scene

supposed to look at the plan, go to the land and show that it fits and that it will work in practice. Then they give you a building permit. And there are supposed to be building inspectors coming round so you meet the standards that you included in your plans. But these inspections – they don't ensure you meet certain rules, they don't even ensure you meet fire regulations. So unless the disabled go to law to ensure that buildings meet their standards, it's not going to happen."

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

Clearly, in every city reviewed in this study there has been positive forward momentum towards making the built environment more accessible to children and adults with disabilities. The rate of that momentum varies significantly from city to city, however, and a great deal remains to be done in every location.

Governments have largely responded to the requirements of the UNCRPD –

albeit to a greater or lesser extent - and have introduced domesticated legislation or regulatory frameworks requiring buildings old and new to meet accessibility standards. But the distance between policy and practice in some of the cities still presents huge barriers to realising the ambitions of people with disabilities to live in a society where they can move around and participate in the daily life of their cities free from physical and practical impediment.

Much depends on the willingness of governments and city authorities to bring about the necessary changes and the readiness of people with disabilities to mobilise, advocate and fight for their rights through the DPOs and NGOs which represent their interests.

3.5 ACCESS TO TRANSPORT

The parlous infrastructure of road networks and the inaccessibility of public transportation systems were almost universally derided by people with disabilities in all the study cities.

“The roads in Addis Ababa are totally inaccessible. The Chinese will build the road today and it looks fine. Then tomorrow, people from the telecommunication company come and they dig holes – so when you return back you find those road works and holes, so it’s very difficult.”

Visually impaired youth focus group member - Addis Ababa, Ethiopia

However, the huge construction projects underway in the city of Addis Ababa continue to create severe problems for people with disabilities who are trying to move around safely in the city. According to many, the problems are getting worse.



Visually impaired youth forced to walk in centre of the road
Addis Ababa, Ethiopia

“Movement generally is very difficult, and most the time, wherever we have to go we have to walk because we really don’t have time to find money for transport. So we have to carry our children on our backs, which is very tiring.”

Focus Group participant, parent of a child with a disability - Lusaka, Zambia

Article 9 of the UNCRPD requires states parties to provide equality of access to transportation systems for people with disabilities.

In most of the study cities, plans to improve transport networks and public transportation systems have been developed, but the magnitude of the challenge facing governments is vast, and only limited improvements have thus far been made.

Reports and observation show some attempts in Johannesburg to ensure that public transport becomes more accessible to people with disabilities. This is particularly true of the Metro Bus and



Inaccessible: a wheelchair bound-man using the road to avoid damaged pavement and pathway
Johannesburg, South Africa

Rea Vaya Bus Rapid Transport System networks. For example, for people with visual impairment, there are lights on both sides of ramps, luminous floor strips and textured handrails. There are access and landing ramps for the physically disabled as well as lowered service counters for wheelchair users. People with disabilities are reportedly offered assistance by staff at stations, and there



Minibus taxis at stations
Lusaka, Zambia

is special signage and an electronic variable messaging system for the deaf. Some buses have on board wheelchair positions and kerb-side lifts.

However, bus schedules are not published in Braille, and access to information for the deaf is a challenge, as members of staff are not trained in sign language. The areas around Rea Vaya stations are often made hazardous or inaccessible by the heavy presence of hawkers occupying space on the streets. Furthermore, access to Metro and Rea Vaya buses is confined to certain parts of the city, with Metro buses in particular reported as being far from the residential areas of the city where many people with disabilities live.

Trains are another form of affordable transport in Johannesburg, but the general consensus is that these are the worst form of transport for people with disabilities. Lack of safety, poor physical design, overcrowding and lack of assistance are the main reasons cited.

Transport systems in the other study countries are neither as varied nor

generally as accessible as those in Johannesburg. Most people rely on road-based bus and taxi transportation, as train networks are either under-developed or, as in the case of Freetown, non-existent.

“Our train system currently is not in its best state. In terms of transportation, the rail caters only for 10% and much of that 10% is freight. It’s not really about passengers.”

Kakuwa Musheke, Ministry of Communications and Transport - Lusaka, Zambia

The country’s Persons with Disabilities Act 6 of 2012 provides for accessible road. It also provides for dedicated parking slots for persons with disabilities. Furthermore, the Act provides for tax exemption for the importation of modified motor vehicles for persons with disabilities.

Very little appears to have been done in any of the cities, other than Johannesburg, to make bus and other transportation systems user friendly to people with disabilities.

"We have a problem with the taxis. For example, you are coming somewhere, you are in your wheelchair or you are standing with crutches. The taxi comes along and slows down, but when he sees you are in wheelchair, he accelerates. That stigma, as if you are not going to pay. You have your money, but they look on you as an inconvenience to them."

Disabled adult focus group participant - Kampala, Uganda

"The transport is inaccessible. Transport is terrible for those with physical disabilities but you will find that there are one or two transport owners who have written in their minibuses that they have some seats reserved for people with disabilities. But generally we could say the transport system is inaccessible."

Wamundila Waliuya, ZAFOD - Lusaka, Zambia

"Sometimes they have referred my child to the University Teaching Hospital, which is very far from here, and it is very difficult to lift my child on and off the bus. You have to lift your child on your own, the driver and conductor are not very helpful with that."

Focus Group participant, parent to a child with a disability - Lusaka, Zambia

A few of Lusaka's larger city buses now have adaptations for wheelchair users to board, but the majority remain inaccessible to the physically disabled. Lusaka's bus stations do not cater for people with disabilities either. Observation reveals that they are crowded and populous, with many obstacles for the wheelchair or crutch

user to negotiate; they are cacophonous, with noise pollution that will inhibit the easy movement of visually impaired people; and the lack of good signage, along with the minibus conductors' habit of calling out bus destinations, does little to assist the hearing impaired in deciding which bus to board.

"At the station there are no guides. We need sounds for us to know that this one is calling for the bus bound for this particular area where we want to go. Those things are yet to come on board – but I believe it's a developmental action not just beneficial to people with visual impairment – but even to others."

Keshi Chisambi, Zambia National Federation of the Blind – Lusaka, Zambia

In Kampala, in addition to taxis and buses, the road is plagued by the notorious *boda-bodas*, motorcycle taxis which weave precariously at high speed in and out of traffic and provide a major hazard for pedestrians with disabilities, particularly the visually impaired.

Taxi drivers are also often reluctant to pick up passengers with disabilities, as one respondent found on conducting an experiment.

"Our taxis – when they see a person with a wheelchair, they just pass that person because they don't want to be inconvenienced. I have even stage managed this. We put a man on the street and filmed it. Out of 10 taxis you would only find one who helped. And yet this person with a disability is supposed to be able to access any taxi, any bus, freely."

Aloysius Kiribaki, Sense International Uganda – Kampala, Uganda

In all the study cities, most contempt was reserved for the ubiquitous minibus taxis, which are probably the cheapest form of local transportation, but which are notoriously difficult for people with disabilities to access, irrespective of the city they live in.

“The situation in terms of minibuses – it’s terrible. It’s pathetic. In fact, I don’t know how the wheelchair users cope, because the people who are managing the buses sometimes they are so rude – and I have heard that people are told that they cannot even come on the bus. So really that is bad and we have to get back and look at that.”

Visually impaired youth focus group member - Addis Ababa, Ethiopia

Kakuwa Musheke, Ministry of Communications and Transport - Lusaka, Zambia

“Many times conductors do not want to let people with visual impairment on their minibus taxis – they say no to them. They may even try to hit us with their vehicles. They do not want to help us. It’s important to raise awareness with these kinds of people.”

“The minibuses won’t take people with disabilities – because some of them, their wheelchairs cannot be folded. Some of them who are using crutches – the drivers won’t even wait. They think – ‘oh, he’s going to waste my time’ - they just zoom off. So getting to respect appointments and deadlines is almost impossible for people with disabilities. Because if able bodied persons are struggling to get transportation, what about people with disabilities? Everybody’s thinking

about his or herself, rushing – they shove past them, push. Sometimes there are real problems at the bus stops and we go there to stop disabled people being maltreated.”

Edward Emmanuel, One Family People - Freetown, Sierra Leone

The Addis Ababa city buses are notorious for being overloaded, especially in the morning and late afternoon rush hours. In such situations, while children with physical impairments have difficulties with mounting and descending, those with visual impairments often miss their destinations. It is worth noting, however, that there are encouraging attempts at accommodating the needs of disabled people with new public transport designs,



Broken surface and narrow pavements create hazards for people with disabilities
Lusaka, Zambia

as in the case of a public bus recently launched by a private manufacturing company, which is reportedly fitted with accessibility features.

Some visually impaired focus group participants in Addis Ababa favoured the minibuses because the conductors call out the destinations, whereas city buses use signage they cannot read. By contrast, and for obvious reasons, hearing impaired respondents favour the city buses.

“The minibuses are better in terms of accessibility than the city buses for the visually impaired, because the big city buses only have numbers, and we cannot see them, so we have to ask for help. Some people will help, others won’t. If they don’t help, you get bored and you stop asking people, so you fail.”

Visually impaired youth focus group member - Addis Ababa, Ethiopia

“There is a problem with minibuses for the hearing impaired. The directions of where they are going should be posted on a minibus. On the big public buses there is no problem because we can see numbers, and they have fixed routes.”

Hearing impaired youth focus group member - Addis Ababa, Ethiopia

Inappropriate practice by minibus conductors, such as charging once for a physically disabled passenger and once for his/her wheelchair, also places an unreasonable financial burden on some respondents.

It’s not easy at all when it comes to accessibility to transport. You have a child, for instance, who is in a wheelchair and you don’t have a

personal vehicle. You have to use public transport. It means you have to carry that child – and that wheelchair - onto that bus – and it has to pay. It becomes an extra cost. And the public transporters, they don’t easily accept a person in a wheelchair – they maybe push them to wait for the next bus, which makes life unbearable for people with disabilities.”

Astrida Kunda, Zambia Association of Parents of Children with Disabilities – Lusaka, Zambia

The state of roads, pavements and street furniture in all of the study cities results in often-hazardous environments for people with disabilities trying to negotiate their way on foot or in a wheelchair.

Lack of street furniture appropriately modified to meet the needs of people with disabilities is an issue in all of the study cities, and a particular issue for those with visual impairment.

“People with visual impairments cannot see the zebra crossings, so they have to rely on others to help cross the roads. Since we get bored always asking for help, sometimes we get angry and don’t like others to assist us, and we will try to cross by ourselves and will face accidents because of that.”

Visually impaired youth focus group member - Addis Ababa, Ethiopia

There is a notable improvement of city roads for people with visual impairments where, at some major traffic junctions, a new traffic light system (although not always functioning) has been installed to provide visually impaired pedestrians with a vocal communication interface. It should also be mentioned in this context that the new city train system is

reportedly designed to be fully accessible for people with disabilities.

“We need to improve in terms of signage and also places where pedestrians can cross and places where vehicles are not allowed. But I think we need also to maybe do something about our traffic rules, because, if you are in Lusaka at a zebra crossing for instance, the drivers will not stop. They will not stop. So, it’s up to you if you want to be bashed. So something has to be done. In other cities like Copperbelt for example, there is a lot of respect for pedestrian crossings. We need to enforce it here.”

Maxwell Zulu – Department of Physical Planning and Housing, Ministry of Local Government –Lusaka, Zambia

Pavements in Kampala, Freetown and Addis Ababa are often badly pitted, or simply not there at all. As a result, wheelchair users were frequently observed using the roads and competing with vehicular traffic, at great risk to their physical safety.

In Johannesburg and other cities, street hawkers who set up shop on the pavements and roadsides form an obvious hazard, particularly for the visually impaired.

“They block the streets and sometimes when you are walking you feel someone just pushing you because you are about to step onto their goods.”

Visually impaired respondent – Johannesburg, South Africa

Poor road maintenance is another barrier to accessible roads in Johannesburg.

Pavements are reportedly poorly maintained. There are broken pavements and uneven surfaces making it difficult for people in wheelchairs and those who are visually impaired to use the road. Similar barriers are present in all the other study cities. Surface water from poorly maintained sewage systems is an additional hazard.

“The roads are not accessible to people with disabilities. The holes stay for a long time. There is lots of sewage so you often find water on the roads. Except for newly constructed roads, most are not accessible.”

Youth focus group member - Addis Ababa, Ethiopia

“Roads are totally inaccessible to persons with visual impairment. On the pavement there are holes....there are poles for power lines, sun shades and trees, which are hazardous. The pavement is not comfortable for people with visual impairment. People park their cars as they like. You find sanitary and construction materials just lying on the road and the roads are often congested. The way people walk is even difficult – they kick our canes and sometimes they break.”

Gebre Teshome, Ethiopian National Association of the Blind - Addis Ababa, Ethiopia

“Roads don’t have ramps, and they are congested and dangerous. Some of our members have residual sight but they cannot move alone in town. It’s very hard for them to move in Kampala. Even drainage points and channels are left on the paths that pedestrians use and they are open. In Kampala they have put some green areas, with flowers, and these are

protected by barbed wire to prevent pedestrians going onto them, which creates a risk for the deaf blind and others.”

Anthony Lussagi, National Association of the Deaf Blind of Uganda – Kampala, Uganda

Another major issue in all the study cities, both observed and reported, is road works. The sub structure of major road networks in the cities often contains utilities channels, such as telecommunications and electrical cabling and water and gas pipelines. Lack of coordination between the utilities companies can often result in roads being excavated and covered over by one provider, and then re-excavated by a different provider within days or weeks. This results in constant hazards for wheelchair users and visually impaired people, and contributes to the long term degradation of road and pavement surfaces.

“I think in our city there is some kind of disorganisation. The streets are also for infrastructure passage – the water system is under the street, the power system is also under the street and the sewage system is under the street. These people are not working together. That is why when the street authority [have] paved over the streets and have finished everything, the water authority will come and dig out – and then another will come at another time.”

Teshome Kebede, Architect and Consulting Engineer - Addis Ababa, Ethiopia

This issue is acknowledged by the City Road Authority in Addis Ababa, which is attempting to improve coordination.

“Integrated planning would go a long way to address this but we have lacked this type of planning. Some of the utility organisations are under the municipality planning and others are under federal government. So, our planning systems are entirely different. There is now an office to facilitate this integration – the office is trying its best to integrate the work of all utilities. Whatever is dug within the city should be covered within 48 hours. I put a target and I think to some extent we are doing fine now.”

