Situational Analysis of Persons with Disabilities in Uganda
Foreword

The Constitution of the Republic of Uganda, Article 35 states “that Persons with disabilities have a right to respect and human dignity, and the State and Society shall take appropriate measures to ensure that they realize their full mental and physical potential”. The Constitution further provides for the enactment of laws and policies to address their concerns. As a result, Government has formulated the Persons with Disabilities Act 2020 which is a key instrument in providing for the rights of persons with disabilities.

The Government has also initiated social protection programmes aimed at improving the wellbeing of vulnerable persons including persons with disabilities, for instance the Special Grant for Persons with Disabilities. Government is committed to mainstreaming disability in development through promoting effective participation, engagement and inclusion of persons with disabilities. However, there are still concerns of violation of rights, discrimination, exclusion and stigmatisation of persons with disabilities in the country.

To further understand these concerns, the Ministry, in collaboration with development partners, commissioned a study on the Situational Analysis of Persons with Disabilities in Uganda to understand the critical challenges that persons with disabilities face in accessing services and how their participation can be enhanced to reduce exclusion.

This Disability Situational Analysis report therefore comes in another key instrument to facilitate evidence-based programming by the different stakeholders engaged in the disability work.

The report highlights inadequacies in areas of access to health, education, governance, communication, skills development, rehabilitation and inclusion, among others that need to be addressed through meaningful and purposive mainstreaming of disability issues in all sectors.

I therefore call upon stakeholders to transfer this Situational Analysis Report recommendations into workable solutions to improve the livelihoods and wellbeing of persons with disabilities. The Government will continue to provide an enabling environment to ensure that persons with disabilities enjoy and exercise their rights through implementation of the existing legal and policy frameworks available.

FOR GOD AND MY COUNTRY

Frank. K. Tumwebaze
Minister
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For Permanent Secretary
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Introduction

The Government of Uganda have made a series of commitments to the rights of persons with disabilities in Uganda. These include affirmative actions in legislation and policy, and quotas for political representation of persons with disabilities at all levels of governance down to the sub-counties. The Persons with Disabilities Act (2020) provides for the respect and promotion of human rights for persons with disabilities. However, despite the good intentions outlined in legislation and policies, gaps remain, in particular how they are implemented, monitored and degrees of compliance.

In order to deliver on the policy areas effectively, the Government of Uganda needs to better understand what the lives of adults and children with disabilities in Uganda look like today, and why there are barriers to the equality and inclusion of persons with disabilities. The aim of this situational analysis is to consolidate the existing evidence base on disability in Uganda, and to help identify and fill in critical knowledge gaps.

The situational analysis will feed into the initiatives currently being undertaken by the Expanding Social Protection II programme to enhance the inclusion of persons with disabilities within social protection. The programme is a key deliverable of Department of Disability and Elderly, Ministry of Gender, Labour and Social Development (MGLSD). The report will inform the design of a new disability-specific programme which will take practical steps to strengthen Uganda’s social protection schemes, with the aim of empowering persons with disabilities, enhancing their inclusion and wellbeing, and enabling them to participate on an equal basis with others.

Methodology

This research examines the challenges persons with disabilities, and their caregivers, face across the lifecycle, and how these challenges vary across a range of intersectional factors such as age, sex, location, impairment type, level of difficulty etc. The situational analysis comprises four interlinked components: a review of the “disability architecture” which examines the structures and support that are currently available for persons with disabilities in Uganda, including policies, legislation, and governance; a “diagnostic” of existing social protection programmes; qualitative life history data; and a nationally representative household survey. Persons with disabilities were identified by the household survey in two ways: the Washington Group Short Set of Questions was applied to all adults aged 18 years and over, and the Child Functioning Module, developed by Washington Group and United Nations International Children’s Fund (UNICEF), was applied to children aged 2 to 17 years.

Understanding disability in Uganda

While the Government of Uganda has made a constitutional commitment to the equal rights and opportunities for persons with disabilities in Uganda, it does not define what “disability” is or who is a person with a disability. However, although there have been a range of definitions and description of disability used across national legislation and policies, most are broadly rights-based. This is in line with the UN Convention on the Rights of Persons with Disabilities (UNCRPD), to which Uganda is signatory. A right-based approach understands disability as an "evolving concept", based on a dynamic interaction between a person’s long-term physical, mental,
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intellectual or sensory impairment and environmental, attitudinal and other barriers that “hinder their full and effective participation in society on an equal basis with others”.

Despite its ostensibly rights-based approach and affirmative actions on paper, Uganda has been subject to criticism from the UN Office for the High Commission on Human Rights (UNOHCHR), following submission of its status report in 2016, about persisting gaps in definitions (especially around mental health), legal remedies and reasonable accommodation. The revised Persons with Disabilities Act (2020) is intended to address these criticisms, although it is not fully compliant with a rights-based approach.

Demographics

In order to effectively deliver programmes and policies that support the promotion and protection of the rights of persons with disabilities, it is important to know how many persons with disabilities there are in Uganda, their age distribution and where they live, and their type of impairment.

Prevalence of disability in Uganda

Overall, the household survey found that 8.5 per cent of Ugandans have a disability. The prevalence of disability increases sharply with age, with around 40 per cent of older persons aged 65 years and above have a disability in Uganda, rising to 57 per cent among those aged 80 years and above. Disability is most prevalent among older persons in Uganda, for as people age and grow frailer, their health decreases and they are more likely to experience age-related impairments. However, since Uganda has a young population, currently the highest numbers of people with disabilities are below the age of 15 years. Disability is predicted to increase substantially across all age groups by 2050. These projections have implications for the policies that Uganda puts in place.

Prevalence of impairment type is also important to measure, as each impairment type interacts with barriers differently. In Uganda, there is little variation between impairments for children. However, adults (aged 18 years and above) have the most difficulty with seeing (4.5 per cent) followed by walking (4 per cent). Furthermore, roughly one-third of all children and adults with disabilities have difficulties in more than one domain.

Household structures

In Uganda, a person’s informal safety net has traditionally been their family as well as their community, with these networks offering financial, physical and emotional support. However, a number of factors, including land fragmentation, high levels of poverty and unemployment, migration, increasing living costs, and the HIV/AIDS crisis, have contributed to an increasing nuclearisation of networks, with Ugandans now more likely to receive support from a smaller, more tight-knit group of family members. Consequently, although households and care structures can be blurred across a compound, living arrangements can provide a good indication of a person’s care networks. Depending on age, impairment type and level of severity, this has implications both for the support that a person with a disability provides, and the support that they receive.

In Uganda, persons with disabilities are more likely to live in larger households than their peers without disabilities. One reason for this is that a household with a person with a disability is more likely to have three or more children living in the household. Larger households may not
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necessarily result in greater support, as they may be more vulnerable to shocks and to falling into poverty due to a higher number of children and older persons who are dependent on working-age members of the household. This has implications for how much financial support and physical care a person with a disability can receive, and, if the person with the disability is also earning income or providing care, this may create a disproportionate care burden for them. It is therefore potentially more challenging for households with persons with disabilities to engage in consistent and reliable income-generating activities, and these households may be more prone to falling into poverty.

Households with persons with disabilities are also more likely to be headed by a woman. The reasons for this are complex, but gender is a significant factor around caring responsibilities and social norms, which in turn can increase vulnerability and lower living standards for the household. It also points to the fact that older persons with disabilities are most likely to be widowed women.

Vulnerabilities and Resilience

Vulnerability is a status which people can fall into or move out of, and it is not, therefore, a predetermined or indeed static status for individuals. Unexpected or unplanned for events – that is, shocks – can occur which drive adults and children into conditions of vulnerability. There are a range of factors that can make children or adults more at risk of vulnerability and shocks.

Standards of living for persons with disabilities

It is well established that poverty and disability are linked. Those who live in poverty are more likely to have a disability, while those with a disability are much more likely to be living in poverty. In Uganda, using national poverty lines, the poverty rate for individuals living in a household with a member with a disability is 31 per cent, compared to 28 per cent for households without a person with a disability. Although these figures are fairly similar, they do not account for the power dynamics within a household which may mean that a person with a disability lives in a greater state of poverty than others in the household. Furthermore, as is discussed below, the additional costs of living with a disability often lower a household’s standard of living.

Using international poverty lines, around half of Ugandans in households with persons with disabilities are living in extreme poverty (less than $1.9 PPP or UGX 2,400 per person per day), and over three-quarters are living in poverty (less than $3.2 PPP or UGX 4,000 per person per day). Only one per cent of persons in households with members with disabilities are living on more than $10 PPP a day.

Furthermore, over 80 per cent of persons with disabilities live on less than UGX 8,000 per day. This is a meagre amount to live on and demonstrates that even if a person with a disability is not considered to be the “poorest”, their standard of living is likely to still be low. Poverty is therefore a dynamic situation and the majority of persons with disabilities are vulnerable to shocks and are likely to fall into poverty at some point in the future.
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Extra cost of living with disabilities

Although households with or without persons with disabilities have similar poverty levels, it is highly likely that the real levels of poverty in households with members with disabilities are underestimated due to the additional costs of disability. In order to maintain a similar standard of living or to perform specific activities, persons with disabilities often incur additional costs in comparison to their peers without disabilities.

As a result, when two households with the same level of expenditure are compared, the household with a member with a disability has a lower standard of living. Any future interventions to address poverty and wellbeing need to ensure that the gap does not widen, leaving person with disabilities and their families behind. This may, therefore, necessitate the provision of additional resources to those households.

Direct costs include the additional costs that persons with disabilities and their families incur to achieve a reasonable standard of living (in comparison to their counterparts without disabilities). Households that include a member with a disability spend close to 39 per cent more on household expenses than households without a member with a disability. This corresponds to approximately UGX 16,500. Furthermore, on average, families of children with disabilities have to spend 31 per cent more than families of children without disabilities on other education-related costs. This is further affected by the level of impairment, and families of children with higher levels of difficulties in one or more functional domains spend on average around 50 per cent more than families of children without disabilities on education costs. These costs are in addition to any school fees and can make sending children to school prohibitive for many families.

Health-related costs include consultation fees, medicine, clinic charges, fees from traditional healers and transportation costs. Households that include persons with disabilities experience much higher rates of health-related shocks yet are more likely not to do anything about it due to health-related costs. A consequence of this could be that illnesses go untreated, and conditions worsen. Notably, persons with disabilities in the wealthiest quintile pay significantly more for health-related costs than their counterparts without disabilities in the other four quintiles, and it is likely that only those in the wealthiest quintile have the means to pay for all (or at least, the majority) of the health-related costs that they need.

The indirect costs of disability relate to a number of issues such as a decrease in productivity, a loss of education and employment opportunities, and insufficient investments. It also includes the foregone economic activities associated with the person with disabilities and other members in the household, as well as more intangible costs such as stress and social isolation. In Uganda, personal assistance is predominantly provided by other household members, as part of their familial care and support networks. Close to 90 per cent of persons with disabilities that have access to some form of personal assistance receive assistance from other household members. Only 11 per cent of the carers from outside the household are non-relatives or from the government.
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Food security and nutrition

Stunting and other mal- or under-nutrition related issues remains a significant problem in Uganda. The household survey found that close to 15 per cent of households with persons with disabilities have a poor dietary diversity consumption, and 55 per cent have either a low or a medium dietary diversity score. This is 2 percentage points more than households with no members with a disability. Households with members with a disability that have younger household heads tend to have better dietary diversity than households with older household heads. This is also observed among different household structures. Less than a quarter of older persons with disabilities living alone have richer and more diverse diets.

Social norms and expectations

Social norms and expectations – especially with regard to stigma and discrimination – can have a significant impact on the vulnerability (and conversely resilience) of adults and children with disabilities across the lifecycle. While discrimination on the basis of disability is outlawed in Uganda, there are still many cases of prejudice and misunderstanding within communities.

Gender norms

Women with disabilities tend to experience more stigma and discrimination than women without disabilities. Gender and disability therefore intersect, and women with disabilities can face double or even triple discrimination. For example, women with disabilities are at greater risk of experiencing sexual violence compared to their counterparts without disabilities.

Men and women with disabilities adhere to social norms around marriage and childbirth, and women are expected to, and indeed in many cases want to, marry and have children, and many men aspire to have at least a second wife, which is supported by the state and by society. While most men and women are living as couples with children, it is not clear if these are cohabiting couples, or formal marriages, but informal cohabiting may contribute to vulnerability. Being legally recognised as the next of kin gives at least some semblance of legal protection to women when they divorce, unlike informal arrangements of living together and having children. Property inheritance, for example, can be a very contested area for women, especially if they are not formally married, or if their husband has a second (or subsequent) wife.

A woman’s capacity for autonomy is severely restricted by gender norms. While women with and without disabilities will often make financial decisions regarding the household, decisions that involve greater amounts of money are normally made by the head of the household, who is often a man. Women in female-headed households have more autonomy but may be in a vulnerable state due to less income (whilst caring for dependents) and fewer assets.

Abuse and violence

Both men and women with disabilities are more likely to experience some form of abuse or violence across the lifecycle than people without disabilities. The qualitative research raised examples of children with disabilities who are hidden away from the community and segregated within the family. Young girls with disabilities are particularly vulnerable, as they are often the target of opportunistic men, many of whom abandon them when they become pregnant. Sometimes these men offer little support and may even be abusive.
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Shocks

The most serious shocks experienced by households including a person with a disability are health, agriculture, climate and food related. The main response (coping strategy) to the shocks was inaction, with 22 per cent giving this response. The consequence of inaction could be that the household falls into a greater state of vulnerability. The next most common responses for coping strategies were that around 17 per cent of households relied either on unconditional support from relatives or using savings instead. A relatively small number sold off assets although it is not clear from the data if the low number is simply because most respondents did not have any assets to sell. Respondents infrequently cited that they relied on support from the government as their primary coping strategy.

Disability Across the Lifecycle

Ugandans face a range of risks and shocks across the lifecycle, and person with disabilities and their families may have even less wherewithal to withstand these shocks and risks for a variety of reasons. There are a range of barriers that create conditions of vulnerability as well as opportunities to strengthen resilience across the lifecycle. None of these conditions are static, and persons move between these phases at different points in their life depending on a range of factors.

Childhood

Past and future vulnerability are intimately linked, and poverty, exclusion and poor-quality services hinder a child’s ability to thrive and lead a full life. It is therefore extremely important that the risks and vulnerabilities that a child with a disability faces are addressed when they are young.

Most impairments acquired in childhood happen after birth, for example from endemic childhood diseases such as (cerebral) malaria, as well as vaccine-preventable diseases. This may include potentially avoidable conditions, which can worsen with limited access to healthcare and/or rehabilitation. Disability among babies and young children is often viewed as a curse, or as a consequence something the parents – particularly the mother – did or did not do when pregnant, which can result in attributions of blame and abandonment.

While children with disabilities are as likely as children without disabilities to be living with their birth mothers as children without disabilities, this proportion declines as they get older, indicating that as they grow, their mothers find it more challenging to look after them. The reasons for this may include lack of access to services and support, as well as stigma and discrimination. Mothers may resort to leaving their children unattended while they go out to find work. Some children are left with other family members to care for them, in particular grandparents, many of whom are struggling themselves.

One of the best starts to life is receiving an education. However, attending school for children with disabilities has a number of additional costs, including transport, uniforms and textbooks. In Uganda, children with disabilities are less likely to attend school than their peers without disabilities, with only 74 per cent of children with disabilities aged between 5 and 18 attending some level of school, compared with 83 per cent of children without functional difficulties.

The percentage of boys with functional difficulties who are not attending school significantly increases at around puberty (12 – 13 years), where close to 40 per cent are not in school. This is
likely to be due to the need for them to work to earn money. Among girls, a similar drop is observed slightly later at 15, where close to 30 per cent are not attending school. This is in line with established issues such as the need to work, menstruation, pregnancy and early marriage.

Impairment type also impacts access levels to education. 54 per cent of children with difficulties in self-care and 52 per cent of children with difficulties communicating have never attended school. There is likely very little support for these children in available schools. Some children, for example, would require an assistant in the classroom.

Even when children with disabilities do attend school, it should be emphasised that it is often poor quality because it has not been designed to accommodate their specific needs. Implementing a fully inclusive education system requires systemic changes and wide-ranging reforms are needed to enable the flexibility that a fully inclusive approach requires, including reforms to the education budget for children with disabilities.

**Youth**

Uganda's youth face particular challenges around education, employment, health, relationships and family life, all of which can have adverse consequences on life chances and opportunities.

Young persons with disabilities' lower levels of educational attainment reduce their chances of accessing decent employment, as they are placed at a disadvantage when compared to their peers without disabilities. There are high levels of unemployment for both young persons with disabilities and young people without disabilities, but while more than half of young men (53 per cent) and two-fifths of young women (40 per cent) without disabilities are currently employed, only a third of young men and women (34 per cent and 30 per cent) with disabilities are currently employed.

The more severe the difficulty, the less likely the person is to be economically active, with women affected more than men, reflecting systemic challenges in accessing the labour market. For those who cannot perform functional activities at all, gender appears to have a significant impact, with a quarter of young men being in employment (24 per cent) compared with only 3 per cent of young women. Impairment type also impacts employment rates, with young people who have self-care or communication difficulties most likely to have never been employed (78 per cent and 72 per cent).

Even when persons with disabilities do have the necessary qualifications, they can struggle to find employment in comparison to their peers without disabilities. This is due to a number of reasons, including discriminatory attitudes towards persons with disabilities and the workplace not being adapted to their impairment.

It is around this age that many young people, particularly girls, begin relationships and have children. Gendered attitudes are entrenched from a very young age, and girls who marry young often endure lasting health and other consequences. For many young women with disabilities, they have children with partners who are often older them and who they are often not legally married to. If she separates from the father, she is likely to receive little to no support from the father, and in these cases, she and her children can be at even greater risk of vulnerability, and in some cases, a different family member must bring up the children instead. In an absence of formal safety nets, children continue to be regarded as an "investment in the future". The qualitative research shows that many young women felt that having children helped them to
fulfil their social role of being a mother. However, children often increased vulnerability as it made young mothers more dependent on others to support them.

**Working age**

The challenges experienced by young Ugandans with disabilities are replicated when they reach 30 – 60 years of age. Similar patterns of employment are apparent: persons with disabilities are less likely to have ever worked than their peers without disabilities, with women less likely to have worked than men. Indeed, more than three quarters of women aged 30 – 60 years who cannot perform functional activities at all have never worked.

By this point in their lives, persons without a disability are more likely to be married than those with a disability. There are stark gender differences as well: 43 per cent of women with a disability are in a monogamous marriage, compared with 67 per cent of men. Furthermore, women are much more likely to be separated or divorced than men. There are similar proportions of people living in monogamous marriages across the impairment types, but people with communication difficulties are more likely to have never married compared with the other difficulty domains.

One of the main reasons for this disparity is how men and women are perceived to be fulfilling their gender roles. If a woman who has a disability is perceived to be unable to be a carer, mother or wife, she is less likely to be able to marry. Similar sanctions are not placed on men, and if a man is wealthy, and able to provide bridewealth and pay for labourers, he is thereby seen as a provider and as a viable marriage prospect. Men with disabilities who are poorer are therefore less likely to marry because they are not able to fulfil this role and therefore struggle to be accorded such social status within their community. For men (and women) with disabilities, bridewealth may be higher than that for a man or woman without disabilities, as the spouse may face greater demands on their labour.

**Older persons**

Although not inevitable, many people experience a decrease in their functions as they age (for example, vision, hearing, cognition, and mobility). This in turn affects both their need for support and care, as well as their ability to work and earn their own income. With increasing life expectancy, shifting living arrangements and greater globalisation, the profile of Ugandans aged 60 years and above is changing rapidly. Without sufficient support, and with decreasing care networks, many older persons are often not able to experience the ‘golden years’ that are envisaged as ideal social roles for older persons, in which they are surrounded by a large, loving extended family. Instead of fulfilling the ‘elder’ role of instilling good morals, mediating conflicts and giving advice, they must continue to undertake physical labour in order to survive.

In Uganda, the majority of older persons with and without disabilities are self-employed or own-account workers. This implies that rather than retiring, older persons will continue working until their ill-health or functional difficulty reaches a stage in which they are forced to stop. This is to be expected as people do not become eligible for the Senior Citizens grant until they reach 80 – and it is only now being rolled out nationally – so they have little option but to continue working or rely on others, thereby becoming more dependent.

Older persons with disabilities are most likely to be living with children, grandchildren or other relatives. For those living alone, there is little available social care to support them, and many may struggle to do chores and obtain enough food. Women are substantially more likely than
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men to be widows, with women with disabilities being the most likely to be widowed. While widowed older men may re-marry, or have younger second or subsequent wives, prevailing social norms do not allow older women to do the same, so they are more likely to not live with a spouse, which can put them in a more vulnerable state, especially if they have fewer assets to which they have access to. If a man’s wife is younger, she may be able to provide him with substantial support, though it should be emphasised that the wife may also have functional limitations and find it difficult to provide support. Given that women are accustomed to being the main caregivers, as they grow older, the shift to needing to be looked after by others may make some feel like they are burdens. Furthermore, older women may end up having to manage the household and support the care of at least one member of their family, as well as their grandchildren. Although living with younger generations provides care and financial support – which is vital in the absence of state social care – larger households have more age-dependent members, which can put them in a more vulnerable state.

Disability Architecture

The disability architecture in Uganda is anchored onto governance and administrative structures, the legal and policy regime, the actors involved (national and international, state and non-state), global and national policy frameworks, the global and national development agenda as well as its financing. Architecture therefore not only describes the processes for the meaningful inclusion of persons with disabilities in the development agenda, but also what the expected outcomes should be.

Political structure

The government has mandated for quotas of representatives of persons with disabilities at all levels of governance. At the legislative level, there are five elected parliamentary representatives for persons with disabilities – one of which must be a woman. This quota system is replicated all the way down to the District (LC5) and sub-county (LC3) level, with each county having two representatives (councillors) for persons with disabilities, one male and one female.

Administrative structure

District local governments or local government councils (LC5) are chaired by directly elected representatives who have both legislative and executive powers. At LC5 level, there are two elected councillors for persons with disabilities on the council (one male and one female – both of whom should have a lived experience of disability). Disability issues therefore should cut across all the functions: however, in reality, disability is often placed within the community development committee, reflecting the national level. Councillors and others therefore work closely with community development officers). Although there is not a specific disability representative at LC1 level, some of the LC1 Chairs interviewed were aware of the need to include what one Chair called the "special interest groups". Persons with disabilities may often find that at the local level (districts and below), many of the councillor seats are vacant. Furthermore, some of those in office may not fully understand their mandate or lack the specific support needed to enable them to participate in council meetings (for example, transport, guides, etc).

Planning and budgeting process

The social development sector only accounts for 0.6 per cent of the national budget (as of the financial year 2019/20), and this is a decrease from 0.9 per cent from the previous year. Yet, within the wider social development sector, persons with disabilities remain an "area of special
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In the financial year 2018/19, a total budget of UGX 7.64 Billion was allocated to district local governments in the medium-term expenditure framework for the implementation of social development activities relating to persons with disabilities. However, it was reported that in many cases, the money remained unspent, and was returned to central government, thereby reducing the likelihood of a similar sized transfer the next financial year. The largest funding envelope is for the Special Grant (28 per cent of the total envelope in the previous financial year). In previous financial years, district local governments were given a "basket" of funds out of which they could choose where to allocate funds, for example, for disability-specific programmes or activities. This led to confusion about eligibility criteria and resulted in underspending of the budgets. This was to the detriment of persons with disabilities, as unspent funds had to be returned and resulted in a reduction in budget lines the following year.

Mainstreaming disability in MDAs

All government ministries, departments and agencies are responsible for including disability in all their activities, using a “twin track” approach, which requires both mainstreaming and specifically targeting disability issues. There are challenges with the mainstreaming of disability by ministries, departments and agencies and local governments, including the quality of the programmes delivered, further hampered by a lack of effective multi-sectoral coordination and ineffective interventions.

The Ministry of Gender, Labour and Social Development

Within the Ministry of Gender, Labour and Social Development (MGLSD), disability is largely included under the Social Protection Directorate which addresses the development concerns of all "vulnerable and marginalised groups." The MGLSD has the Constitutional mandate for disability issues in Uganda, administered through the Department of Disability and Elderly Affairs, which is headed by a Commissioner, under the political supervision of a State Minister (currently a vacant position). The MGLSD oversees the District Community Development Officers, part of the Community Development Departments of Local Government, and whose role it is to implement social development in the districts. In each district, there is usually a focal point for disability and elderly affairs (usually, but not exclusively, a Senior Community Development Officer). The semi-autonomous bodies of the National Council for Persons with Disabilities (NCD) and the Equal Opportunities Commission, also sit within the MGLSD. Key policies include The Uganda National Employment Policy (2011); the National Policy for Older Persons (2009), the Uganda Gender Policy (2007) and the National Social Protection Policy (2015).

The Department of Disability and Elderly Affairs (MGLSD) has the overall mandate for disability policy and social care. The Department has a number of programmes/activities that support persons with disabilities and works closely with the District Community Development Officers) to implement the Special Grant for Persons with Disabilities, rehabilitation centres, and the Community Based Rehabilitation programme which largely no longer exists.

Ministry of Health

The Ministry of Health is responsible for the entire health system, and with regard to disability, is responsible for disability prevention, promotion of health and wellbeing, management of disabilities as well as staffing. However, there is no specific policy on inclusive health, and most of these services are provided through the Disability Prevention and Rehabilitation section. It is unclear whether persons with disabilities enjoy the same level of access to all healthcare as their peers without disabilities, though evidence would suggest not. There is limited disability-
disaggregated information collected by the Ministry of Health to measure inclusion, and what little is included is largely driven by donor priorities, and is not shared between ministries (or other agencies) to improve coordination of service delivery.

**Ministry of Education and Sports**

The Ministry of Education and Sports supports the delivery, coordination and regulation of quality education and sports to all persons in Uganda with the overall aim of national development. Within the ministry there is a Department of Special Needs and Inclusive Education with a disability focal point based within the department. Special education is also a sub-sector working group. Implementing a fully inclusive education system requires systemic changes to curriculum, pedagogy and funding models, so wide-ranging reforms are needed to enable the flexibility that an inclusive education approach requires. Despite its stated commitment of ensuring education for all, and inclusive education specifically, as well as a relatively progressive policy environment, there is still some confusion about what inclusive education is and how it should be implemented in Uganda. Moreover, there are currently 113 Special Needs Education schools across the country, though not in all districts of Uganda. Most are in fact run by non-governmental organisations and faith-based organisations, calling into question issues of quality and consistency. In the education budget there is little thought of the specific needs of children with disabilities beyond allocating a specific amount to Special Education Needs, despite the policy focus on inclusive education. Almost all of the education focused policies currently in use consider children and youth with disabilities to be “vulnerable”, and as such, focus on targeting them as a specific group, rather than on making the wider system more inclusive for all children.

**Disability legislation and policy**

There have been many claims that Uganda’s disability legislative and policy framework is one of the best in the sub-Saharan region. However, it has also already been well-documented that there is a significant gap between what is written on paper, and what is being done on the ground, in particular around funding for the implementation of programmes, awareness of policies, and inconsistencies across policies.

Uganda is a signatory to a number of key pieces of international legislation advocating for the rights of persons with disabilities, including the Convention on Vocational Rehabilitation and Employment of Disabled Persons (1983); the Convention on the Elimination of All Forms of Discrimination against Women; the Convention on the Rights of a Child; and the UNCRPD (2008). All domestic laws should be in accordance with the Constitution (1995) and given the Constitutional commitment to equality for persons with disabilities, it is therefore a Constitutional obligation to respect the dignity and rights of persons with disabilities. In addition, the Equal Opportunities Commission Act (2006), as well as the Children’s Statute 1996 (with its 2016 amendments) also provide for the specific rights of children with disabilities in Uganda. Uganda had already enacted several disability-specific laws: the most recent is the revised Persons with Disability Act (2020). The revised Act is intended to ensure compliance with the UNCRPD, which came into force after the previous Act was legislated. Whilst the language of the Disability Act 2020 employs a human-rights based approach, in the end, the Act also reverts to a medical approach to determining disability if there is a dispute. The categories, particularly that of “mental illness”, blurs intellectual disabilities with mental health conditions, potentially...
Executive Summary

Creating challenges for both groups, as not all persons with intellectual impairments have mental health conditions and vice versa.

Despite the focus on disability in the legislative framework, there are still a range of concerns around the discriminatory language and terms used in these laws (including “imbecile” and person of “unsound mind” to mean persons with mental health conditions or intellectual disabilities), limited enforcement of the laws and, little being provided in terms of legal aid, among other barriers. A further challenge is actually upholding these laws, and empowering persons with disabilities and their families to be able to pursue their rights through the legal system, and to ensure that laws are enforced and penalties for breach of legal provisions are put in place. The Mental Health Act (2018) was revised to address many of the criticisms about terminology and treatment of persons with mental health conditions, though this revision has also not been without criticism. Moreover, it has been noted that while there are laws to prohibit discrimination against persons with physical, sensory, intellectual, or mental disabilities, and which provide for access to education, employment, health services, information, communications, buildings, transportation, and the judicial system for persons with disabilities, the government does not effectively enforce these laws.

While legislation provides a framework for justice in society, policies are created to support the achievement of certain agreed and identified goals. These goals are not legally binding, although laws may be created to make them so. In Uganda, those goals are set out in the country’s national development agenda, Uganda Vision 2040. Persons with disabilities are included in this framework, both as citizens with equal rights, as well as a specifically “vulnerable group”. In the Vision 2040 document, this vulnerability is addressed by underscoring the importance of social protection in ameliorating risks and vulnerabilities for certain groups, including persons with disabilities. Of course, this puts the onus on social protection as being the main way to deal with vulnerability of persons with disabilities, rather than an approach that encompasses all sectors. There is a lack of harmonisation across all the policies, with inconsistencies in definitions and approaches. This is key to delivering a joined-up approach to disability inclusion. The current policy on disability – the Uganda National Policy on Disability – dates from 2006 and was due to be reviewed in 2016. The process was initiated, but not finalised, so in 2019, the MGLSD restarted the Disability Policy Review process.

Across most Ministries, Departments and Agencies, disability is still seen as an issue of “vulnerability”, despite the rhetoric of rights. A much stronger focus on the equity component is necessary to ensure inclusion of persons with disabilities, as well as a recognition of the intersectional nature of these issues (including age, gender, location etc) to ensure disability is mainstreamed across all Ministries, Departments and Agencies. There is a major gap in coordination, and the creation of a specific function to coordinate disability across Ministries, Departments and Agencies would facilitate mainstreaming and inclusion.

While the Government has made attempts to redress historical neglect and exclusion of persons with disabilities (and other groups) through affirmative action policies, in reality, these have been more of a political success than a social one, and the benefits have not reached the majority of persons with disabilities.
Service Provision

Persons with disabilities, along with their caregivers, possess a wide range of skills and talents that should be harnessed and maximised. However, the barriers that they face in Uganda are hindering them from realising their full potential, and many persons with disabilities are being left behind. There are a range of factors that can enhance an individual’s resilience to unexpected shocks, and a key part of this process is state intervention. State supported services – by addressing the needs of persons with disabilities across the life-cycle – can be transformative for everyone. Services that break down barriers, create effective linkages and increase capabilities not only enable persons with disabilities to survive, but also to thrive. Indeed, the support that persons with disabilities need cuts across a range of public services.

A great deal has already been done in Uganda to support persons with disabilities, including political representation and buy-in for disability issues across the government sectors. However, the vast majority of services and resources provides for adults and children with disabilities in Uganda are provided by non-state actors. This is not sustainable, and the Government of Uganda have committed to addressing this gap.

A “twin track” approach is needed – implementing both an overarching and consistent strategy to mainstream disability across all sectors, as well as introducing targeted interventions to ensure their specific needs are addressed. In addition to providing regular financial (and other) support, a broader approach to bolstering resilience is needed, in particular for individuals and families identified as being particularly “at risk”.

Disability assessment

Currently, there is no unified approach to disability assessment in Uganda. For example, assessment for the Public Sector Pension Scheme disability pension is carried out by government medical personnel of the Medical Assessment Board under the Ministry of Health. Meanwhile, Community Development Officers – who have not received appropriate training – also “assess” persons with disabilities for access to grants and other services such as the Special Grant. As well as having no formal system to assess disability, Uganda does not currently have a system of registration of persons with disabilities. Both of these gaps create administrative barriers for persons with disabilities to access services.

Social protection programmes

The Government of Uganda considers social protection as a basic service and human right that ensures the dignity of the country’s citizens. Social protection in the Ugandan context has two broad pillars: 1) Social Security (protective and preventive interventions to mitigate factors that lead to income shocks and affect consumption), which can be direct income support or social insurance; and 2) Social Care and Support Services (usually these provide care, support, protection and empowerment to vulnerable individuals who are unable to fully care for themselves). Existing social provision from the MGLSD is not comprehensive across the lifecycle in Uganda, and households without a member with a disability have greater access to social protection and livelihood programmes than households with a person with a disability.

In order to support the inclusion of persons with disabilities and enable them to enjoy the same standard of living as persons without disabilities, many countries provide a range of social protection interventions, both to cover loss of income and the additional costs of disability. In Uganda, however, there is currently limited income support across the lifecycle and what is
Executive Summary

available does not adequately address the vulnerabilities and risks of persons with disabilities. Key gaps include the lack of income support for children with disabilities, thereby preventing children from having the same start to life as children without disabilities. There should also be a disability benefit for working age adults, that provides income support to the small number who cannot work and compensates those who can work for the additional costs they experience. There is also a lack of a care/support benefit to compensate for the loss of income that family members experience if they must give up work – either partially or completely – to provide care for a person with a disability with significant support needs.

Uganda's flagship social protection programme is the Senior Citizens Grant. This is a tax-financed, old age pension funded by the Government of Uganda and donors. The transfer is currently worth UGX 25,000 per month, and as a non-contributory social pension, the benefit has been designed to provide income support for older Ugandans who do not contribute to the formal sector. It is currently being rolled out nationally to all older persons in Uganda aged 80 years and above. Although ground-breaking, the current design of the Senior Citizens Grant is not able to fully address the financial needs of older persons with disabilities. The real value of the transfer has declined significantly over time, as the benefit is not adjusted to inflation. Furthermore, as the grant is not a disability-specific scheme, it does not take into account the additional costs of disability.

The National Social Security Fund is a savings scheme for employees in formal sector companies with at least five employees. In practice, this means that most persons with disabilities cannot access the scheme as they are not in formal employment, although exact numbers who do access it are not known. It should also be noted that the fund does not provide effective social security as it is a provident fund. Not only are benefit levels low, but it does not provide regular transfers. Furthermore, women are likely to be left out.

Social care and social work for persons with disabilities are still underdeveloped in Uganda. Currently, they comprise a number of small programmes and services overseen and/or delivered by the MGLSD, and include five National Rehabilitation Centres, which cannot be considered social protection.

Health and rehabilitation services

Ugandans with disabilities face many of the same health challenges as their counterparts without disabilities, including HIV/AIDS, but often experience less access to healthcare and treatment, and less good health overall. Nevertheless, there are pockets of good practice, mainly from non-state actors. Costs of healthcare, including transport to health centres, can also be a barrier to accessing services which are otherwise provided free of charge. In addition, overall use of assistive products is low among persons with disabilities. Only 13 per cent of persons with at least a lot of difficulty with functional activities report using devices.

A major reason why persons with disabilities experience less access to healthcare is that they are often not considered a priority area for funding purposes. A significant proportion of the Ministry of Health’s funding derives from international donors who may not prioritise disability issues, and often have a disease-specific agenda (for example, HIV/AIDS, neglected tropical diseases, and malaria).
Executive Summary

Education system

Despite the political will to promote inclusive schools, there is limited budget and resources directed towards ensuring all children with disabilities can attend inclusive mainstream schools. While Uganda is one of the few low-income countries that has a specific budget allocation for children with disabilities, these budget lines do not clearly indicate whether finances are for special or inclusive education. This is important as it relates to the additional costs of disability, in particular the use of additional resources in the classroom, including classroom assistants or support teachers. Moreover, the budget is only 0.1% of the overall education budget.

Uganda has a range of school settings, including “fully inclusive” schools, integrated units (whereby children are taught in a separate unit within a mainstream school, but play with the other children at breaks etc) and special schools (usually impairment-specific, such as schools for the Deaf). The permitted ratio of students to teachers in mainstream schools is currently 45:1. However, classrooms often exceed this, making inclusion of children with disabilities even more difficult. Of the few children with a disability that do access education, 5 per cent access it within an inclusive setting in regular schools, while 10 per cent access it through special schools and annexes. This means that the remaining children who are attending school are not receiving any specific interventions or support. Special needs education is underfunded and poorly mainstreamed across the school system, and many special schools are of poor quality and/or high cost.

Employment and livelihoods

Active labour market programmes are included under the remit of social protection, although they do not fit international definitions for social protection. The programmes largely follow the same approaches and are based on a group model to stimulate income-generating activities. Key programmes for persons with disabilities are the Special Grant, which is a grant, and loans-based programmes for specific interest groups, such as the Uganda Women’s Empowerment Fund and the Youth Livelihood Programme. Some persons with disabilities may also access mainstream opportunities and programmes such as vocational training opportunities and civil service jobs.

The Special Grant provides one-off grants to support groups of persons with disabilities and their caregivers to undertake income generation activities. The programme only covers a limited number of groups, and whilst evidence suggests that it has brought recipients financial and social benefits, it should not be considered social protection as it provides a one-off lump sum payment and does not provide recipients with immediate support for health or education expenses, unless they sell their assets, which many end up doing.

The MGLSD also oversees five rehabilitation and training centres, which function as residential vocational training institutions for persons with disabilities from the age of 16 years up to around 40 years old. Due to budgetary constraints, none of the Centres are operating at full capacity. The Centres have been subject to criticism about the lack of resources, the curriculum not being aligned with wider Business, Technical and Vocational Education and Training policies or practices, poor training, structural issues with the buildings and cases of land grabbing, including by former residents.
Executive Summary

Land, housing and urban development

Land ownership and usage play a significant role in the lives of persons with disabilities, as a source of security (if they have land tenure), as a source of food, and as a place of belonging to a community. A significant number of households with a member with a disability live in a hut or detached house. Furthermore, the majority of respondents live in a brick or mud brick dwelling, with corrugated iron or thatched roofs and earth or sand floors.

Persons with disabilities seldom live in houses that have been adapted to their needs. For example, a person with mobility problems may struggle to use a pit latrine without a slab. In addition, many persons with disabilities live in informal settlements, that are at risk of sudden and extreme flooding, as well as sporadic utilities and refuse collections.

There are currently no government provided housing solutions for persons with disabilities in Uganda, despite policy commitments to support “disadvantaged groups.”

Key Recommendations

Persons with disabilities in Uganda are being left behind, but it does not have to be this way. By supporting persons with disabilities, by giving children the best start to life, by lessening the time and resources that their households must spend on them, persons with disabilities will be more empowered and more visible within society.

State intervention is therefore essential, but this must be sustained and not ad hoc. Current funding is minimal, and much can be done to implement a system that both mainstreams disability across all sectors and programmes, as well as introduces targeted interventions to ensure their specific needs are addressed. The following are some key recommendations that will have a transformative effect for persons with disabilities. However, this is just a snapshot, and further support – that cuts across a range of public services – but be further implemented if there is to be systemic change.

1. Establish a national disability registration process
2. Introduce a universal Child Disability Benefit to provide support for parents of children with disabilities
3. Introduce a disability benefit for working age adults to provide income support to the small number of persons with disabilities who cannot work and compensate those who can work for the additional costs they experience.
4. Extend the age of eligibility for the Senior Citizens Grant to those aged 65 and above.
5. Introduce a care/support benefit.
6. Invest in professionalising and overseeing a national social work system.
7. Strengthen the gender focus in disability inclusion, and vice versa, ensure gender-focused initiatives, such as the Gender and Equity Inclusive Budget Indicators, proactively include women and girls with disabilities.
8. Provide individual and group loans for those who have some experience in running a small business
9. Shift emphasis away from group-based active labour market approaches
Executive Summary

10. Improve access to mainstream programme, by strengthening existing policies and legislation which advocate for affirmative action, for example those aimed at youth, women etc.

11. Train government staff on disability inclusion.

12. Strengthen District Disability Councils.

13. Strengthen coordination mechanisms.


15. Strengthen recourse mechanisms.

16. Re-establish and fund the community-based rehabilitation programme, or fully incorporate it into community development activities.

17. Increase access to resources, such as assistive devices, to facilitate inclusion.
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<tbody>
<tr>
<td>ANC</td>
<td>Antenatal care</td>
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<td>ARTs</td>
<td>Antiretroviral therapy</td>
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<td>BMAU</td>
<td>Budget Monitoring Accountability Unit</td>
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<tr>
<td>BTVET</td>
<td>Business, Technical and Vocational Education and Training</td>
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<tr>
<td>CEDAW</td>
<td>Convention on the Elimination of All Forms of Discrimination against Women</td>
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<tr>
<td>CRPD</td>
<td>Convention on the Rights of Persons with Disabilities</td>
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<tr>
<td>CDO/DCDO</td>
<td>Community Development Officer/ District CDO</td>
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<td>CAO/ACAO</td>
<td>Chief Administrative Officer/Assistant CAO</td>
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<td>CBR</td>
<td>Community-based rehabilitation</td>
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<td>CRC</td>
<td>Convention on the Rights of a Child</td>
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<td>CSBAG</td>
<td>Civil Society Budget Advocacy Group</td>
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<tr>
<td>CSO</td>
<td>Civil society organisation</td>
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<tr>
<td>DDC</td>
<td>District Disability Council</td>
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<td>DFID</td>
<td>UK Department for International Development</td>
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<td>DLG</td>
<td>District Local Government</td>
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<tr>
<td>DPO</td>
<td>Disabled people's organisation</td>
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<tr>
<td>DRD</td>
<td>Disability and Rehabilitation Division</td>
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<tr>
<td>ECD</td>
<td>Early Child Development</td>
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<tr>
<td>ECCD</td>
<td>Early childhood care and development</td>
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<td>EMIS</td>
<td>Education management information system</td>
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<tr>
<td>EOC</td>
<td>Equal Opportunities Commission</td>
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<td>ESPP</td>
<td>Expanding Social Protection Programme</td>
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<td>FBO</td>
<td>Faith-Based Organisation</td>
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<td>FCS</td>
<td>Food consumption score</td>
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<td>FGD</td>
<td>Focus group discussion</td>
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<td>FY</td>
<td>Financial year</td>
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<td>GBV</td>
<td>Gender-based violence</td>
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<td>GLAD</td>
<td>Global Alliance on Disability</td>
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<td>GoU</td>
<td>Government of Uganda</td>
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<td>HIMS</td>
<td>Health information management system</td>
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<tr>
<td>HIV/AIDS</td>
<td>Human immunodeficiency virus/Acquired immune deficiency syndrome or acquired immunodeficiency syndrome</td>
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<tr>
<td>ICF</td>
<td>International Classification and Functioning, Disability and Health</td>
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<td>ICT</td>
<td>Information Communication Technology</td>
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<tr>
<td>IE</td>
<td>Inclusive education</td>
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<tr>
<td>LC (II/III etc.)</td>
<td>Local Councillor (level II/III etc)</td>
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<tr>
<td>MATIP</td>
<td>Markets and Agricultural Trade Improvement Programme</td>
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<tr>
<td>MDA</td>
<td>Ministries, departments and agencies</td>
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<td>MICS</td>
<td>Multi-Indicator Cluster Survey</td>
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<td>MIS</td>
<td>Management Information System</td>
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<tr>
<td>MOH</td>
<td>Ministry of Health</td>
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<td>MOWE</td>
<td>Ministry of Water and Environment</td>
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<tr>
<td>MOWT</td>
<td>Ministry of Works and Transport</td>
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<tr>
<td>MGLSD</td>
<td>Ministry of Gender, Labour and Social Development</td>
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<tr>
<td>MHU</td>
<td>Mental Health Uganda</td>
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<tr>
<td>MICTNG</td>
<td>Ministry of Information Communication Technology and National Guidance</td>
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<td>MOES</td>
<td>Ministry of Education and Sports</td>
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<tr>
<td>NAD</td>
<td>Norwegian Association of the Disabled</td>
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<td>NAADS</td>
<td>National Agricultural Advisory Service</td>
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<tr>
<td>Acronyms</td>
<td>Full Form</td>
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<tr>
<td>NASWU</td>
<td>National Association of Social Workers of Uganda</td>
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<tr>
<td>NCD</td>
<td>National Council for Persons with Disabilities (formally the National Council for Disability, PWD ACT 2020)</td>
</tr>
<tr>
<td>NEET</td>
<td>Not in employment, education or training</td>
</tr>
<tr>
<td>NGO</td>
<td>Non-governmental organisation</td>
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<tr>
<td>NGPSS</td>
<td>National Governance, Peace and Security Survey</td>
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<tr>
<td>NIECD</td>
<td>National Integrated Early Childhood Development</td>
</tr>
<tr>
<td>NIRA</td>
<td>National Identification and Registration Authority</td>
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<tr>
<td>NPA</td>
<td>National Planning Authority</td>
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<tr>
<td>NPHC</td>
<td>National Population and Housing Census (2014)</td>
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<td>NRM</td>
<td>National Resistance Movement</td>
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<tr>
<td>NSG</td>
<td>National Special Grant</td>
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<tr>
<td>NUDIPU</td>
<td>National Union of Disabled Persons Uganda</td>
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<tr>
<td>NUWODU</td>
<td>National Union of Women with Disabilities of Uganda</td>
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<tr>
<td>NUSAF 3</td>
<td>Northern Uganda Social Action Fund (Third)</td>
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<tr>
<td>OWC</td>
<td>Operation Wealth Creation</td>
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<tr>
<td>PMU</td>
<td>Programme Management Unit</td>
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<tr>
<td>SACCO</td>
<td>Savings and Credit Cooperatives</td>
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<tr>
<td>SAGE</td>
<td>Social Assistance Grants for Empowerment</td>
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<tr>
<td>SCG</td>
<td>Senior Citizens Grant</td>
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<tr>
<td>SDGs</td>
<td>Sustainable Development Goals</td>
</tr>
<tr>
<td>SEN</td>
<td>Special Education Needs</td>
</tr>
<tr>
<td>SP</td>
<td>Social Protection</td>
</tr>
<tr>
<td>UBOS</td>
<td>Uganda Bureau of Statistics</td>
</tr>
<tr>
<td>UDHS</td>
<td>Uganda Demographic and Health Survey</td>
</tr>
<tr>
<td>UFDS</td>
<td>Uganda Functional Difficulties Survey</td>
</tr>
<tr>
<td>UHC</td>
<td>Universal Health Coverage</td>
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<tr>
<td>UHRC</td>
<td>Uganda Human Rights Commission</td>
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<tr>
<td>UNAB</td>
<td>Uganda National Association of the Blind</td>
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<tr>
<td>UNAPD</td>
<td>Uganda National Action on Physical Disabilities</td>
</tr>
<tr>
<td>UNCRPD</td>
<td>United Nations Convention on the Rights of Persons with Disabilities</td>
</tr>
<tr>
<td>UNDP</td>
<td>United Nations Development Programme</td>
</tr>
<tr>
<td>UNHS</td>
<td>Uganda National Household Survey</td>
</tr>
<tr>
<td>UNICEF</td>
<td>The United Nations International Children's Fund</td>
</tr>
<tr>
<td>UNMHP</td>
<td>Uganda National Minimum Healthcare Package</td>
</tr>
<tr>
<td>UNOHCHR</td>
<td>United Nations High Commissioner for Human Rights</td>
</tr>
<tr>
<td>UWEP</td>
<td>Uganda Women's Entrepreneurship Programme</td>
</tr>
<tr>
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<td>Village Health Teams</td>
</tr>
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<td>World Food Programme</td>
</tr>
<tr>
<td>WHO-MDS</td>
<td>WHO Model Disability Survey</td>
</tr>
<tr>
<td>WGSSQ</td>
<td>Washington Group Short Set of Questions</td>
</tr>
<tr>
<td>YLP</td>
<td>Youth Livelihood Programme</td>
</tr>
</tbody>
</table>
1 Introduction

The Government of Uganda (GoU) has made a commitment to the equal rights and opportunities for persons with disabilities, as reflected in the Constitution of the Republic of Uganda (1995), as well as the numerous laws and commitments enacted to protect the rights of persons with disabilities. In order to achieve equality for persons with disabilities, the GoU has also instigated a number of affirmative actions, as well as a comprehensive political and administrative system for disability issues, which is complemented by a vibrant civil society to hold the government to account. However, while Ugandan national policies and legislation ostensibly regard disability issues from a human rights perspective, it is less clear if these are actually implemented in practice, or whether this view is entrenched right down to the grassroots level.

