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Uganda's disability data landscape and the economic inclusion of persons with disabilities

report

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Executive summary

For persons with disabilities to benefit from and contribute to society and the economy there needs to be effective policies, programmes and services that support their inclusion, particularly in employment. Reliable information and data on persons with disabilities, known as ‘disability data’, is essential to planning and for decision-making. When it is of high quality, accessible and used effectively, disability data can help organisations of persons with disabilities (OPDs), civil society, government and businesses better understand and prioritise interventions that are vital for supporting persons with disabilities and ensuring their inclusion.

OPDs, civil society and the government have an important role to play in strengthening the landscape of disability data. Developed as part of Development Initiatives’ work on [data to support disability inclusion](#), in consultation with Uganda’s disability rights movement, this report presents an analysis of Uganda’s landscape of disability data. It highlights important data sources, challenges and recommendations, providing a valuable evidence base to inform efforts aimed at strengthening the enabling environment for disability inclusion.

Key findings

Governance of disability inclusion and data in Uganda

There is a complex arrangement of instruments and institutions that governs disability inclusion and the production of disability data in Uganda. There are important gaps in legislation and implementation as well as leadership and scope that constrain the enabling environment for inclusive employment and inclusive data.

Sources of disability data in Uganda

There is limited data in Uganda on disability, but it does exist. The available data is dispersed across multiple sources. This includes sixteen government surveys and censuses, five government administrative systems and several non-government sources.

The use of disability data in Uganda

A culture of regular data use is not commonplace in Uganda. There has been a limited demand for data in general and a relatively short history of data use. This has been exacerbated by limited capacities to use data and challenges with the available data.

Challenges in Uganda's disability data landscape

There are a range of challenges constraining the disability data landscape in Uganda.

Challenges for government data

- Limited resources and capacities hinder data capture by ministries, departments and agencies.
- Data from surveys and censuses is not disaggregated (broken down into categories) to a useful level for the various groups working on disability inclusion.
- The disability data produced by surveys and censuses lacks timeliness.
- Different models of categorising disability in surveys and censuses have led to inconsistencies in the data.
- Stakeholders have reservations about the use of Washington Group Questions.
- Concerns about the reliability of disability data from surveys and censuses reduces trust in the data.
- Perceived difficulties in accessibility of disability data from surveys and censuses have limited the use of disability data.
- The disability data captured by government administrative data systems is very limited in scope, quality, and volume.
- Administrative data systems are not extensively deployed, and persons with disabilities are disproportionately omitted from being counted by them.
- There are problems with collection and storage of information in administrative systems.
- Data from administrative systems is not accessible to most potential users.

Challenges for non-government data

- Resource and capacity constraints hinder the ability of many OPDs to collect disability data.
- Non-government disability data often has limited re-use value as it is project focused.
- The quality of non-government disability data is not trusted by users.
- Limited sharing of disability data ensures lower use.

Recommendations to strengthen the disability data landscape in Uganda

The recommendations formulated by the study were developed collaboratively with OPDs and leading disability data experts in Uganda, following a review of the evidence generated.

- To drive improvements in disability data, Uganda Bureau of Statistics (UBOS) and OPDs should collaboratively institute and implement a formal cross-government and civil society working group.

- A formal, timebound, realistic and resourced Strategy for the Development of Disability Data should be developed, endorsed and implemented. Areas of priority the strategy should look to address are:
 - The creation of a publication schedule of UBOS disability data that meets the data needs of members of the disability movement
 - The improved levels of disaggregation in survey and census data, with focus on providing data by sub-region, category and severity of disability
 - The standardisation of disability questions used in UBOS sources
 - The increased sharing and wider accessibility of disability data for both online and offline users
 - An electronic database of disability data set up in the Ministry of Gender Labour & Social Development or UBOS
 - Strengthening the capacities of local and small OPDs to support their collection of disability data
 - Strengthening the capacities of members of the disability rights movement to support their use of disability data.

Chapter 1: Introduction

This report presents research that was undertaken as part of Development Initiatives' work on [data to support disability inclusion](#).

Economic inclusion of persons with disabilities in Uganda

In Uganda, an estimated 12% of the population have a disability¹ yet 22% of unemployed Ugandans have a disability.² Research indicates that persons with disabilities have less opportunity for employment, particularly as the economy is dominated by subsistence farming.³ This is an important factor in understanding the high levels of poverty among people with disabilities: the 2009/10 National Household Survey found that poverty rates in households where there was a person with a disability were 30% higher.⁴ The coronavirus containment measures of 2020 dramatically disrupted the functioning of both formal and informal employment, and so the current unemployment and poverty rates among persons with disabilities are likely to be higher than shown by the most recent data.

To reduce unemployment, alleviate poverty and grow economic inclusion among persons with disabilities, there needs to be disability inclusive programmes, policies and services. This includes livelihood programmes to generate more economic opportunities, inclusive education programmes to prepare persons with disabilities for future employment, and inclusive health policies to improve the overall health, and therefore productivity and wellbeing of persons with disabilities.⁵

The role of data in disability inclusion

A strong evidence base, made up of quality data and information on persons with disabilities, is critical for informing the design and implementation of disability inclusive programmes, policies and services. Referred to in this report as 'disability data' this evidence base is formed of disability-relevant data from surveys, censuses, administrative systems, and studies, from both government and non-government.

How stakeholders can use disability data to improve disability inclusion

Disability data is required by a wide range of stakeholders working to further disability inclusion in Uganda.

- **Government** at all levels need accurate data on how many people have disabilities, the nature of their disabilities and where they are located to inform decisions, planning and monitoring of policies and services that enable economic inclusion and employment.

- **Civil society and organisations of persons with disabilities (OPDs)** need the above as well as accurate data on inclusion performance to monitor progress against commitments, hold government and donors accountable, build political will and raise the profile of disability inclusion, and inform the targeting of their own programmes.
- **Businesses** need accurate data on the expertise and needs of persons with disabilities to develop opportunities for inclusive employment and target people with disabilities.
- **Persons with disabilities** need accurate data and information on the opportunities available to them to access government services, find employment and further their inclusion.

To access jobs, livelihoods, and achieve economic inclusion, persons with disabilities need to also have been included in basic entitlements such as education, health services and housing. To enable economic inclusion, stakeholders therefore require a broad range of data. For example: to equitably allocate disability grants, ministries need to know how many persons with disabilities live in each district; and to effectively target their community-based rehabilitation programmes, ministries need to know the nature of disability, location, age and gender of service-users.

Strengthening the disability data landscape

To support the needs of different stakeholders and strengthen the enabling environment for disability inclusion, there needs to be a coordinated and sustainable 'disability data landscape'. The disability data landscape can be understood as the various practices of governing, producing, storing, sharing, and using data on persons with disabilities.

In many countries, including Uganda, there are problems with the disability data landscape. The data may not exist or may not be accessible. It may be of poor quality (e.g. inaccurate or out of data). There may be limited practices of using data and limited capacity to support this. These factors constrain progress towards disability inclusion and the employment of persons with disabilities.

OPDs, civil society and the government have an important role to play in strengthening the disability data landscape, but, typically, not enough is known about the disability data landscape for them to make effective change. A common understanding of the data landscape, including the range of data sources, standards, technologies and infrastructures, policies and acts, and the organisations that steward, contribute to, and use them,⁶ is an important baseline from which to design improvements.

Providing the evidence base for action to strengthen the disability data landscape in Uganda

This report seeks to provide an evidence basis for a shared understanding of the disability data landscape in Uganda by presenting findings from an in-depth study. The study identified disability and data-relevant legislation, institutions and policies, as well as the gaps in them and in their implementation. It identified the data captured on disability, the process of data production and other aspects of the data's metadata. It assessed

the data's quality, in turn addressing factors such as accuracy, timeliness, and disaggregation (how it was broken down), and looked at its accessibility. The study also analysed the dynamics around the use of data in the design, implementation and monitoring of policies, services and programmes related to persons with disabilities.

Developed in consultation with Uganda's disability rights movement, this report highlights important data sources, challenges and recommendations, providing a valuable evidence base to inform efforts aimed at strengthening the enabling environment for disability inclusion. The report provides an up-to-date and detailed overview of:

- Governance of disability inclusion and disability data
- Sources of disability data from government and non-government actors
- Challenges in the production, accessibility and use of disability statistics
- Recommendations on how to improve data on disability in Uganda.

Methodology

The study pioneered a new methodology, developed according to the United Nations Convention on the Rights of People with Disabilities principles of inclusion. It adopted a mixed-methods approach that aimed to be inclusive of the perspectives of persons with disabilities at every stage. Development Initiatives shared research planning documents and initial findings for consultation with OPDs and disability experts in Uganda. The study's analysis and recommendations are based on desk research, key informant interviews,⁷ and a consultation workshop with OPDs and experts on both disability and data in Uganda.⁸

Chapter 2: Governance of disability inclusion and data in Uganda

There is a complex framework of instruments and institutions that govern disability inclusion and the production of data on persons with disabilities in Uganda. Yet, there are important gaps in legislation and implementation as well as leadership and scope that constrain the enabling environment for inclusive employment and inclusive data. This chapter presents an analysis of ‘disability governance’ (the provision and management of services) and governance specifically relating to ‘disability data’ (data and information on persons with disabilities) in Uganda.

Disability governance in Uganda

Legislative and institutional framework for disability governance in Uganda

Uganda’s legislative and institutional framework takes into consideration the need to protect and enhance the rights and inclusion of persons with disabilities. Important policy tools for persons with disabilities include the Constitution of the Republic of Uganda (1995) and the Persons with Disability Act (2019). Uganda ratified both the convention and protocol of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in 2008.⁹ The major institutions involved in disability governance are the Ministry of Gender, Labour and Social Development (MoGLSD), particularly its Disability Desk, and the National Council for Persons with Disabilities (NCD). Details of other legislation and institutions identified by interviewees as important for persons with disabilities are presented in the Annex, Table A1.

Government plans for disability inclusion in Uganda

There are various government plans which also seek to address the need to protect and enhance the rights and inclusion of persons with disabilities. The National Planning Authority’s (NPA) Second National Development Plan 2015/16–2019/20 (NDPII)¹⁰ and the MoGLSD’s Social Development Sector Plan 2015/16–2019/20 (SDSP)¹¹ illustrate this. For example, the NDPII commits to design, implement and follow up the integration of human rights and disability responsive policies, while the SDSP commits to enhancing community-based rehabilitation for children with disabilities and to improving access to disability grants for persons with disabilities.¹²

Design and implementation of government plans, policy and strategy for disability inclusion in Uganda

Despite the inclusion of disability within policy tools, there are gaps in policies and plans as the solutions they present are limited in their scope and ambition. For example, interviewees and workshop participants highlighted that, despite the MoGLSD recognising the need for rehabilitation in the SDSPP, it set a target of reaching just 600 children per year between 2015 and 2020. Such policy tools can be characterised as incrementalistic, because in spite of the recognition that there is large-scale need, the solutions proposed are comparatively small. In addition, disability-orientated policies and plans often omit important practical details. For instance, the MoGLSD did not have the funds in place to finance its policy to increase the number of claimants accessing disability grants.¹³

Effective implementation of the plans, policies and strategies related to persons with disabilities has been a challenge in Uganda. In some cases, a policy commitment is not realised because corresponding action fails to materialise or is not sufficient. For example, according to interviewees, very little action was taken by the MoGLSD to realise its commitment to increase the number of claimants accessing disability grants.¹⁴ While the NDPII's commitment to "design, implement and follow up the integration of human rights and disability responsive policies" resulted in the development of the Persons with Disability Act (2019),¹⁵ interviewees reported concerns about this piece of legislation. For example, the criminal penalties for non-compliance with serious elements of the act are lenient and any mention of disability data is entirely omitted.¹⁶

The ministries, departments, and agencies (MDAs) designing and implementing Uganda's disability-relevant policies and plans are under resourced. According to interviewees, the MoGLSD receives just 1% of the central government's annual budget, making it the least funded of all government ministries. The limited funds constrain the implementation of fundamental services. For example, between FY2016/17 and 2020/21 the MoGLSD was able to allocate just UGX 1,500,000 (approx. US\$400) per annum towards its programme to rehabilitate children with disabilities. This equates to UGX 2,500 (approx. US\$0.70) per child per year.¹⁷ Limited resources also often prevent the MoGLSD's Coordination Committee on Disability from fully functioning. Interviewees reported the budget allocated to the NCD in FY2019/20 was UGX 500 million (approx. US\$135,000) despite requests for UGX 4 billion (approx. US\$1,085,000). This resource gap placed significant financial pressure on the NCD and has constrained the size of its research department, which consists of only two people. The scarcity of resources faced by key MDAs prohibit activities beyond the operation of their basic functions. The salaries of staff and social protection payments consume the majority of budgets, leaving limited funds to support activities such as data collection, which subsequently gets deprioritised. As a consequence, the evidence base that MDAs and others have to work with receives minimal investment.