Engineer Fikade Haile, Addis Ababa City Roads Authority – Addis Ababa, Ethiopia

In Johannesburg, new road construction projects, despite being welcome, are creating issues for some people with disabilities. Respondents report that they are not informed in advance when these developments are taking place.

“The same street you walked in yesterday is different the next day. They just build without informing us. What makes it worse is that some of it is not marked properly and there is no early warning. One day I was walking down the street, the next thing I heard a truck passing by; the next thing, someone was pulling me back and sand was blown into my face. I learnt the truck was offloading sand onto a new construction site. This is the same street I walked on three days ago. No one warns you.”

Visually impaired respondent – Johannesburg, South Africa

In Sierra Leone, even though there are provisions in the Persons with Disability Act makes provisions that allows persons with disabilities to easy access

to transportation very few, if any, measures or mechanisms have so far been put in place to implement it.

Whilst streets in the centres of the study cities often do have clearly demarked vehicle and pedestrian walkways - even if they are frequently poorly maintained - streets in suburban and residential areas often present far greater hazards for people with disabilities.

Roads serving communities in poorer districts, where many people with disabilities live, are frequently unpaved gravel or mud tracks littered with stones, pitted with holes and flanked by trenches for surface water runoff.

Some cities have improved, or are planning to improve, these road networks as part of their transport development plans.

“Basically, the government has a plan to change the face of the city. We are going to change these gravel roads into asphalt or cobbles. In the coming three years we are planning to have more than 200 km of cobblestones focussing mainly in the lower income areas.

“There is even an agreement between the community and the government side. The community, as its contribution, will prepare a road up to sub base level – then we’ll take that road and make it cobblestoned. That is the plan which is being implemented, starting last year and continuing now. So the community will be participating. With that we can solve the accessibility problem in the city.”

Engineer Fikade Haile, Addis Ababa City Roads Authority – Addis Ababa, Ethiopia

Governments and city authorities in each of the study countries are developing and implementing plans to improve transportation networks.

There are reported improvements in the road infrastructure in Johannesburg, especially in regard to the roads in some of the townships, which used to be dusty and un-tarred, making them difficult for people with physical and visual impairments to navigate. In some of the townships, both high and residential streets are now tarred, and there is a clear delineation between the roads and the pavements.

Addis Ababa has embarked upon an ambitious transportation development programme, which will take account of the needs of people with disabilities for the first time.

“We are making our city an international city – not only in constructing wider roads and pedestrian walkways, but also giving attention to [the needs of] the disabled. We have started to take some measures to provide access for disabled people here in Addis recently. In doing so, we have included in our standards constructions to facilitate pedestrian crossings, footpaths and the like for the disabled.”

Engineer Fikade Haile, General Manager Addis Ababa City Roads Authority – Addis Ababa, Ethiopia

Many challenges remain in all the study cities if children and adults with disabilities are to be given the liberty to roam their environments freely and without hindrance. Some advances are being made, but given the potential financial implications, it could be years before fully accessible road networks and transport systems are in place in the five cities.

3.6 ACCESS TO ASSISTIVE DEVICES

Achieving the means to move around the city independently is a prerequisite to inclusion and participation for people with disabilities. Access to wheelchairs, crutches, prosthetic limbs, white canes, hearing aids and other assistive devices in the study cities can have an empowering effect on people with disabilities, and can enable them to access environments and services that might otherwise be denied them.

In Addis Ababa, the Ethiopian Centre for Disability and Development reports that over the past years there have been more efforts to provide assistive devices, such as wheel chairs and white canes both by NGOs and the government.

“One of the most important factors to be taken into account is the issue of mobility, because without mobility, even if services were to be available, it would be difficult to access them. So mobility in terms of a priority is very important.”

Francis Chilufya, Zambia Agency for People with Disabilities – Lusaka, Zambia

Article 26 of UNCRPD requires states parties to ‘promote the availability, knowledge and use of assistive devices and technologies designed for people with disabilities, as they relate to habilitation and rehabilitation’. There is no express requirement for governments to fund such devices, and, according to the personal testimonies of people with disabilities, there is little evidence of state provision of assistive devices in the study cities. Despite this, some ministerial representatives claimed that governments do provide assistive devices.

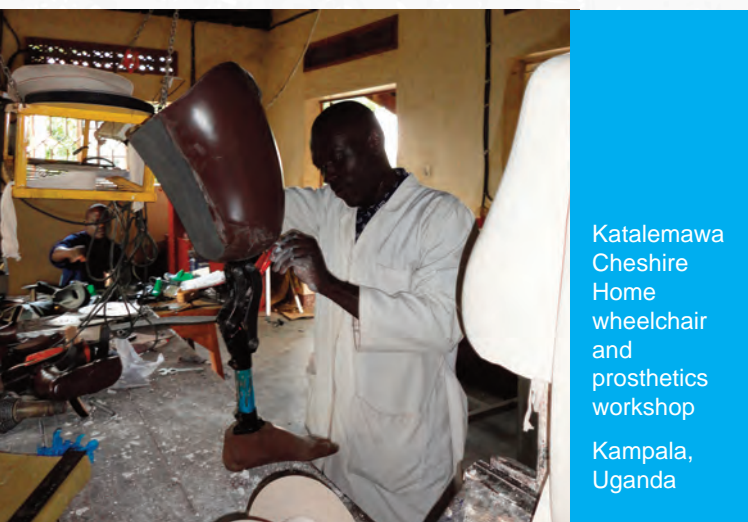
“The Ministry of Health Disability Prevention has five programmes. One on visual impairment; we try to prevent blindness and we have services, such as providing white canes and other rehabilitation services. Secondly, on hearing impairment – we have a community service to assess hearing and provide treatment if possible or refer for hearing aids when available. Thirdly, for older people with disabilities, because most people get some impairment as they get older and they may need spectacles, a hearing aid or a walking stick. Fourthly, we do injury prevention and control – looking at where people get disabilities out of injuries. The fifth is on physical impairment – looking at the physically disabled, and their needs for assistive devices like wheelchairs, artificial limbs and so on.”

Rose Bongole, Ministry of Health Disability Prevention – Kampala, Uganda

“The Department of Social Welfare is very instrumental in providing assistive devices to people with disabilities. There was just a donation being made last week of 73 wheelchairs to people with disabilities that would not access them on their own. So that is already a plan the government has to increase accessibility because I think that when somebody is able to go from point A to point B already you are developing them socially, economically, politically – because they are able to either go to school or go to work or go to the market. The plan is that there should be inclusion of people with disabilities in all sectors of the society.”

Bridget Katati Munungwe, Ministry of Community Development and Social Services – Lusaka, Zambia

In Uganda, the Katelemwa Cheshire Home for Rehabilitation Services provides wheelchairs and other assistive devices to its clients at a subsidised price. It has workshop facilities on site, building tailor made wheelchairs and prosthetic limbs for those who have attended the centre for corrective surgery and rehabilitation.



In Freetown, Sierra Leone most wheelchairs were in states of disrepair. Most have been assembled together by the users themselves using materials from different sources. Several respondents used hand built, hand operated go-karts and buggies to move around. No respondents were aware of any state service provision of assistive devices. Recently in Sierra Leone some international organisations such as Savers International, Hellen Keller International and Handicap International have been working together with Disabled Persons Organizations (DPOs) to freely distribute wheelchairs, crutches, prosthetic limbs and white canes. The recipients of these devices however are largely disabled persons in cities only.

Whilst some ministries purport to provide free assistive devices and others do secure and distribute supplies from donors, as is the case in Zambia, there is clearly a shortfall between demand and supply, and low awareness among respondents with disabilities about the existence of such state assistance.

This places a burden on many people with disabilities, who often can ill afford the cost of securing effective mobility equipment.

“For us [people affected by polio], we put on things called callipers – and these things are not subsidised by the government. So, for us, just to stand up – it’s a cost. One calliper costs around 350,000 Kwachas – so for a person who needs two callipers, like me, I need about 700,000. And that’s just for callipers. I will also need crutches. So, for me, just to stand up, I need about one million Kwachas (approx. US\$197.00). That’s a barrier where the government can’t help. And growing children need to change callipers, roughly every two years. And if you think of someone in a wheelchair it’s worse.”

Darius Banda, Appropriate Paper Technologies (APTERS) – Lusaka, Zambia

Given the importance of assistive devices in providing opportunities for independent mobility to people with disabilities, more concerted efforts should be made by governments in the study countries to provide free or subsidised equipment.

3.7 ACCESS TO HEALTH SERVICES

Article 25 of the UNCRPD concerns the rights of people with disabilities to access appropriate health services. It exhorts states parties to take all necessary measures to ensure that such services are delivered free, or affordably, to people with disabilities, without discrimination and to the same level of quality and variety as those provided to other people.

The reality in the study cities for children and adults with disabilities seeking health services is very different to the obligations outlined in the UNCRPD. Many key facilities and services remain physically or practically inaccessible to certain categories of disabled people; some service providers continue to display prejudicial attitudes; and many caregivers of children with disabilities find it difficult to secure the finances to pay for services which should be delivered free of charge.

In Addis Ababa, for example, numerous hospitals and health centres – including the largest public hospital in the city, the Zewditu Hospital – remain inaccessible to the physically impaired. Since 2012 however, due to the growing awareness about the special needs of people with disabilities there are some improvements in areas such as the provision of information in sign language in some facilities.

“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.”

Reta Getachew, Ethiopian Center for Disability and Development - Addis Ababa, Ethiopia



Inaccessible entrance to one of the largest public hospitals
Addis Ababa, Ethiopia

Respondents in Uganda reported similar concerns.

“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?”

“If you have managed to enter like some of us, you can persist on the crutches. Maybe they want to examine you – but the beds are not adjustable at all. It’s not adjustable to the level you can manage. Whenever you talk of that, they don’t even look at it. I don’t know if the policies are there – when will they be implemented?”

Disabled adult focus group participant - Kampala, Uganda

In Uganda, according to Action on Disability & Development International, efforts are being intensified efforts to provide sign language training to health workers in one of the country’s national referral hospitals and also in some of the regional referral hospitals.

For people with sensory, hearing or visual impairments, health facilities in all the study cities can be equally baffling and inaccessible. Several respondents reported a lack of health care professionals trained in signing, for example.

“One of the biggest challenges is sign language for the hearing impaired. You cannot find a lot of people who can communicate in sign language in any health centres especially in the public – as well as private – centres,

you cannot find a lot. Now the government is trying to train people in sign language.”

Reta Getachew, Ethiopian Center for Disability and Development - Addis Ababa, Ethiopia

“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

“Many of the deaf fear to go to these places because services are not friendly. We have very many cases where people have been turned away because of a failure to communicate to them – someone ends up guessing their need.”

Paul Senteza, Sign Health - Kampala, Uganda

Respondents in some cities reported encountering prejudicial or negative attitudes from health care service providers.

“We are not helped in the way we would want to be helped, and the way we are supposed to be helped. 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

“I would like to see a change in the healthcare system – in the attitude of the people, because it’s very tiring for us to stand in queues the whole day, because these queues are usually very long as this [health centre] is the only place where many people get medical attention, and so it would be good to have a situation where we are attended to first, because we have these children.”

Focus Group participant, mother to a child with disability - Lusaka, Zambia

The issue of preserving client confidentiality was of particular concern to some respondents, especially in the field of sexual and reproductive health service delivery.

“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.”

Disabled adult focus group participant - Kampala, Uganda

“For people with visual impairments – they are coming here [to an HIV/AIDS voluntary counselling and testing centre] but only few in numbers. The problem is they want it to be in secret and confidential but if a person can’t see it is difficult. We tried to go there [into their communities and DPO centres where they meet] and give the service over there but still they said there’s a stigma.”

Almaz Nedi, HIV Counselling and Testing Centre - Addis Ababa, Ethiopia

There are, however, some positive developments identified in the study cities. These are being made possible both through both public and privately funded interventions.

A specialist HIV/AIDS testing centre based in Addis Ababa’s Zewditu Hospital, for example, is fully accessible and recently managed to secure funding for a small team of counsellors trained in signing.



Accessible entrance into a public hospital
Addis Ababa, Ethiopia

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. The irony here, however, is that as this is a private, fee-paying hospital, many of the potential beneficiaries of its accessible features will be unable to afford to attend, given that people with disabilities and families with children with disabilities are among the city's poorest residents.

Numerous respondents reported that government ministries are developing and implementing policies to improve health services for children and adults with disabilities.

“As of now, the ministry has a policy that wherever they are going to do a repair to a hospital, accessibility is a number one priority – because some of those premises never had accessibility. Getting it done across all health facilities depends on many factors, including funding, but our objective is to achieve this in time.”

Rose Bongole, Ministry of Health Disability Prevention - Kampala, Uganda

“If you are poor you can ask your local administrative body to write you a letter to be treated free of charge. Most of the health centres provide health services free of charge. When you are disabled it is likely that you will qualify for free health services.”

Reta Getachew, Ethiopian Center for Disability and Development - Addis Ababa, Ethiopia

“You may have heard of the free healthcare for groups – which are now pregnant women, lactating mothers and children under five. But we within the ministry of health also consider people with disabilities as very, very vulnerable so we are thinking of actually including them which is why we brought up in the policy documents which practices we could include in the health sector to enable us to provide health services to that group.

“You need to have the right kind of human resources that are trained enough, qualified and skilled enough to deal with this particular group of people. Because, when you look at physical disability you need some specialities in those areas – orthopaedics, occupational therapists,



Accessible interior ramp in private hospital provides full access for wheelchair users

Addis Ababa, Ethiopia

physical therapists – you need all of these people and we don't have enough of those in the country. We don't have people who know sign language. We need to train them. Once we have all of these in place, then you can start talking about timeline for implementation."

Sidie Yahya Tunis, Ministry of Health - Freetown, Sierra Leone

As in other areas of accessibility, NGOs and DPOs are playing an increasing role in galvanising improvements in health service provision. Agencies in all the study cities are increasingly providing models for service delivery, which they hope will be replicated by government health authorities, or stepping in to fill gaps in service provision.

"We construct health units in existing health centres – we work with the government on government plots of land at existing health facilities, and using existing health facility physiotherapists at government hospitals. And we also take professionals out into the community to corrective surgery camps – they go down to a regional hospital, say, for one week, where they do plastic surgery, orthopaedic surgery, and so on. So, for us, that is also capacity building of government staff and service provision, and we are constantly reminding them that this is their area so they can carry it on and also begin planning for it."