Despite the fact that adults and children with disabilities officially make up around 12 per cent of the Ugandan population, access to services in Uganda is ad hoc and depends more where a person lives, where programmes are being targeted, whether a person falls into a “priority group” and a variety of other caveats. Not only are services underfunded, but persons with disabilities faces a number of social, cultural, administrative and financial barriers that limit their access to these services.

The Uganda National Social Protection Policy (2015) established a set of strategies to mitigate these factors, in line with existing human rights commitments. Furthermore, Uganda’s current policy on disability – the Uganda National Policy on Disability – dates from 2006 and was due to be reviewed in 2016. In 2019, the Ministry of Gender, Labour and Social Development restarted the Disability Policy Review process, which is still ongoing. Its priority areas of focus are accessibility, participation, capacity building, awareness raising, prevention and management of disabilities, care and support, socio-economic security, research, communication (sign language, tactile and Braille literacy) and budgeting.

In order to deliver on the policy areas effectively, the GoU needs to better understand what the lives of adults and children with disabilities in Uganda look like today, and why there are barriers to the equality and inclusion of persons with disabilities. This report aims to provide a comprehensive overview of the situation for adults and children with disabilities in Uganda.

The aim of this situational analysis is to consolidate the existing evidence base on disability in Uganda, and to help identify and fill in critical knowledge gaps. The report will inform the design of a new disability-specific programme which will take practical steps to strengthen Uganda’s social protection schemes, with the aim of empowering persons with disabilities, enhancing their inclusion and wellbeing, and enabling them to participate on an equal basis with others.

The situational analysis will feed into the initiatives currently being undertaken by the Expanding Social Protection II programme (ESPP II) to enhance the inclusion of persons with disabilities within social protection. The ESPP II is a key deliverable of Department of Disability and Elderly, Ministry of Gender, Labour and Social Development (MGLSD). The overall aims of the programme are:

- Building a greater awareness within Uganda of the challenges faced by persons with disabilities and the importance of building effective social protection systems that address their requirements and enable them to more actively engage in society and the labour market.
1. Introduction

- Strengthening the disability inclusivity of current social protection programmes by reducing barriers to access and building linkages with other services.
- Strengthening policies and institutions to create a more conducive enabling environment for the inclusion of persons within disabilities within social protection.
- Enhancing the inclusion of disability information within national datasets.
- Building an effective system of disability assessment for social protection schemes

The report is structured as follows: after an overview of the methodologies used, we present a summary of existing information around disability nationally to contextualise our findings, including how disability is conceptualised in Uganda. The report then moves on to examine the vulnerabilities and risks that persons with disabilities face, how these impact on them across the lifecycle, as well as some of the ways people negotiate these challenges.

The report then examines the services that are currently provided for persons with disabilities to address these challenges (both social protection-specific services, and more general services that also provide support), and how genuinely inclusive these programmes and services are. The report explores the barriers to accessing services across the lifecycle, as well as the effectiveness, quality and appropriateness of these services and recommendations for creating a more conducive enabling environment for the inclusion of persons with disabilities in Uganda.

This is framed by an analysis of existing governance structures, legislation and policy. Uganda has a rich history of affirmative action for persons with disabilities, so it is important to understand this context. We then move on to discuss specific service provision. Finally, the findings are drawn together to make a set of recommendations around future research and programming, as well as identifying strategic opportunities to strengthen existing policies and practices.
2. Methodology

This research examines the challenges persons with disabilities, and their caregivers, face across the lifecycle, and how these challenges vary across a range of intersectional factors such as age, sex, location, impairment type, level of difficulty etc. The situational analysis comprises four interlinked components: a review of the “disability architecture” which examines the structures and support that are currently available for persons with disabilities in Uganda, including policies, legislation, and governance; a “diagnostic” of existing social protection programmes; qualitative life history data; and a nationally representative household survey.

As Figure 1 demonstrates, the research has taken a participatory approach, working with persons with disabilities, caregivers and representative organisations. This is in line with the Government of Uganda’s (GoU) rights-based approach and its commitment towards promoting disability inclusion. It is hoped that the recommendations that are made will have the potential to be transformative, moving beyond passive inclusion or sensitisation, towards actively ensuring that interventions have the potential to bring about structural change for Uganda’s persons with disabilities.

**Figure 1: Framework for Analysis**

Work commenced for the situational analysis in May 2019, with a formal inception meeting taking place in June 2019. The Department of Disability and Elderly – located within the MGSLD – set up a technical working group, which included representatives from line ministries, the National Council for Persons with Disabilities, and disabled people’s organisations (DPOs). The working group met several times over the course of the research. Ethical approval was obtained from The AIDS Support Organisation (TASO) and submitted to the National Council of Science and Technology. The overview of policies and legislation on social protection and other public services was undertaken in parallel with the other components of work: the diagnostic of current

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2 Report available on request.
3 Full list available on request.
4 https://www.tasouganda.org/
2. Methodology

Social protection programmes fieldwork was undertaken in July and August; life history interviews took place in September and October 2019; and data collection for the household survey was completed in November 2019. A national validation workshop was held in Kampala on the 29th November 2019.5

2.1 Understanding disability in Uganda

While the Government of Uganda has made a constitutional commitment to the equal rights and opportunities for persons with disabilities in Uganda, it does not define what “disability” is or who a person with a disability or disabilities is. However, although there have been a range of definitions and description of disability used across national legislation and policies, most are broadly rights-based. This is in line with the UN Convention on the Rights of Persons with Disabilities (UNCRPD), to which Uganda is signatory. A right-based approach understands disability as an “evolving concept”, based on a dynamic interaction between a person’s long-term physical, mental, intellectual or sensory impairment and environmental, attitudinal and other barriers that “hinder their full and effective participation in society on an equal basis with others” (UN, 2006).

Recently, a biopsychosocial model has also become prominent in Uganda, which includes health conditions and other contextual factors (WHO/World Bank, 2011). However, the medical model (whereby disability is seen as a health-related condition which can be treated and cured), and the charity model, (whereby persons with disabilities are objects of pity who need to be given additional money and other resources because they a person with a disability), remain strong and, indeed, are bolstered by acts of charity from well-meaning donors (e.g. ad hoc donations of equipment) or even by acts of some politicians themselves who provide support to certain groups. This in turn raises expectations about provision, as well as fostering dependency (c.f. Reynolds White 2020). It may also partly explain the emphasis on self-reliance prominent in both the overarching DPO narratives as well as the onus on social protection interventions, for example, the Uganda Women’s Empowerment Programme or the Youth Livelihood Programme, and even the Special Grant, all of which rely on the provision of loans or grants in return for individual and collective work, rather than any kind of social assistance.

As will be discussed, the new Persons with Disabilities Act (2020) is based on the human rights model.6 It uses the same rights-based definition as the previous Bill7 and establishes the fundamental freedoms and human rights for persons with disabilities. The new Act also lists a range of impairments and includes several categories that are seen as specific to the Ugandan situation, including “little people” and persons with Albinism. It also allows for medical determination of a disability if necessary. This raises two key issues. The first is that, if contentious, final determination of disability status still relies on a medical diagnosis of the cause of the impairment, rather than the impact (the functional limitations or participation/activity restrictions that manifest from them). The second point pertains to the number of medical personnel qualified to undertake such assessments – currently in Uganda, there are already huge constraints on medical staff (UNICEF 2015), and few are disability experts.

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5 Agenda available on request
6 At the time of the research, the Act had been passed by the President but was un gazetted.
7 “Disability is a permanent and substantial functional limitation of daily life activities caused by physical, mental or sensory impairment and environmental barriers resulting in limited participations”
2. Methodology

Despite its ostensibly rights-based approach and affirmative actions on paper, Uganda has been subject to criticism from the UN Office for the High Commission on Human Rights (UNOHCHR), following submission of its status report in 2016, about persisting gaps in definitions (especially around mental health), legal remedies and reasonable accommodation (UNOHCHR 2016). The revised Persons with Disabilities Act (2020) is intended to address these criticisms, although as described above, it is not fully compliant with a rights-based approach. Furthermore, some impairment groups feel that their specific issues are not being addressed in general inclusive development and other interventions, and therefore need highlighting. However, if development interventions were genuinely inclusive of all impairment groups, this impairment-specific focus would be less of an issue, although it is acknowledged that some groups, for example, “little people” and persons with Albinism, do in fact face some regionally specific challenges in East Africa (UPR 2016; Bradbury-Jones et al 2018). This point highlights the need to both recognise the rights-based approach to disability, using both functional limitations and participation restrictions, and to identify those who are persons with disabilities for the purposes of accessing social support. This point will be returned to in more detail below.

2.2 Research approach

In order to understand the situation of persons with disabilities in Uganda, the research used a range of methodologies to address the following questions:

1. What are the challenges faced by persons with disabilities in Uganda, and how do they currently negotiate these challenges?

2. How inclusive are existing social protection programmes?

3. How effective are current policies and institutions in creating a more conducive enabling environment for the inclusion of persons with disabilities in Uganda?

4. What information is currently available on disability nationally?

5. How are persons with disabilities currently assessed for existing social protection schemes in Uganda?

To address these questions, three main approaches were utilised: literature review; secondary data analysis; and primary data collection – both qualitative (life histories) and quantitative (household survey). The overall analysis synthesises these findings to provide a nuanced analysis of the situation of persons with disabilities in Uganda.

2.2.1 Literature Review

The initial literature review aimed to evaluate existing evidence on disability in Uganda and identify further knowledge gaps. The literature review included government and institutional legislative and policy documentation, academic articles and grey literature. In total, approximately 130 documents were included in the initial search of literature, comprising information relevant to the situation of persons with disabilities in Uganda. More than 50 additional articles, documents and papers were searched manually and included in the literature.

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8 Excluding duplicates
review. All articles were in English and, apart from seminal texts or key documents, only publications dated after 2008 were included for brevity.

The initial search utilised mainstream search engines such as Google Scholar, academic journals and relevant UN and other institutional knowledge centres. In addition, the researchers requested information and key documentation during consultations with the Government of Uganda and other stakeholders. The reference management software Zotero was used to file and thematically code the articles.

The majority of the papers fell under three main themes: finances and wellbeing [22]; policy and human rights [20]; and health and rehabilitation [18]. It should be acknowledged, however, that there was a great deal of cross-over been the categories (for example, backpain as a cause for inability to work). Papers around education also featured significantly [16], although most were related to school-based interventions. Indeed, there has been a tendency to focus on education to the detriment of other aspects of childhood, such as health, nutrition, and play. Most of the papers focused on “disability” as an overarching concept, and only a few were impairment-specific (e.g. Nodding Syndrome [4]; cerebral palsy [3]; Albinism [2], Autism [2]). Three papers focused on the use of screening tools for classification and assessment of children (Bachani et al 2014; Bachani et al 2016; Kakooza-Mwesige et al 2014). This means that many of the recommendations from these papers are quite general, and focus on mainstreaming, inclusion, participation, etc., rather than specific interventions for (often hard to reach) impairment groups.

2.2.2 Gaps in the evidence

Recent research has highlighted the fluid nature of disability (for example, Mitra et al 2017; Mitra 2018), but it is this temporality, and what it is associated with (onset of impairment, ill-health age, etc.), that is very hard to provide detailed evidence about as yet. As Mitra (2018) notes, where there is little in terms of a social safety net (such as in Uganda), while persons with functional difficulties experience a greater breadth and depth of deprivations than persons without any difficulty, precisely isolating the extent to which structural barriers (for example, social norms, attitudes, and physical environment) and resource constraints contribute to these deprivations and to functional difficulties is more challenging, and not something she was able to do in her own research (Mitra 2018). This links to wider issues around identification and assessment, and some of these details can be picked up through detailed interviewing, using both household data and life histories. This point also relates to the much-discussed issue of poverty and disability, and the direction - which comes first? (Banks et al 2017). To better understand this, more information about subjective wellbeing, social connections and all forms of work more broadly is needed (Mitra 2018). Related to this, there needs to be a clearer understanding of what “severe” disability means, and how it is experienced and the challenges it raises. Finally, there is still a tendency among DPOs and activists to focus on a list of different impairments, and many groups have been historically marginalised and excluded from debates, such as persons with Albinism and “little people”. This highlights ongoing issues of representation and discrimination, which people do not feel the WGSSQ address, and which may overlook or create further challenges around identification and assessment.

Other gaps identified in the initial review of the literature include around children with disabilities. There has been a tendency to focus on education to the detriment of other aspects of childhood, such as health, nutrition, and play. Uganda’s National Integrated Early Childhood Development (NIECD) Policy (2016) offers a promising start for all children and could bolster existing and future child-focused social protection initiatives, although more research is needed.
2. Methodology

on this to draw out the barriers and enablers to early childhood care and development (ECCD) for children with disabilities.

Finally, despite the unprecedented effort to collect information on persons with disabilities in Uganda in recent years (see the following section), previous surveys have not addressed all the gaps, in particular around the additional costs of living with disabilities, measuring poverty and other vulnerability indicators, or the coping mechanisms persons with disabilities adopt when faced with adversity. All these aspects were included in the household survey, as well as in the life history interviews, to explore individual stories and lived experiences. There was also relatively little information about the experiences of children or caregivers, as well as very little evidence on the inclusion of persons with disabilities within existing social protection programmes in Uganda.

2.2.3 Quantitative data and methods

Quantitative data analysis is necessary to underpin the overall research and to provide a robust evidence base on which to build future programmes and policies. The quantitative analysis in this report utilised both primary and secondary data. Secondary data sources were mined to establish what was already known, and a nationally representative household survey was carried out to fill in the gaps.

The secondary data analysis used a rich and varied collection of household survey datasets that already exist in Uganda. As Figure 2 demonstrates, over the last ten years there have been at least seven household surveys undertaken in Uganda, which have either solely focused on disability or have included a disability module to enable the identification of persons with disabilities. Among the surveys is a recently completed nationally representative comparative survey on living conditions of persons with disabilities, although the final results of this survey are not yet publicly available. Each survey covered a breadth of topics including household expenditure and income, demographics, health, labour, discrimination, stigma and violence, and gaps in services. The existing data provides an overview of the socioeconomic characteristics and conditions of persons with disabilities, with each survey plugging some of the gaps left by preceding surveys.
2. Methodology

Figure 2: Last ten years of disability-related survey data in Uganda

![Survey data timeline]

However, despite an unprecedented effort to collect information on persons with disabilities in Uganda in recent years, there are gaps in the existing surveys. For example, using the recent surveys, it is not possible to assess the extra cost of living with disabilities and to measure poverty and other vulnerability indicators of interest. Other aspects which existing surveys do not necessarily touch on include the coping mechanisms that persons with disabilities adopt when faced with adversity. Finally, it is not possible to fully understand how the public perceives persons with disabilities.

To address these persistent gaps, a household survey was designed for the situational analysis that interviewed both households with persons with disabilities and the general population. A detailed overview of the household survey is included in Annex 1. The data analysis consisted of both descriptive and inferential statistic methods – including regression analysis – on questions that inform the existing situation of persons with disabilities. Expenditure-based poverty estimates were calculated using the household survey to provide monetary poverty assessment of persons with disabilities. The methodology employed to estimate the extra cost of living with disabilities follows closely the goods and services used approach and the expenditure equivalence approach which have been widely used across a number of countries (Mitra et al 2017). The expenditure equivalence approach or the standard of living approach uses regression models to estimate the relationship between different standard of living indicators, income and disability. This approach compares standards of living after controlling for income and other relevant observables. These estimates will then build on an equivalence scale which includes households with persons with disabilities. The goods and services used approach focuses on estimating the differentials in schooling and health-related costs among persons with and without disabilities. All analyses were performed using statistics software packages in Stata and R.
2. Methodology

2.2.3.1 Disability as captured by the household survey

Persons with disabilities were identified by the household survey in two ways: the Washington Group Short Set of Questions (WGSSQ) was applied to all adults aged 18 years and over, and the Child Functioning Module, developed by Washington Group and UNICEF, was applied to children aged 2 to 17 years.\(^9\)

Both of these modules have been promoted by the UN as the best tools for large-scale disability assessment (for example, in a census) and are broadly based on the WHO International Classification and Functioning (ICF) framework (Groce and Mont 2017). The Washington Group Questions, specifically the WGSSQ, largely form the approach that the Uganda Bureau of Statistics (UBOS) uses to collect disability statistics. The questions in both modules allow for measurement of prevalence without asking the reductionist question, ”do you have a disability?” to which the only answer can be "yes" or "no", and which often leads to underreporting of disability, for example, due to stigma.

The Washington Group questions are not designed to be used for assessment or diagnostic purposes. There are extended sets available, which cover a broader range of difficulty domains, all of which are available in a range of languages.\(^10\) In this survey, we used the WGSSQ for adults, and the child module for those aged 2-17 years. All quantitative data presented in this report uses the WGSSQ to identify persons with disabilities, unless otherwise specified.

The WGSSQ are a set of six questions that allow for a scaled response. As Box 1 indicates, the level of difficulty is taken as a proxy indicator for the level of impairment/disability. The recommended cut-off is anyone who scores 3 and above on a Likert scale. This means in practice that those with a score of three or above are assumed to experience a high level of functional difficulty, hence the terms “difficulty” and “disability” are sometimes used interchangeably.

Box 1: Washington Group Short Set of Questions (WGSSQ)

In order to provide disability prevalence estimates that are internationally comparable, the Washington Group on Disability Statistics developed a new and improved methodology of measuring disability. Below are the recommend short set of questions on the six core functional domains. The questions would follow an introductory phrase: ”The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM”.

1. Do you have difficulty seeing, even if wearing glasses?
2. Do you have difficulty hearing, even if using a hearing aid?
3. Do you have difficulty walking or climbing steps?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty (with self-care such as) washing all over or dressing?
6. Using your usual (customary) language, do you have difficulty communicating, (for example understanding or being understood by others)?

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\(^9\) The household survey was not designed to capture disabilities of children 0 to 2 years. Because developmental delays among children aged between 0 and 2 years are normal, identifying disabilities in this age group is challenging through standard household surveys.

2. Methodology

For each question, the response categories are:

1. No, no difficulty
2. Yes, some difficulty
3. Yes, a lot of difficulty
4. Cannot do at all

Scores of 3 and 4 are a proxy for disability as recommended by the cut-off for the Washington Group.

The questions in the Child Functioning Module cover children aged between 2 and 17 years. The module is intended to capture functional difficulties in seeing, hearing, walking, fine motor, communication, learning, and emotions across two age ranges: 2 to 4 years, and 5 to 17 years. This allows the questions to be specific to the activities that apply to each of these two age groups. The response categories are similar to the ones in the WGSSQ. Box 2 details the general characteristics of the Child Functioning Module, as was developed by UNICEF and Washington Group.

**Box 2: General characteristics of the module on Child Functioning**

In 2016, UNICEF and the Washington Group finalised the Child Functioning Module for use in surveys. The questions are targeted at children aged between 2 and 17 years and are based on the WHO International Classification and Functioning (ICF) framework and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The questions are designed to capture the number of children with functional difficulties which may place children at risk of experiencing limited participation in an unaccommodating environment. Two age ranges are considered in the module: children aged 2-4 years and children aged 5-17 years, and the questions are tailored according to the activities in both of these groups. There are 16 questions for children aged 2-4 years, and 24 questions for children aged 5-17 years. The functional domains in each age range are:

- **2-4 years**: Seeing, hearing, walking, fine motor, communication/comprehension, learning, playing and controlling behaviour
- **5-17 years**: Seeing, hearing, walking, selfcare, communication/comprehension, learning, remembering, concentrating, accepting change, controlling behaviour, making friends, and affect (anxiety and depression)

For each domain there are both dichotomous yes/no questions and scaled responses similar to those applied in the WGSSQ. Dichotomous yes/no questions are introductory questions and are used to generate skip patterns. Questions with scaled responses are used to capture levels of difficulty. Three types of response categories are used depending on the functional domains. Below are examples questions with the three different scaled responses used in the module:

**Example 1:** Compared with children of the same age, does (name) have difficulty walking? Would you say:

1) No difficulty
2) Some difficulty
3) A lot of difficulty
4) Cannot do at all

**Example 2:** How often does (name) seem very anxious, nervous or worried? Would you say:

1) Daily
2. Methodology

2) Weekly
3) Monthly
4) A few times a year
5) Never

Example 3: Compared with children of the same age, how much does (name) kick, bite or hit other children or adults? Would you say:
1) Not at all
2) The same or less
3) More
4) A lot more

2.2.4 Qualitative research methods

The qualitative research, which was designed to complement the household survey findings, comprised field visits to a total of 10 districts in the north, east, west and central regions of Uganda to undertake individual life history interviews, key informant interviews and focus group discussions (FGDs). All interviews were transcribed, and analysis was undertaken using theme content analysis following a post-fieldwork workshop. Each team leader then drafted a summary of the overall findings, identifying themes and patterns across the lifecycle.

Following an initial selection workshop with representatives of the District government, and civil society, the teams spent two days in each subcounty undertaking around six individual qualitative interviews each (12 in total) with adults with disabilities and/or caregivers of children/adults with disabilities using a life histories approach. As one of the aims of the research was to understand challenges and opportunities across the lifecycle, it was important to try to ensure that interviewees spanned a broad age range. No children under 18 years of age were directly interviewed for ethical reasons, but caregivers of children under 18 were included. As Table 1 demonstrates, a total of 103 life-history interviews were undertaken with adults with disabilities, and 46 with caregivers of children/adults with disabilities in six districts across Uganda (Amudat, Manafwa, Lamwo, Kampala, Kiruhura and Kyankwanzi). In-depth interviews were supplemented with key informant interviews with village leaders, such as the local council (LC1) Chair, elder, or other local level leader. In total, as shown in Table 1, 162 interviews were undertaken.

The life history approach was selected as it can be used to identify key moments in an individual’s life (shocks, pivotal moments, transition points) and how they responded (agency, coping strategies). The approach records the significant events and transitions that occur over a person’s life, but also takes into consideration the more nuanced, subjective factors – such as an individual’s memories, perceptions, relationships, aspirations and regrets – in the choices, behaviours or events that have shaped their lives. This in turn helps researchers understand why people make the decisions and choices they do, alongside the barriers they have experienced, and based on this, what kind of interventions should be put in place to support them (Davies et al 2018). This makes it ideal for understanding the need for social protection, as it can help identify risk factors and periods of vulnerability, as well as coping strategies and mitigation.
2. Methodology

Table 1: Total number of interviews undertaken in each district

<table>
<thead>
<tr>
<th>Districts (of Uganda)</th>
<th>Persons with disabilities</th>
<th>Caregivers</th>
<th>Key informants</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>F</td>
<td>M</td>
<td>F</td>
</tr>
<tr>
<td>Kiruhura District (Western)</td>
<td>8</td>
<td>5</td>
<td>0</td>
<td>11</td>
</tr>
<tr>
<td>Kyankwanzi (Central)</td>
<td>9</td>
<td>8</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Amudat (Northern/Karamoja)</td>
<td>12</td>
<td>8</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Manafwa (Eastern)</td>
<td>5</td>
<td>8</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>Lamwo (Northern)</td>
<td>10</td>
<td>9</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Kampala (Central)</td>
<td>7</td>
<td>14</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>51</td>
<td>52</td>
<td>5</td>
<td>41</td>
</tr>
</tbody>
</table>

Source: Disability Situational Analysis Household Survey 2019

For the social protection “diagnostics” component of the research, a total of 24 focus group discussions (FGDs) were carried out in four districts (Gulu, Kyegegwa, Tororo and Nakasongola) with persons with disabilities and/or their caregivers, as well as some recipients without disabilities of programmes. In total, 215 people participated in the FGDs, which were structured around pre-agreed themes. In addition to the FGDs, 17 in-depth semi-structured interviews were carried out with persons with disabilities benefitting from the Uganda Women Entrepreneurship Programme, the Youth Livelihood Programme, the Special Grant and the Senior Citizens Grant.

In addition to the life history interviews and FGDs, more than 80 key informant interviews were carried out both at national level and in the 10 districts described above. Interviewees included national and local government officials responsible for social protection programmes for persons with disabilities (both disability-specific and mainstream programmes); representatives from DPOs and other civil society organisations; development partners; and NGOs. Interviewers used semi-structured questionnaires and focused on gauging informants’ perceptions around the current situation for adults and children with disabilities in Uganda, their perceptions of the barriers and enablers to enhancing their well-being, as well as their understanding of the role of social protection in supporting this.
3. Demographics

As is common in many countries around the world, Uganda’s various surveys, along with its census, report different levels of disability prevalence depending on the methods used, the location of the survey, etc. Prevalence data are primarily used for planning purposes, and rarely to deliver more disability-specific services. Yet, in its 2016 report, the Office of the United Nations High Commissioner for Human Rights (UNOCHR) noted with concern the lack of systems for collecting, analysing and disseminating information about the situation of persons with disabilities, including refugees (UNCRPD 2016).\(^{11}\)

Unless otherwise stated, all quantitative data presented here are from the household survey.

3.1 Prevalence of disability in Uganda

According to the National Population and Housing Census (NPHC) conducted by UBOS in 2014, 12.4 per cent of the Ugandan population lives with some form of disability. However, this figure has not been free from criticism as similar surveys have generated different prevalence rates. The UBOS figure includes all those who reported at least “some difficulty” in one or more functional domains. This is broader than the inclusion criteria recommended by the Washington Group, which suggests including individuals who report having “a lot of difficulty” or greater.\(^{12}\)

The demand for further data resulted in UBOS undertaking a more detailed study of disability in 2017 – the Uganda Functional Difficulties Survey (UFDS). This is a disability-specific survey which used a sub-sample of the Uganda Demographic and Health Survey (UDHS) 2016 to undertake further analysis of households that identified as having a person(s) with disabilities as a member. Households were re-surveyed using the WGSSQ with the aim of collecting high quality data on functional difficulties. Data were collected on a range of domains, including disability prevalence, causes of impairments, and use of assistive devices; habilitation and rehabilitation; equality and non-discrimination; access to information; accessible transport and access to other human rights.

As can be seen from Table 2, using the WGSSQ and the child functioning module, the situational analysis household survey gives a prevalence of 8.5 per cent of children (over 2 years old)\(^{13}\) and adults with disabilities (defined as an individual having either “a lot of difficulty” or “cannot do at all” in one or more functional domains). Children under two are also excluded from the WGSSQ, as differential diagnosis for children under two can be difficult due to a baby’s developmental stages. UNICEF’s Multi-Indicator Cluster Survey (MICS), which records a range of data on children, has not been carried out in Uganda (although the survey questions are harmonised with the Demographic and Health Survey).\(^{14}\)

As indicated in Table 2 below, if the WGSSQ recommended cut off “a lot of difficulty” or “cannot do at all” are used, then a very different picture emerges. Furthermore, if the surveys also include the WG/UNICEF child functioning module, then estimates are higher. Of the recent surveys

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11 This situational analysis will respond to this request and support the evidence base for monitoring and programming.
12 For some detailed analysis of disability data from the National Population and Housing Census, see: UBOS (2019)
13 There is currently no internationally agreed measure for disability in children under two years old.
undertaken, only the UFDS and the household survey undertaken for this situational analysis include the WG/UNICEF module, as it was released in 2014.

Table 2: Prevalence of disability across different surveys by age groups (“a lot of difficulty” and “cannot do at all.”)

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Children 2-4 years</td>
<td>N/A</td>
<td>0.5%</td>
<td>N/A</td>
<td>3.5%</td>
<td>4.0%</td>
</tr>
<tr>
<td>Children 5-17 years</td>
<td>2.8%</td>
<td>0.7%</td>
<td>3.3%</td>
<td>7.5%</td>
<td>7.8%</td>
</tr>
<tr>
<td>Adults 18+ Years</td>
<td>4.9%</td>
<td>2.5%</td>
<td>9.1%</td>
<td>16.5%</td>
<td>10.1%</td>
</tr>
<tr>
<td>Total</td>
<td>3.2%</td>
<td>1.5%</td>
<td>6.5%</td>
<td>N/A(^{16})</td>
<td>8.5%</td>
</tr>
</tbody>
</table>

A brief explanation as to why the National Population and Housing Census 2014 provides a difference prevalence rate to the situational analysis is provided in Box 3 below.

Box 3: Differences in the prevalence of disability between the 2014 National Population and Housing Census and the 2019 Disability Situational Analysis

At least since 2009, UBOS has been using some form of the Washington Group Short Set of Questions to identify persons with disabilities in national surveys. While this is encouraging and is aligned with international standards, the use of different versions of the tool has meant that estimates of the prevalence of disability are not always comparable across surveys.

For example, in 2014, the National Population and Housing Census used a reduced form of the Washington Group questions. Instead of using the usual six questions in the short set, only four questions were included in the questionnaire covering the following functional domains: seeing, hearing, walking and remembering/concentrating. The questionnaire did not include self-care and communicating/understanding. Furthermore, unlike the Disability Situational Analysis, the child functioning module was also not applied since this module was only defined in 2016. For more information on the Washington Group Short Set of Questions and Child Functioning Module see Boxes 1 and 2.

Results from the Census indicated that 12.4 per cent of the population had at least some difficulty in performing one of the four functional domains. However, when looking at persons with at least “a lot of difficulty” – which is the recommend cut-off by the Washington Group – 1.5 per cent of the population had difficulties in performing at least one of the functional domains. These results are very different and significantly smaller from the estimates presented in this report. Using the complete short set of questions among adults and applying the child functioning module, in 2019, 8.5 per cent of the population have at least ‘a lot of difficulty’ in performing at least one.

\(^{15}\) Uganda National Household Survey
\(^{16}\) The UFDS report does not provide an overall figure, and microdata was not available for analysis. The estimates in the UFDS are not nationally representative and based only on a sub-sample of the DHS 2016 of households that had members with at least “some difficulty” in at least one functional domain in the WGSSQ.
3. Demographics

Currently in Uganda there is no one centrally located source of disability statistics. Though disability data is collected in some management information systems, including the education management information system (EMIS) and the health information management system (HIMS), it is rarely disaggregated beyond age/sex/impairment at national level. Currently, there is no social protection management information system, but this is in development.

Other sources of data include the National Council for Persons with Disabilities (NCD), the National Union for Persons with Disabilities in Uganda (NUDIPU) and various non-governmental and civil society organisations (NGOs and CSOs). These varying sources all use different prevalence rates for their work, which vary according to the methodology used during the data collection, as well as the intention behind the survey. There is no national disability registration scheme as of yet (see Section 7.1.2).

One of the challenges with the focus on functional limitations, particularly using the WGSSQ, is that some types of impairments are excluded. This includes mental health issues, with one study estimating the margin of error to be between 3.6 per cent to up to 35 per cent in Uganda (Mental Disability Advocacy Centre, 2015). A recent online survey conducted by NUDIPU in collaboration with a national radio station, TRAC FM, included questions around mental health, and found that out of 12,469 respondents across the country, 5,860 said that the most common mental health issues in their communities were drug and alcohol addiction; 3,616 people cited depression; 1,496 people had contemplated suicide; and another 1,496 had experienced “strange behaviour” by someone (TRAC FM/NUDIPU 2019). Therefore, despite the plethora of data now available, and in contravention of the tenets of the Constitution and the domestication of the UNCRPD, not all persons with disabilities in Uganda are the same rights and equality of opportunity as other citizens.

3.1.1 Impairment types

As Table 3 demonstrates, according to the survey data, the most prevalent impairment type for adults aged 18 years above is seeing, with around 4.5 per cent of adults reporting either "a lot of difficulty" or "cannot see at all". The next most prevalent impairment type is walking, with 4 per cent of adults having at least "a lot of difficulty" walking or climbing stairs. Other impairments have prevalent rates of at least "a lot of difficulty" ranging from 0.6 per cent (communicating) and 2.6 per cent (remembering or concentrating).

<table>
<thead>
<tr>
<th>Table 3: Level of difficulty of adults by Functional Domain</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>Difficulty walking or climbing stairs</td>
</tr>
<tr>
<td>Difficulty washing all over or dressing</td>
</tr>
<tr>
<td>Difficulty seeing</td>
</tr>
<tr>
<td>Difficulty remembering or concentrating</td>
</tr>
<tr>
<td>Difficulty hearing</td>
</tr>
<tr>
<td>Difficulty communicating</td>
</tr>
</tbody>
</table>

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019
3. Demographics

For all children (in both the 2-4- and 5-17-years age groups) the prevalence rate for impairment type is more uniform across the domains (Table 4). The prevalence rates of the different functional domains among children aged 2-4 varies between 0.5 (fine motor and playing) and 1.1 per cent (communication/comprehension). Similarly, among children aged between 5 and 17 years, there is little variation across the prevalence rates of the different functional domains. Anxiety and remembering have the two highest prevalence rates with 2.1 and 1.6 per cent respectively.

Table 4: Percentage of children with difficulties by Functional Domain

<table>
<thead>
<tr>
<th>Functional Domain</th>
<th>Children 2 - 4 years</th>
<th>Children 5 - 17 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seeing</td>
<td>0.6%</td>
<td>1.0%</td>
</tr>
<tr>
<td>Hearing</td>
<td>0.6%</td>
<td>1.1%</td>
</tr>
<tr>
<td>Mobility</td>
<td>0.9%</td>
<td>1.1%</td>
</tr>
<tr>
<td>Self-care</td>
<td></td>
<td>0.5%</td>
</tr>
<tr>
<td>Fine motor</td>
<td>0.5%</td>
<td></td>
</tr>
<tr>
<td>Communication/Comprehension</td>
<td>1.1%</td>
<td>0.9%</td>
</tr>
<tr>
<td>Learning</td>
<td>0.6%</td>
<td>1.2%</td>
</tr>
<tr>
<td>Remembering</td>
<td></td>
<td>1.6%</td>
</tr>
<tr>
<td>Attention and concentrating</td>
<td></td>
<td>0.6%</td>
</tr>
<tr>
<td>Playing</td>
<td>0.5%</td>
<td></td>
</tr>
<tr>
<td>Relationships</td>
<td></td>
<td>0.4%</td>
</tr>
<tr>
<td>Coping with change</td>
<td></td>
<td>0.5%</td>
</tr>
<tr>
<td>Controlling behaviour</td>
<td>1.3%</td>
<td>1.0%</td>
</tr>
<tr>
<td>Anxiety</td>
<td></td>
<td>2.1%</td>
</tr>
<tr>
<td>Depression</td>
<td></td>
<td>1.5%</td>
</tr>
</tbody>
</table>

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019

As Table 5 demonstrates, the proportion of children and adults with difficulties in more than one domain is 2.8 per cent of the total population, which is roughly one-third of all those with disabilities. Among children, less than 1 per cent of children aged 2 to 4 years have more than one functional difficulty, and close to 3 per cent of children aged 5 to 17 years have more than one functional difficulty. Among adults, 3.3 per cent have more than one functional difficulty.

Table 5: Percentage distribution of Ugandans by number of functional difficulties with age groups

<table>
<thead>
<tr>
<th>Age groups</th>
<th>Number of functional difficulties</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
</tr>
<tr>
<td>2 to 4 years</td>
<td>96.0%</td>
</tr>
<tr>
<td>5 to 17 years</td>
<td>92.2%</td>
</tr>
<tr>
<td>18 years plus</td>
<td>89.9%</td>
</tr>
<tr>
<td>Total</td>
<td>91.5%</td>
</tr>
</tbody>
</table>

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019
3. Demographics

It is challenging to extrapolate data which pertain to human rights issues such as stigma and discrimination from surveys that use the WGSSQ (though see the discussion in Section 4.2.5). Responses to the WGSSQ are a proxy for disability, and therefore do not map directly onto the experiences of some specific impairment groups (in Uganda, these include persons with Albinism, Epilepsy and the little people, as well as caregivers of children and adults with Downs Syndrome, and other mental health and psychosocial conditions). To address this gap, specific questions around Epilepsy, Albinism and "little people" were added to both the UFDS and to the situational analysis household survey (see Box 4).

Box 4: Prevalence of Persons with Albinism and 'Little People'

The situational analysis household survey included questions on several specific impairment groups. The results show that of the 12,169 households interviewed – with information gathered on 59,672 persons – a total of 11 people identified as a person with albinism, which represents 0.02 per cent of the population. A further 62 people identified as "little people", which represents 0.1 per cent of the population. This is approximately 1 in every 1,000 Ugandans, which is slightly higher than global averages.

It is also difficult to measure the "gap" between persons with and without disabilities, and wider inequalities around poverty and inclusion for households with persons with disabilities (for example, Groce et al. 2011; Abimanyi-Ochom and Mannan, 2014). Because of this, the World Health Organisation has developed a more in-depth survey tool, the Model Disability Survey (WHO-MDS). There are crucial differences between these approaches, not least the intended outcome of the survey. This means that in practice, the WGSSQ could be used as an initial baseline for prevalence, then the WHO-MDS to gain more detailed and specific data. To date, all government surveys in Uganda have utilised the WGSSQ, not the WHO-MDS.

3.1.2 Prevalence across age ranges

Figure 3 indicates that the prevalence of disability increases sharply with age, with a very high prevalence rate among older persons. As people age and grow frailer, their health decreases and they are more likely to experience age-related impairments. Indeed, around 40 per cent of older persons aged 65 years and above have a disability in Uganda, rising to 57 per cent among those aged 80 years and above. As is the case in many countries, there is almost no information or data on ageing for persons with pre-existing disabilities in Uganda.

17 https://www.who.int/disabilities/data/mds/en/
18 https://www.ucl.ac.uk/epidemiology-health-care/which-one-use-washington-group-questions-model-disability-survey-0
20 The proportions for those with disabilities are 27 per cent for those aged 65 years and over and 39 per cent for those aged 80 years and over.
3. Demographics

Figure 3: Prevalence of disability by five-year age groups and by sex

As Figure 4 demonstrates, there are also differences in prevalence rates between men and women. Up to 40 years of age, men are more likely to experience a disability but, above 40 years, the prevalence of disability is higher among women. This is in line with results globally, and as Gill et al (2013) explain, the higher rates of disability over an extended period can be explained, at least in part, by the higher mortality rate experienced by older men and the higher initial levels of disability among older women.

However, since Uganda has a young population, the highest numbers of people with disabilities are below the age of 15 years, although there are still a significant number above 75 years of age, which is both due to the accumulation of multiple 5-year age groups, but also the high prevalence of disability among older persons.
3. Demographics

Figure 4: Distribution of persons with disabilities by five-year age groups and by sex

Moreover, as Figure 5 demonstrates, the number of persons with disabilities is predicted to increase substantially across all age groups by 2040. Most strikingly, the number of working-age people living with disabilities will increase to just under two million, which is an increase of 235 per cent. Similarly, for the older age group, the number of older persons with disabilities is predicted to increase over two-fold – with an increase of 221 per cent. These projections have implications for social protection policies and programming that need to be planned for.

Figure 5: Population projection of individuals with disability

Source: Development Pathways, calculations using UBOS’ national population projections by single year and DHS 2016 prevalence rates
3. Demographics

3.2 Household structures

As Figure 6 demonstrates, the situational analysis household survey data suggests that households with members that have some form of disability are likely to be larger (with six or more members) than households without persons with disabilities. This may be because of co-joined households (for example, living with other relatives, such as grandchildren) or because of the number of children (their own and others).

Figure 6: Household size by households with and without persons with disabilities

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019

Indeed, Figure 7 demonstrates that households with a member with a disability are more likely to have three or more children living in the household than a household without a member with a disability. This disparity increases the more children there are in a household, and the children may be the member’s own children, or others living in the household.

Figure 7: Number of children per household

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019
3. Demographics

As Figure 8 shows, whilst persons with disabilities may live in larger households, these households may not necessarily be able to provide sufficient support, as households with a member with a disability more likely to be vulnerable due to a higher age dependency ratio. That is, a higher number of household members are children or older persons who are therefore more likely to be dependent on working-age members of the household. This has implications for how much financial support and physical care a person with a disability can receive, and, if the person with the disability is also earning income or providing care, this may create a disproportionate care burden for them. As outlined further below, it is therefore potentially more challenging for households with persons with disabilities to engage in consistent and reliable income-generating activities, and these households may be more prone to falling into poverty.

Figure 8: Household age dependency ratio by households with and without persons with disabilities and area of residence

![Age dependency ratio graph]

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019

As Figure 9 indicates, households with members that have some form of disability are most likely to be a household that consists of a couple with children, although the likelihood is lower than for a household with no member with a disability. There is also a significant likelihood that the household will be a three-generation household, followed by a household with living arrangements that are classified as “other”, although there is no further information on the make-up of these households. Skipped generation and single-carer households are the next most likely form of living arrangements for households with a member with a disability.

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21 Dependency ratio is calculated as the sum of all dependents in a household (children and elderly members) divided by number of working age adults in a household
3. Demographics

Figure 9: Living Arrangements

A higher proportion of households with persons with disabilities are female-headed compared with households without members with disabilities. As Figure 10 shows, in urban areas, the proportion is 37 per cent (compared with 28 per cent of households without a disability) and in rural areas, the proportion is 34 per cent (compared with 25 per cent). The reasons for this are complex, but gender is a significant factor in caring roles. For example, women are more likely to be the main caregiver of children if they have separated from their partners, and this is the case both for women with disabilities, as well as mothers of children with disabilities. Older siblings who take care of younger siblings are also more likely to be female, and widowed grandmothers are also more likely to care for the children of their grownup offspring who are working elsewhere, compared with widowed grandfathers.

The latter point is determined both by gender roles and the fact that there are more older women than men. Furthermore, women themselves may move to seek work in urban areas, where there are more employment opportunities. These complex issues are discussed in more detail in Section 5 below. Whatever the reason, all these factors increase vulnerability and lower standards of living for the household. It should be noted that although rare, some single male-headed households were interviewed as part of the qualitative research: again, often as the result of a partner (in this case, the wife) leaving her male partner, though for similar reasons (child with disability or partner with disability).

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019

Data does not disaggregate between cohabiting and married.
3. Demographics

Figure 10: Female Headed Households

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019
4. Vulnerabilities and Resilience

Vulnerability is a status which people can fall into or move out of, and it is not, therefore, a predetermined or indeed static status for individuals. Unexpected or unplanned for events – that is, shocks – can occur which drive adults and children into conditions of vulnerability. Pre-existing conditions, including poverty, age, gender and even severity of impairment, may make children or adults more at risk of vulnerability, but they do not make people vulnerable per se; rather, the issue is how these conditions interact across the lifecycle to create vulnerability (United Nations Development Programme (UNDP) 2014). Practitioners and researchers have tended to move away from talking about “vulnerability” to more positive and nuanced discussions about resilience. There are a range of factors that can enhance an individual’s resilience to unexpected shocks, including social protection measures which are discussed in more detail in Section 7 below.

This section provides an overview of how different factors, including additional costs of disability, can contribute to persons with disabilities having a lower standard of living than their peers without disabilities. It then provides a discussion on how social norms and expectations – such as around gender, or even perceptions of disability – can intersect to increase risk of vulnerability. Finally, having explained some of the conditions that can make children or adults be more at risk of vulnerability, the section covers how not only are persons with disabilities more vulnerable to shocks, but how shocks can increase vulnerability, and the coping strategies that households use. A more detailed overview of the challenges faced across the lifecycle is provided in Section 5 below.

4.1 Standard of living for persons with disabilities

It is well established that poverty and disability are linked – as Figure 11 demonstrates, those who live in poverty are more likely to live in poverty while those with a disability are much more likely to be living in poverty (DFID 2000; Banks and Polack 2014). However, the direction of causality for these links are less well known – is it because a person lives in poverty that they are more at risk of disability due to factors such as lack of healthcare, increased vulnerability to malnutrition and preventable diseases, precarious working environments and low quality housing, with reduced access to safe drinking water and sanitation? Or is it that persons with disabilities have a disability due to being forced to live and work in such conditions? These factors are magnified by the associated discrimination and exclusion many adults and children with disabilities experience across the life cycle.
A growing body of research suggests that as countries develop, there may be growing barriers to employment and economic activities for persons with disabilities, and they are increasingly being left behind – and left out – of improved living standards (Groce and Kett, 2013; Mitra 2018). However, there is not yet a consistent pattern for this. While there is evidence to suggest that individuals with disabilities are worse off in terms of educational attainment, morbidity, and health expenditures, the evidence in terms of employment and household material wellbeing is mixed (Mitra 2018). Mitra’s work also shows that, like poverty itself, people transition in and out of the severity of functional difficulties over time (Mitra 2018). Despite this, in Uganda, “[by] quintile, whether by asset index or per capita consumption expenditure, there is not always a linear gradient of prevalence rates, but prevalence is consistently higher in the bottom quintile compared to the top one” (Mitra 2018).

As demonstrated in Figure 12, the household survey indicates that poverty rates among individuals living in households including persons with disabilities is close to 31 per cent, compared with 28 per cent among those living in households without persons with disabilities.\(^{24}\) However, there is great variation depending on background characteristics. For example, differences in poverty rates are more significant among children aged 0-17 years and adults aged 18-59 years, compared with older persons aged 60 years and above. There are also regional differences, with Western Uganda having a much greater disparity in poverty rates between

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\(^{23}\) Though Mitra acknowledges that this could also be due to changes in reporting behaviour.

\(^{24}\) When applying the national poverty lines and adult equivalence scales.
4. Vulnerabilities and Resilience

Households including a person with a disability and households without. However, Northern Uganda has, on a whole, significantly higher poverty rates, which is to be expected, given the earlier conflicts that have taken place in the region. Poverty rates for both types of households are also higher in rural areas compared with urban areas. Interestingly, however, in urban areas, particularly in Central Uganda, persons living in households including persons with disabilities are less likely to live in poverty than those living in households without persons with disabilities. It is unclear why this is the case, although the increased availability of work may be a factor.

Figure 12: Poverty headcount by individual characteristics and whether living in households with persons with disabilities (national poverty levels)

Figure 13 shows the percentage of persons with disabilities living in poverty by level of difficulty and functional domain. Using the national poverty line, 26 per cent of persons with disabilities are living in poverty. The functional limitation most associated with poverty is “communicating”, with close to 40 per cent of persons with a lot of difficulty in communicating or who cannot do it at all living in households below the poverty line. There is not much variation in poverty rates across the other functional domains. Poverty might be expected to be higher among those with higher levels of difficulties, and it therefore follows that persons who cannot do one or more of the functional domains are at greater risk of poverty than those with only a lot of difficulty in one or more functional domains.
4. Vulnerabilities and Resilience

Figure 13: Poverty headcount among persons with disabilities, by main functional domain and level of difficulty

![Figure 13: Poverty headcount among persons with disabilities, by main functional domain and level of difficulty](image)

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019

It is important to emphasise that despite the disparities in poverty rates, the majority of persons with disabilities live in poverty. Figure 14 shows the distribution of Ugandans by different international poverty lines. Around half of Ugandans living in households with persons with disabilities are living in extreme poverty (less than $1.9 PPP or UGX 2,400 per person per day), and over three-quarters are living in poverty (less than $3.2 PPP or UGX 4,000 per person per day). Furthermore, only 1.3 per cent of persons in households with members with disabilities are living on more than $10 PPP a day. Similarly, for persons living in households without a member, only 1.6 per cent live on more than $10 PPP a day.
4. Vulnerabilities and Resilience

Figure 14: Percentage distribution of persons by international poverty lines and whether living in households with and without persons with disabilities (international levels)

<table>
<thead>
<tr>
<th>Category</th>
<th>Living in households without persons with disabilities</th>
<th>Living in households with person(s) with disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Above UGX 12,450 a day ($10 PPP)</td>
<td>1.6%</td>
<td>4.5%</td>
</tr>
<tr>
<td>Between UGX 6,850 - 12,450 a day ($5.50 - 10 PPP)</td>
<td>17.8%</td>
<td>13.9%</td>
</tr>
<tr>
<td>Between UGX 3,990 - 6,850 a day ($3.20 - 5.50 PPP)</td>
<td>50.0%</td>
<td>51.1%</td>
</tr>
<tr>
<td>Between UGX 2,370 - 3,990 a day ($1.90 - 3.20 PPP)</td>
<td>26.1%</td>
<td>26.3%</td>
</tr>
<tr>
<td>Below UGX 2,370 a day ($1.90 PPP)</td>
<td>1.3%</td>
<td>7.5%</td>
</tr>
</tbody>
</table>

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019

Figure 15, which shows consumption distribution from the “poorest” to the “richest”, demonstrates that although only 3 in every 10 persons with disabilities live below the national poverty line, many more are vulnerable to poverty. Indeed, close to 65 per cent live with less than two times the national poverty line. The reality is that poverty is a dynamic situation and many people living in a precarious position just above the poverty line are vulnerable to shocks and will likely fall into poverty at some point in the future.