Disability data governance in Uganda

Legislative and institutional framework for disability data governance in Uganda

Key legislation related to disability data consists of [Article 31 of the CRPD](#) and key institutions include the Uganda Bureau of Statistics (UBOS), the MoGLSD and the NCD. However, Uganda lacks a robust, coherent and integrated approach towards legislation on disability data and lacks comprehensive and authoritative plans to guide its development. The MoGLSD, NPA and UBOS have published separate uncoordinated documents, demonstrating that no individual ministry, department or agency has taken on the responsibility of being the primary lead on this issue.

While there are no domestic laws that explicitly articulate a mandate by the government of Uganda to collect data on disability, the Uganda Bureau of Statistics Act (1998) does stipulate that UBOS must collect *all* statistics needed by the government.¹⁸ UBOS's Department of Population and Social Statistics specifies disability as one of the issues it is responsible for.¹⁹ As a signatory to the CRPD, Uganda has committed to an international agreement to produce, share and use disability data. However, this commitment is not legally binding within Uganda. Article 31 of the CRPD outlines that: "States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention"; "the information collected in accordance with this article shall be disaggregated, as appropriate"; and "States Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility".²⁰

Government policy for developing the disability data landscape in Uganda

Several institutions have laid out policies designed to develop Uganda's 'disability data landscape' (that is, its practices of governing, producing, storing, sharing, and using disability data). However, many of these objectives have not been met. For example, in several policies the MoGLSD has outlined its intention in several policies to build a web-enabled disability Management Information System, including in the National Disability Guidelines (2012), the SDSPP and the National Action Plan for Children with Disabilities (2016/17-2020/21).²¹ However, at the time of writing (September 2020) the Disability Management Information System is yet to materialise, as has further details on planned financing, software, personnel or deployment.

There have also been commitments in policy towards use of data. For example, in the National Disability-Inclusive Planning Guidelines for Uganda (2017), the National Planning Authority (NPA) committed to promoting "evidence-based planning to ensure that planners use context-specific, verifiable data or newly emerging evidence for decision-making".²² However, according to interviewees, government institutions rarely undertake evidenced-informed planning when it comes to designing or managing services for persons with disabilities, citing the lack of data as the primary reason.

Key institutions contributing to the disability data landscape in Uganda

Uganda Bureau of Statistics (UBOS)

UBOS is Uganda's national statistical office, established in 1998 by the Uganda Bureau of Statistics Act.²³ The NPA's National Disability-Inclusive Planning Guidelines for Uganda states that UBOS should "include disability questions in periodic surveys, commission separate disability-inclusion surveys where necessary; and compile progress on disability-specific indicators across the board". It also commits UBOS to, "supporting MDAs and LGs [local governments] with data and reports on disability, as well as "developing a framework and guidelines to support MDAs and LGs to collect, analyse, disaggregate and disseminate data on disability".²⁴

In the past few years, UBOS has commissioned a survey specifically on disability, namely the Functional Difficulties Survey (2017) (FDS), a first of its kind in Uganda.²⁵ According to interviewees, the FDS had major flaws. In particular, "the survey did not provide much detail on what persons with disabilities go through, the causes of disability, or the specific geographic dispersions of persons with disabilities". UBOS is due to follow up on the 2017 FDS in 2022.²⁶ UBOS has also included disability questions in periodic surveys, as outlined in Chapter 3, Table 1.

Interviewees reported that UBOS has not supported MDAs and local governments with their production of disability data or developed a framework or guidelines to grow the quality of disability data. The National Statistics Indicator Framework which UBOS published in 2016 contained only a few references to disability data.²⁷ However, UBOS does collaborate with some OPDs to increase the utility of the disability data it produces. For instance, UBOS worked with the National Union of Women with Disability of Uganda and the National Union of Persons with Disabilities of Uganda to prepare for the National Population and Housing Census (2014).

To continue its progress towards compliance with the National Disability-Inclusive Planning Guidelines for Uganda and Article 31 of the CRPD, UBOS will need to overcome some challenges. This includes a shortage of funds and resources. In some years, just a small amount of activities absorbs most of its budget. For example, the majority of funding from FY2013/14 to FY2015/16 was allocated to the 2014 national census. Therefore, UBOS often relies on financial support from development partners (see Annex, Table A3) and generates extra revenue from consultancy services.²⁸ Other challenges include the lack of a coherent and broadly agreed plan on the development of disability data, high staff turn-over among skilled positions, limited experience of collecting inclusive statistics and limited institutional knowledge about the needs and interests of persons with disabilities.

The National Council for Persons with Disabilities (NCD)

The NCD is mandated by the Persons with Disabilities Act (2019),²⁹ which replaced the National Council for Disabilities Act (2003).³⁰ The NCD has one data-specific function as per the current act (2019), namely, to "carry out or commission surveys, inquiries or investigations on matters relating to violation of rights of persons with disabilities under this Act or non-compliance with this Act by Government, bodies corporate or private

persons”. The data-specific function given in the Persons with Disabilities Act (2019) is an extension of the data-specific function in the National Council for Disabilities Act (2003).

As yet (September 2020), the NCD has not conducted or commissioned any surveys. A significant reason for this has been its lack of financial and technical capacity. As basic running costs take up most of its budget, the NCD has to prioritise the activities it undertakes meaning that data-specific activities are not feasible.

The NCD is not mandated to collect a wide array of disability data, but it is mandated to collect data on violations of disability rights. The extension of the NCD’s data-specific mandate to include the collection of other key disability data would enrich their annual *State of Disability Report* and Uganda’s disability data landscape more broadly. The budgetary shortfalls it already experiences mean it is likely any extension would initially have to be supported financially by a development partner.

Ministry of Gender, Labour and Social Development (MoGLSD): Department of Employment Services (ESD)

The Department of Employment Services (ESD) of the MoGLSD collects and disseminates “labour statistics” and “labour market information”.³¹ Interviewees reported that they expect the ESD to collect such statistics about person with disabilities too. Currently, the ESD does not do this. However, the expectation that the ESD collects labour statistics related to disability may be misplaced, as there appear to be no policies that outline this responsibility. Instead, it appears that the primary focus of ESD has been, and remains, on Ugandan citizens employed abroad. There are no policies or plans which suggest this will change.

Stakeholder interactions

Interactions between Uganda Bureau of Statistics (UBOS) and organisations of persons with disabilities (OPDs)

Uganda’s disability rights movement, formed of OPDs and their allies in government and beyond, has a critical role to play in strengthening Uganda’s legislative, institutional and policy framework for disability inclusion, as well as their implementation, and the achievement of Uganda’s disability commitments. In recent years UBOS has demonstrated a willingness to engage with OPDs. There has now been a range of interactions on issues related to disability data and UBOS regularly engage stakeholders when preparing the questionnaire for censuses and some surveys. Interviewees reported that UBOS usually approach OPDs in one-off exchanges about a specific source, as opposed to working together on a more continuous basis. The OPDs that UBOS engages with tend to be well-established and national in scope.³² These interactions therefore tend to reflect the needs and interests of the ODP involved, rather than the broader disability rights movement – which is composed of national as well as smaller, local ODPs, and, according to multiple interviewees, is fractured in its interests.

Despite the fact that many OPDs recognise similar problems with UBOS’s disability data – such as its perceived inaccuracy and poor disaggregation (the smaller categories data is broken down into) – there have, to date, been no coordinated attempts by OPDs to

collectively address these issues nor any efforts to engage with UBOS as a group. The absence of collective action, where OPDs systematically work with UBOS in a long-term relationship, greatly reduces the scope of future progress. The uncoordinated nature of the existing interactions may be rooted in contradictory beliefs about who should be driving improvements. UBOS believe that demand should drive developments. For example, one interviewee stated, “as a bureau we are demand driven. If no one comes to us to ask, we will not do any collection or analysis focusing on disability for example. They [OPDs] need to press the government”. Conversely, many OPDs believe that the development of UBOS’s disability data should be led by supply. For instance, one interviewee argued that, “the will by the government to produce credible disability statistics shouldn’t be dependent just on demand. It should be done as a public good”.

Lesson from Uganda’s other social movements

To support the disability movement’s engagement on issues of disability data, lessons can be learned from Uganda’s other social movements, such as gender mainstreaming, which has a strong track record in closing critical data gaps.³³ One interviewee commented that, “the disability movement is relatively newer compared say to the women’s movement which is older, more entrenched and has more experience in organising and advocacy, greater intellectual muscle, international intrenchment and funding”. They also added, “there are five regional representatives for persons with disabilities in parliament, but their impact is hard to be seen. In comparison, the women’s caucus in parliament is quite robust. They have the Uganda Women Parliamentarians Association, which is quite vocal in advocating for women’s rights and issues, including fighting for budget allocations to gender issues”.³⁴

The success of Uganda’s other social movements can be seen in the NDPII and SDSP. For example, gender, HIV/AIDS, environment, nutrition, climate change, human rights, social protection, and child welfare are all included in the ‘Integrating Key Cross-Cutting Issues into Programmes and Projects’ section of NDPII’s Development Strategies; however, persons with disabilities are not mentioned. One interviewee explained, “discrimination is illegal – the equity principle of most of our laws infer that you need data and therefore must collect it on all segments of the society. The government, for example, introduced gender equity certification but there’s nothing like that for disability data”. Such discrepancies highlight that the disability movement has not yet leveraged the same political advancement as some other social movements. They also highlight that the government is potentially receptive to the advocacy of social movements.

Chapter 3: Sources, accessibility and use of disability data in Uganda

There is limited data relating to disability available in Uganda, but it does exist. This data is dispersed across multiple sources. It includes sixteen government surveys and censuses, five government administrative systems and several non-government sources. This chapter presents an analysis of issues impacting sources of, access to, and use of 'disability data' (data and information on persons with disabilities) in Uganda.

Sources of government disability data in Uganda

Government surveys and censuses

Between 2009/10 and 2019/20, Uganda Bureau of Statistics (UBOS) collected disability data through one census and eight unique surveys. Some surveys were conducted multiple times.³⁵ The National Panel Survey was conducted five times,³⁶ the National Household Survey four times, and the Demographic and Health Survey (DHS) twice – bringing the total number of UBOS sources that included disability data over the period to sixteen (Table 1).³⁷

Table 1: Sources of disability data from Uganda Bureau of Statistics (UBOS), 2009/10 to present

Year	Source
2009/10	National Panel Survey ³⁸
	National Household Survey ³⁹
2010/11	National Panel Survey ⁴⁰
2011	Demographic and Health Survey ⁴¹
2011/12	National Labour Force Survey ⁴²
	National Panel Survey ⁴³
2012/13	National Household Survey ⁴⁴

2013/14	National Panel Survey ⁴⁵
2014	National Housing and Population Census ⁴⁶
2015	National Service Delivery Survey ⁴⁷
2015/16	National Panel Survey ⁴⁸
2016	Demographic and Health Survey ⁴⁹
2016/17	Manpower Survey Uganda ⁵⁰
	National Labour Force Survey ⁵¹
	National Household Survey ⁵²
2017	Functional Difficulties Survey ⁵³

Administrative data systems

Administrative data is data derived from the functions of public administration, for example relating to registration, transaction and record keeping. There are five administrative data systems operated by ministries, departments and agencies (MDAs) in Uganda which capture data on disability (Table 2). Despite intentions, the government does not implement a disability management information system (MIS) or a disability-focused database.