Dolorence Were, Uganda Society for Disabled Children – Kampala, Uganda

"Most recently we have been working on introducing sign language interpretation in the structure of the

Ministry of Health. We also go on radio and TV talk shows to highlight the various laws and provisions as far as support for children with disabilities."

Samuel Mari, National Council for Disability – Kampala, Uganda

"We have trained a few health workers, but the problem is when you train health providers, you find that they are transferred, so that is the challenge we face."

James Kapembwa, Zambia National Association of the Deaf – Lusaka, Zambia

Respondents in some cities expressed concern that government policies, such as directives making healthcare services free of charge for children and adults with disabilities, were not necessarily filtering down to the service delivery points at community level.

"The new changes in the co-ordination of health services in Sierra Leone also provide access to [free] healthcare for [people with disabilities]. But the point is, do those who deliver these services take this into account? That is the biggest question. Do they care about the needs? Do they give them special attention? Because, I do not think they take them on board. You see people with disabilities around the corridors of these institutions and they are not given the due consideration, they are not given the due service..."

Alpha Kamara, Leonard Cheshire Disability - Freetown, Sierra Leone

According to medical officials, the government failed to make any attempts to implement the provisions for free medical services made in the country's

Persons with Disabilities Act and people with disabilities are forced to pay for medical services in public health institutions.

“Healthwise, these children should be exempted from paying any fees no matter which age [they are]. And they should also not be seen by just ordinary doctors. Each and every health centre should find physiotherapist doctors to attend to them specifically, instead of just a mere doctor.”

Focus Group participant, mother to a child with disability - Lusaka, Zambia

Across the study cities and countries, disability friendly health programmes are being devised by government ministries and efforts are being taken to make existing and new facilities accessible to children and adults with disabilities. The rate of progress varies from society to society, however, and there are understandable frustrations expressed by people with disabilities and their caregivers at the slow pace of change.

“DISABLED PEOPLE... THEY DON'T HAVE SEX. DO THEY?”

Addis Ababa, Ethiopia

Young adults between the ages of 15-24 are generally regarded as being at higher risk of contracting HIV/AIDS than any other demographic group in Africa, with females particularly at risk. Reaching, sensitising and providing services to this group presents agencies working in the field of sexual and reproductive health (SRH) with a series of well recorded challenges. By far the greatest and most overlooked challenge, however, rests with agencies representing the interests of young people with disabilities, which are striving to convince health workers to adapt their services to meet the needs of this particularly vulnerable group. Simply put, many in the able bodied community – including those involved in the field of SRH service delivery –cannot accept the notion that people with disabilities are, or would want to be, sexually active.

In Addis Ababa, the Ethiopian Centre for Disability and Development (ECDD) is engaged in a project, funded by the Packard Foundation, to change these attitudes and make clinics and the services they provide accessible to people with disabilities. The project commenced with baseline research, which revealed some disturbing attitudes.



“We found out that accessibility is the main barrier, and then attitude,” says Liya Solomon, who manages the ECDD project.

“Even if the centres were accessible, the attitude of the service providers was totally unacceptable because they don’t agree that people with disabilities have sexual interests. It came as a shock to us.”

“Whenever a person with a disability goes to use the service, the service providers became surprised: ‘Why do you need this service? Are you sexually interested?’ So they believe that HIV is not an issue for the disabled.”

“But you only have to go onto the streets where people with disabilities are begging – and you can see women with two, three or four children – and you can see how vulnerable they are because they don’t find family planning counselling. They don’t use the services – and that’s why we started the project.” Continued... Interior ramp in private hospital provides full access for wheelchair users – Addis Ababa, Ethiopia

ECDD’s Addis Ababa survey of 24 public health centres and 40 NGO clinics who provide family planning and SRH services found out that almost zero per cent of people with disabilities were availing themselves for services. A subsequent review of barriers showed that, in addition to attitude and physical inaccessibility, the services presented additional particular problems for the visually and hearing impaired. For the visually impaired there are no resources produced in Braille, and contraceptive supplies and anti-retroviral drug bottles do not have Braille labelling, which can result in errors which could lead to unplanned pregnancy or failure to comply with sensitive drug treatment regimes. For the deaf, the lack of health service providers trained in signing leads to confusion or to compromised confidentiality if a non-medical sign language interpreter has to become involved in the consultation.

The ECDD’s sensitisation programmes are proving successful in changing minds and improving the accessibility of services and the physical environment in many health centres.

“Mostly what we do is first, we tell them what disability is,” explains Liya.

“They don’t understand what disability is. And then we tell them what the needs are for each disability type. And after they come to believe that people with disabilities should be part of their services, we will tell them how to include them for each disability type.”

“They are usually totally receptive. It’s not that they don’t want to include people with disabilities. It’s just that they don’t know how to include them.”

3.8 ACCESS TO EDUCATION

“The schools themselves are physically inaccessible and the teachers are not familiar with children with disabilities and the teaching materials are also not accessible. A lot of problems are there...”

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

There can be no doubting the role education can play in lifting children out of poverty and empowering them with opportunities to participate fully in the social and economic life of their countries. Unfortunately, the vast majority of children with disabilities in the study countries are denied opportunities to participate in education. The barriers are enormous and various, ranging from the physical inaccessibility of school buildings, absence of appropriate materials and lack of trained educators, through to the attitudes of parents, who frequently fail to see the value of investing time and money in the education of their children with disabilities.

Article 24 of the UNCPRD exhorts state parties to recognise the rights of people with disabilities to education, and to provide the means and opportunities for them to participate on an equal footing with their able-bodied counterparts. coupled with a raft of international and domestic instruments and policies on the subject, there is a clear presumption in favour of inclusive education for all in all the study countries; and yet the reality is that in most of these countries the vast majority of children with disabilities – as many as nine out of 10 in some states – are excluded from participation in any form of education.

The current situation on the ground in the study cities is typical of the region, with a lack of physically accessible facilities, trained staff and parental reluctance all combining to deny education to children with disabilities. Children with disabilities in the cities do, however, tend to fare better than those in rural communities.

“Children with disabilities accessing education – the numbers are low. Because of inaccessibility, in the rural areas especially, people have to walk for 10, 15, 20 minutes – even half an hour to the school, so for the disabled child you can imagine how difficult it is. So, most of them are out of school.”

Reta Getachew, Ethiopian Centre for Disability and Development - Addis Ababa, Ethiopia

Respondents agreed that some categories of disability are particularly poorly served.

“At the grassroots, teachers teach only for those who hear. Those who cannot hear cannot take part and hearing impaired children can’t go to school. If we miss a class it’s difficult to catch up. If a signing teacher is not available, we miss classes.”

Hearing impaired youth focus group member – Addis Ababa, Ethiopia

Since 2006/7, the Ethiopian Ministry of Education has collected data on school-aged children with disabilities. In 2008/9, only 2.8% of school-aged children had access to primary education, although this figure increased to 3.2% in 2011/12. However, generally, more urban children with disabilities than rural children with disabilities and more boys with disabilities than girls with disabilities were getting access.

“Many children with mental health issues are being thrown out of school. Diagnosing and identifying these children [is hard] – they may not even have a teacher that can identify symptoms until [the child] goes overboard. Many are punished so often that they drop out of school.”

Julius Kayira, Mental Health Uganda – Kampala, Uganda

“In the area of education, among the disabled population of Uganda, it is the deaf blind who have least been catered for by the government. For example, we have one government funded university which trains teachers for the disabled. They train teachers for the deaf, teachers for the blind, teachers who can teach people with a mental illness – but they don’t train teachers for the deaf blind and they also don’t train interpreter guides for the deaf blind.”

Anthony Lussagi, National Association of the Deaf Blind of Uganda – Kampala, Uganda

The lack of local schools that are physically adapted able to accommodate children with disabilities is another barrier to access.

“You go to school and you find that the ramps are not there in some schools. Some schools, you find that the utilities – the washrooms – have small doors and are not meant for children in wheelchairs.”

Samuel Mari, National Council for Disability – Kampala, Uganda

“I know some schools which are not ready to receive children with disabilities. They say ‘we don’t have budget, we don’t have this, we don’t have that’. They are rejecting children with disabilities. Maybe the government needs to issue some policy. Maybe the government needs to allocate some budget. This should be the government’s assignment – and it should begin very shortly, considering the time we have to achieve the MDG of education for all.”

Betelehem Abebe, Ethiopian National Disability Network – Addis Ababa, Ethiopia

A DAY IN THE LIFE OF YOHANNES

Addis Ababa, Ethiopia

Yohannes is 17 years old, and attends an integrated school with disabled and non-disabled students. Yohannes became visually impaired and suffered major neurological damage following a blow to the head given by a schoolteacher, when he was 10 years old, causing him to miss four years of schooling.

I wake up early in the morning. First I wash myself, then I visit my neighbour. He's visually impaired too – and lives alone – so I help to clean his house and get his breakfast before he goes to a museum, where he works as a guide. When I finish helping him I go back home and eat my own breakfast. I take medicines every day which have to be taken with food, so someone at home prepares breakfast for me. Then I go to school. I walk on foot to school. It takes 15 minutes. Since I am only partially sighted, not completely blind, I can walk fast, and I don't really have any problems with getting there, but occasionally when I'm thinking about school, I may collide with people on my way. There is always the national anthem which we have to sing first thing at school. Then we go to the classroom and lessons start. There are always friends who can help me, since they read for me out of books.



Yohannes, Addis Ababa, Ethiopia

The teacher often writes on the blackboard, but I have to rely on listening to what is said and trying to write it down in Braille. The problem is that I cannot keep up with the lesson because when I write in Braille I write slower – it's not equal writing in ink and using Braille. So, I have to rely on others. Although I am partially sighted, it's easier for me to use Braille than a book. I want to be able to read a book with my own eyes, but most are written in small font, and I think it may weaken my eyesight. If it's easy for me to follow the teachers, I will rely on listening, but sometimes I ask a willing friend for help – he reads what's on the board and I write it down in Braille. Since I am a clever student, when others ask me I will help them and they will help me in return. They help me to read and I help them to understand the issue. So we get on together like this. During lunch, sometimes I may play football – but often since I think I may get tired if I play a lot, I would rather sit with other blind students. I share what I picked up from the class with those who are totally blind as, since I am only partially sighted, I feel I am in a better position to them. I don't take a lunchbox to the school but my friends are always willing to share their food with me. So I always have something to eat. After break, the same routine follows in the classroom. When maths, physics and chemistry are being taught, I leave the class. I love English, biology and social sciences. After lunch I go into a special class with other blind students to learn Braille. Then we go back the ordinary classes for the rest of the afternoon. When classes end I return back to my home. When I get home, I'll have a relaxing break. I may go out. There are some shops in my neighbourhood where I meet my friends and have some fun. We walk together and enjoy conversations. After 7.30pm I go back to my home to study. When I study I look at those things I wrote in Braille at school. Since we don't have enough reading materials in Braille, but there are enough in print, I will borrow books hoping someone will help me read at home. After school, my sister helps me read printed materials so that I can write them in Braille and read them for myself.

These barriers have generally been recognised by governments in the study countries, and some countries are moving to improve physical access as a priority.

As regards Lusaka, the Persons with Disabilities Act provides for free and inclusive education, and also requires that all new schools built after 2011 to provide ramps.

“In terms of infrastructure what is it that we have done as a ministry? For a long time we have seen that access has been hampered because of infrastructure that is not friendly and so through the infrastructure unit this time designs are made in such a way that they cater for learners with disabilities. We can talk here of children with physical disabilities, children with visual impairment and children with hearing impairment and say that at this time infrastructure designs have those components in it.”

**Zulu Sammer Size, Special Education Unit,
Ministry of Education – Lusaka, Zambia**

In Sierra Leone the Persons with Disabilities Act includes provision for free public education for persons with disabilities up to tertiary or university level. The Act also protects against discrimination and makes it mandatory for public educational institutions to introduce sign language courses. However, the sign language courses have still not been introduced. Presently, the government is implementing scholarship programmes for persons with disabilities in public tertiary institutions, covering the full tuition fees.

Making appropriate educational resources, such as Braille books, available to

disabled learners is another major barrier, as is the lack of properly trained staff.

“In mainstream schools where teachers are not trained in sign language, [deaf children] may do one or two terms and then they drop out. You’ll find a lot of them trading in Freetown – because they cannot afford the specialist education. It may take a long time for us to properly address the issues of the deaf.”

**Stephen Allie-Korosa, Ministry of Education,
Science and Technology – Freetown, Sierra Leone**

“The biggest challenge is to get teaching aides – so it’s very difficult for children with visual impairments to get materials in Braille, [for] mathematics, English and other subjects.”

Visually impaired youth focus group member – Addis Ababa, Ethiopia

“Our government do not provide learning materials for children that are disabled, particularly those that are visually impaired. It is very difficult for them to go through the normal school system. There are visually impaired people that have to drop out of academic programmes because there are no materials to facilitate it. I have friends who wanted to become lawyers, or people in responsible areas of life, but they cannot because materials are not provided. So this hampers the education of these people and their rights are violated.”

Patrick James Taylor, Human Rights Commission - Freetown, Sierra Leone

“As regards to educational materials – first of all we should admit that materials for learners with disabilities are very expensive. Very, very expensive. And they are not locally available. For example, Braille equipment is not readily available in Zambia – so we have to go to other countries for importation of such materials. And that has become a very big challenge to us looking at the budgetary allocation we have at the ministry.”

**Zulu Sammer Size, Special Education Unit,
Ministry of Education – Lusaka, Zambia**

Some respondents challenged the practice of requiring students with disabilities to sit the same examinations as able-bodied students, which can result in poorer performance.

“We would like to see that every school has a teacher for sign language. We also need to have an exam which is deaf friendly because we have our friends who are born deaf – they have never heard a word spoken. For a deaf person like that to write exact English like a hearing person, it’s very hard. People need to understand that the way a deaf person constructs words is very different to the way a hearing person constructs words. We need a special exam with special marking.”

**James Kapembwa, Zambia National
Association of the Deaf – Lusaka, Zambia**

Free primary education is standard in the study cities. Nevertheless, when local schools are inaccessible, parents of children with disabilities can face both physical and financial challenges trying to use a more accessible school at a distance from their community.