It should further be recognised, however, that Figure 15 demonstrates that over 80 per cent of persons with disabilities live on less than UGX 8,000 per day. This is a small amount to live on, and therefore, even if a person with a disability is not considered to be the “poorest”, their standard of living is likely to still be low.
4. Vulnerabilities and Resilience

Figure 15: Distribution of consumption from “poorest” to “richest” individuals with disabilities

![Graph showing distribution of consumption](image)

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019. This has been capped at the 98th percentile

While poorer people are more likely to be a person with disabilities or living in households including persons with disabilities, they are also likely to experience additional costs associated to disability. What is less clear is what these additional costs are, and how they should be calculated. However, this underestimates the real levels of poverty in households with persons with disabilities since they also face additional costs as a result of their disability (for example, health or transport costs). These figures can vary but, in many countries, they can range between 20-100 per cent more (see WHO/World Bank 2011). As a result, when two households with the same level of expenditure are compared, the household with persons with disabilities has a lower standard of living.

4.1.1 Extra cost of living with disabilities

In order to maintain similar standards of living, persons with disabilities often incur additional living costs in comparison to those without disabilities (Mitra et al 2017). These costs can either be because of disability-specific aid or personal assistance to perform daily activities, or because of the higher cost of day-to-day expenses such as transportation, health services and schooling. Because of these additional costs, standard measurements of monetary poverty can be inadequate for comparing standards of living between persons with and without disabilities. However, there is little or no information of the extra cost of living with disabilities in Uganda, and this remains a fundamental gap in the literature. What is known is that people living in poverty are more likely to be a person with disability, and that they are more likely to experience additional costs related to their disability (Mitra 2018). What is less clear is what these additional...
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costs are, and how they should be calculated, or indeed what the impact of these costs is on individuals and households.

This section provides an overview of the cost of living with a disability in Uganda, as captured by quantitative and qualitative data. The section investigates differences in schooling and health-related costs between persons with and without disabilities, as well as the differentials in household costs. The section also provides estimates of the directs costs as measured by the standard of living approach, in which the direct costs are estimated indirectly “by comparing the standard of living of households with and without persons with disabilities at a given income, having controlled for other sources of variation” (Zaidi and Burchardt, 2005). Finally, this section sheds some light on the indirect costs of disability in the form of foregone economic activities of those who provide personal care to persons with disabilities without pay.

4.1.1.1 Direct costs associated with disability

According to the World Report on Disability (WHO/World Bank 2011), direct costs include the additional costs that persons with disabilities and their families incur to achieve a reasonable standard of living (in comparison to their counterparts without disabilities). For example, these can be out of pocket costs on disability-specific aid, medication, health services, etc. The household survey included detailed expenditure modules, especially on schooling and health-related expenses, along with other household expenditures. The analysis below compares the amount spent on certain expense items between persons with and without disabilities to infer on the cost of living with a disability.

4.1.1.2 Spending on education

The household survey suggests that two of the four main reasons that children with disabilities are not in school is lack of funding and because education/school is too expensive. Schooling costs extend beyond the cost of school fees, and include school-related expenses such as transportation, textbooks, uniforms, supplies and exams fees. It is these complementary costs which can be prohibitive for families of children with disabilities, for as Figure 16 indicates, while the difference in the costs of school fees is minimal between children with and without disabilities, children with disabilities have to spend 31 per cent more than children without disabilities on other education-related costs. On average, these complementary costs represent roughly 35 per cent of total spending on education.

---

25 Difference in mean school fee costs in levels between children with and without disabilities is not statistically different from zero (p-value 0.962), while other education-related costs has a difference in mean that is statistically different from zero (p-value 0.04)
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Figure 16: Cost of education among children 5 to 17 years (in UGX), by disability

![Cost of schooling graph]

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019

Figure 17 indicates that school supplies and uniforms are some of the complementary costs in which children with disabilities pay more than children without. On average, children with disabilities who are attending school pay approximately UGX 32,500 for schoolbooks and supplies, which is 22 per cent more than children without disabilities who also attending schools. There is also a notable difference in the average spending on transportation to and from school, especially as many children with disabilities cannot necessarily travel independently or on the cheapest mode of transportation possible. Mercy’s story, from the qualitative research, is a clear example of how transport costs can be prohibitive for children with disabilities. Mercy has mobility difficulties and struggles to walk to school. In order to travel the half kilometre, she would have to use a boda boda,\(^{26}\) which costs UGX 10,000 each way. This cost is too expensive for Mercy’s household, and as a result, she does not attend school.

\(^{26}\) Motorbike taxi
While simple differences in levels of spending indicate that children with disabilities pay more for their education than children without disabilities, it is important to understand whether these differences remain once other background characteristics are accounted for, such as the age and sex of the child, which grade the child is in, or whether the school public or private. To examine this, log-linear regression models of the log of complementary education cost on disability indicators and child’s school and household background characteristics are applied. Table 6 provides the OLS estimates from the models that captures the differences in complementary education costs between children with and without disabilities. Because the dependent variable is in natural logs, in order to interpret the coefficients as percentage differences, the estimates have to be exponentiated. Point estimates in columns 1 and 2 of Table 6 indicate that the children with disabilities are paying around one-third more than children without disabilities. However, the coefficients are not statistically significant. When looking at children with higher levels of difficulties, the regressions indicate that children that cannot perform at all in one or more functional domains spend on average something around 50 per cent more than children without disabilities on such costs.
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Table 6: Differences in complementary education costs between children 5 to 17 years with and without disabilities

<table>
<thead>
<tr>
<th></th>
<th>(1)</th>
<th>(2)</th>
<th>(3)</th>
<th>(4)</th>
<th>(5)</th>
<th>(6)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disability</td>
<td>0.270</td>
<td>0.288</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>[0.114]</td>
<td>[0.101]</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Level of difficulty</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A lot of difficulty</td>
<td>0.161</td>
<td>0.207</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>[0.507]</td>
<td>[0.411]</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cannot do at all</td>
<td>0.441</td>
<td>0.415</td>
<td>0.441</td>
<td>0.423</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>[0.005]</td>
<td>[0.005]</td>
<td>[0.005]</td>
<td>[0.004]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Controls</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>School grade</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>School type and management</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Child's background characteristics</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Number of observations</td>
<td>7,114</td>
<td>7,013</td>
<td>6,718</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019. Notes: In each column OLS estimates from log-linear regression models of the log of complementary school costs on disability dummies and other school and child’s background characteristics are provided. Coefficients have to be exponentiated to interpret them as percentage differences in costs between children with and without disabilities. Controls include sex, age, current grade attending school, type of school management, type of school, area of residence, region, and wealth quintiles. All regressions use survey weights and standard errors have been clustered at the primary sample unit to account for the complex survey design. P-values are in square brackets.

4.1.1.3 Spending on health

The household survey also asked those who were either ill or injured during the 30 days preceding the survey how much they had spent on different health-related items. This included items such as consultation fees, medicine, clinic charges, fees from traditional healers and transportation costs. Overall, around 90 per cent of persons interviewed who had suffered an illness reported some health-related expense. Figure 18 shows that persons with disabilities spend, on average, much more than those without a disability. While the patterns of the distribution of costs by type of costs are similar for persons with and without a disability, persons with disabilities who had suffered an illness or injury during the 30 days preceding the survey spent close to UGX 60,000 in treatment, compared with less than UGX 40,000 for persons without disabilities who had also suffered an illness or injury.

Assistive devices can be prohibitively expensive for persons with disabilities. For example, according to one person interviewed, a wheelchair costs between UGX 450,000 and 600,000. In comparison, the Senior Citizens Grant provides UGX 300,000 per year to a recipient.
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Figure 18: Health related costs by type of costs and level of difficulty

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019

Figure 19 demonstrates that across different groups of the population, persons with disabilities tend to spend more on health-related expenses. The only notable exception is among older persons, with older persons with disabilities spending less on health treatments than their counterparts without disabilities. In addition, persons with disabilities in the wealthiest quintile pay significantly more than their counterparts without disabilities. As discussed above, 80 per cent of persons with disabilities live on less than UGX 8,000 per day, and so it is likely that only those in the wealthiest quintile have the means to pay for all (or at least, the majority) of the health-related costs that they need, which therefore may result in a reduced likelihood of accessing healthcare for most persons with disabilities, leading to a deterioration in conditions due to the higher health costs.

Figure 19: Health related costs by background characteristics

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019
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Table 7 provides OLS estimates of the difference in health costs between persons with and without disabilities from log-linear regression models. Odd numbered columns provide specifications without controls. As it can be seen from Columns 1 and 2, when accounting for background characteristics, the difference in costs are statistically insignificant, implying the existence of confounders. For example, older persons are both more likely to have a disability and to spend more on health-related items. However, when differentiating persons with a lot of difficulty from those that cannot do at all or more functional domains – Columns 3 and 4 – persons with higher levels of difficulty when compared to those without disability are spending some 20 per cent more in health costs even after controlling for background characteristics.

Table 7: Differences in health-related costs between persons with and without disabilities

<table>
<thead>
<tr>
<th></th>
<th>Dependent variable: natural log of all health-related costs</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(1)</td>
</tr>
<tr>
<td>Disability</td>
<td>0.353</td>
</tr>
<tr>
<td></td>
<td>[0.002]</td>
</tr>
<tr>
<td>Level of difficulty</td>
<td></td>
</tr>
<tr>
<td>A lot of difficulty</td>
<td>0.386</td>
</tr>
<tr>
<td></td>
<td>[0.001]</td>
</tr>
<tr>
<td>Cannot do at all</td>
<td>0.203</td>
</tr>
<tr>
<td></td>
<td>[0.143]</td>
</tr>
<tr>
<td>Controls</td>
<td></td>
</tr>
<tr>
<td>Major Symptom</td>
<td>No</td>
</tr>
<tr>
<td>Person’s and household background characteristics</td>
<td>No</td>
</tr>
<tr>
<td>Number of observations</td>
<td>7,021</td>
</tr>
</tbody>
</table>

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019. Notes: In each column OLS estimates from log-linear regression models of the log of health-related costs on disability dummies and other background characteristics are provided. Coefficients have to be exponentiated to interpret them as percentage differences in costs between persons with and without disabilities. Controls include sex, age, major health symptom, area of residence, region, and wealth quintiles. All regressions use survey weights and standard errors have been clustered at the primary sample unit to account for the complex survey design. P-values are in square brackets.

4.1.1.4 Household costs

As indicated in Table 8, when examining the differences in key monthly household expenses such as housing, transportation and communications, the only observed difference between households with and without persons with disabilities is in housing expenses, which include rent, utilities and household fuels. According to OLS estimates of regressing the log of housing expenses on whether the household has a person with disability or not and all else equal, households with persons with disabilities spend close to 39 per cent more on household costs than their counterparts without disabilities. Using the mean monthly household housing expenses from the survey, this corresponds to approximately UGX 16,500. There are no clear differences in household transportation and communication expenses between households with and without persons with disabilities.
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All persons with disabilities without any support networks may have to rely on paid help to receive the care that they need. This was the case for two widowed older sisters who lived together in Lamwo, who were interviewed during the qualitative research. One sister has severe disabilities and the other is her caregiver. Their main income source is the Senior Citizens Grant (of which only one sister is a recipient) and due to the frailty of the sister who is the caregiver, they have to pay people to do many of their physically strenuous chores, including collecting firewood. Consequently, a significant household cost for the two sister is paying for care.

Table 8: Differences in monthly household costs between households with and without persons with disabilities

<table>
<thead>
<tr>
<th>Dependent variable (in natural logs):</th>
<th>Housing (1)</th>
<th>Transportation (2)</th>
<th>Transportation (3)</th>
<th>Transportation (4)</th>
<th>Commsns. (5)</th>
<th>Commsns. (6)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Household with persons with disabilities</td>
<td>0.071</td>
<td>0.328</td>
<td>-0.456</td>
<td>-0.152</td>
<td>-0.412</td>
<td>0.001</td>
</tr>
<tr>
<td>Controls</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HH background characteristics</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Number of observations</td>
<td>4,053</td>
<td>4,032</td>
<td>4,053</td>
<td>4,032</td>
<td>4,053</td>
<td>4,032</td>
</tr>
</tbody>
</table>

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019. Notes: In each column OLS estimates from log-linear regression models of log of household expenses on disability dummies and other household background characteristics are provided. Coefficients have to be exponentiated to interpret them as percentage differences in costs between children with an without disabilities. Housing expenses include rents, utilities and fuels. Transportation expenses do not include transport to and from schools or health-related services. Communication expenses include cell phone top ups and internet. Controls include sex of household head, household size, dummy for high dependency ratio age of household head, area of residence, region, and asset index quintiles. All regressions use survey weights and standard errors have been clustered at the primary sample unit to account for the complex survey design. P-values are in square brackets.

4.1.1.5 Overall direct costs associated with disability

In order to assess the overall direct costs associated with disability, the standard of living method as proposed by Zaidi and Burchardt (2005) was applied. In their approach, the direct extra cost imposed on households with persons with disabilities is estimated indirectly. This is accomplished by comparing standards of living between households that are similar in a number of observable characteristics but have different disability status, such that, any difference in standards of living is only potentially explained by the disability status.

Two different measures of asset index were considered as standards of living. The first measure is a simple composite asset index formed by 13 different household assets common to households irrespective of disability status such as chair, table, bed, clock and sofa. The second asset index measure is based on principal component analysis of all household assets and assets of member in the household. The first principal component is transformed into an asset index. This approach is similar to that used in the DHS 2016.
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The findings are presented in Table 9 and indicate that there is a strong relationship between household income and different measures of asset index, but no statistically significant relationship between household asset ownership and disability status, despite point estimates indicating a negative relationship. The results are robust to different measures of asset index, and consequently is unable to provide a clear estimate of the extra costs associated with disabilities.

Table 9: Estimates of the direct additional costs associated with disability using the Standard of living approach

<table>
<thead>
<tr>
<th></th>
<th>All households</th>
<th>At least two adults</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>CAI</td>
<td>PCA AI</td>
</tr>
<tr>
<td></td>
<td>CAI</td>
<td>PCA AI</td>
</tr>
<tr>
<td><strong>A. Households with persons with disabilities</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HH income, log</td>
<td>0.34***</td>
<td>0.37***</td>
</tr>
<tr>
<td></td>
<td>(0.06)</td>
<td>(0.06)</td>
</tr>
<tr>
<td>Disability (binary)</td>
<td>-0.13</td>
<td>-0.11</td>
</tr>
<tr>
<td></td>
<td>(0.19)</td>
<td>(0.17)</td>
</tr>
<tr>
<td>Extra costs estimate as % of income</td>
<td>0.37</td>
<td>0.30</td>
</tr>
<tr>
<td></td>
<td>(0.56)</td>
<td>(0.46)</td>
</tr>
<tr>
<td><strong>B. Households with members who cannot perform one or more functional domains</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HH income, log</td>
<td>0.44***</td>
<td>0.48***</td>
</tr>
<tr>
<td></td>
<td>(0.08)</td>
<td>(0.09)</td>
</tr>
<tr>
<td>Disability (binary)</td>
<td>-0.16</td>
<td>-0.19</td>
</tr>
<tr>
<td></td>
<td>(0.35)</td>
<td>(0.33)</td>
</tr>
<tr>
<td>Extra costs estimate as % of income</td>
<td>0.36</td>
<td>0.41</td>
</tr>
<tr>
<td></td>
<td>(0.78)</td>
<td>(0.69)</td>
</tr>
</tbody>
</table>

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019. Notes: Point estimates are OLS from linear regressions. All regressions include household size, number of children, and dummies for regions, household head broad age groups, household head’s gender, land ownership, high age dependency ratio, and whether household is rural. Robust standard errors are in parentheses and have been clustered at the primary sample unit to account for complex survey sampling. The number of observations for the regression in Panel A is 3,106 for all households and 2,196 for households with at least two adults; in Panel B it is 2,145 and 1,612 for the two samples. *** p<0.01, ** p<0.05, and * p<0.1.

4.1.1.6 Indirect costs associated with disability

The indirect costs of disability relate to a number of issues such as loss of productivity from lack of support, to adults and children in education and employment opportunities, insufficient investments, and related loss of taxes linked to the lack of productivity. It also includes the foregone economic activities associated with the person with disability and other members in the household, as well as more intangible costs such as stress and social isolation. All of this makes indirect costs very difficult to quantify.

For persons identified as having a disability, the household survey asked questions on whether they had access to personal assistance to carry day-to-day activities, and in what form personal care was being provided – that is, if carers were being paid and for how many days and hours care was being provided.

As Figure 20 demonstrates, overall, 37 per cent of persons with disabilities receive personal assistance. Children aged 2 to 4 years and older persons aged 60 years and above are more likely
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than any other group with disabilities to have personal assistance. There is very little variation, however, between men and women, areas of residence and wealth quintiles.

Figure 20: Persons with disabilities with personal assistance, by background characteristics

[Graph showing distribution of personal assistance by sex, age groups, area of residence, and wealth quintiles]

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019

Figure 21 shows that across the functional domains, persons with difficulties in self-care are more likely to receive personal assistance than any other domain, with close to two-thirds of all those with self-care difficulties having access to personal assistance. In addition, 39 per cent of persons who “cannot do at all” one or more functional domains receive personal assistance, which is only marginally more likely than persons who have “at least a lot of difficulty”.
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Figure 21: Persons with disabilities with personal assistance, by functional domain and level of difficulty

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019

In Uganda, personal assistance is predominantly provided by other household members, as part of their familial care and support networks. As shown in Figure 22, close to 90 per cent of persons with disabilities that have access to some form of personal assistance receive assistance from other household members. Less than 13 per cent receive assistance from people outside the household, though these people are still likely to be a family member. Only 11 per cent of the carers from outside the household are non-relatives or from the government.

Figure 22: Personal assistance from non-members and members of the household, by background characteristics

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019
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For persons with disabilities who are able to access personal assistance, the assistance is provided frequently. As Figure 23 shows, over half of those with personal assistance receive it on a daily basis. Unsurprisingly, children with disabilities aged 2 to 4 years are most likely to receive care on a daily basis. In addition, persons who "cannot do at all" one or more functional domains are more likely to receive personal assistance than those who reported that they had "at least a lot of difficulty". Finally, men with disabilities who have access to personal assistance are marginally more likely to receive care daily than women with disabilities.

Figure 23: Number of days in the 4 weeks preceding the survey assistance was provided to those with access to personal assistance

As shown in Figure 24, on average, personal assistance is provided for nearly 10 hours a day, on days when assistance is provided. Given that personal assistance is mostly provided on a daily basis, for many this is more than a full-time job. However, less than 3 per cent of those with personal assistance pay for a carer. While it not possible to exactly estimate the foregone economic opportunities of those providing care, it is clear that the indirect costs are high, and that other family members take on a significant care burden, which reduces their economic opportunities elsewhere.
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Figure 24: Average numbers of hours in a day that assistance was provided (on days in which assistance was provided)

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Overall, the analysis above indicates that whilst looking at overall household expenditure does not indicate that persons with disabilities incur additional costs, breaking down the type of cost indicates that persons with disabilities experience greater direct costs of living than their counterparts without disabilities, especially in terms of school and health-related costs. Arguably, there are also high indirect costs in terms of foregone economic opportunities for persons who provide assistance to persons with disabilities – who are generally family members – and who are not paid.

These findings are consistent with a recent literature review conducted by Mitra et al 2017, in which the authors argue that in middle- and low-income countries, estimates of the additional cost of living with a disability are lower as a proportion of household income. This may be a reflection of the lack of disability-related goods and services available in the countries, as the evidence suggests that these costs appear to depend on the level of health services and social protection programmes that are provided by the state. However, in higher-income countries, the evidence suggests that persons with disabilities experience considerable additional costs, although these vary considerably according to the severity of disability, their point in the lifecycle and household composition. It is also worth emphasising that as the majority of persons with
disabilities in Uganda live on low incomes, their ability to make additional, disability related purchases is limited. This was demonstrated above by the fact that persons with disabilities in the wealthiest quintile have significantly higher health costs than persons in the other four quintiles.

4.1.2 Food Security and Nutrition

Stunting and other mal- or under-nutrition related issues remains a significant problem in Uganda. According to UNICEF’s State of the World Children’s Report (2019): three out of 10 children under five years in Uganda are “short for their age” or stunted, and over 53 per cent of children below five years of age are anaemic.27 However, there are still limited interventions focusing on how this links with disabilities, despite the links between malnutrition and disability being well established (see, for example, Kerac etc al 2014; Groce et al 2014; Hume-Nixon and Kuper 2018). One reason for this is that typical measures for assessing malnutrition (for example, height for weight or mid-upper arm circumference) are not always useful if a child has a disability as it can give inaccurate results.

The research demonstrated that food scarcity was a reality in many districts. In Lamwo, for example, a lack of rain at the beginning of the season had led to a poor harvest for most farmers. It was reported that many households in Lamwo were receiving food parcels from the government, consisting of maize (posho), beans, and in some instances, rice, although it was unclear how they were being assessed for these.28 Poor harvests inevitably mean less food, and in such circumstances, families often turn to less nutritious foods to fill themselves up. Children and older persons are particularly at risk of having poor nutrition.

4.1.2.1 Food security indicators

The household survey collected data on food security among households with and without persons with disabilities. Three indicators often used by the World Food Programme (WFP) to assess food security and vulnerability were constructed from the data collected. The indicators are the food consumption score (FCS), the share of household expenditure on food, and the dietary diversity score. Although all three indicators have strengths and weaknesses, the main weakness of the three indicators is that they are measured at the household level, which means that food security at an individual level cannot be assessed. As a result, the analysis is not able to provide information on intra-household food distribution and how this relates to persons with disabilities within the household.

The prevalence of food insecurity according to each of the indicators is provided below. While the food consumption score and the dietary diversity score indicate that households with persons with disabilities perform worse than households without persons with disabilities, the average share of expenditure on food in households with persons with disabilities is marginally lower than their counterparts. Furthermore, the patterns observed through different groups of households with persons with disabilities are not consistent across all three indicators.

28 For example, some households who had been registered to receive the food parcel did not receive them, blaming local incompetence and corruption.
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4.1.2.2 Food consumption score (FCS)

The food consumption score was developed by WFP and is often used to monitor food security across the globe, especially through time. The indicator is based on the diversity and frequency of food intake in the household over the past seven days. The indicator is calculated as the weighted sum of the frequency different food groups are consumed in the household, where the weights are based on the relative nutritional value of each food group. The score is then categorised as poor, borderline or acceptable, following WFP's guidelines.

Overall, as shown in Figure 25, around three-quarters of households with persons with disabilities have acceptable food consumption scores and 6.6 per cent have poor food consumption scores. In comparison, 4 per cent of households with no persons with disabilities have poor food consumption scores. Among households with persons with disabilities, female-headed households are twice as likely to have a poor food consumption score than male-headed households. Households with older heads tend to be worse off than younger headed households. Finally, households in urban and Western regions are better off, with around 85 per cent of households with acceptable food consumption scores.

Figure 25: Food consumption score classification among households with persons with disabilities, by household background characteristics

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019
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4.1.2.3 Dietary diversity score

The dietary diversity score is an indicator which captures how varied food consumption is at the household level. Dietary diversity is a good proxy for nutrient adequacy, as more diversified diets are correlated with caloric and protein adequacy. The indicator is constructed as the sum of the number of food groups consumed at the household level during the seven days prior to the survey. Eight food groups were considered: cereals and tubers; legumes and nuts; milk and dairy products; meat, fish and eggs; vegetables and leaves; fruits; oil and fats; sugar and sweets. Households were classified as having a low dietary diversity (DDS < 4), a medium dietary diversity (DDS = 4 or 5); or high dietary diversity (DDS > 5).

Figure 26 provides the distribution of households according to different dietary diversity classifications. Close to 15 per cent of households with persons with disabilities have a poor dietary diversity consumption, and 55 per cent have either a low or a medium dietary diversity score. This is 2 percentage points more than households with no members with a disability. Households with members with a disability that have younger household heads tend to have better dietary diversity than households with older household heads. This is also observed among different household structures. Less than a quarter of older persons with disabilities living alone have richer and more diverse diets.

Figure 26: Dietary diversity score classification among households with persons with disabilities, by household background characteristics

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019
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4.1.2.4 Share of expenditure on food

The third measure of food security is the share of household expenditure on food. This indicator is based on the existing evidence that households that are vulnerable and living in poverty spend more on food as a proportion of total expenditure and are at greater risk to fluctuations in food prices. While Figure 27 provides the mean in share of expenditure on food, in developing countries the following classification may be used: low share (< 50 per cent), medium share (50 to 60 per cent), high (65 to 75 per cent) or very high share (over 75 per cent) of expenditure on food.

In 2016, the UNHS estimated that the average share of expenditure on food in Uganda was 46 per cent, which was similar to previous rounds of the UNHS. This is less than what was captured by the situational analysis household survey, in which the average share of expenditure on food was 56 per cent, as shown in Figure 27. While these estimates are substantially higher than what is observed in high-income countries where average share is less than 20 per cent, in comparison to other sub-Saharan countries, the share is similar.²⁹

The average share of expenditure on food among households with persons with disabilities is 55 per cent, while the average share among their counterparts without disabilities is close to 56.5 per cent. The difference is not statistically different from zero. Households with persons with disabilities with younger and older household heads are likely to spend a greater share of their total expenditure on food, and the same applies to households in the lower asset index quintiles. There are also regional differences: households with persons with disabilities in Northern Uganda spend, on average, 60 per cent of their total expenditure on food, compared to 48 per cent among households with persons with disabilities in the Central region.

²⁹ Data on share of expenditure on food for a select number of countries can be found at https://www.ers.usda.gov/topics/international-markets-us-trade/international-consumer-and-food-industry-trends/
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Figure 27: Share of expenditure on food among households with persons with disabilities, by household background characteristic

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019

4.2 Social norms and expectations

Social norms and expectations – especially with regard to stigma and discrimination – can have a significant impact on the vulnerability (and conversely resilience) of adults and children with disabilities across the lifecycle. However, most research to date has focused on those who are stigmatised, rather than on those who perpetrate it, so there is little evidence of how stigma or discrimination have been reduced, and in particular what works to reduce or eliminate stigma in low- and middle-income countries (Scior et al., in press; Rohwerder 2018).
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4.2.1 Gender and disability

The literature on the links between gender and disability highlights that women with disabilities tend to experience more stigma and discrimination than women without disabilities. Gender and disability therefore intersect, and women with disabilities can face double or even triple discrimination (see, for example, UN Women 2018). For example, women with disabilities are at greater risk of experiencing sexual violence compared to their counterparts without disabilities. As a recent UN policy brief notes, compared to men with disabilities, globally, women with disabilities are three times more likely to have unmet healthcare needs; three times more likely to be illiterate; twice as likely to be unemployed; and twice as likely to not have access to the Internet. Gender is therefore a huge predictor in shaping outcomes for women and girls with disabilities.

Sadly, this reflects the situation for women and girls with disabilities in Uganda (Devries et al 2014; USAID 2017), and the situational analysis household survey shows that throughout their lifecycle, women and girls experience much more discrimination as a result of their gender (See Sections 4 and 5). Gender plays a significant role in shaping social norms and expectations, and Uganda remains a largely patriarchal society, with both men and women adhering to social norms around marriage and childbirth. Men and women are expected to, and indeed in many cases want to, marry and have children (Reynolds White 2020). Many men aspire to have at least a second wife, which is sanctioned by the state and by society. However, the presence of a second (or subsequent) wife can change family dynamics considerably and is often a factor in relationships breaking down. Rita’s story, in Box 5, highlights both the vulnerability that women with disabilities can experience, and how having children can give women with disabilities some social validation and security.

**Box 5: Rita**

Rita is an 18-year-old girl with physical disabilities and is the mother of a two-month old baby and a two-year old. Her children have different fathers, and although she is not in a relationship with either of them, she sees both fathers occasionally. She lives at home with her parents, who support her. The father of the second child also provides some money for his child. Rita herself said that, because of her disability, she had not believed she would even be able to have children, so even though it was not in ideal circumstances, she is very happy to have the children, even if she is dependent on others to support her and her children.

Marriage can also provide security for both men and women with disabilities, but to a different extent. As highlighted further below, if persons with disabilities are unable to conform to social norms, they are potentially in a much more precarious position. The example in Box 6, of a man with a disability who was able to achieve a respectable social status because he was able to marry, may be less likely for women with disabilities, as if they are unable to effectively contribute to the domestic chores of the household, or are potentially unable to have children, they are less likely to be regarded as marriageable. Furthermore, men with disabilities who are poorer may be less likely to marry because they are less able to provide adequate bridewealth.

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4. Vulnerabilities and Resilience

and to have sufficient assets and are therefore seen as less of a provider. For men (and women) with disabilities, bridewealth may be higher than that for a man or woman without disability, as the spouse may face greater demands on their labour.

Box 6: Michael

In Amudat, Michael is in his seventies and is unable to walk or stand since having contracted childhood polio. He has two wives and is able to socially participate in his community because his marriage accorded him status as head of the household. Through this, he has the right to control the labour of his wives and children and is therefore considered to be economically active. He sustains his livelihood by making beehives, which he sells to other men who make their living from the collection and sale of honey. Michael's social status as a household head was made possible through the investment of his father and brothers in the bridewealth which had enabled his marriage to two women, each of whom has borne him five children. Without his wives, Michael would have struggled to secure a livelihood or maintain his own household.

4.2.2 Stigma and discrimination

Stigma occurs within the context of power differentials between those who do the "labelling" and those who are "labelled", and results in stereotyping, status loss and discrimination (Link and Phelan 2001). The negative impact of stigma has been widely documented and includes poorer mental and physical health (Hatzenbuehler 2009; Meyer 2003), as well as reduced economic opportunities and overall quality of life (Rüsch et al 2005). All of these effects can be seen on persons with disabilities in Uganda. Discrimination is one aspect of stigma – the behavioural dimension. Legislating against discrimination is an important and necessary component of changing behaviour, and often drives changes in behaviour and attitudes at societal and individual level but is not in itself enough. However, we know very little about the exact relationships and the magnitude of effects.

While discrimination on the basis of disability is outlawed in Uganda, there still criticisms from the Office of the United Nations High Commissioner for Human Rights (OHCHR) around some specifically excluded groups, in particular persons with mental health or psychosocial disabilities (Ssebunnya et al 2009; NCD 2019), and lack of access to justice more broadly (NCD 2019). Moreover, there are many barriers to accessing justice and it is also unclear who can hold perpetrators to account when there is a case of discrimination. As the case-study detailed in Box 7 demonstrates, the Chair of the District Disability Council had no mandate to intervene on behalf of a girl who was being poorly treated, because as the girl was over 18, she was technically an adult, and so arguably could make her own decisions. The case also raises a question about whether having money “protects” people from interventions or prosecution.

Box 7: Nelson, Chair of Nakasongola District Disability Council

Nelson, the Chair of Nakasongola District Disability Council, spoke of a family that hid their 18-year-old daughter, who had a disability. The family was “rich”, so other community members thought that the child “was the price they had to pay” for being rich. The Council tried to speak to her father but could not persuade him to let her out of the house; instead, they have built a new house, and she has her own room in the house. Nelson reported that the girl’s mother had wanted her to go to school, but her father would not agree. Nelson had subsequently heard that the daughter had become pregnant (by a casual labourer who was building the new house) and her family did not take her to have the recommended antenatal checks.
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4.2.3 Abuse and violence

Abuse and violence, which can be linked to extreme forms of stigma and discrimination, can take many forms, ranging from bullying and name-calling – for example by children, particularly at school (Devreis et al 2014) – through to physical and sexual abuse and violence. Not all abuse is physical and can include psychological and coercive control. Two recent systematic reviews demonstrate that adults and children with disabilities are at particular risk of abuse and violence in most countries across the world, and that those with mental health conditions, intellectual impairments and communication difficulties are particularly vulnerable (Hughes et al 2012; Jones et al 2012).

In Uganda, research indicates that girls with disabilities are at particular risk of violence, especially sexual violence (HRW 2010; Devries et al 2014), although the reasons why this is the case are not entirely clear. Some studies in the region point to traditional beliefs about disabilities, gender and social norms, along with the fact that girls with disabilities may face higher levels of violence because they are less able to defend themselves or seek help (Devries et al 2014).

Box 8: Emily

Emily who has albinism, lives in Kampala. Perceived by her father and her stepmothers (her mother’s co-wives) as a “ghost” (mugambwa muzimu) she was segregated from the other members of the household, unable to eat with her co-siblings or walk outside with them. When she was seven years old, her father locked her in a “shrine” (essabo)31 where she lived until she escaped at the age of 14. During this time, her father and a local “witchdoctor” (myeawo mwenga) took payments from clients who would visit the “girl ghost”, seeking prayers to the ancestors.

Persons with disabilities are more likely to experience some form of abuse or violence across the lifecycle than persons without disabilities. This is the case both for men and women. As demonstrated in Figure 28, according to the DHS 2016, around 21 per cent of men with disabilities have experienced some sexual abuse in their life, compared to 8 per cent of men without disabilities. The rate is even higher for women, as 34 per cent of women with disabilities have experienced some form of sexual abuse in their lifetime, compared to 22 per cent of women without disabilities. Exposure to physical violence can worsen existing disabilities, making people more vulnerable and potentially more dependent on external support for care and income.

31 A small thatched hut containing animal bones, furs and skin as well as some small live animals such as tortoises.
4. Vulnerabilities and Resilience

Figure 28: Percentage of men and women that have ever experienced sexual violence and in the 12 months preceding the survey

![Bar chart showing percentage of men and women with or without a disability who have ever experienced sexual violence and in the past 12 months.](chart)

Source: DHS 2016

As the case-study in Box 9 emphasises, young girls with disabilities are particularly vulnerable, as they are often the target of opportunistic men, many of whom abandon them when they become pregnant.

Box 9: Faith

Faith, who lives in Lamwo and has a disability, explained how when she was 15 years old, her uncle would bring his friend to the house to have sexual intercourse with her. The man was unable to have children with his wife, so when Faith conceived, the couple took her to live with them until the baby was born. During this time, the wife physically abused her, and once the baby was born, the couple told Faith to leave the child and return to her father’s home. However, before this could happen, the husband died, and Faith managed to escape to her father’s house with her son.

4.2.4 Disability amongst refugees

In the same way that the intersection of gender and disability can lead to double or even triple discrimination, refugee status can also increase the risk of vulnerability for persons with disabilities in Uganda. Article 11 of the UN Convention for the Rights of Persons with Disabilities (UNCRPD), calls on States and other relevant humanitarian actors to ensure the protection and safety of persons with disabilities in all situations of risk, including armed conflict, humanitarian emergencies and natural disasters (UN, 2006). However, specific information about refugees is limited, in part because refugees are often a hard to reach group, so adults and children with disabilities are even harder to reach (Kett and Trani 2012). The impact of migration on health and wellbeing, including the health and wellbeing of persons with disabilities has been well

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32 As agreed with the MGLSD, this report does not have a specific focus on refugees as there is already a report on disability and refugees (Kidd et al 2019a).

33 See also: [https://www.un.org/development/desa/disabilities/refugees_migrants_with_disabilities.html](https://www.un.org/development/desa/disabilities/refugees_migrants_with_disabilities.html)
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documented (Abubakar et al 2018), however there is little specific data about refugees with disabilities in Uganda, despite Uganda hosting the third largest refugee community in the world.34

According to a recent study of refugees in Uganda,35 around a quarter of the country’s 1.22 million refugees report having “some difficulty” in at least one functional domain, 6.4 per cent report “a lot of difficulty” in at least one functional domain, and 0.7 per cent report being “unable to do” at least one functional domain. These figures are based on the WGSSQ, and it should therefore be recognised that the number of refugees with disabilities is likely to be higher than what is recorded, given that the WGSSQ provide limited data around mental health or psychosocial disabilities. These disabilities are likely to be prevalent amongst refugees who have experienced violence, conflict and displacement.

Refugees with disabilities are likely to be younger than the host population with disabilities, indicating both the likelihood of conflict-related causes of impairments, as well as the difficulties that older persons with disabilities face in crossing the border into Uganda. According to data, over half of persons with disabilities reported that an attack or inter-personal violence were the cause of their impairment.36 There is currently limited capacity to identify refugees with disabilities in Uganda, though as Figure 29 shows, from the data that is available, the majority of refugees with disabilities live in the southwestern region of Uganda, and there are more women than men.

Figure 29: Prevalence of disabilities across refugee sub-region, including by gender

Source: Kidd et al (2019a)

35 Kidd et al (2019a)
36 Data in this section comes from the report Kidd et al (2019a) unless otherwise specified.
4. Vulnerabilities and Resilience

Refugees in Uganda tend to be relatively dispersed, rather than camp-based, and in line with global initiatives, and the “self-reliance” model favoured by the Ugandan Government, many have to find jobs as there is very limited support for them from the government or NGOs. Yet only a small proportion of refugees have access to adequate land: 32 per cent of refugees with disabilities live in households with land for cultivation, but only 9 per cent have access to more than 0.5 acres. Women with disabilities are less likely to access land or own livestock than men, and among all those identified as having disabilities, older persons, single-headed households (of working age) and skipped generation households are the least likely to have access to land or livestock.

Another finding of the research was that households with a member with disabilities were less likely to work for wages, and more likely to depend on NGOs and humanitarian agencies for assistance. Many services, including cash for work schemes, are not accessible to persons with disabilities. Moreover, food and cash transfers are currently given to households, rather than to individuals, so there is a possibility that members with disabilities do not receive their share, if they have limited choice or control over the items. This reduces their autonomy and their level of decision making, which are key principles of human rights law.

Refugees with disabilities are given very little additional support if and when they are identified. Overall, refugees with disabilities have poor access to almost all services, apart from healthcare. This may reflect their higher need, or higher perceived need, as a lack of understanding about disability often means that people are referred for health services even if they do not have a healthcare need (Kett and Twigg 2007). Despite this, there is less access to reproductive health services, mental health services or support for chronic and non-communicable health conditions. In addition, it is worth noting that for many of the social protection programmes provided, being a citizen of Uganda is the first requirement – one that refugees do not fulfil.

Finally, disability can be both a cause for and against resettlement in third countries, as some countries will not take refugees with disabilities and others will as part of its resettlement criteria, but there is no data on the numbers of refugees with disabilities who have been resettled outside of Uganda, nor on the numbers who have self-settled across Uganda.

4.2.5 Societal expectations and perceptions

To gain an understanding of how persons without disabilities perceive persons with disabilities, a series of questions were asked to gauge their opinions. Overall, as Figure 30 demonstrates, 72 per cent of persons without disabilities believe that there is at least “a little” prejudice against persons with disabilities in Uganda.

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Figure 30: Level of prejudice respondents without disability feel there is towards persons with disabilities, by sex and region

The survey also asked persons without disability about what proportion of Ugandans they thought lived with disabilities. Figure 31 shows that the majority estimated that 20 per cent had a disability, which indicates that there is a tendency to overestimate, or to include minor (but visible) impairments in their estimation.

Figure 31: Percentage of persons with disabilities respondents without disability feel there is in Uganda, by sex and region
4. Vulnerabilities and Resilience

When persons without disabilities were asked whether persons with disabilities can lead as full a life as persons without disabilities people in Uganda, respondents were fairly evenly split. Figure 32 indicates that 48 per cent stated that they thought they could, while 40 per cent stated that they felt that they could not, on the basis of the health problem/disability. This question is a useful indicator, as one of the possible responses pertained to the presence of societal barriers. As such, respondents' answers can help indicate how widely accepted the social model is in Uganda. Given the responses, it appears that the majority of people still view disability from a medical perspective, and therefore as a problem for the person, rather than seeing it as a wider social issue.

Figure 32: How respondents without disabilities feel whether persons with disabilities can lead as full a life as persons without disabilities people in Uganda, by sex and region

Despite the stigma and discrimination that is present in Uganda, as Figure 33 demonstrates, persons without disabilities respondents overwhelmingly presented themselves as having a positive attitude towards persons with disabilities. Indeed, the majority stated that they would feel "very comfortable" if a person with a disability moved close to them, though notably, the proportion of people who gave this answer was lower when the neighbour had a learning impairment, compared to if the neighbour had a physical or sensory impairment. This is in line with the greater stigma and discrimination that persons with learning impairments experience around the world.
Figure 33: How comfortable respondents without disability would be in interacting with people with a range of impairments if they moved nearby

How would you feel if a person with a disability moved close to you?

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019

Similar patterns can be found when respondents answered how they would feel if their son or daughter (or the son or daughter of a close family member or friend) was in a class at school with a child with a disability. In this scenario, the child with the disability was receiving the necessary help and assistance that they needed. Figure 34 shows that while the majority of respondents stated that they would be “very comfortable” or “fairly comfortable” with this scenario, fewer respondents were comfortable if the classmate had a learning impairment.

Figure 34: How comfortable respondents without disability would be in their son or daughter interacting with children with a range of impairments in school

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019
4. Vulnerabilities and Resilience

Notably, respondents had a slight tendency to think that other people would be more negative about persons with disabilities than themselves. This can be seen in Figure 35. However, in this, respondents were perhaps overstating how positive they would be, as they were cautious about how their responses would be recorded. Overall, the results indicate that persons without disabilities do seem to regard persons with disabilities with a degree of stigma and discrimination, despite laws and policies to the contrary.

Figure 35: Percentage of respondents without disability reporting how comfortable people would feel if someone said negative things about persons with disabilities in different situations

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019

4.3 Shocks and coping strategies

As has been explained above, pre-existing conditions, including poverty, age, gender and even severity of impairment, may make children or adults more at risk of vulnerability. These conditions can therefore make a person more vulnerable to shocks. Mitra explains that in Uganda, “households with moderate or severe functional difficulties, respectively, have 1.3 or 1.8 higher odds of being subject to shocks than households without any functional difficulty” (Mitra 2018), and that there is a significant gendered dimension to this. It is therefore important to understand how households with persons with disabilities cope with unexpected shocks. Among working age families, a breadwinner (usually male) developing a disability can be a major shock, especially if it leads to high health costs, an inability to work and a need for another adult in the family to provide care. For those with pre-existing disabilities, many of the same challenges remain, including higher costs to access work and, potentially, a need for care support. As detailed in Figure 36, data from the situational analysis household survey demonstrates that the most common shocks experienced by all households were illnesses or an accident of a household member, followed by climate-related stocks, such as drought, agricultural challenges, and increased food prices.
4. Vulnerabilities and Resilience

Figure 36: Negatively affecting shocks during the last 12 months by household with and without persons with disabilities

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019

Households that include persons with disabilities experienced much higher rates of health-related shocks, although it is unclear which member of the household experienced ill-health (and it may not, therefore, be the person with a disability). A similar pattern was found in household with at least one member with disability: health-related shocks were most frequently reported, followed by climate-related shocks (Figure 37).
4. Vulnerabilities and Resilience

Figure 37: Most significant shock experienced by households with persons with disabilities during the past 12 months

Figure 38 shows that for households with a person with disabilities, the main response (coping strategy) to the shocks listed above was inaction, with 22 per cent giving this response. The consequence of inaction could be that illnesses go untreated, and conditions worsen. The next most common responses for coping strategies were that around 17 per cent of households relied either on unconditional support from relatives or using savings instead. A relatively small number sold off assets although it is not clear from the data if the low number is simply because most respondents did not have any assets to sell. A small number also obtained credit, although again, it is unclear whether this was because they were unable to obtain credit, or whether they chose not to apply in the first place. Finally, respondents infrequently cited that they relied on support from the government as their primary coping strategy.
4. Vulnerabilities and Resilience

**Figure 38: Primary response of households with persons with disabilities to most significant shock experienced during the past 12 months**

<table>
<thead>
<tr>
<th>Percentage of Households</th>
<th>Households without persons with disabilities</th>
<th>Households with persons with disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did not do anything</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Received unconditional help from relatives/friends</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relied on own savings</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Changed eating patterns</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Obtained credit</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sold livestock</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Engaged in spiritual efforts</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sold crop stock</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sold agricultural assets</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed household members took on more employment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sold durable assets</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sold land/building</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Had to find work</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reduced expenditures on health and/or education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Received unconditional help from government</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intensify fishing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sent children to live elsewhere</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Household members migrated</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Received unconditional help</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Source:** Based on own calculations using Disability Situational Analysis Household Survey 2019. Notes: “Engaged in spiritual efforts” includes prayer, sacrifices, diviner consultations, etc, “had to find work” refers to adult household members who were previously not working, and, “Received unconditional help” includes assistance from NGOs and/or religious institutions.

It should be noted that this means of measuring coping strategies is not fully informative, as it is unclear from the data whether individuals rely on alternative coping strategies such as borrowing food. However, there are likely to only be a finite number of coping strategy options available, and individuals that are less able to access credit could be more reliant on negative coping strategies (such as selling livestock or other large livelihood assets) than they otherwise would have been.

In addition to household income, weather patterns and variable rainfall also increase the risk of vulnerability in Uganda. These factors affect agricultural practices, which in turn have an impact on food security. Having enough food is a daily struggle for many people in Uganda and a lack of rain can exacerbate food insecurity, forcing families to use negative coping strategies such as selling assets (including livestock), taking their children out of school or resorting to environmentally harmful agricultural practices to secure food (WFP 2017; Wichern et al 2019). As indicated in Figure 37, agricultural or climate-related issues were the second most common form of shock. Perhaps linked to this, around 10 per cent of households with a person with disabilities reported changing their eating habits as a coping strategy when there was a shock.

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38 Respondents were asked to rank the top three shocks they experienced in the past year and then asked their responses (up to 3) to each of these shocks.
4. Vulnerabilities and Resilience

Although not recorded in the household survey, the qualitative research found that another coping strategy employed by some families, particularly on the death of a parent, is that the older sibling becomes the de facto parent. Gloria and Naomi’s story in Box 10 provides further insights into this coping strategy.

**Box 10: Gloria and Naomi**

Gloria is a 21-year-old mother of two young children – one aged three and another aged 11 months – who also looks after her 13-year-old sister, Naomi. Naomi had an accident two years before, which resulted in complications and restricted mobility due to delayed treatment. Their father died in 2008, and their mother left to find work shortly after, and they have not seen her since. Initially, the sisters lived with their aunt, but when Gloria moved to her then boyfriend’s homestead, she asked if she could bring her sister to live with them as the conditions were not favourable at their aunt’s. Gloria’s husband works in another district as a casual labourer, so in addition to the housework and childcare, Gloria works in the farm, growing *matoke* and sweet potatoes, as well as taking care of a neighbour’s pigs. They survive by selling surplus sweet potatoes and *matoke*, and on any money her husband leaves them. On average, Gloria earns around UGX 5,000 a week from the garden, which she uses to support the whole family.

One negative coping strategy that arose during the qualitative research was that women with disabilities who are in vulnerable positions may partner with men for security. As Box 11 shows, sometimes these men offer little support, and may even be abusive.

**Box 11: Sylvia and Julia**

Sylvia has a physical disability, that resulted from polio. She moved in with an unsuitable partner after a *boda boda* driver became angry with her for rebuffing his sexual advances and threatened to rape her. Julia, who has albinism, feared for her security as a housemaid, and so decided to cohabit with her partner. However, he is violent and abusive towards her, and often leaves her without any money to maintain the household and on occasion she cannot feed their children. Julia rations her money so that she can both feed her family on “lean” days and save enough towards her children’s school fees.
5 Disability Across the Lifecycle

To examine the experiences of adults and children with disabilities in Uganda, a lifecycle approach was used. This broadly allows the exploration of impact (for example, of disability) across the different stages of a person’s life, starting at birth (or even before birth) and ending at death. This has implications for the provision of support and services for persons with disabilities across their lifecycle. As discussed above, Ugandans face a range of risks and shocks across the lifecycle, and person with disabilities and their families may have even less wherewithal to withstand these shocks and risks for a variety of reasons (Kidd and Gelders 2017). This section of the report discusses the challenges that persons with disabilities face across the lifecycle, and further details about the impact of disability with regard to accessing services are presented in Section 7.

Figure 39 summarises factors than enhance resilience or increase vulnerabilities across the lifecycle for persons with disabilities in Uganda. As noted above, these are not static, and persons move between these phases at different points in their life depending on a range of factors which are discussed below.

Figure 39: Vulnerabilities and resiliencies across the life course
5. Disability across the Lifecycle

5.1 Early childhood

The challenges faced by persons with disabilities can begin even before birth, depending on the level of ante- and postnatal healthcare received by the mother, as well as the actual process of birth. Even if the birth occurs in a health centre, the level of healthcare worker training, or screening systems in place are not currently adequate enough to identify the range of congenital anomalies a child may experience (GoU 2016). Moreover, even if they are identified, there are limited services or support available for parents and children with disabilities (Smith et al 2018). UNICEF estimates that only around 10 per cent of children with disabilities benefit from rehabilitation services, the absence of which can increase the severity and scale of their impairment (UNICEF, 2014). Many children go on to acquire impairments due to illness, distance from health services, lack of vaccination and other prevention measures, as well as the overall absence of effective health support, including rehabilitation services (UNICEF 2014).

As Figure 40 demonstrates, most impairments acquired in childhood happen after birth, for example from endemic childhood diseases such as (cerebral) malaria, as well as vaccine-preventable diseases. This may indicate a high number of potentially avoidable conditions, which can worsen with limited access to healthcare and/or rehabilitation. Disability among babies and young children is often viewed as a curse, or as a consequence something the parents – particularly the mother – did or did not do when pregnant, which can result in attributions of blame and abandonment (e.g. Bannik 2017).

