MEASURING CHILD DISABILITY: PILOTING A FUNCTIONAL ASSESSMENT TOOL IN CHILDREN AT THE IGANGA-MAYUGE HEALTH AND DEMOGRAPHIC SURVEILLANCE SITE IN UGANDA

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Abstract

Disability is a dynamic and complex phenomenon. Across the globe, disability is considered a major development priority especially in low-and-middle-income countries (LMICs). Sustainable Development Goal 17 emphasizes the importance of high quality, reliable and timely availability of disability data to monitor the progress of other disability related Sustainable Development Goals (SDGs) on inclusive education (Goal 4), inclusive employment opportunities (Goal 8), social, economic and political inclusion (Goal 10), and accessible cities and public spaces (Goal 11).

According to the World Report on Disability reliable data on disability are lacking for most LMICs. Disability among children is even less understood due to lack of standardized and easy-to-use population-based tool. Globally, there are about 93 million (one in 20) disabled children less than 15 years of age living with moderate or severe disability. To address this gap in disability measurement among children, the UNICEF and Washington Group developed a child disability assessment (C-DAS) tool for children 5-17 years of age. This 24-question and 13-domain tool has not been validated in Africa including Uganda where disability among children ranges between 2-13%. This thesis addresses this gap and comprises of three papers.

The first paper is titled “Adaptation and validation of a child functional assessment tool at the Iganga-Mayuge Health and Demographic Surveillance Site in Uganda”. It assesses adaptation of the tool for implementation at the Iganga-Mayuge Health and Demographic Surveillance Site in Uganda and presents its psychometric properties.

The second paper is titled “Measuring child functioning: assessing correlation and agreement between caregiver and child responses at the Iganga-Mayuge Health and Demographic Surveillance Site in Uganda”. This paper assesses correlation and agreement between responses of child-caregiver pairs.

The third paper is titled “Factors associated with child disability at the Iganga-Mayuge Health and Demographic Surveillance Site in Uganda”. It examines disability categories and presents factors associated with disability among children.

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Abbreviations

CBR	Community-based rehabilitation
C-DAS	Child disability assessment tool
EFA	Exploratory factor analysis
HICs	High-income countries
ICF	International Classification of Functioning, Disability and Health
ICT	Information and communication technology
IM-HDSS	Iganga-Mayuge Health and Demographic Surveillance Site
INDEPTH	International Network for the Demographic Evaluation of Population and Their Health Network
IQR	Interquartile range
JH-IIRU	Johns Hopkins International Injury Research Unit
JHU-MU E-TRIAD	Johns Hopkins University-Makerere University Electronic Trauma, Injuries and Disability in Uganda
KMO	Kaiser–Meyer–Olkin test of sampling adequacy
LMICs	Low-and-middle-income countries
MICS	Multiple Indicator Cluster Survey
MUSPH	Makerere University School of Public Health
SDGs	Sustainable Development Goals
SES	Socioeconomic status
TQ	Ten Questionnaire
UN	United Nations
UNICEF	United Nations Children’s Fund
WB	World Bank
WG	Washington Group
WHODAS 2.0	WHO Disability Assessment Schedule 2.0
WHO	World Health Organization

Chapter 1: Introduction and background

Introduction

Across the globe, disability is considered a major development priority especially in low-and-middle-income countries (LMICs) [1-3]. Regarded as a human rights issue by the World Health Organization (WHO) and United Nations Children's Fund (UNICEF), five out of 17 Sustainable Development Goals (SDGs) specifically focus on inclusion of individuals with disability; Goal 4 focuses on inclusive education, Goal 8 on equal and inclusive employment opportunities, Goal 10 on social, economic and political inclusion of individuals with disabilities, Goal 11 on accessible cities, transport services and public spaces, and Goal 17 emphasizes the importance of high quality, reliable and timely availability of disability data to monitor the progress of other disability-related SDGs [4, 5]. Disability indicators specific to targets under these goals are developed to assess progress of SDG implementation at national and subnational level. These goals, and their associated targets and indicators, are a major milestone in understanding the needs of individuals with disabilities and their inclusion in national and subnational level economic and social policies. Table 1.1 lists SDGs specific to disability and their targets and indicators.

Disability is a complex phenomenon and, based on the International Classification of Functioning, Disability and Health (ICF), is defined as interactions between impairments at the body level in the context of a person's health condition as well as contextual factors specific to their environment (Figure 1.1) [6]. Disability can have significant impact on individuals, their families and the society. It is regarded as a cause and consequence of poverty [7]. In many LMICs, disability is highly stigmatized and can lead to social exclusion and discrimination. For children with disability, this often means a life in isolation and exclusion from education and future employment opportunities, as well as a lack of access to health services [3, 8-11]. This puts them at risk of falling in a cycle of poverty and leads to vulnerabilities that result in a higher likelihood of them experiencing violence and being abused[3].

Estimates from the WHO put the global prevalence of disability at 15%, or 1 in seven people in the world. Globally, there are about 93 million (one in 20) disabled children less than 15 years of age living with moderate or severe disability [2, 3]. According to UNICEF, between 120 – 150 million children under 17 years of age live with some form of disability [12]. About 90% of these children live in LMICs [2, 3, 8, 11, 13]. Children from households that are poor or belong to certain ethnicities are more likely to experience disability [3]. The estimated prevalence of moderate to severe disability in the African region is 15.3% [11]. According to the WHO, the main causes of disability in the African region include infectious diseases - polio and leprosy; noncommunicable diseases like congenital malformation and cerebral palsy; injuries such as road traffic crashes; and health service errors such as inappropriate treatment [14]. However, it is important to point out that the World Report on Disability acknowledges that these numbers are an underestimation and that reliable data on disability – prevalence, type, and causes – are lacking for most LMICs [11].

Measurement of disability at the population level has been particularly problematic due to the complexity of the disability phenomenon [13, 15, 16]. This has been further exacerbated, especially in LMICs, by prevailing socio-cultural norms. How a society defines disability is often a reflection of these norms and contemporary views around the issue [6-11]. The field of disability, too, has evolved in its conceptualization of disability over the past several decades - moving from defining disability as a purely medical phenomenon to a complex interaction between impairments at the body level, in the context of a health condition, as well as contextual factors specific to the environment in which the individuals live [1, 6, 15, 16]. This has had a direct implication on population-based assessments of disability and its impact on individuals, families and the society. Furthermore, tools developed in high-income countries (HICs) may not be directly applicable to LMICs due to differences in context within which disability is assessed [13, 17, 18].

Rationale

While disability in LMICs is not well understood, it is even less so among children in these settings. One of the main problems has been the lack of standardized, easy-to-use instruments that could be used to understand child disability [11, 19]. This has led to the lack of comparable burden estimates and hampers the development and evaluation of appropriate policies and programs to address the needs of children with disabilities [19]. Socio-cultural issues in LMICs also cast a shadow on these individuals through stigmatization and lack of acceptance [11, 20] in some settings. These children may be seen in a negative light, leading parents to hide them or limit their exposure to society [21].

Understanding not only the existence and type of disability but also its impact on the child is, therefore, crucial as they go through different stages of growth and development, which can influence their participation and functioning in their environment and society [13, 22].

Development in children is contextualized based on their immediate environment, where family and living circumstances play an important role in the development process and their ability to adapt within their social environment [13]. In addition to the home, the school (for those fortunate enough to go) becomes an important environment for children, especially in their later years of growth. One aspect of these environmental interactions is the level of functioning that children with disability have with respect to, for example, vision, hearing, mobility, self-care and social interactions [23]. Functioning is a spectrum that could range from none/minimal difficulty to severe difficulties and depending on where a child is on that spectrum, s/he could have different implications in terms of development and growth, and these could be influenced by their immediate environment and their ability to accommodate. However, there is scarcity of data from LMICs on functioning for children with disability, as well as their interaction with their environment [24]. The overall aim of this study was to adapt and validate the child functioning tool in Uganda to get a reliable and initial picture of extent of disability among children in Uganda. Such evidence is critical in developing programs to cater for the needs of these children and create lifelong opportunities for them [11].

Literature review

The literature review includes discussion of International Classification of Functioning, Disability, and Health framework and how it applies to children, commonly used tools for disability assessment in children, work conducted by Washington Group on Disability Statistics (WG) and UNICEF to develop child disability assessment tools for comparable data collection, and a brief description of a study that used the UNICEF/WG tool.

International Classification of Functioning, Disability, and Health framework (child and youth version)

The WHO modified the International Classification of Functioning, Disability and Health (ICF) framework and adapted it for children and youth (ICF-CY) to better understand needs of children with disability as they grow [13, 15]. The framework was proposed in 2007 to account for disability in children, which differs from adults in several ways. Children differ from adults in terms of their anatomy and body functioning. Their needs and requirements change as they go through the various stages and early years of development, especially in terms of their activities and interactions with their immediate environment.

Furthermore, since ICF-CY is based on ICF, it also helps in applying ICF to children when they become adults; this can inform continuity of care based on the type of disability (Figure 1.1). The framework is applicable to children up to 17 years of age and comprises functioning and contextual factors [6, 13]. *Functioning* relates to anatomical structures and functioning of body and activities, as well as participation at the individual level and at the level of the society. The *contextual factors* include environmental factors (immediate to more general environment of the disabled individual) and personal factors. It is the interplay and interaction of these factors that determine the extent of disability in an individual [13, 15].

Tools for assessing disability in children

Efforts to assess motor, cognitive, language, and social functioning in children has focused on using various tools often already used by clinicians. Most tools, for example, the Mental Retardation Adaptive Behavior Scale or Griffith's Scale of Mental Development, assess intellectual disabilities. The Ten Questionnaire (TQ) is a screening tool which assesses disability in children between 2-9 years of age and was found to be suitable for severe disabilities but tends to miss mild to moderate disabilities in populations. In addition, TQ was developed for use in a two-step process, where children screened in step one was needed to be followed by clinical assessment in step 2. However, step 2 is rarely conducted, especially in LMICs settings, due to limited resources available for clinical assessments [25, 26]. In addition, there is lack of data at the population level due to costs associated with acquiring these tools and their training requirements [17, 18, 24]. Moreover, countries that do have data on child disabilities lack a consistent and systematic approach for assessing such disabilities in children [3, 13].

UNICEF and Washington Group Module on Child functioning

The Multiple Indicator Cluster Survey (MICS) administered by UNICEF introduced a disability module for children in 2000 and collected data in 50 surveys from various

LMICs. However, in 2011 UNICEF collaborated with the Washington Group (WG) to revise and develop a disability tool for assessing child functioning [27]. The Washington Group was established under the United Nations (UN) Statistical Commission as a UN city group in collaboration with United Nations Children's Fund (UNICEF). The WG undertook the task to develop a set of questions to assess disability in children. These questions were developed based on the ICF-CY framework. It resulted in the development of two versions of a child disability assessment tool— one for children between 2-4 years and the second for those between 5-17 years [23, 28]. The tool covers the domains of vision, hearing, walking, communication, learning, relationships, and playing. In addition, the domains of emotion, behavior, concentration and coping with change were also added to get a better understanding of child development and functioning. The questions were developed based on the previous work that the WG has done to assess disability data in adults [29]. Children under 2 years of age are not included due to the challenge associated with assessing developmental delays in such young children. In addition, cultural norms tend to vary and can influence a child's developmental milestones during infancy [23, 27].