In South Africa and Johannesburg, the National Institute for the Deaf provides training courses tailored for persons with hearing impairments on occupational training, work experiential training, job placement, support in the workplace and mediation in the workplace.

“You may find that most of our people do not have enough resources to enable a child to move from point A to point B especially if the distances are long as the case is for the severely disabled. Other issues are like those of carrying the child on the back because the child cannot walk to school even if it is 5km away. And so you find they don’t have aides like wheelchairs to help them get into school, to help them getting to school. And so that also becomes a problem.”

**Zulu Sammer Size, Special Education Unit,
Ministry of Education - Lusaka, Zambia**

EDUCATION FOR ALL: INCLUSIVE EDUCATION

Freetown, Sierra Leone

While the majority of schools in Freetown remain effectively closed off to children with disabilities, there are some which have taken on the challenge of creating an accessible environment for all students in their catchment areas.

One such school is the REC Primary School, which is situated on the eastern fringes of the city, where large numbers of people with disabilities reside. The combination of an enlightened, progressive head teacher who has made it his business to get sensitised on the issue of disability, and a visible local population of children with disabilities needing education has resulted in a school where disabled and non-disabled children are learning side by side. *"Our vision statement is to create a child friendly environment for all categories of children, regardless of their disability or physical make up,"* says Head Teacher Sylvanus Adecampbell. *"I very much believe in inclusivity, because first of all it will reduce the illiteracy rate in this country. Previously when these disabled children were not considered for education it was very, very hard – but now by including them at least you will empower them in one way or another to become useful citizens in society. And so we deem it very wise to get all forms of disabilities included in our school system, for not only the improvement of the individual but for the benefit of the country in general."*

Sylvanus benefitted from a series of sensitisation workshops on inclusive education hosted by UNICEF, which inspired him to implement basic adaptations to his school buildings, such as the introduction of wheelchair friendly ramps. He feels that the government of Sierra Leone should be doing more to ensure that children with disabilities can access education. *"Most of the time when you talk to officials, they say government has financial problems and so they cannot undertake such ventures, so I would say it's good that UNICEF has stepped in to help the situation, but government actually should do something more to help the country, because if a child is educated it brings development to the nation."* REC Primary is close to a number of communities founded and run by people with disabilities, such as the Polio Women and Girls' Collective. Two of the Collective's members, Kadijah and Elsie - both aged 15 and wheelchair users - attend classes at the school.

Their lives and prospects were transformed when they came to live at the Collective, thanks to the support of its Chairperson, Mariama Jallah. *"When I was living with my parents, life was very, very difficult for me because they couldn't afford to pay my school fees,"* says Elsie. *"But now I am with Auntie Mariama, she is paying my school fees and I am glad to be with her."* *"Here in school there are different subjects like mathematics, composition, English language and I am glad to be in school because it makes me educated and be self-reliant. And I even do sports in my wheelchair which is very, very interesting for me."* Despite being older than their able bodied classmates, due to the fact that they were initially denied any educational opportunities, both girls have integrated well into the daily life of the school. Sylvanus Adecampbell and his staff worked hard to prepare the able bodied pupils in advance of the arrival of the disabled students. *"First of all we sensitised the children,"* he says. *"We built up that moral uprightness in them to accept personalities who are different. We encourage them to love one another regardless of their physical make up. So, most of the time, you will see them helping to push their wheelchairs, or playing together. They know these girls' situation, they pity their situation, but they realise they are all one. They are all made equal. They are all free."*

In some countries, such as Ethiopia, attending public high school is free. Other countries do charge fees, but some are now recognising the additional costs and hardships faced by parents of children with disabilities, and are trying to accommodate them.

"I want to say that, as a ministry, we have tried to be very, very flexible with children that fail to pay user fees in these institutions. We have tried to bend the rules for everyone paying to a large extent. We are not very hard on them. But, currently, yes, each child who goes into high school is supposed to pay user fees."

**Zulu Sammer Size, Special Education Unit,
Ministry of Education - Lusaka, Zambia**

Private and special schools are generally fee paying institutions, though some offer bursaries and support poorer students. The combination of user fees and often great distances to reach special schools, however, frequently operates as a deterrent to parents.

"I have tried to get my son to school, but there are costs attached to that. I would have to pay around 350,000 Kwacha [approximately US\$70], which is very difficult for me, but I will try to look for that. And then there are other costs because it's quite a distance from where I live to the place where I found the school – it's a special school, where he will board. But I have to make time to go and pick him up from time to time. And I haven't been able to meet these costs yet."

**Focus Group participant, parent of a child
with a disability - Lusaka, Zambia**

Special needs training of teachers is in its infancy in most of the study cities, and what training there is frequently proves inadequate. Once again, it is children with visual impairment and hearing impairment who are most affected by this deficiency in skills training.

"Special needs education is a new field in the country. It was started in 2005 and now about five teacher education colleges in five universities have opened departments. So we are assisting these departments, for example we are funding research, we are buying books for them and we are working on capacity building also."

**Alemayehu Woldekirkos, Special Education
Expert at the Ministry of Education – Addis
Ababa, Ethiopia**

Parental attitude is another major barrier to children with disabilities accessing education. Aside from the commonplace practice of concealment of disabled children in the family home, many parents simply do not recognise the value of investing in education for a child with a disability, whilst they will happily send that child's able-bodied siblings off to school.

"The children are hidden in homes. And when you interview the parents, it's not deliberate – they tell you that the teacher couldn't teach this child or that other teacher will be laughing at [their] child, or that it is expensive to take this child to school. Or that this school is not accessible. And then some school managers have been turning the children back saying that 'we have no teachers to help these children'."

**Wamundila Waliuya, ZAFOD - Lusaka,
Zambia**

Parental attitudes and resistance to change also present additional barriers for policymakers in moving towards a policy of inclusive education, which is generally accepted in all study countries to be the way forward. Some parents resist this trend and continue to call for their children to attend special schools.

“A special school is better for my child, because if I take her to a government school where there is no special education they’ll be looking at her! How come this child is like this?”

Focus Group participant, parent of a child with a disability - Lusaka, Zambia

“I would like government to provide a school where only these children [with disabilities] will be learning because if they are with other able bodied children they tend to mock them or say discriminatory words about them. “Look at this child – he is disabled.” So that affects the child. But when they are together – disabled children – they tend to laugh and enjoy themselves, because they understand the problems they all face.”

Focus Group participant, parent of a child with a disability - Lusaka, Zambia

Students attending inclusive schools, however, are firm advocates for the system.

“I think it’s totally good to include children with disabilities in mainstream schools. Because I feel non-disabled students will have a better understanding and improved attitude towards people with disabilities. So if you tell a non-disabled person today about this person with a disability, he won’t understand the issues affecting the disabled person at all. It’s when

that person begins to socialise with disabled people – that person will have improved understanding and try to help. This will at least address the challenges facing people with disabilities – so it’s good”.

Disabled youth focus group member - Addis Ababa, Ethiopia

“I feel inclusive education is very, very good. When people with visual impairment learn together with non-visually impairment learn together with non-visually impaired student – it’s even good for the non-disabled students. What we are seeing now is that students with visual impairment are coming top of their clases and can help non-visually impaired students to learn. The relationship between disabled and non-disabled is very good – it is almost brotherly/sisterly.”

Visually impaired youth focus group member – Addis Ababa, Ethiopia

Representatives from NGOs and DPOs were equally in favour of inclusive education policies, but also recognised some of the challenges in achieving it.

“We appreciate and acknowledge the government’s move towards inclusive universal primary education, which, in general terms ought to be free. Every child has the right to go to school. But a deaf child cannot just go to school – because they need the right teachers. They need the right environment. And in Kampala the general schools are not yet properly equipped for deaf children. There are hardly any teachers in general schools who can use the necessary sign language for communication.”

Paul Senteza, Sign Health – Kampala, Uganda

“From our experience, it’s good that children learn in an inclusive setting. It would be ideal for every child, because in real life you interact with everyone in the wider community, so it would be good to go to a mainstream school. But it involves a lot of changes that are not going to come within a short period of time. So I know at the moment there is a policy being discussed at the Ministry of Education – an inclusive education policy is in the offing. But you cannot do everything at once, we can talk about inclusive education but we may have to start with a unit in mainstream schools, a transition to what we desire.”

Dolorence Were, Uganda Society for Disabled Children – Kampala, Uganda

“We have to put together a project on inclusive education – this could have a major impact, whereby we work to ensure that children with disabilities can be accepted – or mainstreamed – into ordinary schools. The type of school system we have – there is not enough effort being made to ensure that children with disabilities can be included in the type of school structure that we have.”

Issa Turay, Handicap International – Freetown, Sierra Leone

Ethiopia has developed a special needs education strategy to tackle its huge shortfall in educating children with disabilities through inclusive education.

“The objective of this special needs education programme is to reduce the gap which exists in school between the out of school children – especially children with disabilities – and the non-disabled children, and to achieve

education for all. So, under this we are working mostly to bring these children into primary schools, secondary schools and assisting them, plus we are capacity building on teacher education.”

Alemayehu Woldekirkes, Special Education Expert at the Ministry of Education – Addis Ababa, Ethiopia

According to this expert on special education employed by the Ministry of Education, the task ahead of Ethiopia is to find places for an estimated 1.6 million children with disabilities currently missing out on educational opportunities, representing almost 97% of the total eligible population. The ministry’s own statistics show that just 47,463 students with disabilities were in Ethiopian schools in 2009/10. The strategy has set a hugely ambitious five-year target for getting the ‘missing’ into schools – some 320,000 per year – yet there is little optimism that this can be achieved. In fact, the Special Needs/Inclusive Education Strategy of Ethiopia of 2012 points to numerous weaknesses in inclusive education in the country, e.g. lack of commitment of implementers, limited capacity, awareness, funds and data in the area of school children with disabilities and their specific needs.

“We can prepare this ambitious plan because policy makers gave their own ideas on this issue, and they [the government] accepted it. Policymakers know about the resources, about the different opportunities and I think they have ideas. Actually, it is ambitious – and I don’t think it will work. Because the special needs education department at the ministry does not function well. We are only three experts under special needs education. At the

regional level trained personnel are very rare, awareness is very weak – so due to this may be it doesn't function."

Alemayehu Woldekirkes, Special Education Expert at the Ministry of Education – Addis Ababa, Ethiopia

Zambia's government also endorses inclusive education.

"First of all our principle in the Ministry of Education is that as far as possible our mode of education for learners with disabilities will be that of inclusion – that is, as much as possible. But the policy does not end up there because we look at the gaps that we have in terms of financing. We are saying that special schools will still continue until perhaps such a time when we shall be able to sustain learners with disabilities in these other [mainstream] schools. And basically those special schools are for those who have got profound or severe disabilities.

"Currently we are revising our education policy – it is still at a stage that is very raw. But we have included an issue of learners with special needs at all levels to be given free education – and if free education cannot be given, then... government bursaries should be given to all learners at all levels to cut off their expenses. Seriously, we hope this is going to pass, because it is backed also by the Education Act of 2011."

Zulu Sammer Size, Special Education Unit, Ministry of Education - Lusaka, Zambia

Sierra Leone has also created a special needs function within its Ministry of Education, which is charged with developing policy on the issue.

"Issues relating to the education of the handicapped, accessibility, scholarship, books and things like that have all been included in the policy, which is yet to be finalised. We have been endeavouring to ensure that things that relate to the education of the handicapped are included and focused upon and financed in the same way as the education of other children. In addition to that there is also a 10 year education plan which has looked at issues of disability closely in all its aspects."

"As I see things now we have started slowly, but as the years roll on we will be gradual in doing things and as we move forward we will suddenly be able to prioritise the issues of the handicapped. The first stage has accomplished. Putting things on paper and saying, this is the low. And then the resources will come in. We will need to train more teaches, so a lot of things will be moving on concurrently to ensure the handicapped are treated the way they deserved to be treated."

Stephen Allie-Korosa, Ministry of Education, Science and Technology – Freetown, Sierra Leone

Most respondents agreed that the situation for people with disabilities wanting to enter tertiary education is improving in the study cities.

"New universities are being established across Ethiopia. In Addis Ababa University there are around 200 visually impaired students. You can also find them in various colleges and there a number of post graduate and doctorate students. They are also supported by affirmative action [positive discrimination] in so far as the minimum score required for a student

whit a disability to go into tertiary education is lower than that required of an able bodied student. The subjects that many students with visual impairment are studying include law, sociology, languages and history and from the training side it is teaching.”

Gebre Teshome, Ethiopian National Association of the Blind – Addis Ababa, Ethiopia

“Even here, it is only very recently that people with disabilities are joining universities. Even in my time – we were only like 10 people with disabilities in the whole university. But nowadays there is a new education policy that has paved the way for many more to join.”

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

“This is the first time in the history of the country, if you qualify as a handicapped student you are getting into tertiary education – university – recognised and sponsored by the government. You take your credentials to the ministry, present your acceptance letter and the nature of your disability – we write a covering letter straight to the student secretary and through to the Minister himself and automatically you are able to get the award. They do not usually go to the same interviews that the so called normal candidates attend.”

Stephen Allie-Korosa, Minister of Education, Science and Technology – Freetown, Sierra Leone

“When you look at the general education standards, those with

physical disabilities have excelled even into tertiary education. Then the blind have followed behind into tertiary education. But very few deaf people get into tertiary education. For example in Zambia we only have got one deaf person who has undergone university education and currently we have got another one deaf person who is in university. But this person who underwent a degree education went to university early in the 1970s – so from the 1970s we had never any deaf person in university until now. We’ve had blind people going. The physically disabled do not have too many problems – in the physical environment, they can be lifted around from one lecture room to another. For those with intellectual disability, of course, the education system is a nightmare.”

Wamundila Waliuya, ZAFOD - Lusaka, Zambia

Efforts are clearly being made in all the study cities and countries to improve access to education for children and adults with disabilities. The scale of the challenge is enormous and the rate of progress varies from city to city, country to country. But the value of investing in education for all cannot be underestimated, as it benefits both the individual and contributes to the development of society in general.

“Poverty and disability are interwoven, so if people are poor they are easily vulnerable to disability, maybe because of lack of balanced diet, immunisation and diseases and so on. If they are disabled and don’t get education, they don’t get health, or employment – so, again they remain poor. So, it is a vicious circle.