Figure 40: Age of onset of disability by age groups

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019

39https://apps.who.int/iris/bitstream/handle/10665/136975/ccsbrief_uga_en.pdf?sequence=1
5. Disability across the Lifecycle

It is largely the responsibility of the Village Health Teams (VHTs) to support new mothers and provide advice, some basic treatments and other support. However, VHT members have no specific training on disability issues, and so it is unclear how many children they identify as (potentially) having an impairment, nor what referral mechanisms they use, aside from the general reporting forms.\(^{40}\)

It is clear that the life chances of children who are born with, or acquire, a disability varies enormously depending on the severity of their impairment and their family situation. In life history interviews, most adults who had acquired their disability in childhood emphasised the importance of the family environment, including support from a parent or close relative, particularly the mother, in determining their later life opportunities. This in turn formed the basis of their social situation as adults. Gendered differences in attitudes towards children with disabilities were remarked upon by male and female interviewees in all districts, including the limited value some fathers placed on children with disabilities: “A father will say what is the problem? We will have other children. He can push this one aside. He can say ‘let malaria take this one’”.

5.2 School age\(^{41}\)

While children in Uganda typically start school at six years old, children with disabilities often start later for a range of reasons. There is no accurate data on dropout or retention rates for children with disabilities, and it has been noted that Uganda struggles to ensure all children and adolescents with disabilities receive an adequate education. One Ugandan study cites an 80 per cent attendance rate for children without disabilities compared to only 52 per cent among those with disabilities (Okimait 2014).\(^{42}\) Furthermore, both the GoU and UNICEF estimate that around 90 per cent of children with a disability are limited in their ability to attend school, and that they are at a higher risk of dropping out or not completing school (MGLSD 2011; UNICEF 2015). Research indicates that children with disabilities – particularly girls with disabilities – who enrol in school in Uganda but then drop out at increasing numbers across the school years, do so for a range of factors, including a lack of specialist teachers, a lack of accommodations in the classroom, violence, and falling pregnant (Nyende 2012, Moi 2012, Devries et al 2014).

In Uganda, the situational analysis household survey confirms that children with functional difficulties are less likely to attend school. As Figure 41 demonstrates, only 74 per cent of children with a disability aged between 5 and 17 years attend some level of school, compared with 83 per cent of children without a disability.

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\(^{40}\) Interview with District Health Educator, Nakasongola District.

\(^{41}\) The Disability Situational Analysis Household Survey captured information on education and schooling of all household members aged 5 years and over. For the purpose of this section, “school age” is classified as 5-17 years.

\(^{42}\) Source: UNHS (2009/10).
5. Disability across the Lifecycle

Figure 41: School attendance among children aged 5-17 years by disability

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019

Overall, there is little difference between the proportion of girls and boys with disabilities who are currently attending school. There is, however, some variation by age and sex. For example, Figure 42 indicates that the percentage of boys with disabilities who are not attending school significantly increases at 12 and 13 years, with close to 40 per cent not in school. Among girls, a similar drop is observed slightly later at 15, with close to 30 per cent not attending school. This is in line with established issues such as the need to work to earn money, menstruation, pregnancy and early marriage.

Figure 42: School level of children aged 5-17 years with functional difficulties by age and sex

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019
5. Disability across the Lifecycle

Figure 43 shows school attendance of children by functional difficulty. For children aged 5-17 years, those who have at least “a lot of difficulty” in self-care, communication or in making friends are the least likely to be currently attending school. Children who have had difficulties in accepting changes in routine, controlling their behaviour or in making friends are the most likely to have attended school in the past but have since dropped out. Finally, children who have difficulties with self-care or communicating are the most likely to have never attended school.

Figure 43: School attendance among children aged 5-17 years with disabilities, by domain

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019

It is often mothers who bear the brunt of the burden of childcare and have to eke out a living as a single parent. As a result, some children with disabilities are left with family members to care for them, in particular grandparents, many of whom are struggling themselves. Many children with disabilities can remain hidden away from the community for a number of years. Furthermore, child protection is a significant issue for children with disabilities, with several studies reporting that they are more likely to experience mental and physical abuse than their counterparts without disabilities, particularly for girls with disabilities. Additionally, they and their families are less likely to utilise existing child protection mechanisms (Banks et al 2017, Devries et al 2014, Nyende 2012, Moi 2012, Devries et al 2014). Boys and men with disabilities are not excluded from discrimination, and as discussed in Section 4.2 above, some impairment groups are more susceptible to facing stigma, such as people with mental health conditions and learning disabilities, although this varies in different countries across the world.

5.2.1 Relationships

As highlighted in Figure 44, just under three quarters of children with disabilities live with their birth mothers, and this rate is almost the same as for children without disabilities. This proportion declines with age, which may indicate a change in circumstances as the child becomes older and more difficult to manage. However, the decline slows down after 10 years of age, and notably,
5. Disability across the Lifecycle

Children with disabilities aged 15-17 years are slightly more likely to live with their mother than children without disabilities.

Figure 44: Percentage of children aged 5-17 years living with mother by disability and age groups

It has long been a practice in Uganda for family members to leave their children with relatives – sometimes because they have no child of their own, or because they need someone to look after them – and sometimes because of a death of a parent or the parent leaving to seek work. Some of these arrangements work out well, but not all do, and for those taking on additional children, particularly children with disabilities, the state does not provide caregiver support. There is, however, an Alternative Care Policy for children in Uganda which promotes fostering as an alternative to institutionalised care or adoption. The only support groups available are civil society-led, such as parent groups. These means support is ad hoc, inconsistent and has to be pro-actively sought.

5.2.2 Adolescents

Becoming an adolescent is a challenging time, especially for adolescents with disabilities. There is often a concern, if not amongst the adolescents themselves, but expressed by their families and social groups, that adolescents with disabilities will have fewer friends, fewer opportunities for friendships and lower participation in social and recreational groups. This is due to adolescents potentially spending less time with their friends outside of school hours and therefore being less likely to belong to an integrated friendship group. For those who do not attend school, there are even fewer opportunities still. The concern here is that this could inevitably lead to greater vulnerability of social exclusion, stigmatization, victimisation and

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43 From survey data it is only possible to observe directly the mother or the primary caretaker
44 Ref alternative care policy
5. Disability across the Lifecycle

loneliness, all of which impact the adolescent’s self-esteem, social competence skills, mental health, identity.

The lack of social opportunities — work and/or relationship-wise — could also impact on adolescents with disabilities’ ability to find partners and/or get married, therefore making them more likely to remain at home under the care of their parents or guardians. This could have further negative psychological impacts on younger persons with disabilities but also places added economic financial stress on households with persons with disabilities. In terms of bridewealth, and the ‘fulfilment’ of their gender role and dynamics involved with marital arrangements within Uganda, this would disproportionately impact families with adolescent girls with disabilities, but will also affect families with boys with disabilities too.

The literature review suggests that young persons living with disabilities are neglected over matters of sex and family planning. Imalingat Deo, a young person with a disability, stated at a National Family Planning Conference in 2019, that “Most of the Deaf community are unaware of health services that include family planning mostly because they are not empowered and some are illiterate. There is therefore need to reach out to these groups so that they can as well benefit from such programmes.”46 A Women’s Refugee Commission (2014) report—called “We have a right to love”—spoke of the intersection of issues faced by young people with disabilities living as urban refugees in Kampala, Uganda in terms of sexual and reproductive health and discrimination and violence. Many of the young women with disabilities felt they were looked down upon due to the perception of their disabilities and were often forced or felt compelled into early marriage. They also lacked general awareness about what health programmes were available to them, and had received limited sex education (including awareness of sexual transmitted infections prevention). There were also reports of forced sterilisation and vulnerability to violence and/or sexual violence.47

5.3 Youth

Uganda's youth face particular challenges around education, employment, health, relationships and family life, all of which can have adverse consequences on life chances and opportunities (see, for example, Aniyamuzaala 2012 for a discussion on this).

Figure 45 shows the literacy rates of youth who took part in the household survey. Young persons with disabilities have lower literacy rates compared with their peers without disabilities. 43 per cent of young men with disabilities and 50 per cent of young women with disabilities are unable to read or are only able to read parts of a sentence, compared with 34 per cent of young men and 38 per cent of young women without disabilities. Furthermore, young men with disabilities (and young women, though to a lesser degree) have lower literacy levels than both young men and women without disabilities.

46 UNFPA (2019).
48 Following the Disability Situational Analysis Household Survey, “youth” is broadly classified as 18-30 years.
5. Disability across the Lifecycle

Figure 45: Literacy of women and men 18-30 years, by disability

Poor literacy rates for persons with disabilities results in a curtailment of life chances, such as limited employment opportunities (Lang and Murangira 2009; World Bank 2009) and poorer health outcomes. This is exacerbated by a lack of catch-up or adult literacy programmes for persons with disabilities, despite Uganda having a Functional Adult Literacy (FAL) Programme. This appears to have been more successful for certain groups (for example, women without disabilities) than for persons with disabilities.\(^{49}\) None of the persons with disabilities interviewed in the life history qualitative research had attended any FAL programmes. Moreover, there are few accredited training institutions or, indeed, necessary technologies available to provide support for persons with disabilities to enable them to access further education and training.

If students succeed in transitioning through the education system, it is reported that there are a number of allocated places for students with disabilities at tertiary level (Emong and Eron 2016). However, students are required to have the requisite examination scores to be allocated a place, as well as a certificate of eligibility from the National Union of Persons with Disabilities (NUDIPU).\(^{50}\) GoU data suggests that around 25,000 students are enrolled in tertiary education,\(^{51}\) although it is unclear how many of these are students with disabilities, as this data are not available nationally.


\(^{50}\)http://aydu.org/accomplishments.html

\(^{51}\)http://www.education.go.ug/#eluid7cb9cc0d
5. Disability across the Lifecycle

5.3.1 Employment

Youth unemployment rates are very high in Uganda and even higher for youth with disabilities. This is in part linked to a lack of education and training, but also to stigma and discrimination which continues across working age. The GoU has made a concerted effort to revitalise youth training, as outlined in the Business, Technical and Vocational Education and Training (BTVET) Act (2008). However, the Act only makes passing reference to disability issues (Omona et al. 2017). The associated Skilling Uganda: BTVET Strategic Plan 2011-2020 does make provisions for the targeted inclusion of youth with disabilities. Overall, however, the BTVET sector in Uganda has been subject to criticism, in particular over the lack of funding and attention to training centres, the lack of trained staff, links to the private sector and overall poor image of the BTVET (GoU 2019).

The household survey also shows high levels of unemployment for both young persons with and without disabilities, although unemployment rates are higher for persons with disabilities. Figure 46 indicates that 53 per cent of young men and 40 per cent of young women without disabilities are currently employed. This is compared with 34 per cent of young men and 30 per cent of young women who have “at least a lot of difficulty” in a domain. For youth who cannot perform functional activities at all, gender has a significant impact, with 24 per cent of young men being in employment compared with only 3 per cent of young women.

**Figure 46: Percentage of youth 18-30 years employed, by disability and level of difficulty**

<table>
<thead>
<tr>
<th></th>
<th>No disability</th>
<th>At least a lot of difficulty</th>
<th>Cannot do at all</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disability</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No disability</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>At least a lot of difficulty</td>
<td>34</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cannot do at all</td>
<td>24</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
<td></td>
<td>53</td>
</tr>
<tr>
<td>Female</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disability</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No disability</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>At least a lot of difficulty</td>
<td>40</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cannot do at all</td>
<td>30</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
<td></td>
<td>40</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
<td></td>
<td>45</td>
</tr>
</tbody>
</table>

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019

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52 For the purposes of these results employment is defined as those who are working for wages, self-employed or own-account workers. Note that this definition is only applicable to this study, following the Model Disability Survey and is not necessarily comparable to UBOS unemployment estimates, as the survey used different questions on work.


56 Unemployed individuals in this survey were identified as those that were not currently working but looking for work. Note that this definition is only applicable to this study, following the Model Disability Survey and is not comparable to UBOS unemployment estimates.
5. Disability across the Lifecycle

Impairment therefore has an impact on rates of employment for young people with disabilities. Figure 47 shows that young persons with difficulties seeing and walking are most likely to be employed (39 per cent and 35 per cent respectively), whereas persons with self-care and communication difficulties have much lower rates of employment (17 per cent and 14 per cent).

**Figure 47: Employment rates by impairment type**

Furthermore, Figure 48 indicates that young men and women without disabilities are the least likely to not be in employment, education or training (NEET), (29 per cent and 40 per cent), whereas young women who are unable to perform functional activities are the most likely (82 per cent). This is substantially higher than the 61 per cent of young men who “cannot do” functional activities, implying that gender does influence young persons with disabilities’ likelihood of being NEET. In addition, impairment also influences a young person with disabilities’ chances of being NEET. Young persons with difficulties seeing or walking are the least likely to be NEET (41 per cent and 40 per cent), whereas 78 per cent of young persons with difficulties in self-care are NEET.
5. Disability across the Lifecycle

Figure 48: Percentage of youth 18-29 years who are not in employment, education or training (NEET), by disability

<table>
<thead>
<tr>
<th>Disability</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No disability</td>
<td>29</td>
<td>40</td>
<td>38</td>
</tr>
<tr>
<td>At least a lot of difficulty</td>
<td>44</td>
<td>54</td>
<td>52</td>
</tr>
<tr>
<td>Cannot do at all</td>
<td>61</td>
<td>82</td>
<td>75</td>
</tr>
<tr>
<td>Total</td>
<td>134</td>
<td>220</td>
<td>188</td>
</tr>
</tbody>
</table>

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019

A similar picture emerges for young people who have never been employed. Young men and women without disabilities are the least likely to have never been employed (42 per cent and 51 per cent respectively). In comparison, 81 per cent of young women who are unable to perform functional activities have never been employed, which makes them the most likely to have never been employed. Furthermore, 69 per cent of young men with disabilities who “cannot do” activities have also never been employed. The type of impairment is also a factor, and youth who have self-care or communication difficulties are most likely to have never been employed (78 per cent and 72 per cent), whereas those with walking or seeing difficulties were the least likely (51 per cent and 54 per cent).

While some of interventions that tackle unemployment, such as the Youth Livelihood Programme (YLP), are ostensibly inclusive, they do have some conditionalities attached (see Section 7). Furthermore, it is difficult to tell whether any of the income-generating opportunities have improved the livelihoods or wellbeing of youths generally, and youths with disabilities specifically (Bukenya et al. 2019).
5. Disability across the Lifecycle

5.3.2 Marriage and relationships

It is around this age that many young people, particularly girls, begin relationships and have children. According to the “Girls Not Brides” campaign,57 Uganda has the 16th highest prevalence rate of child marriage in the world. Customary or informal marriages, whereby a girl lives with a (usually older) man, are more common than registered civil or religious marriages, and 11 per cent of the currently married 15-19 year old girls are married to men who have more than one wife.58 Gendered attitudes are entrenched from a very young age, and girls who marry young often endure lasting health and other consequences (Ninsiima et al 2018).

The household survey found that about 2.3 per cent of girls aged 12-17 years with a disability are married, and a similar number without any functional limitations are also married. As can be seen in Figure 49, young men and women with disabilities are less likely to be in monogamous marriages compared with young people without disabilities. However, the survey did not make a distinction between marriage and cohabitating, and these terms were sometimes used interchangeably by respondents. Young women, both with and without disabilities, are also more likely to be separated or divorced than men.

Figure 49: Marital status of youth 18-30 years by disability

![Figure 49: Marital status of youth 18-30 years by disability]

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019

When disaggregating by impairment types, Figure 50 demonstrates that the survey found that young people with seeing and walking difficulties were most likely to be in a monogamous marriage. Young people with communication difficulties were least likely to be in a monogamous marriage and most likely to never have been married. In this age group, the rates of divorce were not high, but people with seeing difficulties were slightly more likely to be divorced compared with the other difficulty domains.

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57 https://www.girlsnotbrides.org/child-marriage/uganda/
58 Ibid
5. Disability across the Lifecycle

Figure 50: Marital status of youth 18-30 years with disability by disability

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019

While many of the women with disabilities interviewed wanted to have children, others spoke of unplanned – and unprepared for – pregnancies. Una’s story, which features in Box 12, is an example of this.

Box 12: Una

Una is a 20-year-old woman who is both blind and has a physical disability. She had a brief relationship when she was 18 with a local boy whom she knew and trusted. She even took a HIV test at his bidding, which he paid for. He told her his test was negative and she believed him. Una did not disclose the results of her test. When she discovered she was pregnant, she was initially happy, but when her mother confronted the boy’s parents, he denied all knowledge and his family moved away from the area. Una’s child is now two years old and is being brought up mainly by her grandmother.

5.4 Working age

According to stakeholders within the labour sector, UBOS and the International Labour Organization, “working age” in Uganda is defined as 14-64 years. However, for the purposes of this section, “working age” is broadly defined as 30-60 years, although, in reality, most adults begin working long before that, often in subsistence farming, and many go on working long after the age of 60. Nevertheless, Mitra’s (2018) findings demonstrate that persons with functional difficulties are more likely to stop working even before retirement age. The findings of this household survey also indicate this.
5. Disability across the Lifecycle

5.4.1 Employment

As Figure 51 indicates, the patterns of employment that started to emerge in the youth age group are replicated among adults with disabilities. Both men and women with disabilities who took part in the survey were less likely to have ever worked compared with adults without disabilities. In general, women were less likely to have ever worked compared with men, which may be a reflection of gender norms in Uganda. Perhaps surprisingly, women who reported at least a lot of functional difficulties had similar rates of employment compared with women without disabilities, though this may be due to a lack of alternative choices. However, more than three quarters of women who cannot perform functional activities at all have never worked.

When disaggregating by impairment type, results showed that nearly two-thirds of people with communication difficulties had never been employed. By contrast, people with walking and visual difficulties were least likely to never have been employed (between a quarter and a third of people with these difficulties).

Figure 51: Percentage of adults 30-60 years who have never worked, by disability and level of difficulty

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019
5. Disability across the Lifecycle

Persons with disabilities are less likely to be currently working than their counterparts without disabilities. Figure 52 shows that men who have at least a lot of functional difficulties are substantially more likely to be in work than women with or without disabilities. Similar proportions of men and women who are unable to perform functional activities at all report being currently in work (21-26%).

**Figure 52: Percentage of adults 30-60 years employed, by disability and level of difficulty**

Of the persons with disabilities who are currently working, there is a reasonably even split across the different types of impairment. The exception to this is people with communication and self-care difficulties, who are substantially less likely to be working than people with other kinds of difficulties. This may mean that the impairment type – other than in self-care and communication – may not be the limiting factor in people accessing employment.

Illiteracy can be a major barrier to employment, and as Figure 53 shows, the DHS survey (2016) found that men and women with disabilities have higher rates of illiteracy compared with their counterparts without disabilities. Gender also has an impact on literacy rates, with women having higher rates of illiteracy than men, and women with disabilities being most likely to be illiterate.
5. Disability across the Lifecycle

Figure 53: Literacy of women and men 30-45 years, by disability

Source: DHS 2016

5.4.2 Marriage and relationships

Figure 54 indicates that overall, women with disabilities are more likely than women without disabilities to have been married, rather than to be currently married. They are also slightly more likely to have never been married, meaning they may now live alone or in a female-headed household. Men with disabilities are more likely to be married than women with disabilities, although 9 per cent never marry. The household survey also indicates that there are similar proportions of people living in monogamous marriages across the impairment types, but people with communication difficulties are more likely to have never married compared with the other difficulty domains. People with hearing difficulties are also marginally more likely to be divorced than people with other types of impairments.

Figure 54: Marital status of adults 30-60 years by disability

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019
While most men and women are living as couples with children, it is not clear if they are cohabiting or in a formal marriage. Informal cohabiting may contribute to vulnerability, as being legally recognised as the next of kin gives at least some semblance of legal protection to women when they divorce, unlike informal arrangements of living together and having children. Furthermore, as was also discussed in Section 3.2, men and women with disabilities are more likely to be living in a three-generation household than their counterparts without disabilities.

These findings are also consistent with the finding that was discussed in Section 3.2, that there are higher age dependency ratios amongst households with persons with disabilities. Having a higher number of dependents means that such households are more vulnerable, particularly if they are female-headed. It also means that they are less able to deal with adverse shocks than households with smaller age dependency ratios or households without persons with disabilities.

Negotiating relationships can be a challenge for persons with disabilities. Many adults with disabilities and their partners face stigma and discrimination, for example around pregnancy, childbirth and their ability to take care of their children. For some women, giving birth to a child with a disability can even lead to abandonment (see, for example, Ahumuza et al 2014). Women in both formal and informal marriages risk losing their homes and land, as inheritance laws are often ignored and not enforced. Women with disabilities may fare even worse than their counterparts without disabilities, as Ugandan customary law prohibits persons with disabilities from inheriting land (Groce et al 2014).

For both men and women in Uganda, families are often the greatest source of support, so having children is what the anthropologist, Reynolds Whyte, calls “the great life project” (2020). It is one to which many people aspire to, even if they have to do it alone. During the qualitative research, the people interviewed were no different. Children are often seen as a form of security – an “investment in the future”, as is indicated by Marie’s story in Box 13. However, it is unclear from the interviews if this is more or less the case for men and women with disabilities compared to men and women without disabilities. Furthermore, for some women with disabilities, having children was both a coping strategy, as well as “validation” of them as women. Having children was seen as shared experience with other women, even if it placed them in a precarious living situation.

Box 13: Marie

Marie, aged 41, is a person with a disability who is also a mother of a child with a disability. She emphasised the value of her children, asserting that “[my] children are [my] wealth as [I] do not have anything else”. For Marie, her children are an investment for the future, to provide support both to her and the other members of her family as they age.

Many working age family members have the responsibility of caring for adults and/or children who need additional support or supervision – this could be for children or adults with severe health conditions, including having HIV/AIDS, or those with impairments who cannot be fully independent (who may be their spouses), or even for frail elderly parents. Adults – particularly working age women – may also be caring for their children. All of this can put a severe burden on caregivers, including physical, psychological, social, time, and financial burdens (see, for example, Namale et al 2019; Thrush and Haytner 2014).
5. Disability across the Lifecycle

As Thrush and Haytner (2014) note in their review of caregiving in low- and middle-income countries, this burden of care is often against a backdrop of shifting social and support structures linked to urbanisation and migration, in which “traditional” notions of family and care provision are being challenged. Additional structural challenges, including lack of resources – especially limited medical, educational, and social services, as well as hardship and food insecurity – may all add to this burden. While it is clear from the household survey that there are a higher number of three- or more-generation families amongst households with a person with a disability compared to without a person with a disability, the direction of care is less clear. For example, it is unclear whether children are caring for older and/or infirm grandparents, or grandparents are caring for and/or supporting children with functional limitations.

While by this stage of their lives, some men with disabilities have begun to form second families, for others, their ability to marry often depends on whether their family can provide bridewealth, which determines who and how they can marry. According to some informants, for men with disabilities, bridewealth may be higher than for a man without disability, as he is seen as “a less attractive” marriage option for the potential wife and her family, as she may face greater demands on her labour. Men with disabilities also face other challenges. For example, one interviewee, a blind amputee, was told by people in his community to “continue with life” and “forget” about his disability. Despite the good intentions behind the sentiment, it also clearly demonstrates the lack of awareness that other persons without disabilities of the community may have about persons with disabilities.

While unmarried men have to negotiate their single status through family and social networks, some, for example, continue to live in their parents or siblings’ home. Single women without children may fare somewhat differently, although they are also dependent on family support. They are also perhaps more vulnerable in other ways, as Box 14 demonstrates.

**Box 14: Rebecca**

Rebecca is 46 years old and has a physical disability. She is currently in a relationship with a married man. She started the relationship without any HIV testing, as her partner convinced her he was safe, and they are not currently using any form of contraception. Rebecca did not disclose her HIV status. Her partner makes promises about the things he will buy her, but as of yet, nothing has materialised as he has limited financial means. Rebecca wants to find an unmarried partner, but so far “…all she gets are married men.” She is unable to have children and has not made any plans for her future.

As is apparent, in Uganda, a woman’s capacity to live an autonomous life is severely restricted by gender norms. While being single may give women more autonomy around decision-making, if this is not matched with economic empowerment, then women will be able to be fully autonomous. Currently, women with and without disabilities lack autonomous decision-making within the household. For example, men are expected to make the decisions on how much money is spent and on what; who can and cannot go to school; which children can remain living at home and who else is permitted to live in the household.

Despite a few examples to the contrary, the care and upbringing of children – especially young children – is still largely the responsibility of mothers. Men – fathers – may largely be the “providers” if they are still around, although it should be emphasised that even when fathers are present, mothers will often still earn money in addition to their caregiving duties. When fathers are not present, however, both caregiving duties and the provision of income are, in general, the mother’s responsibility. Mothers who lack the wherewithal to do this may choose to send their...
5. Disability across the Lifecycle

children to relatives, such as grandparents, with the understanding that they will return to claim them back at some point. For others, this is a pragmatic decision to enable them to seek work elsewhere with the aim of earning more money to support their children. Box 15 shows the struggles of a single mother, who is also caring for a young child with a disability.

Box 15: Margaret

Margaret is a single mother of five children, including a very young child with disability. Margaret lives in one room in a trading centre in Kiruhura. Margaret’s husband left her a decade previously, and she was required to move out of the family home. Since then, her situation has deteriorated. She manages to survive through casual work and manual labour, as well as by sending some of the older children to live with their uncle. The family also receive support from an international organisation to ensure the children go to school. Her youngest child was fathered by a man who already has a family, and he rarely gives Margaret any money to support their child.

Caring therefore has a gendered dimension and helps determine who will provide care to a person with a disability. Box 16 provides an example of Annette, who as a woman, has taken on the primary care responsibilities of her sister-in-law, who has a disability.

Box 16: Annette

Annette looks after her sister-in-law, Alice, as well as Alice’s four children, and they all live together in the same compound. Alice is around 54 years old and has intellectual disabilities and possibly epilepsy. When Annette married into the family, Alice was being looked after by her husband, but since he died, Alice and her children have become Annette and her husband’s responsibility. Of Alice’s four children, the first three were born to her husband, but no one is sure who the last child was fathered by. The family can afford to have a housemaid, who also helps care for Alice. They pay her UGX 50,000 per month.

Figure 55 shows that for men with disabilities, their primary assistance comes from their wives. In contrast, women with disabilities receive their primary assistance from their son or daughter. Carers may not be regularly attending school, or even work or training, but, as they are rarely living with a disability themselves, they slip through the net of disability-specific programmes, making them very vulnerable.
5. Disability across the Lifecycle

Figure 55: Relationship of primary personal assistance to adults with functional difficulty by sex

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019

5.5 Old age

Though not inevitable, people often experience a decrease in their functions as they age (for example, vision, hearing, cognition, and mobility). This in turn affects both their need for support and care, as well as their ability to work and earn their own income. The Disability Situational Analysis Household Survey classifies “old age” as 60 years and above. The average life expectancy for men is 63 and for women, 65, and around 3 per cent of the Ugandan population are aged over 60 years (Sengupta and Kidd 2019). However, with increasing life expectancy, shifting living arrangements and greater globalisation, the profile of older adults in Uganda is changing rapidly (Wandera et al 2017). With some exceptions, the Senior Citizens Grant (SCG) is in the process of being rolled out to all individuals over the age of 80 (see Section 7 below).

5.5.1 Relationships and living arrangements

In a recent report – “Facing our Future – Ageing in a Changing Uganda” (Sengupta and Kidd 2019), the authors note how the extended family forms part of an older person’s social safety net, along with their community. These bonds of social capital can be called on to provide financial, physical and emotional support and resilience, and without these, a person becomes vulnerable. These bonds are reciprocal, and begin long before old age, including in family living arrangements. Two-thirds of older persons live with their extended families, but there are many older persons who live only with young or school-age children. It has long been the case that young children are sent to live with their grandparents, to care for or learn from them. However, crises such as the HIV/AIDS epidemic, in which a large number of children were orphaned, as well as an

59 Figures provided by UBOS.
increasing need for parents to migrate in search of work, have obliged a greater number of grandparents to become the primary caregivers of their grandchildren.

While widowed older men may re-marry, or have younger second or subsequent wives, prevailing social norms do not allow older women to do the same, so they are more likely to be alone. There is little available social care to support those living alone (Sengupta and Kidd 2019). As demonstrated in Figure 56, the situational analysis household survey found that older persons with disabilities are slightly more likely than older persons without disabilities to be living alone or in skip-generation households. They are also less likely than persons without disabilities to be living with their children.

**Figure 56 Living arrangements of adults 60+ years, by disability**

The number of older men with disabilities living alone was smaller than women. However, Francis, described in Box 17, is one exception.

**Box 17: Francis**

Francis is an 83-year-old man with a severe physical disability. He has never married because he could not afford to, and as he already struggled to earn a living, he did not want to take on any additional responsibilities. However, he would have liked to have had children, and even accepted responsibility for some of the pregnancies in his village, whether he was the father or not. Despite this, once the children were born, they were given to other men. These actions upset him and he eventually “switched his mind away from women and producing children”. He now lives alone in very poor conditions, surviving primarily on SCG money, and lamenting his lack of planning for his old age. He has limited assets, and does not own any animals, not even a chicken.

As shown in Figure 57, it is clear that gender significantly influences the marital status of older persons, which has implications for the care and support they receive. Women are substantially more likely to be widows than men, with women with disabilities being the most likely to be widowed. Men, including men with disabilities, are more likely to be married, suggesting that they are more able to remarry a younger wife following the death of a spouse. It also points to the higher life expectancy of women than men.
5. Disability across the Lifecycle

**Figure 57: Marital status of adults 60+ years by disability**

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019

Edgar’s story, discussed in Box 18, demonstrates how many older men with disabilities feel dependent on their wives for support in old age.

**Box 18: Edgar**

Edgar, from Manafwa, has been blind since childhood. He echoes the feelings of many men about being and staying married: “If you have no wife who is ready to feed you for free you can become a beggar!”. For some men then, marriage is a “coping strategy” – it is a means of ensuring that they have someone who will look after them and care for them.

The marital status of persons with disabilities when disaggregated by type of difficulty is consistent across all domains. This is due to around half of people (predominantly women) in all domains being widowed. The remainder of all persons with disabilities tend to be in either monogamous or polygamous marriages. Given the often substantial age gaps between men and women when they marry, as their husbands become frailer and are less able to work and provide support, women may end up managing the household and caring for at least one member of their family, as well as their grandchildren. Enid’s story, detailed in Box 19, provides a snapshot of some of the strain younger wives are under when they are required to provide substantial care for their older husbands.
5. Disability across the Lifecycle

### Box 19: Enid

Enid is in her 50s and lives with her husband and family in Kiruhura. They had married when she was 13 and he was 32, although they did not have their first child until she was around 20 years old. At some point before they married, her husband experienced a brain bleed (infarct), which left him with convulsions and severe pain. Despite this, he was able to work for most of his life, and the family reared cattle as is typical in the district. As her husband grew older, however, he was unable to continue working, so they sold six cattle and moved to their current homestead. Here, they rented some land and worked for the landlord. Currently, neither of them work, but they still rent the house. They live with two of their six children; one child is around 18 years and the other is around 16 years old. Their other children live elsewhere and are “servants” on other farms. Her husband is now in his 70s and has a lot of difficulty with hearing, communicating and mobility. He is able to do some activities of daily living himself with assistance from Enid. She communicates with him by sitting next to him and shouting loudly.

Although Enid is her husband’s main carer, and still has two children living at home, she herself is living with HIV, and is on antiretroviral therapy (ARTs), which are supplied by an NGO every two months. She was diagnosed several years ago, following a brief extra-marital affair. She believes her husband is unaware of her diagnosis, and she has decided to leave it like that as he would not really understand. Enid suspects, however, that some of her children know. Although the family is currently managing, Enid explained that if the situation deteriorates, there is nothing much she can do – “she cannot marry [him] and then fail to look after him”. She said it does not make her tired or cross, and she will always take care of him, even if she has to do more for him if his ability for self-care becomes worse. However, when asked about her hopes for the future, she said she “wants God to take away her husband.”

Given that women are accustomed to being the main caregivers, as they grow older, the shift to needing to be looked after by others may make some feel like they are burdens. However, a number of factors may impact their decision to receive care. One example can be seen with Penny, who made the choice to move in with her daughter-in-law. While Penny, a widow who is now in her mid-60s, has a mild physical disability, she was also diagnosed as HIV positive in her early 50s, and now takes regular ARTs. As she cannot look after her garden and provide food for herself as she once could, she has moved in with her daughter-in-law, in anticipation of needing additional support in the future. She knew that her daughter-in-law would provide it, in addition to caring for several children herself.

### 5.5.2 Employment

Older persons who have at least a lot of difficulty in a functional domain are more likely to have never been employed compared to their younger counterparts. This may indicate that education and affirmative action have had some impact on employment rates for persons with disabilities, but this should be interpreted with caution. As Figure 58 indicates, women overall, and particularly those who are unable to perform functional difficulties, are the least likely to have ever worked. More than half of women who have at least a lot of difficulty have also never engaged in employment.

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60 See note above about the social stratification amongst groups in this district.
5. Disability across the Lifecycle

Figure 58: Percentage of adults 60+ years who have never worked, by disability and level of difficulty

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019

High rates of lifelong unemployment were consistent across all difficulty domains. Figure 59 indicates that persons who have difficulties remembering are least likely to never have been employed. However, this may be a reflection of late onset remembering difficulties, with people developing a disability due to age-related health problems.\(^{61}\)

Figure 59: Percentage of adults 60+ years with disability who have never worked, by functional domain

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019

\(^{61}\) Age of onset was not captured in the survey, therefore it is not possible to report this definitively
5. Disability across the Lifecycle

Employment rates are significantly higher for persons without disabilities compared to persons with disabilities. Figure 60 shows that both men and women without disabilities are much more likely to be employed than persons with at least a lot of difficulties of either sex. Notably, however, only 19 per cent of women with at least a lot of difficulties are employed, compared with 48 per cent of men.

**Figure 60: Percentage of adults 60+ years employed, by disability and level of difficulty**

![Percentage of adults 60+ years employed](source)

*Figure 61 demonstrates that older persons with seeing, hearing and walking difficulties have similar rates of employment (between 18 and 19 per cent). Less than 10 per cent of persons with self-care and communication difficulties are employed, whereas 25 per cent of persons who have difficulties remembering are employed. Again, the higher employment rate for persons with difficulties remembering may be an indication of late-onset functional difficulties.*
5. Disability across the Lifecycle

Figure 61: Percentage of adults 60+ years with disability employed, by functional domain

As indicated in Figure 62, older persons with disabilities are more likely than their peers without disabilities to either be not working or retired (either due to age or a health condition). This can increase a person’s vulnerability, as their reduced income makes them more dependent on their relatives. However, their relatives may also be living on low incomes and struggling to both care for their own children and their older relatives. The result can either be that poverty increases across the household, or that the older person with a disability experiences greater social exclusion.

Figure 62 also shows that the majority of older persons with and without disabilities are self-employed or own-account workers. This implies that rather than retiring, older persons will continue working until their ill-health or functional difficulty reaches a stage in which they are forced to stop. This is to be expected as people do not become eligible for the SCG until they reach 80, so they have little option but to carry working or rely on others, thereby becoming more dependent.

Figure 62: Current working status of adults 60+ years with work experience, by disability

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019
6 Disability Architecture

This section sets out to both describe and analyse the framework for the sets of rules and institutions governing all aspects related to disability in Uganda - the “architecture”. The disability architecture in Uganda is anchored onto governance and administrative structures, the legal and policy regime, the actors involved (national and international, state and non-state), global and national policy frameworks, the global and national development agenda as well as its financing. Architecture therefore not only describes the processes for the meaningful inclusion of persons with disabilities in the development agenda, but also what the expected outcomes should be.

6.1 Political Structure

The government has mandated for quotas of representatives of persons with disabilities at all levels of governance. At the legislative level, there are five elected parliamentary representatives for persons with disabilities – one of which must be a woman. This quota system is replicated all the way down to the District (LC5) and sub-county (LC3) level, with each county having two representatives (councillors) for persons with disabilities, one male and one female. These five representatives can be fielded by political parties, or through electoral colleges within the National Union of Disabled Persons of Uganda (NUDIPU), the umbrella organization representing people with disabilities in Uganda or the National Council for Persons with Disabilities.

The MPs are considered to broadly represent the four main regions of Uganda (north, south, east and west), although the female (Fifth) candidate represents all women in the country. It has been argued that while having these quotas in place has raised the profile of disability (or other “group” specific) issues within the political structure, it has also been difficult for these representatives to effect change on a single-issue mandate, particularly around social development projects, necessitating collaborations on the ground, as well as links to other potential funders, such as NGOs (Muriaas and Wang 2012).

There are guidelines for the election of MPs representing persons with disabilities, which include regulations that state a person is not qualified for election as an MP if they are “of unsound mind” – although it is unclear how this is determined. There are also educational requirements (to Advanced Level standard or equivalent), which is likely to exclude a significant number of adults with disabilities. There are some allowances for those with specific impairments (such as assistance with voting). Furthermore, the inclusion of MPs with disabilities has improved with more attention to their access needs (for example, Sign Language interpreters in parliamentary sessions).

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62 Though previously they could only be elected through NUDIPU.
63 There was a plan mooted to do this in 2013, but it was voted out (NCD 2017)
64 https://www.ec.or.ug/?q=info/guidelines-election-mps-representing-persons-disabilities-pwds
6. Disability Architecture

6.2 Administrative structure

In Uganda, the Executive, headed by the President, is responsible for the direct implementation of laws, policies and programmes. The Legislature is responsible for promulgation and passing of laws, as well as budgetary allocation (for which they have an ex-officio monitoring and oversight role). The Judiciary is responsible for the legal system, including monitoring of human rights.

Political and legal decisions are delivered through a national administrative structure. Currently, there are officially 134 Districts and 7 cities, although the number of districts has increased significantly over the past decade to accommodate changing political and administrative boundaries. District local governments (DLGs), or local government councils (LC5) are chaired by directly elected representatives who have both legislative and executive powers. They are directly accountable to their electorate. At LC5 level there are also Administrative Units Councils (headed by the Chief Administrative Officer [CAO]) who advise on planning and implementation of services, so LCs have both political and technical functions. This structure is replicated to LC2 level. LC1s have an elected village Chair, who also heads an executive committee. The Constitution (1995) and Local Government Act (1997) codified these structures and the level of political authority and financial autonomy for each level of local government. While districts have a major role in public service provision, ultimately all decisions (including budget allocation) are made by central government (particularly regarding healthcare and education). Importantly, the District councils are responsible for some of these services, including health centres and dispensaries (the first line of health access for many communities) as well as overall community development. Urban councils have more financial and planning autonomy, as well as being responsible for service delivery in urban areas, including Kampala.65

Figure 63: Administrative units in Uganda (as of 1st July 2020)

<table>
<thead>
<tr>
<th>National level</th>
<th>Executive, Legislative and Judiciary - divided into sectors, ministries, department, agencies and institutions</th>
</tr>
</thead>
<tbody>
<tr>
<td>LC V</td>
<td>City and District (8 cities &amp; 135 districts)</td>
</tr>
<tr>
<td>LC IV</td>
<td>Municipality (34 Municipalities)</td>
</tr>
<tr>
<td>LC III</td>
<td>Sub County/ Town council/ City Division/ Municipal Division (1,567)</td>
</tr>
<tr>
<td>LC II</td>
<td>Parish/ Town-board / Ward (7,793)</td>
</tr>
<tr>
<td>LC I</td>
<td>Village/ cell (nearly 58,000)</td>
</tr>
</tbody>
</table>

6. Disability Architecture

At LC5 level, there are two elected councillors for persons with disabilities on the council (one male and one female – both of whom should have a lived experience of disability). Disability issues therefore should cut across all the functions: however, in reality, disability is often placed within the community development committee, reflecting the national level. Councillors and others therefore work closely with community development officers (CDOs).

At district level, elected Councillors for Persons with Disabilities can have other functions, for example, one of the Councillors for People with Disabilities interviewed in Tororo District was also the Speaker of the District Assembly. He explained that his responsibilities as a councillor were to “ensure that policies are inclusive, and that the money meant for people with disabilities [are] actually reaching them.” At the LC5 level they are also members of the District Special Grant Selection Committee by their position.

The female District Councillor for Persons with Disabilities in Kyegegwa noted that her role included mobilising “...people with different disabilities to from groups and women to join UWEP programmes.” However, she acknowledged that with regard to her role on the Selection Committee, she “needs training in enterprise selection and management.” She also explained that she advocates for women and persons with disabilities at the sub-county councils and women council meetings, as well as working with local organisations to provide free assistive devices for persons with disabilities in the district. She also sometimes goes on local radio to provide information about disability issues (including on the distribution of the assistive devices).

In Nakasongola, the male Councillor representing persons with disabilities in the District Council noted that his role was to “...ensure that persons with disabilities are included in all government, and particularly social protection programmes.” He elaborated that the councillors representing persons with disabilities should be facilitated with transport means, presumably highlighting a gap in their capacity to act as advocates if they are unable to travel around the districts. In many districts, including Nakasongola, distances between homesteads are quite substantial, making community activities challenging without wherewithal, especially for persons with mobility or other difficulties.

Although there is not a specific disability representative at LC1 level, some of the LC1 Chairs interviewed were aware of the need to include what one Chair called the “special interest groups”. She has been the LC1 Chair in her village in Kyankwanzi District for the past twenty years, and said her main function is to “convene community meetings (baraza).”66 Issues in her community include access to water, land and grazing rights. There are about 20 persons with disabilities in her village (about a quarter of whom are children, looked after either by their parents or relatives). She explained that the community does not segregate persons with disabilities, but they do receive very limited support from the government, and all she can do is “advocate for their rights”. She also works with the Councillors for Persons with Disabilities about any issues in her community (although there is only one in her District, as the other had unfortunately passed away and not yet been replaced). In addition to offering advice and support, she can also refer persons with disabilities to the office of the CDO. Overall, she thinks the villagers’ attitudes towards persons with disabilities are “not too bad”. When asked about specific policies around disability, she explained that she knows that “they have to be protected”. With regard to responsibility, [children with disabilities] should be given an education, and it was the

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66 A Kiswahili word meaning “community dialogue”, these are actually a Presidential directive to improve community engagement (https://www.iser-uganda.org/images/Baraza_Policy_Brief.pdf)
Disability Architecture

responsibility of the parents to do this. When probed specifically about support from the government, she spoke about the need for assistive devices, such as wheelchairs "for movement". She also thought that the government should provide "special schools" for children with disabilities, and she had not heard about any inclusive education policy.

As illustrated by the example above, persons with disabilities may often find that at the local level (districts and below), many of the councillor seats are vacant. Furthermore, some of those in office may not fully understand their mandate or lack the specific support required to enable them to participate in council meetings (for example, transport, guides, etc). A recent review found that these situations were particularly acute in newly formed districts and municipalities (NUDIPU/NAD 2019). There were some examples of good practices by Councillors in enabling the rights of persons with disabilities, particularly in Sheema and Bushenyi Districts (both of which previously had community-based rehabilitation programmes (ibid). However, it is clear that such practices are not uniform across all districts. The review makes a comprehensive range of recommendations, including policy reform, participatory budgeting and monitoring, and training councillors on issues such as democratisation.

However, it could be argued that these recommendations focus on political inclusion, rather than social inclusion, and may still not benefit the majority of persons with disabilities in Uganda.

6.2.1 Planning and Budgeting Process

The Comprehensive National Development Planning Framework (CNDPF, 2009) provides a holistic approach to long-term planning in Uganda and is based on Uganda Vision 2040. It describes the process by which plans are produced by sector, decentralised local planning systems, how they would be integrated into National Development Plans (NDP), and the roles and responsibilities at each level of national development planning process (NPA 2017). These stages are the ten-year Medium-Term National Development Plan, the five-year National and Sector Development plans (which operationalise the ten-year National Development Plan and Vision 2040). A similar five-year planning cycle is undertaken at Local Government level, along with annual plans and budgets. These processes of planning shall be "...participatory, comprehensive and inclusive in terms of representation and content." (NPA 2017: 11). These plans are aligned to budgets. The GoU is currently operating under the National Development Plan III (NDP III), which has among its goals: "Increased household incomes and improved quality of life", and "Increased productivity and wellbeing of the population." Furthermore, one of its key development strategies will be to "improve access and quality of social services."67 However, according to a recent report, “The Equal Opportunities Commission reported that 80 per cent of government agencies did not spend any funds on addressing concerns of persons with disabilities while 90 per cent did not commit to any interventions targeting persons with disabilities in the next five years.” (US State Department 2018).

Once the National Planning Authority (NPA) has initiated the next phase of the planning cycle (the 10-year or five-year National Development plans), MDAs are invited to submit development plans and budgets in line with the priority areas identified. The Ministry of Finance, Planning and Economic Development then coordinates the preparation and presentation of the national

67 GoU (2020).
budget. This includes the District level budgets for each sector. District Local Government (DLGs) are given guidance on how to prepare, and spend, budgets.

The social development sector only accounts for 0.6 per cent of the national budget (as of the financial year [FY] 2019/20), and this is a decrease from 0.9 per cent from the previous FY 2018/19 (GoU 2019a). Yet, within the wider social development sector, persons with disabilities remain an “area of special concern”. In the FY 2018/19, a total budget of UGX 7.64 Billion was allocated to DLGs in the medium-term expenditure framework (MTEF) for the implementation of social development activities relating to persons with disabilities. However, it was reported that in many cases, the money remained unspent, and was returned by LGs to central government, thereby reducing the likelihood of a similar sized transfer the next FY.68 The largest funding envelope is for the Special Grant (28 per cent of the total envelope in the previous FY), with 5 per cent allocated to the CBR programme. However, this programme is non-existent in most districts, so it is clear why there may be some confusion about what and how to spend the budget.

In previous FYs, DLGs were given a “basket” of funds out of which they could choose where to allocate funds, for example, for disability-specific programmes or activities. This led to confusion about eligibility criteria and resulted in underspending of the budgets. This was to the detriment of persons with disabilities, as unspent funds had to be returned and resulted in a reduction in budget lines the following year.69 DCDOs are not always fully aware of the total amount they will receive in their budgets in the first place (which is to do with the difference between what is allocated and what is actually received), making budgeting and planning more difficult. The end result of either of these processes is that persons with disabilities potentially miss out on what meagre funding there currently is for disability issues.

Once District Local Government budgets have been agreed and approved by the MOFPED, they are transferred from central government ministries to the DLGs with guidance on the details of eligible and non-eligible activities for specific programmes. Not all programmes are monitored in the same way, and specific donors and funders will have additional reporting requirements. Government programmes are discussed in more detail below, but the Guidance on the National Special Grant for Persons with Disabilities has just been revised (November 2019) to be more in line with the existing structures of the YLP and Uganda Women’s Entrepreneurship Programme (UWEP).

Despite providing details on permitted activities to the DLGs, the MGLSD has limited capacity to monitor how the funds are actually used at the district level. Local grants to DLGs are dispersed on a quarterly basis, and DLGs send quarterly reports on spend across all their programmes. These reports are currently received as hardcopies in the MGLSD, although there are plans to integrate these reports into the general electronic financial monitoring system. In order to facilitate communication, it holds annual consultations with each DLG, and there are also quarterly sector working group meetings with chairpersons of the district CAOs, DCDOs, Town Clerks and District Planners.

What is clear is that as plans devolve to local level, indicators of disability inclusion become less prominent, despite the intention of bottom-up as well as top-down planning processes. The gap is also reflected in current coordination mechanisms, which though weak at national level, seem

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68 Interview with Senior Policy Analyst, MGLSD.
69 Interview with Senior Policy Analyst, MGLSD.
to be slightly more effective than at District or Sub-County (although this does depend on location).

6.3 Accountability

As per the National Development Plan II (NDP II), the accountability sector is composed of two sub-sectors: audit, and economic and financial management services. The large range of sector institutions include the Ministry of Finance Planning and Economic Development (MOFPE) as well as the Uganda Revenue Authority; the Uganda Bureau of Statistics; the Ministry of Local Government (Inspectorate); and the Bank of Uganda and the Uganda Retirements Benefits Regulatory Authority (URBRA). The Governance structure of the accountability sector provides for three committees, namely the Leadership Committee, the Steering Committee and the Sector Working Group. As stated on the website, the core values of the accountability sector are integrity; transparency and accountability; value for money; professionalism; commitment and teamwork; and gender equality and equity.

To support the effective delivery of these values, a Budget Monitoring Accountability Unit (BMAU) was established within the MOFPE. The overall aim of this unit is to monitor priority projects and programmes, which consist of “physically inspecting and verifying the information in performance contracts and quarterly performance reports.” As part of this, it has developed a role in monitoring gender equity and inclusion indicators, as well as producing several disability-related policy briefing papers. BMAU reports are distributed to “MPs, government officials, development partners and civil society organisations....[the] Unit also has a direct reporting line to the ministry’s senior management so that priority concerns can be flagged.”