Table 2: Sources of administrative data on persons with disabilities from ministries, departments, and agencies in Uganda

Organisation	Administrative data system
Ministry of Gender Labour & Social Development	Case Management Information System Child Helpline
	Gender-based Violence Management Information System
Ministry of Health	Health Management Information System – District Health Information Software
Ministry of Education and Sports	Education Management Information System ⁵⁴
National Registration and Identification Authority	Birth Registration

Content of government disability data in Uganda

Types of questions used to collect data

In some of the sources, listed in Table 1, UBOS generated disability data through **direct questions** on disability. For example, in the Functional Difficulties Survey (FDS) (2017) and DHS (2016) data was collected on “visual, hearing, mobility, communicative, and cognitive” functional difficulties. The FDS also collected data on “psychological/intellectual” difficulties. The 2014 census collected data on “visual, hearing and mobility” disabilities, as well as on “memory”. Examples of disability-related questions that UBOS asked in the census are: “do you have difficulty seeing, even if wearing glasses?” and “do you have difficulty hearing, even if using a hearing aid?”. The responses UBOS provided for each question were “no – no difficulty, yes – some difficulty, yes – a lot of difficulty, cannot do at all”.

In other sources, UBOS generated disability data by asking **indirect questions** on disability. For example, in the National Household Survey (2016/17) and National Panel Survey (2015/16) UBOS provided “disability” as one of four multiple choice answers to questions such as “what was the main reason that you were absent from your job last week?” (National Household Survey), and “what was the main reason why you did not seek work or try to start a business in the last four weeks?” (National Panel Survey).

Level of detail and disaggregation

Disability data from UBOS sources is often disaggregated by age, gender and geography (e.g. rural/urban). More detailed disaggregation of UBOS disability data, such as employment/economic activity, household income, savings and assets, access to the internet, health status, and literacy, are less common, but are present in some data sources, as shown in Table 3.

The aspects of data collected by UBOS relevant to disability are often limited in scope and can lack detail, whereas the socio-economic, health and education aspects of the same data are typically detailed. Usually the levels of disaggregation available are reduced to the binary of ‘disability, yes or no’ or more traditional categories of disability (e.g. seeing, hearing, cognitive). Very few sources allow data to be disaggregated by the severity of disability or disabilities.

Questionnaire frameworks

UBOS has not adopted a standardised framework for its questionnaires. The disability questions used in its surveys have been based on three different types of questionnaire frameworks: Washington Groups Questions (WGQs), modified WGQs and national frameworks. These different frameworks have been used interchangeably and intermittently. For example, between 2013 and 2016, UBOS collected disability data in six sources, using three rounds of National Panel Survey, one DHS, a National Service Delivery Survey and the national census. Nationally defined questions were used in the National Panel Survey and the National Service Delivery Survey, whereas WGQs were used in the DHS and modified WGQs were used in the census. A unique set of questions has been used each time UBOS has used nationally defined questions.⁵⁵

Table 3: Examples of the contents of disability data from Uganda Bureau of Statistics (UBOS) sources

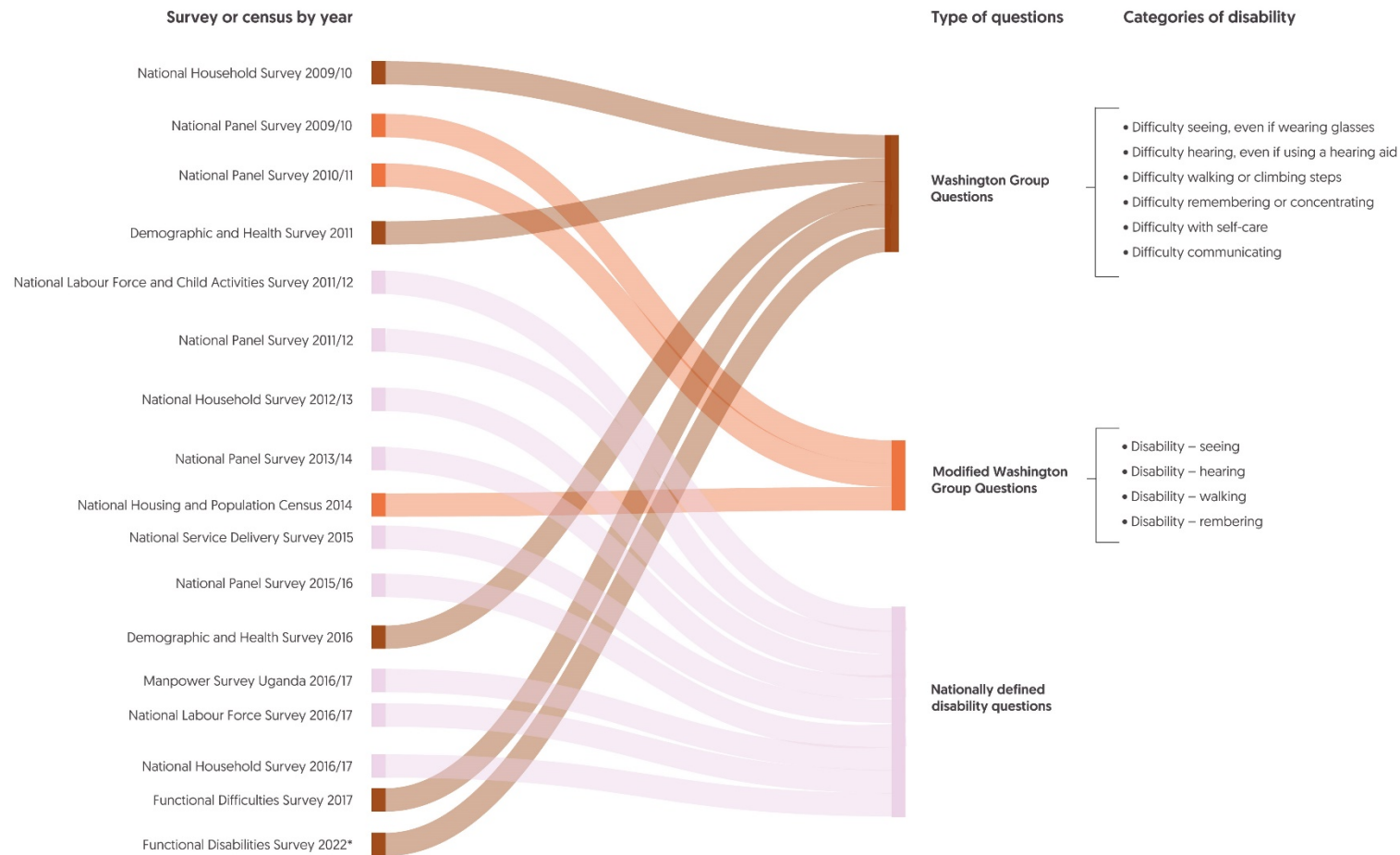
Source	Disaggregation for disability	Other disaggregation available	Types of questions
Functional Difficulties (2017)	Categories provided: visual, hearing, mobility, communicative, cognitive, psychological/intellectual selfcare	Age, gender, rural/urban, household population and composition, rehabilitation, access to information and ICT, accessible transport, equal recognition before the law (equality and non-discrimination)	Washington Group Questions, ⁵⁶ with additional questions added
National Household Survey (2016/17)	Contains indirect questions on disability, with “disability” as one option of four multiple choice answers for questions, such as “what was the main reason that you were absent from your job last week?”	Age, gender, rural/urban, region, household expenditure, poverty estimates, poverty trends, household assets, household earnings, financial savings and investments, credit access and use of mobile money, economic activities in the community, use of agricultural extension services	Nationally defined questions
Demographic Health Survey (2016)	Categories provided: visual, hearing, mobility, communicative, cognitive, selfcare	Age, gender, location (region, rural/urban, “special areas”, e.g. islands and greater Kampala), employment, occupation, household wealth, wealth index, household population and composition, internet usage, control over women’s and men’s earnings and ownership of assets, educational attainment, literacy, marital status, nutritional status of children, nutritional status of adults, nutritional status of women and men	Washington Group Questions
National Panel Survey (2015/16)	Contains indirect questions on disability, with “disability” as one option of four multiple choice answers for questions such as “what was the main	Age, gender, location (region, rural/urban), labour force participation rate, employment to population ratio and unemployment rate, economic activities in the community, access to government safety net programmes, poverty estimates, poverty trends, household	Nationally defined questions

reason that you were absent from your job or business last week?"

assets, household earnings, income sources and access to financial services, financial savings, credit access and use of mobile money, use of agricultural extension services, current schooling status of persons aged 6 to 24 years, literacy, education attainment (persons aged 15 years and above), health status of the population, client satisfaction with health services

National Housing and Population Census (2014)	Categories provided: visual, hearing, mobility, memory	Age, gender, location (region and district, rural/urban), economic activity, distribution of the population, population density, urbanisation, possession of a birth certificate, educational status, and literacy	Modified Washington Group Questions
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Figure 1: Questionnaire frameworks used for different Uganda Bureau of Statistics (UBOS) sources



Note: *The next round of disability data UBOS is scheduled to collect is the Functional Difficulties Survey in 2022.

Table 4: Estimates of disability prevalence and frameworks used by different surveys

Survey	Framework	Estimate of disability prevalence	Further disaggregation
Functional Difficulties Survey (2017) ⁵⁷	Washington Group	18.6%	Male: 17.3%
			Female: 19.8%
Labour Force Survey (2016/17) ⁵⁸	Nationally defined	6%	18+ years of age: 6.55%
			5–17 years of age: 7.5%
			2–4 years of age: 3-5%
Demographic and Health Survey (2016) ⁵⁹	Washington Group	6.5%	
Census (2014) ⁶⁰	Washington Group	12.4%	
National Household Survey (2009–2010) ⁶¹	Nationally defined	15.9%	Urban: 11%
			Rural: 16.8%

Challenges with government disability data in Uganda

There are a range of challenges constraining the disability data landscape in Uganda. For government data, challenges include the following.

Limited resources and capacities hinder data capture by ministries, departments and agencies (MDAs)

“With DHIS2 [District Health Information Software 2], form completion rate is a problem anyway, and persons with disabilities come last on the rung in everything so the gaps about them will be large” – Respondent from OPD

Data collection by MDAs in Uganda is hindered by their lack of financial resources: the MoGLSD is considered by interviewees to be “pitifully underfunded”; UBOS relies on

financial support from development partners, which influences its focus; and the NCD's two-person research department conducts mostly qualitative desk research rather than in-depth data-led studies. Limited resources also constrain the ability of many local government offices and facilities to capture data, particularly on disability. Interviewees reported that, "data capture [using the Health Management Information System (HMIS)] at health centers is burdensome due to low manpower in clinics, so nurses both treat patients and enter HMIS data" and "the HMIS questionnaire is already big and time-consuming, the small staff at a health unit may not capture everyone". They also commented that teachers often struggle to fulfil their responsibilities with respect to the Education Management Information System (EMIS) due to overload from other responsibilities.

Data from surveys and censuses is not disaggregated to a useful level for those working on disability inclusion

"The problem of lack of disaggregation cuts across the whole spectrum of UBOS data. There is limited disaggregation in the national census data and limited disaggregation in surveys" – Respondent from OPD

Data disaggregation refers to the level of detail in which data can be divided into sub-groups such as disability type, gender, age, geographic location, socio-economic group, etc.⁶² To be useful for policy design, budget allocation, programme planning and monitoring progress, data needs to be highly disaggregated. Almost all interviewees emphasised inadequate disaggregation as a key challenge with disability data produced by UBOS surveys and censuses. One interviewee explained, "we do not know how many persons with disabilities are in each age category, region, or socioeconomic category".

Broadly speaking, issues around disaggregation for surveys can be categorised into two inter-related groups: those concerning sample design (e.g. disaggregation by geographic location) and those concerning questionnaire design (e.g. disaggregation by categories of disability).

Interviewees highlighted that a lack of disaggregation by geographic region is a major concern. Much of the data cannot be disaggregated beyond the regional level to districts, counties, and municipalities as it becomes unrepresentative. Typically, a given geographic area can be represented by a sample size of 800 to 1,000 people. Therefore, to generate data disaggregated to the level of Uganda's 134 districts a minimum sample size of 107,200 is needed. Currently, the average sample size of UBOS household surveys that have generated disability data is 7,195 (see Annex, Table A2). This number exceeds that required for regional disaggregation but falls far short of the levels needed to enable district-level disaggregation.

Issues around categories of disability in government sources are a product of questionnaire design. Interviewees stressed that some categories of disability are missing from the data. For example, psychosocial disabilities are entirely omitted and UBOS has only recently started collecting data related to albinism and dwarfism. Interviewees also

noted that, “there is no sufficient data on women with disabilities”. Adjusting current questionnaire frameworks would solve this issue.