So, in the education and the training policy it is stated that education or training prepares relevant personnel who build the economy of the country – so education is very important. Nowadays the measurement is, if a country has a lot of educated people it is a developed country. If a country has few educated people, it is an underdeveloped country – so even the measurement is in this form. So educating a citizen, whether he is disabled or non-disabled, is very important to develop the economy of the country. Giving education to people with disabilities especially can assist them to use their talents and contribute to the economy of their country.”

Alemayehu Woldekrkes, Special Education Expert at the Ministry of Education – Addis Ababa, Ethiopia

3.9 ACCESS TO INFORMATION

“Information is power. And if people with disabilities don’t have information about themselves, about the policies...the policies are there, but many of us are not aware that they are in place. Maybe that’s why those policymakers do not implement them.”

Adult focus group member – Kampala, Uganda

Article 21 of the UNCRPD requires states parties to provide people with disabilities with the ‘freedom to seek, receive and impart information... on an equal basis with others and through all forms of communication of their choice...’ The current reality on the ground in the five study cities is very different, however.



Hearing impaired students using a DPO funded resource centre

Addis Ababa, Ethiopia

All modes of communication are restrictive for children and adults with very kind of disability, whether it is libraries proving physically inaccessible to wheelchair and crunch users, or lack of Braille signage and materials and computers equipped with JAWS software (which converts the written word into the spoken word), or the absence of trained sign language communicators who can convey information to the hard of hearing, some of whom cannot read or write.

“There are many libraries in the town - and the national library has another library within it for the visually impaired - but it is totally inaccessible for people with visual impairments, so even though they have computers with JAWS no person with visual impairment is accessing the service because the road to the library is inaccessible.”

Gebre Teshome, Ethiopian National Association of the Blind, Addis Ababa

Johannesburg has set up people's centres throughout its administrative regions that can be visited by residents to get information. It also has a call centre and website where people can get information. The city reportedly uses social workers in regional offices, awareness campaigns and publications to communicate information to the general public about disability. The city's policy on disability has also been produced in Braille. There is no doubt that some people benefit from using these communications channels. However, people with disabilities reportedly find accessing information in the city difficult. Poor attitude among city officials charged with assisting enquirers was frequently cited by children with disabilities and their caregivers.

“They don't care; the way they look at you, they don't care. They care about their salary; I think they think we are sick in our heads... you wait in a queue the whole day with the child on your back and they go and leave to drink tea and they come and talk to each other.”

Focus group participant, parent to a child with disability – Johannesburg, South Africa

Similar attitudes were reported in other study cities.

“We have a very few members who can communicate in businesses, such as banks, on their own. But they are hard of hearing and partially sighted rather than totally deaf blind. The majority don't even know how a bank operates. Even those who can use sign language and tactile communication cannot communicate with bank officials. They need to have someone with them.”

Anthony Lussagi, National Association of the Deaf Blind of Uganda – Kampala, Uganda

The failure of commercial service providers to take account of the information needs of people with disabilities was also identified by respondents. Telecommunications companies in Kampala, currently take no account of the special needs of hearing or visually impaired people in their product ranges, for example, and cite the fact that all of the equipment they sell is imported from abroad so they have no control over accessibility features as Braille keypads.

Television broadcasters in Uganda also make little or no effort to include on

screen sign interpretation in their programming.

“National providers like Uganda Broadcasting - they should be able to at least in some of their programmes, if not all, include some sign language captions. That would go some way to make the city and the nation friendly to hearing impaired people.”

Paul Senteza, Sign Health - Kampala, Uganda

Lack of accessible communications and information channels is a particular – and potentially lethal – issue in the field of health service provision.

“When you look at information, some categories of disability, they don’t get the proper help. For example, the information on medical issues is not in Braille at all. And we have blind people who are supposed to get that information – but they don’t. They get second hand information from other people. When you look at HIV/AIDS medication, there is a very big challenge because the pills are many, there are no Braille markings and sometimes they can make a mistake.”

Adult focus group participant - Kampala, Uganda

“If you are a blind person, or deaf or physically disabled like me, you go to the health centre or the pharmacy to buy condoms, they will first laugh. I participated in one study about young people with disabilities - where we went into the communities. [Able-bodied] people were sure that young PWDs [people with disabilities] were not sexually active – that’s what has put many of them at risk. Parents of

children with disabilities - sometimes they don’t bother, they don’t think about these children. When they educate their other children about safe sex - they don’t bother about their children with disabilities. They get no information – that is why they get raped and sexually assaulted.”

Adult focus group participant - Kampala, Uganda

As in so many other areas where the rights of children and adults with disabilities are concerned, NGOs and DPOs are coming forward to fill information and communication gaps that would be better served by governments or commercial concerns.

Blind South Africa has taken the initiative to make information accessible to the visually impaired. They identify articles in the media and produce them in Braille through a monthly magazine.

In Lusaka, a National School for the Blind runs a comprehensive library and resource centre; and in Addis Ababa, the Ethiopian National Disability Network maintains a resource centre for people with disabilities at its head office.

Access to quality information and communication remains problematic for people with disabilities in all the study cities, especially for those with sensory impairments. This situation is likely to persist until governments take a lead and both improve public information and communication channels and require – by law, if necessary - private institutions to do the same. If states parties are to meet the commitments they have signed on to through ratification of the UNCPRD, however, such changes will need to take place eventually.

3.10 ACCESS TO RECREATION, SPORT AND PLAY FACILITIES

Providing the same opportunities for children with disabilities that are enjoyed by their able-bodied peers means guaranteeing not just the fundamentals, such as access to education, health services and the environment, but also access to opportunities that will enhance and improve the *quality* of their lives. The right of children with disabilities to participate in recreational activities engage in sports and play on an equal footing is an indication of how far any society has moved towards achieving inclusion.

Article 30 of UNCRPD requires states parties to recognise the right of persons with disabilities to take part on an equal basis with others in cultural life, recreational, leisure and sporting activities. Unfortunately, most of the study cities demonstrated little in the way of developing such facilities and opportunities for their disabled citizens. Of the five study cities, Johannesburg has probably achieved most on this front, though even here, progress has by no means been substantial.

The city has a wide range of public recreation and sporting facilities, including playgrounds, social clubs, parks, a zoo, heritage sites, museums and swimming pools. There have been only very minimal attempts to make such facilities accessible, however, to children with disabilities. This is particularly true of children with disabilities other than physical impairments.

Attempts at making these facilities accessible include making motorised wheelchairs available at Johannesburg zoo, and including ramps and paved

walkways in some locations. The city also funded construction of the Nkanyezi Stimulation Centre Park, which is designed to cater to children with intellectual, physical and visual impairments. The park includes a wheelchair maze, paved alleys, a merry-go-round for children with mobility impairments, wheelchair friendly swings, and a 'touch and smell' greenhouse. No other study city reported any similar facilities for children with disabilities, and there were few reports of any real attempt to make play facilities accessible.



Merry-go-round for children with mobility and intellectual impairment

Johannesburg, South Africa

In Kampala, for example, one of the city's major shopping malls, which is largely accessible for people with disabilities, includes a rooftop playground where parents can leave their children whilst they shop. This playground is the only part of the mall which is not accessible to children with physical disabilities.

Respondents in all cities reported that children with disabilities rarely play with

able-bodied children, partly because local playgrounds are not adapted to their needs, but also because issues of social stigma prevail.

“The fact is that what we are experiencing these days is that children with disabilities are not playing that much. I’m not saying that they don’t play at all but it’s really challenging for them to play with other able-bodied children. One fact is that their parents don’t allow them to integrate with other children – that’s due to the stigma. In this country the problem is not only for children with disabilities, but also for their parents. Parents will be excluded within their community for having a child with a disability. The other thing is that most people think that disability is transferable – that it can transmit to others. So, most children with disabilities are really denied their right to play with other children.”

Aychesh Molla, Ethiopian Center for Disability and Development - Addis Ababa, Ethiopia

The experience is similar in Lusaka, where parents try to come together as often as possible to provide their children with opportunities for interaction and play.

“We might have a Christmas party, for example, where we will invite people to donate a few things – drink, food and so on – and then bring those children together. They play football, they dance – those who can – and they interact.”

Astrida Kunda, Zambia Association of Parents of Children with Disabilities – Lusaka, Zambia

Zambia’s Paralympics Committee is a government body that was established in 2005 to organise and regulate sports for people with disabilities. Although the infrastructure of Lusaka is not up to standard, there are places where some people with disabilities can participate in sport and recreation. These include the University Teaching Hospital Special School, Bauleni Street Kids Centre and the Kabulonga Boys High School. The Olympic Youth Development Centre is a more recently established building that is accessible to people with disabilities.

In some of the study cities, DPOs have formed to provide children with disabilities with creative outlets.

One World Family in Freetown, for example, provides young people with disabilities with access to performing arts training. Successes include a truly innovative drama and dance troupe comprised of hearing impaired performers, and a rock band, whose members are all living with a variety of disabilities.

In Addis Ababa an organisation has evolved which works to overcome stigma by providing opportunities for young children with disabilities to mix with able-bodied children.

“There is one organisation here called Artists Development Vision which includes inclusive play in their activities – mixing children with disabilities with able-bodied children. Since it’s for children at earlier ages, it’s all about play – so inclusive play is the major activity.” That kind of thing is there but I don’t see usually specific adjustments

being made to make disabled children play with able bodied children.”

Reta Getachew, Ethiopian Centre for Disability and Development – Addis Ababa, Ethiopia

In Johannesburg, parental and DPO initiatives have not focused so much on initiatives to ensure accessible recreational facilities for children with disabilities. It was observed that whilst other access issues are obvious to respondents, accessible recreational facilities were not considered an issue until brought to their attention. There seems to be a sense that children with disabilities do not play like other children. In fact, many parents, especially those with children with intellectual and visual impairments, reported that their children were not capable of engaging in recreational activities.

The seriousness with which the study cities and countries take the issue of providing children and young people with

disabilities with opportunities to engage in sporting and recreational activities, is perhaps best illustrated by the way in which they support those who excel in such pursuits.

For the 2008 Paralympic games in Beijing, Ethiopia fielded just two Paralympic competitors, as did Zambia; Uganda fielded one; South Africa sent 61 competitors; and Sierra Leone didn't participate at all.

Given the pressures on the study cities and societies to bring about huge changes in the welfare and rights of citizens with disabilities across a whole range of fundamentally important issues essential to their lives and wellbeing, it's likely that real improvement in sports, recreation and cultural pursuits will be a long time coming. Nevertheless, in ratifying the UNCRPD, all the study societies have committed to achieving these changes in the future.



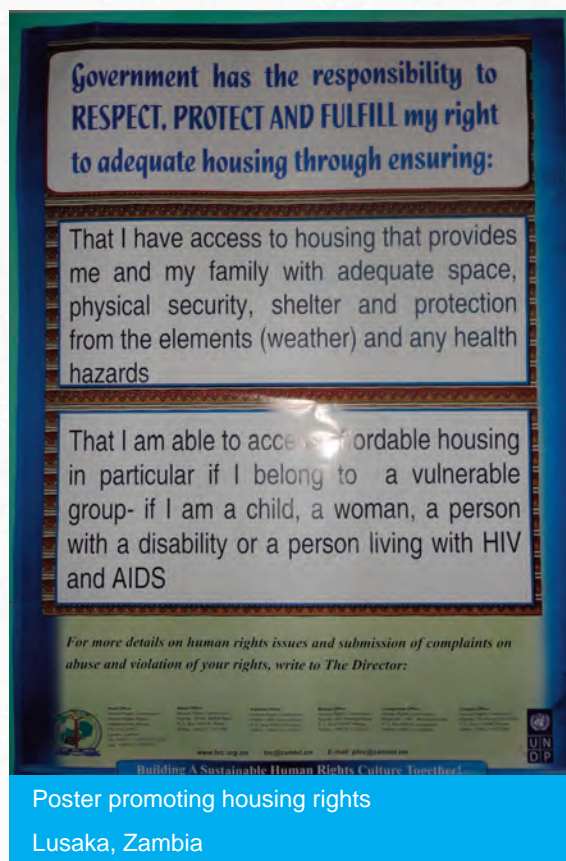
Park with no wheelchair access
Johannesburg, South Africa

3.11 ACCESS TO SHELTER AND HOUSING

Article 28 of UNCPRPD requires states parties to recognise the right of people with disabilities and their families to have a decent standard of living, including providing them with access to public housing programmes.

Securing protected housing is an issue for people with disabilities in most of the study cities. Many are forced to resort to begging and may find themselves living on the streets, which has obvious implications for their health and psychological wellbeing, especially for children with disabilities or the children of people with disabilities.

Some respondents reported that they frequently encountered problems with landlords who mistrusted their ability to pay rent, and would move them on at the first opportunity.



"Housing is a problem. We usually rent houses and sometimes if we fail to pay the rent we are chased out of it. And sometimes, because we have a disabled child, the landlord or owner of the house wouldn't want to lease it to us at all. We have to keep shifting from one environment to another, which isn't good for our children."

Focus Group participant, parent to a child with disability - Lusaka, Zambia

Another key issue is that, whilst those responsible for public buildings and private commercial buildings may be responding to the challenge to make their premises more accessible for people with disabilities, there is a complete dearth of adapted public or private housing in the study cities.

"I haven't come across any homes which are adapted for disability. I think if there are any, probably I'm just not aware of them. We don't have public housing programmes at the moment. Even those institutional houses, they have not taken into account issues of disability."

Maxwell Zulu, Department of Physical Planning and Housing, Ministry of Local Government – Lusaka, Zambia

People with disabilities living in the city of Freetown face more severe and disturbing issues around shelter and housing than their counterparts in the other study cities. Many are forced through extreme poverty to band together and occupy abandoned public buildings.

"It's a very big problem for children with disabilities. If you go through the streets of Freetown you'll see a lot of

children with disability. It's because most of them are squatting in empty buildings – some are government abandoned buildings, some are private properties of people, but they only occupy these buildings because they are not used."

Patrick James Taylor, Human Rights Commission - Freetown, Sierra Leone

A Freetown social worker explains at disturbing length the difficulties faced by people with disabilities in securing and holding on to shelter, in the face of frequently violent reactions from the authorities.

"Disabled people often come together in groups – and I believe this is because they are pushed there from home. Their parents really find it very hard to accept them, so they have no choice but to look for dilapidated buildings whereby they can all come together and have a house. They live in properties with no proper sewage systems and things like that. And when they try to rent decent properties, the landlords will not rent them to them because they are disabled. They don't want them in the neighbourhood as they might lower the value of other properties.