Despite this, it could be argued that while this process has increased the focus on gender equity, this has not necessarily increased its impact on the ground. Moreover, as discussed in Section 6.5.11 below, the onus has tended to be on gender equity, rather than broader and/or intersectional issues such as disability and ageing, as per the compliance monitoring process and budgetary allocations. Changes to the way the budget envelop is allocated may shift this balance.

6.4 Monitoring and Coordination

According to the National Disability Inclusive Planning Guidelines, disability inclusion is supposed to be monitored bi-annually by Sector Working Groups (SWGs), who will also undertake annual reviews in collaboration with development partners and other stakeholders. These annual reviews “will focus on assessing performance on disability inclusion during the previous fiscal year and determining actions and spending plans for the year ahead” (NPA 2017). The guidelines also provide clear directions for planning, budgeting and monitoring of multi-sectoral disability interventions in Uganda, including a glossary of terms, a list of potential interventions and suggested indicators. However, although they were developed in 2017, they were only formally launched in January 2019. This means that as of yet, there is little evidence of them having been

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70 Note, however, that as of 2020, the National Development Plan III is in effect.
71 For full list see: https://www.finance.go.ug/mofped/accountability-sector
72 Ibid.
6. Disability Architecture

utilised or of the SWGs undertaking any annual review, or indeed of how operational many of the SWGs are. There is no specific disability sector working group, rather it is supposed to be mainstreamed across all the SWGs. In reality, it is predominantly discussed in the Social Development SWG (under social protection for vulnerable groups).  

According to the research, the NPA, along with UBOS, have formed a Sector Working Group around the implementation of Sustainable Development Goal (SDG) 1 (“To end poverty in all its forms everywhere”). The NCD is a member of the group and will support the planning for improved livelihoods of persons with disabilities in Uganda (NCD 2019). However, there is very minimal mention of disability in the current GoU SDG Roadmap, aside from as a planned action: “2.3 Develop cross cutting issues planning guidelines where non-existent e.g. disability” (GoU 2018a) – which were in circulation in 2017, though formally launched in 2019.

6.5 Mainstreaming disability in MDAs

According to the National Disability Inclusive Planning Guidelines for Uganda (2017), all government ministries, departments and agencies (MDAs) are responsible for including disability in all their activities, using a “twin-track” approach, which requires both mainstreaming and specifically targeting disability issues. The Guidelines themselves “...are designed to support planning teams in sectors and local governments to identify, analyse, include, monitor, and evaluate disability issues as an integral part of their plans and budgets.” (GoU 2017). The guidelines acknowledge there are challenges with the mainstreaming of disability by MDAs and Local Governments, including the quality of the programmes delivered, further hampered by a lack of effective multi-sectoral coordination and ineffective interventions (GoU 2017). However, whilst these guidelines highlight some fundamental challenges around mainstreaming, as they were not formally launched until 2019, the proposed transformative actions for persons with disabilities have been delayed.

A brief overview of each of the ministry’s current responsibilities for disability inclusion follows, with a particular focus on the MGLSD, which currently has the overall mandate for disability inclusion.

6.5.1 The Ministry of Gender, Labour and Social Development

The social development sector is led by the MGLSD, whose mandate is “to empower citizens to maximise their individual and collective potential by developing skills, increasing labour productivity, and cultural enrichment to achieve sustainable and gender-sensitive development.” It therefore aims to promote employment and productivity, positive cultural values, rights of vulnerable groups and gender responsive development. The MGLSD comprises 10 departments, all of which should mainstream disability across their core work, including the Department of Youth and Children’s Affairs, Gender and Women’s Affairs and Equity and Rights. However, while some departments have managed to do this more successfully than others, disability mainstreaming remains weak across the ministry in general (GoU 2017).

77 DFID (2000).
78 For full list see here: https://mglsd.go.ug/about-us/
6. Disability Architecture

Within the MGLSD, disability is largely included under the Social Protection Directorate which addresses the development concerns of all “vulnerable and marginalised groups.” The MGLSD has the Constitutional mandate for disability issues in Uganda, administered through the Department of Disability and Elderly Affairs, which is headed by a Commissioner, under the political supervision of a State Minister (currently a vacant position). The MGLSD oversees the District Community Development Officers (DCDOs), part of the Community Development Departments of Local Government, and whose role it is to implement social development in the districts. In each district, there is usually a focal point for disability and elderly affairs (usually, but not exclusively, a Senior CDO). The semi-autonomous bodies of the National Council for Persons with Disabilities (NCD) and the Equal Opportunities Commission (see above – this also sits under Justice, Law and Order), also sit within the MGLSD.

Key policies include:

- The Uganda National Employment Policy (2011) – This specifically acknowledges the rights of persons with disabilities to be included in the labour market, which is a key strength. However, it is weak on the implementation plan, budget and Management Information System (MIS) (Omona et al 2017).
- The National Policy for Older Persons (2009) – In this, older adults with and without impairments are a key target group.
- The Uganda Gender Policy (2007) – This highlights the intersectional nature of gender and disability. It predates work on “transformative action”.
- The National Orphans and Other Vulnerable Children Policy (2004) – In this policy, children “affected by disability” are a key target.
- The Uganda National Youth Policy (2016) – The policy specifically includes youth with disabilities as a target group and uses a rights-based approach.
- The National Equal Opportunities Policy (2006) and related Equity Promotion Strategy (2012) – This specifically includes persons with disabilities as a target group, although the strategy focuses on a medical model of disability.
- The National Child Labour Policy (2007) - Children who are “vulnerable to child labour due to disabilities” are a key target group for this policy.
- The National Social Protection Policy (2015) – Adults and children with disabilities are a key target group for this policy.
- The National Adult Literacy Policy (2014) – Persons with disabilities have historically been excluded from policies, despite being a specific target in the National Adult Literacy Policy. There are debates as to whether this programme should be in MGLSD or MOES (Bananuka and Katahoire 2019).
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6.5.1.1 Department of Disability and Elderly Affairs

The Department of Disability and Elderly Affairs (MGLSD) has the overall mandate for disability policy and social care. It is staffed mainly by technical staff, some of whom have a background and training in gerontology and some of whom have a background and training in disability (predominantly as community-based rehabilitation officers). In addition to the Commissioner and an Assistant Commissioner, there is a Principal Gerontologist, a Principal Rehabilitation Officer, two senior gerontologists, two senior rehabilitation officers (SROs), a Rehabilitation Officer and a gerontologist. In addition to the eight ministry-based staff, there are five rehabilitation officers who manage the five vocational rehabilitation centres for persons with disabilities. The main functions of the Department are to:

- Formulate and review policies, laws, guidelines and standards that address the concerns of persons with disabilities (PWDs) and older persons.
- Raise awareness among the policy makers, service providers and communities on the rights and needs of PWDs and Older Persons.
- Build capacity of PWDs and Older Persons to effectively participate in the development process.
- Ensure that inequity and exclusion of PWDs and older persons in accessing services across all sectors at all levels is addressed.
- Network with other stakeholders on issues of persons with disabilities and older persons.
- Provide support supervision to Local Governments, monitoring and evaluation of programs on Disability and older persons.

As can be seen from this list (taken from the MGLSD website), technical and administrative functions are blurred, and administrative functions such as submitting workplans and staff appraisals are highlighted as a specific role, rather than as a matter of normal administrative procedure. There is also no specific mention of coordination of MGLSD work on disability mainstreaming (though this is covered to some extent in the NPAD). As the details of the older persons programme have been outlined in a previous report (Sengupta and Kidd 2019), here we focus mainly on the programmes that relate to persons with disabilities, acknowledging there is some cross over between the programmes and recipients themselves.

The Department has a number of programmes/activities that support persons with disabilities, and works closely with the District Community Development Officers (DCDOs) to implement these:

- **The Special Grant for Persons with Disabilities** - Which offers financial support (grants) to groups of persons with disabilities and caregivers to undertake income generating activities. It is funded from the LDGs from a central budget from the MGLSD. This is discussed in more detail in Section 7.5.2 below.
- **Five Rehabilitation Centres** – These are located in Arua (North), Lweeza and Kireka (Central), Jinja (East) and Ruti (Western). All of the rehabilitation centres are centrally

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79 Personal Communication
80 [https://mglsd.go.ug/rehabilitation-centers/](https://mglsd.go.ug/rehabilitation-centers/)
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funded and function as vocational training institutions. This is discussed in more detail in Section 7.5.3 below.

- **The Community Based Rehabilitation (CBR) Programme** – Although it no longer exists in this form, and the CBR “budget” has been merged with overall funding, districts are free to choose to allocate funds to a “CBR” programmes if they wish. This tends to only be the case in “model” districts, where the programme was piloted. The CBR programme was an innovative programme based on the WHO model which offered a range of services from awareness raising, health and nutrition assessments, counselling, assistive devices and livelihoods programmes. Funding to each district is now so limited as to render the programme practically non-existent.

6.5.1.2 National Council on Disability

The National Council for Persons with Disabilities (NCD) is a public institution established by an Act of Parliament in 2003. It is a national body, with a structure replicated to sub-country level. Its work is undertaken within the existing legal frameworks in the country, along with national social development plans. The NCD is a semi-autonomous body within the structure of the MGLSD. The NCD Act (2003) gives the NCD a wide-ranging mandate, to:

- Monitor and evaluate the extent to which Government, NGOs and the private sector include and meet the needs of persons with disabilities in their work.
- Act as a national body through which the concerns of persons with disabilities can be communicated to Government and non-government actors for action.
- Advocate for the promotion of activities undertaken by institutions, organisations and individuals for the promotion and development of programmes and projects designed to improve the lives of persons with disabilities.
- Carry out or commission surveys and investigations in matters or incidents relating to violation of persons with disabilities’ rights and take appropriate action.
- Consider and recommend ways and means of controlling the unnecessary increase of disability in Uganda.
- Assist the Electoral Commission in conducting free and fair elections for parliamentary and Local Government Council representatives of persons with disabilities.
- Identify and give guidelines on disability interventions and mainstreaming to organisations working for persons with disabilities.
- Hold representatives’ Annual General Meetings for review and planning purposes.
- Mobilise resources for use in the performance of the Council’s work.

Given the scope of the mandate, it is unclear whether the NCD has the capacity or budget to deliver on all of these areas. However, it has begun to deliver on some of them, such as undertaking research and evaluations, although these have been mainly within the government

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81 https://mglsd.go.ug/community-rehabilitation-programme-for-the-disabled/
82 https://www.ncd.go.ug/about-us/our-functions
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sector. It is also unclear how much power the NCD really has, or what “teeth” it has, for example with regard to violations, or finding “ways and means of controlling the unnecessary increase of disability in Uganda”, which would require significantly more resources and investment than is currently provided, particularly at District level.

The NCD structure extends from national down to sub-county level. At the national level, the Council has 22 members, and is the policymaking and governance arm of the NCD. The technical arm of the NCD, the Secretariat, is headed by an Executive Secretary, who is appointed by the Minister (MGLSD) upon recommendation from the Council. The Secretariat undertakes the overall planning and delivery of the mandate. The Council consists of:

- Eight regional representatives (persons with disabilities – four male and four female)
- One parent of a child with disability
- One professional and experienced person in disability (usually an NGO or CSO representative)
- One representative of youth with disability
- One representative of the Federation of Uganda Employers
- One representative of NGOs working with persons with disabilities
- One Member of Parliament representing persons with disabilities
- Representatives from Ministries of:
  - Local Government
  - Public Service
  - Justice and Constitutional Affairs
  - Works, Housing and Communications
  - Education and Sports
  - Health
  - Gender, Labour and Social Development
  - Finance, Planning and Economic Development

The eight line ministries are represented in an ex-officio capacity, usually through the appointed disability focal point (in general, a midlevel or senior ranking civil servant), while the remaining 14 representatives are approved and appointed by the Minister of State for Disability and Elderly Affairs. There is a four-year term of office, which can be renewed once. As with the NCD itself, it is not clear how much real decision-making power the Council has.

83 All of whom are approved and appointed by the Minister of State for Disability and Elderly Affairs (currently a vacant position).
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The same governance structure is replicated at the district, city, municipality, division, town and sub-county levels, where the respective local government chairpersons appoint members to serve a three-year term. The National Council sits quarterly, but at district level and below, councils do not necessarily sit regularly, due to lack of funds. The National Disability Steering Committee, comprising ministries, departments, agencies and other institutions, is supposed to meet and discuss disability-related concerns and matters as they arise but is not currently active (NCD 2019).

One of the main functions of the NCD is the oversight of the dispersal of the Special Grant (National and District levels), as well as monitoring disability inclusion in other grants such as the YLP and UWEP and other district level activities. The overall budget of the NCD in FY 2017/18 was UGX 1.236 billion (US$335,000), although the actual release was UGX 958 million (US$260,000). While this was a significant increase on the previous two years (NCD 2019), it was still not seen as enough to undertake all the requisite activities, and by the Executive Secretary’s own admission, such a small budget makes them limited in their capacity to function effectively (NCD 2019). Budgets for monitoring disability-related programmes, including the Special Grant, are included in the overall budget, and must be taken off at District level, leading to confusion on the behalf of recipients as to the total amount they were expecting, and so many of the District level meetings do not take place. Moreover, at District level, the role of the NCD representatives and the Councillors can become blurred and are often the same person with different functions, again leading to confusion. This may also be a result of the limited budget and capacity.

For example, the Chair of the Nakasongola District Disability Council (DDC) reported that their Council has not met for three years as there is very little budget to hold meetings. The DDC has no office or administrative staff. It is made up of the Chair (who has been in post for seven years; two district councillors (one male and one female), one DPO representative (NUDIPU), the ACAO and CAO. The total budget allocated to the DDC is UGX 500,000 per quarter for all activities (selection meetings, monitoring visits etc). In order to do this, they divide up responsibilities for the sub-counties between them and try to monitor the groups monthly and share their findings. In reality, they are unable to do this much monitoring. According to the Chair, NUDIPU used to provide the budget via the Norwegian Association of the Disabled, a donor organisation that funded many disability issues in Uganda in the 1990s and early 2000s.

The Chair of the DDC reported that their function is to work with the DCDO to monitor Special Grant groups and mobilise people to form groups. They are also responsible for monitoring the YLP, as well as the Functional Adult Literacy (FAL) programme and the National Agriculture Advisory Service (NAADS) – although they only actually monitor groups and activities when there are funds. There are 13 Special Grant groups in his District (one in each sub-county), and around 1900 persons with disabilities in the district, according to him.

The Chair further noted that from district level (LC5) and below, there is often some blurring of political and administrative roles, with some actors representing both the government (councillors) as well as the National Council for Persons with Disabilities (NCD) and even in some cases, the umbrella DPO (NUDIPU). It could be argued that this weakens the position of both

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84 Ibid, though in reality some serve longer.
85 Interview with Senior Policy Officer, MGLSD.
86 The DLG can also convene an “exceptional meeting” if specific circumstances warrant it – this “special council” includes the Chair, the disability councillors, the DEO, DCDO, DIS, DHO, Snr finance officer, NGO rep and one parent/carer.
87 https://www.naads.or.ug/
entities, as the councillors (and NCD) represent the state, while the other (NUDIPU) represents civil society, so there is a need to maintain separate voices to ensure accountability.

### 6.5.1.3 Coordination

While the MGLSD has the mandate for disability and social inclusion, the NCD is mandated by the Disability Act (2006) to undertake the overarching coordination. However, it struggles to provide this service for a number of reasons, in particular due to a lack of technical capacity in some areas, and limited funding and resources from national to district levels (NCD 2019). The NCD works closely with other human rights bodies, including the EOC and UHRC, as well as the umbrella DPO NUDIPU, but its main reporting line is to the MGLSD. So, although it is supposed to work in tandem with all MDAs, in reality, disability issues are seen as the focus of a small department within the MGLSD and inter-sectoral coordination between the MDAs towards disability issues is therefore fragmented, which can lead to duplication and/or a lack of clarity on responsibilities, which in turn may affect service provision. This lack of coordination is not only apparent at national level, but right down to the districts, where capacity of the District Councils for Disability (DCDs) still needs strengthening (NCD 2019). Disability-specific coordination meetings are supposed to take place regularly, led by the MGLSD, but in practice they are ad hoc and tend to be called when there is a specific programme to address. This has led to calls for a dedicated disability coordinator to work across line ministries. However, if this position were to be created within the MGLSD, it would need to have some powers. Creating an oversight and monitoring body for disability at a higher level, as has happened for gender issues, would increase the likelihood of delivering on commitments. Suggestions already include placing such a position within the Prime Minister’s Office or the Office of the President.

### 6.5.2 Ministry of Health

The health sector aims to “provide the highest possible level of health services to all people in Uganda through delivery of promotive, preventive, curative, palliative and rehabilitative health services at all levels”.\(^ {88}\) The Ministry of Health (MOH) is responsible for the entire health system, and with regard to disability, is responsible for disability prevention, promotion of health and wellbeing, management of disabilities as well as staffing. However, there is no specific policy on inclusive health, and most of these services are provided through the Disability Prevention and Rehabilitation section. Some of these services can be considered disability-related, such as the provision of hospital, community and home-based rehabilitation and therapeutic services, provision of assistive devices such as prosthetics and orthotics, while others focus on the prevention of impairments (such as immunisations and treatment for disabling conditions), as well information on disability prevention and management and general medical services to all – including persons with disabilities. However, it is unclear whether persons with disabilities do enjoy the same level of access to all healthcare as their peers without disabilities, though evidence would suggest not (see, for example Mulumba, et al. 2014). There is no specific policy on inclusion of persons with disabilities in the health sector. Moreover, there is limited disability-disaggregated information collected by the MOH to measure inclusion, and what little is included is largely driven by donor priorities and is not shared between ministries (or other agencies) to improve coordination of service delivery (McPherson et al. 2017). It is unclear what the specific budget allocation is for disability within the overall budget.

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Key policies:

- **National Health Policy (2010)** – This only mentions persons with disabilities in passing: the first about physical access to health centres, the second around lack of material for assistive devices. None of the guidelines about district health provision have anything about disability inclusion.

- **National Integrated Early Childhood Development (NIECD) Policy (2015)** – This does include specific targets for disability, and cuts across several key MDAs. Ownership lies with the MGLSD.

- **Uganda National Minimum Healthcare Package (UNMHCP)** – This is not a policy but a framework for the delivery of universal health coverage (UHC), introduced in 1999. It has been challenged on its lack of disability inclusion.

- **Uganda One Health Strategic Plan (2018 - 2022)** – Again, this is a framework for delivery, and is not a policy. There is no specific mention of disability.

Uganda has committed to SDG 3 (“Good health and wellbeing”), as well as Article 25 of the UNCRPD – “the right to the highest attainable standard of health without discrimination on the basis of disability”. However, according to Omona et al (2017), the health sector is one of the weakest in terms of inclusive policies, with an underlying assumption that adults and children will be included along with “all Ugandans”. While there is ambition to attain universal health coverage (UHC) for all citizens (though the Uganda National Minimum Healthcare Package [UNMHCP]) (Kadowa 2017), there are no policies relating to adults and children with disabilities specifically, which risks their (albeit unintended) exclusion, although disability is occasionally mentioned in key policies and strategies. There is an MOH focal point based in the Disability and Rehabilitation Division. Finally, given the suggested indicators in the guidelines, it can be inferred that there are significant gaps in measuring disability inclusion across the health sector.

The Health Information Management System (HIMS) currently collects very limited data about disability, despite government commitments towards data disaggregation. It is perhaps unsurprising then that the Budget Monitoring Accountability Unit outlines a number of challenges to accessing healthcare services for adults and children with disabilities. These include challenges in service provider attitudes, lack of equipment, and lack of prioritisation of certain specific medications for some disabling conditions, including albinism, epilepsy, and mental illness (BMAU 2019a). They also make the important point that equity needs in the health sector are only partially met, as the number of variables such as location, age, and disabilities, “…allows the ministries, departments and agencies (MDAs) an opportunity to focus on other components of equity and score a Pass mark, while neglecting the disability component.” (BMAU 2019a). In order to overcome some of these barriers, it makes three specific policy

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93 Linked to this, in the northern region, there is a neurological condition known as ‘Nodding Syndrome’ - recent research has linked this to a form of epilepsy and onchocerciasis though research into its precise aetiology is ongoing (https://www.who.int/onchocerciasis/symptoms/nodding Syndrome/en/).
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recommendations: i) that the MoH should adopt holistic planning in the next Health Sector Development Plan and NDPIII to ensure universal access to health services; ii) the MoH and National Medical Stores should expand tracer medicines to include those that address special conditions for persons with disabilities; iii) the MoH should provide training to health workers in basic sign language interpretation and other key skills to ease access to services for persons with disabilities. In addition, staff ethical conduct should be strictly enforced (BMAU 2019a). Notwithstanding the difficulties of ensuring all healthcare workers are trained in basic sign language, the need to “twin-track” disability as both a mainstream issue and a targeted one is really highlighted here.94

6.5.3 Ministry of Education and Sports

The Ministry of Education and Sports (MOES) supports the delivery, coordination and regulation of quality education and sports to all persons in Uganda with the overall aim of national development. Within the MOES, there is a Department of Special Needs and Inclusive Education,95 with a disability focal point based within the department. Special education is also a sub-sector working group.96 The sector comprises a range of MDAs who, in line with existing legislation (including the Education Act, 2008),97 are committed to ensuring that all children of school-going age and all individuals who are interested in acquiring an education have equal opportunity, regardless of their social class, ethnicity, background or disabilities. This includes the provision of special and inclusive education up to tertiary level and beyond.98 However, while the GoU advocates inclusive education from ECD through to tertiary level (see, for example, Lynch et al 2011), the draft Special Needs and Inclusive Education Policy to determine this is still under review (and has been since 2011). While this policy will apparently clarify issues such as student-teacher ratios, it is yet to be agreed or even harmonised.

Implementing a fully inclusive education system requires systemic changes to curriculum, pedagogy and funding models, so wide-ranging reforms are needed to enable the flexibility that an inclusive education (IE) approach requires (Sarton et al 2017). Therefore, despite its stated commitment of ensuring education for all, and IE specifically, as well as a relatively progressive policy environment, there is still some confusion about what IE is and how it should be implemented in Uganda. Moreover, there are currently 113 Special Needs Education (SNE) schools across the country, though not in all districts of Uganda. While some are funded by the MOES budget, as they were mandated by the Uganda National Institute of Special Education Act (1995), most are in fact run by NGOs and faith-based organisations (FBOs), calling into question issues of quality and consistency. In the education budget there is little thought of the specific needs of children with disabilities beyond allocating a specific amount to Special Education Needs (SEN), despite the policy focus on IE. Special education constitutes a very small percentage of the overall special education budget, which this FY totals UGX 2.63 Billion (including a budget for career guidance for Special Education Needs (SEN) teachers).99 It is a reduction on previous

94 The concept of “twin track” came from DFID (2002) as a way to think about delivering both targeted and mainstream inclusive programmes – so persons with disabilities are included in these mainstream programmes, but there is acknowledgement they may need some additional resources/support to be on the same level as everyone else and ensure equity.
95 http://www.education.go.ug/special-needs-inclusive-education/
97 Which focuses on pre-primary, primary and post primary education
99 https://budget.go.ug/dashboard/
years, which may demonstrate a commitment towards shifting from special education to inclusive education. Although Uganda is one of the few governments to commit enough resources to ensure disability-inclusive education, as noted in the “Costing Equity” Report, the budget does not clearly indicate whether these finances are for special or inclusive education (International Disability and Development Consortium /Light for the World 2016).

Key Policies:100

- National Integrated Early Childhood Development (NIECD) Policy – This includes specific targets for disability and cuts across several sectors (led by MGLSD).
- Education and Sports Sector Strategic Plan 2017/18 – 2019/20 – This discusses equity and inclusion in line with SDG commitments.
- Basic Education Policy for Educationally Disadvantaged Children (2006) – This Policy is in the process of being revised and renamed as the Non-Formal Education Policy. Drafting began in 2011 and it is still to be finalised.

Almost all of the education focused policies currently in use consider children and youth with disabilities to be “vulnerable”, and as such, focus on targeting them as a specific group, rather than on making the wider system more inclusive for all children. The current Education Management Information System (EMIS) does collect data on children with “special needs”, and further disaggregates by type, but this can only measure the number of children in school, and it is therefore difficult to assess the learning needs of those not currently in school.101

6.5.4 Ministry of Local Government

The role of the Ministry of Local Government (MoLG) is primarily to coordinate the implementation of the GoU decentralisation policy, with the aim of having “...democratic and accountable local governments capable of delivering efficient and sustainable services to the people, thereby bringing about socio-economic transformation in the country.”102 The Local Economic Development Policy (2014),103 highlights that it will “…mainstream cross cutting issues in LED [local economic development] e.g. Gender, HIV/AIDS, Environment and Vulnerable segments of the population. Interventions include: Ensuring concerns of special interest groups like women, youth and people with disabilities are addressed at the initiation, design and implementation of the local community projects.” (Uganda National LED Policy 2014: 16)

In addition to its oversight role, the MoLG also implements some programmes, such as the "Markets and Agricultural Trade Improvement Programme" (MATIP), which is in line with its mission to bring about socio-economic transformation. Although the MATIP feasibility study highlighted that the “majority of the people that derive their livelihoods from the markets are the women, the elderly and People with disabilities”, it is unclear from the programme design how persons with disabilities are being specifically included in the programme.104

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102 https://www.molg.go.ug/content/about-us
According to the *National Disability Inclusive Planning Guidelines for Uganda* (2017), the MoLG will “...oversee Local Governments’ compliance with statutory requirements and adherence to national policies and standards, including these disability-inclusive planning guidelines...[and] include disability-inclusion criteria and indicators in its support to Local Governments” (GoU 2017a).

### 6.5.5 Ministry of Agriculture, Animal Industry and Fisheries

This large sector is led by the Ministry of Agriculture, Animal Industry and Fisheries (MAAIF), and includes food security and nutrition. One of its affiliated agencies, the National Agriculture Advisory Services (NAADS), is mandated to “manage the distribution of agricultural inputs to farmers for sustainable household food security and incomes.” NAADS has previously developed guidelines on the inclusion of youth with disabilities. It also works through the Operation Wealth Creation (OWC) to ensure the principles of equity and inclusion are applied to beneficiary targeting, and “additional focus is given to special interest groups such as youth, veterans and people with disabilities.” It is not clear what guidance is provided to ensure this is done, nor the specific budget.

**Key Policies:**

- **National Agriculture Policy (2015)** – In this policy, disability is only included as part of a wider “vulnerable group”.

- **Agricultural Sector Strategic Plan (ASSP) for 2015/16 to 2019/20** - Under the priority areas identified in the ASSP, a key area of focus is “Increasing access to critical and quality Agricultural Inputs for smallholder farmers including Women, Youth, Older persons and People with disability”. Despite this, disability is not one of the five cross cutting issues in the ASSP, which are: gender; youth; environment and climate change; HIV/AIDS; and food and nutrition security.

### 6.5.6 Ministry of Information Communication Technology

The Information Communication Technology (ICT) sector is led by the Ministry of Information Communication Technology and National Guidance (MICTNG). The sector has developed a specific policy – the ICT and Disability Policy (2017) – which is a comprehensive policy to address a range of needs and acknowledges that ICT can be applied to promote development in sectors such as education (e-learning), health (e-health), employment (e-workers, e-employers) and to provide affordable services (for example, social protection). Persons with disabilities will therefore contribute to the growth of ICT as well as use ICT to empower themselves. The comprehensive policy talks about liaising with other MDAs, and there is a focal point within the MICTNG. However, the policy is currently awaiting cabinet approval. Uganda has signed and ratified the Marrakesh Treaty, which aims to facilitate access to reading for blind and visually impaired individuals.

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105 [https://www.agriculture.go.ug/](https://www.agriculture.go.ug/)
107 [https://www.naads.or.ug/?s=disabilities](https://www.naads.or.ug/?s=disabilities)
110 [https://ict.go.ug/](https://ict.go.ug/)
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impaired persons.\textsuperscript{111} ICT will play a major role in this transformation, although again, it is not clear what budget has been earmarked for this.

6.5.7 Ministry of Lands, Housing and Urban Development

The Ministry of Lands, Housing and Urban Development’s mission is to “ensure sustainable land management, planned urban and rural development and decent housing for all.”\textsuperscript{112} In order to do this, it encompasses a large number of departments with relevance for disability inclusion in planning, design and housing.

Key Policies:

- Uganda Land Policy (2013) – This policy talks about equal rights for, and mainstreaming of, persons with disabilities and other marginalised and “vulnerable” groups in land disputes, inheritance claims and other sector activities.

- National Physical Planning Guidelines and Standards (2011) – This document mentions the provision of access ramps to social service buildings and provides guidelines for the number of dedicated parking spaces for persons with disabilities in public and hospital parking. Despite these efforts, it is unclear what steps the Ministry has taken towards ensuring these guidelines and standards are upheld, including budget allocation.

6.5.8 Ministry of Water and Environment

Led by the Ministry of Water and Environment (MoWE),\textsuperscript{113} the water and environment sector consists of two sub-sectors: water and sanitation, and environment and natural resources. Both sectors have relevance for persons with disabilities, although currently the focus appears to be more on gender as a cross-cutting issue.

Key Policies:

- Uganda National Climate Change Policy (2015) – This policy talks about giving “special attention to the improvement of the resilience of vulnerable groups to climate change.”

- Environment and Social Safeguards Policy (2018) – This policy provides a framework to coordinate existing legislation and policy related to the sector, including human rights policy. Again, persons with disabilities are specifically mentioned as part of a “marginalised and vulnerable group,” although the context is that all projects should avoid being to the detriment of these groups, rather than any active engagement to uphold their rights.

The MoWE “Clients Charter” does highlight that the ministry “shall seek to ensure that the services offered to clients/service users are in line with their needs and expectations. The Ministry shall also pay special attention to needs of disadvantaged, persons with disabilities and other vulnerable groups.”\textsuperscript{114} While still focusing on persons with disabilities as inherently vulnerable, it does at least give persons with disabilities some leverage to complain if they feel

\textsuperscript{111} http://www.worldblindunion.org/english/our-work/our-priorities/pages/right-2-read-campaign.aspx
\textsuperscript{112} http://mlhud.go.ug/about-us/
\textsuperscript{113} https://www.mwe.go.ug/
\textsuperscript{114} https://www.mwe.go.ug/sites/default/files/library/CLIENTS%20CHARTER%202018-2022_0.pdf
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their rights are not being upheld in the sector. Again, budgets are aligned with donor and other priorities.

6.5.9 Ministry of Works and Transport

The Ministry of Works and Transport (MoWT) is responsible for transport infrastructure and development, and therefore has a significant impact on the lives of persons with disabilities. While there is no obvious policy or budget focus on disability, the Ministry has implemented some work on gender mainstreaming.

Key Policies:

- National Transport Master Plan (2008 – 2023)\textsuperscript{115} – The document does not mention any specific groups. However, the Ministry has previously released documents on gender mainstreaming, including a Policy Statement and Guidelines for Mainstreaming Gender into the Road Sub-Sector.\textsuperscript{116}

6.5.10 Justice, Law Order (JLOS)

The mission of the JLOS sector is to “Improve the safety of the person, security of property, observance of human rights and access to justice for accelerating growth, employment and prosperity.” It aims to do this primarily through the rule of law\textsuperscript{117}, and includes the judiciary, police and other security apparatus. It is therefore in charge of overseeing the upholding of international and national legal obligations, as well as ensuring that citizens hold up their side of the contract. Access to justice and human rights and accountability are among the sector’s priority areas. Both the Uganda Human Rights Commission (UHRC) and the Equal Opportunities Commission (EOC) fall under the judiciary sector, and their mandates are outlined briefly below.

6.5.10.1 Uganda Human Rights Commission

The Uganda Human Rights Commission (UHCR) is mandated by the Constitution (Article 52: 2) to monitor human rights compliance, report abuses and submit annual reports to Parliament on the state of human rights and freedoms in the country. It works with other human rights bodies and MDAs to ensure the human rights of persons with disabilities are upheld, including making specific recommendations in their annual reports. The commission is technically an independent body, and is headed by appointed Commissioners; however there have been complaints about the extent of its powers, as well as its willingness to criticise those in power. Members of the Commission work closely with the JLOS sector, as well as with other appointed commissions, such as the National Disability Council, and UN agencies and international and national organisations. The website also has an online reporting portal for complaints.

\textsuperscript{115} http://www.works.go.ug/documents/national-transport-master-plan-2008-2023/
\textsuperscript{117}https://www.jlos.go.ug/index.php/about-jlos/mission-and-objectives
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6.5.10.2 Equal Opportunities Commission

The Equal Opportunities Commission (EOC)\(^{118}\) was mandated by the Equal Opportunities Act (2007). Its role is to ensure compliance with the regulations governing “…equal opportunities for all and affirmative action taken in favour of groups marginalised on the basis of sex, age, race, colour, ethnic origin, tribe, birth, creed or religion, health status, social or economic standing, political opinion or disability or any other reason created by history, tradition or custom.”\(^{119}\) The EOC is led by appointed Commissioners who serve for a fixed term. It also provides advice, training, research and monitoring around equal opportunities. Regarding disability, the EOC notes that it will:

“…use its mandate to ensure that the state and other non-state actors are compliant with equal opportunities and affirmative action in favour of PWDs and do involve the PWDs in the design of interventions that are addressed to them as a special interest group.”

The EOC has a complaints function, and also delivers specifically funded projects around equal opportunities. To date, it would appear that the EOC has had more success with gender inclusion than disability inclusion.

Members of both the EOC and UHRC work closely with state and non-state actors, including the National Council for Persons with Disabilities (NCD), NUDIPU and other DPOs, as well as a range of international and national organisations.\(^{120}\) The UHRC and the MGLSD are key members of the Human Rights and Accountability Working Group.\(^{121}\)

6.5.11 Gender and Equity Compliance Monitoring

Since 2015, the GoU, through the mandate of the EOC (see above), has undertaken gender and equity compliance monitoring of national budgets. The aim of this process is to “strengthen [its] commitment to realise equal opportunities in Planning and Budgeting” through the introduction of the Public Finance Management Act (2015). This requires all sectors, ministries, departments and agencies (MDAs) and Local Governments to ensure that their budgets, budget policy frameworks and Ministerial Policy Statements are “gender and equity responsive.” In return, they are issued with a Certificate of Compliance from the Minister of Finance Planning and Economic Development in consultation with the EOC. To ensure compliance, budgets are scored against markers, with 40 per cent allocated to gender inclusion markers. Disability of all categories/types of impairment, geography (ethnic minorities and hard to reach/live locations), and age (children, youth and older persons) are each allocated 20 per cent (for an overall total of 100 per cent). Any ministry with a score below 50 per cent is not issued with the certificate of compliance and is asked to revise its ministerial policy statements. In turn, the EOC recommends that no budget is signed off to that MDA (EOC 2018). Overall scores are highly variable across sectors, and the EOC makes a series of recommendations to improve them, including that all ministries should have a gender and equity focal point (ideally from the Planning Units/Functions).

\(^{118}\) http://www.eoc.go.ug/
\(^{120}\) http://www.eoc.go.ug/eoc-projects
6. Disability Architecture

Sectors tend to score higher on gender mainstreaming than the other parameters, given the weighting. According to the data provided in the most recent report from the EOC, scores on gender and equity compliance monitoring related to disability were weak across the board, with an average disability compliance score of 25 per cent across all the sectors (EOC 2018). To address this disparity, the EOC has proposed an adjustment to weight all parameters equally in the final scoring (NCD 2019). The National Disability Inclusive Planning Guidelines (2017) also take into account this assessment criteria (NPA 2017).

Compliance monitoring is part of a suite of tools, including Gender and Equity Compacts for eight key sectors; a National Gender and Equity Compendium; and a Gender and Equity Compliance Guide for Parliamentarians. The aim of these is to support affirmative action on behalf of the Government of Uganda to ensure certain groups – often those typically seen as marginalised, including gender (women), age (youth, children, adults and older persons), and persons with disabilities – are afforded adequate coverage in national development plans. In order to support the active inclusion of gender in budgets, the Uganda Bureau of Statistics (UBOS) produced a National Compendium on Concepts and Definitions on Gender Statistics (2013), which harmonises definitions and concepts. It is worth considering whether such a compendium might be necessary to ensure disability mainstreaming and harmonisation across the sectors.

6.6 Disability Legislation and Policy

There have been many claims that Uganda’s disability legislative and policy framework is one of the best in the sub-Saharan region (Katsui & Kumpuvuori 2008; Lang & Murangira 2009; NCD 2019). However, it has also already been well-documented that there is a significant gap between what is written on paper, and what is being done on the ground, in particular around funding for the implementation of programmes, awareness of policies, and inconsistencies across policies (Lang & Murangira 2009; Omona et al 2017; Price 2018). This section reviews key pieces of legislation and policy and discusses the reasons why this gap lessens the impact of the hard-won gains of the Constitution, the National Policy on Disability in Uganda (2006) and the Persons with Disabilities Act 2020, as well as the domestication of the UNCRPD, which Uganda ratified in 2008.

In accordance with the broader constitutional aims, Uganda’s development framework, Vision 2040, includes persons with disabilities, both as citizens with equal rights, as well as a specifically vulnerable group. Within Vision 2040, social protection is underscored as a key way to address this vulnerability and to address the risks and vulnerabilities for certain groups, including persons with disabilities. However, here is perhaps the first challenge – shifting to understanding social protection as a right for all citizens, rather than as it is currently seen – as a necessity mainly for those who are at risk or vulnerable.

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122 Not available online.
123 Education and Health; Agriculture; Works and Transport; Energy and Mineral Development; Information and Communications Technology; Justice, and Law and Order;
126 Currently under revision
Currently in Uganda, whilst in law, persons with disabilities are enfranchised with the same rights as all citizens, at the same time, particularly in the policy discourse, they are seen as potentially at "risk" and "vulnerable" on the basis of their disability. The problem with this perspective is that it has the potential to see the disability (or rather, the persons with disabilities) as being the problem (a medical model view), rather than why and how persons with disabilities are made more vulnerable by society in the first place (a biopsychosocial view). Only viewing disability as a medical issue to be "cured", or as an object of charity, removes the focus from the structural, environmental and attitudinal barriers that persons with disabilities encounter. The MGLSD itself has highlighted the multidimensional aspect of vulnerability (MGLSD 2011, cited in OPM 2013). A multidimensional approach is necessary to address the issues in society that create the conditions for vulnerability. As noted above, the GoU has already made significant commitments – including legal commitments – to addressing this inequality. However, despite the good intentions outlined in legislation and policies, gaps remain, in particular how they are implemented, monitored and degrees of compliance. The main government accountability structures are through reporting mechanisms, review boards, as well as human rights related organs such as the EOC, UHRC and the NCD. However, as has been discussed, these organs face a number of challenges in undertaking these responsibilities.

Donors can wield significant power around policy decisions. DFID in particular has made significant commitments to disability inclusion, as evidenced by the co-hosting of the Global Disability Summit in London in 2018, DFID’s Disability Inclusion Strategy (2018 to 2023) and its focus on disability inclusion across all its funded programmes. DFID is also the co-chair of the Global Alliance on Disability (GLAD). Disability inclusion is also a priority area for DFID in Uganda. Within the country, donor coordination is primarily through the SWGs. Disability comes under the Social Development Sector, and although there is no specific SWG on disability, it does feature in the social protection sub-group. However, there are a number of challenges with coordination of the existing SWGs (Roberts and Sejjaaka 2017).

6.6.1 Disability Legislation

Uganda is a signatory to a number of key pieces of international legislation advocating for the rights of persons with disabilities, including the Convention on Vocational Rehabilitation and Employment of Disabled Persons (1983); the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW); the Convention on the Rights of a Child (CRC); and the UNCRPD (2008). All domestic laws should be in accordance with the Constitution (1995) and given the Constitutional commitments to equality for persons with disabilities, it is therefore a Constitutional obligation to respect the dignity and rights of persons with disabilities. In addition, the Equal Opportunities Commission Act (2006), as well as the Children’s Statute 1996 (with its 2016 amendments) also provide for the specific rights of children with disabilities in Uganda. Uganda had already enacted several disability-specific laws: the most recent is the revised Persons with Disability Act (2020). The revised Act is intended to ensure compliance with the

130 https://gladnetwork.net/
132 It was the domesticating of this piece of legislation that led to the establishment of the five vocational rehabilitation centres across the country (ILO 2004:8; Lang & Murangira 2009:5).
133 These are of course underpinned by the ICCPR and ICSCR.
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UNCRPD, which came into force after the previous Act was legislated. Its precursor, the Persons with Disabilities Bill (2018) was read before a Parliamentary Committee in 2018, and was passed contingent on a number of amendments being made to strengthen the rights of persons with disabilities in Uganda, including strengthening "coalitions between state and non-state actors", and increasing the amount to funding provided to "achieve full dignity and equality of persons with disabilities in Uganda on an equal basis with fellow citizens." The President then passed the Bill into an Act, which has the specific aim to:

"...provide for the respect and promotion of the fundamental and other human rights and freedoms of persons with disabilities; to re-establish the National Council for Disability as the National Council for Persons with Disabilities; to transfer the property of the Uganda Foundation for the Blind to the National Council for Persons with Disabilities; to provide for the local government councils for persons with disabilities; to repeal the Persons with Disabilities Act, the National Council for Disability Act and the Uganda Foundation for the Blind Act and to provide for related matters."

As the Constitution does not define what disability is – or rather, who a person with a disability is – in the Ugandan context, this has led to a range of definitions and description of disability across national legislation and policies, which though similar, can lead to variations on interpretation. The new Persons with Disabilities Act (2020) defines disability as:

"a substantial functional limitation of a person’s daily life activities caused by physical, mental or sensory impairment and environment barriers, resulting in limited participation in society on equal basis with others and includes an impairment specified in Schedule 3 to this Act."

Whilst this is in line with the UNCRPD, Schedule 3 of the Act (2020) lists the following categories of disability:

1. Mobility impairment caused by cerebral palsy, amputation of a limb, paralysis or deformity
2. Hearing disability including deafness and hard of hearing
3. Visual disability including blindness and low vision
4. Deaf and blind disability
5. Mental illness including psychiatric disability and learning disability
6. Little people
7. Albinism
8. Multiple disability

The Act further clarifies that when determination of a disability is required, a "medical doctor with the relevant expertise or an expert appointed by the Council, shall carry out an examination to confirm the disability."

6. Disability Architecture

Therefore, despite the language of rights, in the end, the Act also reverts to a medical approach to determining disability if there is a dispute. The categories, particularly that of “mental illness”, blur intellectual disabilities with mental health conditions, potentially creating challenges for both groups, as not all persons with intellectual impairments have mental health conditions and vice versa. The categories also have the potential to cause confusion for those whose conditions do not fit neatly into one specific category, for example, persons with conditions such as cerebral palsy but no mobility impairment, which not all persons with cerebral palsy have, though it is acknowledged that conditions can change over time.

Given its focus on re-establishment of the National Council for Persons with Disabilities, the District Council for Persons with Disabilities, and the Sub-County Councils for Persons with Disabilities, the Act spells out the composition of these Councils, as well as clarifies issues around stipends etc.

In accordance with its affirmative action commitments, Section 13(3) of the previous Persons with Disabilities Act gave ministers the authority to determine a quota or percentage of persons with disabilities to be employed. This was not enforced by statutory instrument and currently there is not a set quota either for the public or private sector (East Africa Centre for Disability Law and Policy, 2018). NUDIPU has therefore recommended implementing the quota system for employment of persons with disabilities in public and private sectors (NUDIPU, 2016). The new Act reaffirms this right to determine an employment quota for persons with disabilities, though it remains to be seen if it will be enacted.

The previous Act also mandated for a quota of funded places in universities for students with disabilities, and though the revised Act does not specify a quota, it does state that all schools and institutions of higher learning must provide for all access and inclusion requirements of learners. It specifies the same across the health sector (including provision of rehabilitation services), and employment sector, and underscores the principles of affirmative action.

Finally, despite the focus on disability in the legislative framework, as noted above, there are still a range of concerns around the discriminatory language and terms used in these laws (including “imbecile” and person of “unsound mind” to mean persons with mental health conditions or intellectual disabilities), limited enforcement of the laws and, little being provided in terms of legal aid, among other barriers (UNOHCHR 2016). A further challenge is actually upholding these laws, and empowering persons with disabilities and their families to be able to pursue their rights through the legal system, and to ensure that laws are enforced and penalties for breach of legal provisions are put in place (Nyombi and Kibandama, 2014). The Mental Health Act (2018) was revised to address many of the criticisms about terminology and treatment of persons with mental health conditions, though this has not been without criticism (Mugisha et al 2019). However, it has been noted that while there are laws to prohibit discrimination against persons with physical, sensory, intellectual, or mental disabilities, and which provide for access to education, employment, health services, information, communications, buildings, transportation, and the judicial system for persons with disabilities, the government does not effectively enforce these laws (US State Department 2018).

135 And is not without criticism, see Emong (2014)
6. Disability Architecture

Therefore, while there are numerous pieces of legislation that exist or are in process of being enacted that aim to protect the rights of persons with disabilities in Uganda, there are a range of barriers to full enjoyment of these rights, not least that many pieces of legislation are being held up at the final stage, waiting for Presidential approval, which is required for all new pieces of legislation or policy, or gazetting, which is required to convert them into law. It is unclear why there is this delay. There are also challenges with accessing the judicial processes for persons with disabilities, and criticisms that existing human rights bodies do not have the requisite powers to address many of the issues raised (US State Department 2018).

There have been a number of criticisms about access to justice for persons with disabilities in Uganda, including lack of assistance and support in courts, as well as the limited understanding of disability by the sector in general (NCD 2019). Whilst at national level, much of the discourse is around rights, there is much less talk of duty-bearers’ responsibilities towards persons with disabilities. It was striking just how little any of the people interviewed during the research talked about rights and responsibilities (see also Reynolds Whyte 2020).

6.6.2 Disability Policies

While legislation provides a framework for justice in society, policies are created to support the achievement of certain agreed and identified goals. These goals are not legally binding, although laws may be created to make them so. In Uganda, those goals are set out in the country’s national development agenda, Uganda Vision 2040. Persons with disabilities are included in this framework, both as citizens with equal rights, as well as a specifically “vulnerable group”. In the Vision 2040 document, this vulnerability is addressed by underscoring the importance of social protection in ameliorating risks and vulnerabilities for certain groups, including persons with disabilities. Of course, this puts the onus on social protection as being the main way to deal with vulnerability of persons with disabilities, rather than an approach that encompasses all sectors. As noted above, the GoU has already made significant commitments to addressing this inequality. However, despite the good intentions, gaps remain, particularly in other sectors. This is despite the fact that there are supposed to be disability focal points in the other MDAs, though it is unclear how or if this is enforced. Additionally, the assumption persists that disability inclusion is the responsibility of the Department of Disability and Elderly Affairs (MGLSD), rather than being cross-sectoral.

At national level, Uganda has 18 government sectors, and over 50 ministries within these sectors. Of these, 12 have the most relevance for disability mainstreaming and inclusion. While the MGLSD has the overall mandate for disability, delivered through the Department of Disability and Elderly Affairs, given the affirmative action policies and legislation in the country, there are a number of policies across the sectors that directly or indirectly refer to disability. However, whilst these may appear to be positive on paper, there are numerous challenges with implementation.

A recent policy review examined key policies in each of the areas of education, employment, social protection and health, as well as the framework within which they were developed (Omona et al 2017). The content of each policy was assessed and scored using an existing validated scoring method and analysed against six criteria: rights of people with disabilities, accessibility,
6. Disability Architecture

inclusivity, national implementation plan, enforcement mechanism, budgetary concerns and Management Information Systems (MIS). Each of these criteria was given a value between 1 (weak) and 4 (high) on the extent to which disability issues are acknowledged in each criterion. In terms of policy content, social protection policies scored the highest overall (2.7), followed by education (1.9), employment (1.6) and health (1.5).

While this may look promising on paper, the scores highlight gaps in the policy and implementation processes. For example, in the education sector, while the Special Education Policy scores well around its content on rights (score 4) and accessibility (4), it does not score well on its links with the Education Management Information Systems (1), meaning that it is hard to track data on children with disabilities within the system. Across three of the four policy domains, rights scored highest, with the exception of health, while budget allocation, implementation plans, and MIS scored the weakest (except in social protection).

One of the key challenges is the extent to which inclusion happens when a policy is aimed at "all Ugandans", without mentioning persons with disabilities as a specifically targeted group. Empirical evidence would suggest that they are not. A further challenge is that this evaluation only scored the policies themselves, not the related programmes or their implementation, which would give a further idea of gaps. However, the findings highlight the ongoing issue that Uganda has strong policies on paper, indicating a good level of political buy-in, but the context does not seem to convert into benefits for persons with disabilities. This is consistent with the view that while there is good political awareness about disability issues ("talking the talk"), this does not necessarily convert into action ("walking the walk").