The current levels of disaggregation mean that government surveys and censuses often do not contain relevant information to meet the needs and interests of different persons with disabilities and OPDs. The lack of coverage and disaggregation in UBOS disability data therefore undermines its potential utility.

To cater for the disaggregation needs of *all* persons with disabilities and OPDs is not feasible, as UBOS would have to overcome practical constraints inherent in surveys and censuses, such as the limited number of questions that can be asked in such exercises and the difficulties of financing large surveys. Ideally, stakeholders would reach consensus on which levels of disaggregation would benefit the largest proportion of users, while being conscious of what is feasible for data collection systems to deliver. Other data needs and interests could then potentially be met using other systems, such as administrative data systems.

The disability data produced by surveys and censuses lacks timeliness

“UBOS surveys are too spread out, the most recent was in 2017, there needs to be one every year” – Respondent from government

Between 2009 and 2017, UBOS published a total of sixteen surveys and censuses that contained disability data. At the time of writing (in September 2020), UBOS most recently published disability data in 2017.⁶³ Given the relative abundance of data produced through the previous seven years, the current three-year gap is comparatively large. The next round of disability data UBOS is scheduled to collect is the Functional Difficulties Survey in 2022. By that point there will have been a five-year gap.⁶⁴

Concerns about the reliability of disability data from surveys and censuses reduces trust in the data

“Surveys tend to come up with different numbers – UDHS [Uganda Demographic and Health Survey] has its numbers, UNHS [Uganda National Household Survey] its own, UNPS [Uganda National Panel Survey] also. The outcome is always surprising, the reliability of the numbers is a problem” – Respondent from government

Many interviewees held the perception that UBOS disability data is unreliable. For example, one interviewee commented that none of UBOS’s disability data has been “tested for quality by an auditing team”. Another interviewee suggested that, “many people do not declare disability during surveys”, and there was a general agreement that underreporting of disability is more pervasive than overreporting. One interviewee from

an OPD explained that because of the inaccuracies “when you are writing a report and you are going to present a paper, you cannot quote any figures with confidence”.

Conversely, some interviewees argued that the data is accurate. A government respondent explained that UBOS surveys are prepared and conducted by professional, trained staff using representative samples and following both national and international standards and guidelines. Some interviewees also felt that the 12.4% disability rate reported by the 2014 census was roughly accurate.

Different models of categorising disability in surveys and censuses have led to inconsistencies in the data

“The Functional Disabilities Survey used Washington Group Questions which have many limitations as they do not sufficiently look at several disabilities, such as psychosocial disabilities”

– Respondent from OPD

As shown in Figure 1, surveys and censuses in Uganda have adopted a number of different systems for categorising and measuring disability. While the use of different frameworks has caused inconsistency and reduced comparability between surveys, even surveys which have consistently used the same framework have produced different prevalence numbers, as shown in Table 3.

Stakeholders have reservations about the use of Washington Group Questions (WGQs)

The reputation of WGQs as the leading global standard for collecting accurate and comparable disability statistics is growing. However, despite this, and UBOS’s role in the development of the Washington Group,⁶⁵ there were strong concerns among some research participants about the use of WGQs. Multiple interviewees felt that WGQs “are not appropriate in the African context”, with one interviewee going so far to claim that “they are culturally insensitive”.⁶⁶ The limitations of the short set of questions were recognised by respondents, with one noting that, “WGQs do not capture psychosocial disabilities”. The distrust of WGQs went much deeper than this though. One interviewee argued, “we have to be aware of the limitations of the WGQs and their impact on the accuracy of disability reporting”. Another comment that, “WGQs takes a person’s opinion, which is not enough”.

Perceived difficulties in accessibility of disability data from surveys and censuses have limited the use of disability data

Some OPDs interviewed held misinformed beliefs about the availability and accessibility of UBOS data. For example, one interviewee claimed, “it is hard to come to UBOS if I need data, because it would take me the whole day to visit UBOS to request for data”. In fact, there are multiple ways to request UBOS data without physically visiting the institution, or even without using a computer or telephone. Clearer communication about

this by UBOS, MDAs and large OPDs could keep the disability rights movement informed of all the mechanisms through which UBOS data can be requested and accessed, as well as the different forms which it can come in (for example, in reports, in raw data, etc.).

The disability data captured by government administrative data systems is very limited

“The systems that are there are the result of politics in the Ministry and the politics of donors. No one has taken up the cause of administrative data systems” – Respondent from OPD

There has been a lack of tangible efforts to better integrate the capturing of disability data into the administrative data systems which exist, or to create a system that solely focuses on disability, such as a registry of persons with disabilities, in Uganda. Therefore, sections of existing administrative systems which collect disability data are underdeveloped and produce negligible amounts of disability data. For example, the EMIS produces data only on limited indicators such as the completion and retention rates of students with disabilities. And, where it does exist, data is often not useful, as the use of non-standardised questions limits the potential for cross-system analysis. For example, the Gender-based Violence Management Information System asks, “do you have any disabilities, yes or no?”, whereas the birth registration form asks, “disability if any?”.⁶⁷

Administrative data systems are not extensively deployed, and persons with disabilities are disproportionately omitted

“Many people with epilepsy still consult traditional medicine men and healers, therefore it is likely that the system underreports their prevalence” – Respondent from OPD

Existing administrative data systems in Uganda are deployed in a limited number of settings. For example, one interviewee explained, “there is a lot of focus on primary education data but [...] there is no EMIS for secondary schools or tertiary/technical education institutions”. Another interviewee noted that more public health facilities report into DHIS2 (District Health Information Software 2) than private health facilities. Filling these gaps would improve the coverage of disability data.

In general, administrative data systems only collect data from persons who engage with or use an administered service. Those people who do not engage with government services are omitted from the corresponding data systems. This particularly affects the records associated with persons with disabilities, as they may not engage with services as often as other groups. The MoGLSD reported, for example, that in 2015 it assisted 1,828 people out of a total of over three million persons with disabilities in the country. One interviewee pointed out that, in Uganda, “there are persons with disabilities that are not in school, a vast majority – who collects data on them?”.

There are problems with collection and storage of information in administrative systems

Most of the administrative systems can be described as 'hybrid systems', in that they are partially paper-based and partially digital. For example, within the MoGLSD, data is manually collected at sub-county level and submitted on paper to district-based community development officers; these officers then aggregate the records and submit, in paper-format, to the MoGLSD, where it is then entered into a digital information management system or database. Similarly, in the Ministry of Health's HMIS local health clinics submit paper-based aggregated data to district statisticians who key the data into DHIS2 on a monthly basis. The HMIS is the most sophisticated of all the administrative data systems as data is input at the district level, and by a biostatistician.

Using hybrid systems means that some of the benefits gained by completely digitising data capture – such as a reduction in human errors, reduced labour, and instant outputs – are lost. The systems are also siloed and are not interoperable with one another, which represents a missed opportunity to combine the systems to generate data that is of better quality.

In some instances, perverse incentives inhibit accurate data collection. For example, one interviewee claimed that due to budget allocation processes “teachers sometimes have incentives to overreport, and other times have incentives to underreport”.

Data from administrative data systems is not accessible

The primary reason disability data from government administrative systems is not widely used, is that access to it is blocked for institutions which do not implement the systems.⁶⁸ This disconnect feeds into the false belief held by some interviewees that Uganda's administrative systems contain no disability data: “there is no disability data in the HMIS/DHIS2”, “MDAs all collect data but have nothing on disability, the GBV [gender-based violence] database has no information concerning persons with disabilities”.

Sources of non-government disability data in Uganda

Non-government studies and surveys

In addition to government entities, a number of OPDs and other types of organisations collect disability data in Uganda. This includes development partners (e.g. the UK's Department for International Development⁶⁹ and the Netherland Development Cooperation), multilateral organisations (e.g. Unicef, World Health Organization and International Labour Organization), universities, medical groups and NGOs (domestic and international). These groups usually conduct surveys or qualitative studies themselves, but sometimes commission consultants to carry out the work on their behalf. These efforts are often motivated by shortcomings in government disability data.

Development partners (bilateral and multilateral organisations), directly and indirectly, dominate the production of disability data outside of government. Their own sources (e.g. scoping papers or databanks) are themselves significant features of Uganda's disability

data landscape. And, because they provide funding, the needs and interest of these groups also tend to dictate which data is collected by the other types of actors in the country (e.g. medical groups, universities or Ugandan OPDs) and when data is collected. According to one interviewee, “donor interests affect what work OPDs do, and where the focus should be. Most of them are only accountable to their donors rather than to their members or the country in general”.

OPDs that have collected disability data include the National Union of Disabled Persons of Uganda (NUDIPU),⁷⁰ National Union of Women with Disabilities of Uganda, Uganda National Association of the Blind, Uganda Parents of People with Intellectual Disabilities, Epilepsy Support Association of Uganda (ESAU), and Triumph Uganda. Examples of data collected by universities and medical groups are the works led by the current State Minister for Health and current President of the Uganda Medical Association.^{71 72}

Non-government administrative systems

Many OPDs and other organisations operate their own administrative data systems. The majority of these systems consist of records of membership and records of beneficiaries as and when they access services. Most OPDs operate paper-based systems that are very modest. According to one interviewee, “many OPDs do not even have a typewriter, let alone a computer, therefore most still use simple exercise books to keep bits of information on their members”. However, a few organisations implement more sophisticated systems. For example, ESAU registers an individual when they become a member and issues them with a personalised membership card. This is the case for all 10,500 members. ESAU also records when members collect medicines from their services in a dedicated registry.

There is at least one employment-based administrative system in operation, which is owned by the Uganda Nation Association the Blind. However, an informant explained that, it is “very small, it currently holds around 120 persons with disabilities and does not include their skills sets”.

There are two separate plans to create systems that collect data on persons with disabilities and their employment. NUDIPU committed to building a skill-set focused data bank of persons with disabilities in its strategic plan for 2020–2024, and Cheshire Services Uganda committed to creating an “accessible online database bringing persons with disabilities job seekers and employers together” as one of the outputs for their program Increasing Access to Waged Employment for Persons with Disabilities in Kampala 2018–2020.⁷³ Neither system is operational yet.

The Uganda Nation Association the Blind and Cheshire Services Uganda are not well placed to implement data systems for persons with disabilities and their employment indefinitely.⁷⁴ Such systems are expensive to run and require large-scale deployment to generate significant amounts of data. Therefore, a more sustainable option would be for the state to collect economic and employment disability data and to construct and maintain a database. The MoGLSD, UBOS, the NCD, or NUDIPU possess the structural foundation needed. Moreover, the remit of the MoGLSD’s ESD and UBOS includes responsibility for this.

Challenges with non-government data in Uganda

There are a range of challenges with non-government data which are also constraining the disability data landscape in Uganda. These include the following.

Resource and capacity constraints hinder the ability of many organisations of persons with disabilities (OPDs) to collect disability data

“For the majority [of OPDs] there are few resources to use in running the organisation, let alone to collect data” – Interviewee from development partner

Development partners, international OPDs and other NGOs operating in Uganda typically have funds to generate disability data. However, the majority of Ugandan OPDs face significant resource constraints, which usually translate into a lack of knowledge when it comes to data collection. According to one interviewee, many OPDs “do not have computers and operate from people’s homes” and “the vast majority do not have monitoring and evaluation staff or officers with research or data skills”. A national ODP explained that: “We have 15 staff, 11 of whom are junior support staff and 4 of whom are managerial staff. We have no data, research or monitoring and evaluation department right now. The Executive Director, as per the Human Resources manual, performs those functions”.

Countering the claims that resource constraints limit data collection, one interviewee from a government entity argued that OPDs do not value data enough to produce it. Likewise, an interviewee from a national ODP explained: “Saying that few resources is the cause is not enough. Even with few resources you can collect data. It is interest, more than budget, that causes lack of data among OPDs”.

Non-government disability data often has limited re-use value as it is project focused

Disability data collected by or on behalf of development partners is usually collected in an ad hoc manner for the purposes of a given programme of activities. Moreover, it is nearly always a secondary objective or output which complements a primary intervention. One interviewee explained, “collecting data is usually tied to an individual project; project-driven work means donor-driven work, hence donor priorities are the focus”. Another noted that, “data collection is not proactive; it is haphazard and dictated by donors”. This means that, beyond the context of the project it was collected to inform, the data’s potential utility is minimal.