"It's very difficult. They find an empty building where no one has been living for quite some time. They survey it – they know who's there, who's around – and they go there very late in the day – one or two o'clock in the morning – and they capture the house and start living there. But at the end of it all there is always eviction. I've witnessed about four evictions since I've been here, whereby the police have used tear gas, and where they have even broken some of the people

with disabilities' legs or got their hands twisted or dislocated. A lot of things like that happen.

"It was not so long ago that they emptied an occupation on a local street – there were about 150 disabled persons and they were forcefully evicted. These people were trying to support themselves by working as tin smiths, dying materials, tailoring – but when the police went there on the orders of the court, they used force. They didn't consult with organisations working with people with disabilities to go and liaise and talk to the people, and maybe relocate them. You shouldn't go there to turn them upside down. You should go to help them build more structures.

"And these evictions separate families. Most of the women are not in a good position. They go into begging, they are demoralised, their kids can't go back to school, their property is stolen – so it is like starting from scratch again. When the police go to their houses they leave sadness, tears and blood."

Edward Emmanuel, One Family People - Freetown, Sierra Leone

A ministry official acknowledges the fact that evictions take place and is keen to emphasise that, with the passage of new disability legislation in Sierra Leone, the housing situation for people with disabilities living in the city should improve.

"The Act, to be very fair, I haven't been able to have a copy or read through it. But I think we will endeavour to change things for them to access shelter through providing affordable land and subsidised land they can afford.

"I empathise with them and I want them to be as comfortable as I am. I wanted to show you what we have done for them. Because they came here when they were evicted and the minister was so embracing and we wasted no time in ensuring that they had a piece of land. There were some organisations who claimed that they were going to shelter them, and we provided land for them. And I just wanted to show you that, in fact, we have been able to come to the rescue of those who want to provide accommodation for them."

Dr William L Farmer, Ministry of Lands, Country Planning and the Environment - Freetown, Sierra Leone

The quality of land doled out by the ministry for people with disabilities is often of variable quality, frequently in the most isolated and inaccessible parts of the city, such as its eastern fringes. Observation of one such community, the Skills Training Centre for Polio Victims, revealed a steep, muddy entrance almost impossible for any wheelchair user to negotiate independently.

"When this land was first given to us we tried to put up some structures so that we could manage the land and our families, but the community still

doesn't want us here – they vandalise our structures and steal our equipment.

"We have complained to the authorities but nobody seems to pay attention to it. They always tell us that we have donors and that the donors should buy land for us rather than grabbing community land. We tell them, we too are part of Sierra Leone. We are Sierra Leoneans and no one can drive us off this land – it's meant for us. So this is the stress we are having in this organisation."

Member of the Skills Training Centre for Polio Victims – Freetown, Sierra Leone

Providing permanent, affordable, safe and secure homes and shelter for people with disabilities and their families is an essential pre-requisite to lifting these communities out of the extreme poverty in which many find themselves. Government and local authorities in all the study cities must redouble their efforts to provide accessible housing and end discriminatory practices which prevent people with disabilities laying down roots in communities and finding the stability from which they may find employment and secure stable educational opportunities for their children.

A DAY IN THE LIFE OF BOAZ

Kampala, Uganda

Boaz was left physically disabled by Polio. Aged 22, he lives independently, supports himself and is studying to be an accountant.

“Every morning when I wake up, I have loads of things to do for myself. Where I stay we do not have showers fixed to the wall, so I have to get water from a well, carry it to my house put it in a basin, then take it to the shower rooms, and shower from there. It is a challenge for me, because I cannot hold two crutches and carry water at the same time. So, every time I need to carry water from the well, I have to pay someone to do that for me.

“Breakfast, I prepare for myself. But the challenge comes when I need to lift the charcoal stove. The landlady where I live does not allow us to heat it inside, so I have to heat it outside and then carry it in when it is very hot and it is heavy. I burned myself once when I dropped the stove, but it didn’t cause too much damage.

“Every morning I also have to wash the clothes I put on yesterday, so I need to prepare myself for everything that comes across my life. And it means I have to carry the clothes to the hanger lines, and that is hard for me. So really, I need help on that. Thanks to God, I have a very good neighbour and, for example today, he helped me do these things.

“To get transport, everyday I need to reach the road. Because I live deeper in the slum areas I have to walk about 200 metres to the road, and that is a real challenge even when there is no traffic.

“Every day I do network marketing [selling items at the roadside] – and you cannot do that from a car. If you are in a car you will miss four or five people every kilometre who could be helpful to you. So you have to walk. And, believe it or not, every day I probably walk three or four kilometres. And coming back, I sometimes have to walk or else go deep into town to get a taxi. I find it hard – whenever I’m walking I’m carry a bag, which sometimes has products in it and can be heavy.

“After working, at 4pm I have to go to school. Every day I am studying computerised accounting – it’s a certificate course, because I could not manage to go to the university, as I had to find ways of paying for myself. So I have to do what I can afford. So that is the course I am doing. The Institute is quite challenging. I take stairs – which you cannot imagine! They are steep. It’s challenging, but every day I have to go to school. It is hard for me. You are tired. Your chest is tired. Your arms are tired from all that busy day. So you even at times fail to pick up what you are being taught. I finish school at 8pm.

“There’s something I’m working towards that keeps me going. One day, when I have a family, my family will not be lacking basic necessities. You know, there is a post-polio condition – someone told me that after you reach 40 years old, some people with polio get progressively weak. You cannot manage to do heavy work at that time. So the reason I am working very hard now is because, before that time comes, I’ll really get somewhere. God willing, if I get a wife and have kids, then I want my kids to always appreciate their father. So that’s why every day I wake up and I am inspired to do everything I can to go ahead with life.”

3.12 ACCESS TO EMPLOYMENT AND THE WORKPLACE

If a child with disability is fortunate enough to secure a proper education in any of the study countries, the next progressive step towards ensuring that he or she can thrive and prosper will be entering into paid employment. Yet, for many children with disabilities, that may not be a viable future, due to the persistence of discriminatory employment practices and the simple fact that workplaces are often either inaccessible or incapable of meeting the special needs of employees with disabilities. Without gainful employment opportunities, many people with disabilities find themselves trapped in a cycle of poverty and deprivation, often resorting to street begging to survive.

Article 27 of the UNCPRPD calls upon states parties to recognise the right of persons with disabilities to work on an equal basis with others, and to ensure this through a variety of enabling measures.

Most of the study countries have enacted legislation to protect the employment rights and opportunities of people with disabilities. For example, Zambia's Persons with Disabilities Act (2012) and Sierra Leone's *Proclamation No 568 – Right to Employment of Persons with Disability* (2008) both provide clear legislative frameworks governing equal employment opportunities for people with disabilities. Ethiopia, Too, has developed comprehensive equal opportunities legislation, after consulting with disability organisations.

“The first proclamation that we worked with the government on was an equal opportunities proclamation – in the first version of the proclamation we were members for the committee, so we were involved in the drafting. And in the second version we were consulted.

“There are three important provisions of this proclamation – one is the entrance examination, when you want



Smiths at work at the Handicap Action Movement workshop
Freetown, Sierra Leone

to be employed you apply, and if two people are equally qualified then priority should be given to people with disabilities. And two, if you fail in the exam – if you suspect that you were failed because of your disability, then you can appeal to a court – but you are not expected to bring evidence – the burden of proof lies on the employer. This is the only proclamation where the burden of proof lies this way, other than the anti-corruption proclamation.

“It also obliges the employer to avail any assistive devices and an assistant person, if necessary if they employ a disabled person.”

Gebre Teshome, Ethiopian National Association of the Blind - Addis Ababa, Ethiopia

Yet, as with so many policies relating to persons with disabilities, the reality on the ground is very different. Despite the existence of laws, respondents report that little effort has been made to sensitise employers on their duties and responsibilities to people with disabilities.

“The government has already developed a national law on equal opportunities for people with disabilities. But when you go down to the community or the lower structures of government they are not much aware of this law.”

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

Lack of educational opportunities for many children with disabilities, which often leaves them illiterate and without any practical skills to offer potential

employers often rules them out of consideration for most commercial or skilled job opportunities.

“Very few people with disabilities have appropriate qualifications, because they lack sufficient opportunities, and even those who are qualified, the employers are not convinced to employ them because of their disabilities.”

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

Even where people with disabilities have gained education and skills, workplaces remain physically inaccessible, and employers are often reluctant to invest in special equipment, such as JAWS software for the visually impaired, or will find other excuses to deny employment.

“As a graduate, I have been denied many jobs because of issues to do with accessibility. One – a certain bank – told me that they wondered whether I could always be there on time, given that I had to use my wheelchair, so they said they were sorry, they could not give me a job because they felt I would never be on time.”

Adult focus group participant - Kampala, Uganda

“Accessibility at the workplace is a problem. You’ll find that in most places. It’s either the physical environment that’s going to be a problem or just the working environment itself is not there. Take, for example a blind person – to go to the workplace and ask the employer – I will need Braille paper and one or

two other things to help me – such as a computer with proper software. Well, the employer may not think that person is the one for him.”

Francis Chilufya, Zambia Agency for People with Disabilities – Lusaka, Zambia

One senior human resource manager in Kampala pointed to the general lack of sensitisation initiatives as a cause of bad practice amongst employers in the city.

“I don’t feel that companies are accessible whether private or government and I also don’t feel that information in that area is readily available. You almost need to be looking for it.”

Mukiibi Sussie, Smile Communications Uganda Ltd – Kampala, Uganda

DPOs generally undertake awareness raising which is primarily the responsibility of government. Lack of resources can prevent DPOs from doing a comprehensive job, but clearly any effort is better than none at all.

“The workshops we have conducted have helped make improvements – some employers who attended have tried to make a conducive environment for people with disabilities and have tried to encourage opportunities for the employment of people with disabilities at their institutions. So there are changes at some places, but still there are problems generally with employment for people with disabilities.”

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

“Recently I was involved with another organisation that holds what it calls ‘industry nights’. So, if it’s the financial sector they will invite people from the fiancé sector. If it’s telecommunications, they will invite people from the telecommunications sector and so on. And they have different people with different kinds of disabilities present – like the blind, the deaf, the physically disabled and so on, and we were able to interact with some of these young people – they stood up and presented themselves.

“For me it was the first time that I went to what call a disability talent market, because you don’t see that anywhere. Maybe because of our culture, I don’t know why, these people have been kept away behind locked doors. But you don’t find these people much. And I think it’s may be because of that culture that we still have not reached that point where we have buildings or set ups that allow easy access. Out of that industry night we were able to see what different disabled people can do, and we actually employ one now in an IT role.”

Mukiibi Sussie, Smile Communications Uganda Ltd – Kampala Uganda

The failure of employers to make opportunities available to people with disabilities has led some groups in Sierra Leone form small co-operatives or enterprises, as a means of basic livelihood. This is usually done with minimal assistance from government, other than the provision of plots of land. These co-operatives specialise in blacksmithing, tailoring, dyeing materials and producing cooking pots. They include the Skills Training Centre for

Polio Victims, the Polio Women and Girls' Development Association and the Handicap Action Movement. The Sierra Leone Association of the Blind also trains disabled and non-disabled people in bakery skills.

“Before joining this organisation, I was a street beggar. I used to sleep in shop doors or under market stalls and tables and we encounter a lot of trouble – sickness and all the rest. And for you to earn your daily bread was a problem. Since I joined this organisation I have learned a lot of skills and I can live independently on my own without having to go on the street to beg. I see begging as like totally losing my human dignity. I am proud to be a disabled. I don't mind that.”

Member, Skills Training Centre for Polio Victims – Freetown, Sierra Leone

Legislative frameworks for equal employment opportunities are in place in the study countries. Education, national sensitisation programmes for employers, and enforcement of the legislative provisions are clear priorities if opportunities for the next generation people with disabilities to improve their own lives and contribute to the economic development of their countries are to be achieved.

3.13 BARRIERS TO IMPLEMENTING DISABILITY FRIENDLY POLICIES

When requested to identify key issues which were preventing progress for people with disabilities in achieving their rights and equality of opportunity, respondents in all of the study cities demonstrated remarkable consistency. Ten core barriers to implementation of



Sewing workshop at Handicap Action Movement

Freetown, Sierra Leone

the UNCRPD emerged from these discussions.

1: Failure to recognise the complexity of disability and respond to the differing needs of people with disabilities

The widespread failure among officials at all levels to recognise the breadth of disability types and to develop policies and interventions which meet the specific needs of people with these different types of disability.

Policymakers believed that ‘disability’ was synonymous with ‘physical impairment’, and so inevitably focussed their attentions on this aspect when developing policy.

“There is still a problem on the understanding of what disability is and what the extent of the disability type is for a person to be considered disabled. The concept itself is not that much clear. So, for example, if you go to the central statistics of the Ethiopian Government they can tell you how they count the number of people with disabilities during the census. But they are not familiar with the type of disabilities and the categories of disability. So the understanding is a problem.”

Teshome Deressa, Federation of Ethiopian National Association of People with Disabilities – Addis Ababa, Ethiopia

“What’s mentioned [in legislative and policy documents] is ‘persons with disabilities’, not just persons with physical disabilities – but the government implementing organisations who are responsible to implement

these plans, they understand people with disabilities as persons with physical impairment – so when the documents refer to accessibility and so on they think it’s only for persons with physical impairment.” But it’s the responsibility of other NGOs and DPOs to try help these organisations to understand that people with disabilities do have different needs.”

Gebre Teshome, Ethiopian National Association of the Blind - Addis Ababa, Ethiopia

Such attitudes, some respondents reported, could lead to particular hardships for people with sensory or intellectual impairments. They argue that this can result in disproportionate allocation of resources to address issues of physical impairment at the expense of other types of disability. Respondents felt that this was due to lack of understanding rather than any deliberate prejudicial attitude.

“It is not because of a bias, but more because of limited knowledge and exposure even by the decision makers. But also it is due to the limited resource envelop. If they say they will add on, say 10,000 shillings for each disabled child at a school, it is easier and more visible to add on a ramp, rather than providing Braille books and sign language. Once a ramp is done - but a sign language interpreter has to be paid continuously. So people go for the cheaper options – but I don’t think it’s bias.”