Finally, the review identified a lack of harmonisation across all the policies, with inconsistencies in definitions and approaches. This is key to delivering a joined-up approach to disability inclusion. The current policy on disability – the Uganda National Policy on Disability – dates from 2006 and was due to be reviewed in 2016. The process was initiated, but not finalised, so in 2019, the MGLS restarted the Disability Policy Review process.

It is worth noting that the Uganda National Policy on Disability (2006) was enacted the same year as the UNCRPD came into force, so there has been much debate about how aligned the policy was with the UNCRPD, along with the Disability Act (which has since been revised). Since that time, there were discussions on developing guidelines to support the implementation of policy. Subsequently, a National Action Plan for Children with Disabilities (2016/17 – 2020/21), was developed in 2016. This was the result of a joint scoping study by the MGLSD and UNICEF in 2014 that highlighted the need to clarify roles and responsibilities of the various government institutions to realise the rights and full potential of children with disabilities, and to improve the protection mechanism for them. The National Action Plan focuses on CBR as the overarching approach, as well as identifying a number of priority action areas:

1. Performance Enhancement (of all stakeholders)
2. Participation and inclusion of children with disabilities

139 The team also included a potential score of 0.5 points for differentiation, hence total scores.
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3. Coordination and Networking

4. Developing and enforcing the legal and policy Framework on children with disabilities

The Action Plan outlines targets, indicators and a monitoring and evaluation schedule. As Figure 64 demonstrates, responsibility ultimately sits with the MGLSD.

Figure 64: Structure of the National Action Plan for children with disabilities

It is unclear how much progress has been made on this as the Steering Committees are not fully functional, and there are no reports available. The adult equivalent of this, the National Program and Plan of Action on Disability 2009 – 2013,\textsuperscript{141} has been superseded by the Disability Inclusive Planning Guidelines (2017),\textsuperscript{142} which were already discussed above.

\textsuperscript{141} National Program and Plan of Action on Disability, 2009-2013, Ministry of Gender Labour and Social Development, Government of Uganda
6. Disability Architecture

6.6.3 Governance Challenges

Across most MDAs, disability is still seen as an issue of “vulnerability”, despite the rhetoric of rights. A much stronger focus on the equity component is necessary to ensure inclusion of persons with disabilities, as well as a recognition of the intersectional nature of these issues (including age, gender, location etc) to ensure disability is mainstreamed across all MDAs. There is a major gap in coordination, and the creation of a specific function to coordinate disability across MDAs would facilitate mainstreaming and inclusion. While on the one hand, having a specific department focusing on disability and elderly affairs may bring some visibility to the issues, on the other, it perpetuates the idea that they are an inherently “vulnerable group”, and without the necessary resources and power, issues of both persons with disabilities and older persons remain side-lined. Moreover, whilst there are some similarities in terms of issues for persons with disabilities and older persons, they are clearly not the same, and should be treated as such. For example, it is unclear to what extent those working on children's affairs within the MGSLD liaise with those working on children with disabilities, yet these two areas are more related to each other than children with disabilities and older persons. Not only does the MGLSD need to be more integrated, but all other MDAs need to work on including persons with disabilities in their programmes, not just as a “vulnerable group” but as citizens with the same rights as everyone else.

Part of the problem is clearly the relatively small budgets allocated to the social development sector in comparison with the health or education sectors, for example. Given the not-insignificant amount of work around disability issues that the social development sector is expected to do, it is worth remembering that the sector only accounts for 0.6 per cent of the national budget (FY 2019/20). It is therefore unlikely that many of the necessary costs and resources will be met, so it is perhaps unsurprising that many of the initiatives to address the inequalities and exclusions faced by adults and children with disabilities are not fully functioning as yet. However, in the same way that the MGLSD cannot be responsible for all aspects of disability, it should not be expected to fund all necessary interventions. However, it is even less clear whether there is any ring-fenced money in other MDAs to support the equity and inclusion of persons with disabilities. Given the commitments to mainstreaming, or at least equity and inclusion, there needs to be similar budget commitments which enhance the overall ability of adults and children with disabilities to access healthcare, education, employment and other sectors and services on an equal basis to their counterparts without disabilities.

Uganda has made attempts to address equity and inclusion though affirmative action policies and programmes, and indeed, there are some persons with disabilities who have benefited from these actions, largely in the political sphere. Yet, despite this long history of activism and the positive policy environment, equity and the inclusion of persons with disabilities have not achieved the levels they should have reached. Furthermore, there is still an overall lack of awareness by all levels of stakeholders, from policymakers themselves down to village level councillors, about many of the policies that support both affirmative action specifically and inclusion more broadly. This results in a partial implementation of existing policies, as well as a reduced impetus to design new ones as there are already procedures in place on paper.

Implementation, monitoring and coordination would be facilitated by a strengthening of cross-sectoral work around disability-inclusive development, and the much-delayed establishment of the National Disability Steering Group. This would facilitate disability mainstreaming and monitoring across all sectors, and give more power to existing structures, in particular the NCD, which currently has a mandate, but does not have any real resources or power to actually hold
any MDAs or others to account if they do not deliver on policy commitments. This can be clearly seen, for example, in the long delays in reviewing policies at cabinet level. The MGLSD itself has limited capacity to implement all the interventions required (and indeed legislated) to ensure full inclusion and rights of persons with disabilities, especially a very small and under-funded department within the MGLSD, with limited resources and powers.\textsuperscript{143} Not only that, but it needs a more specific mandate if it is to function at a higher level. Given the stated commitments to affirmative action for persons with disabilities, there is a need to dedicate more specific resources and shift responsibilities for oversight of these national policies outside of the department. This could be through ensuring that disability is a cross-cutting issue in, for example, the Office of the President whose aim it is to “provide Leadership in Public Policy Management and Good Governance for National Development”\textsuperscript{144} or to increase overall resources to deliver existing policy commitment. There could also be a specific unit with the MOFPED, as well as within existing human rights bodies such as the EOC.

Linked to this is the need to harmonise disability across the various affirmative action mechanisms, including the Gender and Equality Budget Process, which needs to synchronise with the \textit{National Disability Inclusive Planning Guidelines (2017)} to ensure that one does not "trump" the other in terms of equity scoring. Now that the guidelines have been formally launched, there needs to be further promotion of the use of these guidelines, as well as training around them, and the development of agreed indicators of inclusion.

As is the case in many other countries, disability issues tend to get "lumped" together in one ministry – often, as in the case of Uganda, within the MGLSD. This can lead to other ministries assuming that \textbf{all} issues related to disability are the responsibility of the MGLSD, even issues such as health and education. Addressing adult literacy is a good example of this, as despite acknowledgement of massive gaps in literacy for adults with disabilities, very little seems to have been done to ensure they are included in Functional Adult Literacy (FAL) programmes.\textsuperscript{145}

Finally, related to all this is the issue of accountability. Currently it is the NCD that is mandated to provide oversight and accountability, but given their limited resources, and even more limited capacity to actually hold any MDAs or people to account, they are somewhat restricted in what they can actually do. The EOC and UNHR have more powers, but as yet have had a limited role to play around disability as it applies to social development. This also speaks to the limitations on actually using any of the legislation that is in place – there are very few \textit{pro bono} legal services for persons with disabilities,\textsuperscript{146} and the justice system still faces numerous challenges in ensuring the inclusion of persons with disabilities, all of which are highlighted in the recent state of disability report (NCD 2019). Many of these initiatives are focused on legislation – in particular human rights laws – but as one paper notes, legal frameworks can only go so far, and more work

\begin{footnotesize}
\begin{itemize}
\item \textsuperscript{143} This is not just a problem in Uganda – see for example Kidd et al (2019b).
\item \textsuperscript{144} https://www.op.go.ug/
\item \textsuperscript{145} https://uil.unesco.org/case-study/effective-practices-database-litbase-0/functional-adult-literacy-fal-programme-uganda
\item \textsuperscript{146} The CSO Legal Action for People with Disabilities is an exception to this: https://www.facebook.com/apdug/?hc_ref=ARToB21PYWfmH9IpI4_VfusdR9u39shIiHGDvD3vn7ufBEeo-3mdmct3QogCuyvRtQj-4&_xts_[0]=68ARBvOUbdOvoHb9iq1ML9ui679i6e1X0eP1KJpaaP74cUdOqWfIPNePe01-pCBOf6eGeE00D7w7oSkV19IAWvxas8WwaZafKzpiP_nNGzqgbWBrzAYe50uAFLHRU15sCT-GA-Za6MaUvIyOwoc4Gv6p6lIdPCXcOLnQmvg62_t0wOBEdgHV8wqal_85MYXOM7ux6U1S14Q52sXOUp-bT6pXW-8AUvQojOPFJoZ4ohHx14C8T-vk43kF3F3Y-ZRduDF-UyeBugip5-4iscnFAx9XgKXmeMthrB1hA3QwtauwAzvKObtliC-t0iidHSV7mc3CPY4QWhb46ug&__tn__=kC-R
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6. Disability Architecture

is needed to strengthen civil society and social policy initiatives to fully address and ensure inclusion (Nyombi and Kibandama 2014).

6.6.4 Policy Challenges

While the GoU has made attempts to redress historical neglect and exclusion of persons with disabilities (and other groups) through affirmative action policies, in reality, these have been more of a political success than a social one, and the benefits have not reached all persons with disabilities. This can be argued for several reasons. The first is budget allocation: in order to hold MDAs accountable to policy commitments, all centrally allocated budgets are to be assessed by the EOC for gender and equity compliance using the weighted scoring system discussed above. This weighting inevitably leads to a (necessary, given the status of women and girls in Uganda) focus on gender equity, but ignores intersectionality between the groups, or indeed how the budget should be spent beyond a series of indicators. This, in turn, means that while gender, age and disability (as well as other factors leading to marginalisation and exclusion) may be considered, genuine transformation of behaviours and attitudes remains only partially addressed at policy level. Moreover, given the weighting, sectors would inevitably focus on gender mainstreaming and less on the other parameters as that scores the highest points. Apparently the EOC has proposed an adjustment to the scoring procedure to ensure that all parameters are effectively considered in the final score of the MDAs (NCD 2019), although it is unclear if this has been approved as yet. Gender equity is much needed in Uganda, but part of the problem is to understand broader processes of exclusion and marginalisation, for example, how gender interacts with age, location and disability to compound marginalisation and exclusion. Moreover, these scores only assess the budgets, not the actual implementation of inclusion – thus there is a gap in understanding how effective mainstreaming is on the ground.

While some ministries already have disability-specific policies in place, such as the Ministry for Information and Communication Technology (ICT), which has an ICT for Disability Policy,147 and a focal point for disability, others continue to see disability from the perspective of having a specific need, rather than as an issue of human rights and equity. For example, the Ministry of Education and Sports has a Department of Special Needs Education (headed by a Commissioner), and the Ministry of Health (MOH), has a Disability Prevention and Rehabilitation section. Disability focal points from both these ministries are from these divisions. None of these are large or well-funded departments. Moreover, even when there are disability focal points in place, it is unclear what the mandate of this position is, whether it is enforced or funded, or indeed how they are coordinated in the absence of the recommended coordination mechanisms (such as the NCD). Moreover, as noted in the National Disability Inclusive Planning Guidelines, how budgets are allocated to mainstream disability issues across the sectors is unclear. The guidelines present a series of sample targets and indicators for the MDAs (GoU 2017a).

There is also a lack of harmonised definitions across all policies, not just those focusing on disability issues, but also healthcare, education etc. For example, not only is the current education policy unclear about whether funds are for inclusive or special education, it also does not allow for health assessments, provision of assistive devices or indeed any of the additional resources students with disabilities may need, or who should provide the budget for them. This may in part be due to the lack of data on the additional costs of disability, as well as current mechanisms for funding (GoU 2018). It is also due to the lack of coordination between sectors, for example to

6. Disability Architecture

refer children with disabilities between the education and health sectors. It should be noted that many of these challenges in the education sector are not unique to Uganda but are part of a wider set of issues around education for children with disabilities globally (UNESCO 2018).

Another challenge is around the feasibility of some of these policy directives. An example of this is the proposal to train all teachers in Sign Language (as outlined in the Special Education Policy). Not only would this be an enormous and costly undertaking, but it is not in line with the recommended practices to support inclusion, which are that the resources should be allocated to the child/adult with disabilities themselves to ensure they are used to support their needs. So, rather than all teachers being proficient in Sign Language, the student would have a dedicated support worker/interpreter in class, hospital or workplace with them as needed. However, as there are few government funded mechanisms in place to identify the support needs for children or adults with disabilities, the few mechanisms that are available (for example, for provision of assistive devices) have limited means of coordinating across sectors.
7. Service Provision

A key means of increasing persons with disabilities’ resilience is through the implementation of government services. Services that break down barriers, create effective linkages and increase capabilities not only enable persons with disabilities to survive, but also to thrive. Figure 65 indicates the support that persons with disabilities need, and how it cuts across a range of public services.

**Figure 65: The support required by persons with disabilities cuts across a range of public services**

A significant portion of the national budget in Uganda is made up of donor contributions, including for service provision. This funding often comes with a set of conditions, and reflects donor priorities. As disability is a key human rights concern, multilateral donors, in particular the UN, have made disability inclusion a key component of their work, and this is reflected in their organisational mandates and funding priorities. UNICEF in particular works on issues of children and disability, the ILO on employment and disability, and the United Nations Development Programme (UNDP) on the SDGs and disability. Bilateral donors, in particular DFID, have made significant commitments to disability inclusion, as evidenced by DFID’s co-hosting of the Global Disability Summit in London in 2018, and its focus on disability inclusion across all its funded programmes. DFID is also the co-chair of the Global Alliance on Disability (GLAD). Disability inclusion is a priority for DFID in Uganda, and as such, is reflected in its programme priorities. Other donors, including the Norwegian Government, have a long-standing commitment to

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150 [https://gladnetwork.net/](https://gladnetwork.net/)
disability issues in Uganda, primarily through the Norwegian Association of the Disabled. The Norwegian government funded the early CBR programmes in Uganda, and remains a key donor, though not for the CBR programme specifically.

In addition to government delivered services, a large number of NGOs work directly or indirectly on disability issues in Uganda. Some organisations are disability-specific (such as SightSavers\textsuperscript{152} or Humanity and Inclusion\textsuperscript{153}), while others are more mainstream organisations, which include persons with disabilities in their work, such as WaterAid\textsuperscript{154} or Plan International,\textsuperscript{155} as well as other international and national organisations that may already be engaged in disability-focused work (such as budget monitoring, etc.), often in collaboration with DPOs. Faith Based Organisations (FBOs) also deliver a significant amount of education, health and social care for adults and children with disabilities in Uganda, although they are often subject to criticism of paternalistic and medicalised approaches to disability. FBOs are subject to the same controls as NGOs, although a draft bill to control their activities was dropped by parliament earlier this year.\textsuperscript{156} Many service providers deliver through partnerships with government MDAs, although in the case of disability provision, most programmes are rarely provided nationally due to the size of the programme budgets etc.

Oversight of NGO operations is undertaken by the NGO Bureau, a function within the Ministry of Internal Affairs (MIA).\textsuperscript{157} According to its website, there are currently 13,000 registered NGOs across the country (international and national).\textsuperscript{158} The Bureau is currently clamping down on unregistered NGOs.\textsuperscript{159} The Uganda National NGO Forum is a civil society member organisation which has a range of programmes and activities, including representing NGOs at various Government fora and leading CSOs in different policy consultative processes.\textsuperscript{160} They promote the work of civil society through a range of programmes, including hosting the Uganda Governance Monitoring Platform, conducting regular performance audits for the Parliament of the Republic of Uganda and the NRM Government and implementing the “Citizens’ Manifesto Initiative”. Although some articles about disability are available on its website, it is unclear if it engages in any other disability-specific work. Other more specific coordination mechanisms include the Disability Right Fund and the Disability Funders Forum, although there is little information available about either of these fora.

The national umbrella (DPO), the National Union of Disabled Persons of Uganda (NUDIPU), has been active within the East African region for over 30 years, providing an alternative voice for persons with disabilities with a wide variety of impairments, as well as parents and caregivers of adults and children with disabilities.\textsuperscript{161} From its early engagement with the Norwegian Association of the Disabled (NAD), in particular around CBR, NUDIPU has grown considerably, and in addition to the umbrella membership of impairment-specific groups (for example, Uganda National Association of the Blind (UNAB); Uganda National Association of the Deaf; Uganda

\textsuperscript{152} https://www.sightsavers.org/where-we-work/uganda/
\textsuperscript{153} https://www.hi-us.org/uganda
\textsuperscript{154} https://www.wateraid.org/where-we-work/uganda
\textsuperscript{155} https://plan-international.org/uganda
\textsuperscript{156} https://www.parliament.go.ug/news/3097/mp-drops-bill-regulate-religious-organisations
\textsuperscript{157} Their mandate, under the NGO Act (2016), is to “register, regulate, coordinate, inspect, monitor and oversee all NGO operations in the country”.
\textsuperscript{158} https://www.mia.go.ug/content/ngo-bureau
\textsuperscript{159} http://www.ngoforum.or.ug/2019/11/19/update-on-ngo-validation-exercise/
\textsuperscript{160} http://www.ngoforum.or.ug/history-of-ngo-forum/
\textsuperscript{161} http://nudipu.org/history/
National Action on Physical Disabilities (UNAPD) and Mental Health Uganda (MHU), members also include the National Union of Women with Disabilities of Uganda (NUWODU) and youth organisations. Uganda’s DPOs offer a counter-narrative to the state view, in the form of a “Shadow Report” on the implementation of the UNCRPD. Representatives of NUDIPU sit on the board of the NCD, as well as numerous other committees and technical working groups, as well as advocacy groups such as the Civil Society Budget Advocacy Group (CSBAG). NUDIPU also has the mandate to recommend persons with disabilities for reductions on car tax for adapted vehicles and to recommend students for funded places at university under government affirmative action schemes, and NUDIPU representatives are present on university councils and higher education councils. DPOs also have a variety of international partners that they partner with to deliver a range of development activities, including research (such as the recent Living Conditions Survey) and economic empowerment programmes, including setting up of Savings and Credit Cooperatives (SACCOs) for persons with disabilities.

As is demonstrated below, access to services in Uganda is ad hoc, and depends more on where a person lives, where programmes are being targeted, whether a person falls into a “priority group” and a variety of other caveats.

This section provides a brief overview of the disability assessment procedures that are in place in Uganda. The section then discusses, in the following order, the following GoU programmes: Uganda’s social protection programmes; its health and rehabilitation services; its education system; its employment and livelihood programmes; its agriculture programmes; and land housing and urban development.

7.1 Disability assessment

Currently, there is no unified approach to disability assessment in Uganda. For public sector workers who want to claim sickness or disability benefits, assessment for the Public Sector Pension Scheme (PSPS) disability pension is carried out by government medical personnel of the Medical Assessment Board under the Ministry of Health. People with chronic illnesses such as HIV/AIDS are also eligible for the disability benefit. Other sources of assessment are health centres, particularly at district level, and while there is no formal assessment form, there is the possibility of including information in medical cards. Anecdotal evidence also suggests that some health centres keep “registers” of children with disabilities (although this may be the child’s medical record book).

Other sources of assessment include actors that may not have the appropriate qualifications to correctly assess the level, type or impact of disability. DPOs, for example, can provide confirmation of disability status for persons wishing to access some disability-specific services or places (such as reserved places in universities). Similarly, Community Development Officers (CDOs) also “assess” persons with disabilities for access to grants and other services such as the Special Grant, which is discussed in more detail below. These assessments are based on subjective opinions, and therefore run the risk of inappropriate assessment or categorisation.

162 https://csbag.org/
163 http://nudipu.org/portfolio/economic-empowerment/
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7.1.1 Registration of persons with disabilities

As well as having no formal system to assess disability, Uganda does not currently have a system of registration of persons with disabilities, in part because there are no specific benefits attached to registration. This creates a number of administrative obstacles for persons with disabilities. In their review of disability identity cards (ID cards), or registration cards, Mont et al (2016) note that such cards have a four-fold purpose:

- To enable eligibility for additional benefits not included in regular social protection programmes;
- To allow for recognition as a protected category in law;
- As a statement of official recognition by a government with regards to its responsibilities for the rights and needs of persons with disabilities (and can therefore be an advocacy tool to leverage these);
- As a way to collect administrative data to improve policies related to inclusion and disability

In Uganda, the actor best placed to have a system that registers persons with disabilities is the National Identification and Registration Authority (NIRA), which is mandated to register all citizens of Uganda, and to assign a National Identification Number (along with identity cards where applicable). While NIRA collects basic data on disability, this is self-reported and selected from one of five categories on the form (blind, deaf, physical, mental or "dumb"). When the data are inputted into the NIRA MIS, there is no option to categorise by the level of severity of the impairment. However, there are some extended options for categorisation under "physical" when inputting into the system. No information about disability status is included on the registration card, although it is stored in the database. The information is not currently reported on. Access to the information is restricted, and entities that want access must apply to the NIRA legal office and abide by strict terms and conditions of privacy.

According to a Senior Registration Officer interviewed in the NIRA Regional Office in Gulu, there is an awareness of the gaps around the inclusion of persons with disabilities, and activities are currently being undertaken to try to ameliorate these gaps, including working with the MGLSD to identify the "hardest to reach", with plans to do outreach at parish level (FY 2019/2020). However, there are very limited resources to carry out household-level registration, and currently NIRA does not provide any other support for persons with disabilities. UBOS is working on improving the data on disability (who are on the Board of NIRA), as there is an awareness that they need to revise the fields on disability categories, as they are not adequate for assessment; however, the timeline for this is not known. However, while this might address the issue of registration more broadly, it would still require additional follow up to ascertain the level of support required. Aside from the very limited information collected by NIRA, there is currently no harmonised data collection or formal registration system for person with disabilities in Uganda. NUDIPU does register its member organisations, but not individuals.

By way of comparison, in Kenya, the National Council for Persons with Disabilities is responsible for undertaking registration of all adults and children with disabilities. However, registration is slow and importantly, does not interface with the government’s MIS for the cash transfer for persons with severe disabilities (Kabare 2018), meaning that there are missed opportunities for harmonisation and avoidance of further duplication. Given the numerous challenges that have
been identified in the registration process for NIRA and the Senior Citizens Grant in Uganda, it is likely that similar challenges would likely occur in Uganda.\textsuperscript{165}

Registering persons with disabilities for such cards is not without a number of challenges, the most obvious of which is the scope and capacity to assess who is a person with a disability, given all the challenges outlined above. Mont and colleagues go further, noting that: "a poorly run and poorly funded system could waste limited resources and in a worst-case scenario, actually disenfranchise some people with disabilities who legitimately would benefit from state support." (2016). Depending on the country, benefits provided are usually limited to those whose disability restricts the type of work that they can do, which is taken as a proxy for the severity of the disability and, depending on the system, identifying persons that qualify as living in conditions of poverty. Other social security benefits are designed to cover the additional costs associated with disability (for example assistive devices, transportation and/or personal assistants). These are not necessarily linked to work or poverty status, although people usually have to meet thresholds defined by eligibility determination guidelines (Mont et al 2016). These assessments are usually undertaken by a medical professional, which may mean the assessment is not based on a social or rights-based model of disability, but rather more typically a medical model of impairment.

The main problem with this type of assessment is the assumption that the condition has the same impact on everyone, regardless of their age, sex, where they live, etc. Overall, disability determination is less complicated when it is not tied to work capacity (as it is in many high-income countries). Some countries base determination on a community assessment (for example, Vietnam), but Mont and colleagues argue that if the assessment is based on the WHO International Classification of Functioning, Disability and Health (ICF) model, then a community assessment is not appropriate. Other factors that have to be taken into consideration during the assessment are the duration of incapacitation. In the end, many decisions are based on the discretion of the assessor, which is obviously not unproblematic (Mont 2016). Based on their findings, the authors make a series of recommendations, including having a very clear rationale for the establishment of such a system, so that the assessment for eligibility matches the need for the system, for example, if it is to assess work eligibility (Mont et al 2016).

Nepal has a well-established colour-coded disability identification system, where the colour of the card provided relates to the level of access to service provision that has been determined by the assessment. However, there are numerous challenges to accessing the card in the first place, including a cumbersome application process, which is a lesson Uganda may well want to consider. The review also makes a series of recommendations, including the removal of restrictions on the number of benefits or varying benefit levels persons with disabilities can access, as it would account for the multiple sources of vulnerability. The authors also note that complementary interventions may be needed in addition to the registration card to address discrimination and marginalisation of disability, as well as overlapping vulnerabilities such as gender and caste (Banks et al 2019). Again, these are all issues that the GoU needs to take into consideration when planning services.

\textsuperscript{165} See Schjoedt et al (2019)
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7.2 Social Protection programmes

The right to social security ensures the right to an adequate standard of living and income security whenever we experience challenges and risks across the lifecycle. As discussed above, persons with disabilities experience particular vulnerabilities, including additional costs of living, as well as a greater likelihood of low pay or unemployment. Furthermore, as a person ages, they are more likely to develop a disability. It is therefore essential that an effective social protection system is implemented, not only to provide recipients with an adequate standard of living, but to provide them with similar opportunities to their peers without disabilities.

Social protection, as part of an arsenal of anti-poverty assistance programmes, has been lauded as a significant component of poverty reduction measures in recent decades (see, for example, Barrientos 2013). An inclusive lifecycle social protection measures can play a key role in addressing the vulnerabilities and wellbeing of persons with disabilities across the lifecycle, and indeed it is enshrined as a right in the UNCRPD (Banks et al. 2017b; Kidd et al. 2019b). A recent systematic review of the available literature noted the need to both assess disability more broadly, as well as to understand the specific needs of recipients with disabilities, so as to not perpetuate exclusion (Banks et al. 2017).

Benefits for persons with disabilities should not solely be adequate for monetary needs, but should also meet other needs, which include, inter alia, food security, nutrition, social relations, and dignity. To provide adequate support to persons with disabilities, programmes should take into account the extra costs of living with a disability. These include paying for assistive devices, rehabilitation services and medicines (where they are not provided by the state), transport and personal assistance (WDR 2011).

7.2.1 Social Protection Provision in Uganda

The GoU defines social protection as public and private interventions to address risks and vulnerabilities that expose individuals to income insecurity and social deprivation, leading to undignified lives. The Government considers social protection as a basic service and human right that ensures the dignity of the country’s citizens (Uganda National Social Protection Policy, 2015). Social protection in the Ugandan context has two broad pillars: 1) Social Security (protective and preventive interventions to mitigate factors that lead to income shocks and affect consumption), which can be direct income support or social insurance; and 2) Social Care and Support Services (usually these provide care, support, protection and empowerment to vulnerable individuals who are unable to fully care for themselves).

As Figure 66 highlights, existing social provision from the MGLSD is not comprehensive across the lifecycle in Uganda. While there may be complementary programmes for adults and children with disabilities, such as early childhood interventions or special education programmes, these are not stand-alone social protection programmes, but rather interventions that enhance social protection. In addition, many children and adults are unable to access these programmes as they are not delivered at the level of the individual, but rather at school, at work, or in a group.

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Figure 66: Social protection and livelihood schemes across the life cycle

Figure 67 shows results from the household survey and demonstrates that households without persons with disabilities have greater access to government programmes (such as social protection and livelihood programmes) than households with persons with disabilities. Aside from the Special Grant (which is specifically for persons with disabilities), persons without disabilities therefore have greater access to government social protection and livelihood programmes.

Figure 67: Households accessing social protection and livelihood programmes, by disability

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019

167 The Youth Venture Capital Fund became the YLP (https://www.independent.co.ug/rethinking-youth-fund/)
As will be discussed further below, although many of the programmes detailed in Figure 66 and 67 are classified as social protection programmes in Uganda, they are not considered social protection programmes according to international definitions. Therefore, several programmes, including the Special Grant for Persons with Disability, will be discussed further in Section 7.5 which covers Employment and Livelihood programmes.

Uganda’s social protection system is not currently providing persons with disabilities with regular income support, nor are their additional costs being covered. Key gaps in Uganda’s social protection system include the lack of income support for children with disabilities, thereby preventing children from having the same start to life as children without disabilities. There should also be a disability benefit for working age adults, that provides income support to the small number who cannot work and compensates those who can work for the additional costs they experience. There is also a lack of a care/support benefit to compensate for the loss of income that family members experience if they must give up work – either partially or completely – to provide care for a person with a disability with significant support needs. Figure 68 demonstrates that type of disability specific and disability relevant schemes that Uganda should have in place.

Figure 68: Disability specific and disability relevant schemes that Uganda should have in place

7.2.2 Social security in Uganda

Social Security refers to protective and preventive interventions to mitigate factors that lead to income shocks and affect consumption. Social security comprises two groups of programmes:

a. Direct Income Support, such as the Senior Citizens Grant (SCG);

b. Social Insurance, which are contributory programmes that mitigate livelihood risks and shocks associated with retirement, loss of employment, work-related disability and ill-health. In Uganda, the Public Service Pension (PSPS) and
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National Social Security Fund (NSSF) are usually defined as social insurance, although as the PSPS is non-contributory and the NSSF is a savings mechanism, they would not be defined as such internationally.

a) Senior Citizens Grant\textsuperscript{168}

The Senior Citizens’ Grant (SCG) is a tax-financed, old age pension funded by the GoU and donors. The transfer is currently worth UGX 25,000 per month, and as a non-contributory social pension, the SCG has been designed to provide income support for older Ugandans who did not contribute to the formal sector. This is especially important in a country such as Uganda, in which the majority of older persons worked informally, and it is considered an essential means of providing income support for older women, who are less likely to have contributed to social insurance schemes when they were young.

The SCG was first piloted as part of the first phase of the Expanding Social Protection (ESP) programme, with funding from the United Kingdom’s Department for International Development (DFID), Irish Aid and UNICEF. During the first phase of the programme, the SCG commenced in 3 districts in 2011 and was expanded to 15 districts by 2014, selected and based on a vulnerability ranking within each of Uganda’s four main regions (Gelders and Athias, 2019). Within these districts, older persons aged 65 years and above (60 and above in Karamoja) were enrolled on the programme. The programme was later scaled up in 2015, to an additional 20 districts but the eligibility criteria was changed – due to budgetary constraints – and it was delivered to the “100 club”. This meant that the oldest 100 recipients in each sub-county were selected as recipients for the programme.

The SCG is currently being rolled out nationally to all older persons in Uganda aged 80 years and above. This is a significant achievement and will make the programme universal, expanding to 85 new districts including Kampala. The GoU recognises the need to further reduce the age of eligibility, and Parliament has recommended that the Government should introduce a roadmap for reducing the eligibility age from 80 to 65 years within three years from the year of the national rollout. Until that happens, an estimated 820,000 people aged between 65 and 80 years will be left without support.

The MGLSD, working through the directorate of social protection and the Expanding Social Protection Programme - Programme Management Unit (PMU), manages the SCG. Under Phase I of the ESPP, the programme maintained its own district offices. Under Phase II, the programme established seven Regional Technical Support Units (RTSU),\textsuperscript{169} each of which provide technical support to a specified catchment area. At the district level, the SCG is mainstreamed within local governments through the community services department. Parish chiefs, parish development committee members and village council chairpersons (or their delegates) lead parish and community-level implementation.

Given the eligibility age of the programme, it is unsurprising that a significant proportion of beneficiaries have disabilities. As discussed in Section 3.1.2 above, while not all older persons will experience difficulties, many impairments are related to the ageing process, such as hearing

\textsuperscript{168} The Senior Citizens Grant have been reported on previously (Schjoedt et al, 2019), so we only briefly discuss the SCG here.

\textsuperscript{169} These are in Kiboga, Kyenjojo, Gulu, Nebbi, Kaberamaido, Moroto and Kamuli Districts.
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and sight deterioration. This lessens older persons’ ability to work and is a reason why pensions are so essential in old age.

A survey carried out by the programme team shows that 96 per cent of all beneficiaries report at least “some difficulty” in one or more domains, while 59 per cent report “a lot of difficulty” or “cannot do at all” in one or more domains (ESPP 2018). The findings indicate that of those who reported difficulties:

- 84 per cent of beneficiaries of the SCG have a visual impairment
- 54 per cent have hearing difficulties
- 72 per cent have mobility difficulties
- 62 per cent have cognitive difficulties
- 33 per cent have self-care difficulties
- 11 per cent experience communication difficulties

Unfortunately, the data does not indicate which impairments are pre-existing disabilities, and which are age-related. There are significant differences between the needs and capabilities of persons who are born with disabilities – or acquired them earlier in life – and older persons with age-related disabilities. For example, older persons who acquired visual impairments later in life are unlikely to have received training, or to have experience navigating their environment, without sight. Similarly, older persons with acquired hearing impairments are unlikely to have learned sign language, and so are unlikely to be able to communicate in this way.

The programme has put in place a robust IT based Management Information System (MIS), which is housed within the ESPP-PMU. The MIS enables the programme to keep track of registered households, calculate and reassess eligibility for the SCG, generate beneficiary lists, generate payroll lists for the payment service provider, reconcile payments data and generate monitoring reports. The MIS does not contain complete information on disability, but this is due to be improved in the future, when the use of the new registration tool that includes the Washington Group questions has been implemented. While the questions are a globally recognised standard for ensuring comparable disability statistics, it should also be recognised that the questions have limitations: they provide a measure of functional limitations, but are not necessarily effective at identifying all forms of disability (in particular mental disabilities); nor do they indicate the age of onset (although additional questions around this can be added in).

The MGLSD has recently completed a pilot project in Karamoja with SightSavers International to offer eye care services to SCG beneficiaries at paypoints. Beneficiaries are examined, treated, and if necessary, operated on to correct any eyesight problems. Fifty-five per cent of the eye diseases are cataracts, about 20 per cent are trachoma, and a further key category is bacterial conjunctivitis. SightSavers ensures that the necessary equipment and drugs, including antibiotics, are available at the District Hospital, working in partnership with the regional hospital in Moroto.

While the impact of the SCG has been extensively evaluated, there has not been an evaluation that has looked specifically at the accessibility of the programme for persons with disabilities. Furthermore, it is possible that although the programme is currently increasing coverage to all persons aged 80 years and above, administrative barriers will mean that not all older persons with disabilities will access the programme. Some will likely be excluded as a result of barriers in obtaining NIRA registration, and other barriers to access (described in Section 7.1.1 below).
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Indeed, in a global overview of social protection systems for persons with disabilities, Kidd et al. (2019b) note that during the implementation stage, persons with disabilities can face barriers around “communications on the existence of schemes and application criteria that are not adapted to the requirements of some persons with disabilities; complex application processes that are challenging to navigate; the difficulties and costs associated with travelling to registration centres; challenges in entering registration centres; and, limited capacity and discriminatory attitudes among staff receiving applications.”

The current design of the SCG is also not able to fully address the financial needs of persons with disabilities. The real value of the transfer has declined significantly over time, as the benefit is not adjusted to inflation. As the programme is intended to provide income replacement for those who can no longer work, the amount is clearly inadequate. Furthermore, as the SCG is not a disability-specific scheme, it does not take into account the additional costs of disability. In Nakasongola, the Chair of the District Disability Council explained that the eligibility age for the SCG should be reduced to 55 years for persons with disabilities, and that the benefit amount should increase to UGX 30,000 a month. He emphasised that older persons with disabilities were unlikely to be saving part of their benefit, as they had too many additional costs.

A final gap in the SCG is that it is “pension-tested” and as such, people who receive the Public Service Pension (PSPS) are not eligible for the SCG. It is worth noting that given the relatively low value of the pension transfers, this exclusion criteria should be reconsidered, and other exclusion criteria avoided.

b) The Public Service Pension

The Public Service Pension (PSPS) is a tax-financed, non-funded “Pay as You Go” scheme for all public service employees (including civil servants, teachers, police and prisons service, judicial service, local government service, former employees of the defunct East African Community, and the Uganda People Defence Forces). The PSPS benefits are available for all government employees down to the Parish Chiefs. The PSPS covers a range of benefits, including a retirement pension; a disability benefit; a survivor’s benefit; a marriage benefit (for women who retire upon getting married); and an early retirement or redundancy payment (in the case of dismissal). Early retirement is possible for staff who have reached 45 years of age and who have worked for at least 10 years.170

Claiming benefits requires a recommendation from superiors that a situation has arisen that necessitates access to the benefit. In the case of disability, the claimant should also provide documentation from a medical doctor. Assessment for the disability pension is carried out by government medical personnel for the Medical Board under the Ministry of Health. People with chronic illnesses such as HIV/AIDS are also eligible for the disability benefit. The Medical Board determines the level of disability and whether the injuries were sustained at work or not. Additional payments are given in the case of work injuries.

It takes, on average, a year to process a claim for the disability benefit and to make the first payment. The length of time is dependent upon which point the budget cycle is at when the claim is made. Payments are delivered into the bank accounts of members, however, no particular steps have been taken to ensure that persons with disabilities can access payments, such as

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ensuring that minimum standards have been implemented to ensure that the delivery of the pension is disability-sensitive.

Given the limited inclusion of persons with disabilities in the public service workforce (apart from in political appointments), the number of persons with disabilities who are accessing the programme is fairly low, although the exact number is not known.

c) National Social Security Fund

The National Social Security Fund (NSSF) is a savings scheme for employees in formal sector companies with at least five employees. In practice, this means that most persons with disabilities cannot access the scheme as they are not in formal employment, although exact numbers are not known. Workers contribute 5 per cent and their employers contribute 10 per cent of gross salary. There is no data available on the number of persons who currently benefit from this, nor have specific measures been taken to ensure that processes of registration, application and payments are accessible for persons with disabilities. It should be noted that the NSSF does not provide effective social security as it is a provident fund. Benefit levels are low and losing value it does not provide regular transfers. Furthermore, women are likely to be left out (McClanahan et al., forthcoming).

The programme provides both an old age benefit and an invalidity benefit, both of which can be important means of support for persons with disabilities. However, as it is currently designed, it is a one-off lump sum payment from the accumulated savings of the beneficiary, which likely means that the money is spent immediately, negating any security in the longer term.

To access the invalidity benefit, clinical notes or documents indicating the applicant’s history of illness, together with the doctor’s recommendation, are required to prove loss of work capacity. This presents challenges around confidentiality. The claimant may also be required to see the NSSF doctor for assessment. In order to access the benefit, the fund member must have either a “permanent total disability” that prevents the member from performing the work that they could before the disability began, or a “permanent partial disability” that prevents the member from earning reasonable living.

7.2.3 Social care and support services

According to the Uganda National Social Protection Policy (2015), social care and support services are a range of services that provide care, support, protection and empowerment to vulnerable individuals who are unable to fully care for themselves. Social care and social work for persons with disabilities are still underdeveloped in Uganda. Currently, they comprise a number of small programmes and services overseen and/or delivered by the MGLSD, and include five National Rehabilitation Centres (MGLSD, 2015), which cannot be considered social protection.

Current formal social care and support services include resettlement of abandoned and street children; care and protection of children in conflict with the law; institutional support for vulnerable children, persons with disabilities and older persons; care and support for gender-based violence victims/survivors; community-based rehabilitation for persons with disabilities; and community-based care and support for older persons. However, the limited scope of social care and social work in Uganda means that there are few state-run centres for children or adults with disabilities, and only one government-funded residential care home for older persons. In
addition, government services are restricted to persons with “severe disabilities”, although there is no definition of what this means, or who qualifies.

Most residential care homes for adults and children are provided by NGOs, calling into question their sustainability, as well as issues of standards, compliance, monitoring and accountability of services. Given the lack of a national social work system, which is discussed in more detail further below, the majority of persons with disabilities have limited access to support or services, unless it is provided by NGOs. Most social care provision is based on community development models, such as the Community Based Rehabilitation (CBR) programme, which was funded by the Norwegian Government and based on WHO CBR principles. Donor funding stopped some years ago, although some of the volunteers, and methods, remain in place on the ground.

Current mechanisms for referral are ad hoc, and rely primarily on CDOs, Probation officers and District Health Officers (DHOs). At village level, Village Health Teams (VHT) volunteers and CBR volunteers (where they exist) may conduct some follow-ups of adults and children with disabilities who have identified needs, but the process is ad hoc and not part of their training or duties. As it stands, VHT and other community volunteers – and, indeed, the few available social workers or other health personnel – have not had the necessary training to develop their knowledge and capacity around disability issues. In addition, there are no standardised disability assessment tools available to be used by CDOs, healthcare or social workers.

7.2.4 Social Work

Existing social work and other social protection programmes are limited in their capacity to support adults and children with disabilities. An affiliate branch of the International Federation of Social Workers (IFSW), the National Association of Social Workers of Uganda (NASWU), falls under the remit of the MGLSD. The NASWU has around 1,492 individual members and 22 institutional members. At district level, it is the responsibly of CDOs along with Probation Officers (for children and families of concern) to “manage” cases and refer according to need. They are usually supported by District level Social Protection Committees. There is no real system of case management, and only a relatively small social work service.

The social work profession is not regulated or protected in Uganda, and anyone trained in a humanities or social science field can be employed as a social worker. Moreover, despite the number of graduates increasing, Bukuluki et al (2019) explain that, “Social work students in Uganda do not expect to get a social work job after their graduation.” Furthermore, social workers are not necessarily knowledgeable about disability-specific issues. For example, whilst Makerere University teaches a training programme for Social Workers,171 disability, as a subject, was only recent added to the course.172 In addition, Bukuluki et al (2019) found that social work students’ motivation to work with persons with disabilities ranked in the middle, in terms of their choice of career post qualification.

In the current approach, adults and children with disabilities are seen as inherently vulnerable. Furthermore, children are considered to be the responsibility of the Probation and Social Welfare Officers (who are part of the Community Development Department within the MGLSD), which

171 https://swsa.mak.ac.ug/
172 Personal communication with Makerere University School of Social Work and Social Administration.
increases the risk of criminalising children who are in conflict with the law. Developing a stronger social work and social care system in Uganda would enable a more coherent and focused approach to cases. A social work service that adequately addresses the needs of persons with disabilities should be divided, to focus separately on children and adults, as they both have very different needs, including around protection. However, to develop such a system would require properly trained staff, sufficient resourcing and effective oversight.

7.3 Health and Rehabilitation Services

The situation around access and inclusion for persons with disabilities in healthcare services is a challenge globally, and SDG 3 (“Ensure healthy lives and promote wellbeing for all at all ages”) targets are unlikely to be met without a concerted effort to include persons with disabilities. On average, persons with disabilities are more likely to experience poor health than people without disabilities. Subsequently, they need available, accessible, acceptable and quality health services like anyone else, in addition to the specialised medical treatment or rehabilitation services that persons with certain impairments may also need. Despite often having a greater need for healthcare, evidence suggests that persons with disabilities face numerous barriers to accessing affordable and equitable healthcare (Kuper and Heydt 2019). In Uganda, issues around healthcare access for persons with disabilities relate also to issues of poor healthcare services more generally.

Early childhood interventions have been identified as a means of improving child survival as well as overall growth and development. In one of the few pieces that looks at the specific implications of Early Childhood Care and Development (ECCD) practices in Uganda for children with disabilities, Okimait (2014), writes of the need for a multi-sectoral approach which takes into account individuals, the home setting and wider community. The work pre-dates the National Integrated Early Childhood Development Policy of Uganda (NIECD Policy, 2016) and associated national Action Plan, which was launched in 2016. The policy is aimed at all children aged between 0 and 8 years old, and children with disabilities are specifically identified as needing to be included in the ECCD work, including early identification and assessment and appropriate referral and support. However, ECCD is still under-resourced in Uganda, despite calls to increase funding. The MGLSD is the designated lead agency for the implementation of the NIECD Policy, and an M&E framework has been developed to monitor this, although it is unclear the extent to which targets have been met.

7.3.1 Access and availability

Ugandans with disabilities face many of the same health challenges as their counterparts without disabilities, including HIV/AIDS, but often experience less access to healthcare and treatment, and less good health overall (Nyirenda et al 2013). This is particularly applicable to women with disabilities who also live with HIV/AIDS (Nampewo, 2017). Nevertheless, there are pockets of good practice, mainly from NGOs and CBOs (Tun et al, 2016). Costs of healthcare, including

173 The Probation Service was not a key area of focus for this review, given the overlap with the law, but it would be worth considering undertaking further research in this area to ascertain how they currently respond to the issues of disability.
175 https://mglsd.go.ug/niecd/
176 For more information see https://www.unicef.org/uganda/media/1671/file/NIECD%20newsletter%20(No.4).pdf. Also note the UDHS did anthropomorphic measures for children 0 – 5 years, but only asked questions around functional limitations for children above 5 years old so there is no data available on children with disabilities and nutrition.
transport to health centres, can also be a barrier to accessing services which are otherwise provided free of charge, including ARTs. Given the GoU commitments to disability inclusion, persons with disabilities should enjoy the same degree of access to these programmes as anyone else (Barrett and Marshall, 2013).

A major reason why persons with disabilities experience less access to healthcare is that they are often not considered a priority area for funding purposes. A significant proportion of the Ministry of Health’s funding derives from international donors (MoH 2010) who may not prioritise disability issues, and often have a disease-specific agenda (for example, HIV/AIDs, neglected tropical diseases, and malaria).

While HIV and AIDS prevalence has reduced in Uganda, it remains high amongst certain groups, in particular young women. Given the pervasive gender norms regarding women and sex, it is perhaps unsurprising that women have higher HIV rates than men in Uganda. According to Avert, the global HIV education and awareness NGO, HIV prevalence is almost four times higher among young women aged 15 to 24 than young men of the same age. Reasons for this include gender-based violence (including sexual abuse), and a lack of access to education, health services (including antiretroviral therapy [ARTs]), social protection and information about how they cope with gender-related inequities and injustices. Avert highlight that young Ugandan women who have experienced intimate partner violence are 50 per cent more likely to have acquired HIV than women who have not. It can be assumed from the above that young women with disabilities are at even greater risk, as they have less autonomy and access to services and information than their peers without disabilities (Hanass-Hancock 2009).

A number of health conditions and impairments are related to poor antenatal (ANC) and delivery care (Ndibazza et al 2011). As UNICEF notes, “An emerging concern centres around children with disabilities, whose condition is often the result of ante- and neonatal complications related to capacity constraints in the delivery of basic health services” (2015). Data from the DHS (2016) indicates that around 98 per cent of all women in Uganda have received some form of ANC from a skilled provider (with no real difference in terms of access between women with or without disabilities). The skilled provider was overwhelmingly a nurse or midwife. The survey did not measure the quality of the care received, and it is difficult to extrapolate from the data the extent of complications and capacity constraints. Furthermore, 65 per cent of mothers with disabilities had their child delivered in a health facility, compared to 73 per cent of mothers without disabilities. This therefore means that mothers with disabilities will have less access to services in the event of any birth complications than mothers who had their child delivered in a health facility (DHS 2016).

Children and older adults have the highest rates of disabilities in Uganda, but often have the least access to healthcare (GoU 2019a). There are limited services and support available for parents and children with disabilities (Smith et al 2018). As discussed in Section 5.1 above, many children acquire impairments due to illness, distance from health services, lack of vaccination and other prevention measures, along with an overall absence of effective health support, including rehabilitation services.179

177 https://www.avert.org/professionals/hiv-around-world/sub-saharan-africa/uganda#footnoteref9_shsb5lu
178 https://www.avert.org/professionals/hiv-around-world/sub-saharan-africa/uganda
7. Service Provision

There are a number of specialist units within government hospitals, for example, for children with hydrocephalus, or state-run orthopaedic and orthotic centres, and these are typically based at National Referral Hospitals (Mulago and Butabika), or at one of the 14 Regional Referral Hospitals (including one attached to the Gulu Regional Referral Hospital). However, access to such specialist services remains a challenge for most parents. There are also some NGO or partly privatised centres such as CORSU (which only provides orthopaedic and plastic surgeries). These centres often operate on a principle of “pay what you can afford”, accepting a down payment based on what the parent can afford, as well as receiving donor or other additional funding. CORSU also runs a private hospital which supplements free surgery for children. There are very few centres like this across Uganda, although they provide a vital support function to the government. It is worth noting that many government-trained doctors have to either undertake additional specialist training at centres like CORSU or travel overseas. The doctors are required to pay for these additional skills themselves, which increases the likelihood that they will return to private rather than government service to recoup their outlay.

During the qualitative interviews, the research found several cases of mothers who had stopped taking their children with hydrocephalus for the recommended routine monitoring visits at local clinics or regional referral hospitals, largely due to the fact that decisions about this kind of spending, including the costs of travelling to the hospital, lay with the children’s fathers, who had decided against continuing. Mothers were aware that such decisions had to be negotiated in relation to the father’s multiple obligations towards their other children. One mother reported that her husband stopped her from taking her child for more tests as he had not seen any improvements. Without surgical intervention, the child’s condition is likely to deteriorate further. Surgery for hydrocephalus is only available at the regional centres, and costs are often prohibitive. Although parents can pay in instalments, fear of debt discourages seeking further treatment.