The quality of non-government disability data is not trusted by users

“The disability movement has done a lot in trying to collect information on their own people, but government has offered no support” – Respondent from OPD

The impression among some research participants was that sources of non-government disability data are normally unreliable. One participant argued that, “there is no reliable data developed independently by OPDs”. Another explained that, “we carried out a baseline survey in 2012 but could not establish accurate data in terms of numbers for persons with intellectual disabilities in Uganda”.

Higher quality data sources are difficult to achieve because resource constraints preclude groups from hiring teams of skilled data experts (e.g. statisticians, data scientists etc.) and from obtaining large sample sizes in surveys. Additionally, several OPDs, universities and medical groups (some of whom complete data collection on behalf of or in collaboration with development partners) feel they have not received consistent support from the government to enable them to develop more robust institutional capacity for data collection.

Despite concerns about quality, the organisations that capture their own data still tend to use it to inform decisions about the project it was collected as a part of. They also typically recycle it again in the future if possible. For example, one interviewee said that their organisation conducted a survey in 2012 and despite the data’s inaccuracies they still refer to it. However, the interviewee also emphasised that their organisation has mostly come to depend on UBOS data, because eight years had passed since the organisation had collected its own data. In many cases even the organisations which collect disability data in surveys cannot produce it regularly enough to meet their own needs.

Limited sharing of disability data ensures lower use

Organisations with their own disability data usually store it internally, either on closed-access computer systems or in paper archives, and do not pro-actively share it with their peers. One interviewee explained that, “data sharing among OPDs is very limited”, while another that, “data sharing is not systematic; it happens haphazardly depending on who is requesting for it, most OPDs keep the data to themselves; it is not even shared online; this is a big problem”. As a result, organisations that do not collect their own data are almost entirely precluded from accessing these sources. In turn, the potential for them to make of use them is significantly reduced.

Similarly, the data collected in non-government administrative systems sits in siloes and are closed to external use. The extent to which OPDs and other NGOs make use of their own records, or the records of a peer, is not entirely clear. However, that no interviewees reported using this type of data is a strong indication of the low value attached to it.

Demand and use of disability data in Uganda

A culture of data use has been slowly developing in Uganda. However, there is a long way to go before disability data is widely used. Where disability data is used, it is mainly to inform or strengthen advocacy campaigns, to design strategies, plan projects, undertake monitoring and evaluation, and to support funding applications and reports. There is limited evidence that disability data is used widely in the design, implementation and evaluation of programmes, policies and services aimed at improving disability inclusion and inclusive employment.

“Some actors use disability data in their work; the vast majority do not” – Respondent from OPD

Use of data has been significantly constrained by challenges in data quality, accessibility and relevance, as outlined previously, but there are other factors that have impacted on data use.

Firstly, demand for both government and non-government data on disability is growing, but this growth in demand is emerging from a low starting point. There has been a relatively short history of data use by MDAs, OPDs and civil society, with the value of disability data only being realised lately in some pockets. Interviews confirmed that data from UBOS was in highest demand, and that UBOS provides the most commonly used sources of disability data for MDAs and OPDs. However, it was also reported that “demand for disability data is not as robust as demand for gender data”. Interviewees explained that the majority of grassroots OPDs in Uganda are not invested in data. For example, one interviewee outlined, “we have not seriously tried to access data”. Some interviewees considered some aspect of data use, such as monitoring and evaluation, as being imposed by donors rather than something they could genuinely benefit from.

Secondly, limited capacities and confidence to use disability data are widespread. This includes the technology (computers, software, internet and electricity) to access and process quantitative data, as well as the technical skills to analyse and apply it. One government interviewee emphasised though that non-government actors are diverse in their abilities and interests, and that “while most do not have the capacity to use data, some do”. The general lack of skills led one interviewee to state, “quantitative data means nothing to some of us; we can’t make sense of them”. Both MDAs and OPDs also highlighted that quantitative data was only of limited use to them, as they felt it omits the day-to-day realities of persons with disabilities, or “the stories behind the numbers”.

Chapter 4: Conclusion

This report presents the findings of a study which investigated the data assets available in Uganda to support the growth of inclusive programmes, policies and services for persons with disabilities, and identified some of the data challenges that need to be overcome to facilitate progress towards disability inclusion and inclusive employment.

The study revealed a complex landscape of policy tools and stakeholders, and the existence of limited 'disability data' (data and information on persons with disabilities) across multiple sources. The study also revealed the lack of coordination and joined-up guidance; gaps in implementation of legislation; challenges in the collection, availability and quality of disability data; and the low demand and capacities to use data as constraining features of the disability data landscape. None of the key government ministries, departments or agencies (MDAs) have assumed leadership over the production or governance of disability data. There is a lack of clear domestic legislation mandating the protection and enhancement of the disability data landscape, and an absence of a dedicated plan or strategy for the development of disability data. More could be done to implement Article 31 of the United Nations Convention on the Rights of Persons with Disabilities; and Uganda Bureau of Statistics (UBOS) has emerged as a potential leader in this, owing to its expertise in data, experience collecting disability data in a range of surveys, and its engagement with organisations of persons with disabilities (OPDs).

Members of the disability rights movement have an important role to play in building wider awareness and action on disability data, potentially learning from the success of other social movements, such as the women's rights movement, in order to grow their influence within Uganda's broader political economy. However, they will have to overcome challenges, not least the lack of resources, technical capacity and, in some places, a lack of (or even resistance towards) interest in disability data.

Throughout the research process, the study engaged with a wide range of stakeholders who were keen to see – and willing to play a role in – the strengthening of Uganda's disability data landscape. In investigating the production, sharing and use of disability data in Uganda, the study identified a range of challenges and opportunities to improve this data, and in turn, to improve the policies, programmes and services aimed at ensuring the economic inclusion of persons with disabilities.

Recommendations

The recommendations formulated by the study were developed collaboratively with OPDs and leading disability data experts in Uganda, following a review of the evidence. They are representative of the opinions expressed by a range of actors, including those from OPDs, civil society groups, governmental entities and development partners.

A Uganda Disability Data Working Group should be instituted to drive improvements in disability data

To drive efforts aimed at strengthening Uganda's disability data landscape, actors from across government and civil society should collaboratively establish a Uganda Disability Data Working Group. The mandate of the group could also include overseeing the recommendations highlighted in this report. Such a group would improve the coordination and quality of disability data, strengthen interaction between UBOS and OPDs, and grow the standing of the disability movement in relation to data issues.

UBOS should take the lead in setting up the Working Group, working closely with umbrella OPDs such as National Union of Disabled Persons of Uganda and National Union of Women with Disabilities of Uganda. The Working Group would need to be representative of all disability stakeholders, including key government MDAs (such as the Ministry of Gender Labour & Social Development (MoGLSD), the National Council for Disabilities, the Ministry of Health, the Ministry of Education and Sports, the National Planning Authority etc.), national and local OPDs representing all persons with disabilities, and key development partners, as well as expert data organisations. Authority should lean towards OPDs, and local groups should have fair representation.

It is recommended that development partners and multilateral organisations which are already active in Uganda in the area of disability data allocate some resources towards financing the Working Group and allocate resources towards ensuring state-produced disability data is of satisfactory quality. The growing focus on measurement against the Sustainable Development Goals and the principle of 'leave no one behind' means that disability issues and needs are likely to come sharply into focus over the next decade, and this move could be harnessed to invite interest from development partners new to the area of disability data.⁷⁵

A Strategy for the Development of Disability Data should be developed, endorsed and implemented

A key priority for the Uganda Disability Data Working Group should be the production of a Strategy for the Development of Disability Data that lays out a vision and realistic action plan for the strengthening of Uganda's disability data landscape. The formal document should be tied to other existing and relevant developmental strategies in Uganda. It should also be timebound and backed-up with adequate resourcing. The Working Group should publish its fully developed policies in the Strategy.

Evidence collected in this study indicates that the Working Group should address the following priority areas in the Strategy.

Creating a timely schedule of surveys to collect disability data that satisfies needs

The Strategy for the Development of Disability Data should rationalise a schedule for the more regular incorporation of disability indicators into UBOS's routine data production. This should be done in close consultation with UBOS whether or not UBOS are members of the Uganda Disability Data Working Group.

The census is held decennially and current indications suggest that the Functional Disabilities Survey (FDS), or something similar, will be conducted every five years. If both patterns hold, between 2020 and 2030 the census will be conducted in 2024 and rounds of the FDS will be conducted in 2022 and 2027. It is likely that data collected in the years between censuses and the FDS will be collected as a part of other surveys.

Contributing to the standardisation of disability questions used in UBOS sources

The Strategy for the Development of Disability Data should articulate UBOS's commitment to either applying the Washington Group Questions (WGQs) framework or to developing an alternative national framework. This should be done in close consultation with UBOS whether or not UBOS are members of Uganda Disability Data Working Group.

If the Working Group chooses to apply WGQs then they will need to make a concerted effort to sensitise the questions to the Ugandan context – for example, by ensuring that the functional disabilities covered by WGQs are representative of the conceptualisations of disability held by OPDs and persons with disabilities in Uganda, as well as ensuring that questions are asked in a way which does not encourage underreporting.

If the Working Group chooses to apply a national framework to enable domestic standardisation then they will need to carry out a mapping to international standards. It is generally more difficult to collect accurate data using complicated question frameworks. The WGQs were developed for pragmatic simplicity; any national framework would benefit from a similar approach. Any national framework should also be compliant with the Convention on the Rights of Persons with Disabilities.

A framework should be in place prior to the FDS (2022) and used again in the national census (2024).

Ensuring the increased utility of the levels of disaggregation in survey and census data

The Strategy for the Development of Disability Data should clarify the types and levels of disaggregation (how data is broken down into categories) to ensure that disability data in Uganda meets the needs of the disability movement and can more effectively support decision-making, while maintaining appropriate data responsibility and privacies. This should be done in close consultation with UBOS whether or not UBOS are members of the Uganda Disability Data Working Group.

One area of disaggregation which interviewees suggested should be improved is the categories of disability captured in the data, with specific attention being paid to psychosocial disabilities, albinism, and the continued integration of little people. They also indicated that disaggregation by social protection and other social programmes was important. These problems can be solved by adjusting questionnaire frameworks in accordance with needs.⁷⁶ The Working Group should consult to determine what data is needed by members of the disability movement and communicate this with UBOS.

Identifying opportunities to further disaggregate existing disability data that may have been overlooked

The Strategy for the Development of Disability Data should outline UBOS data collected after 2015 to be re-analysed by UBOS to achieve the highest possible levels of

disaggregation for the data, such as detailed disaggregation by economic activity, gender, age, etc. This data should then be made widely available.

Improving the sharing and accessibility of disability data for both online and offline users

The Strategy for the Development of Disability Data should provide a plan for the application of mechanisms to facilitate easy access to all of UBOS's disability data for all OPDs and persons with disabilities. This should be done in close consultation with UBOS whether or not UBOS are members of the Uganda Disability Data Working Group.

Examples of mechanisms include a disability data tab on UBOS's website which contains up-to-date data displayed in user-friendly dashboards, and links to every source of disability data the agency has published. It is also important to ensure that information is available in paper formats through user-friendly mechanisms, and is free of charge. For example, UBOS could produce regular, multi-sectoral or thematic factsheets on disability (e.g. on school enrolment, healthcare access, political involvement, etc.) and distribute them via the National Council for Persons with Disabilities, National Union of Disabled Persons of Uganda and National Union of Women with Disabilities of Uganda, and through local facilities (e.g. schools, health facilities).

Creating an electronic disability database to be managed by the Ministry of Gender Labour & Social Development (MoGLSD) or Uganda Bureau of Statistics (UBOS)

The Strategy for the Development of Disability Data should provide a plan for a real time, cross-departmental, electronic disability database. The database should intersect with information from other Management Information Systems (MISs) relating to education, health, economy/employment, etc.

This would require the disability data sections of the Health MIS (HMIS) and the Education MIS (EMIS) to be strengthened, standardised and developed further, with a view to them feeding into the new disability database. A separate, concise yet detailed disability module should be added to HMIS and EMIS tools to ensure more comprehensive disability data is collected in these systems. Thorough rationalisation of modules content is strongly encouraged. The same should be done for any MISs the Uganda Disability Data Working Group recommends should feed into the disability database.

The database should not contain personal data on all parts of people's lives. For instance, even in relation to health a disability database should not have access to a person's complete medical record. The database should be adequately anonymised and made open access upon request, with data made available in user-friendly dashboards. Paper reports should also be made openly accessible and widely available.

