

Multi-Country Overview of Barriers and Opportunities for Children and Adolescents with Disabilities in the Eastern and Southern Africa Region SYNTHESIS OF EIGHT COUNTRY REPORTS

November 2022

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Foreword

Globally nearly 240 million children have some form of disability, around 29 million of them live in Eastern and Southern Africa. This represents 1 in every 10 children. Children with disabilities experience life very differently compared to other children. Their life is often marked by exclusion and compounding deprivations. Compared to children without disabilities, children with disabilities are more likely to be stunted and not attend school, whereas children with disabilities from poorer households are even further disadvantaged.

This baseline situation analysis provides an overview of the barriers and opportunities children with disabilities face in Kenya, Lesotho, Mozambique, Rwanda, Uganda, Zambia and Zimbabwe. Much progress has been made to address the rights and needs of children with disabilities in the region, particularly with regard to legal and policy frameworks. However, the analysis draws attention to the lack of implementation of laws and policies, rooted in the lack of management and coordination mechanisms, limited disability disaggregated data, and capacities and budgeting gaps. Services are largely non-existent and not available at community level. Prevailing negative attitudes and behaviors affect demand for services. For example, many parents hide children with disabilities at home and do not send them to school. Enduring poverty among families with children with disabilities also affects access to services. Without social protection measures, families are not able to address additional disability related costs such as transportation and assistive devices.

Governments are recommended to adopt measures to address negative social norms, establish necessary services at community level and build capacity of frontline workers to deliver inclusive quality services, ensure national and local coordination of services, cost expenditure of services and ensure sufficient allocation of budget for community-based services, and strengthen national statistical systems to ensure collection and use of disability disaggregated data across all sectors.

UNICEF is committed to continue collaborating with government and other partners to address the recommendations of this analysis. Sustainable development starts with those furthest left behind.

Mohamed M. Malick Fall Regional Director UNICEF Eastern and Southern Africa

Abbreviations and acronyms

| ACPF | African Child Policy Forum |
|------------|---|
| CDC | US Center for Disease Control |
| CEDAW | UN Convention on the Elimination of Discrimination Against Women |
| CFM | Child Functioning Module |
| CPIMS | Child Protection Information Management System |
| CNAS | National Council of Social Action, Mozambique |
| CPWA | Children's Protection and Welfare Act 2011, Lesotho |
| CRC | UN Convention on the Rights of the Child |
| CRPD | UN Convention on the Rights of Persons with Disabilities |
| CSO | Civil Society Organization |
| DCF | Disability Coordination Forum, Rwanda |
| DHIS2 | District Health Information Software, version 2 |
| DHS | Demographic and Health Survey |
| DMIS | Disability Management Information System |
| EARC | Educational Assessment and Resource Centres, Kenya |
| EICV | Integrated Household Living Conditions Survey, Rwanda |
| EMIS/IEMIS | (Integrated) Education Management Information System |
| ESARO | UNICEF Eastern and South Africa Regional Office |
| ESAR | Eastern and Southern Africa Region |
| FCDO | Foreign and Commonwealth Development Office, UK |
| GBV | Gender-based violence |
| HIV-AIDS | Human immunodeficiency virus, acquired immune deficiency syndrome |
| HDI | Human Development Index |
| HMIS | Health Management Information System |

| ICT | Information and Communication Technology |
|---------|--|
| INGO | International Non-governmental Organisation |
| ISO | International Organization for Standardization |
| KII | Key Informant Interview |
| MCDSS | Ministry of Community Development and Social Services, Zambia |
| MGLSD | Ministry of Gender, Labour and Social Development, Uganda |
| MICS | Multiple Indicator Cluster Survey |
| MINALOC | Ministry of Local Government, Rwanda |
| MINEDH | Ministry of Education and Human Development, Mozambique |
| MoSD | Ministry of Social Development, Lesotho |
| Μου | Memorandum of Understanding |
| MPI | Multi-dimensional Poverty Index |
| NCPD | National Council of Persons with Disabilities; Rwanda, Uganda |
| NCPWD | National Council for Persons with Disabilities, Kenya |
| NDFPWD | National Development Fund for Persons with Disabilities, Kenya |
| NGO | Non-governmental Organization |
| NORAD | Norwegian Agency for Development Cooperation |
| OPD | Organization of Persons with Disabilities |
| PWDE | Persons with Disability Equity Act, Lesotho |
| SDG | Sustainable Development Goals |
| SINTEF | Stiftelsen for industriell og teknisk forskning, Norway |
| SNE | Special needs education |
| UNFPA | United Nations Population Fund |
| UNICEF | United Nations Children's Fund |
| USAID | United States Agency for International Development |
| WASH | Water, sanitation and hygiene |
| WGQ | Washington Group Questions |
| WHO | The World Health Organization |
| ZAPD | Zambia Agency for Persons with Disabilities |
| | |

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Executive Summary

Purpose and methodology

This report is intended to inform UNICEF's work¹ to advance the rights of children and adolescents with disabilities through multi-sectoral programming and social protection measures. It is based on eight country assessments covering the countries of Kenya, Lesotho, Madagascar, Mozambique, Rwanda, Uganda, Zambia and Zimbabwe.

The country assessments are based on original desk research and key informant interviews undertaken in 2021 by a small group of in-country researchers. They contain valuable up-to-date information, data and insight. The summaries and annexes for each assessment provide further specifics and useful catalogues of laws, stakeholders, civil society organisations and donor programming and set out next steps.

This report adds a layer of regional analysis to the assessments. It is designed to be a compact summary², highlighting commonalities and particularities to inform strategic recommendations for UNICEF, donors and governments on how the situation for children with disabilities can be improved.

It is hoped that this regional report and the country assessments will be read together, shared widely and treated as essential tools to inform and enrich disability inclusion work in the Eastern and Southern Africa region (ESAR).

Findings

Overview

Although there have been improvements since the Convention on the Rights of Persons with Disabilities (CRPD) came into being, the needs and contributions of persons with disabilities continue to be underrepresented globally and those of children with disabilities even more so. Their neglect is further cemented when placed under the umbrella categories of 'children' or 'persons with disabilities', reducing their visibility even further, as happens in the Eastern and Southern African Region (ESAR) countries with the exceptions of Rwanda and Uganda which have more explicitly included children with disabilities in mainstream policies and programmes.

Social norms

Negative personal and social beliefs, behaviours and norms persist across the region. These attitudes are based not only on traditional and folk beliefs but also linked to more 'modern' beliefs, including some associated with major world religions³. At worst, children and adults with disabilities are considered dangerous outcasts, and sometimes seen as 'possessed' or supernatural. Abuse, wilful neglect and murder, including the infanticide of children with disabilities, is justified rather than condemned within the dominant norms⁴.

- 1 Supported by the Norwegian Agency for Development Cooperation (NORAD)
- 2 Additional desk research provided further clarification where necessary
- 3 This is an area for more research the assessments did not consider beliefs and practices of major religions; however Christianity has traditionally viewed disability as something that can be 'prayed away' and beliefs that great faith and financial contributions can 'cure' it are associated with evangelical sects, including 'mega-churches' such as those found in Zimbabwe and Kenya.
- 4 However, there appears to be a lack accurate confirmation of this. Data is also unavailable on medical or home-induced abortions in cases of suspected foetal abnormalities or genetic issues. Obviously there are great sensitivities around these issues and collection of such information is difficult and possibly discouraged by research ethics committees.

Constitutional and legal provisions

Provisions exist in all countries which explicitly or implicitly cover children with disabilities, usually through a country's constitution and also in specific legislation which implicitly supports the Convention on the Rights of Persons with Disabilities. Legal provisions against discrimination and for equal rights and/or opportunities are also common. However, only Rwanda and Zimbabwe have significant levels of mainstreaming of disability inclusion into policies and programmes beyond the education sector. Legal provisions in other ESA countries give little attention to children with disabilities in relation to nutrition, WASH, child protection, social protection and ICT.

Management and coordination

Governments typically have several coordination bodies and a range of mechanisms and working groups. These will usually be managed by the main national body overseeing disability work. There are sectorlevel groups that might take a view on children with disabilities and an overall NGO coordination body⁵. Institutional arrangements are also intricate. Disability inclusion is commonly the responsibility of the whole of government; the ministry with overall charge is rarely influential or well-resourced.

Budget expenditure, allocation and disbursement

While there has been a noticeable increase in interest and support from the donor community, particularly on the heels of State reports to the CPRD Committee, national budgets remain low and are usually focused on education. They often do not even cover programming to meet other basic needs for children with disabilities.

Data

Quality and disaggregated data on children with disabilities remain fundamentally scarce and inconsistent across many sectors. This limits demand, and evidence-based policy, programming and advocacy. National statistical systems (NSS) struggle to generate consistent, timely and relevant data and this makes it difficult to frame coherent, clear and well prioritized response to demand.

For example, varying approaches to measuring disability across censuses and surveys mean that often data are not comparable even within countries. Furthermore, there are virtually no sectoral data related to children (and adults) with disabilities on access to water, sanitation, and hygiene, including child protection services. On health, nutrition and violence-related indicators, data are either far too sporadic and seldom disaggregated by disability. There are increasing efforts to remedy these shortcomings; some countries have signed up to the Inclusive Data Charter and implementation of national MICS that can provide population-level estimates on the situation of children with and without disabilities.

Supply side: Access to services, facilities and information

The country assessments found that;

- · Gender disparities and girls' rights are neglected;
- Inclusive education is generally a strong policy priority but not implemented at ground level;
- National budgets do not properly fund the training of specialist frontline workers such as special education teachers or trained therapists;
- There is a serious lack of policy or action to make the physical environment accessible to all;
- Assistive devices are prohibitively expensive;
- Government institutions, and especially health services, are rarely properly equipped to support communication and information exchange with children and adults with disabilities

Demand side: Financial access & direct and indirect costs

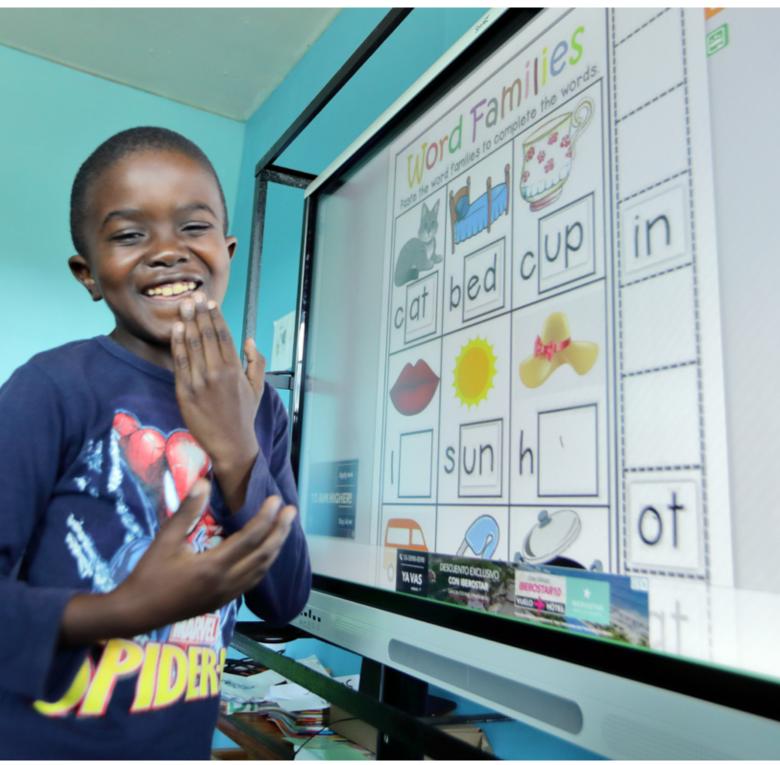
Poor data makes it difficult for governments and donor partners to effectively reach children with disabilities; and in this region, any assistive equipment beyond basic mobility devices is beyond the reach of most ordinary families and national health and education budgets.