In 2012-2013, field testing of the tool for 5-17 year olds was conducted in two rounds in several different settings, including India, Belize, Oman, Montenegro, and the USA, resulting in the development of a final version that was used for this study [25, 30-32]. The main respondents of the tool are caregivers of children. However, WG also conducted cognitive tests in the US to assess differences in the understanding of a question by both caregivers and children (11-17 years), finding high levels of agreement between the two groups. This testing has not been conducted in any other setting [33]. As of now, the tool for the 5-17-year age group has not been validated in Africa (or Uganda).

A recent study from South Africa has used the UNICEF/Washington Group tool for 2-4-year-old children in its 2011 General Household Survey and National Census to generate epidemiological evidence on child disability and to identify types and extent of disabilities. An advantage of this tool is that it does not need clinicians to administer it; it can be implemented easily by field staff [34]. The Washington Group/UNICEF tool for 5-17-year-old children was validated in school settings in Fiji in 2015 with the objective to determine if the UNICEF/Washington Group tool can be used by teachers to identify children at risk of disability for timely referral for further assessment and interventions [35].

Standardized methods to assess disability as part of national surveys has positive implications for a country, and it allows monitoring of progress by making comparisons at national and international levels. Developing polices and interventions to address the needs of disabled children and rehabilitation programs is possible using reliable data, and such data can be a means of understanding the needs of disabled children based on their sex and age [3, 24]. Currently, there is a lack of standardized tools to assess disability in children at a population level [24]. In addition, the use of a single set of questions for both adults and children, without specifically asking about children with disability, is inappropriate; some surveys ask about child disability using questions designed for assessing adult disability [24].

Disability in Uganda

Uganda is a nation of 42.8 million people located in East Africa [36] (Table 1.2). About 50% of its population is female, and more than 70% lives in rural areas of the country [36]. The population of the country is young with a median age of 15.8 years and life expectancy of 65.7 years at birth [1, 37] (Figure 1.2 and 1.3). The crude birth rate and crude death rates are 42 and 9 per 1,000 people, resulting in a younger population [36, 38] (Table 1.2). However, due to high proportion of younger population, the age dependency ratio is 108%, while 38% of the population lives below the international poverty line <$1.25/day [36, 39]. This disparity in population growth and dependency is further aggravated by lack of healthcare in the public sector. Health expenditure per capita is US$52, and out-of-pocket expenditure is 41% of the total health expenditure [36].

The burden of disease in children between 5-19 years of age is still mainly attributed to communicable diseases like HIV, malaria, and diarrhea. However, non-communicable diseases like skin diseases and asthma as well as injuries from road crashes, drowning and falls are also contributing to the disease burden [1] (Figure 1.4). This “triple burden” of diseases is crippling for a fragile economy when people must pay for their own healthcare. Furthermore, with survival of a young population with disabilities and lack of public rehabilitation facilities, the burden of care falls on families.

The 2002 Uganda Population and Housing Census estimated that there are about 2% disabled children in Uganda, [40] and according to the 2014 census, 12.5% of individuals in Uganda have at least one type of disability [40]. Estimates from the UNICEF and the

Ministry of Gender of Uganda put this number at 2.5 million disabled children (13% of the population) in the year 2014, with only 9% of them attending primary school and 6% attending secondary school [41]. Of the children with disabilities in Uganda, only 10% have access to schools that meet their needs, and only 5% of disabled children going to public school receive specialized education [42]. These estimates are worrisome and underscore the significant impact that disability can have on the development and future life opportunities for these children.

Previous work in Uganda developed and applied instruments to assess disability among adults at the Iganga-Mayuge Health and Demographic Surveillance Site (IM-HDSS) [43, 44]. To overcome socio-cultural issues impeding the identification of individuals with disability, the Washington Group on Disability Statistics' (WG) approach was used to identify individuals with specific limitations in key areas of functioning such as vision, hearing, upper and lower limb mobility, self-care, and communication [43-45]. Through this approach the prevalence of disability in adults was found to be 9.4% in IM-HDSS, with difficulty in vision being the most common type of disability. Being male, older age, and lower socioeconomic status (SES) were associated with physical disability [43]. Disabled adults were found to have greater difficulty in getting around, life activities, and participation in society [44]. One interesting finding from this study was that many of these limitations had been life-long, implying that they either began in childhood or earlier; this study expands such measurement effort to children, and generates data to address the gap that exists in disability studies in LMICs.

It is important to note that on papers, Uganda has policies for inclusion and integration of individuals with disabilities including children. In 1966, the Government of Uganda implemented a policy related to provision of technical support to disabled people. In 1995, articles were added to the constitution, including protection of disabled individuals against discrimination and ensuring their representation in the Parliament [14]. According to the Children Act 1997, children with disabilities will have equal opportunities related to education and health [46]. The Persons with Disabilities Act (2006) mandates the government to provide education and disability rehabilitation to children with disabilities [47]. Uganda is also a signatory of the 2008 Convention on the Rights of Persons with Disabilities and the 1983 International Labor Organization Convention on Vocational Rehabilitation and Employment of disabled persons [9, 48]. There have been efforts to develop rehabilitation programs at district levels and build schools for children who are deaf, and there is also a national steering committee on community-based rehabilitation (CBR) [48]. Uganda is a member of the African Rehabilitation Institute, which is involved in research and capacity development on disability prevention and rehabilitation in the African region. It provides support to governments and both national and international NGOs to ensure inclusion of individuals with disabilities and facilitates provision of rehabilitation services [14, 48]. Table 1.3 gives summaries of various polices and acts related to individuals with disabilities in Uganda.

These policies show that Uganda realizes the importance of inclusive education and equal opportunity for the disabled. However, among the key challenges to implementation of these policies and monitoring them is the lack of population level data on disability [21].

This is a major gap in addressing the burden of disability, especially among children, since such data is scarce, and their needs are not understood. Through this study, data generated can be used to stimulate discussion around programs and policies as well as further research to understand and address the needs of children with disability in Uganda. This is in line with SDG goal 17, which emphasizes the importance of availability of quality data.

Overall goal

The overall goal of this study is to explore and validate new standardized population-based approaches for measuring functional disability in children in LMICs.

Specific aims

This study focused on children between 5-17 years of age living in the Iganga-Mayuge Health and Demographic Surveillance Site (IM-HDSS) in Uganda and used standardized disability assessment tools for brief and in-depth assessment of their functioning.

The specific aims are to:

1. Adapt and validate a child disability assessment tool (C-DAS) applicable to children between the ages of 5-17 years at the IM-HDSS in Uganda
2. Assess correlation and agreement of C-DAS responses between children (11-17 years old) and their caregivers at the IM-HDSS in Uganda
3. Assess factors associated with disability among children between 5-17 years at the IM-HDSS in Uganda

Conceptual framework

This study is based on the ICF-CY framework and focused on understanding limitations of children with disability in terms of their physical activity and participation. This was measured through assessment of child functioning. In addition, cause, duration, type and extent of disability were also assessed. It is crucial to conceptualize disability within contextual factors that affect the disability of an individual (Figure 1.5). Therefore, an in-depth assessment of personal, caregiver and environmental factors of children with disability was also conducted; these covered questions related to birth history, vaccination history, parental factors, household socioeconomic status, caregiver information, access to school, medical care and rehabilitation services.

Overall methodology

This *cross-sectional* study was conducted from September 2018 – January 2019. It adapted and validated C-DAS to the Ugandan context and focused on assessing disability in children between the ages of 5-17 years of age living in IM-HDSS. The assessment was related to children with physical disability, which included difficulty in vision, hearing, mobility, communication, cognition and anxiety and depression.

Study site

IM-HDSS, located in Eastern Uganda, covers the districts of Iganga and Mayuge (Figure 1.6). The site is part of the International Network for the Demographic Evaluation of Population and Their Health Network (INDEPTH) and was established in 2005 as a field research site for Makerere University [49-51]. About 38% of the IM-DSS is peri-urban and is located mostly around Iganga, and females comprise about half of the population. IM-

HDSS has a crude birth rate of 21.1 per 1000 live births and a crude death rate of 4.2 per 1000 live births [51].

IM-HDSS has 20 healthcare facilities, including two district level hospitals with capacity of 200-beds in each hospital. Over 89,000 individuals living in about 18,000 households are followed up in IM-HDSS. It conducts census level data collection two times a year on births, deaths, pregnancies and their outcomes, and in- and out-migrations [50]. In addition, IM-HDSS also collects data on access to health services, causes of death, relevant socioeconomic and education data, non-communicable diseases and injuries [43]. All households, schools, and healthcare facilities are geocoded, and a record of their GPS coordinates is available in IM-HDSS's data system [51].

Since 2005, 20 rounds of data collection have been completed as of January 2019 [50]. Data collection was conducted by trained field staff in Lusoga, the local language. All field assistants come from the Iganga and Mayuge districts. Any data collection outside of regular rounds is termed "Special studies," and such research work is undertaken after approvals from IM-HDSS and Makerere University. The data for special studies is also collected by the same field assistants, who are given additional training before the beginning of "Special studies" data collection. This study was considered a special study, and field assistants were specifically trained for it.

This study was nested within an ongoing parent study to pilot electronic data collection for injuries and disability at the IM-HDSS in Uganda. The parent study builds upon the collaboration between the Johns Hopkins International Injury Research Unit (JH-IIRU) and Makerere University School of Public Health (MUSPH) through the Johns Hopkins University-Makerere University Electronic Trauma, Injuries and Disability in Uganda (JHU-MU E-TRIAD) program. JHU-MU E-TRAID aimed to strengthen capacity at the faculty level to employ cutting-edge information and communication technology (ICT) for research and training on trauma, injuries, and disability. As part of JHU-MU E-TRIAD program, an e-project focusing on using innovative ICT approaches to collect, manage, and analyze data on injuries and disability was developed. The purpose of the e-project was to pilot electronic versions of the injury and disability modules. These modules were implemented in paper format during a previous study conducted at IM-HDSS between 2008 – 2009 [43, 44]. Subsequently, the modules were integrated into IM-HDSS and collected disability data in three rounds.

The IM-HDSS relies predominantly on paper-based data collection, [52, 53] and the process from data collection to entry into a database and analysis involves multiple steps [54]. However, the site is now transitioning to electronic data collection for efficient and timely availability for analysis. As part of the e-project, a pilot using tablet-based data collection was conducted in round 19 (May - August 2017), while the current study was conducted between September 2018 – January 2019. The parent project had led to the development of new e-tools to collect data on injuries and disability (part of this study) and will serve as a basis for the subsequent migration of paper-based data collection to electronic data collection for the entire IM-HDSS system.

Study respondents

Respondents were caregivers of sampled children (5-17 years of age) and were asked questions related to child functioning and contextual factors. Children between 11-17 years of age were also asked questions from C-DAS to assess difference in responses between them and their caregivers.

Study tools

Short set questions on disability (Module A)

This study used the tool developed by the Washington Group and modified it for use at IM-HDSS [29, 43]. It has 6-questions for brief disability assessment and uses a 4-level Likert scale (0= no difficulty, 1=some difficulty, 2=a lot of difficulty and 3=cannot do at all) and score ranges from 0 – 18. It focuses on activity limitations to identify individuals with disability and covers six domains--vision, hearing, walking, upper body mobility, self-care and communication--and takes approximately 10 minutes to administer based on previous work [29, 43, 45, 55]. The questions are basic in nature and administered at a national level during a census or surveys. The main purpose of this tool is to identify individuals who are at potential risk of limitation in their basic life activities, for example walking, hearing, and seeing. These questions allow comparisons to be made at the country level and within countries by generating data on prevalence of disability and its type. This in turn can help with determination of social inclusion of such individuals in terms of educational and employment opportunities [29].