Paul Senteza, Sign Health - Kampala, Uganda

2: Failure to collect accurate data on disability

The lack of accurate data on the numbers of people with disabilities in the study countries can lead to severe under estimations by the authorities. If policymakers do not recognise the scale of need in their society they are likely to prioritise resources elsewhere and/or make fewer resources available than are actually required to support the needs of people with disabilities.

“One of the major barriers has been the lack of adequate information on disability, and the data is lacking. There has not been that much significant or steady research on the issue of disability. So data is very important for the development of issues here. International figures show the level of disability in Ethiopia, but there has been no country specific study so data is lacking in this country.”

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

“Politics is a game of numbers. Maybe the government looks at our numbers as being not substantial.”

Disabled adult focus group member – Kampala Uganda

“I feel that people who are making policies don’t have adequate information to see that there’s a need here - they need statistics - they need numbers. People believe in numbers – and if there is no information flowing from the ground... they are not going to see the need to do anything about it.”

Precedence Gertrude Kapulisa, Community Based Interventions Association - Lusaka, Zambia

3: Lack of capacity among Disabled Persons Organisations

DPOs in their country were often not sufficiently resourced or mobilised to advocate effectively for policy changes. Efforts in each of the countries were often too fragmented to work collaboratively towards a common cause.

“Another problem is the disability movements in the country. I’m sorry to say, but they have not been able to help us. There is too much segregation within these groups, for instance.”

Disabled adult focus group participant - Kampala, Uganda

“The problem is the issue of capacity of DPOs in the country. If you are strong, if you can lobby, if they can influence the donors, I think they can attract attention and win funds. The capacity of DPOs – when you apply for funding your proposal should be good and attractive – and I think many of the DPOs are not strong in this regard. You have to have the capacity to pull resources from donors.”

Teshome Deressa, Federation of Ethiopian National Association of People with Disabilities – Addis Ababa, Ethiopia

“The problem is that, every time we call meetings it’s the same crew. So, we make the feast and we feed ourselves. We never invite outsiders. So, in the long run, the messages never get out.”

Disabled adult focus group participant – Kampala Uganda

"We have a weak voice when it comes to parents' associations. Because sometimes, if parents can make a lot of noise I think government will listen. Me, as a professional, if I go they will say 'she wants a job – she is just advocating because she wants to keep her job'. But if a parent stands up and talks...The voice of the parents' associations haven't been well co-ordinated.

Precedence Gertrude Kapulisa, Community Based Interventions Associations – Lusaka, Zambia

"One factor is that the leaders of disability or councils from the local village level, to the regional level and even up to the national level – how many of them really appreciate these policies? And how many are pushing for these to be implemented?"

Spokesperson for Disabled Youth and Parents Association – Kampala Uganda

4: Lack of consultation with people with disabilities or their representative organisations

Government officials frequently do not adequately consult properly with those best placed to offer guidance on the needs of people with disabilities when developing policy and programmes. I.e. with the DPOs themselves.

"We are not consulted. We have policymakers at different levels, right from village level up to the parliament. If they are doing anything we are supposed to be consulted on behalf of others.

"I have represented people with disabilities politically and everything

we talk about remains on paper. That's the unfortunate part of it. And I think we are being used just as a scapegoat. We are there – but whatever we discuss, remains on paper. It's very frustrating – especially for me, as a wheelchair user, who is there to do something constructive – and you find something should be taking place but there is no approved plan. And at times, the plan is there, but they think, for example, making a parking space for you will take too much time, so they just leave it out."

Disabled adult focus group participant - Kampala, Uganda

"Unless our politicians take us seriously as voters – because in a constituency there may be 1,000 people with disabilities and 40,000 able bodied people – then our policies will continue to be in books, but not implemented."

Disabled adult focus group member – Kampala Uganda

5: Lack of financial investment in disability

While progress has been achieved with respect to governments' willingness to introduce policy and law aimed at promoting equal rights and opportunities for people with disabilities, there was still a severe lack of the necessary investment and making the resources available to put these policies in practice.

"If you cannot find financial support, you cannot do anything. This is a very big challenge."

Betelhem Abebe, Ethiopian National Disability Network - Addis Ababa, Ethiopia

“The other challenge would be the resources. When they are looking at implementation the resources are never available. Priorities are given to defence, to minister of transport. Priorities are in other areas. Even when it comes to education, when they are prioritising budget lines within the education ministry, special needs is one of the least funded. The commissioner of Special Needs Education gave us a speech on Monday and she was saying: ‘Yes, we are prioritising special needs education but I am sorry to inform you that we are the least funded unit within the Ministry of Education.’

**Aloysius Kiribaki, Sense International
Uganda – Kampala, Uganda**

“We believe that budgets should not be a reason for not including people with disabilities because they should have a share in this country. The government even states – ‘this country is poor’ – and the disability issue is considered as like an extra issue. We feel that was why they took such a long time to ratify the Convention – it is because the government feels it doesn’t have enough money - especially if you see the accessibility article – Article 9 – it says that all buildings should be accessible.”

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

Some respondents noted that lack of financial resources was compounded by the fact that what little there was had been badly managed or misapplied.

“We may generally agree to the principle that disability is not

adequately funded. That point is not refutable. The point that people are not keen to discuss is the efficiency with which resources which do exist are used. If the few resources that are available were used much better, would it make a difference? ...For example, lots of funds are left at the headquarters in the name of support supervision by the ministry, which they never do. And very few, almost no, resources are sent to the teachers, who are the frontline supervisors.” Why should the minister or the commissioner for special needs education allocate to themselves lots of allowances to go and mont9irl a school? There are always arguments that more funds are allocated to administrative type of activities at the headquarters than they are allocated at the actual point of service.”

**Joseph Walugembe, Action on Disability in
Uganda – Kampala, Uganda**

6: Failure to integrate disability at government and civil society levels

Disability had not been adequately integrated, particularly within different ministries level, and therefore there is a lack of accountability for disability in different sectors.

“Now we are following the human rights framework and mainstreaming there should be someone deliberately focusing on disability under transport, under communications – in health there is a small department, and in education – but there should be someone in every ministry.”

**Paul Senteza, Sign Health – Kampala
Uganda**

“Whilst they may have the policies, they don’t have people with responsibility within a certain organisation or ministry to ensure that the policy and provisions are implemented.”

Reta Getachew, Ethiopian Centre for Disability and Development – Addis Ababa, Ethiopia

The ministry [with overall responsibility for disability] is pushing for implementation, but how many in other ministries are really appreciating this? If the department for children, say, think that this is a subject for disability and not our concern it will be difficult to get implementation – it needs to be cross-cutting. Some much as there is political will, the technical teams that actually have to implement the policies do not really understand what disability is. They don’t understand the needs of people with disabilities and they don’t know exactly what they have to do.”

Spokesperson for Disabled Youth and Parents Association – Kampala Uganda

“There is a great deal of work to be done, because for a long time there was a belief that all issues related to disability have to be done by one organisation and by one ministry, so where we are now talking about mainstreaming it’s a very big challenge, because it’s a position of not only monitoring but also educating the various ministries that they need to do this. There’s an arrangement where all ministries are supposed to have focal persons on disability – that too is a challenge – ministries have to identify the right staff to do that kind of work. And currently there’s no

establishment for such kind of positions – the responsibility is given to existing member of staff.”

Francis Chilufya, Zambia Agency for People with Disabilities – Lusaka, Zambia

“The idea of cross cutting is still not taking root here. Other department don’t see it as their responsibility to see that disability is included. To me, disability should be everywhere – we are not to different community – we are part of Ugandan society.”

Meldah Tumumunde, Uganda National Action on Physical Disability – Kampala Uganda

Furthermore, disability is inadequately integrated across the whole of civil society in the study countries. Civil society organisations representing, for example, the interests of children, women or people with HIV, consistently failed to take account of people with disabilities when planning and programming their activities.

“The limited mainstreaming of issues of disability is also a concern, because all things to do with disability are seen as a disability affair. Today, as I know, the children’s lobby is much stronger than the disability lobby, but the children’s lobby will not concern itself with how accessible buildings are for children with disabilities, because they think that is a ‘disability issue’. So if we had – say – somebody advocating for the girl child, who would significantly consider the girl child with a disability and whether the toilet facility they are using is good enough, that would make a difference.”

Joseph Walugembe, Action on Disability in Uganda – Kampala, Uganda

“We are in a culture where people think that people with disabilities must be taken care of by DPOs. They forget that however much we have a disability we are human beings first and foremost. I am a woman first – and the disability comes in later. Perhaps here is a lack of interaction between us. We need more, so that they can begin to understand what happens to us.”

“By doing advocacy we hope that income can be planned for by government and other civil society organisations – which is where much of our advocacy is focused – because NGOs like World Vision, Plan Uganda – they look after children as well, but they normally forget the disabled child. But if we advocate all the time those civil society organisations should mainstream and so should the government.”

Dolorence Were, Uganda Society for Disabled Children – Kampala Uganda

7: Lack of overt references to disability in the Millennium Development Goals

The Millennium Development Goals (MDGs), which were framed in 2000 and which govern international efforts to eradicate world poverty by 2015, do not make any express references to the needs of children or adults with disabilities. This has negatively impacted on the capacity international funding partners from purposively supporting programmes for people with disabilities. The lack of explicit provision for people with disabilities in the MDGs has led to development partners and NGOs inadequately considering them in the design and implementation of development work.

“We have something published by the international development and disability consortia here – it points out the eight MDG goals and tries to put disability into the context of those goals. For example, the first goal is to eradicate extreme poverty and hunger – and you can see that 82% of people with disabilities live under the poverty line. So, even at international level disability is not getting the priority. So, we need to put disability on the front line. I think maybe these days because of the UN Convention... there are some changes that we are seeing. But these goals were set in 2000 and the UN Convention came into force in 2006 – so for six years there was nothing.”

Betelhem Abebe, Ethiopian National Disability Network - Addis Ababa, Ethiopia

“The donors, their attention is minimal – they put attention on HIV/AIDS and clean water and so on and in their programmes they have no system in which people with disabilities’ needs are represented. They have to have an inclusion strategy in their programmes. They are purporting to reduce poverty in Ethiopia but the people who are living in extreme poverty are people with disabilities. If they want to raise the poor up, then they have to focus on people with disabilities.”

Teshome Deressa, Federation of Ethiopian National Association of People with Disabilities – Addis Ababa, Ethiopia

“We want donors to say to organisations that they support that – say you are writing a proposal for children – make sure you include children with disabilities as well. That would have solved a lot of problems.”

DFID [the UK Department for International Development] is a very big donor. They give money to a number of NGOs that work at the grassroots level. So, if they demanded their grantees include disability – make sure that you target people with disabilities in your proposals – it would help. But the problems are – one, they are not interested in funding disability related issues and – two, even if they fund other projects they are not interested in asking their grantee organisations to make sure that people with disabilities are covered. That is a big issue.”

Reta Getachew, Ethiopian Center for Disability and Development – Addis Ababa, Ethiopia

8: Lack of training and sensitisation for key service providers across all sectors

The failure to properly train and equip professionals who have daily contact with children and adults with disabilities is a barrier to inclusion. Professionals in public services, such as education, health, policing and civil service, and those working in commercial organisations were identified as being ill equipped to address the needs of people with disabilities.

Some people living with specific types of disability experience particular hardships as a result of the low awareness and of their particular needs.

“You need to begin with the education sector. Expose the majority of teachers, right from their own training, to be able to communicate in sign language. If there was a nearby school that had one or two teachers

able to sign that would be a starting point. And not just the training of the teachers but also all other services – law enforcement, health – hospitals – they should by law have people who can sign.”

Paul Senteza, Sign Health - Kampala, Uganda

“There is a lack of skilled community based rehabilitation workers and teachers for the deaf blind. You’ll find that teachers who have done special needs education – they are teachers that have got general training – they will be taught about deafness, blindness, and other about deaf blindness – they are green. And in any case, if you have just done a small course, you are not really competent enough to handle deaf blindness.”

Aloysius Kirbaki, Sense International Uganda – Kampala, Uganda

“Many children with mental health problems are punished for being naughty. They are not understood by their teachers, or their families.”

Julius Kayira, Mental Health Uganda – Kampala, Uganda

9: Failure to implement and enforce laws and policies on the ground

Despite the existence of a wealth of policy and legislation, there is little evidence of practical implementation and therefore limited impact for those being affected by disabilities.

“Children with disabilities are not the first priority in Uganda – they are in a secondary category, which shows government thinking on the issue. The

primary categories are street children, children in conflict, children who are heading families and HIV/AIDS orphans. We need key prioritisation of this category.”

Connie Kekihimbo, Katalemwa Cheshire Home for Rehabilitation Services – Kampala, Uganda

“Now we have the Disability Act. Just understanding the meaning of disability in Sierra Leone is a problem itself. It’s a matter of being proactive in addressing the issue of disability in Sierra Leone. That’s the question – are we? We are not.”

Alpha Kamara, Leonard Cheshire Disability – Freetown, Sierra Leone

Full implementation is unlikely to take place unless policymakers include provisions that compel actors to comply and include penalties for those who do not.

“I think the biggest problem is that there is no law at the moment which actually compels designers [of buildings] to consider having structures that will be fully accessible to people with disabilities. So I think to make a step that would eradicate this challenge is by first working with the law. Putting out policies that will actually compel designers and architects in their designs, so accessibility is actually promoted.”

Chipuso Kavimbi, Engineering Institute of Zambia – Lusaka, Zambia

Evening some cases, a more pro-active approach, including seeking legal redress, is needed to ensure implementation takes place.

“There are a lot of laws in Sierra Leone we do not pay attention to. I think people with disabilities have to work to get it in force. If, for example, they want to get into a building and they can’t, and they find a lawyer and go to court about it, then people will pay attention. But if they just let it rest then nothing will happen.”

Leslie Clarkson, Consulting Engineer – Freetown, Sierra Leone

10. Persistent negative public, official and parental attitudes

There are widespread reports of the negative attitudes towards disability that persist at every level in almost all societies, and which can work to prevent the development of a truly enabling environment for people with disabilities.

Prejudice and discrimination, whether deliberate or prompted by negligence or ignorance, starts within the families of children with disabilities and percolates up through grassroots communities and all strata of society to the upper echelons of government.

“There is still a general poor attitude. Here, traditionally, people look at a disabled person as a curse, as a misfit, as somebody not worth being near others, and because that has come a long way it is still within the people.”