The country assessments found:

- Families with children with disabilities tend to be poorer than other families, yet face additional costs for care and service access.
- Education costs are a barrier. Most countries do not fund school attendance beyond primary level even where secondary education is mandated by law.
- Persons with disabilities usually have higher healthcare costs and insurance schemes often restrict care for disability related conditions.
- Assistive technology, other than basic mobility support, usually has to be imported and so is expensive and in short supply.
- Costs are gendered, in the sense that most caregivers are female and their access to education and income-earning potential is likely to be restricted if they care for a person with a disability.

The country assessments provide the foundational research for this regional report. For details and specifics regarding method, evidence reviewed and limitations,⁶ the reader should refer back to the relevant country assessment. To facilitate such cross-referencing, this regional report largely follows the content and order of the country reports.

6 This approach avoids overuse of footnotes so that this regional report remains succinct and easy to read. Citations, references and detail about methodology, information sources, evidence consulted, grounds for their analysis and conclusions are in the country assessments.



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1 Introduction

Purpose and approach of the regional synthesis

UNICEF, in partnership with the Norwegian Agency for Development Cooperation (NORAD), is supporting eight countries in the Eastern and Southern Africa Region (ESAR) to advance the rights of children and adolescents with disabilities through multi-sectoral programming and social protection measures at country level. This report is intended to inform that work. It offers a regional overview based on analysis of country studies commissioned in 2021-2022 by UNICEF Eastern and Southern Africa Regional Office (ESARO) and carried out by Forcier Consulting. The countries examined are Kenya, Lesotho, Madagascar, Mozambique, Rwanda, Uganda, Zambia and Zimbabwe.

The analysis has been guided by the Convention on the Rights of the Child (CRC) and the Convention on the Rights of Persons with Disabilities (CRPD) aiming to reach an overall understanding of the deprivations and inequities faced by children and adolescents with disabilities in the eight countries while highlighting opportunities for advancement.

Country-level findings are intended to support disabilityinclusive policies and advocacy efforts and guide programming efforts at the country level; meanwhile, this synthesis aims to summarise the knowledge and evidence presented in those studies⁷ to strengthen regional partnerships, strategies, guidance, advocacy and communication and to address gaps, barriers and opportunities.

Methodology

The methodology for the regional synthesis began with close readings of each of the eight country reports and a review of key informant interviews. This was followed by data extraction⁸ and summarising the facts and figures from the secondary data and primary qualitative data according to each of three determinants: enabling environment; and supply- and demand-side conditions.

Factors contributing to an enabling environment of children with disabilities:

- Social norms, practices and beliefs
- Legislation/policy; adequacy of laws and policies
- Management; coordination roles and accountability; partnership
- Budget expenditure, allocation and disbursement of resources

Supply-side conditions:

- Access to adequate services, facilities or information
- Availability of essential commodities/inputs

Demand-side conditions:

- Social norms, practices and beliefs
- Financial access; direct and indirect costs for services/practices

Secondary data drawn on for the country reports include publicly available datasets such as the Multiple Indicator Cluster Surveys (MICS), texts of national and international laws, documentation of programmes targeting children with disabilities, and previous situation analyses on children with disabilities in the eight countries.

⁷ The country studies undertaken by Forcier for UNICEF are referred to throughout this report as 'country assessments'.

⁸ Extraction tables, showing which information was found in each report, are provided as annexes. Construction of these tables is shaped by the information provided by the original research.

The primary data is drawn from key informant interviews with stakeholders in each country and at the regional level. These interviews were conducted with donors, government ministry officials, multilateral organizations, non-governmental organizations, service providers, and statistics bureaus. The table below presents the type and number of interviews conducted in each country.

The analysis derives from the individual country assessments, using the same text at times to stay true to the original research. Relevant citations are provided where additional sources were used. Whenever possible, examples from every country are provided with case studies and highlights of the challenges, opportunities and successes. However, differences in data collection and approach mean there cannot be complete uniformity in the type or depth of information unearthed by the country researchers and so, at times, illustrations are country-specific.

Note: The country assessments provide the foundational research for this regional synthesis and this is where citations and more granular detail can be found.⁹

Situation of children with disabilities in ESAR

There has been great progress in the Eastern and Southern Africa Region in recent decades. More children survive and they have more opportunities to reach their full potential. Since 1990, the under-five mortality rate has dropped by 66 per cent (from 165 deaths per 1,000 live births in 1990 to 55 deaths in 2019), while stunting prevalence among children under five decreased from 53 per cent in 1990 to 32 per cent in 2019 – a decline of 39 per cent. In primary education before the COVID-19 pandemic, fewer children were out of school than ever before, with education systems able to cut the out-of-school rate by more than half (36 per cent in 2000 to 17 per cent in 2018). However, much of that progress did not reach children with disabilities, and what progress had been made for them has been reversed since the pandemic.

The 2011 World Disability report estimated that the prevalence of disability in 2011 among children aged 0-14 years was 5.2 per cent. However, in sub-Saharan Africa the rate among children aged 0-14 was estimated to be higher than the global average – at 6.4 per cent

| Country | Disability service providers | Donors | Government | Multilateral | NGO | Statistics bureau |
|------------|------------------------------------|--------|------------|--------------|-----|----------------------|
| Kenya | 3 | 0 | 3 | 1 | 5 | 1 |
| Lesotho | 3 | 0 | 5 | 2 | 4 | 0 |
| Madagascar | 4 | 1 | 3 | 2 | 3 | 1 |
| Mozambique | 4 | 1 | 3 | 1 | 5 | 1 |
| Rwanda | 4 | 1 | 2 | 1 | 5 | 1 |
| Uganda | 2 | 0 | 4 | 1 | 3 | 1 |
| Zambia | 4 | 1 | 3 | 1 | 5 | 1 |
| Zimbabwe | 2 | 1 | 0 | 1 | 4 | 0 |
| Regional | 0 | 0 | 0 | 5 | 2 | 0 |

Table 1: Key informant interviews by country

9 This approach avoids overuse of footnotes so that this regional report remains succinct and easy to read. Citations, references and detail about methodology, information sources, evidence consulted, grounds for analysis and conclusions can be found in the country assessments.

– mainly driven by inadequate healthcare and nutrition, leading to higher rates of impairment that are preventable or treatable if detected early or supported adequately. Disability is also highly correlated with poverty. The most recent data report on children with disabilities showed one in ten of the world's 240 million 0-17 year-olds have a disability.¹⁰ In ESAR, the disability prevalence among children aged 0-17 years is one in ten (an estimated 28.9 million).

Good health, nutrition and quality inclusive education are fundamental for building prosperous societies and fulfilling the rights of all children. However, children with disabilities are often marginalized and excluded from access to services and meaningful participation. Children with disabilities also are more likely to be partially immunized or not immunized at all. While malnutrition can cause disability, children with disabilities are also more likely to be impacted by malnutrition due to lack of access to food and discrimination; for instance, they may be given less food when families need to prioritize the use of scarce resources.

Children with disabilities are more likely to be denied their right to education. Furthermore, schools are not

yet inclusive enough to cater for their needs, and those who do attend schools are likely to have lower performance in reading and numeracy than their peers. Children with disabilities face three to four times higher risk of violence and abuse than children without disabilities and this is likely aggravated by the lack of social support for those who care for them, and discrimination, physical violence and killings based on misconceptions and superstition. Incidents of physical and sexual abuse are greater when children with disabilities are placed in institutions.

The COVID-19 pandemic has also threatened to leave the most marginalized population groups even further behind. Evidence points to limited measures by governments responding to the pandemic to protect the health and safety of children with disabilities in communities and institutions and their access to healthcare, medicine, life-saving supplies, food and education. Children who relied on schools for access to food and medicine were largely left unassisted when schools closed and remote learning (online, radio, TV) programmes were rarely able to take into account the needs of children with disabilities for assistive technology and other help to access content.



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2 Overview and synthesis

2.1 The enabling environment

Social norms

Challenges and opportunities

Overall, negative personal and social beliefs, behaviours and norms persist across the region. Unfortunately, children with disabilities are considered to have little value and girls with disabilities are further undervalued due to gender stereotypes around marriage and childbearing. The assessments for Lesotho and Rwanda show children with disabilities are generally considered to be incapable of feeling or forming social connections. Dehumanising and devaluing creates the conditions for further mental, physical, and sexual abuse, denial of affection and support, bullying and harassment, and forced confinement and denial of basic rights and services – including by family members.

Levels of care and support are impacted by norms that typically place disproportionate responsibility for all caring roles on female relatives. ¹¹ Mothers and grandmothers are typically the primary carers of children with disabilities, as with most children. In Kenya, Rwanda and Uganda it is reported that it is not unusual for fathers to abandon the family, increasing the burden on the mother. Assessment respondents did not examine the potential role siblings might play in caring for siblings with disabilities and this is an area for further research that asks how sibling carer responsibilities might be determined by gender, how this might impact study and play, and what impacts stigma has on siblings.

Stigmatizing attitudes which associate disability with bad luck and lays blame on families (particularly on mothers) contribute to the isolation of the children and their carers.¹² A common belief across the region is that the mother must have broken a taboo for which the disability is the divine punishment. In parts of Mozambique and Zambia, people often avoid water sources used by mothers of children with disabilities fearing contamination that could spread the disability. Stigma appears to attach predominantly to the children with disabilities and their mothers rather than to fathers.¹³ As a result, children with disabilities are often hidden away, not registered at birth and not allowed to socialise with other children. In Zambia, it is reported that to avoid marginalisation, parents may pass children with disabilities to other relatives. In Rwanda, respondents reported families removing children with a disability to an institution. In Kenya, the Autism Society reports that some children with autism are chained up at home, and others are locked in institutions catering for persons with mental health issues. Families often do not take advantage of provisions which could help a child with a disability get a strong start in life, such as seeking timely healthcare or enrolling them in school.

Gender norms impact the treatment and experience of children with disabilities. The Uganda Functional Difficulties Survey (Government of Uganda, UNICEF, 2018) found that girls with disabilities were less likely to be currently enrolled in school or to have ever attended school, compared to boys with disabilities. Unusually, the Uganda Functional Difficulties Survey showed that boys with disabilities are more likely to report experiencing sexual and physical violence than

13 For further specific examples of negative social beliefs by country please see Annex One.

¹¹ See The Girls' Friendliness Index in Annex Ten for ranking of the ESAR countries on attitudes to girls.

¹² It seems likely that families with more than one member with a disability become even more isolated.

girls with disabilities,¹⁴ although the anecdotal evidence for most countries is the opposite, possibly pointing to an area in need of further research. Overall, it is widely acknowledged that girls with disabilities face additional challenges; for instance, the perception that they are less able to defend themselves or seek help or that being unable to fulfil expected roles for women and girls will make them particularly vulnerable to abuse and exploitation.¹⁵

Negative attitudes to children with disabilities are reported even among service providers such as schools and health care facilities in Kenya, Lesotho, Mozambique, Uganda and Zambia where respondents said children with disabilities are looked at as a 'waste of resources'. Some teachers and parents are said to resist inclusion as it reduces the schools' mean score, or means less attention for other children.¹⁶ Even when a teacher or health care provider is supportive, they rarely have adequate knowledge, capacity and resources to provide for specific needs of many children with disabilities.