Annie’s story, in Box 20, provides an example of the challenges of being able to pay for healthcare for a child with hydrocephalus. However, many parents of children with a variety of health conditions face similar challenges.

180 https://health.go.ug/hospitals
181 https://corsuhospital.org/
Box 20: Annie

Annie is a 24-year single mother living in an informal settlement in Kampala. Her baby son was diagnosed with hydrocephalus and referred by a government hospital to a private hospital in Kampala. Doctors informed her that they could perform surgery on her child, by inserting a shunt which would drain the excess cerebrospinal fluid from his brain, thereby reducing pressure and neurological damage. However, the surgery would cost four million shillings, a prohibitive sum for a single mother, who received no support from the child’s father. She echoed many other mothers’ distress:

“I just cried and cried; I was so stressed... I am a single mother and not working. I had no hope of finding this amount of money. The father offered no help... he ran away. I cried so much, but in time I said, if God wants, he can take the child, I’m too tired.”

Annie decided to take matters into her own hands and used the internet to find a hospital that could perform the surgery on her son for considerably less money (UGX 950,000). The doctors there agreed to treat the child after an initial payment of UGX 200,000, which her sister gave her. However, Annie is now in debt to the hospital, and owes them UGX 750,000 which she is unable to pay. This is causing her enormous stress, especially as her son may require additional surgery to reposition the shunt to ensure it is working properly.

7.3.2 Affordability

Current discussions about the development of a national health insurance system in Uganda could be a potentially problematic development. Article 25 of the UNCRPD (the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability) clearly states that states should: “Prohibit discrimination against Persons with Disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner.” Currently, there is no specific arrangement for free healthcare for persons with disabilities, though some medications and services are available free of charge through the UNMHCP, including malaria tablets, anticonvulsants, and ARTs. However, in practice, it is often difficult to access these medications, and this depends on a range of factors, including availability of supplies, where the patient lives, etc. For the majority of those interviewed, health centres at the subcounty (LC3) level are the first point of entry for accessing healthcare. According to one health worker respondent, some district health centres apparently keep a register of all children with disabilities, who are then followed up by the DCDOs, although again, this seems to be an ad hoc rather than formalised practice.

Proposed shifts to community financing or other systems of health financing (see Mathew 2017) risk being detrimental to many adults and children with disabilities, although there is no mention of health insurance in the Health Disability Compact (NUDIPU 2018). However, the NUDIPU notes that there has been an overall decline in funding for disability and rehabilitation – from UGX 144 million in FY 2014/15 to UGX 6.8 million in FY 2016/17 (NUDIPU 2018). Uganda’s per capita spending on health is low when compared to the WHO recommended minimum level of US$84 per person/year, standing at US$51 in 2016. Furthermore, despite the abolition of user fees in government facilities, out-of-pocket expenditure remains the major healthcare financing
mechanism in Uganda, which in turn can lead to high chances of catastrophic expenditure on health within households (Basaza et al 2019). Given that sudden ill health is a major shock for all households, in particular households with persons with disabilities (as discussed in Section 4.3) there is a high chance this could disproportionately impact on them and their families.

7.3.3 Quality

It is unclear what sort of training healthcare workers at any level receive on disability inclusion. However, there is a tendency to focus on disability as a health issue, rather than a human rights issue. This may perpetuate misunderstandings among both patients and healthcare workers, as well as expectations of a “cure”. Box 21 provides one such example.

**Box 21: Rose**

One young mother, Rose, explained that a doctor had indicated during a check-up that her son, who was a baby, “had a problem.” He did not specify what the problem was, or if he did, Rose had not understood what she was told. Subsequently, her son did not seem to develop at the same rate as her other children, so she took him to a number of private clinics and healthcare practitioners in order to obtain a diagnosis. She spent a lot of money on this but did not receive any answers.

Eventually, her husband told her to stop as they had no money left. Rose feels very dissatisfied by this, as she wants to “know what is in his head”, as she is worried that he “…might become mad in the future”. In order to cope, she prays to God, and does not discuss anything about her son with her husband.

From this and many of the other interviews, it is clear that many parents and caregivers do not know the correct diagnosis for their child. This may be because healthcare professionals have tried to explain the diagnosis and prognosis to parents, which, for a variety of well-established reasons they do not understand, or because the healthcare professionals are reluctant to be the ones to give an uncomfortable – and life changing – diagnosis to parents. Either way, the evidence suggests that parents who are aware of the diagnosis are much better prepared to support their child.183

7.3.4 Rehabilitation

According to the WHO, only one in 10 people worldwide have access to the assistive products and services they need. The reasons for this include a lack of awareness about provision, the limited availability and high cost of products, and a shortage of trained personnel able to provide basic assistive products.184 The situation in Uganda also reflects these challenges (see Smith et al 2018). According to UNICEF, only 10 per cent of children with disabilities who require rehabilitative health services receive them (Sarton et al 2017: 8). Disability-specific health services are provided through several departments within the Ministry of Health (MOH), primarily the Disability and Rehabilitation Division (DRD) (under Community Health) and the Mental Health Division (Clinical Services). The DRD has only four senior staff, and resources are minimal. As with other ministries, there are weak coordination mechanisms, despite structures ostensibly being in place, leading to a lack of collaboration and joined-up services.

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183 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6244143/
184 https://www.who.int/phi/implementation/assistive_technology/gate-fact_sheet.pdf?ua=1
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While provision of the services and assistive devices is through the MoH, the MGLSD also provides funding for rehabilitation services. This is a legacy of the earlier community-based rehabilitation (CBR) programme, which is no longer functional (see Section 7.3.3 above). While on the one hand using a CBR framework moves away from seeing disability only from a medical perspective, and places it within a matrix of other needs and services, it could be argued that by leaving the provision of assistive devices up to the DLGs discretion, there is a risk that persons with disabilities may fall through the gaps and not be able to access any services or products. Without adequate guidance – or funding – then DLGs will remain unclear as to exactly what they can spend this money on. Moreover, depending on the type of devices purchased, costs may be very high compared to available budget.185

Finally, as noted earlier, the MGLSD runs five Rehabilitation Centres. These do not provide physical rehabilitation, but rather vocational training, so are discussed in the relevant section below (see Section 7.5.3).

7.3.5 Assistive products

As Figure 69 demonstrates, overall use of assistive products is low among persons with disabilities. Only 13 per cent of persons with at least a lot of difficulty with functional activities report using devices. 14 per cent of men use assistive devices, along with 12 per cent of women, so there is little difference in usage between both. In addition, 28 per cent of people aged over 60 years use assistive products, compared to only 3 per cent of children aged between 2 and 17 years.

Assistive product usage varies depending on the impairment type. Persons with walking or self-care/fine motor control difficulties most frequently report using assistive devices, whereas only a very small proportion of adults with communication difficulties or children with learning difficulties use assistive devices.

185 The WHO recognise this is an issue globally and have developed the Priority Assistive Products List for government toward to achievement of Universal Health Coverage (https://www.who.int/phi/implementation/assistive_technology/global_survey-apl/en/)
The household survey found that respondents do not have access to a wide range of assistive devices. Of the people who use mobility assistive products, 13 per cent use canes and sticks and 2 per cent use crutches. There are very few people with any other kind of mobility product. For example, only 0.5 per cent have a wheelchair. The majority of mobility/self-care assistive products were obtained from sources other than shops/pharmacies, health facilities or donations (64 per cent), and 17 per cent were donated. Health facilities provided the majority of seeing assistive products (41 per cent). Pharmacies and donations were almost equally frequent (28 per cent and 27 per cent) sources of seeing devices.

There is a substantial unmet need for persons with disabilities. Over half of persons with mobility and self-care difficulties who do not currently have assistive products report needing them. Furthermore, very few people have access to hearing or communication assistive products (n=3), with 50 per cent of people with hearing and communication difficulties needing an assistive product. In contrast, 93 per cent of respondents who have vision difficulties and who already have assistive devices have additional unmet needs. Two-thirds of respondents with vision difficulties who do not have assistive devices have an unmet need, with 47 per cent of those who do not have at least one assistive product needing spectacles, and 12 per cent needing magnifiers.

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186 This table is based on the question “Does NAME use any assistive products, such as glasses or a cane?”
7.4 Education System

As part of its wider commitments to the UNCRPD, Uganda has committed to upholding Article 24 of the UNCRPD, (the right to [inclusive] education), as well as SDG 4 (“Inclusive and equitable quality education and promote lifelong learning opportunities for all”). Despite these commitments, a recent review highlights a concerning trend in Uganda, in that the number of children with disabilities accessing all levels of education (pre-primary, primary, secondary) is falling, with the transition from primary to secondary school being particularly problematic. The review highlights that certain groups are more likely not to be in school, in particular girls with physical, multiple and learning difficulties, children with physical and multiple impairments, and children living in geographical areas where enrolment is lower overall (Sarton et al 2017). Other gaps identified in the review include a lack of inclusive early childhood development programmes (ECD), despite a progressive policy around ECD, and a general lack of education facilities in some districts. While education is ostensibly free – and there are bursaries for tertiary education for students with disabilities – many parents and children struggle with the additional costs of uniforms, books, transport and fees charged by the school, as well as stigma and discrimination (Emong and Eron, 2016).

Gender has a significant impact on school attendance for children with disabilities. Figure 70 indicates that while the main reason for not attending school is sickness or calamity in the family for both boys and girls, this is more pronounced among boys. This would indicate that boys are more expected to drop out and start earning money to support the family when the household experiences such a shock. A lack of funding is also one of the main reasons why children with disabilities are not in school, but this is more pronounced for girls than boys, indicating a gender bias in the decision over who to support their schooling. Indeed, Figure 70 shows that parents are more likely not to want to send girls with disabilities to school than boys.
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Figure 70: Main reason for children with disability not attending school

The reasons why parents may not want to send girls with disabilities to school are complex but can include fear for their children’s safety going to and from school, and anxiety about how they will manage in school. This can result in some parents and/or caregivers being over-protective, and (unintentionally) restricting children’s opportunities, for example, for education. Box 22 provides one example of this.

Box 22: Beatrice

Beatrice, a 13-year-old girl with epilepsy, is looked after by her paternal grandmother. Her absent father sends money, but this is done irregularly, as he has many other children to provide for. Her mother left when her father remarried. Beatrice initially attended school, but according to her grandmother, because she had convulsions, she was taken out of school when she was 10. She now spends her day helping her grandmother with the household chores, although she is not allowed to enter the kitchen alone for fear that she may fall into the fire. Consequently, Beatrice is mainly restricted to one room in the house, and if she goes out anywhere, she is escorted by her grandmother. Her grandmother is very fearful that Beatrice is vulnerable to abuse.

Despite the political will to promote inclusive schools, there is limited budget and resources directed towards ensuring all children with disabilities can attend inclusive mainstream schools. While Uganda is one of the few low-income countries that has a specific budget allocation for children with disabilities, these budget lines do not clearly indicate whether finances are for special or inclusive education (International Disability and Development Consortium /Light for the World 2016). This is important as it relates to the additional costs of disability, in particular

Source: Based on own calculations using Disability Situational Analysis Household Survey 2019
the use of additional resources in the classroom, including classroom assistants or support teachers (Price 2018). Moreover, the budget is only 0.1% of the overall education budget (NCD 2019a). This low-level of allocation may be exacerbated by the limited data available about children with disabilities from the education management information system (EMIS), which aggregates total numbers in school by age/sex/impairment, but does not capture dropout rates, or those not in school, thereby giving a lower rate than it is in reality.

Uganda has a range of school settings, including “fully inclusive” schools, integrated units (whereby children are taught in a separate unit within a mainstream school, but play with the other children at breaks etc) and special schools (usually impairment-specific, such as schools for the Deaf). The permitted ratio of students to teachers in mainstream schools is currently 45:1. However, classrooms often exceed this, making inclusion of children with disabilities even more difficult. Of the few children with a disability that do access education, 5 per cent access it within an inclusive setting in regular schools, while 10 per cent access it through special schools and annexes (UNICEF 2012, cited in Sarton et al. 2017). This means that the remaining children who are attending school are not receiving any specific interventions or support. Teachers receive some training on special needs/inclusive education as part of their pre-service training, and if they wish to specialise, they can take a Master’s degree or Diploma in Special Education at Kyambogo University.187

Education is perhaps the sector where the discrepancies between “mainstreaming” (full and equitable inclusion in regular, non-segregated schools), and targeted – or “special” schools ( segregated into specialist schools) – are most keenly highlighted. Special needs education is underfunded and poorly mainstreamed across the school system, and many special schools are of poor quality and/or high cost. It is unclear if the budgets for special education are for special schools or the inclusion of children with disabilities in mainstream schools (International Disability and Development Consortium / Light for the World 2016). Evidence suggests that children with disabilities are much less likely to be in school (at any level) than their peers without disabilities, although this depends on the type and severity of their disability.188

7.4.1 Pre-Primary and Primary

Children in Uganda typically start school at six years old. However, children with disabilities often start later for a range of reasons, including the financial situation of their parent/caregiver, in which the family has to decide which child will go to school and which will stay at home due to limited funds. Often the child with a disability is assumed not to be able to learn, and so is not sent to school at all. One challenge is to have an accurate idea of the numbers of children who are out of school, which is harder to measure. In Uganda, it is estimated that only around nine per cent of children with disabilities regularly attend school,189 although it is unclear if this means they have never gone to school, or whether they have dropped out.

For some children, school is where their health conditions or impairments are initially identified, although there are no routine screening programmes (for example, hearing or vision) that are implemented in schools in Uganda. School-based health services are primarily based around health promotion,190 with other vertical programmes (such as de-worming) being implemented

187 https://kyu.ac.ug/academic-units/faculty-of-special-needs-rehabilitation/
188 UNICEF (2014).
189 Interview, SEN Directorate, MoES
190 https://health.go.ug/community-health-departments/school-health
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as donor funds permit. Vaccination programmes may also be delivered at school-level. However, children have to be in school to access these, so often children with disabilities miss out on these other opportunities as they are not able to attend school (Trani et al. 2011).

There are a range of reasons why children may not be receiving any specific interventions or support for their specific impairment needs, including a lack of identification and assessment processes, a lack of understanding of the needs of children with varying types of impairment, and subsequent inappropriate responses and provision (Sarton et al. 2017). This is particularly the case for assistive technologies (AT)\textsuperscript{191}. The MOES has recently developed a disability identification tool, and allied “Resource Guide to the Learning Needs Identification Tool”, which helps teachers, parents and others identify around 21 different impairments commonly seen in children in Uganda, and what support those children may need in a mainstream classroom. While it will be a useful guide for parents and teachers and other allied professionals, and it will support improved identification, it does not offer much in the way of guidance on where and how to access the additional resources that the child and parent may need beyond the classroom. Ensuring adequate availability of AT for mobility is important since such technologies have been found to create greater community participation in Uganda, especially in education and employment (Abimanyi-Ochom and Mannan, 2014). Harnessing technology and innovation for inclusion was one of the commitments the GoU made at the Global Disability Summit in London (2018)\textsuperscript{192}.

7.4.2 Secondary

Research indicates that children with disabilities – particularly girls with disabilities – do enrol in school but drop out at increasing numbers across the school years. This is due to a range of factors, including a lack of specialist teachers, a lack of accommodations in the classroom, violence, and pregnancy (Nyende 2012, Moi 2012, Devries et al 2014).

For parents, cost is a significant factor in the decision of whether or not to send their children to school. During the qualitative research, some parents with disabilities also emphasised that they did not trust the quality of government schools, and that they preferred to save up enough money to send their children to private school instead. Alex and Otis’ stories, in Box 23, is one example of this.

Box 23: Alex and Otis

Alex, who rents land in order to grow maize, prefers to save up and send his 13 year old son to a private school, paying fees of UGX 70,000 per term, as he and his wife think he “would get a better education” there.

Another man, Otis, who is 57 years old, sends his youngest son to a private school, but struggles to pay the fees. When asked why he did not send his son to a government school, he laughed in derision. Almost everyone interviewed noted the costs attached to free universal education.

\textsuperscript{191} There are also some very interesting pilots taking place in Uganda, though none are without challenges, and none have been scaled up yet, see for example: Morgado Ramirez and Holloway (2019), which talks about the impact of an AT intervention in mainstream schools for children with visual and/or hearing disabilities.

\textsuperscript{192} Ibid. \url{https://health.go.ug/affiliated-institutions/hospitals#-targetText=The%20total%20number%20of%20hospitals,PNFP%20and%2027%20are%20private}. 
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As Figure 71 indicates, despite the stated preference of sending their children to private schools, the household survey results show that the majority of students with and without disabilities attend government-run schools in all regions. The exception is in the Central region, where students are more likely to attend private schools. In most regions, young persons with disabilities are more likely to attend government schools than students without disabilities, with the exception of the Northern region.

**Figure 71: School management, by student’s disability and region**

![Bar chart showing school management by student's disability and region](chart.png)

*Source: Based on own calculations using Disability Situational Analysis Household Survey 2019*

7.4.3 Tertiary and TVET

Given the limited education and employment opportunities for young persons in Uganda, the GoU has made a concerted effort to revitalise youth training, as outlined in the Business, Technical and Vocational Education and Training (BTVET) Act (2008). The Act only makes passing reference to disability issues (Omona et al 2017), although the associated plan of action, *Skilling Uganda: BTVET Strategic Plan 2011-2020*, does make provisions for the targeted inclusion of youth with disabilities. However, the BTVET sector in Uganda has been subject to criticism, in particular due to a lack of funding and attention to training centres, a lack of trained staff and links to the private sector and overall poor image of BTVET (GoU 2019b).

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7.5 Employment and Livelihoods

As noted above, issues around employment and livelihoods form part of the social development agenda in Uganda. As part of its overall commitments to the UNCRPD, in particular Article 27 ("the right of persons with disabilities to work, on an equal basis with others") and the SDGs (in particular SDG 8, "to promote sustained, inclusive and sustainable economic growth, full and productive employment and decent work for all"), Uganda has acknowledged the rights of workers with disabilities. These rights are also acknowledged in its National Employment Policy (2011) and include commitments to, inter alia, the collection of disability-disaggregated data, the removal of employment-related barriers and employer sensitisation around disability issues. Uganda also provides tax incentives for employers who employ persons with disabilities, although as of 2014, there had not been a single application for this (Nyombi and Kibandama, 2014). This likely reflects the very low numbers of persons with disabilities in formal employment. Furthermore, the limited support that the government does provide is largely directed towards the formal sector (the NSSF and PSPS), and therefore, it is unlikely to reach the majority of persons with disabilities who are working, as they are largely based in the informal sector, or, for example, in agricultural production.

As discussed in Section 3.1.2 above, Uganda’s population skews young. However, not only do many young women and men with disabilities enter their working life with lower education levels, but they face both discrimination and higher costs when seeking work, as well as lower incomes when they obtain employment. While some of the interventions to tackle unemployment, such as the Youth Empowerment Programme (YEP), are ostensibly inclusive, they do have some conditionalities attached, which are discussed below. Furthermore, it is difficult to determine whether any of these income generating opportunities have improved the livelihoods or wellbeing of youths generally, and youths with disabilities specifically.

As is demonstrated by Danny’s story in Box 24, even if students with disabilities manage to successfully progress through their education, this does not always convert into employment opportunities.

Box 24: Danny

Danny is a graduate who has a diploma in Environmental Science. He has never been employed in the field he is trained in since he graduated nine years ago. In fact, he has only been employed once, as a receptionist at an organisation for persons with disabilities. He is currently unemployed and feels frustrated, as he notes: "I feel so discouraged as I have a diploma in environmental science but still, I cannot get a job. No one will employ me because I am blind… this is what? Discrimination, yes and stigmatisation”.

Poor literacy rates for persons with disabilities result in a curtailment of life chances, such as limited employment opportunities (Lang & Murangira 2009; World Bank 2009) and poorer health outcomes. This is exacerbated by a lack of catch-up or adult literacy programmes for persons with disabilities, despite Uganda having a Functional Adult Literacy (FAL) Programme, which seems to have been more successful for certain groups (for example, women without disabilities) than for persons with disabilities.194 Moreover, not only are there only a few accredited training

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Institutions, the limited technology available to support persons with disabilities limits their opportunities of accessing education and training. Miriam’s story, in Box 25, describes how she feels as if a lack of support has left her trailing behind her peers without disabilities.

Box 25: Miriam

Miriam is a 46-year-old woman, with a physical impairment. She explained that: “Even if I work all day, I can’t get the same as what my neighbour is getting. I cannot upgrade. We people with disabilities are like old people. We can do less, and we aren’t as strong. I look at my friends I was at school with, my age-mates. Some of them have got big farms and businesses. All my efforts are used just getting by. The government says leave no one behind but I am unable to catch up.”

7.5.1 Active labour market programmes

According to the ILO, active labour market programmes and/or policies are:

“Interventions that help people find sustainable jobs, promoting directly or indirectly the creation of productive jobs, improving qualifications and productivity of people and guaranteeing links between those looking for jobs and employers.”

The GoU has developed a range of grant-focused active labour market programmes for its citizens. They are included under the remit of social protection, although they do not fit international definitions for social protection, and so are included here. The programmes largely follow the same approaches and are based on a group model to stimulate income-generating activities. Key programmes for persons with disabilities are the Special Grant, which is a grant, and loans-based programmes for specific interest groups, such as the Uganda Women’s Empowerment Fund and the Youth Livelihood Programme. Some persons with disabilities may also access mainstream opportunities and programmes such as vocational training opportunities and civil service jobs.

7.5.2 The Special Grant for Persons with Disabilities

The Special Grant for Persons with Disabilities is a livelihoods programme which provides one-off grants to groups in support of various activities to enhance income generation. The objective of the grant is to improve the incomes of persons with disabilities through the creation of employment and increased productivity. Due to limited monitoring of programme expenditure, there is no central data available on the number of people benefitting from the Special Grant, nor how much they receive. The MGLSD reportedly expects to reach 22,500 persons with disabilities annually through the programme, which corresponds to about one per cent of the estimated population of persons with severe disabilities (or about 3 per cent of the working age population with a severe disability). The limited funds available mean that only a few groups are supported every year. The Special Grant is funded through an envelope of ear-marked funding for activities for persons with disabilities, which also includes funding for Community Based Rehabilitation. Out of the UGX 7.64 billion transferred from the Ministry of Finance to DLGs, the Special Grant is the largest envelope within the budget, taking up 28 per cent of the funding, or about UGX 2.14 billion per year. Currently, there are about 134 districts in Uganda, which means

196 For full review of programmes, please see the companion report Social Protection Diagnostics (Schjoedt et al 2019)
197 Please see Social Protection Diagnostics (Schjoedt et al 2019)
that on average, each district receives around UGX 15 million (about USD 4,000) per year, which is a very small amount. Even though the number of districts has increased, the budget for the Special Grant has reduced from around UGX 3 billion to UGX 2.1 billion, which means that there is less money available for Special Grant groups in each district.

The implementation guidelines provided by the MGLSD to DLGs specifies that the grant should be targeted at the “most vulnerable” persons with disabilities. However, the guidelines do not include any vulnerability criteria or further guidance on how to assess vulnerability, but simply state that the intended beneficiaries are “groups and associations of persons with disabilities at community level”, as well as parents and caregivers of children with disabilities. In practice, eligibility is determined by CDOs and the District Disability Council. The guidelines specify the following criteria for accessing the fund:

- Groups of people with disabilities, Parents and Caregivers of Children with Disabilities, uni-disability groups.
- Applying groups should have a minimum membership of 10 people (considering the gender balance).
- The group executive will consist of the Chairperson, Vice Chairperson, Secretary, Treasurer and Mobiliser.
- The group must present a copy of the registration certificate from the Sub County, Town Council Municipality or District.
- Members of a group should be residents of the same village, parish or sub-county.
- The group has to present a project proposal to the relevant District committee.
- The applications should bear passport size photos of the members of the executive.
- A group should have been operational for at least one year in order to be considered for this grant.

The guidelines also specify that organisations must have the ability to “effectively utilise the grant for the stated purpose and that all categories of impairments should benefit.” There is no specific process for assessing disability to prove eligibility for the benefit, nor is there any process for ensuring the inclusion of a range of impairments. This lack of guidance and processes means that people with invisible disabilities, including mental disabilities, are more at risk of being excluded. The fund is only for income generating activities such as agricultural production, metal work, tourism, and woodwork.

The Guidelines for the National Special Grant for Persons with Disabilities (NSG) were updated in December 2019. While most of the criteria remain the same, the requirements regarding the size of the group have changed, and a group can now be as small as five members. This was a response to criticisms that it was difficult to find 10 persons with disabilities in the same parish, and that bringing together groups from a wider geographic area would make it difficult to work together as distances would be too far apart. Individuals and groups are required to register, form groups and open bank accounts before their application – which is written in English - can even be considered, which already creates a number of barriers for persons with disabilities.
7. Service Provision

The grants are allocated through District Special Grant Committees. Members of this committee include representatives from the District Council for People with Disabilities (the local branch of the NCD). One interviewee, Patrick, is Chair of the Gulu District Disability Council (DDC). This automatically excludes him from applying for a Special Grant at district level, however he was able to successfully apply at the level of the municipality (which has grants up to UGX 1.5 million, and which funded 6 groups during the FY 18/19). He received his funding in FY 17/18, and his group purchased 15 goats – one for each member, which they distributed amongst group. Most still have at least one goat. Patrick explained that part of the role of the DDC is to monitor government and NGO disability programmes, but it has limited capacity to do this due to a lack of budget. In reality, the DDC is only able to monitor groups in the municipality, and it has not been able to monitor any other groups apart from Special Grant groups. Patrick explained that the DDC could be more active and responsive if the funds for monitoring groups were increased.

A number of barriers contribute to the low application rates for the Special Grant. Patrick explained that there are various reasons why persons with disabilities do not apply, including distance, with those further away from the trading centres missing out. However, the DDC does try to support them. A further barrier is administrative, as the process has many stages including registration, verification, certification, opening a bank account, and obtaining photos (individual and group). It is therefore challenging for many persons with disabilities, particularly those who are vulnerable, such as those who have "poor housing, and are neglected by [their] family...".

There is blurring between older persons with or without disabilities and whether they should access the Special Grant. This particularly applies to older persons who are under 80 years of age, and who are therefore not yet eligible for the SCG. In practice, in some groups, older persons are included, whereas in other group, they are excluded. When asked if older persons can be described as persons with disabilities, one Chair of a DDC stated "yes, to an extent...", but then talked about a Special Grant group that included two parents of children with disabilities, with the rest being older persons. However, the older persons were told that they "did not qualify" as they were "just old".

Nelson has been Chair of Nakasongola District Disability Council for the past seven years. There is a total of 13 Special Grant groups (one in each sub-county), and the total is around 190 persons with disabilities. However, he thinks that many persons with disabilities who should be in the groups are not benefitting because of registration and membership fees (according to Nelson, it costs UGX 5,000 to register and a further UGX 5,000 in membership fees). Another challenge is that many persons with disabilities do not have any disposable income, and so spend the little money they earn on essential items rather than saving it.

In Nakasongola, most of the population live in poverty and do not own land. However, Nelson explained that those who live in extreme poverty can be identified as those who only eat “plain food” (starch without sauce) or eat fewer meals; single women; and those whose houses are in very poor condition. Unfortunately, even though those who live in extreme poverty are the most in need of the Special Grant, they are the least likely to attend meetings – for example, this may be because they have no clothes to wear. When asked who are left out, Nelson stated: "the blind, as they can’t see how much money they are getting"; epileptics; the Deaf "are ok, they can do work, but may not get the communications about the meetings"; people with mental health conditions; and parents of children with disabilities, although “they are represented on the

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7. Service Provision

board”. He also knows of group members who are not delivering on their commitments – for example, they will sell their allocated animals in order to receive money but will tell the monitoring team that the animal died. He understood why they did this, however, because they are “…poor and want money, therefore the goats don’t get a chance to multiply, and lose value”. However, goat rearing is still one of the main activities people want to do.

Nelson also highlighted a common issue, that persons with disabilities see the Special Grant as “their own”, so do not apply for other funds, such as the Youth Livelihood Programme. Nevertheless, he emphasised that the council and DCDO try to sensitise people about the fact that they should also join other groups, which has resulted in some groups being more inclusive – and “in fact, these are doing better”. Nelson also explained that he thought this has led to a reduction in discrimination in his district. He also noted that the DCDO and District Inspector of Schools have a radio programme to “motivate people with disabilities every week”.

Nelson explained that the number of applications for the Special Grant in Nakasongola district is far fewer than those for other grants, such as the Youth Livelihood Programme and the Uganda Women’s Entrepreneurship Programme. This reflects the smaller amount of funding that is available for the Special Grant. In his district, he explained that the DDC is only involved in the selection process for the Youth Livelihood Programme and the Uganda Women’s Entrepreneurship Programme if there are persons with disabilities’ in the group, although this is unverified.\textsuperscript{199} The selection criteria seems to be based on fairness, rather than quality, with a rationale that all groups have an equal chance of accessing the grant. The council tries to prioritise by location (for example, if the parish has not received any funds before), and if a group is not successful in one quarter, they are rolled over to the next. It therefore seems that most applications receive funding eventually. In Nakasongola, there are currently six applications pending, but Nelson explained that he was sure that most would receive funding in the next quarter – four groups would be selected (at a value of UGX one million each) and the remaining two would roll over to the next quarter and would be top of the list. Nelson further emphasised that delays can occur at any point in the process, including opening of bank accounts, registration and/or the payment processes. As far as he was aware, no specific support is provided to assist persons with disabilities, although in many cases, the CDOs provide help.

An evaluation of the performance of the Special Grant by the NCD (2018) found that the allocated UGX 3 billion was shared across all districts, and there was some evidence of new businesses being developed, increased social interactions, and the formation of a savings culture. Furthermore, some beneficiaries were able to pay school fees for their children and access basic health needs. However, the evaluation also found that the money was too little for the number of districts, there was a lack of clear guidelines, and the proposed National Steering Committee has not sat since the Grant began operating. In addition, the evaluation reported that there were allegations of corruption and misappropriation of grant funds at district and beneficiary level. One of the biggest challenges was the merging of the grant into the social development fund, making it impossible to monitor (although with the new percentage allocations being introduced in FY19/20, this may change). Further criticisms include the lack of a baseline by which to monitor improvements, the little training that is provided on how to apply for the grant, and a “charity” focus in which the grant is perceived as a handout, rather than a rights-based empowerment process, although perhaps was the intent behind the grant.

\textsuperscript{199} Bearing in mind the criteria for both includes persons with disabilities in the groups.
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The NCD made a number of recommendations, including strengthening market analysis to better inform those in need; providing training in basic business management skills; introducing tighter regulation and monitoring, including the National Steering Committee; and increasing funds. Several of these recommendations were taken up in the revised Guidelines for the National Special Grant for Persons with Disabilities, which were updated in December 2019.200 The revised guidelines now include a provision for a National Programme Coordinator, who will have overall responsibility for the programme. However, this obviously only addresses coordination of the National Special Grant (NSG). At district level, the NSG will be coordinated by the (Senior) Community Development Officer (CDO) who is already responsible for disability and elderly affairs. An overall monitoring and evaluation strategy is in development as well, so was not provided with the guidelines. However, the guidelines note a range of M&E tools, including that an, “Impact evaluation using an appropriate evaluation design will be undertaken periodically to measure impact. Other specific studies such as Beneficiary Assessment, Tracer study and Community Score Card or Citizen Report Card will be conducted” (MGLSD 2019). The guidelines also include templates of the application form, the business plan, budget and cost analysis. As before, the MGSLD has final approval for funding for the Special Grant. As this is a new process, it remains to be seen how effective its implementation will be, however, numerous DLGs have reported confusion about the purpose of the fund.

The evidence from the research also suggests that the main barrier to accessing the Special Grant is the very limited funding available. Only a few groups in each district can benefit each year, and the benefits provided are too limited to be meaningful. In addition, the requirement to form groups and submit proposals is also a significant barrier for persons with disabilities. As discussed above, there may not be sufficient persons with disabilities in an area to form a group, and there are significant expenses associated with registering groups, opening bank accounts etc. Furthermore, the development of proposals requires both skills and resources that many persons with disabilities may not necessarily have been afforded the opportunities to have.201 Indeed, respondents felt that persons with disabilities should receive better training on business skills and management training.

“Well the capable persons with disabilities will be able to form the groups – and one or two people will run the groups. Other members are passive participants. Communities are complex, it takes time to understand the real issues.” Principal Assistant Secretary, Tororo District Government

“Before, the groups did group projects, but they had challenges with management. One person ends up doing the project alone and the project dies. So now each member gets their own goat” Chair, Kyegegwa District Association of the Deaf

On the one hand, while some of the people interviewed felt that participation in a group increased transparency and cooperation, there were also suggestions that the Special Grant contributes to segregation, as it is regarded as being specifically for persons with disabilities, rather than facilitating inclusion in mainstream programmes such as the YLP and UWEP (despite there also being quotas for persons with disabilities in the groups). This exclusion continues across other ministries and departments, from the national- to district-level, and may be partly

200 The name was amended but the term Special Grant and National Special Grant are used interchangeably and mean the same thing.
201 Please see Social Protection Diagnostics (Schjoedt et al 2019)
due to the limited understanding among district officials of what inclusion means, and what it takes to include persons with disabilities in practice, along with a lack of guidelines to assist them. These misinformed opinions continue, despite there being representation of Councillors at the District level.

Finally, the Special Grant should not be considered as a social protection programme. It provides a one-off lump sum payment and does not provide recipients with immediate support for health or education expenses, unless they sell their assets, which many end up doing. In many cases the grant is split into individual benefits for each group member once the money is paid, which makes it seem counterproductive to require the formation of groups in the first place. It may be more effective to provide individual rather than group-based benefits, especially if combined with business support and/or more in-depth skills training. Group based livelihood support is also unlikely to lead to sustainable job creation or income for most people, as more systematic support would be needed to aid the development of markets and value chains, along with the integration of low-income producers.

Monitoring and evaluation systems must be strengthened, and resources increased, in order to effectively monitor both the progress of the groups and how the programme is being implemented in the districts. Overall costs – such as registering groups at the sub-county – should also be reduced. There is also the real risk that the programme is a burden for persons with disabilities, as they are required to spend significant resources on registering for the programme and must then wait for a long period of time in order to receive limited support, with no real sustainability.

7.5.3 Government Rehabilitation Centres

The MGLSD oversees five Rehabilitation Centres. These centres function as livelihood training centres for persons with disabilities and enrol students from the age of 16 years up to around 40 years for residential skills training courses. The centres are managed by Rehabilitation Officers (ROs), who report to the Senior Rehabilitation Officer via the monthly Senior Management Team meetings at the MGLSD, in which waiting lists, training needs etc are discussed. The Rehabilitation Officers are predominantly young civil servants, with very little training or experience in rehabilitation or disability.

According to the ROs interviewed, none of the Centres operate at full capacity due to budget constraints. Kireka, Arua and Jinja currently have around 50 students each, and Lweeza has about 20. However, these numbers are not fixed, and are significantly below capacity, as each Centre should cater for around 100 students. Whilst the Ruti Centre is closed for renovation, the other Centres are in poor condition from decades of underinvestment. The Centres have been subject to criticism about the lack of resources, the curriculum not being aligned with wider BTVET policies or practices, poor training, structural issues with the buildings and cases of land grabbing, including by former residents (NCD 2014).

Although the training is meant to last 12 months – from June to July – in practice, many students return for a second year to complete their training as the Centres often run out of funds before the training has been completed. All training is ostensibly provided for free, including board and

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Please see Social Protection Diagnostics (Schjoedt et al 2019)

Though only one has had any training in disability or rehabilitation - most are social science graduates in the civil service scheme (interview).
lodgings, which are covered by the budget from the MGLSD. Training is based around standard vocational training courses of carpentry, metalwork, beauty, tailoring and crafts, but availability is largely based on the existing instructors’ skills. In theory, students can register at one Centre, but be sent to another if the training is not available at the Centre they enrolled at. However, if the Centre is full, the student is put on a waiting list for the following year. There are currently waiting lists at all five Centres.\textsuperscript{204}

Potential trainees can be referred by several sources, including CDOs and DPOs. A letter of recommendation is required to register for assessment by the Centre, along with an assessment by the District Medical Officer (DMO) or local health centre to confirm their disability. According to the SRO, the centres can cater for most types of impairments, but not mental health conditions. A medical assessment is undertaken by a nurse based at the Centre, who confirms the degree of disability, functional limitations, etc of the applicant. If the nurse is unsure about disability status, or needs a second opinion, the student will be referred to a medical officer. There is a simple form to fill out about disability status. The student is also assessed by the Rehabilitation Officer to determine what the student wants to learn and if this matches their capabilities. Once students have completed their training, they can return home, although in practice, many do not, and they tend to remain in or near the Centres. These means that, as with “special schools”, there tends to be communities of persons with disabilities living nearby.

Upon graduation, there is no specific process of notifying referees, nor are graduates provided with any start-up packages, or indeed, any business contacts.\textsuperscript{205} This means that although graduates have completed their training, they may not have the resources to start working. Furthermore, there is no system to formally follow-up with graduates. None of the Centres have outreach programmes, so CDOs are the only means of connection, but this is done on an ad hoc basis. Consequently, it is not possible to track if students have accessed other services, or, indeed, if they have put the skills they learnt to use. It is therefore difficult to measure the impact of these programmes. However, by chance during one of the interviews, the research team did meet a successful graduate from a rehabilitation centre who now uses the skills he acquired from the Centre. Aaron’s story is described in Box 26.

Box 26: Aaron

Aaron is a young man from a farming background with a physical disability. Because of his disability, he did not start school until he was 10 years old. His mother and father worked hard to put him through school, looking after other people’s cows and selling crops to earn money. Aaron graduated from secondary school and was selected to attend the government vocational rehabilitation centres in Mbarara (Ruti Rehabilitation Centre). He wanted to learn how to make shoes, but it was not taught at the Centre. Nevertheless, Aaron persevered and with the support of the staff at the Centre he learnt how to make shoes, and after graduating, he obtained a job as a shoemaker. He works very long hours, and lives on-site at the shoe shop, paying rent to his boss. Aaron earns enough to hire a houseboy for five days a week, whom he pays UGX 20,000 to assist him with chores such as cooking and washing. Aaron is saving up to set up his own shop, and eventually wants to have a wife and children.

\textsuperscript{204} Interview with SRO.

\textsuperscript{205} When the centres were first set up (in the 1980/90s) – students would get job placements and resettlement packages, but there are no longer any funds for this.
While Aaron appears to be one of the more successful students, in reality, the numbers who graduate from these Centres each year is very small, and it has been argued that the Centres perpetuate a segregated model of disability, rather than ensuring that those with disabilities enjoy the same level of access to existing mainstream training programmes (NCD 2014). However, it is difficult to obtain accurate data on the numbers of persons with disabilities who are enrolled in existing BTVET programmes,\(^{206}\) despite commitments to inclusion in the Business, Technical and Vocational Education and Training Act (2008).

### 7.5.4 The Youth Livelihood Programme\(^ {207}\)

The Youth Livelihood Programme (YLP) follows the same model as other livelihood grants and is designed as a group-based loan scheme for income generating activities. Its focus is groups of unemployed youth aged between 18 and 30 years. The YLP provides loans of a maximum of UGX 12.5 million, although some exceptions can go up to UGX 25 million instead. The loans are interest-free the first year to incentivise prompt repayment, with a five per cent interest rate added on the subsequent years. Loans are to be repaid within three years, following an agreed payment schedule. This is adapted to the nature of the project and the business plan. There is some possibility of rescheduling, but if loans are not repaid as agreed, the district may take legal action to recover the funds. The repayment rate was around 53 per cent in FY 2018/19, and although this has increased since the inception of the programme, there are some groups that are not expected to ever be able to repay the funds. The programme has come under criticism of corruption, and it has been alleged that some groups are promised dispensation in return for political support – this is sometimes cited as a reason why youths with disabilities do not “bother” to apply.

The YLP Guidelines specifically state that activities should include some specific categories of youth, such as single parents, those with disabilities, and dropouts from schools and training institutions. Furthermore, at least 30 per cent of participants should be female (GoU 2019). Given these criteria, it might be expected that youth with disabilities are well represented. However, there is no specific target for the number of young women and men with disabilities, nor does the programme document provide any specific guidance on how to define or assess disability or how to ensure inclusion of young persons with disabilities. According to data from the programme MIS (GoU 2019), 6,770 young persons with physical disabilities (persons with other disabilities are not mentioned) have been reached by the programme so far, which is 2.8 per cent of the total number of beneficiaries. While this percentage corresponds more or less to the prevalence of “severe” disability (“has a lot of difficulties” or “cannot do at all”) among young people, it is not possible to determine that level of difficulty that these youth with disabilities have (so in fact may have only a little difficulty, in which case the numbers should be much higher). Either way, youth with disabilities are underrepresented in the programme.

At the national level, the MGLSD YLP programme team works with a number of public and private business incubators and other stakeholders to improve inclusion rates of young persons with disabilities. The “Make 12.4% Work” project supports the inclusion of youth with disabilities in work through the production of booklets that are aimed at employers and persons with disabilities themselves. The booklets give practical summaries of a range of activities, along with

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\(^{206}\) \url{http://www.btvet-uganda.org/}

\(^{207}\) For all full discussion of the YLP, please see report Social Protection Diagnostics (Schjoedt et al 2019)
the costs and types of work/support for different impairment groups. \(^{208}\) Under this initiative, the team is also making videos to document and incentivise youth with disabilities, all with the aim of increasing and supporting the inclusion of youth with disabilities into the YLP.

In general, Deaf persons do not benefit from the YLP, and this is also the case across a range of programmes in Uganda. Blessing’s story, in Box 27, is one such example.

**Box 27: Blessing**

Blessing, a young Deaf woman in Kyegegwa, explained that nobody has invited her to join a YLP group, even though she would like to be part of one. She knows there are many youth groups, but does not know of any individual groups, so cannot join. She explained that: “Nobody like the CDO has come to talk about the groups of youths to me. We went as a group to visit the CDO and present our application, but our group was not considered.”

District focal points for the YLP are responsible for monitoring the programme, and 10 per cent of the overall funding for the programme is used for this purpose. Similar to the Special Grant, members of the Youth Councils are also supposed to monitor the projects but have insufficient resources to do so. District focal points submit quarterly reports to the MGLSD against key performance indicators, such as the number of groups, the number of women, and the repayment rate. However, as youth with disabilities are not a specific target, this is not reported against. The programme MIS includes data on the number of beneficiaries with disabilities, and whilst this is disaggregated by gender, there is no disaggregation by impairment type or degree of severity of the disability.

An MGLSD commissioned quantitative impact evaluation of the YLP has shown that after one year, the programme had not significantly increased weekly cash earnings, either as reported by the youth themselves or as a sum of earnings. At end line, the treatment and control youth earned on average UGX 77,552 and UGX 87,133, respectively. The evaluation did not examine the impact that the programme had on young persons with disabilities specifically (Bukenya et al. 2019).

While many DDCs are already working to support the mainstreaming of disability into the YLP, there are a number of challenges that make it difficult for youth with disabilities to access the programme. The first is the requirement to submit written proposals, which may present a barrier for young persons with disabilities both in terms of skills and resources. Groups require registration, which may necessitate having a national ID card, and this may prevent some persons with disabilities from registering with groups if they do not have one. Membership fees and other costs may also reduce the likelihood of youth with disabilities participating. Another challenge is the requirement that group members are from the same village, as there may not be enough youth with disabilities in the village. The inclusion of young persons with disabilities in mainstream groups therefore requires more sensitisation about inclusion, and more resources to support their participation, such as enhancing communication for Deaf youth. Another option, focusing on self-reliance, would be to provide individual loans to young people who already have a business, or want to start a business, in tandem with support and skills development. This may increase the likelihood of success and return on investment. \(^{209}\)

\(^{208}\) A project funded by the UK National Lottery, led by Light for the World (http://wecanwork.ug/).

\(^{209}\) For full discussion of this please see Social Protection Diagnostics (Schjoedt et al 2019).
7. Service Provision

Perhaps one of the biggest barriers is the contradiction that the programme targets “vulnerable youth”, who, by definition, may be the least able to access the programme without specific support, and even if they do, may experience challenges with the group and/or repayments. Providing regular payments to this group rather than a one-off loan would be a more stable and reliable source of income, which they could use in ways more appropriate to their needs and which would be more in line with social protection goals.

7.5.5 The Uganda Women’s Entrepreneurship Programme

In addition to the YLP and Special Grant, women between the ages of 18 and 79 years\(^\text{210}\) can apply for the Uganda Women’s Entrepreneurship Programme (UWEP). Although the UWEP was initially implemented in 2015, it was rolled out nationally in FY 2016/17. The programme is designed to address the specific challenges that women face in undertaking economically viable enterprises including the limited access to affordable credit, limited technical knowledge and skills for business development, limited access to markets, and limited information regarding business opportunities. Similar to the YLP, the UWEP functions as a national revolving loan fund, providing loans to groups of 10 - 15 women. Typical projects pertain to agriculture, craft making, beauty salons, catering and other enterprises. Projects are not generally based on market research, but on the expectations and experiences of the women.

Priority groups that are targeted by the UWEP include single mothers, widows, survivors of gender-based violence, women with disabilities, women living with HIV/AIDS, women who are heads of households, slum dwellers, women living in hard to reach areas and ethnic minorities (GoU 2016). UWEP has a comprehensive Operations Manual, which states that “the Programme interventions will as much as possible be sensitive to and have special considerations for women with disabilities”. Whilst the manual mentions women with disabilities as part of the target group of vulnerable women, it does not provide any further guidance on how to ensure inclusion of women with disabilities beyond that, nor does it provide any specific guidance on how targets or quotas for the number of women with disabilities included in the programme are monitored or enforced. As far as the research could ascertain, there has not been any training on disability for local level officials involved in managing the UWEP.

Groups have a total of three years to repay their loans. During the first year, the loan is interest free, and there is a five per cent interest rate in subsequent years. Loans are repaid quarterly according to agreed repayment schedules. The maximum loan that is provided is usually UGX 12.5 million, although there have been exceptions, in which loans have reached up to UGX 25 million. The UWEP has supported 9,381 projects involving 117,551 women during the 2016/17 and 2017/18 financial years (4,690 projects and 58,775 individuals per year). According to the programme’s MIS data from the MGLSD, 27,164 women with disabilities have so far benefited from the programme, which is 23 per cent of total participants to date. However, the research found that overall, women with disabilities do not find the programme very accessible or inclusive:

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\(^{210}\) For full discussion of UWEP, please see Social Protection Diagnostics (Schjoedt et al 2019)

\(^{211}\) The upper age limit was recently increased from 65 to 79 years in response to the increase of the eligibility age of the SCG to 80 years to ensure lifecycle coverage.
“They say ‘we have money for women, but you have a disability so we cannot give it to you. The money is for women.’ We do not yet know of women who have received this money who are persons with disabilities and yet we are also women.” (Women with disabilities, Kyegwa).

There is no specific disability assessment mechanism for the programme, and as with the YLP and Special Grant, women with disabilities face a number of challenges during the application process, including access and inclusion in awareness raising meetings, proposal development, and stigma around their ability to work, which may make other women hesitant to include them as they depend on them to pay back their share of the loan. Women with disabilities find it difficult to participate in mainstream groups as well as forming their own groups, due to the number of requirements. Furthermore, while a larger amount of funding is available through the UWEP than the Special Grant, the fact that it is a loan, rather than a grant, deters many women with disabilities from accessing it in the first place. If they do apply, the application process is very long and requires significant time and resources, as with all the group-based grants.

There has been no evaluation of the UWEP programme to date, so it is difficult to measure the impact that it has had on women with disabilities. Disability disaggregated data should be monitored and there should be performance indicators for disability inclusion in the programme. However, the programme would likely be more accessible, as well as have a better impact, if credit were provided to individuals who already have business experience. This could be group or individual loans. Given the stated aim of targeting specific groups of women, a number of affirmative actions could and should be introduced, such as setting a target (quota) for the number of women with disabilities, reducing the required number of group members, and waiving the five per cent interest rate after the first year for groups of women with disabilities.

As with the Special Grant and the YLP, for women considered to be particularly vulnerable (for example, some women with disabilities), unconditional income support through a social protection cash transfer programme would be more appropriate to their needs.

### 7.5.6 Northern Uganda Social Action Fund (NUSAF 3)\(^{212}\)

NUSAF 3 is a cash and/or food for work and livelihoods programme designed to address poverty and vulnerability in Northern Uganda. It is currently in its third phase and is funded by a World Bank loan.\(^{213}\) It is implemented by the Office of the Prime Minister (OPM) and the Inspectorate of Government and is supported by a national Technical Support Team headed by a Director and staffed by relevant technical experts. The programme is implemented by local government entities at the district, sub-county, parish and village levels in beneficiary areas.