It is important to note that Module A is already translated into Lusoga (the local language) and was implemented at IM-HDSS for brief disability assessment in individuals 5 years and above at the household level [43, 44]. Module A was first introduced at the IM-HDSS site in 2009, and since then, three rounds of data have been collected using Module A (2011, 2014 and 2017). Currently, adults (18 years and older) identified to have disability based on Module A are administered a detailed disability assessment tool, the WHO Disability Assessment Schedule 2.0 (WHODAS 2.0), which was introduced at IM-HDSS in 2011 and was also used for data collection in 2017 [43, 44]. The data collection in round 19 was the first time IM-HDSS piloted electronic data collection of Module A and WHODAS 2.0. However, children (that is individuals less than 18 years) are not given any in-depth assessment for their disability. This study is therefore an extension of the current disability work being done at IM-HDSS.

Child Disability Assessment tool (C-DAS)

A detailed Child Disability Assessment (C-DAS) tool was developed by the UNICEF/Washington Group on Disability Statistics [23]. C-DAS focuses on basic, everyday activities and has an expanded set of questions to assess functioning of a child. Like Module A, it can be administered at population level and can draw comparisons across time and countries. The tool is administered to the caregiver of a child identified to have disability using Module A [23]. The tool was developed to cover the ICF-CY domains of vision, hearing, mobility, self-care (including feeding and dressing), communication, learning, concentration, and anxiety and depression. It comprises 24-questions with responses on a 4-level Likert scale (0= no difficulty, 1=some difficulty, 2=a lot of difficulty and 3=cannot do at all). The score ranges from 0 – 39 and takes about 20-25 minutes to complete [28]. The domains covered in C-DAS are seeing, hearing, walking, self-care, communication, learning, remembering, concentrating, accepting change, controlling behavior, making friends, anxiety, and depression.

Module A and C-DAS were administered at the same time.

C-DAS translation

For this study, C-DAS was pre-tested and revised based on input from a pre-test, as well as field staff and supervisors. C-DAS was translated to Lusoga by two independent translators well-versed in English and Lusoga. The Lusoga translation was reviewed by one of the IM-HDSS field coordinators to check for any discrepancies between the translated versions and finalized Lusoga version. The Lusoga version was then back translated by a third translator. Author (NZ) compared the English translation with the original tool to identify any inconsistencies. The tool was pre-tested to ensure that questions were clearly stated and comprehensible for respondents. The final version used for data collection was developed in consultation with IM-HDSS field coordinators and supervisor [56]. Figure 1.7 shows translation and back-translation process of C-DAS.

Data related to household head and household members, household asset variables, child and caregiver demographics (age, gender, education), caregiver employment status, child birth, vaccination, sibling information, school and work history, child disability information (type, cause, duration, use of assistive devices), and health seeking practices were also collected from caregivers.

Sampling frame

Sampling frame for this study was drawn from household and individual listings available from the latest IM-HDSS rounds - round 19 and round 20. Data from a pilot conducted as part of round 19 served as basis for identifying children with disabilities who were between 5-17 years of age. This was done using data from Module A that was administered at the household level. A total of 377 children between the ages of 5-17 years were identified to have some form of disability based on round 19 Module A data. Their IDs were then confirmed for active status in round 20, which had been completed four months (May 2018) before the beginning of this study in September 2018. Based on the round 20 check for active IDs, 342 children out of 377 from round 19 were found to have active IDs in round 20 (29 were more than 17 years, one had died, 4 had moved to another location within IM-HDSS, and one had moved out of IM-HDSS). Active IDs mean that these children were present at the IM-HDSS site as of round 20; hence, all these 342 children were included in this study. (Figure 1.8).

In addition to children with disability, for the C-DAS validation and understanding of disability associated factors, a sample of 1,273 without disability was computed to detect a difference of 1% between the groups of children with versus without disability, assuming alpha of 5% and power of 80%. Thus, the total sample required was 1,615: 1,273 children without disability and 342 with disability. However, to account for non-availability, refusals, and out-migrations from the site, the sample for children without disability was increased to 1,500. At the time of this study, 35,062 children between 5-17 years of age (excluding 342 with disability) were residing at the IM-HDSS. A stratified (based on sex of child) sample proportionate to the population size of children without disability was drawn from the list of 35,062 children. The formula used for sample size calculation was:

$$\left(\frac{\text{Total sample size required}}{\text{Population size}} \right) \quad \text{x} \quad \text{Stratum size}$$

Table below gives sample size calculation for each stratum.

Sample size calculation	Male	Female
Total sample size	1,500	1,500
Population size	35,062	35,062
Stratum size	17,216	17,846
Calculation	(1,500/35,062) * 17,216	(1,500/35,062) * 1,7846
Stratified sample	737	763

A random list of IDs was drawn from each stratum using STATA version 14, [57] and a unique study ID was assigned to children in both groups. Thus, our working sample included 342 children with disabilities and 1,500 children without disabilities, giving a total of 1,842 children whose caregivers were approached to participate in the study. Only one child per household was selected.

It is important to note that the distinction between children with disability and without disability was made for sampling purpose only to ensure that the sample for this study did not miss children with disabilities. The analysis for this study was conducted on the pooled sample of respondents who agreed to participated in the study.

Data quality and management procedures

Data collection for the three aims was done by field staff at the IM-HDSS. These staff members were trained in conducting community-based data collection as well as responsible conduct of research. They were given additional training related to administration of C-DAS. A 2-day, in-person training session was conducted where IM-HDSS field staff and supervisors were trained on the objectives of child disability assessment, methods to employ for data collection and ethical issues. Each question in the tool was explained to field staff and supervisors, followed by role-play activity to allow practice for the staff and to get feedback from the team. This was followed by pre-testing with 46 caregivers. Daily debriefings were conducted to explore issues related to administration of C-DAS, difficulty level of questions and their responses, level of understanding of respondents and suggested changes by the staff.

Disability is stigmatized, and interviewing children with disability is a sensitive topic. Therefore, the data collection team at IM-HDSS was trained specifically on handling this vulnerable population without causing distress to them, their caregivers and families. Since this work builds on prior work on disability, where Module A was administered for brief assessment for children with disability, the topic of disability was not new to caregivers. However, special measures were taken to ensure that children were at ease during administration of C-DAS. For this purpose, assistance from the child's caregiver was sought as needed, to explain the purpose of study to the child. This was especially important where a child had problem in hearing and communication. In cases where a child was not able to assent, s/he was not enrolled into the aim 2 study and its reason was noted.

Data collection was done using a tablet-based platform that was developed and pre-tested based on available local resources at the IM-HDSS. Caregiver and child forms were uploaded separately for data collection. The platform included English and Lusoga versions of questions, which were developed in Microsoft Excel .xls format and uploaded to KoBoToolbox (https://www.kobotoolbox.org/) for data collection. Questions had a check box and free text entry formats to enter responses. Questions were designed to allow skip patterns where appropriate. Mandatory fields were also marked which addressed issues related to missing data. In order to reduce load related to entry of IM-HDSS IDs, the unique study ID was linked with IM-HDSS IDs at the back-end. This helped to address issue related to errors in ID entry. The Kobo app was downloaded to android tablets to allow for data collection using a user-specific password. These forms were accessible in the field to field assistants and didn't require internet or Wi-Fi connect to fill them.

Once an interview was completed, the form was saved on tablets. Field supervisors checked saved forms at the end of the day, and completed forms were uploaded daily using office Wi-Fi to a secure cloud server. The electronic forms were submitted to a secure, encrypted cloud server, with no copy available on the tablet after submission to the cloud server. The server was only accessible to authorized study team members at IM-HDSS and JHSPH. This ensured data confidentiality and security. Data were downloaded daily from the server in MS Excel. Caregiver and child data were merged at the end of data collection using unique study IDs. Analysis was conducted in STATA 14.

Regular communication with IM-HDSS study team was maintained. Regular field visits were done to ensure that the study was implemented as per protocol and that the electronic data collection forms were properly stored and transmitted. Tracking sheets were developed for monitoring the progress of the study. These helped in planning visits when respondents were not available during the first visit. It included unique study ID, child's age and sex, head of household information, interview status for caregivers and children (complete, refusals, not available, exited or out migrated), and number of attempts made to collect data. Three attempts were made to approach respondents when respondents.

Ethical considerations

Ethical review and approval for this study was obtained from the Institutional Review Boards of the Johns Hopkins Bloomberg School of Public Health, USA, and both the Makerere University School of Public Health and the Uganda National Council for Science and Technology.

Oral consent was obtained from caregivers, while parental permission and assent was taken before interviewing children between 11-17 years of age. A child was interviewed only after their caregiver had been interviewed and had given permission to interview the child. No child interview was conducted before their caregiver's interview. If a caregiver or child refused to participate in the study, C-DAS was not administered to them. Caregivers were explained the purpose of the study, risk and benefits related to participation in the study, data confidentiality, and voluntary participation.

Ethical issues related to children and vulnerable populations are crucial to consider. Interviewing children with disabilities is not without it risks; however, it is important to note that lack of availability of evidence related to a child's perspective on their disability can hamper development of interventions that address their needs and requirements (27). Children between 11-17 years go through major changes, and it is critical to understand their limitations as reported by them. This data aimed at understanding differences in responses between children and their caregivers, and to generate evidence that can guide development of interventions to facilitate caregivers in understanding the needs of their growing children. Additionally, it will help children in understanding their condition in order to develop a conducive environment for their growth and adjustment in society as adults. The IM-HDSS employs a system of unique identifiers, and these were linked with unique study IDs, thus no names or other personal identifiers were reported in electronic forms or in data transfers or data analysis, nor will it be used in future publication of results.

This study generates evidence to understand disability in Uganda and can guide development of interventions geared towards their specific needs during their years of growth and development. There may be a possibility that respondents expected some monetary or health related benefit for their child; however, the purpose of the study was explained in the consent, and participants were informed about benefits and risks associated with the study. It was made clear that the study will not provide them money or treatment, nor will it affect their treatment or healthcare. There were no unforeseen events associated with any study participant during the data collection phase.