The combined impact of these beliefs is enormous. Respondents and independent research in several countries state that social norms are *the* crucial factor in the welfare of children with disabilities. In Madagascar a UNICEF study¹⁷ found that 'although worsened by poverty, deprivation and inequalities for children with disabilities are generally caused by cultural factors and discrimination within the household'. In Zimbabwe, a respondent said that 'a combination of religious and cultural beliefs and practices pose the biggest barriers to the rights, welfare and inclusion of children with disabilities'.

Addressing negative beliefs

Case study from the Zimbabwe Country Assessment

In Zimbabwe most children with disabilities come from extremely poor families with a high number of illiterate household members who have little awareness of the causes of disability. Such households tend to subscribe more to negative traditional beliefs and practices such as seeking out spiritual and herbal treatments to 'cure' the disability.

The Ministry of Public Service, Labour and Social Welfare are, therefore, using different media platforms to raise awareness and generate positive attitudes towards persons with disabilities. This includes challenging myths that associate disability with witchcraft, evil spirits and the breaking of traditional taboos. Additionally, UNICEF has been collecting evidence to inform social interventions and improve public attitudes; and many NGOs engage with traditional leaders and local people in communities through advocacy and dialogue to influence positive change towards children with disabilities.

However, there are indications of change in the overwhelmingly negative norms described in the country assessments. Positive attitudes are more associated with urban areas and relate more to children with physical disabilities.¹⁸ This suggests a connection between an increased visibility of children with disabilities – especially in mainstream education and mainstream media – and increases in positive attitudes.

There is a lack of evidence for all ESAR countries on the current dynamics of social norms and positive norm change around attitudes to children with disabilities.¹⁹ Similarly, little work is being done to target negative

14 In a five-country study, boys reported more physical violence than girls in 20 out of 21 categories.

15 According to the UN Department of Economic and Social Affairs, while women with disabilities are more likely to suffer sexual violence than women without disabilities or all men, the percentage of men and women with disabilities who experience violence and abuse are similar (UN Flagship Report on Disability and Development 2018, advance unedited copy). Girls with disabilities are particularly vulnerable to rape and attack where there is a belief that sex with virgins is lucky or curative.

- 16 In Rwanda teachers fear contagion and parents don't want classes to be missed.
- 17 See further reading: UNICEF, October 2020.

¹⁸ According to the country assessments the stigma attached to disability is believed to be worse in rural areas, but it is not exclusive to the remote and uneducated, also persisting in urban areas and across all sectors of society.

¹⁹ Some notable exceptions to this are; the Ugandan Functional Difficulties Survey (2017); the Kenyan report on killing and confinement of children with disabilities (2018); the report on educational barriers for children with albinism in Mozambique (2019); the report from Rwanda on violence against children and youth with disabilities in institutional settings (2018).

social norms that inform attitudes to children with disabilities. Most groups and projects representing persons with a specific disability are not primarily focused on awareness-raising and they generally support adults rather than children.²⁰

The one social norm being tackled is segregation; there is a growing emphasis on educational inclusion across the region. Evidence from Kenya suggests integration of children in mainstream schools has resulted in less negative attitudes towards some disabilities, but evidence from Lesotho concludes that norm change work (including programmes supported by UNICEF) is challenging and has not been impactful.

Limited quantitative data on how gender affects exclusion and inclusion – both for girls and boys – remains a significant gap. The assessments identified a few examples of creative projects for girls with disabilities which aim to address discriminatory attitudes and behaviours rooted in both disability and gender, such as a dance project for girls with disabilities in Rwanda which aims to reduce exclusion. While research increasingly covers such topics,²¹ overall there were few projects or programmes identified during the country assessments that focused on girls with disabilities. Those that do exist typically focus on young and adult women, such as UNFPA Mozambique's 'We Decide'.

Gender-based violence interventions all address norm transformation in some way, and there is some evidence of investments in these areas that specifically target youth with disabilities, including projects supported by UNICEF and UNFPA. Importantly, all of these interventions relate to gender issues for girls. However, across the region there remains a lack of attention to how norms around masculinities affect the socialisation of boys with disabilities, and no support or programmes of this kind were identified during the assessments.

Highlights by country

In **Kenya**, key informants state that increased visibility of and interaction with children with disabilities within communities has led to more open discussions about the well-being of persons with disabilities. The increase of inclusive and integrated schools and debates about integrated and segregated systems are encouraging more parents to have their children assessed, enrolled in education and regularly attending schools²².

In **Mozambique**, perceptions of persons with disabilities' capacity to develop and contribute to their families and communities has improved over the last decade. This gradual change has been prompted by advocacy and awareness-raising initiatives from many stakeholders. The raising of disability inclusion in mainstream information channels has been particularly important.

In **Rwanda**, there are now more children with disabilities in school. It is generally believed that infanticide of children with disabilities doesn't happen and that more parents recognize children with disabilities need protection and have rights. Recent official documents have removed dehumanizing terms for persons with disabilities.

In **Zimbabwe**, the Government of Zimbabwe and other stakeholders report that the prevalence of negative social and cultural beliefs and practices towards children with disabilities has decreased over the last decade.²³

- 20 Each country report contains an annex which details relevant programmes being undertaken by government, international agencies, donors and national civil society groups.
- 21 Studies relating to girls with disabilities and gender based violence are available for parts of Africa, for example Botswana and Malawi, but not for all ESAR countries: see further reading Kvam and Braathen, 2006 & Hanass-Hancock et al., 2018.
- 22 Nevertheless, one disability service provider noted that this trend toward acceptance of children with disabilities in schools is limited to physical disabilities, and those which are easily explained.
- 23 It goes on to say, 'The Government took strategic actions favouring a positive change on disability issues by the creation of legal, policy and institutional frameworks on disability; resulting in commitment of international donor partners to mainstreaming disability in development programs; strong and sustained advocacies by organizations of persons with disabilities and other NGOs; and sustained strategic public engagement and enlightenment using diverse channels of communication and tools.'

In **Lesotho²⁴**, **Uganda²⁵** and **Zambia²⁶**, while the country assessments note some increases in positive attitudes, the overall evidence is at best mixed.

Legislation

Opportunities and challenges

All countries except Madagascar have enshrined the rights for persons with disabilities in their constitutions and or/amendments, and the principle of nondiscrimination is mandated by the constitutions of most countries. Mozambique's constitution specifically recognizes the rights of children with disabilities. Rwanda's and Uganda's constitutions recognize the rights of persons with disabilities but do not specifically mention children. All countries assessed have specific acts covering disability issues.

Most countries have ratified or acceded to the Convention on the Rights of Persons with Disabilities (CRPD) and all except Lesotho and Madagascar have submitted reports to the CRPD Committee on its implementation.²⁷ Five countries – Madagascar, Rwanda, Uganda, Zambia and Zimbabwe – have also signed the Optional Protocol, which enables individual complaints against the state. Mozambique and Rwanda have legal systems which automatically ensure the CRPD is binding without further legislation and Madagascar has a specific ratification act (2014-31). In Zimbabwe, Parliament is yet to approve and domesticate the law.

Children with disabilities are specifically mentioned in the Mozambique Constitution, the Child Protection Acts of Rwanda and Uganda, and the Persons with Disability Acts of Lesotho and Zambia. Lesotho and Uganda have specific acts which also explicitly address the needs and rights of children with disabilities. Madagascar specifically refers to the rights of children with disabilities in its CRPD ratification act. In other countries, legal provision for children with disabilities is not specified but is implied in the use of the words 'children' or 'persons with disabilities'. While Zimbabwe's provisions are far-reaching, the Constitution refers to 'persons' and mentions children only in relation to social protection as part of the Social Welfare Assistance Act.

Many countries, including Kenya, Lesotho and Mozambique, do not have explicit provision for children with disabilities around issues of nutrition, sanitation, or information and communication technology (ICT) unless it is in the school context.²⁸ Table 2 lists some noteworthy country-specific definitions of disability.

- 24 In Lesotho, the move towards inclusive education and the increased visibility of children with disabilities in communities is believed to have led to some improvements in attitudes. However, according to the country assessment these changes are slow and piecemeal.
- 25 In Uganda in 2021-22, UNICEF funded the Interventions for Disability in Early Childhood project which identified problematic attitudes including stigma and which aimed to increase access to early learning opportunities for children with disabilities, including through awareness-raising.
- 26 The Zambian country assessment states, 'There is little evidence to understand how or if community perceptions of children with disabilities have changed in the past 10 years. Anecdotal evidence suggests that there has been a positive shift in perception where many Zambians are becoming more accepting of children with disabilities. However, other reports suggest this differs across region and socioeconomic class, with many rural and remote areas not receiving as much education and awareness-raising, in addition to (sic) specialized support services and resources around disabilities as urban areas. In remote areas especially, many cultural initiation ceremonies exclude children with disabilities, which increases marginalization and rejection from the community.'
- 27 As of 2022, Lesotho's report is overdue by eleven years, and Madagascar's is overdue by five years.
- 28 For Zimbabwe it is understood that the gaps in legal provisions for children in these sectors are in the process of being addressed.

Definitions of disability are not always given in law and when they are, they sometimes reflect only the medical model of disability.

Table 2: Defining Disability

Defining Disability

Kenya, in its 2007 Constitution, recognizes disability as 'any physical, sensory, mental, psychological or other impairment, condition or illness that has, or is perceived by significant sectors of the community to have, a substantial or long-term effect on an individual's ability to carry out ordinary day-to-day activities'.

In **Madagascar**, the constitution mentions 'physical or mental incompetence' related to career work capacity, and the Labour Law Article 104 repeats this definition. This bias towards evaluating disability only in the context of ability to work is amended by the CRPD ratification act.

Zambia defines disability in its 2016 Constitution (Amendment 2016, Art 266) as 'permanent physical, mental, intellectual or sensory impairment that alone, or in combination with social or environmental barriers, hinders the ability of a person to fully or effectively participate in an activity or perform a function as specified in this Constitution or as prescribed'.

Rwanda and **Zimbabwe** do not refer to barriers, defining disability as 'hearing, vision, physical and intellectual impairments'.

Gaps and bottlenecks in implementation of laws and policies are also evident. Respondents in Kenya attribute this to factors shared with other ESAR countries:

"...a lack of budgetary allocation for implementation;²⁹ inadequate clarity on what constitutes a disability; a lack of prioritization of disability; inadequate monitoring and enforcement mechanisms; a lack of involvement of service providers and organizations of persons with disabilities in planning and implementation; insufficient collaboration between government departments providing services and other actors; and negative perceptions of disability among some policy makers and implementers."³⁰ Implementation gaps due to administrative issues such as low technical capacity are common to all countries.³¹ Causes include the lack of an oversight body (mentioned in the Madagascar country assessment); lack of clear responsibilities (Mozambique); lack of coordination (Uganda and Zambia); and stigma (Rwanda). Additionally, the assessments for Kenya, Lesotho, Madagascar and Rwanda point to a deficit in political will.

Highlights by country

Lesotho's legal provisions include the right to education, care support for children with severe disabilities, and safeguarding provisions.

Madagascar's CRPD ratification act (2014-031) provides for the right to birth registration and nationality. Decree 2001-162 on the implementation of Law 97-044 provides for education, standards of infrastructure, training specialised teachers and integrating disability into in-service training of teachers. Order 24666/2004 on disability cards enables discounts for services such as travel, health and some special education; the Labour Code guarantees access for persons with disabilities to private and public institutions for learning and training.

Mozambique's constitution explicitly mentions that persons with disabilities have equal rights (article 37) and that children with disabilities are protected from discrimination (article 121)

Rwandan law mandates punishment for causing disability in a child; the law also guarantees certain medical care including prosthesis and orthosis for persons with disabilities.