The MoGLSD should preside over the establishment and on-going management of the electronic disability database. Therefore, creating the plan for the disability database should be done in close consultation with the MoGLSD whether or not the MoGLSD are members of the Working Group. This is in line with the Second National Development Plan 2015/16–2019/20 and the Social Development Sector Plan, and due to the fact that the MoGLSD is the government entity which oversees the protection and enhancement of persons with disabilities' needs and interests. UBOS should assist the MoGLSD, and if

the MoGLSD cannot establish the system then UBOS should take on the work. In either case, creating the plan for the disability database should also be done in close consultation with UBOS whether or not UBOS are members of the Working Group. The UBOS Act (1998) provides some precedence for both of these scenarios: “the Bureau shall render technical assistance in the establishment and utilization of central public registers which serve to perform administrative duties for the public sector, business and industry, and which can be used for statistical purposes”; and, UBOS should “collect routine administrative statistics”.

The National Identification and Registration Authority’s *My Country, My Identity* campaign (2014 and 2016) saw 14.8 million register for a national identity card, and was a part of still ongoing efforts to issue all Ugandans with a National Identity Number (NIN).⁷⁷ If all Ugandans received a NIN and it was used as a common record in key MISs, interoperability between the disability database and the systems it extracts information from would be made much easier.⁷⁸ Therefore, the Working Group should use the Strategy to advocate for NIN to be used as a common record standard for MISs.

Strengthening the capacities of local and small OPDs to support their collection of disability data

The Strategy for the Development of Disability Data should lay out a plan to increase the quality of subnational OPDs own administrative data systems.

This may include the creation of toolkits by the Uganda Disability Data Working Group to help OPDs establish, restructure, standardise, maintain or scale-up their administrative data systems. This should be conducted with a view to increasing OPDs own use of the administrative data that they collect. Focus should also be on building capacity for the production of disability data by other small, local level organisations, such as the MoGLSD’s district level community development officers.

Basic skills such as proper record keeping, report writing, and communication could act as a catalyst for understanding and appreciating disability data.

Strengthening the capacities of the members of the disability rights movement to support their use of disability data

The Strategy for the Development of Disability Data should lay out a plan to increase use of disability data by MDAs and OPDs. The focus should be on increasing overall ability to analyse and use data in policy and programmatic design and implementation, as well as in advocacy work and in holding mandated actors to account. MDAs and OPDs also need to know all the ways that major forms of disability data (e.g. UBOS sources and electronic disability databases) can be accessed. If possible, this should be tied to general capacity building programmes of relevant offices (e.g. on how to design policy).

Glossary of key terms and list of acronyms

Glossary

Disability data	Information and data on persons with disabilities.
Disability data landscape	The various practices of governing, producing, storing, sharing, and using disability data.

Acronyms

ASC	Annual School Census
CRPD	Convention on the Rights of Persons with Disabilities
DHIS2	District Health Information Software 2
DHS	Demographic and Health Survey
EMIS	Education Management Information System
ESAU	Epilepsy Support Association of Uganda
FDS	Functional Difficulties Survey
FY	Financial year
HMIS	Health Management Information System
MDAs	Ministries, departments and agencies
MIS	Management Information System
MoES	Ministry of Education and Sports
MoGLSD	Ministry of Gender Labour & Social Development
NCD	National Council for Persons with Disabilities
NPA	National Planning Authority
NPDII	Second National Development Plan
NUDIPU	National Union of Disabled Persons of Uganda
OPD	Organisation of persons with disabilities
SDSP	Social Development Sector Plan
UBOS	Uganda Bureau of Statistics
UN	United Nations
UNFPA	United Nations Population Fund
USAID	US Agency for International Development

Annex

Table A1: Key legislation for promoting disability inclusion in Uganda

Legislation	Relevance to promoting disability inclusion
The Constitution of Uganda (1995) ⁷⁹	Political Objective XVI of the constitution states that: “society and the State shall recognise the right of persons with disabilities to respect and human dignity”. The constitution also states that: “All persons are equal before and under the law in all spheres of political, economic, social and cultural life and in every other respect and shall enjoy equal protection of the law” (Section 21, “Equality and freedom from discrimination”).
Local Government Act (1997) ⁸⁰	This act specified that district councils, subcounty councils, city division councils “shall consist of two councillors with disabilities, one of whom shall be a female, representing persons with disabilities” (Section 10, “Composition of district councils”). It also stated that municipal division councils and town councils “shall consist of two councillors with disabilities representing persons with disabilities” and that the executive committee at each parish and village administrative unit shall, among others, include “the chairperson of the organisation for persons with disabilities at the parish or village level who shall be secretary for persons with disabilities affairs” (Section 47, “County chairperson; parish and village executive committee”).
National Council for Disability Act (2003) ⁸¹	This act established the National Council for Disability and outlined its objectives, functions and compositions. Examples of objectives include: “to promote the implementation and the equalisation of opportunities for persons with disabilities”, and “to monitor and evaluate the impact of policies and programmes designed for equality and full participations of persons with disabilities” (Section 5, “Objectives of the council”).
Parliamentary Elections Act (2001) ⁸²	This act specified that: “There shall be the following representatives of special interest groups in Parliament for the purposes of paragraph (c) of clause (1) of article 78 of the constitution [...] for persons with disabilities, there shall be five representatives, at least one of whom shall be a woman [...]” (Section 11, “District Women Representatives and Special Interest Groups”).

Persons with Disability Act (2006) ⁸³	This act outlined legislation in relation to the “right to quality education and health”, “employment of persons with disabilities”, “accessibility” (specifically, infrastructure and transport), “discrimination in relation to goods, services and facilities”, “other social rights”, and “complaints and judicial proceedings” (Sections II–VIII).
Employment Act (2006) ⁸⁴	This act outlined: “There is established a Labour Advisory Board which shall consist of [...] one representative of persons with disabilities” among others (Section 21, “Labour Advisory Board”). It also stated that the Labour Advisory Board shall make recommendations on the minister regarding the regulation of the employment of persons with disabilities, and “shall advise the Minister [meaning, the minister responsible for labour matters] on the following”: “the formulation and development of a national policy on vocational rehabilitation and the employment of persons with disabilities” (Section 22, Functions of the Board).
Persons with Disability Act (2019) ⁸⁵	<p>This act outlines legislation in relation to: “Determination of a person with a disability”, “Rights of persons with disability and non-discrimination”, “The Secretariat”, “Local Government Councils for Persons with Disabilities”, “Financial provisions” and “Elections for persons with disabilities” (Sections I–VIII).</p> <p>This act repealed the National Council for Disability Act (2003): “the National Council for Disability established under the National Council for Disability Act, 2003 and in existence at the commencement of this Act, shall continue in existence under this Act as the National Council for Persons with Disabilities” (Section 16, “The National Council for Persons with Disabilities”). Many responsibilities added, continued or extended; for example, “develop projects and schemes for self-employment or sheltered employment for persons with disabilities” and “transfer the property of the Uganda Foundation for the Blind to the National Council for Persons with Disabilities” (Section 17, “Functions of Council” and Section 18, “Management of property registered in names of Uganda Foundation for the Blind”, respectively).</p> <p>This act repealed the Persons with Disability Act (2006). Many responsibilities added, continued or extended; for example, “to provide for the local government councils for persons with disabilities” (Part V, “Local Government Councils for Persons with Disabilities”).</p>

Table A2: Key institutions for promoting disability inclusion in Uganda

Institutions	Relevance to promoting disability inclusion
Members of Parliament	Members of Parliament were mandated in the Parliamentary Elections Act (2001), and by extension the Ugandan Constitution (1995), to, among other things, protect and extend the rights of persons with disabilities to respect and human dignity, and to enact laws appropriate for the protection of persons with disabilities.
The Ministry of Gender, Labour and Social Development	The Ministry of Gender, Labour and Social Development is mandated to “mobilize and empower communities to harness their potential while protecting the rights of vulnerable population groups”. ⁸⁶ It has a dedicated Disability Desk which primarily oversees the implementation of the Special Disability Grant (funds are controlled by the District Level Special Disability Grant Steering Committee), ⁸⁷ a Directorate of Social Protection which primarily implements the Youth Livelihood Program that funds approved youth groups (sometimes organisations of persons with disabilities), ⁸⁸ and a Coordination Committee on Disability.
The National Council for Persons with Disabilities	The National Council for Persons with Disabilities is composed of a host of actors. These include representatives from the Ministry of Local Governments, the Ministry of Finance, the Ministry of Health; the Ministry of Education and Sports, the Ministry of Gender, Labour and Social Development, the Ministry for Public Service, the Ministry of Justice and Constitutional Affairs the Ministry of Works, Housing and Communication, as well as two persons with disabilities, a male and a female, which represent each region, and one parent of a child with disabilities. Among other things, the National Council for Persons with Disabilities “facilitates action by communicating the concerns of persons with disabilities with Government and other non-government actors”, ⁸⁹ and also “advocates for the promotion and development of programs and projects designed to improve the lives of persons with disabilities”. ⁹⁰
Ministry of Education and Sports	The Ministry of Education and Sports has a Department of Special Needs and Inclusive Education which coordinates and supports the provision of special needs and inclusive education. ⁹¹

Table A3: Metadata for household surveys that contain disability data, 2009 to present

Year	Survey	Lead	Main support agencies	Other support agencies	Period of data collection	Sample size
2009–2010	National Panel Survey ⁹²	Uganda Bureau of Statistic (UBOS)	Government of Netherlands	World Bank	September 2009 – August 2010	3,123
2009–2010	National Household Survey ⁹³	UBOS	Government of Uganda	–	May 2009 – April 2010	7,000
2010–2011	National Panel Survey ⁹⁴	UBOS	Government of Uganda	World Bank and United Nations Population Fund (UNFPA)	October 2010 – September 2011	3,200
2011	Demographic and Health Survey ⁹⁵	UBOS	Government of Uganda	US Agency for International Development (USAID), UNFPA, Unicef, World Health Organization, Irish Aid, UK Department for International Development, ICF International	June 2011 – December 2011	9,033
2011–2012	National Labour Force and Child Activities Survey ⁹⁶	UBOS	International Labour Organization, World Bank	US Department of Labour, International Organization for Migration	November 2011 – April 2012	6,293
2011–2012	National Panel Survey ⁹⁷	UBOS	World Bank	Government of Uganda, UNFPA, government of Netherlands	November 2011 – November 2012	3,123

2012–2013	National Household Survey ⁹⁸	UBOS	Government of Uganda	Economic Policy Research Centre	June 2012 – June 2013	6,887
2013–2014	National Panel Survey ⁹⁹	UBOS	World Bank, government of Netherlands	Government of Uganda	September 2013 – August 2014	3,123
2015	National Service Delivery Survey ¹⁰⁰	UBOS	UK Department for International Development	–	2015	10,101
2015–2016	National Panel Survey ¹⁰¹	UBOS	Government of Netherlands	World Bank	February 2015 – February 2016	3,123
2016	Demographic and Health Survey ¹⁰²	UBOS	Government of Uganda	USAID, Unicef and UNFPA	June 2016 – December 2016	18,506
2016–2017	National Labour Force Survey ¹⁰³	UBOS	Government of Uganda	–	November 2016 – July 2017	4,105
2016–2017	National Household Survey ¹⁰⁴	UBOS	Government of Uganda	Unicef and the Economic Policy Research Centre	June 2016 – June 2017	15,672
2017	Functional Difficulties Survey ¹⁰⁵	UBOS	Government of Uganda	Unicef and UK Department for International Development	2017	7,438

Notes

¹ Uganda Bureau of Statistics (UBOS), 2016. National Housing and Population Census 2014. Available at: <https://uganda.unfpa.org/en/publications/national-population-and-housing-census-2014-0>.

² UBOS, 2018. National Labour Force Survey 2016/17. Available at: https://www.ubos.org/wp-content/uploads/publications/10_2018Report_national_labour_force_survey_2016_17.pdf. Please note that these figures indicate the approximate scale of inclusion but are not directly comparable due to differences in definitions and collection methodologies.