Aloysius Kiribaki, Sense International Uganda – Kampala

“My point is that there has been a total, total collapse for the civil service structure. They just sit in their offices. They are not doing what they are supposed to do. So, that results in a

lack of support and supervision. If one school gets away with that poorly constructed building and it stands, that in itself provides motivation for the next school to build that way. If a hospital facility comes up and does not care about anything about accessibility and is licensed, that in itself does not provide a motivation to the next investor in health facility to take account of accessibility standards. So, government ineffectiveness and lack of supervision are really key problems."

Joseph Walugembe, Action on Disability in Uganda – Kampala, Uganda

A change in attitude and public perception has to come from within the disabled community. People with disabilities must work to change attitudes and, if necessary, fight for their entitlement to equality.

"Although some of us do go to school and get jobs – most people don't see the value in us. We are 10 per cent. How many among the 10 per cent are worth being mentioned? Are these worth giving something to? Because out of the 10 per cent you find that the

bigger majority is asking for money. They will always come asking – 'will you please give me?' not, 'will you please help me?' So, we have that dependency syndrome. Financially and otherwise – so unless we really change from that perspective of showing ourselves as beggars then the attitude will always be bad."

Disabled adult focus group participant – Kampala, Uganda

"There must be an intrinsic something from them [people with disabilities]. It must come from their hearts, that, yes even though we are in this situation, we have a role to contribute to national development. Let us move away from this alms giving, this alms receiving. There is no dignity in begging. So, it has to come from them as well. These rights have to be given to them, but they also have a responsibility for improving themselves. So whilst the government is pushing harder and harder for them, they also have a responsibility."

Alpha Kamara, Leonard Cheshire Disability - Freetown, Sierra Leone

CHAPTER 4

4.1 RECOMMENDATIONS

“Personally, I’m convinced that no man is really opposed to change. So it is really only a question of time, because the Government has committed itself by ratifying the UN Convention. We are still putting pressure to government to implement the UN Convention. I believe within five years’ time you will find changes.”

**Aloysius Kiribaki, Sense International
Uganda – Kampala, Uganda**

Respondents from all the study cities were very clear about what needs to happen next in their cities and countries if full inclusion, accessibility and equality are to be achieved for people with disabilities. With one or two exceptions, most remain optimistic about the future, though all recognise the magnitude of the challenges facing stakeholders in achieving implementation of UNCRPD in their countries.

The following key recommendations for action emerged from the study.

1. Commit to implementation

Respondents uniformly acknowledge the existence of positive and comprehensive policy and legislative frameworks in their respective countries. The call on government and other responsible agencies now is to commit to implementing policies on the ground.

“We want to see a proactive approach by all actors – government, community stakeholders – everybody on board that supports the action towards lifting people with disabilities out of poverty. To popularise the Disability Act, take it down to community level, involving a lot of people in doing this, including the people with disabilities themselves – they have to be involved so that the government is aware of the issues. In doing this I think a remarkable progress will be made in improving the lives of people with disabilities.”

**Alpha Kamara, Leonard Cheshire
Disability – Freetown, Sierra Leone**

States parties to the UNCRPD should publish clear, costed and time specific plans for policy implementation. Progress should be monitored, in accordance with UNCRPD directives, by an independent agency with powers to make recommendations and call failing state, public and private actors to account.

2. Introduce clear sanctions for failure to comply with laws and regulations

Respondents were clear on the need to have policy and regulatory frameworks with ‘teeth’, allowing sanctions to be applied to those who fail to comply with clear legal requirements. Many feel that too many policies currently in force are insufficiently enforceable, allowing implementing agencies to comply only

partially, or avoid compliance altogether, without consequences. This is particularly relevant in terms of access to the built infrastructure and transport, as testimonies were littered with examples of failure to comply with regulations on accessibility.

I would want to see the environment made accessible, because for me, without a fully accessible environment, we will never be able to access our rights. More than that, we need government to enforce the implementation of the law – because if government is not coming in and saying ‘this must be done’ we are depending on the mercy of the implementers and that’s dangerous to us.

Meldah Tumumunde, Uganda National Action on Physical Disability - Kampala, Uganda

“The legal framework needs to be adjusted so that it gives more punitive measure for those people who do not comply with requirements. At the moment it’s more of a negotiated settlement.”

Michael K Kabungo, City planning Department, Lusaka City Council – Lusaka, Zambia

“The clear priority is enforcement. I don’t care honestly what you feel about a ramp – whether it looks ugly or beautiful – but the point is that if it is a law and a requirement, may you please comply?”

Joseph Walugembe, Action on Disability in Uganda – Kampala, Uganda

Laws, policies, and regulations should be backed by clearly defined sanctions enforceable against those who fail to comply. States parties should take measures to promote awareness of these sanctions to relevant stakeholders.

3. Prioritise people with disabilities in resource allocation

States parties are consistently failing to make enough resources available to bring about UNCRPD implementation. Recognising that people with disabilities are among the poorest and most excluded members of society and prioritising their needs in the implementation of country development and growth plans is a pre-requisite to achieving equality of opportunity. Failing to do so will ultimately lead to the failure of poverty alleviation programmes, as people with disabilities form such a large proportion of the underclass in all of the study countries. Prioritising budgets in their favour, to bring about access to education, health and employment and to enable people with disabilities to participate fully in their societies, will help lift them from poverty and dependency and turn them into contributors to their countries’ economic growth and prosperity.

“We need to see resources released. We have the skills, but not enough resources. We need funding and the skills to be able to realise the dream.”

Dolorence Were, Uganda Society for Disabled Children – Kampala, Uganda

“I would wish that in five years we would have a Lusaka where people with disabilities are able to interact

freely in the society – freely in the fact that certain basics are made available so that they can lead as normal a life as possible. This will mean that government must do its part and civil society as well. In planning and executing policies all interested parties will have to take into account issues of disability as they take into account other areas of life.”

Francis Chilufya, Zambia Agency for People with Disabilities – Lusaka, Zambia

States parties should actively prioritise resources to meet the needs of people with disabilities across all areas of government responsibility.

4. Improve statistical collection methodologies to capture accurate data on numbers of people with disabilities

The WHO currently estimates that approximately 15% of any given population is living with a disability of one sort or another. Yet, as this report demonstrates, states parties are consistently under-estimating the population of people with disabilities in their countries. This creates an unwillingness to invest sufficient resources to meet their needs. Developing strategies that will enable improved capturing of data and knowledge of actual numbers will inevitably create an imperative to increase resource allocation to support this seriously under-served, significant population.

“Yes, we have a number which has been provided by central statistics through the population census which is done every

10 years, but the disability movement is disputing the statistics. We have refused the statistics thinking they are underestimated. We don’t know what standard they have been using for checking people with disabilities and we have evidence that the enumerators were not able to identify specific disabilities – so we believe there has been an underestimation.”

Wamundila Waliuya, Zambia Federation for the Disabled – Lusaka,

Zambia States parties should develop data collection methodologies and implement strategies to record accurately the numbers of people with disabilities, and clearly classify their disability types in accordance with internationally recognised definitions.

5. Explicitly integrate disability across all government departments and agencies

Whilst respondents in some study countries reported that efforts to mainstream disability across government departments were being taken, the process has yet to be fully implemented.

“Each ministry must have a disability plan in their programme, with enough resources to implement those programmes.”

Masser Ssenyando, Sign Health Uganda – Kampala, Uganda

“Just like HIV has been mainstreamed, we would want disability to be mainstreamed. Let it be discussed and planned for. Our desire is to ensure that information is flowing from the ground to ministry headquarters –

which currently isn't the case – so that they start planning for this. The national cake is for everyone, even the children with disabilities. They should be reached, whether they are in the rural areas, whether they are in the urban areas. We want government to partner with us.”

Precedence Gertrude Kapulisa, Community Based Interventions Association - Lusaka, Zambia

States parties should appoint individuals in each ministry with specific responsibility for disability, to ensure that the issue is properly reflected in all aspects of government policymaking.

6. Promote inclusivity across civil society

Respondents recognised the need to engage with other civil society organisations, to encourage them to include people with disabilities in their operational activities as a means of achieving full inclusivity.

“We need more stakeholders working together – we’re beginning to see other stakeholders who represent children generally, or on other issues, beginning to consider the issue of disability.”

Connie Kekihimbo, Katalemwa Cheshire Home for Rehabilitation Services - Kampala, Uganda

States parties and disability-focused NGOs and DPOs should work to mobilise the rest of civil society to

include reference to children and adults with disability in their programming and activities.

7. Invest in training and capacity building for key service providers across all sectors

There are clear gaps in the knowledge and capacity of professionals in education and health, and other public and private service providers, which need to be addressed if children and adults with disabilities are to achieve their rights and full potential.

“A conducive policy environment by itself is not enough. I think there has to be a lot of capacity building initiatives for the implementer. And there is also a need for awareness campaigns for the implementers and other important capacity building measures from the national level to the local level.

Teshome Deressa, Federation of Ethiopian National Association of People with Disabilities – Addis Ababa, Ethiopia

“Education: it is key. If they are educated, their future can be bright.”

Beatrice Guzu, National Union of Women with Disabilities of Uganda – Kampala, Uganda

States parties should invest in training and capacity building – particularly in the fields of education and health - to improve the entitlement, and equality of access, to these services for children and adults with disabilities.

8. Increase international donor community support for children and adults with disabilities

Failure to expressly address the needs of children and adults with disabilities in the Millennium Development Goals has undoubtedly hampered efforts to improve their status and progress. Other marginalised groups in society have been the focus of international poverty alleviation efforts. Donors are beginning to recognise the importance of mainstreaming people with disabilities into their support programmes, but more needs to be done, despite the recessionary global environment.

“I know that USAID is in the process of developing a disability strategy and once it's done anyone sending a proposal will need to incorporate a strategy for disability. From the international and national disability movements there will be some changes that we'll see in the next few years. But it might not be as we hope, because it needs a very huge amount of financial resources and considering the country's financial capacity it might not be easy. And we cannot totally depend on international sources of funding – especially nowadays with the international economic crisis.”

Betelhem Abebe, Ethiopian National Disability Network - Addis Ababa, Ethiopia

International donors should develop disability alleviation strategies, ensuring that all funding proposals from all sources reflect and take account of the needs of children and adults with disabilities as a particularly vulnerable group.

9. Pro-actively promote public awareness about the rights and needs of people with disabilities to create an enabling environment for positive change

NGO and DPO efforts to raise awareness of the situations faced by people with disabilities and to improve on prevailing negative attitudes at family, community and national levels are not, of themselves, going to be sufficient to achieve a favourable shift in public perceptions. A national problem requires a national response, which only governments can facilitate. It is the responsibility of governments to engage in large-scale programmes of awareness and sensitisation, working in partnership with community groups, DPOs and NGOs to change hearts and minds to create an enabling environment for improving the lives of people with disabilities.

“The most important thing is that once everybody is positive towards the needs of children with disabilities, they will be able to make a plan for them – and once there is a plan they will be able to benefit like every other child in this country. It begins from your neighbour – if you look at me as someone who has no importance to society then I will never benefit. You can have all the money, but because of the perception and exclusion from the family they [children with disabilities] will not benefit.”

Connie Kekihimbo, Katelemwa Cheshire Home for Rehabilitation Services - Kampala, Uganda

“We hope that government will take issues of disability very, very seriously. We hope they will take and popularise the Disability Act down to community level. That is important, if there is the right information....If the information is streamed down to the community what we will see is a change in attitude towards people with disabilities. It doesn't stop at enacting – it doesn't stop at just creating the policy. You have to take it down, provide the support, where necessary.”

Alpha Kamara, Leonard Cheshire Disability – Freetown, Sierra Leone

States parties should invest in national programmes of awareness and sensitisation, working in partnership with community groups, DPOs and NGOs to change general public, community and family attitudes to people with disabilities.

4.2 CONCLUDING REMARKS

“For me, today, I believe Sierra Leone has come of age after celebrating its 50th anniversary. More needs to be done to make sure that it can reach the UN Millennium Development Goals, and having consultative meetings helps to get people to know what's really happening at the grassroots. I believe things will work out right if you continue to move on like that.”

Edward Emmanuel, One Family People – Freetown, Sierra Leone

The United Nations Convention on the Rights of Persons with Disabilities represents a milestone in the human rights movement. Following 40 years of campaigning and struggle, dating back to the American civil rights movement which inspired it, the governments, groups and activists working on behalf of people with disabilities finally achieved comprehensive recognition of those people's entitlement to participate in society on an equal footing.

The fact that so many nation states have so readily and rapidly embraced and signed on to the treaty gives some indication of how long overdue the Convention was, and how pressing and vital the need to transform the lives and opportunities of people with disabilities around the world.

With the Convention now signed and ratified across much of the planet, the challenge remains to see it fully implemented. Nowhere is that challenge greater than on the continent of Africa. Not only are African countries behind much of the rest of the world, in terms of their historical treatment and care of people with disabilities, accessibility of existing infrastructures and paucity of service provision, but they also face the greatest economic challenges and competing developmental priorities in bringing about the huge transformations required. Yet the evidence from the five countries and cities studied shows that the process of UNCPRD implementation has commenced, and that that process appears to be inevitable and irreversible.

Political will for reform is apparent in all the study countries. The only questions that remain are to do with the timeframe for implementation; the issue of changing the hearts and minds of the able-bodied majority to acknowledge and embrace the rights of their disabled brothers and sisters; and the allocation of sufficient resources to bring about the necessary transformation of every aspect of society. These are monumental challenges and, some might argue, insurmountable in the current global economic environment. Yet NGO and DPO commentators, and people with disabilities young and old in all the study cities, remain broadly optimistic about the future.

Given the scale of the challenges, it will clearly take a generation or more before people with disabilities achieve anything like full equality of opportunity in the study countries. Governments must act to implement the positive policy

frameworks they are creating; NGOs, DPOs and individuals living with disabilities must mobilise and unite to monitor implementation, and be prepared to challenge and call government, public and private institutions to account; and the international donor community must prioritise and include the needs of people with disabilities in its support for programmes to achieve the Millennium Development Goals.

The true inheritors of efforts being made in the study countries today are likely to be the current generation of children with disabilities. If the promise of the UNCRPD is achieved in each of the study countries, then they will be the first generation of adults with disabilities to take their place as members of societies that recognise their rights as citizens to live and participate on an equal footing with their able-bodied counterparts, without let or hindrance.