One of the key components of NUSAF 3 is “Labour Intensive Public Works”. This is targeted at “poor and vulnerable” households and provides a total of 54 days of work to participating households over the lifetime of the project. Participants are paid UGX 4,000 a day up to a total of UGX 216,000 over the project period for this work. Although the programme is meant as a household benefit, in practice it provides payments to individual workers, and large households are allowed to have more than one member participating in the programme. Ten per cent of the funds are set aside for “Direct Support”, which is provided to people who are deemed unable to

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\(^{212}\) As this is a complex programme which is extensively discussed in the Social Protection Diagnostics report (Schjoedt et al 2019), only the key findings are presented here.

work and for whom it is therefore not mandatory to participate in the work (although it is encouraged that people participate to the extent of their ability). Those unable to work are identified by “Community Watershed Committees”. People on Direct Support receive the same amount as those participating in the public works component. The Community Watershed Committees also select which works will be undertaken each year and prepare multi-year watershed plans, with each watershed including several villages. Community Watershed Committees are required to include women, in order to ensure that women are involved in the decision-making process – for example, when selecting the types of public works activities to be adopted and their locations. There is no requirement for persons with disabilities to be represented, although in practice, they were represented on several committees that were interviewed for the research.

While NUSAF 3 has not been designed to be accessible for persons with disabilities, the research found that persons with disabilities may be included in the programme by community leaders (Schjoedt et al 2019). However, as there is limited training and guidelines available, inclusion is ad hoc rather than coordinated. An assessment of the impact of NUSAF 2 on the lives of persons with disabilities in one sub-county in Gulu District similarly found that there had been no consideration made for the various needs of persons with different types of impairments (Ngirabakunzi & Malinga, 2013).

In order to overcome the multiple barriers to inclusion, a more targeted effort needs to be made to ensure the engagement and participation of DPOs in the planning and implementation of the programme. Furthermore, disability inclusive guidelines on assessment of disability and/or work capacity should be developed. As with several other programmes discussed above, the introduction of targets or quotas for the numbers of persons with disabilities enrolled in the programme may increase inclusion. However, this would need to be in tandem with overall guidance on inclusion in public works programmes, such as specific tasks, provision of adapted tools and accessibility of work sites. All of these issues are already in policy and legislation in Uganda.

7.6 Agriculture programmes

Agriculture is the backbone of the Ugandan economy, and according to the household survey, after health-related shocks, climate related shocks (agriculture-related, drought, irregular rainfall, food price fluctuations) were the biggest household shocks, for both households with and without disabilities. While this may reflect the impact that the climate is having on agricultural production globally, there is limited data available on the inclusion of persons with disabilities in efforts to adapt agricultural practices in low- and middle-income countries.214 While there is a small but growing literature around disability and climate resilience (Kett and Cole 2018), limited attention has been paid to the inclusion of persons with disabilities to address these challenges in Uganda, as evidenced by the lack of policy focus.

As demonstrated in Figure 72, according to the household survey, land ownership between households with and without persons with disabilities does not vary significantly, although it should be remembered that this is at the level of the household, and so it is not clear who has control of the land. Women are less likely to own land than men due to inheritance laws and divorce, putting women in a more precarious position if they lose the land. In Uganda, the burden

of cultivation (as well as domestic work and childcare) falls largely to women (see, for example, Peterman 2010; FAO 2017).

**Figure 72: Agricultural land ownership by whether household has a member with disabilities and size of land**

Agricultural production, including growing crops (especially matoke and maize), are undertaken by households with and without persons with disabilities alike. Figure 73 demonstrates that there is little difference between households with and without persons with disabilities in terms of livestock ownership, with poultry and goats being the most popular (and easiest) to farm. Agricultural production and animal husbandry are popular activities for the group-based livelihood interventions under the Special Grant, YLP and UWEP. However, as noted above, many groups divide up the assets, and informants reported that individuals ended up having to sell these assets to meet unexpected costs, for example medical treatment. In addition, it is less clear how disability-inclusive the training or follow-up activities are, that are provided, for example, by agricultural extension officers.
There are a number of other programmes focused on agriculture across Uganda, and one of the largest is the Operation Wealth Creation (OWC). Originally implemented by the National Agriculture Advisory Service (NAADS), in 2013, the President invited the military to support delivery to improve effectiveness. OWC does not deliberately include or exclude persons with disabilities, although there were some examples given during the qualitative interviews of households that were given cattle because they had a member with a disability. In order to benefit, households must register to undertake farming activities, such as planting trees. This entails a registration fee, which one interviewee reported costs UGX 20,000 to register as a member, and a further UGX 10,000 to obtain farming implements for two seasons. In some areas, there are restrictions on the type of crops that can be farmed. In addition to the registration fees, other challenges include a lack of awareness about programmes and the speed in which they can be accessed. Patrick, the Chair of the DDC in Gulu, explained that in his sub-county, persons with disabilities were too slow to access the livestock distribution point, and the unclaimed cattle were returned to government and not distributed. He suggested one solution to this would be to provide transport for persons with disabilities.

Other interviewees reported that land ownership is a prerequisite to accessing these programmes, and the size of the land determines the type of animal provided (if a person is lucky enough to be selected). For example, ownership of an acre of land would qualify the beneficiary for a cow, a goat, or fruit trees etc. Those that do not own any land are unable to benefit from the programme. Even if there is some confusion over criteria, it is clear that programmes such as the OWC largely benefit those with some existing resources. While this means they are more likely to be able to take care of the animals or crops and ensure they become profitable, it also means that those without do not benefit, which further perpetuates their lack of assets.

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215 http://operationwealthcreation.org/what.html
7. Service Provision

7.7 Land, Housing and Urban Development

Land ownership and usage play a significant role in the lives of persons with disabilities, as a source of security (if they have land tenure), as a source of food, and as a place of belonging to a community. Many people move to find better land, or available land, or to work on someone else's land. Owning land and a house are key goals for most persons with disabilities interviewed, due to the security that these assets provide for both them and their families. Working hard and owning land and livestock are seen as key to escaping poverty and hunger, and interviewees emphasised that those who are not able to “dig” (farm) are literally unable to feed themselves and must rely on others to support them.

This means that those living in areas where there is "common land", or very little available land – such as in urban areas – will struggle to find security for themselves and their families. These people may, for example, rent out their labour to others, working on the land for a negotiated daily rate. Others who have moved to urban areas may end up living in precarious accommodation, often in informal settlements. These areas of the city are prone to sudden and extreme flooding. One woman, Miriam, who is in her forties and has mobility difficulties, lives in the Kawempe informal settlement. She told of how her home is located in a swampy area which floods when it rains. Water can often reach up to a metre or more inside the house. Signs of flooding in the settlement are clearly visible, as doors and surrounding areas are covered in sand in expectation of further flooding. In Kampala, there is a slum clearance programme underway to make space for a new flyover as part of a road expansion project. This means the homes and places of employment, such as markets, are in a very precarious situation.

Informal settlements generally lack services, which reduces the standard of living that inhabitants can enjoy. Utilities such as electricity are often connected illegally or not at all. Refuse collections are sporadic. Residents of informal settlements are generally among some of the poorest and most vulnerable within any city, and those with disabilities living in these circumstances may find their vulnerability is compounded even further as a result.

A small number of persons with disabilities living in informal settlements in Kampala have some access to capital and have invested in income generating projects, such as cattle or land. Often, they invest in their natal homes, which they intend to return to in the future. It is common to meet families in rural areas who are “caretaking” such properties for their relatives.

As Figure 74 indicates, a significant number of households live in a hut or detached house. Furthermore, the majority of respondents live in a brick or mud brick dwelling, with corrugated iron or thatched roofs and earth or sand floors. These would be typical of the houses in rural areas. Overall the types of houses people live in are similar for households with and without persons with disabilities.
Figure 74: Housing conditions by whether the household has a member with disabilities

Panel A: Type of dwelling

- Hut
- Detached house (single or multi-...)
- Room /rooms in Main House
- Semi-Detached House
- Tenement (Muzigo)
- Other

Panel B: Type of roof

- Iron sheets
- Thatch/palm leaf
- Concrete
- Mud
- Other

Panel C: Type of wall

- Burnt bricks with cement
- Unburnt bricks with mud
- Burnt bricks with mud
- Unburnt bricks with...
- Cement blocks
- Other
Property inheritance can be a very contested area for women, especially if they are not formally married, or if their husband has a second (or subsequent) wife. Even if a woman does legally inherit property, it can still be a source of tension and dispute with other family members, which can put their lives in a very precarious position. This can also be a problem if a child with disabilities’ mother is single, widowed or in a vulnerable position in terms of her relationships. Hellen’s story, detailed in Box 28, provides further insights into this situation.

**Box 28: Hellen**

Hellen married her husband when she was 19 years old and moved to live with him in his compound. He had been given land by the government as part of a land redistribution scheme in Kiruhura District. Hellen’s house has concrete walls and a tin roof, and there are two other huts in the compound. The family own five cows, and also takes care of cattle for other people too. Their primary income source comes from selling milk.

Hellen was her husband’s second wife. He already had another family, and two of his children still live in the compound. She was much younger than her husband, and they had eight children together, including Stephen, their second youngest, who is now six years old. Stephen has a disability, although Hellen does not know much about it, only that he “can’t walk, can’t talk and can’t hear.” Her husband died in 2018, and Hellen inherited a share of the land and house. This is a constant source of tension between her and her husband’s eldest son, who “inherited the throne” [became head of the family]. Hellen is worried about the future, for example, if one of them wants to sell their share of the land. The son owns the cows, but they are in a dispute about this too. Hellen stated that even though she has very few assets of her own, she will fight for Stephen to receive his share, and will report it to the government if he does not.

There are currently no government housing solutions for persons with disabilities in Uganda, despite policy commitments to support “disadvantaged groups.”
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7.8 Water and environment

Access to water and sanitation is a fundamental human right shared by all. Figure 75 indicates that overall, households in Uganda tend to have similar levels of access to drinking water, with the majority of households using a borehole.

Figure 75: Main drinking water source by whether the household has a member with disabilities

Sanitation facilities are also similarly accessed, and Figure 76 demonstrates that slightly more households with persons with disabilities use a pit latrine without a slab, compared with households with and without persons with disabilities. Furthermore, 29 per cent of households with persons with disabilities use a pit latrine with a slab. It is likely that these facilities are not designed to accommodate the specific needs of persons with functional difficulties. Furthermore, as Figure 76 only shows toilet facility access on a household level, it does not reflect the indignities some persons with disabilities may face in accessing these facilities.

Figure 76: Type of toilet facility and whether it is shared by whether the household has a member with disabilities
7. Service Provision

Infrastructure for water and sanitation is overall quite poor in Uganda, but it is particularly poor in informal settlements, and many lack basic services and amenities. In settlements in Kampala, public water taps are the primary source of water and a household typically pays between 100 to 200 Ugandan shillings to fill a large jerry can. Some residents (those with land tenure) may have their own mains water tap and can charge others for use. Those who cannot afford piped water collect and boil water from springs or groundwater. Most of the water is contaminated, and pit latrines often overflow. Waterborne diseases such as cholera and typhoid thrive in such conditions. Large reservoirs of stagnant water also provide breeding grounds for mosquitos and malaria is rife.

7.9 Programme Challenges

Exclusion from both disability-specific and mainstream programmes happens as a result of limitations in capabilities, not just as a result of impairments, but also as a result of high levels of illiteracy, low levels of education, and a lack of self-confidence among persons with disabilities. Illiteracy and limited education are particularly limiting for programmes such as the Special Grant, UWEP and YLP which require the development of project proposals and completion of forms in written English. There is also a cumbersome (and expensive) registration process, which requires both individual and group registration and photo identification. Whilst the system was set up to reduce fraud, it can be a barrier to many. Payment systems vary in how accessible they are, and the opening of bank accounts can be costly and may require several trips to district headquarters. A main barrier to accessing payments is the travel distance and associated costs.

Limited access to education also presents a barrier to accessing other types of services and to inclusion in society in general. Deaf people are particularly disadvantaged by the limited availability of sign language teachers and interpreters, with many never learning sign language and therefore lacking the ability to communicate. Many persons with disabilities also lack the confidence or self-efficacy needed to demand services.

Widespread stigma, prejudice and misunderstandings also present a barrier to accessing programmes, in particular social protection programmes. Many people view persons with disabilities as people who cannot work and will not be able to contribute, which is part of the reason for the limited participation of persons with disabilities in mainstream programmes such as YLP and UWEP.

Besides more resources, there is a need for a comprehensive capacity building programme to be implemented for all relevant officials and service providers in order to improve understanding of disability. This also includes training key people in sign language or setting aside resources for paid sign language interpreters in key institutions, including district offices and health centres.

It is clear that despite GoU commitments to the contrary, coverage of existing social protection programmes is tiny, and there are significant gaps in what little coverage there is. These gaps are particularly acute for children with disabilities, as there is currently no specific fund for them. Although the Special Grant is also aimed at parents of children with disabilities, this is problematic for several reasons. The first is that as it is a livelihoods-based grant, it takes the parent away from caring for a child as the assumption is that they have to work. The second is that it reduces the number of places available for persons with disabilities, meaning that groups could, in theory, entirely consist of parents and caregivers, and not persons with disabilities themselves. This is at the very least disempowering and absolves the need for the GoU to
consider its responsibilities towards persons with disabilities, particularly those who are unable to participate in group-based activities themselves.

Most available programmes provide limited support and cannot be considered “social protection” as they only provide short-term or one-off grants or loans. While they may provide some assistance covering basic needs, they cannot provide persons with disabilities with the support they need to live independently. The SCG is the only regular transfer available, and even this does not provide a benefit which is sufficient to cover the needs of older persons with disabilities, for example for medical attention or assistive devices.

The second issue pertains to the quotas in these programmes. While setting a specific quota would on the one hand at least attempt to ensure inclusion of persons with disabilities, in line with affirmative action policies, it risks only addressing the “low hanging fruit” – those with mild to moderate disabilities (or visible disabilities) while ignoring those who are less visible. On the other hand, there is a risk that groups will only include the target number, whether this addresses the needs of all persons with disabilities in the district or not. Moreover, quotas may not change how persons without disabilities view persons with disabilities, as it may encourage the already existing view that persons with disabilities are tokenistic, thereby not enabling the required social change.

The third issue is that while group-based livelihood interventions have some benefits including socialisation, accountability and the possibility of undertaking larger projects than would be possible on an individual basis, these groups are not necessarily disability-inclusive. Persons with disabilities may need additional support (for example, access to assistive devices, Sign Language interpreters) in order to be able to participate in the programme in the first place, and this support is not currently offered nor is it available in the majority of places.

Finally, existing monitoring and evaluation mechanisms need to be better resourced – not just financially, but also in terms of capacity. Staff need training and to be made aware of how to increase opportunities for adults and children with disabilities so that they can fully reach their potential. Moreover, in line with much of the focus on employment and livelihoods programmes for persons with disabilities in other low-income countries, the onus has been on getting people into work, rather than on how to retain them in employment once they are working (Mitra, 2018).
8 Discussion and Recommendations

One of the most striking findings from this research is the extent to which most households in Uganda are living with similar levels of deprivation. This means that the majority of households are vulnerable to shocks, for example, catastrophic health expenditure or crop failure, which can force people into extreme poverty. Poverty and vulnerability are therefore not a static status. However, the experience of poverty (and vulnerability) is mediated by a range of factors, including disability status. Households with persons with disabilities are more likely to spend more on health-related expenses and are more likely to have experienced an illness or injury than their counterparts without disabilities. The issue of health expenditure has implications for the discussions around the introduction of national health insurance, and how to ensure persons with disabilities are not excluded from accessing free healthcare in the future.

Similarly, lack of funds is one of the main reasons why children with disabilities are not in school, and further analysis has shown that on average, children with disabilities spend more on schoolbooks, supplies and transportation than their peers without disabilities. The amount also increases with the level of severity of the impairment. This means that the more impaired a child is, the more money the parents/caregivers will need to spend, increasing the likelihood of them not attending school. Perhaps unsurprisingly, it appears that the higher the income of the household, the more money the family spends on their child with disabilities. This reaffirms the issue that children in the poorest and most vulnerable households are the least likely to have any additional resources.

The research also highlighted issues about lack of trust in the quality of current service provision, particularly in the education sector, with many parents making complex decisions about whether to send their child to public or private school, trading cost for quality. The research also raised the issue of the additional costs associated with attending school, and whether there are goods or services available to support the inclusion of children with disabilities. For example, accessible transport services and assistive devices are not widely available in most districts.

The research also found that households with a member with a disability spend more on housing expenses (rent, utilities and household fuel). Again, this means that if money runs out, these households may not be able to pay these expenses, increasing their vulnerability. It is clear that for the majority of households, they have little choice other than to work, even if the work is very low paid or precarious. Those that cannot work are mainly reliant on their family members, community or church; again, this makes households very vulnerable.

It is clear that gender is a significant factor in social vulnerability. Women and girls with disabilities are more vulnerable to shocks and challenges than their male counterparts. This is not due to their impairment, but because of their gender. Existing initiatives to counteract gender inequality in Uganda need to include women and girls with disabilities much more proactively than they currently do, and there needs to be specific targets and indicators to demonstrate this inclusion – the EOC gender inclusive budget indicators are a start, but more needs to be done.

There is also a need to identify vulnerable and at-risk families more proactively. According to the data presented here, 8.5 per cent of the population of persons with disabilities have a disability severe enough to affect their functional abilities in education, employment, etc. There are already
some existing mechanisms in place to help identify this group, and some form of registration is likely to be necessary in order to facilitate access (NIRA or otherwise). However, as the findings show, the level of severity of disability is not the only factor which creates vulnerability, as there are a range of other "risk factors" for individuals and families. These are already well-established, and include household dependency status, female-headed households, death of a parent, as well as less established factors such as siblings taking exams. A more coherent and systematic approach to identifying and supporting such individuals and families is needed. This may not always need to be in the form of financial support or services (although they are necessary) but should also include regular contact with support staff to monitor progress.

There is clearly a need for earlier and better interventions, ideally ones that are alert to "risk factors" for individuals and families. These should start in communities and healthcare facilities, ensuring adequate training on early detection and prevention of impairments, as well as a system of social workers to support individuals and families identified, in particular those at risk of social vulnerability, such as female-headed households. A case management system would provide much needed consistency and would support harmonisation of different sectors. Currently, a major issue is a lack of collaboration between MDAs at national level, as well as limited support being provided to individuals and families outside of existing programmes such as the Special Grant. Currently individuals and families are expected to shoulder the additional burden that disability can bring without any state support. Furthermore, very little attention has been given to supporting caregivers (outside of some NGOs), despite the fact that they form the majority of social care providers in the country.

While a number of affirmative action policies and programmes have been implemented to try to ensure inclusion of adults and children with disabilities, these have largely been a success in the political sphere. While this may be helpful for raising awareness and increasing the profile of (some) persons with disabilities, it has not converted to social success. This can be measured by the extent of mainstream inclusion of persons with disabilities in national development efforts. It is clear that despite affirmative action and favourable policies, most ordinary persons with disabilities face challenges in their daily lives, across their lifecycle. This means that most adults and children with disabilities do not enjoy to the same level of access and inclusion as their counterparts without disabilities. It is crucial to ensure that policies, programmes and interventions intended to lift people out of poverty and ensure enjoyment of rights do not leave persons with disabilities behind. Currently in Uganda, the gap between households with and without persons with disabilities is not that wide, but this highlights that current interventions have not had the intended impacts as yet and it is crucial to ensure that going forward, efforts are made to ensure those who are particularly vulnerable are more proactively included in these efforts, in order to close any equity gaps.

A radical change of strategy is needed to ensure this conversion to social impact, with a coherent and coordinated approach, greater investment and an overarching strategy that includes targets and indicators, as has been implemented for gender policies. Given the cross-cutting nature of disability, which is reflected in many of the MDAs own policy statements, it may also be necessary to move disability to an overarching ministry, such as the Office of the President, or the MOFPED. Such a move would also address the issue of how the GoU can monitor its spending on disability across all sectors, thereby mainstreaming disability rather than focusing on small programmes.
8. Discussion and Recommendations

such as the Special Grant and rehabilitation centres. Current approaches do little to mainstream disability and can in fact have the opposite effect.

Social protection is a right for all citizens and is part of the social contract between citizens and the state. However, there needs to be a much stronger emphasis on what this social contract entails – whilst the citizen is the rights holder and the state is the duty bearer, it should be determined what this means in terms of responsibilities of the state, what current policies are, what resources are available, and how citizens can access them. There is a need to shift away from the perspective that social protection is only for those who are at risk or vulnerable – especially because in Uganda, most citizens are vulnerable to the vagaries of the climate, ill-health or other shocks. An individual benefit based on disability status would therefore enable adults and children (and their caregivers) more autonomy and choice about how they spend their money. For example, they would be better able to address the additional costs of disability, such as personal assistants, transport or assistive devices.

Linked to this is the need to provide social protection across the lifecycle to improve the lives of all its citizens, not just to older adults as is currently the case. Access to other interventions (such as a child benefit, disability benefit for working-age adults, and a pension) across the lifecycle are essential for persons with disabilities, as well as for their families and caregivers. Given the current gap in provision for children, a child disability benefit may form the basis to start a programme, with the eventual aim of providing a disability benefit for working-age adults to provide income support to the small number of persons who cannot work, and to compensate those who can work for the additional costs they experience. Access to one programme (for example, a disability benefit) should not automatically exclude the beneficiary from another benefit, such as the SCG, although it may be capped, as it is in some countries. These benefits need to be in tandem with other support mechanisms (for example, transport discounts and the provision of assistive devices). Eligibility and funding for this requires further analysis on implementation (see McClanahan et al 2019).

How such a system for persons with disabilities is assessed and administered will require some thought – few low- or middle-income countries have managed to utilise a rights-based approach in their assessments for social protection benefits. South Africa, for example, has an assessment system in place for its means-tested disability benefit, but the process has been criticised (Goldblatt 2009; Hanass-Hancock and McKenzie, 2017). Lessons already learned which should be replicated include not restricting the number of benefits or varying the benefit levels that persons with disabilities can access in order to account for multiple sources of vulnerability (Banks et al 2017b). A regular and predictable payment would help address issues of inequality, and may even lead to the intended self-reliance, independence and other aspects that DPOs have always championed, but not quite succeeded in achieving by using the language of rights.

Many existing structures are either not functioning or are functioning at a suboptimal level. Almost all sub-county structures need more resources to effectively carry out their work, including liaising with persons with disabilities. Persons with disabilities are represented through members of the Disability Councils, the district councillors and the Unions of Persons with Disabilities and the various DPOs. However, all of these bodies lack resources (and in some cases, capacity) to carry out their mandate effectively in order to organise and advocate on behalf of persons with disabilities and, some argue, this perpetuates segregation. Councillors representing persons with disabilities can play an important role in advocating for inclusion of persons with
disabilities, but they need training on, for example, the relevant legal provisions and disability rights. In addition, more resources should be made available to enable them to carry out effective advocacy work and connect with grassroots disability organisations.

Households of persons with disabilities face the same shocks as households without persons with disabilities, in particular health- and climate-related shocks. However, it is also clear that in both the health and agriculture sectors, as well as all other sectors, despite affirmative action policies, there is more work that needs to be done to ensure the inclusion of persons with disabilities, including, for example, providing more training on disability for healthcare workers (including VHTs). Disability is not one of the five cross-cutting issues for the agricultural sector even though agriculture is a significant source of shocks for households.

A “twin track” approach is needed – implementing both an overarching and consistent strategy to mainstream disability across all sectors, as well as introducing targeted interventions to ensure their specific needs are addressed. In addition to providing regular financial (and other) support, a broader approach to bolstering resilience is needed, in particular for individuals and families identified as being particularly “at risk”. While the aim is to close the gap between persons with and without disabilities, overall improvements to the economy and society would benefit everyone and lessen the perception that one group are benefitting more than another.

Relying on donors and NGOs to provide goods and services that should be provided by the state perpetuates a culture of dependency and expectation (Reynolds White 2020). It also means that persons with disabilities have to rely on their families and community for support, rather than the state. This may unintentionally perpetuate social – and gendered – norms, such as seeing persons with disabilities as “helpless”, or needing to have large family sizes, and using children as carers. While large families are not in themselves an issue, if there is a greater dependency amongst the family, then it puts the family at greater risk of vulnerability.

There is a need to have a more consistent approach to the delivery of existing programmes and policies. While numerous affirmative actions have been enshrined both in law and in policies, delivery of these actions is inconsistent. While some people benefit, others do not, and this can be due to location, age, gender or type and severity of impairment. Developing a more consistent way to identify persons with disabilities and to connect them to services would be a logical approach here (acknowledging that registration cards are not unproblematic). Here the links between healthcare services and broader assessment processes could be strengthened. Specific agreed targets and indicators around disability inclusion need to be incorporated into national development plans. These targets have to be realistic, and in line with the evidence base, internationally recognised standards and the UNCRPD.

Linked to this, while Uganda has passed anti-discrimination legislation and a number of affirmative action policies, recourse mechanisms are far less clear. How can persons with disabilities claim justice if they are discriminated against, for example, in education or employment? These need to be communicated to a much wider audience, including those who are engaged in discriminatory practices, so that they are made aware that it is illegal to do so. Legal action needs to be in line with wider behavioural change programmes and initiatives, such as public campaigns around inclusion. The national umbrella DPO, NUDIPU, has already run several successful campaigns, but more needs to be done.
Finally, it is also important to realise the limitations of what can be achieved by one ministry. There are already plans in place to revise the National Disability Policy, and this is the ideal opportunity to revitalise a national disability coordination group. The role of NUDIPU as an umbrella organisation also needs to be better communicated. The setting up of a youth-specific arm is a positive development, but many impairment groups appear to feel their interests are not represented by NUDIPU. This is in part because it has grown considerably over the years, but also because the boundaries between its role as a civil society organisation and its political role are often blurred, leading to further confusion.

There is a great deal that has been done in Uganda to support persons with disabilities, including political representation and buy-in for disability issues across the government sectors. There is a need to capitalise on this good-will, but not at the expense of other groups, and it is important to ensure that this good-will reaches beyond the national-level political sphere to the grassroots level. In order to address existing gaps, there is a need to strengthen both disability-specific programmes and access to mainstream social protection programmes and services across the lifecycle for persons with disabilities. Since funding for disability is currently negligible, a significant increase in funding overall is needed to provide the support that persons with disabilities need and are entitled to. The following recommendations have the potential to make interventions – and approaches – be genuinely transformative, with the potential to change the lives of Ugandan adults and children with disabilities for the better.

8.1 Overall recommendations

1. **There is a need for systemic change.** To really address these issues, the system needs to be overhauled, including leadership, coordination, implementation, and the monitoring and evaluation mechanism. Quick wins would be to:
   a. Consider moving disability issues to an oversight office, such as the Office of the President – this would support the social changes needed, as well as the political aims.
   b. Establish the National Disability Steering Committee to aid overall communication and collaboration.
   c. Fund and appoint a position of National Coordinator for the National Disability Steering Committee to support cross sectoral mainstreaming of disability issues (ideally in OPM).

2. **Establish a national disability registration process.** This is necessary to identify persons with disabilities and connect them to services and benefits. Assessment should be based on functionality and social exclusion indicators and should be updated regularly to take into account changes across the life-course.

3. **Introduce a Child Disability Benefit.** Children make up a significant proportion of persons with disabilities in Uganda, so this would be aimed at parents/caregivers of children with disabilities aged up to and including 18 years of age. It should be a universal benefit and have a transfer value of at least the value of the SCG. Providing support to parents of children with disabilities would be an important part of improving access to resources for children with disabilities, as well as improving the lives of their caregivers.
8. Discussion and Recommendations

4. **Introduce a disability benefit for working-age adults.** This should provide income support to the small number of persons who cannot work and compensate those who can work for the additional costs they experience. It should have a transfer value of at least the value of the SCG.

5. **Extend the age of eligibility for the SCG to those aged 65 and above.** This will provide more effective coverage for older persons with disabilities, although will not cover the additional costs that they experience. However, the transfer value should be increased to provide income replacement and the transfer value should be indexed to inflation. For those working in the formal sector, the NSSF should be converted to a social insurance scheme that provides monthly payments of a sufficient enough value to provide income security in old age.

6. **Introduce a care/support benefit.** This is to compensate for the loss of income that family members experience if they must give up work – either partially or completely – to provide care for a person with a disability with significant support needs.

7. **Invest in professionalising and overseeing a national social work system.** Case management, if it exists at all, is undertaken by district level CDOs and Probation Officers. Developing and strengthening the social work function and creating a specific department for social work and social care within the MGLSD would strengthen coordination and case management.

8. **Strengthen the gender focus in disability inclusion, and vice versa, ensure gender-focused initiatives, such as the Gender and Equity Inclusive Budget Indicators, proactively include women and girls with disabilities.** This would require specific targets and indicators on gender and disability to demonstrate this inclusion.

9. **Improve existing income generating programmes.** Provide individual and group loans for those who have some experience in running a small business. The most effective strategy is likely to be to ensure that persons with disabilities have access to existing programmes that provide affordable credit to small-scale entrepreneurs.

10. **Shift emphasis away from group-based approaches.** In active labour market programmes, while self-reliance may work for some, it does not for all, and may in fact lead to counter-productive behaviour such as selling off assets and precarious living circumstances. Individual grants should also be made available for eligible cases, and more support given to groups.

11. **Improve access to mainstream programmes.** Strengthen existing policies and legislation which advocate for affirmative action, for example those aimed at youth, women etc. This will require a three-fold approach:

   a. Develop realistic targets and indicators (in line with evidence, internationally recognised standards, and the UNCRPD), in both programme guidelines as well as national development plans. Data on disability should be included in programme MIS, and existing tools, such as the *National Disability Inclusive Planning Guidelines*, should be implemented and enforced.
8. Discussion and Recommendations

b. Ensure representation of persons with disabilities on programme selection committees and provide additional resources for this as needed (for example, Sign Language interpreters).

c. Strengthen existing recourse mechanisms for complaints (for example, the ombudsmen). If none exist, develop them.

12. Train government staff on disability inclusion. Disability mainstreaming should be a core component of pre-service training for government staff, as well as part of continuous personal development (CPD). This could be undertaken in collaboration with the NCD and/or NUDIPU and will facilitate earlier identification and assessment of adults and children with disabilities.

13. Strengthen District Disability Councils. The Councils need to be strengthened and capacitated, both financially and in terms of understanding their mandates and how they fit within wider policy and programme interventions. Providing members with a small regular stipend instead of “sitting allowances” may incentivise them to be more proactive.

14. Strengthen coordination mechanisms. In addition to the DDCs, Sector Working Groups and Disability Focal Points need to be established and should receive appropriate funding and guidance.

15. Proactively identify vulnerable and at-risk individuals and families. A more coherent and systematic approach towards identifying and supporting at-risk individuals and families is needed. This includes social workers with dedicated cases that they can work on both to build up trust with individuals and families and to bolster their resilience.

16. Strengthen recourse mechanisms. Legal action needs to be in line with wider behavioural change programmes and initiatives, such as public campaigns around inclusion. Existing recourse mechanisms for discrimination cases need to be strengthened, and the Justice, Law and Order sector should be proactively engaged to develop precedent where there is none.

17. Re-establish and fund the CBR programme, or fully incorporate it into community development activities. This will need effective guidelines, training/capacity building and support. Given the length of time since the programme was effective, the latter would be preferable.

18. Increase access to resources to facilitate inclusion. For example, assistive devices should be provided through existing healthcare structures, with proper assessment and fitting, as well as personal and classroom assistants, sign language interpreters, etc. Additional budgets need to be made available to provide for these resources and should be complemented by para-professional staff such as physiotherapists and occupational therapists, who are currently under-represented in the health sector.
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Annex 1 Household Survey


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Annex 1 Household survey

Introduction

This annex provides a detailed overview of the household survey carried out as part of the Situation Analysis of Persons with Disabilities by the Ministry of Gender, Labour and Social Development (MGLSD) and Development Pathways.

The survey had two target groups: households with a person with a functional difficulty; and comparison households in which all members have no functional difficulty in any domain. The sample was designed to provide indicator values representative for: (a) the country as a whole; (b) urban and rural areas; (c) the four regions of Uganda (Central, Northern, Eastern, and Western); and (d) households with a child with functional limitations and households with an adult with functional limitations. Refugee households are not explicitly included as a survey domain, because of resource constraints and the availability of other recent studies that have focused on disability among refugee households in Uganda.216

Objective

The core objective of the survey was to collect information needed to estimate the “cost of disability” and the resource needs of persons with disabilities relative to the population as a whole. This is critical for determining adequate levels of income support and for prioritising service provision. Direct costs associated with disability are wide-ranging including additional out of pocket costs required for health services, medication, help with daily activities, disability-specific aid, etc. Indirect costs include foregone economic activities (e.g. work) associated with the individual with disability and their primary carer(s) in the household.

Sampling frame

The survey applied a multi-stage sampling approach, which was based on a stratified design with probability proportional to size selection of enumeration areas (EAs) in the first stage and sampling of a fixed number of households in each selected EA in the second stage. This procedure gives each household in the same area roughly the same probability of being chosen.

Primary sampling units

The sampling frame used for drawing the primary sampling units is the frame of the Uganda National Population and Housing Census conducted in 2014. The sampling frame is a complete list of 79,825 census EAs covering the whole country, created by the Uganda Bureau of Statistics (UBOS). An EA typically represents a village in rural areas and a city block in urban areas. Its average size is 119 households in urban areas and 85 households in rural areas. For the survey, institutional EAs are excluded from the sampling frame. The sampling frame contains information about the EA location, type of residence (urban or rural), and the estimated number of residential

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216 In 2017, the UN funded a comprehensive survey on the vulnerability of refugees – with a sample size of 5,000 households – that included a disability module. A study on disability in a refugee context was drafted in 2019 for WFP and DFID.
households at the time of the census operation. A base map that delineates the EA geographic boundaries is available for each EA.

**Secondary sampling units**

In each selected EA, a full household listing and screening was carried out to produce a sampling frame from which to select households with members with functional difficulties and similar comparison households with no functional difficulties. The screening process used the Washington Group Short Set of Questions on Disability (WGSSQ) for adults 18 years and over, and the WG/UNICEF Module on Child Functioning for children 2-17 years.

**Sample design and implementation**

The target sample size was 4,448 households, consisting of 2,224 households with functional limitations and 2,224 control households with no functional limitations. The sample size calculations took into account the available budget and time for the survey, its precision requirements as well as existing data on the prevalence of disability in Uganda.

**Stratification and selection of sampling units**

The sample design employed multi-level stratification to help reduce sampling errors. Stratification is the process by which the survey population is divided into subgroups or strata that are as homogeneous as possible using certain criteria. Within each stratum, the sample is designed and selected independently.

**Enumeration areas**

In the first stage of sampling, EAs were stratified into the four regions of the country (Central, Northern, Eastern, and Western). All regions were stratified into urban and rural areas, yielding a total of 8 sampling strata. Within each of these strata, EAs were sorted according to administrative units in different levels (districts, counties, sub-counties, and parishes) to provide further implicit geographical stratification and, finally, by the EA size (number of households).

EAs were selected using systematic sampling with probability proportional to size (PPS). To minimise the time spent on the household listing operation, very large EAs with more than 150 households were partitioned into reasonably sized segments, and a random selection of those segments will be made to bring the size for the household listing and screening to around 100 households. Very small EAs – with less than 50 households – were combined with a neighbouring EA to satisfy the minimum measure of size.

**Households with functional limitations**

In the second stage of sampling, after completion of the household listing and screening, households were stratified into two groups: households with a member with functional limitations (at least some difficulty in any domain); and households with no members with any functional limitations (no difficulty in all domains).

Households with functional limitations were selected as follows. First, a “disability score” was calculated for each individual household member, by summing up the answers to the WG questions (ranging from 0 for “no difficulty” to 3 for “cannot do at all”), applying min-max
normalisation and multiplying the resulting value by 100. The disability score has a minimum value of 0 and a maximum value of 100, with many possible values in between. Next, households were assigned the highest individual score from among all its members and sorted based on their disability score. The households with the highest disability scores were selected for the in-depth interview.

**Control households with no functional limitations**

For each sampled household with functional limitations, a “control” household with no limitations was identified in the same EA that was as similar as possible in terms of household size, sex ratio, and dependency ratio. If there were multiple matches with identical values, then the control household was randomly selected from among the matches.

**Sample allocation to strata**

Table 10 shows the allocation of EAs and households according to region and urban/rural areas. Based on a fixed sample take of 16 households with functional limitations and 16 control households without functional limitations, the survey selected 139 EAs, 50 in urban areas and 89 in rural areas. The survey was designed to interview 4,448 target and control households, 1,600 in urban areas and 2,848 in rural areas.

<table>
<thead>
<tr>
<th>Region</th>
<th>EAs allocated</th>
<th>Households with functional limitations</th>
<th>Target and control households allocated</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Urban</td>
<td>Rural</td>
<td>Total</td>
</tr>
<tr>
<td>Central</td>
<td>28</td>
<td>21</td>
<td>49</td>
</tr>
<tr>
<td>Western</td>
<td>9</td>
<td>23</td>
<td>32</td>
</tr>
<tr>
<td>Eastern</td>
<td>7</td>
<td>24</td>
<td>31</td>
</tr>
<tr>
<td>Northern</td>
<td>6</td>
<td>21</td>
<td>27</td>
</tr>
<tr>
<td>Total</td>
<td>50</td>
<td>89</td>
<td>139</td>
</tr>
</tbody>
</table>

The fixed sample take per EA takes into account information obtained from the 2016 UDHS, which administered the Washington Group Short Set of Questions to the population 5+ years. It found that 6.5 per cent of the population had a lot of difficulty or could not function at all in at least one domain and could therefore be classified as living with a disability. Overall, 19.2 per cent of households had a household member with a disability. This implies that, in an average EA with a size of 92 households, the expected number of households with severe functional difficulties is nearly 18. In this survey, the WG/UNICEF module on child functioning for those aged 2-17 years is used during the household listing and screening, which is likely to deduct a higher number of children with disabilities than the WG Short Set. The selection procedure using the disability score ensures that interviewers prioritise those households with members with the most severe functional limitations.
Survey questionnaire and survey instruments

The household survey consisted of two interviews. In a first stage, households were listed and screened according to the Washington Questions on disability. In the second stage, a sample of households screened were selected for in-depth interviews. Table 11 below lists all the modules used during the different stages of the surveys.

The questionnaire was prepared in English and translated into 7 major regional languages: Luganda, Lango-Acholi, Lugbara, Ateso, Ngakarimojong, Runyankore-Rukiga and Runyoro-Rutooro. The questions in the questionnaire were based on questions from tried-and-tested modules of previous surveys in Uganda or in similar context. The interviews used a computer-assisted personal interviewing (CAPI) software – Survey Solutions by the World Bank.

Table 11: Survey questionnaire modules

<table>
<thead>
<tr>
<th>Phase</th>
<th>Modules</th>
</tr>
</thead>
<tbody>
<tr>
<td>Listing and screening</td>
<td>Household roster</td>
</tr>
<tr>
<td></td>
<td>Child and adult functioning</td>
</tr>
<tr>
<td></td>
<td>Education</td>
</tr>
<tr>
<td></td>
<td>Health</td>
</tr>
<tr>
<td></td>
<td>Work history and benefits</td>
</tr>
<tr>
<td></td>
<td>Non-work income</td>
</tr>
<tr>
<td></td>
<td>Consumption expenditure</td>
</tr>
<tr>
<td>In-depth interview</td>
<td>Assistance, assistive products and facilitators</td>
</tr>
<tr>
<td></td>
<td>Assets and household ownership</td>
</tr>
<tr>
<td></td>
<td>Shocks and coping strategies</td>
</tr>
<tr>
<td></td>
<td>Perceptions of persons with disabilities</td>
</tr>
</tbody>
</table>

Training, pre-test and data collection

Training of enumerators and supervisors took place between the 1st and 8th of October 2019 in Makerere University, School of Economics. Training was provided by the MGLSD, Development Pathways, and Policy Analysis and Development Research Institute (PADRI) – a survey firm hired to select, train and contract the enumerators, as well as manage all logistics of the field work. A pre-test of the survey tools was carried out in 3 enumeration areas of Buikwe on the 5th of October 2019.

Field work for the survey commenced following the training of enumerators. For 5 weeks between the 10th of October and the 15th of November 2019, 12 teams of supervisors and enumerators listed and interviewed households in 139 EAs across all four regions of Uganda. The teams were hired and managed by PADRI with supervision from the MGLDS and Development Pathways. Each field team was composed of enumerators and one supervisor. Overall, 80 enumerators and 12 supervisors were contracted and trained for the survey. The size of the teams was defined according to the workload in each of the subregions, and the allocation of the teams to the different regions was based on the main local language. The MGLSD provided each team with letters of introduction for the Chief Administrative Officer (CAO) in each district. The teams used local guides to move around the EAs.
Response rates

The total number of households listed was 13,129, of which 12,169 households were screened. This is close to 93 per cent of listed households (Table 12). In urban areas, 90 per cent of households listed were screened compared to 94 per cent in rural areas. The main reason for incomplete interviews during the listing and screening phase was the absence of an adult household member during the household visits.

Table 12: Response rate of households listed

<table>
<thead>
<tr>
<th>Interview Results</th>
<th>Urban</th>
<th>%</th>
<th>Rural</th>
<th>%</th>
<th>Total</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Completed interviews</td>
<td>4,538</td>
<td>90.0%</td>
<td>7,631</td>
<td>94.4%</td>
<td>12,169</td>
<td>92.7%</td>
</tr>
<tr>
<td>No adult household member at home</td>
<td>175</td>
<td>3.5%</td>
<td>131</td>
<td>1.6%</td>
<td>306</td>
<td>2.3%</td>
</tr>
<tr>
<td>Entire household absent</td>
<td>67</td>
<td>1.3%</td>
<td>114</td>
<td>1.4%</td>
<td>181</td>
<td>1.4%</td>
</tr>
<tr>
<td>Refused</td>
<td>78</td>
<td>1.5%</td>
<td>47</td>
<td>0.6%</td>
<td>125</td>
<td>1.0%</td>
</tr>
<tr>
<td>Dwelling vacant, demolished or not found</td>
<td>135</td>
<td>2.7%</td>
<td>135</td>
<td>1.7%</td>
<td>270</td>
<td>2.1%</td>
</tr>
<tr>
<td>Child-headed household</td>
<td>14</td>
<td>0.3%</td>
<td>6</td>
<td>0.1%</td>
<td>20</td>
<td>0.2%</td>
</tr>
<tr>
<td>Other reasons</td>
<td>34</td>
<td>0.7%</td>
<td>23</td>
<td>0.3%</td>
<td>57</td>
<td>0.4%</td>
</tr>
<tr>
<td>Households listed</td>
<td>5,041</td>
<td>100%</td>
<td>8,087</td>
<td>100%</td>
<td>13,129</td>
<td>100%</td>
</tr>
</tbody>
</table>

A total of 4,202 households screened were sampled for in-depth interviews. The response rate of in-depth interviews was close to 97 per cent, overall. The total number of completed in-depth interviews was 4,054. Table 13 provides a breakdown of the number of interviews in each region by area of residence.

Table 13: Households sampled

<table>
<thead>
<tr>
<th>Region</th>
<th>Target and control households sampled</th>
<th>Target and control households completed interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Urban</td>
<td>Rural</td>
</tr>
<tr>
<td>Central</td>
<td>798</td>
<td>654</td>
</tr>
<tr>
<td>Western</td>
<td>304</td>
<td>680</td>
</tr>
<tr>
<td>Eastern</td>
<td>168</td>
<td>630</td>
</tr>
<tr>
<td>Northern</td>
<td>188</td>
<td>780</td>
</tr>
<tr>
<td>Total</td>
<td>1,458</td>
<td>2,744</td>
</tr>
</tbody>
</table>
Annex 2  Glossary of Terms

This glossary of terms is based on the “Glossary of Census terms” from the UBOS (2019). Terms not taken from the aforementioned glossary of census terms are marked with *

Geography

Enumeration Area (EA) – A demarcated area meant to be covered by one enumerator for purposes of census enumeration.

Residence – Classification of EAs between rural, peri-urban and urban areas

Urban Areas – All gazetted cities, municipalities, town councils and town boards

District – A district in Uganda where a person was enumerated. As of 1st July 2020, there were 135 districts in Uganda.

Household

Household – A group of persons who normally live and eat together.

Head of Household – A person who is acknowledged as the head by other members either by virtue of age or social standing in the household. The head has primary authority and responsibility for household affairs.

Household Size – The number of persons residing within a household in a particular area.

Age Category

Early childhood* – Persons of either sex who are aged 0 to 8 years.

School age* – Persons of either sex who are aged 8 to 16 years.

Youth – Persons of either sex who are aged 18 to 30 years.

Working age* – Persons of either sex who are aged 14 to 64 years as defined by UBOS and the International Labour Organization to be “working age”. For the purposes of this report, the section on “working age” focuses on persons aged between 30 and 60 years so as not to overlap with the sections on “youth” and “older persons”. However, most adults begin working long before that, often in subsistence farming, and many go on working long after the age of 60.

Older Persons – Persons of either sex who are aged 60 years or more.

Age Dependency Ratio – The ratio of persons in the dependent ages (generally under 15 years of age and 65 years and over) to those in the economically productive ages (15–64 years) in a population.

Disability and Personal Characteristics

Persons with Disabilities* – Individuals identified in the Disability Situational Analysis Household Survey either as “having a lot of difficulty” or “cannot do at all” in at least one of the six functional
Annex 2: Glossary of Terms

domains in the Washington Group Short Set of Questions (WGSSQ) or the Child Functioning Module (See Box 1 and 2 in the main document for further information).

Disability Prevalence* – The proportion of the population living with a disability. This report uses estimates from the Disability Situational Analysis Household Survey 2019.

Additional Costs of Disability* – The additional costs that persons with disabilities incur in comparison to those without disabilities.

Assistive devices* - Assistive devices are those whose primary purpose is to maintain or improve an individual’s functioning and independence to facilitate participation and to enhance overall well-being. They can also help prevent impairments and secondary health conditions.217

Marital Status – The current marriage relationship between a man and a woman. This is as reported by the respondent without verification of its legal status.


Ugandan Population – People who belong to any of the Ugandan tribes or persons from a non-Ugandan Ethnic Group who are citizens of Uganda.

Orphan – A child (aged less than 18 years) who has lost either or both biological parents.

Sex Ratio – The ratio of males to females in a given population, usually expressed as the number of males for every 100 females.

Education

Literacy – The ability to write and read with understanding, in any language.

Literacy rate – The total number of literate persons in a given age group, expressed as a percentage of the total population in that age group.

School – Any institution of learning that offers formal education between Primary 1 and Senior 6. It is usually full time and excludes pre-primary nursery education.

Educational Attainment – The highest level of formal education/training completed irrespective of the examination results obtained.

Housing Definitions

Dwelling Unit – The building that is actually occupied by a single household. This is irrespective of the size of the household, building size or intended use.

Detached Housing Unit – A stand-alone independent residential unit intended for the habitation of a single household.

Semi-detached house – One of a pair of single-family houses joined by a common wall and forming a structural unit.

217 https://www.who.int/disabilities/technology/en/
Annex 2  Glossary of Terms

Tenement – A low-rent dwelling unit, located in a slum of informal settlement, often ageing and in substandard condition, poorly maintained and overcrowded; it is commonly referred to as “Muzigo”.

Household Facilities

Drinking water* – Drinking water from a source that is defined as one that, by nature of its construction or through active intervention, is likely to be protected from outside contamination, in particular from contamination with faecal matter.

Sanitation* – A toilet facility that hygienically separates human excreta from human contact.

Kitchen – A room or space in a dwelling that is set apart for storage of food and various operations involved in the preparation and serving of meals and cleansing of dishes and cooking utensils.

Toilet – A room containing a facility through which human waste is disposed of. Such a facility may be a sanitary fixture with a seat and bowl containing water to flush away human waste after use, OR a covered pit with a hole through which one gets rid of waste liquid or waste matter from one’s body.

Labour

Employment rate* – The proportion of the total labour force that is currently employed, where employment is defined as those who are working for wages, self-employed or own-account workers. Note that this definition is only applicable to this study, following the Model Disability Survey and is not comparable to UBOS employment estimates.

Unemployment rate* – The unemployment rate is the proportion of the unemployed population to the total labour force. Unemployed individuals in this survey were identified as those that were not currently working but looking for work. Note that this definition is only applicable to this study, following the Model Disability Survey and is not comparable to UBOS employment estimates.

Under-employment* – Persons are considered to be in time related underemployment if they are employed but with insufficient working time and are wanting and available to work more hours. This is not calculated using the Disability Situational Analysis Survey 2019.