Uganda's constitutional articles include the prohibition of discrimination on the basis of disability, and mandatory representation of persons with disabilities in parliament. The Persons with Disabilities Act (2020) specifically upholds equal rights for children with disabilities and nondiscrimination in education and health.

Zambia has extensive educational provisions in law: the Education Act (2011) pledges to expand educational provision for children with disabilities; the Persons

- 30 Additionally, in Kenya administrative decentralization has resulted in distinct variations in policy and implementation between districts.
- 31 Zimbabwe expects this to improve due to recent legal changes.

²⁹ In Lesotho it is expected that bottlenecks will reduce and implementation improve following the adoption of the Persons with Disability Equity Act (2021).

with Disabilities Act (2012) covers inclusive and special education with provisions for support and allowances to cover extra costs and for physical access issues.³² Zambia is a notable exception here: the Constitution includes the concept of 'barriers' in its definition and specifically references the need to ensure access to healthcare, sports and recreational activities, public spaces and infrastructure, economic productivity and livelihoods for all persons with disabilities.

Zimbabwe's Disabled Persons Act and National Disability Policy guarantees rights to basic services such as education, social protection, family life and healthcare, including sexual and reproductive healthcare.

Management and coordination

Challenges and opportunities

Overall, management and coordination are complicated by the plethora of national and international bodies whose work includes support for children with disabilities. Responsibilities are shared by a web of ministries, departments, agencies, commissions, working groups and clusters. In some cases, government coordination is expected to be achieved through the creation of a focal point or complemented by administrative guarantees across ministries.³³ Commonly a cluster system is also used by international agencies, and some countries may have a specific disability working group (usually headed by UNICEF). Typically local NGOs have at least one coordination umbrella body for the many civil society organisations working on the disability inclusion agenda. Sometimes near-parallel systems coordinate local civil society and international organizations.

These complex dynamics present local NGOs with particular difficulties. Local NGOs often feel that international coordination instruments do not sufficiently include them.³⁴ Likewise, governments themselves do not always engage directly with their local NGOs. For

example, in Kenya it was reported that the government works through its own National Council for Persons with Disabilities (NCPD) rather than directly linking with Organizations of Persons with Disabilities (OPDs).

Governments typically have several coordination bodies and mechanisms and working groups: at least one for inter-ministerial work, and one which covers development actors, business partners, NGOs, donors, etc. These are managed by the main body overseeing disability work, and sometimes the NCPD. Some have sector-level groups under which children with disabilities might fall and an overall NGO coordination body (in a few countries there are several NGO coordination bodies.) Countries with devolved administrations might also have local level coordination. For example, in Uganda, councils for persons with disabilities at district and sub-county level are responsible for the implementation and monitoring of disability-related policies in their respective jurisdictions.

How the different groups and fora relate depends in part on whether they are staffed by strong individuals who can work across silos, and this makes levels of collaboration highly variable. Relationships can also reflect historical and political trends. For example, Mozambique's inter-ministerial coordination is the responsibility of the National Council of Social Action (CNAS), a committee headed by the Ministry of Gender, Children and Social Action. CNAS was established in 2015 and its creation was opposed by OPDs 'out of fear that these changes would give disability issues less attention compared to other areas - children and women'. This suggests that war veterans, who enjoy particular political support and to whom most disability inclusion efforts have historically been directed, feel they 'own' the disability inclusion agenda. Lack of concern for children and/or women with disabilities is more or less the norm, and the African Child Policy Forum has documented how most OPDs in Africa do not have any significant emphasis on children with disabilities.³⁵

The responsibility to monitor and report on the implementation of the CRPD has, in many cases,

35 See further reading: ACPF 2014b.

³² The Technical Education, Vocational and Entrepreneurship Training Act (1998) sets a 10 per cent quota for tertiary education of persons with disabilities.

³³ Such as Mozambique where the ministry holding the disability portfolio (the Ministry of Gender, Children and Social Action) has signed an MoU with the Ministry for Education (MINEDH) for activities related to children with disabilities.

³⁴ Example from the country assessment for Mozambique.

been given to a specific body established for this purpose – almost always based in the ministry which holds the main portfolio related to disability. Typically, this is a ministry of social affairs and/or gender, although in some cases CRPD monitoring is the responsibility of the justice ministry or of a specialist (human rights) commission. Lesotho, Rwanda and Zambia have established directorates to oversee disability inclusion issues including implementation of the CRPD.

| Country | Ministry with overall mandate for disability issues | Other significant institutions/information |
|------------|--|---|
| Kenya | Ministry of Gender, Children and Social Development has the mandate for disability issues at the central level. NCPWD part of this Ministry. | In addition there is a National Gender and Equality Commission (NGEC). CRPD is monitored by the Human Rights Commission. |
| Lesotho | The Ministry of Social Development drives disability mainstreaming plans. | Works closely with the Ministry of Development Planning in mainstreaming disability into the National Strategic Development Plans e.g. for 2018-23. |
| Madagascar | The Ministry of Population, Social Protection and Promotion of Women oversees the National Disability Inclusion Plan and monitors laws and programmes. | There is also an Interdepartmental Committee on Disability. The Ministry of Education has an Inclusion of Disability Observatory to monitor inclusion of persons with disabilities in sectoral policies and plans. |
| Mozambique | The Ministry of Gender, Children and Social Action oversees disability. It does not implement but has focal points for mainstreaming disability, including in provinces, and chairs the inter-ministerial body responsible for coordination. | Discussions in 2021 to design a cross-ministerial plan for needs of persons with disabilities. |
| Rwanda | The Ministry of Local Government has the mandate at central level, mainstreaming disability inclusion into planning and national policy. CRPD is overseen by the NCPD which is part of this Ministry. | The Ministry of Gender and Family Promotion is the main coordinator for support to vulnerable children. Each ministry/agency has a focal point for disability inclusion. Administrative units at local level are responsible. |
| Uganda | The Ministry of Gender, Labour and Social Development collects data, publishes plans and policies and implements. It is responsible for the National Action Plan for Children with Disabilities and hosts the NCPD. | No Data. |
| Zambia | The Ministry for Community Development and Social Services is key; the Zambian Agency for Persons with Disabilities sits in this ministry and is tasked with mainstreaming disability inclusion, data, and coordination. | No Data. |
| Zimbabwe | The Ministry of Public Service, Labour and Social Welfare has primary responsibility for national activities and oversees ministries for all coordination. | Human Rights Commission, gender commissions. |

Table 3: Responsibility for disability inclusion by country

As Table 3 shows, the ministry with overall charge of the disability inclusion agenda is frequently a body with a primarily welfare-focused mandate, and such ministries are not always powerful or well-resourced. This complicates coordination and management. As a result, key institutions or bodies responsible for disability inclusion are frequently ineffective. In the case of Zambia, the Agency for Persons with Disabilities (ZAPD) - part of the Ministry of Community Development and Social Services - has a mandate to coordinate and promote disability mainstreaming across government. However, it is 'not viewed as a powerful organization within the government hierarchy, with no authority over other ministries to compel them to mainstream disability when providing services'. This is a common problem for institutions with mainstreaming mandates in many countries; few have the authority or levers to compel change.

A complicated and often fragmented web of management further weakens enforcement of disability inclusion mandates. Usually, management involves a central ministry which has overall responsibility for most of the portfolios relating to disability inclusion. This ministry may be tasked with disability mainstreaming, such as driving a process to ensure disability is taken into account in national planning or ensuring the national statistics office collects disability data. It might also implement projects. There may also be a separate agency for disability, an agency for oversight of CRPD (which may or may not be in the key ministry), and various commissions such as for human rights, and for women's rights. The agency that oversees implementation of the CRPD might also oversee a government's coordination mechanism, as in Rwanda where the Disability Coordination Forum (DCF) works under the National Council for Persons with Disabilities (NCPD).

Typically, Ministries of Health, Education, Gender, Social Welfare, Sport, Culture, Transport and Infrastructure carry most of the responsibilities for mainstreaming disability. Where a separate ministry focuses on policy areas such as youth, local government, community development and urban development, they too will typically be involved. Exceptionally for ESAR, in both Lesotho and Uganda the ministries with responsibility for ICT have developed disability accessibility plans. With the exception of Lesotho, justice ministries or departments of correction rarely have any significant role in coordination. Regardless of where the disability inclusion portfolio is placed, the ministries with most significant levels of activities related to children with disabilities tend to be those dealing with education and health, and insufficient attention is given to children with disabilities in other policy portfolios.

Highlights by country

Kenya has several coordination mechanisms, including government and non-government entities. The Ministry of Gender, Children and Social Protection hosts the National Council for Persons with Disabilities (NCPWD) which in turn works with numerous other bodies such as the 100 disability assessment committees nationwide. Nonetheless, duplication and a lack of funding impedes effective coordination of the delivery of services and products to children with disabilities and to persons with disabilities in general.

In **Lesotho**, the Ministry of Social Development contains a Disability Services Department, which is responsible for rehabilitation, legal enforcement of rights, child protection, funding assistive technology, running the cash transfer programme, covering medical fees for children with disabilities, and driving national disability inclusion plans.

Madagascar reports positive levels of coordination. The leading partner for the ministries is the local Platform of the Federations of People with Disabilities. They have a pool of trainers providing training on CRPD to public and private organizations and are the main vehicle for implementation of inclusive education.

In **Mozambique**, notwithstanding the coordination mechanisms there is still a lack of effective information exchange, which is reported to lead to suboptimal planning for children.

In **Rwanda**, despite the abundance of coordination platforms, coordination on the ground remains fragmented. The Disability Coordination Forum (DCF) is one platform for guidance and cooperation between the government and NGOs, and between government entities. Each ministry/agency has a disability focal point. At the local level, administrative districts are responsible. Other disability inclusion coordination platforms include the Rwanda Education NGO Coordination Platform, the Child Development Subcluster, and the Rwanda Coalition Platform. In Uganda, the Ministry of Gender, Labour and Social Development collects data, publishes plans and policies and implements the only existing social protection programme for persons with disabilities. It runs the Department of Disability and Elderly Affairs and the NCPD, and is responsible for the National Protection Policy and the National Action Plan for Children with Disabilities. It also runs the national coordination mechanism for youth. However, coordination remains fragmented between government entities which risks duplication of efforts and lack of clarity about responsibilities. Currently there is no known national coordination mechanism with disability issues as its sole thematic focus to liaise between government and development partners³⁶. To some extent, the lack of coordination extends to local level district councils for persons with disabilities, although this varies by location.

In **Zambia**, coordination is lacking among government agencies and with third-party stakeholders. The main government actor in disability programming is the Ministry of Community Development and Social Services (MCDSS), which is primarily responsible for disability policies. In 2012, the government established the Zambia Agency for Persons with Disabilities (ZAPD) to coordinate inter-agency efforts, but the agency is reported to be underfunded which hinders its ability to act as an effective coordinating body.

In **Zimbabwe**, there are operational gaps such as poor coordination and duplication of functions among the agencies. For issues specific to children with disabilities, there are no current or planned mechanisms to coordinate or encourage interaction between ministries and agencies. Since the National Disability Policy was approved in February 2021, this looks likely to change and coordination mechanisms are being revised.

Budget expenditure, allocation and disbursement

Challenges and opportunities

More than half of the assessment countries provide funds in national budgets explicitly for children with disabilities; however, only Rwanda has fully costed its disability-related needs, making it impossible to accurately judge how adequate funding is or whether it is allocated where most needed.