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Tables

Table 1. 1: Disability-related Sustainable Development Goals (SDGs), targets and indicators*

Sustainable Development Goals	Targets	Indicators
Goal 1: No poverty	1.1 Poverty	1.1: Percentage of persons with disabilities below $1.25 (PPP) per day
	1.3 Social protection	1.3: Percentage of persons with disabilities covered by social protection, or percentage of persons with disabilities receiving benefits
	1.5 Impact of disasters	1.5: - Percentage of deaths from persons with disabilities among all deaths due to disasters - Percentage of injured/missing/relocated/evacuated persons with disabilities among all injured/missing/relocated/evacuated due to disasters
Goal 3: Good health and well-being	3.2 Under 5 mortality rate	3.2: Under-five mortality rate for children with disabilities
	3.8 Health coverage and financial risk protection	3.8: - Percentage of persons with disabilities receiving needed health services - Percentage of persons with disabilities receiving needed assistive technologies - Proportion of households with persons with disabilities facing catastrophic health expenditure - Proportion of households with persons with disabilities facing impoverishing health expenditure
Goal 4: Quality education	4.5 by 2030, eliminate gender disparities in education and ensure equal access to all levels of education and vocational training for the vulnerable, including persons with	4.5: - Primary and secondary school net attendance ratio for children with disabilities

	disabilities, indigenous peoples, and children in vulnerable situations	- Percentage of teachers in service who have received in-service training in the last 12 months to teach students with special educational needs
	4.a build and upgrade education facilities that are child, disability and gender sensitive and provide safe, non-violent, inclusive and effective learning environments for all	4.a: - Percentage of schools (primary, lower and upper secondary) with adapted infrastructure and materials for students with disabilities
Goal 5: Gender equality	5.2 Violence against women	5.2 - Percentage of women and girls with disabilities subjected to physical and/or sexual violence
	5.6 Sexual and reproductive health	5.6 - Percentage of women and girls who make decisions about their own sexual and reproductive health and reproductive rights, disaggregated for persons with/without disabilities
Goal 6: Clean water and sanitation	6.1 Access to water	6.1 - Percentage of population using safely managed drinking water services, disaggregated for persons with/without disabilities
	6.2 Access to sanitation	6.2 - Percentage of population using safely managed sanitation services, disaggregated for persons with/without disabilities
Goal 8: Decent work and economic growth	8.5 by 2030 achieve full and productive employment and decent work for all women and men, including for young people and persons with disabilities, and equal pay for work of equal value	8.5 - Unemployment rate, disaggregated for persons with/without disabilities
Goal 10: Reduce inequalities	10.2 by 2030 empower and promote the social, economic and political inclusion of all irrespective of age, sex, disability, race, ethnicity, origin, religion or economic or other status	10.2 - Percentage of positions in public institutions (national and local legislatures, public service, and judiciary) held by persons with disabilities - Voting turnout as a share of voting-age population disaggregated by disability - Percentage of government websites which meet the ISO/IEC 40500:2012 of accessibility for Web content

		- Percentage of population owning a mobile phone, disaggregated for persons with/without disabilities - Percentage of population with disabilities with internet access, disaggregated for persons with/without disabilities
	10.4 Social protection	10.4: Percentage of persons with disabilities covered by social protection, or percentage of persons with disabilities receiving benefits
Goal 11: Sustainable cities and communities	11.2 by 2030, provide access to safe, affordable, accessible and sustainable transport systems for all, improving road safety, notably by expanding public transport, with special attention to the needs of those in vulnerable situations, women, children, persons with disabilities and older persons	11.2 - Percentage of public transport vehicles meeting the minimum national standards for accessibility by persons with disabilities
	11.5 Impact of disasters	11.5: - Percentage of deaths from persons with disabilities among all deaths due to disasters - Percentage of injured/missing/relocated/evacuated persons with disabilities among all injured/missing/relocated/evacuated due to disasters
	11.7 by 2030, provide universal access to safe, inclusive and accessible, green and public spaces, particularly for women and children, older persons and persons with disabilities	11.7: - Percentage of public buildings meeting the ISO 21542:2011 standards on accessibility and usability of the built environment - Percentage of public green spaces (parks and recreational facilities) meeting the minimum national standards for accessibility by persons with disabilities
Goal 16: Peace, justice, and strong institution	16.9 Birth registration	16.9 - Percentage of children under 5 whose births have been registered with civil authority, disaggregated for children with/without disabilities

Goal 17: High quality, reliable and timely availability of disability data	17.18 by 2020, enhance capacity building support to developing countries, including for LDCs and SIDS, to increase significantly the availability of high-quality, timely and reliable data disaggregated by income, gender, age, race, ethnicity, migratory status, disability, geographic location and other characteristics relevant in national contexts	17.18: Percentage of countries with data for all disability related indicators and disability disaggregation of the SDG framework, in the last 5 years
*Disability specific indicators for SDG Advocacy Toolkit developed in partnership with United Nations, International Disability Alliance, and International Disability and Development Consortium [5]. Green rows are specific to disability		

Table 1. 2: Demographic, child education, health, immunization coverage and economic indicators for Uganda

Indicators	Value	Year	Source *
Demographic indicators			
Total population (in thousands)	42,862.96	2018	WB
Female population (% of total population)	50.5		
Rural population (% of total population)	77		
Population median age (years)	15.8	2014	WHO
Education			
Adult literacy rate, population 15+ years (%)	73.9	2016	WB
Primary school net attendance ratio (male) (%)	81.3	2008-12	UNICEF
Primary school net attendance ratio (female) (%)	81.1		
Secondary school net attendance ratio (male) (%)	16.2		
Secondary school net attendance ratio (female) (%)	18.7		
Health indicators			
Life expectancy at birth (in years)	65.7	2017	GBD
Crude birth rate (per 1,000 people)	42	2016	WB
Crude death rate (per 1,000 people)	9		
Adolescent fertility rate (births per 1,000 women ages 15-19)	111		
Total fertility rate per woman	5.6		
Annual population growth rate (%)	3.3		
Immunization coverage (%)			
Bacillus Calmette-Guerin (BCG)	82	2012	UNICEF
Diphtheria, tetanus, and pertussis vaccine (DTP 1)	89		
Diphtheria, tetanus, and pertussis vaccine (DTP 3)	78		
Polio 3	82		
Hepatitis B 3	78		
Hemophilus influenzae type b (Hib3)	78		
Economic indicators			
Age dependency ratio (% of working-age population)	108	2017	CB
Gross National Income per capita (Atlas method, current USD)	$660	2016	WB
Population below international poverty line <$1.25/day (%)	38	2007-11	UNICEF
Total health expenditure (% of Gross domestic product)	7.2	2014	WB, WHO
Public health expenditure (%of government expenditure)	11.0	2014	WB
Health expenditure per capita (current US$)	52		
Out-of-pocket health expenditure (% of total expenditure on health)	41.0		

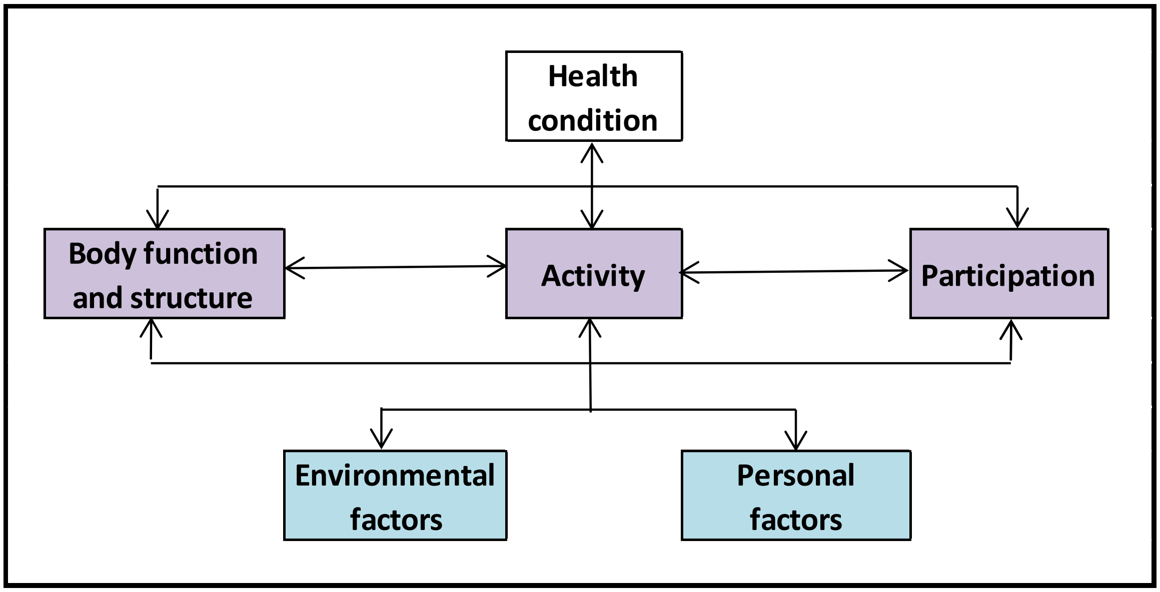
*Source: The World Bank Open Data (WB), 2016 [36]; WHO Country profile Uganda (WHO) [37]; UNICEF, Uganda Statistics (UNICEF) [39]

Table 1. 3: Disability related polices and acts in Uganda

Year	Name
1966	Policy related to provision of technical support to disabled people
1995	Articles added to the constitution related to protection of disabled individuals against discrimination and ensuring their representation in the Parliament
1997	Children Act emphasis the need for early assessment and diagnosis to initiate early treatment and rehabilitation
1998	Uganda Communications Act promotes use of devices that help individuals with hearing impairment
2003	National Council for Disability Act for monitoring and evaluation of rights of individuals with disabilities
2006	Persons with Disabilities Act uses rights-based approach to provide equal opportunities to individuals with disabilities
2013	National Policy on Disability in Uganda calls for government to train medical workers on managing patients with disabilities
2015	Uganda National Minimum Health Care Package calls for increase access to services for individuals with disabilities
2016	Children Amendment Act protects children against discrimination and includes healthcare providers and government in addition to parents as relevant duty bearers

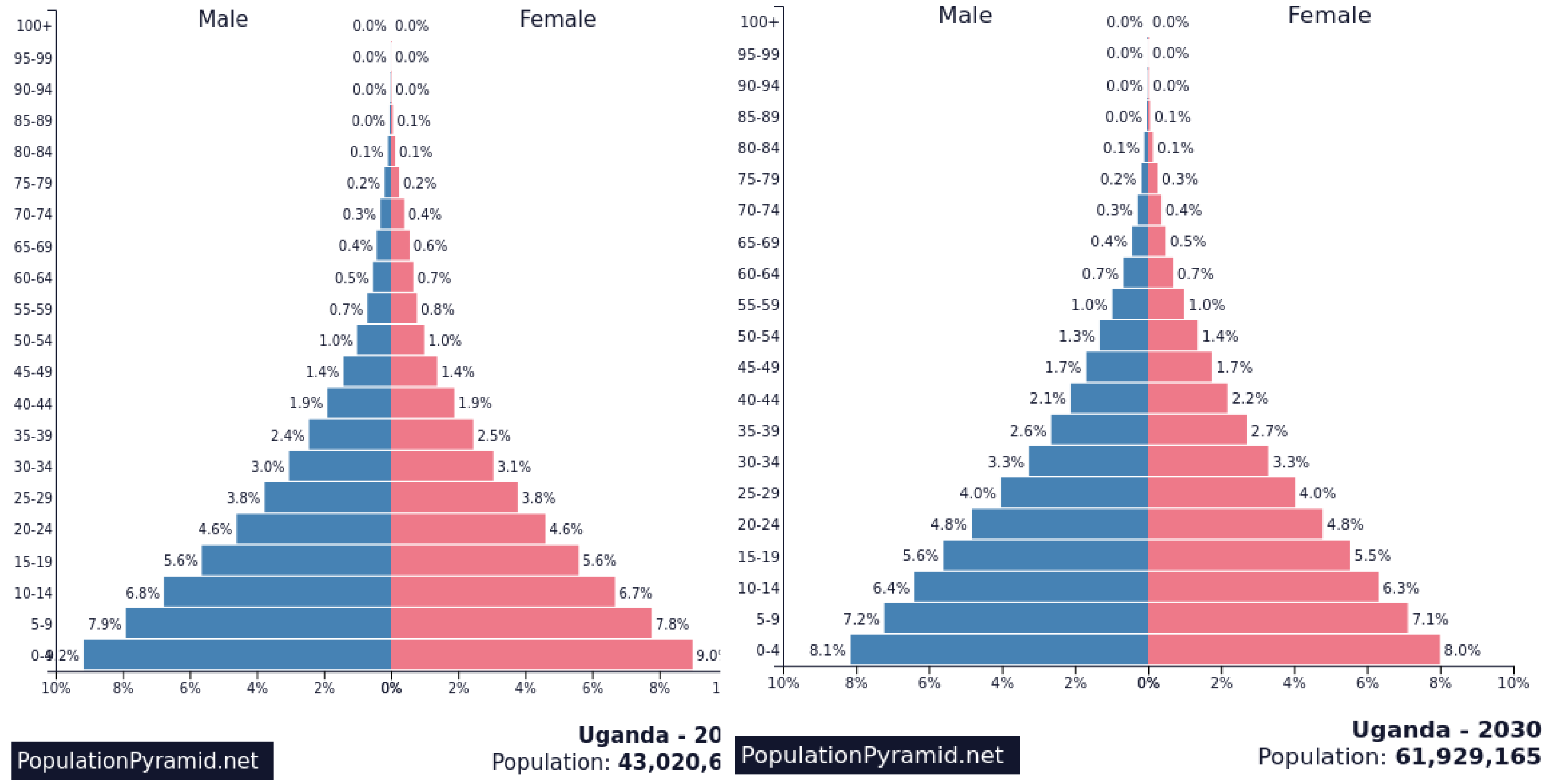
Figures

Figure 1. 1: Conceptual Framework for the International Classification of Functioning