³ According to the situational analysis conducted by the Inclusion Works consortium in 2019, this is as a result of barriers including inaccessible transport; the actual and perceived skills and education levels of persons with disabilities; the low self-esteem and self-confidence of people with disabilities; as well as the fact that persons with disabilities have less human, social, physical, financial and natural capital than persons without disabilities. See: Rohwerder B., 2020. Inclusion Works Situational Analysis. Available at: <https://asksource.info/resources/inclusion-works-uganda-situational-analysis>

⁴ UBOS, 2010. National Household Survey 2009/10 Abridged Report. Available at: <https://catalog.ihnsn.org/index.php/catalog/2119/related-materials>. More updated data was collected by the 2016/17 National Household Survey, however when findings were reported, data on persons with disabilities was aggregated with other 'vulnerable groups' including orphans and widows. See: UBOS, 2018. National Household Survey 2009/10. Available at: https://www.ubos.org/wp-content/uploads/publications/03_20182016_UNHS_FINAL_REPORT.pdf

⁵ Examples in Uganda include: the Technical Vocational Education and Training Policy from the Ministry of Education and Sports; Disability Grants from the Ministry of Gender, Labour and Social Development; and community-based rehabilitation services from the Ministry of Health. See: Ministry of Education and Sports, 2019. Technical Vocational Education and Training Policy. Available at: http://www.education.go.ug/wp-content/uploads/2020/05/FINAL-TVET-POLICY_IMPLEMENTATION-STANDARDS_IMPLEMENTATION-GUIDELINES_19TH_MAY_2020.pdf; Ministry of Gender, Labour and Social Development (MoGLSD), 2016. Social Development Sector Plan (SDSP). Available at: <http://www.npa.go.ug/development-plans/sector-development-plans/>; Make 12.4% Work, The Ministry of Gender, Labour and Social Development, <https://wecanwork.ug/ambassador-mglsd> (accessed 13 May 2020)

⁶ Overseas Development Institute, What is a data ecosystem map?, <https://theodi.org/article/data-ecosystem-mapping-tool/> (accessed 13 May 2020)

⁷ 31 respondents were interviewed from ODPs, government agencies and civil society. Research took place between March and August 2020.

⁸ The desk research included the review of government publications (acts, plans, budgets, etc.), industry reports, technical briefings, articles from academic journals, media reports, databanks, and documentation from development projects, among other sources. The key informant interviews were conducted with: relevant ODPs, government ministries, departments and agencies; university departments; and development partners. Due to coronavirus restrictions, these key informant interviews were conducted via online communications. Guiding questions included: "What sources of disability data exist in Uganda?", "How is disability data collected in Uganda?", "Can stakeholders access disability data in Uganda?", "Do stakeholders use disability data in Uganda? If so, for which activities?", "How do disability data stakeholders interact with each other?". The consultation workshop was also held online. Key findings from the desk review and interviews were presented and discussed at the workshop, and recommendations identified. Inputs from workshop participants were incorporated into the study's report.

⁹ United Nations Treaty Collection, https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsq_no=IV-15&chapter=4 (accessed 14 June 2020)

¹⁰ Government of Uganda, 2014. Second National Development Plan (NDP II). Available at: <http://www.npa.go.ug/development-plans/national-development-plan-ndp/>. NDP II prioritises investment in five areas considered to have the greatest multiplier effect on the economy, which are: agriculture; tourism; minerals, oil and gas; infrastructure development; and, human capital development.

¹¹ Ministry of Gender, Labour and Social Development (MoGLSD), 2016. Social Development Sector Plan (SDSP). Available at: <http://www.npa.go.ug/development-plans/sector-development-plans/>

¹² As part of its commitment to improve access to disability grants, the SDSP set a goal to increase the number of claimants from 0 in 2015 to 45,000 in 2020.

¹³ The policy assumes that "adequate funds will be made available in time" but makes no further assurances on how these assumptions will be realised. For instance, it does not provide options for financial support, or suggestions on which ministries, departments or agencies, or development partners should be involved.

¹⁴ In September 2019, to assist the MoGLSD in its Expanding Social Protection programme, Development Pathways undertook fieldwork in six districts in Uganda as part of a wider situational analysis of persons with disabilities. This indicates that in the last year the MoGLSD may have begun work towards attaining disability inclusion. Please note that Expanding Social

Protection has historically been, and still is, aimed primarily at the elderly. See: Development Pathways, Research on disability in Uganda underway, <https://www.developmentpathways.co.uk/news/research-on-disability-in-uganda-underway/> (accessed 20 June 2020)

¹⁵ Government of Uganda, 2019. The Persons with Disabilities Act 2019. Available at:

<https://ugandajournalistsresourcecentre.com/uganda-persons-with-disabilities-act-2019/>

¹⁶ There is a maximum fine of approximately UGX400,000 (roughly US\$108) and maximum prison sentence of one year for crimes such as non-consensual scientific research, non-consensual sterilisation, and discriminatory torture towards persons with disabilities.

¹⁷ MoGLSD, 2016. SDSP. Available at: <http://www.npa.go.ug/development-plans/sector-development-plans/>

¹⁸ Government of Uganda, 1998. The Uganda Bureau of Statistics Act 1998. Available at:

<https://ulii.org/ug/legislation/consolidated-act/310>

¹⁹ Uganda Bureau of Statistics (UBOS), 2018. Extended Strategy Plan for Statistics. Available at: <https://www.ubos.org/about-us/strategic-plan/>

²⁰ United Nations, Article 31: Statistics and data collection, <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-31-statistics-and-data-collection.html#:~:text=States%20Parties%20shall%20assume%20responsibility,persons%20with%20disabilities%20and%20others> (accessed 13 May 2020)

²¹ MoGLSD, 2016. National Action Plan for Children with Disabilities. Available at:

<https://eprcu.org/children/publications/development/protection-and-participation/child-participation/national-action-plan-for-children-with-disabilities-2016-17-2020-21>

²² The National Disability-Inclusive Planning Guidelines for Uganda also gives multiple “examples of possible interventions” relating to disability data. For instance, to “disaggregate data on enrolment, retention and completion by disability type (according to the Washington Set of Questions – used by the 2014 national census, and other evolving methodology), in the EMIS and other instruments”, to “collect disability-disaggregated data in the HMIS [Health Management Information System]”, and “to collect poverty data disaggregated by disability”. See: National Planning Authority, 2017. National Disability Inclusive Planning Guidelines for Uganda. Available at: <http://npa.go.ug/wp-content/uploads/2018/08/Disability-Inclusive-Planning-Guidelines.Final-for-approval-14.03.2018-FINAL.pdf>

²³ UBOS houses the Directorate of Population and Social Statistics, which is responsible for population, housing, and social statistics, and the Directorate of Statistical Coordination Services, which is responsible for coordinating users and producers of statistics, promoting statistical system coordination, monitoring and supervision of the NSS etc. Both of these directorate are important for disability data. See: Government of Uganda, 1998. The Uganda Bureau of Statistics Act 1998. Available at:

<https://ulii.org/ug/legislation/consolidated-act/310>

²⁴ National Planning Authority, 2017. National Disability Inclusive Planning Guidelines for Uganda. Available at:

<http://npa.go.ug/wp-content/uploads/2018/08/Disability-Inclusive-Planning-Guidelines.Final-for-approval-14.03.2018-FINAL.pdf>

²⁵ The Functional Difficulties Survey (FDS) was based on a subsample of the Uganda Demographic and Health Survey (2016) and carried out in households that had persons with disabilities at the time of the survey. The main objective of the FDS was to collect data on functional difficulties in Uganda to help in the monitoring and evaluation of disability-related programmes and interventions, including national and international development agenda frameworks such as the National Development Plan II, the Global Agenda 2030 and the Africa Agenda 2063. See: UBOS, UK aid and Unicef, 2017. Functional Difficulties Survey 2016/17. Available at: <https://www.unicef.org/uganda/reports/uganda-functional-difficulties-survey-2017>

²⁶ Note that Development Initiatives does not consider the 2022 FDS to be a source because although it has been committed to it has not been completed yet.

²⁷ UBOS, 2016. The National Standard Indicator Framework. Available at: <https://budget.go.ug/sites/default/files/Annex%208a-National%20Standard%20Indicator%20Framework.pdf>

²⁸ Development Initiatives, unpublished. Data for Children – Uganda Joint Diagnostic and Action Plan.

²⁹ Government of Uganda, 2019. Persons with Disabilities Act. Available at:

<https://ugandajournalistsresourcecentre.com/uganda-persons-with-disabilities-act-2019/>

³⁰ Government of Uganda, 2003. National Council for Disability Act. Available at:

<https://ulii.org/system/files/legislation/act/2003/2003/national%20council%20for%20disability%20Act%202003.pdf>

³¹ MoGLSD, Department of Employment Services, <https://mglsd.go.ug/employment-services/> (accessed 17 June 2020)

³² There are concerns among some that umbrella OPDs such the National Union of Disabled Persons of Uganda or the National Union of Women with Disabilities of Uganda do not represent all groups, for example interviewees highlighted that membership of the National Union of Disabled Persons of Uganda does not include ODPs which represent persons with autism.

³³ Gender mainstreaming can be defined as: “incorporating specific concerns and experiences related to gender equality and women’s empowerment into all policies and programmes, in all sectors, so that women and men benefit equally from development, and inequalities are not perpetuated”. See: UN Women, 2014. Gender Mainstreaming in Development Programming,

https://www.researchgate.net/publication/337304676_Gender_Mainstreaming_in_Development_Programming_Guidance_Note (accessed 14 May 2020)

³⁴ Interviewees also observed that “as the ‘leave no one behind’ agenda covers everyone, it does not focus on any one vulnerable group, hence causes with more global movements, support and money, like gender, get more attention”.

³⁵ The original list of verified sources was derived from: UBOS, 2015. National Statistical Metadata Dictionary. Available at: <http://library.health.go.ug/publications/statistics/national-statistical-metadata-dictionary>. According to some documentation,

UBOS conducts an Annual Labour Force Survey, which it developed from the Urban Labour Force Survey, which may contain disability data. Development Initiatives has not been able to find evidence of this survey. For latest accessible survey, see:

UBOS, 2018. National Labour Force Survey 2016/17. Available at: https://www.ubos.org/wp-content/uploads/publications/10_2018Report_national_labour_force_survey_2016_17.pdf

³⁶ A panel survey is conducted annually and mainly looks at socioeconomic indicators. Its sample consists of the same households each year. It is undertaken to cover the gaps between the more comprehensive national household surveys.

³⁷ Note that more updated data was collected by the 2016/17 National Household Survey, however when findings were reported, data on persons with disabilities was aggregated with other 'vulnerable groups' including orphans and widows. It is likely that this is case with other UBOS surveys too. See: Uganda Bureau of Statistics (UBOS), 2018. National Household Survey 2016/17. Available at: https://www.ubos.org/wp-content/uploads/publications/03_20182016_UNHS_FINAL_REPORT.pdf

³⁸ UBOS, 2010. National Panel Survey 2009/10. Available at: <https://microdata.worldbank.org/index.php/catalog/1001>

³⁹ UBOS, 2010. National Household Survey 2009/10 Abridged Report. Available at: <https://catalog.ihnsn.org/index.php/catalog/2119/related-materials>

⁴⁰ UBOS, 2010/11. National Panel Survey 2010/11. Available at: <https://microdata.worldbank.org/index.php/catalog/2059/related-materials>

⁴¹ UBOS, 2012. Demographic and Health Survey 2011. Available at: <https://www.dhsprogram.com/publications/publication-FR264-DHS-Final-Reports.cfm>

⁴² International Labour Organization, 2017. National Labour Force Survey 2011/12. Available at: <https://catalog.ihnsn.org/index.php/catalog/6785/related-materials>

⁴³ UBOS, 2013. National Panel Survey 2011/12. Available at: https://microdata.worldbank.org/index.php/catalog/2059/related_materials

⁴⁴ UBOS, 2014. National Household Survey 2012/13. Available at: <https://catalog.ihnsn.org/index.php/catalog/4620/related-materials>

⁴⁵ UBOS, 2013/14. National Panel Survey. Available at: <https://microdata.worldbank.org/index.php/catalog/2663/pdf-documentation>

⁴⁶ UBOS, 2016. National Housing and Population Census 2014. Available at: <https://uganda.unfpa.org/en/publications/national-population-and-housing-census-2014-0>

⁴⁷ UBOS, 2016. National Service Delivery Survey 2015 Report. Available at: <http://library.health.go.ug/publications/surveys/national-service-delivery-survey-report-2015>