In Kenya and Uganda funding was significant. In Kenya, more than US\$ 48 million was allocated to special needs alone, and more than US\$ 12.5 million for cash transfers and the national disability fund. However, Kenya is also cutting crucial parts of budgets related to human resources, including funding for the Educational Assessment and Resource Centres (EARC) which assess and refer children with disabilities. While Uganda has not costed its disability inclusion needs, it is the only country that expressed confidence that its funding levels for disability inclusion are adequate.

While Mozambique and Zimbabwe also allocated funds for persons with disabilities, the amount was lower and narrowly allocated, and there is no up-to-date information on the likely cost of disability inclusionrelated needs of either country. In Mozambique, almost all current allocations are for the development of guidelines and not for actual support services.

Zambia appears to have modest allocated funding (US\$ 2.6 million under the social welfare budget) and Madagascar does not appear to have made any specific allocation for children with disabilities.

Lesotho and Rwanda have not made their national budgets available to the public. However, Rwanda was the only country to have fully costed its disability inclusion-related needs, estimating US\$ 28 million over four years. The country assessment notes, however, that allocations for all Ministry of Local Government (MINALOC)³⁷ social protection work barely reaches US\$ 88,000, making it highly unlikely that disability related needs are adequately funded.

³⁶ Although the government intends to have one developed by 2023.

³⁷ This ministry is responsible at the regional level for disability issues and services.

International donor resourcing, which is an important source of funding for disability inclusion, is believed to be increasing for all target countries except Kenya. This increase is linked explicitly to increased international commitments and interest created by national reporting to the Commission on the Rights of Persons with Disabilities. Rwanda and Uganda, in particular, have seen significant increases in some areas. In Mozambique, UNICEF is increasing its commitments, but overall donor support is inconsistent. Donor support is evaluated in the assessments as being good-to-strong for six countries, with information lacking for Zambia and Zimbabwe. Rwanda and Uganda both acknowledge that international donor funds and technical support have been crucial for data and knowledge collection, namely the funding of demographic and health surveys and research on children with disabilities.

As detailed above, there are funding gaps for disability inclusion in all assessed countries, with the possible exception of Uganda. In the case of Lesotho, budgets did not cover COVID-19 related needs for children with disabilities. In Madagascar, the specific directorate addressing disability is reported to lack funds and faces further cuts. In Mozambique, inclusive education support for teachers represents only one per cent of the special needs budget. Uganda notes resourcing gaps, Zambia's Disability Trust Fund is only allocated US\$ 100,000, and Zimbabwe faces 'chronic' levels of underfunding.

It is also notable that international funding for disability inclusion is mostly attached to education and health, leaving large gaps in support across other sectors. In Kenya since COVID, the focus has been on education and sanitation for all out-of-school children and digital learning materials. Most of Lesotho's international donor support is directed to health or inclusive education.

Overall, poor financial data is a problem across the countries assessed. The failure to cost disability related needs in all assessed countries except Rwanda is of particular concern since it makes adequate funding allocations difficult, if not impossible, to determine. Often budget funding allocations for disability are unclear or not delineated. Funding is often only allocated as part of a wider provision in areas such as health and education, making it impossible to calculate allocations and expenditure accurately.

See Annex Four for further information on financing by country.

Highlights by country

Kenya's assessment notes that 'increased attention towards children with disabilities in recent years has reportedly led to positive and increased funding'. However, there has been a notable decline in funds allocated within the national budget. The National Fund for the Disabled saw a decline of 72.7 per cent from 2018 to 2019, from US\$ 1.3 million to US\$ 4.7 million. Allocations for vocational training were cut by 32.2 per cent in 2019 and 9.1 per cent in 2020. The funding gap for special needs education in primary schools is approximately US\$ 5.5 million, while for secondary schools the funding gap has doubled. Funding for Educational Assessment and Resource Centres (EARCs) has been reduced by 74.7 per cent over two years.

Lesotho's social protection schemes are more extensive than in other countries but in general they still do not cover all the additional expenses for children with disabilities. The Ministry of Social Development provides social protection programmes, including public assistance, free health care, child grants in the form of cash-transfers, and bursaries for vulnerable children to support families, including those of children with disabilities.

Madagascar's support for the education of children with disabilities has decreased. The government had previously introduced incentive programmes to reduce financial barriers to schooling, including for children with disabilities. These included abolishing school fees and setting up school cafeterias (with a significant budget increase in the last year)³⁸, and providing school kit and other essential materials. Progress slowed after the financial crisis of 2009, and parents are still required to fund their children's schooling.³⁹

³⁸ Committee on the Rights of the Child. Replies of Madagascar to the list of issues in relation to its combined fifth and sixth periodic reports, November 2021. UN doc. CRC/C/MDG/RQ/5-6.

³⁹ The estimated cost of sending a child with a disability to school is US\$ 50 per month and includes educational support, school meals and rehabilitation costs. While parents are required to pay only a quarter of this, many still cannot afford it. Specialized services are even more expensive, ranging from US\$ 75 a month for a social assistant to US\$ 125 to send a child to a special school.

In **Mozambique**, the Economic and Social Plan and State Budget for 2022 allocated just over US\$ 1,000 of the state budget to persons with disabilities under dedicated budget lines for sign language and accessibility. There are also two budgets (of just over US\$ 100,000) for reviews of appropriate policies for children, and for persons with disabilities and the elderly, and both are externally financed. A dedicated budget line of approximately US\$ 31 million funds training of primary school teachers in inclusive education. The overall social protection budget in 2021 was approximately US\$ 158 million, approximately one third of which is allocated to unconditional cash transfers for vulnerable households which includes those with children with disabilities.

Rwanda has costed its policies and donor funds have increased since the submission of its CRPD report. The National Policy of Persons with Disabilities' Four-Year Strategic Plan (2021–2024) estimated that inclusion interventions for children with disabilities would cost upwards of US\$ 28 million over the 2021-2025 timeframe. Specifically, US\$ 25 million for inclusive education, US\$ 1.8 million on child protection and US\$ 425 million on health-related interventions over four years. Donor contributions mentioned include: the World Bank's US\$ 209 million Quality Basic Education for Human Capital Development project, which contains a significant disability component; USAID's US\$ 3.5 million for family-based care of children, which includes children with disabilities⁴⁰; and UNICEF's funding of surveys including the Demographic Health Survey (DHS) 2019. Additionally, the World Bank has committed US\$ 200 million to quality basic education including disability friendly classrooms and WASH, and US\$ 9.7 million for children with disabilities during COVID.

In **Uganda**, funds to the Department for Disability and Elderly Affairs (DEA)⁴¹ increased 314 per cent over the last three years, in part due to donor support of COVIDrelated activities. Allocations to the DEA are shown as reaching US\$ 38 million for the fiscal year 2022/23, and US\$ 1 million for special needs education in the Ministry of Education and Science, US\$ 23,000 of which is for disability, rehabilitation and occupational health. Donor support largely mainstreams children with disabilities; the European Union provided US\$ 6.9 million for the INCLUDE programme which supports psychosocial care and learning for mothers and children with disabilities. The World Bank devoted 10 per cent of its Digital Acceleration Project (US\$ 20 million) to a component for persons with disabilities. There are also multi-lateral and donor funds from UNICEF, UNFPA, FCDO and USAID for various on-the-ground projects that impact children with disabilities. In the past this has included funding for the Functional Difficulties Survey 2017 and the DHS 2016.

Zambia's 2022 budget document explicitly mainstreams issues of gender, youth and disability throughout the budget categories and across ministry programmes. The trends are for budgetary increases. Programming includes cash transfers, support to schools and centres, vocational training and inclusion of children in sports. Of the social welfare budget, US\$ 2.6 million (81 per cent) is budgeted for disability affairs and US\$ 1.62 million is allocated for schools and support centres for persons with disabilities. The main organisations delivering programmes which integrate disability inclusion are UNFPA, UNICEF, World Bank and the World Food Programme. However, no details are given of expenditure on programming for children with disabilities.

In **Zimbabwe**, free or subsidized services are provided by funds given to the Ministry of Public Service, Labour and Social Welfare from UN agencies, and to NGOs from development partners. UNICEF receives at least US\$ 1.5 million from Norway's Multi-sectoral Fund. Despite this, there is a chronic shortage of resources and in 2017 only US\$ 800,000 was allocated in the national budget for persons with disabilities.

40 The 'Tubarerere Mu Murayango' project.

41 In the Ministry of Gender, Labour and Social Development.



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Data

Findings

Article 31 of the Convention on the Rights of Persons with Disabilities mandates signatories to collect data and produce disability disaggregated statistics, the aim of which is to identify barriers and create policies aligned with the Convention.⁴² Despite this, there are considerable gaps in disability data disaggregated by age, sex, and by nature of the disability both globally and for the ESAR countries. Data is particularly scarce on how children and adults with disabilities are affected

by issues around sanitation, WASH, nutrition, and child protection. Even in Rwanda, which has the strongest data among the eight countries assessed, these gaps are evident. Typically, health, nutrition and violence indicators are either not disability disaggregated, or – in the case of violence against children – are not collected regularly or even reported at all.

Increasing efforts to remedy these omissions include the creation of the Inclusive Data Charter (of which Kenya is a signatory); the Disability Data Initiative (which has produced annual reports by focus area since 2021); and the Disability Data Portal (which features SDGrelated data⁴³). However, none of these are yet

Table 4: Showing disability disaggregated SDG data for the assessment countries

| Disability- | SDG indicator description | Lesotho | | Madagascar | | Zimbabwe | |
|--|--|---------|------|------------|------|----------|------|
| disaggregated SDG indicators | | | NFD | FD | NFD | FD | NFD |
| SDG 4 quality education | 4.1.1 Percentage of children aged 7-14 who demonstrate foundational reading skills (per cent) | 36.4 | 44.8 | 22.8 | 23.4 | 30.9 | 45.9 |
| | 4.1.1 Percentage of children aged 7-14 who demonstrate foundational numeracy skills | 11.6 | 15.3 | 3.0 | 7.9 | 18.4 | 25.4 |
| | 4.2.1 Percentage of children age 3-4 years who are developmentally on track in literacy-numeracy, physical, social-emotional, and learning domains and psychosocial well-being, by sex (per cent) | 41.2 | 75.6 | 48.0 | 67.9 | 43.8 | 71.7 |
| SDG 5 gender equality | 5.3.1 Proportion of women aged 20–24 who were married or in a union before age 18 (per cent) | 13.3 | 16.5 | 57.1 | 39.4 | 18.0 | 34.0 |
| SDG 8 decent work and economic growth | 8.7.1 Proportion of children aged 5–17 years engaged in child labour (per cent) | 33.5 | 31.6 | 46.7 | 47.0 | 34.3 | 27.1 |
| SDG 16 peace, justice and strong institutions | 16.2.1 Proportion of children 1–14 years who experienced any physical punishment and/or psychological aggression by caregivers in the past month (per cent) ⁴⁴ | 81.4 | 75.6 | 88.1 | 86.5 | 74.5 | 64.7 |
| | 16.9.1 Proportion of children under 5 years of age whose births have been registered with a civil authority (per cent) ⁴⁵ | 53.3 | 50.3 | 82.8 | 79.4 | 52.3 | 56.1 |

Source: Zimbabwe 2019 MICS Survey; Lesotho 2018 MICS Survey; Madagascar 2018 MICS Survey.

42 CRC and CEDAW do not mention data.

⁴³ Overall, data for the 44 child-related SDG indicators are not disaggregated by disability status in neither The Sustainable Development Report Dashboard nor the UNICEF dashboard on child-related indicators.

⁴⁴ Children age 1 year are excluded, as functional difficulties are only collected for age 2-14 years.