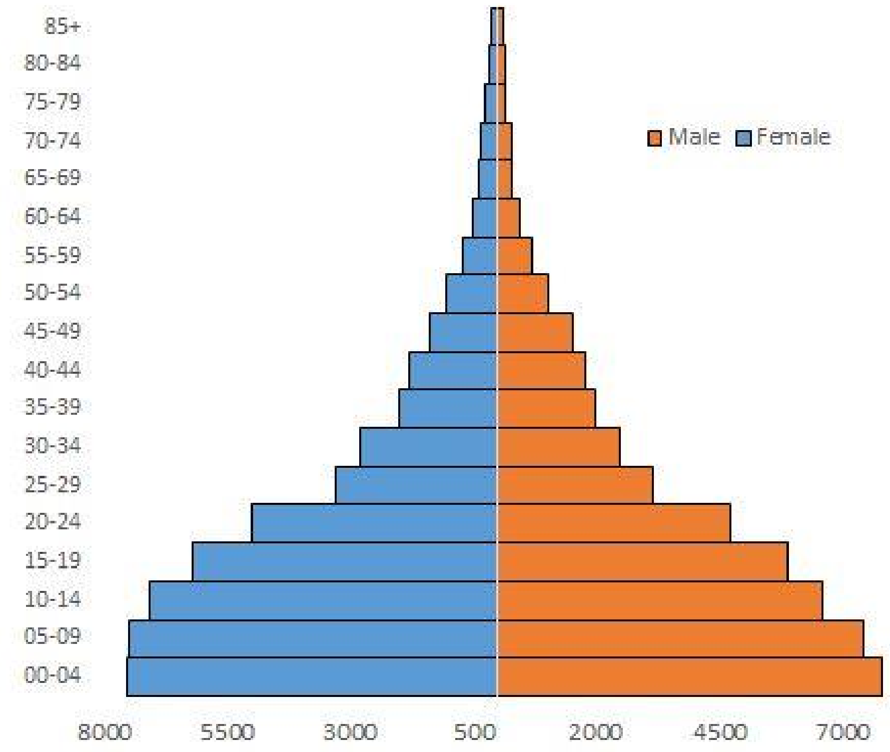
Source: [6]

Figure 1. 2: Population pyramid of Uganda, 2018 and 2030 (projected)



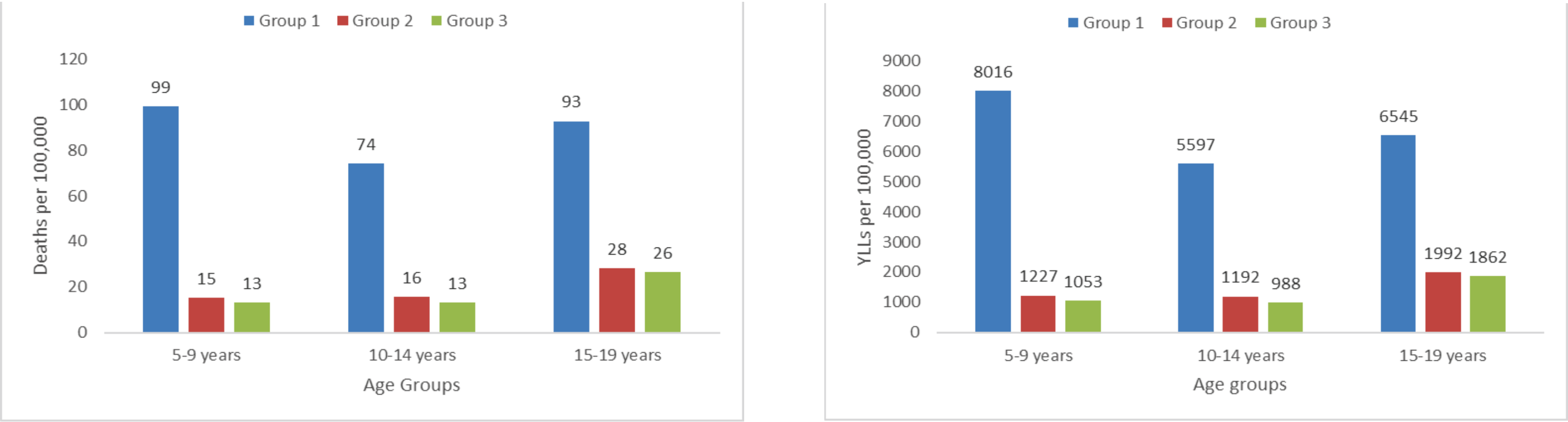
Source: Population Pyramid – Uganda [38]

Figure 1. 3: Population pyramid of Iganga-Mayuge Health and Demographic Surveillance Site, 2018 (based on round 20 population)



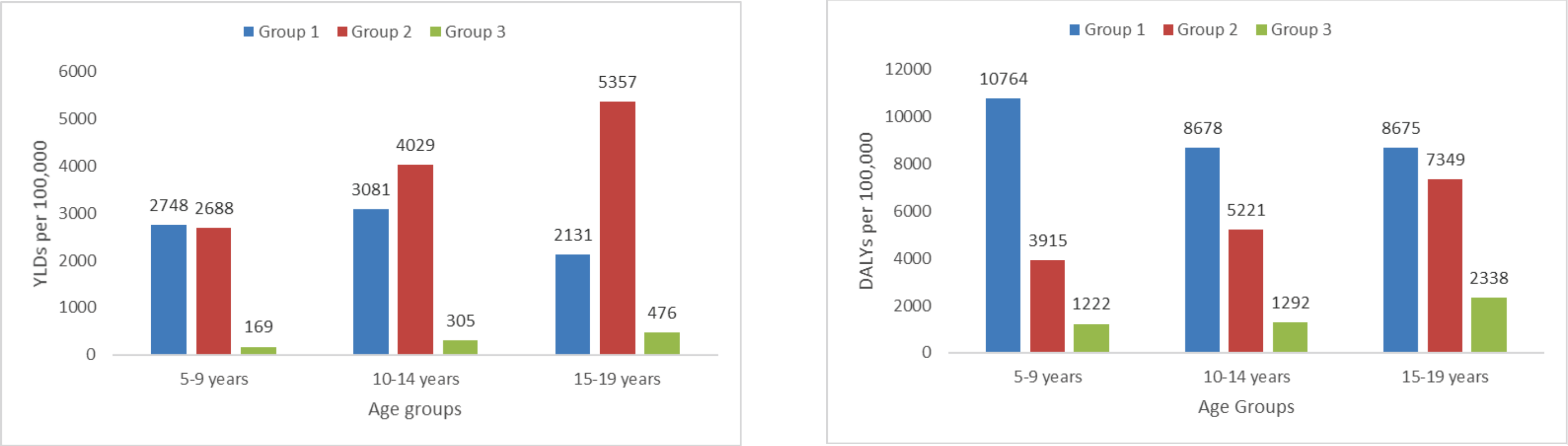
Source: IM-HDSS data

Figure 1. 4: Estimated burden of disease among children (5-19 years) in Uganda, 2016



a. **Death per 100,000**

b. **Years of Life Lost (YLLs) per 100,000**



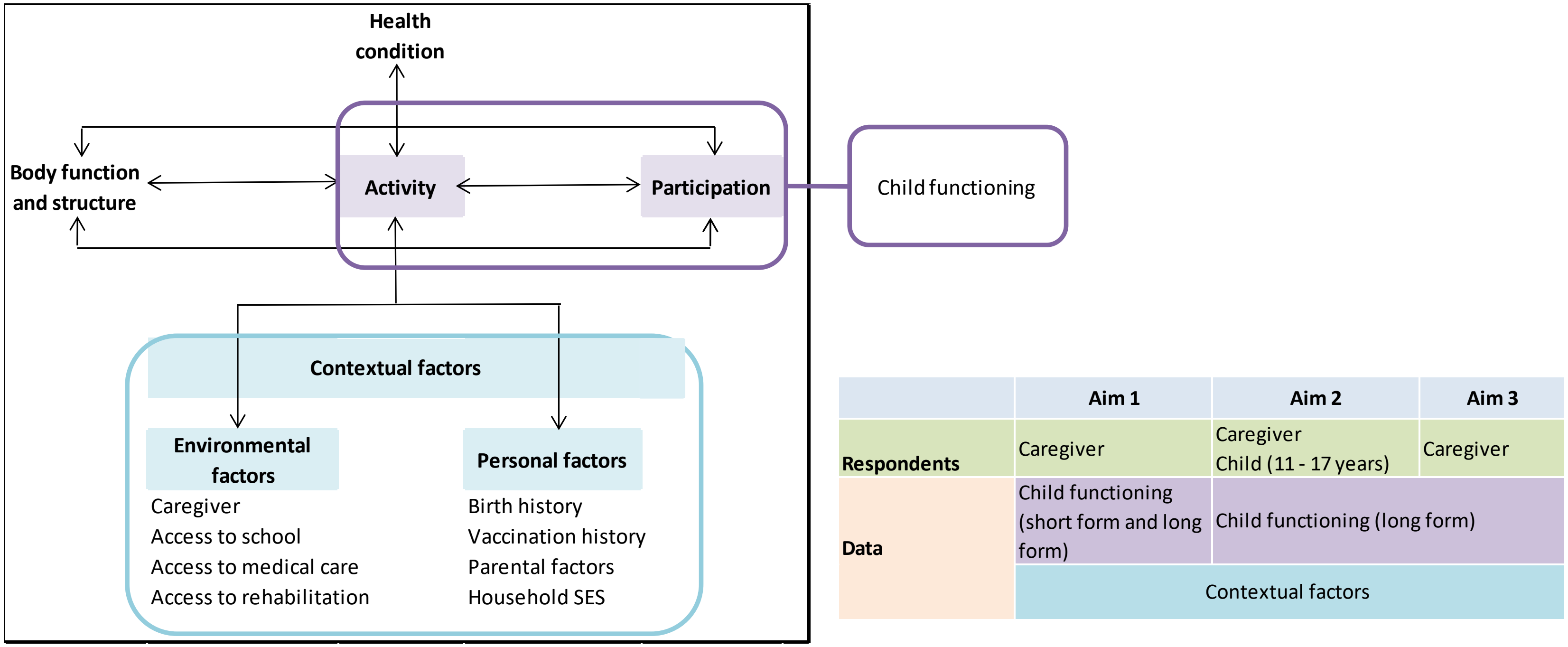
c. **Years of Life Lived with Disability (YLDs) per 100,000**

d. **Disability Adjusted Life Years (DALYs) per**

Group 1: Communicable diseases, maternal, perinatal & nutritional disorders
Group 2: Non-communicable diseases
Group 3: Injuries