⁴⁸ UBOS, 2015. National Panel Survey 2015. Available at: <https://microdata.worldbank.org/index.php/catalog/3460/related-materials>

⁴⁹ UBOS, 2018. Demographic and Health Survey 2016. Available at: <https://dhsprogram.com/what-we-do/survey/survey-display-504.cfm>

⁵⁰ UBOS, 2018. Manpower Survey Uganda 2016/17. Available at: https://www.ubos.org/wp-content/uploads/publications/08_20182018_Uganda_Manpower_Survey_Report.pdf

⁵¹ UBOS, 2018. National Labour Force Survey 2016/17. Available at: https://www.ubos.org/wp-content/uploads/publications/10_2018Report_national_labour_force_survey_2016_17.pdf

⁵² UBOS, 2018. National Household Survey 2016/17. Available at: https://www.ubos.org/wp-content/uploads/publications/03_20182016_UNHS_FINAL_REPORT.pdf

⁵³ UBOS, UK aid and Unicef, 2017. Functional Difficulties Survey 2016/17. Available at: <https://www.unicef.org/uganda/reports/uganda-functional-difficulties-survey-2017>

⁵⁴ Historically, Uganda has implemented an Education Information Management System (EMIS) and/or an Annual School Census (ASC) at different points. See: The Ministry of Education and Sports (MoES), EMIS, <http://www.education.go.ug/emis/> (accessed 22 June 2020). Previously the ASC was the predominant method, but more recently EMIS has been re-operationalised. See: DHIS2 Community, Updates on DHIS2 for Education Management Information System in Uganda, <https://community.dhis2.org/t/updates-on-dhis2-for-education-management-information-system-emis-in-uganda/37746> (accessed 22 June 2020). ACS statistics were published in annual 'Education Abstracts'. Typically, these included very little data concerning students with disabilities; for example, the 2017 edition (the most recent edition) contained one table showing attendance disaggregated by six categories. See: MoES, 2017. Education Abstract 2017. Available at: <http://www.education.go.ug/wp-content/uploads/2019/08/Abstract-2017.pdf>

⁵⁵ Nationally defined questions are those composed by UBOS that do not explicitly reference other countries' and/or international bodies' questionnaire frameworks.

⁵⁶ Washington Group Questions are "designed to provide comparable data cross-nationally for populations living in a variety of cultures with varying economic resources", using the World Health Organization's International Classification of Functioning, Disability and Health as a conceptual model. See: Washington Group on Disability Statistics, Conceptual Framework, <https://www.washingtongroup-disability.com/about/conceptual-framework/> (accessed 20 June 2020)

⁵⁷ UBOS, UK aid and Unicef, 2018. Functional Difficulties Survey 2016/17. Available at: <https://www.unicef.org/uganda/reports/uganda-functional-difficulties-survey-2017>

⁵⁸ UBOS, 2018. National Labour Force Survey 2016/17. Available at: https://www.ubos.org/wp-content/uploads/publications/10_2018Report_national_labour_force_survey_2016_17.pdf

⁵⁹ UBOS, 2018. Demographic and Health Survey 2016. Available at: <https://dhsprogram.com/what-we-do/survey/survey-display-504.cfm>

⁶⁰ UBOS, 2016. National Housing and Population Census 2014. Available at: <https://uganda.unfpa.org/en/publications/national-population-and-housing-census-2014-0>

[population-and-housing-census-2014-0](#)

⁶¹ UBOS, 2010. National Household Survey Abridged Report 2009/10. Available at:

<https://catalog.ihnsn.org/index.php/catalog/2119/related-materials>

⁶² Unicef, 2020. Producing Disability-Inclusive Data. Available at: <https://data.unicef.org/resources/producing-disability-inclusive-data-why-it-matters-and-what-it-takes/#:~:text=Inclusive%20data%20are%20key%20to,data%20collection%20processes%20and%20outcomes>

⁶³ In 2019 UBOS published a 'Persons with Disability Monograph' complete with statistics and analysis based on the data from the 2014 census. UBOS, 2019. Persons with Disabilities Monograph. Available at: https://www.ubos.org/wp-content/uploads/publications/09_2019DISABILITY_MONOGRAPH_FINAL.pdf

⁶⁴ A comment made by an interviewee touches on an important discussion: "UBOS normally includes disability issues in general surveys which makes key issues of disability crowded into other issues. There have rarely been any disability-focused surveys, save for FDS [Functional Difficulties Survey] in 2017". In other words, the discussion is whether targeted surveys or questions being integrated into other surveys will produce better quality disability data. The interviewee is suggesting that surveys which "target" disability are more desirable, e.g. FDS. On the other hand is the option integrate questions into other surveys. Surveys like FDS are expensive and it should be noted that the two options are not mutually exclusive.

⁶⁵ UBOS participated in Washington Group meetings from its inception and hosted the annual meetings in 2006.

⁶⁶ Such views were widespread among the organisations of persons with disabilities (OPDs) interviewed, and many felt that Washington Group Questions (WGQs) were donor imposed, rather than collaboratively developed. This is an area that both the Washington Group and UBOS could address with further consultation with Uganda's OPDs.

⁶⁷ Government of Uganda, 2015. Registration of Persons Act. Available at: <https://ulii.org/ug/legislation/act/2015/4-6>

⁶⁸ Actors may be able to contact appropriate ministries, departments and agencies (MDAs) requesting access to their data. However, the right to this information is not guaranteed in law, hence MDAs can ignore or refuse requests without consequence.

⁶⁹ Following a merger, the UK's Department for International Development has been replaced with the Foreign, Commonwealth and Development Office.

⁷⁰ National Union of Disable Persons of Uganda (NUDIPU) and Makerere University researched persons with disabilities living conditions but have not published this research.

⁷¹ For example, Dr Richard Irdo, President of the Uganda Medical Association, has lead studies into understanding the nodding syndrome and the effects of malaria on the brain. Uganda Medical Association. See: Uganda Medical Association, Dr Richard Irdo, <http://uma.ug/dr-richard-irdo/> (accessed 17 May 2020)

⁷² Studies listed are those talked about by interviewees during key informant interviews.

⁷³ In collaboration with National Union of Disabled Persons of Uganda and National Union of Women with Disability of Uganda.

⁷⁴ It is uncertain whether the data bank proposed by NUDIPU in its 2020–2024 strategic plan is a genuinely new idea. It has been talked about since 2002 but with no avail. Similarly, there is no information about Cheshire Services Uganda's database to provide an update.

⁷⁵ The Netherlands Development Cooperation and Finnish International Development Agency are organisations which have both highlighted their intention to improve disability data in light of the 'leave no one behind' agenda.

⁷⁶ However, the challenge presented by achieving sub-national disaggregation down to the district level is a significant one. Considering the largest sample size of a survey that has collected disability data to date is 18,506 (demographic health survey, 2016), financing a survey with a sample size greater than 100,000 people will a significant undertaking.

⁷⁷ Digital Identity, 2019. Country Profile: Uganda. Available at: <https://citizenshiprightsafrika.org/digital-identity-country-profile-uganda/>

⁷⁸ The costs of doing this would be made less as the data generated by NIN registrations, HMIS, DHIS2, etc. is already stored electronically.

⁷⁹ Government of Uganda, 1995. Constitution of Uganda. Available at: <https://ulii.org/ug/legislation/consolidated-act/0>

⁸⁰ Government of Uganda, 1997. Local Governments Act. Available at: <https://ulii.org/ug/legislation/consolidated-act/243>

⁸¹ Government of Uganda, 2003. National Council for Disability Act. Available at: <https://ulii.org/system/files/legislation/act/2003/2003/national%20council%20for%20disability%20Act%202003.pdf>

⁸² Government of Uganda, 2001. Parliamentary Elections Act. Available at: <https://ulii.org/system/files/legislation/act/2001/2001/parliament%20elections%20Act%202001.pdf>

⁸³ Government of Uganda, 2006. Persons with Disability Act. Available at: https://www.ilo.org/dyn/natlex/natlex4.detail?p_lang=en&p_isn=88100&p_country=UGA&p_count=135&p_classification=08.01&p_classcount=4

⁸⁴ Government of Uganda, 2006. Employment Act. Available at: http://www.oit.org/dyn/natlex/natlex4.detail?p_lang=en&p_isn=74416

⁸⁵ Government of Uganda, 2019. Persons with Disabilities Act. Available at: <https://ugandajournalistsresourcecentre.com/uganda-persons-with-disabilities-act-2019/>

⁸⁶ DEVEX, Ministry of Gender, Labour and Social Development, <https://www.devex.com/organizations/ministry-of-gender-labor-and-social-development-uganda-133491> (accessed May 10 2020)

⁸⁷ Individual persons with disabilities can make claims, and organisations of persons with disabilities can also make claims on behalf of its members. However, the amount of money given is very small, hence therefore people tend to club together to get a bigger pay out in order to invest in something they couldn't could not have done otherwise, e.g. the mill in the case featured in this source: Epilepsy Support Association of Uganda, Our Success Stories, Metu Metu Esau Branch – Moyo District, <http://www.epilepsy.org.ug/story.html> (accessed 12 May 2020)

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- ⁸⁸ This is not exclusively focused on persons with disabilities.
- ⁸⁹ National Council for Persons with Disabilities, About National Council for Disability, <https://www.ncd.go.ug/about-national-council-disability> (accessed 18 May 2020)
- ⁹⁰ National Council for Persons with Disabilities, About National Council for Disability, <https://www.ncd.go.ug/about-national-council-disability> (accessed 18 May 2020)
- ⁹¹ Ministry of Educations and Sports, Department of Special Needs and Inclusive Education, <http://www.education.go.ug/special-needs-inclusive-education/#:~:text=Special%20Needs%20%26%20Inclusive%20Education%20%2D%20Ministry%20of%20Education%20And%20Sports&text=The%20mandate%20of%20the%20Ministry,the%20Ugandan%20State%20and%20Government> (accessed May 10 2020)
- ⁹² Uganda Bureau of Statistics (UBOS), 2010. National Panel Survey 2009/10. Available at: <https://microdata.worldbank.org/index.php/catalog/1001>
- ⁹³ UBOS, 2010. National Household Survey 2009/10 Abridged Report. Available at: <https://catalog.ihnsn.org/index.php/catalog/2119/related-materials>
- ⁹⁴ UBOS, 2010/11. National Panel Survey 2010/11. Available at: <https://microdata.worldbank.org/index.php/catalog/2059/related-materials>
- ⁹⁵ UBOS, 2012. Demographic and Health Survey 2011. Available at: <https://www.dhsprogram.com/publications/publication-FR264-DHS-Final-Reports.cfm>
- ⁹⁶ International Labour Organization, 2017. National Labour Force Survey 2011/12. Available at: <https://catalog.ihnsn.org/index.php/catalog/6785/related-materials>
- ⁹⁷ UBOS, 2013. National Panel Survey 2011/12. Available at: https://microdata.worldbank.org/index.php/catalog/2059/related_materials
- ⁹⁸ UBOS, 2014. National Household Survey 2012/13. Available at: <https://catalog.ihnsn.org/index.php/catalog/4620/related-materials>
- ⁹⁹ UBOS, 2013/14. National Panel Survey. Available at: <https://microdata.worldbank.org/index.php/catalog/2663/pdf-documentation>
- ¹⁰⁰ UBOS, 2016. National Service Delivery Survey 2015 Report. Available at: <http://library.health.go.ug/publications/surveys/national-service-delivery-survey-report-2015>
- ¹⁰¹ UBOS, 2015. National Panel Survey 2015. Available at: <https://microdata.worldbank.org/index.php/catalog/3460/related-materials>
- ¹⁰² UBOS, 2018. Demographic and Health Survey 2016. Available at: <https://dhsprogram.com/what-we-do/survey/survey-display-504.cfm>
- ¹⁰³ UBOS, 2018. National Labour Force Survey 2016/17. Available at: https://www.ubos.org/wp-content/uploads/publications/10_2018Report_national_labour_force_survey_2016_17.pdf
- ¹⁰⁴ UBOS, 2018. Uganda National Household Survey 2016/17. Available at: https://www.ubos.org/wp-content/uploads/publications/03_20182016_UNHS_FINAL_REPORT.pdf
- ¹⁰⁵ UBOS, UK aid and Unicef, 2017. Functional Difficulties Survey 2016/17. Available at: <https://www.unicef.org/uganda/reports/uganda-functional-difficulties-survey-2017>

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