⁴⁵ The indicator with foundational difficulties disaggregation only covers children age 2-4 years

delivering significant data for children (including for girls) with disabilities beyond education-related information. Kenya has a Disability Inclusive Data Charter Action Plan and a technical working committee on disability statistics, and Lesotho's National Strategy for the Development of Statistics aims to fill gaps including the collection of data on children with disabilities.

National MICS supported by international agencies increasingly cover some aspects of issues that impact children with disabilities, though these are not comprehensive in the countries assessed here. Of those countries, only Lesotho, Madagascar, and Zimbabwe have SDG-related disability disaggregated data sourced from the MICS. Other countries include one or more questions on disability in their DHS (Rwanda 2019-20 and Uganda 2016) but are not yet reporting on disability disaggregated data for the SDGs.

All eight countries carry out national censuses and household surveys, but questions related to disability are not uniformly present; the censuses of Kenya and of Zambia, for example, do not cover functional difficulty. There are some limited instances of national data collection being complemented by studies (usually localised) undertaken by local NGOs or research institutions.

Challenges

Given some of the region's above-average SPI scores (Table 5) which captures macro level aspects of the overall statistical capacities, country level disability statistics situation were in some cases suboptimal. The Kenya assessment found that existing data is considered 'unreliable and cannot be trusted'; the Zimbabwe assessment reported a 'general apathy toward the collection of data on children with disabilities, and a lack of disaggregation of child-related data by disabilities', and found data to be 'insufficient, incoherent, inaccurate, and unreliable'. It is not unusual to find significant variations, for example, between global World Health Organization estimates and national figures, or across different surveys. This means policymakers often have to rely on data that is incomplete, inconsistent or outdated. Even when systems are in place to direct the regular and timely collection of data, there are still few standardised procedures for data collection, management, dissemination and sharing across ministries or entities. This means that national surveys are not comparable either nationally or internationally, and quality is not always assured.

Key limitations in country-level data collection include the following:

- Data disaggregated by disability is most common in education sectors and, to a lesser extent, health;
- The 21 UNICEF ESARO countries use DHIS2 as the main software for their health management information systems yet many have not formatted DHIS2 to include data on disability;
- Data is rarely disaggregated by disability and age in policy and implementation areas such as humanitarian response and emergencies, sanitation, water, nutrition, or access to ICT;
- Data related to sexual and reproductive health or violence against children and social protection is rarely disaggregated by disability;
- Data related to SDGs and children with disabilities is only available where countries have conducted MICS (Lesotho, Madagascar and Zimbabwe);
- National statistical plans and budgets do not always explicitly cover disability – in Mozambique, for instance, disability data has no allocated funding under the national data strategy, and Uganda's current plan only mentions vulnerability;
- It is expected that COVID-19 will have created further data gaps across 2020 and 2021.

Case studies: Challenges and successes in data management

Madagascar: There is a difference in the ways the national census and the MICS questionnaires approach disability. In the general housing survey and census, data is collected at the household level based on the lists provided by the lowest administrative unit. However, data collection is poorly implemented and the medical definition of disability is adopted. Many actors collect data on an ad-hoc basis to inform their disability programming, each with different criteria. School data is often compiled by relying on second-hand information from parents and untrained or poorly trained teachers and principals whose understanding of the relevant issues varies.

Mozambique: The national statistical system lacks disability inclusiveness and is challenged by lack of funding, technical capacity and outdated legislation that does not reflect international standards. Health-related statistic collection does not cover children with disabilities, including statistics collected for the HMIS, for national surveys related to HIV/AIDSs and malaria, or by patient tracking systems. The DHS conducted in 2011 did include questions related to sight. Social protection data is most often related to adults with disabilities who collect pensions or other benefits. COVID-19 data has not focused on disabilities, and there is a lack of disability disaggregated data on sexual and reproductive health and emergencies.

Rwanda: The Ministry of Education regularly collects and publishes education statistics (in the form of the annual Education Statistical Yearbook) which include indicators such as the number of learners with disabilities in school, number of adapted facilities for learners with disabilities and the number of special needs-trained teachers. The data is collected through survey questions appropriate for each level which are then integrated into EMIS. The survey questionnaire for primary to secondary levels includes, for instance, questions on the use of toilets for learners with disabilities, the number of staff with disabilities and the number of children with disabilities within a particular school, further disaggregated by type of disability.

Data on the health of persons with disabilities are currently collected through regular demographic, health and vulnerability surveys (DHS and EICV). The NCPD is currently developing a separate Disability Management Information System which will be used to register and categorize persons with disabilities online. Disaggregation of data from the three main recent surveys on disability – the 2012 census, the Fifth EICV and DHS – was relatively detailed. The 2012 census has been complemented by thematic reports, including one dedicated to persons with disabilities and data disaggregated by many variables including sex and age group.

Statistical capacity

The National Statistical Performance Index (SPI)⁴⁶ data reveal that all the eight study countries score above the SPI average for Africa (51.3 per cent), with Uganda and Rwanda exceeding the global average of 63 per cent, and Zimbabwe not far behind at 61.7 per cent. In terms of trends, most countries show slight increase in their SPI score over the 2016–2019 period although this varies considerably. In Kenya, Uganda and Zambia progress has been less than 10 per cent while the score in Madagascar and Zimbabwe has increased significantly (33 and 45 per cent respectively).

Washington Group Questions

All the ESAR countries are starting to integrate the Washington Group Questions (WGQ) into their national surveys, reducing dependence on a medical model of disability and gathering more accurate data. Lesotho adopted the WGQs in 2011. Madagascar used the Child Functioning Module in its MICS, which is itself an adapted version of the WGQ for children. Mozambique committed to fully adopt the WGQ in 2018, and the latest census partly uses them. Rwanda adopted them and used them in their DHS in 2019–20. Uganda has widely applied the WGQ and has used four out of six of the WGQ domains in its census, household survey, DHS, Functional Difficulty Survey, and situational analysis of persons with disabilities. Zambia used the

WGQ in a living conditions survey in 2006, and the 2022 census will include the WGQ. Zimbabwe reports that there are adult and child function modules in their last MICS but routine reports such as the Primary and Secondary Education Statistics Report do not disaggregate by disability. Kenya lags behind, having only recently decided to adopt the WGQ.

Highlights by country

Kenya: In 2021, the government published the Disability Inclusive Data Charter Action Plan, which aims to engage ministries, counties, departments and agencies, and non-state actors in coordinated collection, analysis and use of comprehensive disaggregated disability data. It has also created a technical working committee dedicated to disability statistics.

Lesotho: The government has sought out extensive technical support for data collection from multilateral organizations. Data on children with disabilities collected by the national government and others is increasingly being used in strategic planning, advocacy and programming; the Ministry of Social Development (MoSD) commissioned a situational analysis in 2019 to inform the National Disability Mainstreaming Plan 2021–2025 and a study in 2021 on inclusive education; the National Strategy for the Development of Statistics aims to fill gaps, including those on children with disabilities.

Madagascar: In 2013, a group of doctors refined the Ministry of Health's database on rehabilitation to include demographic, diagnostic and treatment information. The database has since been updated in all major rehabilitation centres countrywide and is being used to inform the national rehabilitation plan. Additionally, the Education Sector Plan 2018–2022 aspires to create an updated and reliable inclusive education database and regional and local platforms to support the decentralized services of the Ministry of National Education. A training guide is planned to support uniformity in data collection and inform disability identification at the district level.

Uganda: The Ministry of Gender, Labour and Social Development (MGLSD) collects data on persons and children with disabilities, including through its Situation Analysis of Persons with Disabilities in Uganda. The ministry is in the process of developing a disability management information system (DMIS) which will automate administrative processes particularly as relates to 'special grants'.

| Country | 2016 | 2017 | 2018 | 2019 |
|--------------------|------|------|------|------|
| Kenya | 55.9 | 57.3 | 55.0 | 54.5 |
| Lesotho | 49.0 | 54.4 | 55.7 | 55.2 |
| Madagascar | 39.0 | 41.7 | 50.2 | 52.0 |
| Mozambique | 50.0 | 55.4 | 54.8 | 56.2 |
| Rwanda | 60.1 | 67.4 | 66.7 | 67.3 |
| Uganda | 65.3 | 69.1 | 68.0 | 67.6 |
| Zambia | 54.4 | 58.8 | 59.5 | 59.0 |
| Zimbabwe | 42.6 | 50.3 | 59.5 | 61.7 |
| Sub-Saharan Africa | 48.1 | 50.0 | 51.6 | 51.2 |
| World | 58.4 | 60.1 | 62.8 | 63.0 |

Table 5: Statistical Performance Index (World Bank)



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2.2 Supply side

Findings

All eight assessed ESAR countries are classified by UNDP as 'developing' on the Multi-dimensional Poverty Index (MPI)⁴⁷ and face extensive challenges in providing services to their people given limited budgets, governance inefficiencies and significant levels of corruption.⁴⁸ Their citizens are more likely to be living below the national poverty line, earning less than US\$ 1.9 a day. All have an MPI value for 2021 which is worse than the average for sub-Saharan Africa. All have a higher percentage of citizens than average in the developing country category living on less than US\$ 1.9 a day. In Kenya, Lesotho, Uganda and Zimbabwe, however, average rates are slightly above the sub-Saharan average.

Rwanda, Mozambique, Kenya and Uganda have a history of conflict, adding factors such as national intergenerational trauma to the overall development picture; many assessed countries host large numbers of refugees and displaced people, or count among their populations many orphans and widows, and adults who have acquired disabilities due to war and HIV/AIDS.

These countries lack adequate infrastructure, including quality roads and public transport.

Education and health coverage across the region is uneven and, generally, even less well-resourced is social and child protection. The labour force lacks trained professionals, including those able to support persons with disabilities. Economic migration by skilled workers such as experienced healthcare professionals means that essential services suffer from human resourcing problems. State sector salaries, including those for health and education, tend to be low, so well-educated people are more likely to be attracted to the international, non-governmental or banking sectors. For example, in Madagascar only 3 per cent of primary teachers have a professional diploma and in Mozambique 53 per cent of teachers have no formal educational qualification. Yet populations are young; high percentages are under 18 years old and need sound educational support to improve their life chances and contribute to their country's economy.

Climate change is causing increased flooding, droughts and epidemics, placing additional pressure on water and food security and pushing prices up. COVID-19 punctured supply chains, increased costs, stretched health, education and social services, reduced vaccination and screening, led to increases in negative coping strategies (sex work, human trafficking) and more domestic and gender-based violence. In at least two assessed countries, Lesotho and Madagascar, the budget for COVID-19 measures was met by moving allocations from services for persons with disabilities.

Challenges

Under these circumstances provision of quality basic services for everyone is a challenge, and the majority of services end up focused on cities. Rural and remote areas tend to have fewer services, lack infrastructure, and face more poverty. Respondents in Zambia noted that rural families have to travel up to five hours to get medication. Existing services are rarely extensive or free: education, health and ICT all demand funding from families for school uniforms, registration, basic equipment, transport and medicine.

In many countries prevalence of disability is higher among the already vulnerable, and costs for supporting a child with a disability are higher than for a child without a disability. This means that children with disabilities are more likely to be born into underprivilege, and the cost of their care drains already low household budgets. In these cases, the role of the state and of voluntary services takes on even greater importance.

Except for a small amount of training, very little attention is given to children with disabilities as service users, and a particular gap is in training health professionals to communicate effectively with them. With the exception of Rwanda, there is no specific water, sanitation and hygiene provision for children with disabilities (including in schools and for epidemics

⁴⁷ UNDP (United Nations Development Programme), 2021; Global Multidimensional Poverty Index (MPI), 2021; UNDP (United Nations Development Programme).