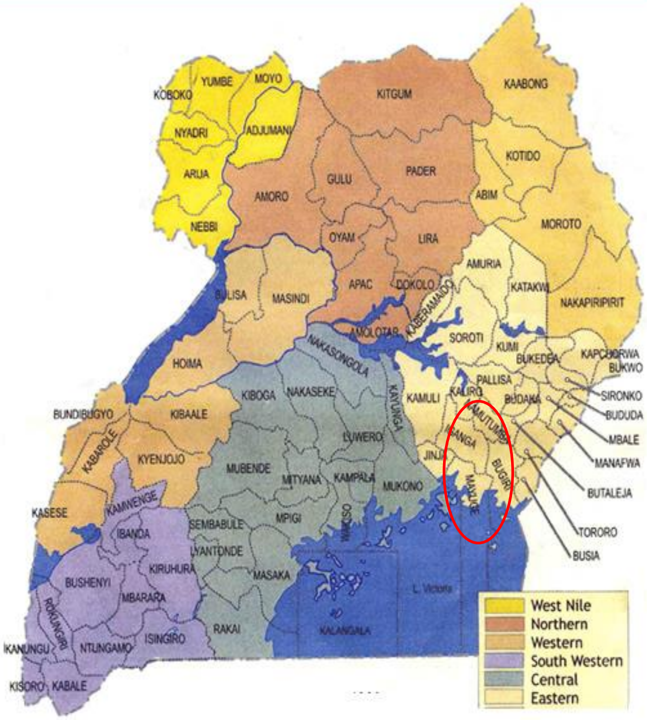
Source: Global Burden of Disease study 2017. IHME
Website: http://vizhub.healthdata.org/gbd-compare/

Figure 1. 5: Conceptual framework for measuring child disability at Iganga-Mayuge Health and Demographic Surveillance System site



	Aim 1	Aim 2	Aim 3
Respondents	Caregiver	Caregiver Child (11 - 17 years)	Caregiver
Data	Child functioning (short form and long form)	Child functioning (long form)	
	Contextual factors		

Figure 1. 6: Map of Uganda and Iganga-Mayuge Health and Demographic Surveillance System site



Source: Google

Figure 1. 7: Flow chart of translation process of Child Disability Assessment tool

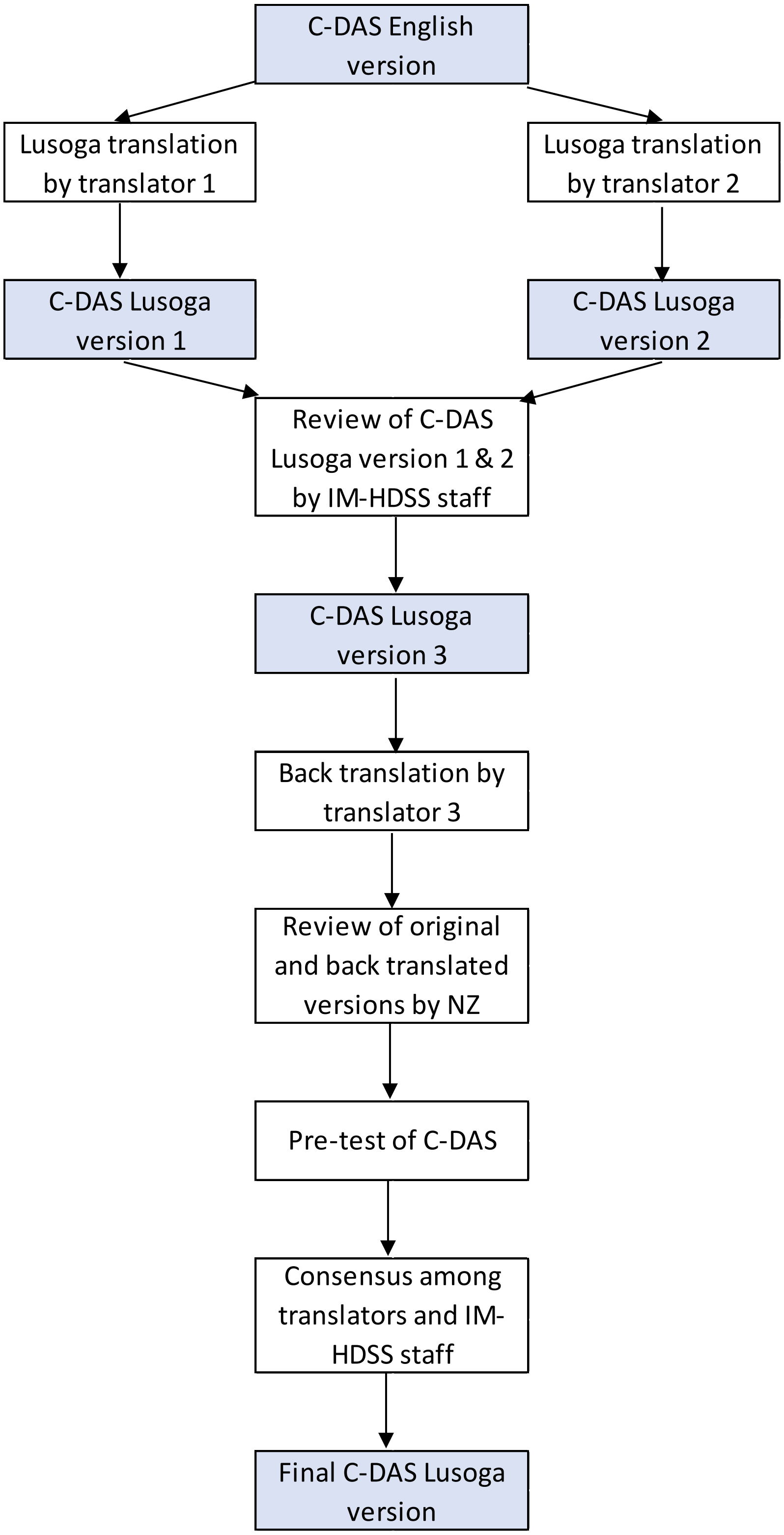
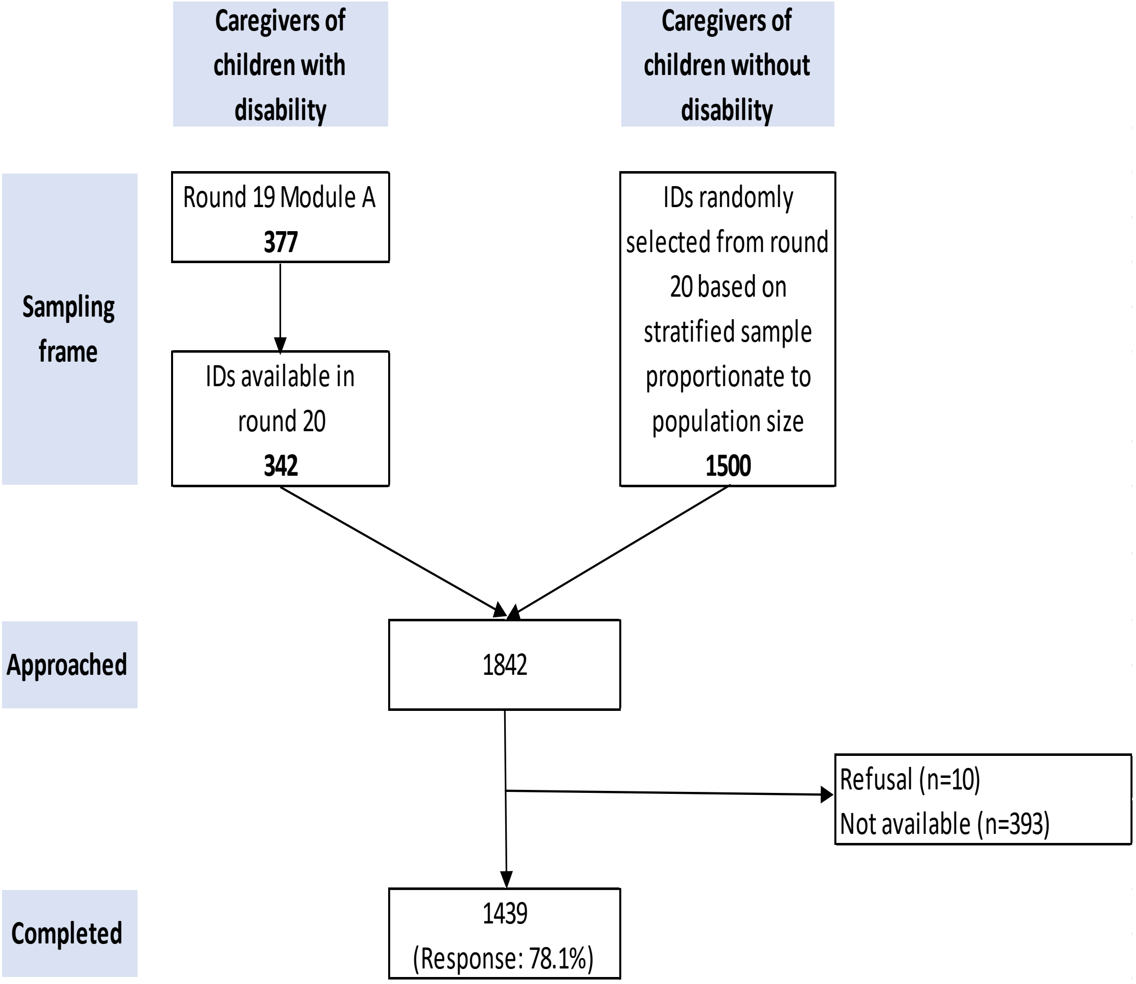


Figure 1. 8: Flow chart of caregiver enrollment for Child Disability study



Chapter 2: Adaptation and validation of a child functional assessment tool at the Iganga-Mayuge Health and Demographic Surveillance Site in Uganda (Paper 1)

Abstract

Introduction: The child disability assessment tool (C-DAS) was developed by the UNICEF and Washington Group on Disability Statistics to assess child functioning among children between 5-17 years of age. The overall aim of this study was to explore psychometric properties of the C-DAS tool applicable to children between the ages of 5-17 years at the Iganga-Mayuge Health and Demographic Surveillance Site (IM-HDSS) in Uganda.

Methods: This was a cross-sectional study conducted between September 2018 – January 2019 at the IM-HDSS. Respondents were caregivers of children between 5 to 17 years of age who were administered a short 6-question Module A and an in-depth 24-question C-DAS; data was collected electronically using tablets. The responses were recorded on a 4-point Likert scale. Descriptive analysis was conducted on child and caregiver demographic characteristics. Exploratory factor analysis (EFA) was done to assess underlying factor structure, dimensionality and factor loadings. Cronbach's alpha was reported as an assessment of internal consistency. Face validity was assessed during the translation process, and concurrent validity of C-DAS was assessed through comparison with Module A.