⁴⁸ On the 2021 Corruption Perceptions Index, out of 180 countries, Rwanda comes in the top 30 per cent at number 52, Lesotho just misses being in the top 50 per cent at number 96, and all other ESAR countries are in the bottom half of the ranking: Zambia ranking 117, Kenya 128, Uganda 144, Madagascar and Mozambique at 147, and Zimbabwe at 157.

and pandemics). There is an overall failure to tailor public information to persons with disabilities, and particularly children with disabilities. For example, COVID-19 messaging was rarely adapted for persons with disabilities. Lesotho was an exception, providing special training with targeted messaging for children with disabilities.

Child protection tends to be limited, though some countries (notably Madagascar) do have networks at the community level which are reported to be able to provide a high standard of care. Social protection services are limited and only a few countries have specific national funds for persons with disabilities. Protection measures such as response to violence and access to justice and support are generally very limited⁴⁹. Additionally, dehumanising social beliefs contribute to greater levels of vulnerability to violence, abuse and exploitation for children with disabilities.

Interventions for children with disabilities, including those of donors and NGOs, are generally in the education sector rather than tackling community level social inclusion, and within education there is virtually no attention to sport or play. To some extent, Zimbabwe and Madagascar are exceptions; both report community level programming around protection. Lesotho has some paralympic provision for children, and in Zambia children with disabilities are reported to have more play items than children without disabilities. Nutrition, sanitation and water programming rarely explicitly considers the needs of persons with disabilities. When such projects do cover children with disabilities, this is usually in the context of school; for example, adjusting school-feeding programmes to suit the needs of children with disabilities.

This means that the many children with disabilities who are out of school are not reached by mainstream programming⁵⁰. Lesotho stands out for having a policy that explicitly mainstreams disability in nutrition provision, and Mozambique does have some programmes to teach families with children with disabilities about appropriate nutrition.

Gendered needs are inadequately addressed: Negative gender norms present girls with disabilities with

additional barriers. Their reproductive health needs are neglected; they are less likely to have access to assistive devices than boys and men; and they are discriminated against in terms of food provision. In some countries birth registration is complicated or requires a father's presence (for instance, Mozambique). The Zambian assessment revealed that the gap in mean schooling years is larger by gender than by disability status.

Carers are most likely to be female and to suffer from gender-based stigmatization, isolation and disempowerment. Teachers, social workers and basic health providers are also likely to be female. All these vocations are badly paid and poorly resourced. Carers are also likely to lack additional internal resources to meet the demands of caring for a child with a disability. A small amount of UNFPA programming and GBV programming addresses gender, but overall there is a lack of attention by donors and implementers to gender around the issues of how best to support carers, increase their resilience and reallocate care responsibilities to men.

Policy evaporation is the norm. Where policies exist, they are not implemented. For example, the Kenyan National Health Policy of 2014 specifies a child's right to basic nutrition and health care, and the right of a person with disabilities to 'reasonable access to health facilities, materials and devices'. It also provides for hygiene, sanitation, rehabilitation and referrals for learners with disabilities. However, in reality there is a lack of provision. And while the National Adolescent Sexual and Reproductive Health Policy (2015) acknowledges the right to access for adolescents and youth, there are no provisions for children with disabilities in health facilities.

Social protection funds are inadequate: National social funds, national health support and other state payments for the vulnerable tend to have very restrictive clauses which mean they only cover persons with the most 'severe' levels of disability, and severity is defined differently in different countries. To apply for funds, the child must be registered as having a disability, and in many countries these registration procedures are

⁴⁹ Only one country assessment gave any significant attention to access to justice for children with disabilities

⁵⁰ The exception to this appears to be Rwanda. Madagascar has also made recent efforts with UNICEF to introduce inclusive WASH programming as over 48 per cent of schools either have no sanitation or limited sanitation, and 63 per cent of schools have no access to drinking water.

typically difficult and costly and therefore not often attempted. $^{\mbox{\scriptsize 51}}$

Highlights by country

In **Kenya**, 13 out of 18 free-to-view TV stations now have sign language provision.

In **Lesotho**, the Education Act allows books in the school system to be printed in braille without additional copyright authorization; and paralympic sports are included in the remit of the Sports Commission.

In **Madagascar** gaps between persons with disabilities and other young persons in education are closing; the proportion of children and young persons with disabilities achieving at least a minimum proficiency level in reading Malagasy is 39.8 per cent, compared to 42.8 per cent of learners without disabilities. The proportion of children and young persons with disabilities achieving at least a minimum proficiency level in mathematics is 30 per cent, compared to 34.9 per cent of learners without disabilities.⁵²

In **Mozambique** during the COVID-19 pandemic, efforts were made to adapt informational and educational materials for persons with disabilities, including through programmes by TV Surdo, a Mozambican NGO for young persons with disabilities.

Rwanda has extensive legislative provision for inclusive education and has exceeded its targets for school adaptations. Moreover, teachers are actively being provided with support on how to achieve educational results for children with disabilities.

In **Uganda**, the recent passage of the Persons with Disabilities Act of 2020 required all public and private television stations to provide sign language in all newscasts. An ICT and Disability Policy has been drafted that aims to improve access for persons with disabilities including through addressing disability in ICT infrastructure, skills development and awareness raising.

In **Zambia** in 2017, ZAPD signed an agreement with the Zambia Information and Communications Technology Authority to increase access for persons with

disabilities, and to increase production of accessible ICT products.

Zimbabwe has a specific sector plan for improving capacities in the education sector, including support in SNE for teacher trainers at the university and various training programmes for staff, teachers and principals.

Capacity for disability inclusive programming

Findings

All country assessments except those for Rwanda and Zimbabwe show a general lack of resourcing and significant gaps in public financing to build capacity, with donor funds mostly from UNICEF and the World Bank supporting a limited number of interventions. Where data was available it showed an overall lack of human resources, usually coupled with reduced budgets for staff (see Kenya in particular). The assessments for Lesotho, Madagascar and Mozambique found that technical capacities of service providers (teachers, health workers, educators etc.) are absent or low for the support of children with disabilities. On the plus side, Madagascar, Mozambique and Zambia reported some capacity building and training underway, albeit almost exclusively in the context of health and education.

Challenges

Lack of human resources, skills and training: Recruitment, placement and training of educational and health staff, including in universal design for learning and in the health issues facing persons with disabilities, are all very limited. Many teachers lack the expertise to support children with disabilities and all teachers are given very little training on inclusive education. Across ESAR there is a general shortage of staff for all healthcare roles, and a lack of specialised training on the specific needs of patients with disabilities. For example, Zambian doctors working with patients living with HIV have little knowledge or capacity to interact with children with disabilities who are living with HIV.

⁵¹ Typically, such social protection funds limit grants and do not allow more than one grant per family.

Inclusive programming needs attention. It was found that international multilateral financial support and programming does not always explicitly address likely impact on children with disabilities. UN World Food Programme nutrition programmes, World Bank cash-transfer schemes, UNDP poverty-reduction programmes and WHO health programmes were all found to be lacking this dimension.

In health settings, absence of information materials available in alternative formats: Patients with disabilities which impact their ability to read or comprehend must often rely on carers for interpretation of communication with health providers. The risk is that the child's wishes are not prioritized, and they are disempowered.

Kenya in particular faces a crisis around the education of children with disabilities. While the national education policy of Kenya recognises inclusive education as the goal, in reality most children with disabilities are in special education and budgets have been cut dramatically. The Ministry of Education admits that learners with disabilities do not currently benefit from any of the policies and provisions related to essential services.

Children with disabilities need a diverse range of services and despite extensive legal commitments to inclusion, particularly in education, none of the countries reviewed have been able to adequately provide these. Key areas in which they lack capacity include, but are not limited, to staffing and financial resources. Most countries report that funds for disability work, including from the donor community, have decreased, partly due to reallocations in response to the pandemic. The exceptions are; Rwanda, where efforts to improve accessibility of educational facilities are reportedly on track; and Zimbabwe, where the assessment reports that resourcing is adequate.

During the recent pandemic only a small number of countries had support from international donors to train staff and provide inclusive health materials for those with disabilities. Lesotho is among the countries reporting that no provision was made. In those countries where television broadcasts include sign language, children with disabilities and their families might have had a greater chance of receiving good information on health and other issues. Ramps for physical access might be considered a low technology and lower-cost assistance for children and adults with mobility issues, but they are not widespread across educational or health or other facilities (such as government offices, courts and police stations) in the region. The possible exception to this is Zambia, where surveys report that 80 per cent of families find the schools accessible.

All countries reported a serious lack of qualified staff in education and health sectors and a further lack of specialists. Percentages of those with teaching diplomas vary from only 3 per cent of teachers in Madagascar to 47 per cent in Zambia. Some countries such as Lesotho and Zambia note they have welltrained staff but not enough of them.

Highlights by country

Mozambique stands out for positive investment in disability, inclusion and accessibility capacity-building by government, local NGOs and international stakeholders. A new, inclusive education strategy places emphasis on teacher-training, followed by the training of healthcare professionals in rehabilitation services and building the capacity of Organizations of Persons with Disabilities. However, in all ESAR countries initiatives to train specialists in other sectors, such as the police or other public officials, are rare.

Availability of essential commodities

Findings

To support wellbeing and inclusion for children with disabilities and make it possible for them to access key services, such as health, education and ICT, a wide range of hardware, technology and day-to-day consumables are needed. Research in Zimbabwe shows key commodities include wheelchairs, walking canes, braille textbooks, hearing aids and their batteries, sunscreen lotions, assistive technologies, inclusive recreational kits and money for day to day needs and emergencies. Most countries do not have ecosystems for assistive products and services. Costly assistive technology (AT) is either donated by INGOs or procured by national governments from abroad, and this means that it is usually in short supply and that maintenance is difficult. Children with disabilities particularly (and especially those with limited verbal ability) are likely to outgrow equipment or be given a device that does not suit their needs.

Most countries (with the exceptions of Rwanda and Uganda) report that AT and even braille paper has to be imported and/or is expensive so few facilities or families purchase them. Only a few countries report some limited capacity to produce assistive products locally.

Schools and healthcare settings rarely have disabilityspecific plans and budgets. Learning material and health information is rarely provided in accessible formats. If children with disabilities are enrolled in school, teachers face the challenge of tailoring learning materials to their needs such as sourcing texts in braille. If a young person with a disability seeks out medical care, they may well find that health professionals cannot spare the time needed to understand their specific needs.

Very few who need hearing or vision aids are given them and if they are, it is likely to be old or badly fitted due to poor supply, technical limitations, and/or lack of expert fitting capacity.

Systems that identify children with disabilities and their needs are essential for allocation of assistive products. Rwanda and Mozambique have legislation and programmes for provision of orthopaedic equipment, wheelchairs and crutches (possibly prompted by advocacy for and by war veterans with disabilities) but this does not guarantee delivery of these services. Kenya reports that essential services to identify children with disabilities and refer them for treatment or assistance have been reduced.

It is reported that girls and women are less likely to receive AT than their male counterparts.

Challenges and opportunities

In Mozambique, access to AT is limited by lengthy and complicated bureaucratic procedures. Public procurement regulation is currently not in line with the ISO international classification and mostly not covered by government provisions. In Zimbabwe, despite governmental support, AT is in short supply,⁵³ the availability and quality of technical support for equipment is being cut, and inadequate in-country training support has led to poor technical capacity. Many specialists have left the country to seek better opportunities.