Results: Out of 1,842 caregivers approached, 1,439 (78.1%) participated in the study. The mean age of children was 11.06 ± 3.59 years, 51.4% were males, and 86.1% had a primary caregiver, with mother being the most common caregiver. Based on EFA, vision, hearing, walking, selfcare, communication, learning, remembering, concentrating, accepting change, behavior control, and making friends loaded on factor 1, and this factor represents "motor and cognition," while anxiety and depression loaded on factor 2, which mainly represents "mood". Cronbach's alpha for the overall C-DAS was 0.899 (good internal consistency). Cronbach's alpha for each extracted factor was excellent – 0.904 for motor and cognition, and 0.902 for mood. C-DAS had acceptable face validity. Spearman's rank correlation between overall C-DAS and Module A scores was 0.51 (p-value <0.001), showing a positive correlation. The overall mean C-DAS score was 2.47±3.82 out of 39. The mean score for Mood (1.35±1.42 out of 6) was higher compared to Motor and Cognition (1.12±3.06 out of 33). Comparing Module A and C-DAS Likert responses, the percent agreement tended to be greatest for "cannot do at all." However, percent agreement for "some difficulty" and "a lot of difficulty" was around 70%.

Conclusion: C-DAS is a unidimensional, two-factor, valid and reliable scale for assessing disability in Uganda. It is an easy-to-administer tool that can help in deeper understanding of context-specific burden and extent of disability in children between 5-17 years of age.

Introduction

Measurement of disability at the population level has been particularly problematic due to complexity of the disability phenomenon [1-3]. This has been further exacerbated, especially in low-and-middle-income countries (LMICs), by prevailing socio-cultural norms. How a society defines disability is often a reflection of these norms and contemporary views around the issue [4, 5]. In addition, the field of disability has evolved in its conceptualization of disability over the past several decades - moving from defining disability as a purely medical phenomenon to a complex interaction between impairments at the body level, in the context of a health condition as well as contextual factors specific to the environment in which the individuals live, making disability a complex phenomenon to assess [1, 2, 5, 6]. This has had a direct implication on population-based assessments of disability and its impact on individuals, families and the society. Furthermore, tools developed in high-income countries (HICs) may not be directly applicable to LMICs due to differences in context within which disability is assessed [3, 7, 8].

One of the main problems in understanding disability among children has been the lack of standardized, easy-to-use instruments that could be used to measure child disability [4, 9]. This has led to a lack of comparable burden estimates and hampers the development and evaluation of appropriate policies and programs to address the needs of children with disabilities [9]. Understanding not only the existence and type of disability but also its impact on children is therefore crucial as they go through different stages of growth and development, as disability influences their participation and functioning in the environment and society [3, 10].

Globally, one in 20 children under 15 years of age live with moderate or severe disability; about 90% of these children live in LMICs [3, 4, 11-13]. The estimated prevalence of moderate to severe disability in Africa is 15.3% [4]. According to the WHO, the main causes of disability in the African region include infectious diseases such as polio and leprosy; noncommunicable diseases like congenital malformation and cerebral palsy; injuries such as road traffic crashes; and health-services errors such as inappropriate treatment [13]. However, it is important to point out that the World Report on Disability acknowledges that these numbers are an underestimation and that reliable data on disability – prevalence, type, and causes- are lacking for most LMICs [4].

Efforts to assess motor, cognitive, language, and social functioning in children has focused on using various tools often already used by clinicians. Most tools, for example the Mental Retardation Adaptive Behavior Scale or Griffith's Scale of Mental Development, assess intellectual disabilities. The Ten Questionnaire (TQ) is a screening tool which assesses disability in children between 2-9 years of age and was found to be suitable for severe disabilities but tends to miss mild to moderate disabilities in populations. In addition, TQ was developed for use in a two-step process, where children are screened in step one followed by clinical assessment in step 2. However, step 2 is rarely done, especially in LMICs settings, due to limited resources available for clinical assessments [14, 15]. There is lack of data at the population level due to costs associated with acquiring these tools and their training requirements [7, 8, 16]. Moreover, countries that do have data on child disabilities lack a consistent and systematic approach for assessing such disabilities in children [3, 17]. Therefore, standardized methods to assess disability as part of national surveys has positive implications for a country; it allows monitoring of progress by making comparisons at national and international levels.

The Multiple Indicator Cluster Survey (MICS) administered by United Nations Children's Fund (UNICEF) introduced a disability module for children in 2000 and collected data in 50 surveys from various LMICs. In 2011 UNICEF collaborated with the Washington Group on Disability Statistics (WG) to revise and develop a disability tool for assessing child functioning [18]. The Washington Group was established under the United Nations (UN) Statistical Commission as a UN city group in collaboration with United Nations Children's Fund (UNICEF). The WG has undertaken the task to develop a set of questions that can be used to assess disability in children. These questions were developed based on the ICF-CY framework. It resulted in the development of two versions of a child disability assessment tool: one for children between 2-4 years and the second for those between 5-17 years [19, 20]. (Figure 2.1). The tool covers the domains of vision, hearing, walking, communication, learning, relationships, and playing. In addition, the domains of emotion, behavior, concentration and coping with change were also added to obtain a better understanding of child development and functioning. The questions were developed on the basis on the previous work that the WG had done to assess disability data in adults [21]. Children under 2 years of age were not included due to the challenges associated with assessing developmental delays in such young children. In addition, cultural norms tend to vary and can influence a child's developmental milestones during infancy [18, 19]. The UNICEF/WG tool is an important data source for monitoring SDGs. The tool can present disaggregated data to help determine burden associated with child disability and facilitate development, implementation, and monitoring of intervention [22]. As of now, the tool for children in the 5-17 years age group has not been validated in Africa (or Uganda).

The overall aim of this study was to explore psychometric properties of the child disability assessment tool (C-DAS) applicable to children between the ages of 5-17 years at the Iganga-Mayuge Health and Demographic Surveillance Site (IM-HDSS) in Uganda. More specifically, this study developed a Lusoga version of C-DAS from its English version and conducted psychometric evaluation of the tool to assess its underlying factor structure, dimensionality, reliability and validity.

Methods

Study site

Iganga-Mayuge Health and Demographic Surveillance Site (IM-HDSS) is located in Eastern Uganda and covers the districts of Iganga and Mayuge. The site is part of the International Network for the Demographic Evaluation of Population and Their Health Network (INDEPTH) and was established in 2005 as a field research site for Makerere University [23-25]. About 38% of the IM-DSS is peri-urban and is located mostly around Iganga town; females comprise about half of the population. IM-HDSS has a crude birth rate of 21.1 per 1000 live births and a crude death rate of 4.2 per 1000 live births [24].

IM-HDSS follows over 89,000 individuals living in about 18,000 households. It conducts census level data collection two times per year on births, deaths, pregnancies and their outcomes, and in- and out-migrations [25]. In addition, IM-HDSS also periodically collects data on access to health services, causes of death, relevant socioeconomic and education data, non-communicable diseases and injuries [26]. Since 2005, 21 rounds of data collection have been completed as of June 2019 [23].

This study was nested within an ongoing parent study to pilot electronic data collection for injuries and disability in IM-HDSS. The main aim of the parent study was to strengthen local capacity to employ cutting-edge information and communication technology (ICT) for research and training on trauma, injuries, and disability. The purpose of the parent study was to pilot electronic versions of injury and disability data modules; these modules were implemented in paper format during previous studies conducted at IM-HDSS between 2008 – 2009 and subsequently were integrated into IM-HDSS; data was collected in three rounds [26, 27]. The IM-HDSS relies predominantly on paper-based data collection, [24, 25] and the process from data collection to entry into a database and analysis involves multiple steps [28]. However, the site is now transitioning to electronic data collection for efficient and timely availability of data for analysis. A pilot using tablet-based data collection was conducted in round 19 (April - June 2017), and was used as a sampling frame (see section below) for the current study on child disability.

Study tools

Two tools were implemented as part of this study. Their details are provided below:

Short set questions on disability (Module A)

This study used a modified version of the Washington Group short-set (Module A) [21, 26]. It has 6-questions for brief disability assessment that use a 4-level Likert scale (0= no difficulty, 1=some difficulty, 2=a lot of difficulty and 3=cannot do at all). Scores range from 0 – 18 such that the higher the score, the greater the difficulty. It focuses on activity limitations to identify individuals with disability and covers six domains: vision, hearing, walking, upper body mobility, self-care and communication. Previous studies conducted at the IM-DSS and elsewhere found that it takes approximately 10 minutes to administer, and the questions are well understood by respondents [21, 26, 29, 30]. The main purpose of this tool is to identify individuals who are at potential risk of limitation in their basic life activities, for example walking, hearing, and vision. The WG administered Module A during field testing of C-DAS in Serbia [31].

It is important to note that Module A was already translated into Lusoga (the local language) and was implemented at IM-HDSS for disability assessment in individuals 5 years and above at the household level [26, 27]. Module A was first introduced at the IM-HDSS site in 2009, and since then it has been implemented three more times (2011, 2014 and 2017). Currently, adults (18 years and older) identified to have a disability based on Module A are followed-up using a more detailed disability assessment tool to further characterize the implications of their activity limitation on different life domains. The WHO Disability Assessment Schedule 2.0 (WHODAS 2.0) is used for this purpose and was first implemented at the IM-HDSS in 2011, with another round conducted in 2017 [26, 27].

The data collection in round 19 (April – July 2017) was the first time IM-HDSS piloted electronic data collection of Module A and WHODAS 2.0. Since the WHODAS is only applied to individuals over 18 years, disability among children has not been further studied at the IM-DSS. Thus, this study focused on this age group and is therefore an extension of the current disability work being done at IM-HDSS to allow for a better understanding of disability among children.

Child Disability Assessment tool (C-DAS)

This study utilizes a detailed Child Disability Assessment (C-DAS) tool developed by the UNICEF/Washington Group on Disability Statistics [19]. C-DAS focuses on basic, everyday activities and has an expanded set of questions to assess functioning of a child. Like Module A, it can be administered at the national level and allows for comparisons across time and countries. The tool is administered to caregivers of children previously identified to have disability using Module A [19]. The tool was developed to cover the ICF-CY domains of vision, hearing, mobility, self-care (including feeding and dressing), communication, learning, concentration, and anxiety and depression. It comprises 24-questions with responses on a 4-level Likert scale (0= no difficulty, 1=some difficulty, 2=a lot of difficulty and 3=cannot do at all). These questions result in 13 domains with scores ranging from 0 – 39; the higher the score, the greater the disability. It takes about 20-25 minutes to complete. The 13 C-DAS domains include vision, hearing, walking, self-care, communication, learning, remembering, concentration, accepting change, behavior, making friends, feeling anxiety, and feeling depression [20].

C-DAS translation

The C-DAS has been through several field tests already; however, the psychometric properties have not been established in Uganda or elsewhere [20]. C-DAS was translated to Lusoga by two independent translators well-versed in English and Lusoga and aware of the local context. The Lusoga translations were reviewed by one of the IM-HDSS field coordinators to check for any discrepancies between the translated versions. The Lusoga version was then back-translated by a third translator. Author (NZ) compared the English translation with the original tool to identify any inconsistencies. The tool was pre-tested with 46 respondents to ensure that questions and responses were clearly stated and comprehensible for respondents. The final version used for data collection was developed in consultation with IM-HDSS field coordinators and supervisor. (Figure 2.2). The translation and back-translation helped in assessing face validity of the Lusoga version of C-DAS.