A recent study in Lesotho shows rural schools lack supplies for children with visual impairment; another study of secondary schools revealed lack of resources and finances to help teachers ensure inclusion of all children. Lack of braille or interpretation resources is identified as a cause for higher dropout rates among children with disabilities. Underfunded schools are not likely to have resources such as hearing aids, visual aids or other tools for children with physical disabilities. It is reported that if a child with disabilities is referred for AT, it takes at least two years for them to receive it, and devices are often low quality and need repairs or frequent replacement.

Some provision of materials and commodities and technical specialists is reported by Kenya, Madagascar, Mozambique and Zimbabwe. In these countries, government, some local NGOs and international charities provide mobility aids such as wheelchairs. There is some reported provision of free prosthetics by NGOs in Kenya. In Mozambique – and this is unusual for ESAR – some equipment such as wheelchairs or tricycles can be assembled in-country but components still have to be imported. Cumbersome government procurement and access procedures and nonenforcement of ISO standards create further issues with quality and supply.

⁵³ The Government of Zimbabwe provides free assistive technology to persons with disabilities, including children with disabilities, under an assistive technology programme administered by the Department of Disability Affairs. Assistive technology is also provided through the National Rehabilitation Centre (Ruwa). The National Disability Policy sets quality control for the provision of assistive devices.

There is some direct production of materials such as the transcription of primary school books to braille in Mozambique. In Madagascar, some donor-funded dedicated programmes include provision of inclusive education materials (primarily, it seems, books in braille) but specific funding for AT procurement is very limited. Supply is further limited by the high prices, import taxes and transport to remote communities.

Case study: Hardship funds for education in Kenya

Kenya allocated funding to help families in hardship with education costs, and children with disabilities can receive grants from the National Development Fund For Persons With Disabilities (NDFPD) administered by the National Council for Persons with Disabilities (NCPWD). Grants cover 75 per cent of the fees for secondary and tertiary education, vocational training, vocational rehabilitation centres, universities and special educational establishments. The amount funded is for tuition fees and may include boarding. The applicant is expected to cover the remaining 25 per cent, although the disability fund (NDFPWD) will pay 100 per cent of expenses if the applicant provides evidence of extreme poverty.

Highlights by country

In all the assessed countries, only one programme – in **Madagascar** – references the lack of assistive technology and learning materials for children with disabilities at the local level; although its scope is limited, it has set up vocational training programmes to manufacture assistive products using locally available materials.

In **Mozambique**, AT such as wheelchairs, crutches, hearing devices and screen readers are produced outside the country and must be purchased at a high cost and imported. While the procurement of AT is theoretically covered by a tax exemption, in practice local NGOs still have to pay high customs charges. A second issue is that some materials might not be appropriate to the specific context of Mozambique because, for instance, there are differences in regional variants of sign language or in some areas there is no access to electricity to recharge devices.

In **Zambia**, the education sector lacks AT resources such as accessible software, braille embossers and braille paper. Purchase of equipment necessary for children with disabilities (braille paper, specialized medical equipment, etc.) is near impossible to finance on current budgets for either government or NGOs, especially since much of the equipment must be imported. Not only is AT supply limited, but children with disabilities have limited awareness of AT. In the 2015 Zambian national disability survey, only 47.5 per cent of children with disabilities knew of the existing AT that could help them and only 6.5 per cent reported having an assistive product.

2.3 Demand side

Financial access, direct and indirect

Findings

The lack of credible data on the exact number of children with disabilities, or on the disability-related costs of accessing basic support, services and ICT and assistive technologies makes it difficult for governments and donor partners to effectively reach children with disabilities.

While countries might have some basic data on health and education costs for children with disabilities, costings for most other sectors are lacking, especially for sanitation, nutrition, WASH, child protection, social protection and ICT. Anything beyond basic mobility devices is not only beyond the reach of an ordinary family but also usually beyond national health and education budgets.

The assessments for all countries show:

- An overall lack of relevant data on direct and indirect costs, making policy development and budgetary allocation problematic.
- Families with children with disabilities tend to be poorer than other families, yet they face extra costs for care and service access. Even where grant funding is offered, it often does not cover all children and all situations; even when education is free (as in Rwanda) schools may impose charges for supporting children with disabilities.
- Education costs are a barrier; in Kenya, for example, special schools have high fees and even if a child has a bursary there are extra costs. Most countries have no functioning system for funding school attendance beyond primary level even where secondary education is mandated by law.
- Higher healthcare costs are associated with having a disability. Insurance schemes often restrict care for persons with disabilities, disability related conditions, and are not universal; for example, in Kenya healthcare is free only for children under the age of five. Some systems require the child's birth to have been registered; in Mozambique, for instance,

only about one in two children are registered and in Uganda, around one in three children are not registered. Access to healthcare is more expensive for adults with disabilities than for others, and it is likely this would also be the case for children.

Assistive technology, other than basic mobility support, usually has to be imported and so is expensive and in short supply. Governments in Kenya and Lesotho make some AT provision but coverage is inadequate. High costs mean the quality of any government-provided technology tends to be low, the country assessments report. Only two countries report some - very limited - capacity to locally manufacture basic assistive products. The assessments also report that when an assistive product is provided, the costs of servicing, fitting and maintenance mean they are often little used or even discarded. Data is lacking for most countries, but we know that in Mozambigue at least one in three persons with disabilities discontinue using assistive products they have been allocated.

Challenges

Generally, households with children with disabilities are made disproportionately poorer by the additional costs associated with specialised care. As the cost of providing for the needs of children with disabilities tends to be high, families cannot always take proper care of them and this sets up a vicious circle in which lack of care may worsen their health.

A range of drivers, some not immediately obvious, increase expense and so widen the unmet needs of children with disabilities. Services tailored to children with disabilities are more specialized. They may need equipment and aids that need to be replaced or adjusted as they grow. Even routine services, such as vaccination, may cost more in terms of transport costs, carers to chaperone and time off work. The registration of a child with a disability (at birth or otherwise) requires a medical assessment, usually at a hospital, again incurring additional cost.

Costs depend on each child's specific situation. The Kenyan assessment notes that the cost of education and healthcare differs by disability. Children with sensory disabilities, such as those with hearing, speech or vision loss, pay relatively less compared to children with intellectual or developmental disabilities. For

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example, the cost of educating a child with cerebral palsy would also involve a special diet, diapers and specialised seats. Children with intellectual or developmental disabilities may need regular medication, such as drugs to control epilepsy. The cost of assistive products might be higher for children with physical disabilities.

Costs are also gendered. A mother or other female caregiver caring for a child or family member with a disability has many more demands on her time and this reduces her income-earning options and increases her vulnerability. She may only be able to take on work which can be done from home (piece work, sex work) and is less likely to be able to train or continue education. The wellbeing and education of other children in the household may suffer – poorly educated and poorly paid parents are less likely to be able to access information on how to support and take care of their families – and siblings, especially sisters, may be compelled to take on extensive caring responsibilities.





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3 Recommendations

The recommendations below provide complementary generalised suggestions for ways forward. For specific detailed recommendations for each country please see the individual country reports.

Social norms

- In line with their obligations under CRPD Article 8, governments should develop clear and measurable national strategies on social and behaviour change for acceptance and inclusion of persons with disabilities, in partnership with local organizations and researchers already working in the space.
- Governments should consider investing in research on attitudes and message testing to support positive messaging on inclusion of persons with disabilities and to combat harmful stereotypes.
- Governments should consider engaging trusted local figures such as village chiefs, teachers and religious figures to advocate for awareness, acceptance and empowerment in their communities, leveraging existing community programmes.
- OPDs, parents and community actors such as frontline workers should be engaged in social behaviour change work.

Legislation and policy

- Governments should take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities, and to take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes.
- Legal harmonization is needed for countries to ensure their laws and policies are in conformity with the CRC and CRPD. Where medical definitions of disability still exist in law, they should be adjusted to align with the CRPD.
- Governments should take steps to ensure CRPD reporting is timely and accurate with up-to-date data and evidence.

- Governments should establish mechanisms to implement recommendations/concluding observations of human rights treaty bodies.
- Governments should adopt anti-discrimination legislation and explicitly prohibit disability as a ground for discrimination, with a clear remedy.
- Revised media and IT laws could encourage greater accessibility for adults and children with disabilities. For example, regulation could ensure television transmissions and cinema films have sign-language. Government leadership can be demonstrated by adopting such reasonable accommodation measures in their press conferences and public meetings.
- Governments should address policy gaps in services for children with disabilities in areas such as social protection, nutrition, water and sanitation, public health messaging, general public awareness and information campaigns.
- Gender issues, especially around care, should be explicitly addressed. Mothers, grand-mothers and sisters face specific challenges, discrimination and negative economic impact as a result of caring for children, young people and adults with disabilities.

Management and coordination

- Governments should mandate coordination and information-sharing among government bodies with responsibilities for disability inclusion, stipulating more clearly the division of responsibilities and authority.
- It is recommended that, where lacking, national mechanisms are created to coordinate governance of disability inclusion that give specific attention to age and gender. Where national mechanisms do exist, their responsibilities and decision-making power should be strengthened.
- Inclusion of staff with disabilities and inclusive management practices should be a mandatory part of management training.
- Governments should invest in developing their own specialists in disability inclusion to provide more effective national leadership.

• Governments, in liaison with local disability advocacy groups, should leverage public and private partnerships to invest in a more inclusive future.

Budget expenditure, allocation and disbursement

- Governments should invest in costing disability related expenditure to more accurately assess whether budgets are appropriate and adequate. Systems should make disability related expenditure simple to identify and measure.
- Budget disbursements for services for persons with disabilities should be decentralized.
- Budgets for relevant national institutions and mechanisms should be reviewed to ensure that disability inclusion is being mainstreamed across sectors.

Data

- Governments should invest in having a population level survey on the situation of children as part of their multi-year statistical plans, such as MICS, for a more comprehensive and consistent data generation on the situation of children with disabilities.
- Governments should further strengthen administrative data systems to ensure children with disabilities are systematically included across services through developing and integrating relevant tools and trainings, such as in EMIS, HMIS, CPIMS.
- Governments should ensure data collection protocols are standardized and based on the WGQs and the CFM, to improve accuracy and comparability aligned with the social model of disability.
- Governments should invest in trainings on inclusive survey and research protocols for government researchers and enumerators, including familiarising staff with WGQs and the CFM.
- Governments should take a stronger leadership role with NGOs and research institutions, encouraging them to standardize and improve the comparability of data collected on children with disabilities.

Capacity for disability inclusive programming

- Governments should seek to measure, review, and annually report on the number of staff with disability inclusion training. Appropriate minimum levels of institutional expertise should be established and exemption protocols for staff transfers should be considered to prevent loss of expertise in key agencies.
- Government should work with their civil service training bodies or local universities to establish high-quality disability inclusion training certificate programs. This can include:
 - Inclusion of trainings for government officials who are responsible for planning, policy, budgeting and data collection, where they work together with regional experts to fill in gaps and strengthen implementation.
 - basic training for frontline workers in all sectors on inclusion of children with disabilities.
 - simplified trainings developed for those with lower education levels which still address key components such as attitudes, knowledge and skills related to disability inclusion.
- Mainstream training for community health workers, teachers, and emergency responders should include methods of early identification, screening, and referral of children with disabilities.
- Governments and service providers should strengthen referral pathways for all types of violence, neglect and abuse to improve access to children with disabilities including to increase their awareness of services that exist, and to mainstream disability inclusion across gender-based-violence and childprotection networks.
- Governments should ensure child helplines are accessible and alternative communication formats such as text and audio are offered.
- Governments should build capacity of OPDs to hold their governments accountable.

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