Study design and respondents

This was a *cross-sectional study* conducted between September 2018 – January 2019. Respondents were caregivers of children between 5 to 17 years of age who were administered Module A and C-DAS. At the time of the study, there were 35,062 children between the ages of 5-17 years who were residing in the IM-HDSS.

Sampling frame

Sampling frame for this study was drawn from household and individual listings available from the latest IM-HDSS rounds - round 19 and 20. Data from a pilot conducted as part of round 19 served as basis for identifying children with disabilities who were between 5-17 years of age. This was done using data from Module A that was administered at the household level. A total of 377 children between the ages of 5-17 years were identified to have some form of disability based on round 19 Module A data. Their IDs were then confirmed for active status in round 20, which had been completed four months (May 2018) before the beginning of this study (September 2018). Based on the round 20 check, 342 children out of 377 from round 19 were found to have active IDs (29 were more than 17 years, one had died, 4 had moved to another location within IM-HDSS, and one had moved out of IM-HDSS). Active IDs mean that these children were present at the IM-HDSS site as of round 20; hence, all these 342 children were included in this study.

In addition to children with disability, for validation of C-DAS, a sample size of 1,273 was computed to detect a difference of 1% between the groups of children with versus without disability, assuming alpha of 5% and power of 80%. This resulted in a total sample size of 1,615: 1,273 children without disability and 342 with disability. However, the sample size of children without disability was increased to 1,500 to account for non-availability, refusals, and out-migrations from the site. At the time of this study, 35,062 children (excluding 342 with disability) between 5-17 years of age were residing at the IM-HDSS. Stratified (sex) sampling proportionate to the population size of children without disability (n=35,062) was performed after removing the 342 children with disability from the round 20 active IDs. The formula used for sample size calculation was:

$$\left(\frac{\text{Total sample size required}}{\text{Population size}} \right) \text{ x } \text{ Stratum size}$$

Table below gives sample size calculation for each stratum.

Sample size calculation	Male	Female
Total sample size	1,500	1,500
Population size	35,062	35,062
Stratum size	17,216	17,846
Calculation	(1,500/35,062) * 17,216	(1,500/35,062) * 1,7846
Stratified sample	737	763

A random list of IDs was drawn from each stratum using STATA version 14 [32]. Thus, sample for this study included 342 children with disabilities and 1,500 children without disabilities, giving a total of 1,842 children whose caregivers were approached to participate in the study. A unique study ID was assigned to all 1,842 children included in the sample. Only one child per household was selected. Figure 2.3 gives enrollment of caregivers.

It is important to note that the distinction between children with disability and without disability was made for sampling purpose to ensure that sample for this study does not miss children with disabilities. The analysis for this study was conducted on the pooled sample of individuals who agreed to participated in the study.

Sample size

The sample size calculation for psychometric analysis was based on two rules [33, 34]. The first rule suggests taking a ratio of subjects to items: a ratio of 5-10 respondents per item to about 300 respondents [35-37]. C-DAS has a total of 24 questions. Going by the 5:1 or

10:1 rule, a sample size in the range of 120 – 240 was obtained. The second rule suggests having a minimum total sample size; according to this, a sample size of 100 is poor, 200 is fair, 300 is good, 500 is very good, and 1000 or more is excellent [38]. The suggested minimum size is between 400-500 participants. Thus, based on these rules, this study had a sufficient sample size (n=1,842) to conduct psychometric analysis. Having a larger sample size increases stability of factor analysis results and conclusions. A larger sample also helps in replication of results to assess generalizability of the tool [33].

Data collection and management

After obtaining oral informed consent, data were collected through face-to-face caregiver interviews using a tablet-based platform that was developed and pre-tested using available local resources at the IM-HDSS. The platform included English and Lusoga versions of questions, which were developed in Microsoft Excel .xls format and uploaded to KoBoToolbox (https://www.kobotoolbox.org/) for data collection. Questions had a check box and free text entry formats to enter responses. Questions were designed to allow skip patterns where appropriate, and mandatory fields were also marked. This ensured that there were no missing data for Module A and C-DAS. In order to reduce work-load related to entry of IM-HDSS IDs, the unique study ID was linked with the IM-HDSS IDs at the back-end in order to address issues related to errors in ID entry. The Kobo app was downloaded to android tablets to allow for data collection using a user-specific password. These forms were accessible in the field during data collection and did not require internet or Wi-Fi connection. Once an interview was completed, the form was saved on the tablet. Field supervisors checked saved forms at the end of the day, and completed forms were uploaded daily using office Wi-Fi connection to a cloud server. The electronic forms were submitted to a secure, encrypted cloud server with no copy available on the tablet after submission to the cloud server. The server was only accessible to authorized study team members at IM-HDSS and JHSPH. This ensured data confidentiality and security. Data were downloaded daily from the server in MS Excel (.xls and .cvs format).

Data analysis

Descriptive analysis

Descriptive analysis was conducted to assess demographic characteristics of children and their caregivers. Binary and categorical variables are reported in percentages and mean with standard deviation as well as median and interquartile range (IQR) are reported for continuous variables.

Exploratory factor analysis (EFA)

Disability is a latent variable and cannot be measured directly. Using the ICF framework, UNICEF/WG developed C-DAS, which measures functional disability in children using 24-questions resulting in 13-domains which are measured directly. The domains included are vision, hearing, walking, self-care, communication, learning, remembering, concentrating, accepting change, controlling behavior, making friends, anxiety, and depression. Through C-DAS, these domains indirectly measure disability. Exploratory factor analysis (EFA) is a data reduction method and is also used for construct validity [33, 39]. It identifies an underlying factor structure of a set of directly measured variables and an associated number of latent constructs or factors. EFA also helps to determine if there is only one underlying latent construct being assessed by the domains or whether there are other constructs related to the given results.

The eligibility to use items for EFA is determined by using two tests. First, the Bartlett's test of sphericity is used to test the null hypothesis that the items are not correlated. To perform EFA, the Bartlett's test needs to be statistically significant, which means that there are sufficient intercorrelations between variables to conduct the factor analysis [40]. Second, the Kaiser–Meyer–Olkin (KMO) provides a measure of sampling adequacy. KMO identifies items that are related and also provides unique information on the factors identified by the EFA. Higher values of KMO indicate overlap of variance between variables but not to the point of hindering the analysis due to multicollinearity [41, 42]. As guidelines, KMO of 0.00 - 0.49 is unacceptable, 0.50 - 0.59 is miserable, 0.60 - 0.69 is mediocre, 0.70 - 0.79 is middling, 0.80 - 0.89 is meritorious, and 0.90 - 1.00 is marvelous. Having larger values is better and indicates a measure of overall or shared variance between pairs of variables [41]. Since Likert scale response for C-DAS is considered in this analysis, polychoric correlation of the domains was assessed. Polychoric correlation gives the measure of association between ordinal variables. Its value range is between 1 and -1. A value of 1 or -1 mean perfect correlation while value of 0 means no correlation [43].

EFA has three main steps: (a) determining the number of factors, (b) selecting an extraction method, and (c) choosing a rotation method. Criteria for retaining factors included: (a) Kaiser criterion of an eigenvalue of greater than 1, and (b) number of factors to the left of scree plot elbow. Eigenvalue shows total variance accounted for by each factor. It accounts for most of the variance explained by the underlying factor [33, 42].

There are various extraction methods in EFA that give factor loadings for every item on every extracted factor. The method used for this study was iterative factor analysis, which does not require any distributional assumption for the underlying factors. In this study, EFA was performed using promax rotation (oblique rotation), which assumes that the extracted factors are correlated. Factor loadings of ≥0.30 are considered for EFA. The number of factors retained, their respective eigenvalues, uniqueness (variance unique to the variable and not explained by other variables) and estimation method for model fit are reported for the EFA.

Reliability

The reliability of C-DAS was calculated using Cronbach's alpha, which is a measure of internal consistency. Cronbach's alpha of ≥0.9 is excellent, ≥0.8 is good, ≥0.7 is acceptable, ≥0.6 is questionable, ≥0.5 is poor and <0.5 is unacceptable [37]. Cronbach's alpha for the extracted factors is also reported [44].

Validity

Face validity was assessed through translation and back-translation process as well as pre-testing of C-DAS. Concurrent validity, a type of criterion validity, was assessed by administering C-DAS and Module A concurrently. Criterion validity allows assessment of the relation between two tools or measures that measure the same construct. In this study, C-DAS was compared with Module A, which was already validated at IM-HDSS and has been implemented several times at the IM-HDSS site [26, 27]. Since C-DAS and Module A were administered at the same time, concurrent validity (type of criterion validity) is reported using the Spearman's rank correlation coefficient. The hypothesis was that those with high Module A scores will also have high C-DAS scores [33, 45]. Spearman's rank correlation coefficient is reported when the response variable is ordered and there is a monotonic relation between the variables. Its value ranges between -1 to +1. The values are interpreted as "very weak" for values between 0.00-.19, "weak" for 0.20-0.39, "moderate" for 0.40-0.59, "strong" for 0.60-0.79, and "very strong" for 0.80-1.0 [46]. In addition to assessing correlation between C-DAS and Module A scores, Likert scales responses of C-DAS and Module A were also compared using percent agreement, which is the percentage having the same C-DAS response for a given Module A response. Cohen's Kappa was also calculated to account for chance agreement between the two tools. Its value varies from 0 to 1 where 0 mean reflects chance agreement and 1 mean reflects perfect agreement. Values between 0.1 – 0.20 show slight agreement, 0.21 – 0.40 is fair agreement, 0.41 – 0.60 is moderate agreement, 0.61 – 0.80 is substantial agreement, and 0.81-0.99 is near perfect agreement [47, 48]. Data analysis was conducted using STATA version 14 [32].

Ethical approval

The study was approved by the institutional ethics committees of the Johns Hopkins Bloomberg School of Public Health, USA and both the Makerere University School of Public Health and the Uganda National Council for Science and Technology in Uganda.

Results

Descriptive analysis

Out of 1,842 caregivers approached, 1,439 (78.1%) respondents consented to participate in the study and were included in this analysis. The mean reported age of children was 11.06 ± 3.59 years; 51.4% were males. Over half the children had not completed their vaccinations. Over half of the children belonged to a nuclear family system, and about a quarter were in the poorest wealth quintile (Table 2.1). More than 80% had a primary caregiver, with mother being the most common caregiver. Average age of the primary caregiver was 41.15 ± 11.69 years, with education up to primary (59%) (Table 2.2).

Exploratory factor analysis

The Bartlett's test for sphericity was statistically significant (p-value <0.001), rejecting the null hypothesis that items are not correlated. KMO for sampling adequacy was 0.898, which is meritorious. Polychoric correlation showed that all domains are positively correlated, and most were statistically significant. Based on guidelines for interpretation of correlation coefficient, coefficient of >0.5 was considered to have strong correlation between the variables. Very strong correlation was found between self-care, communication, learning, remembering, concentration, accepting change, behavior control, and making friends, with correlations ranging between 0.50 – 0.95. The correlation between anxiety and depression was 0.89.

Based on eigenvalue criteria of values >1 and scree plot (Figure 2.4), two factors were retained using principal components analysis. The first factor had an eigenvalue of 8.62, and the second had an eigenvalue of 1.35, explaining 66.32% and 10.41% of the total variance respectively. Together, the first two factors explain 76.73% of the total variance. Pattern matrix of rotated factor loadings showed that vision, hearing, walking, selfcare, communication, learning, remembering, concentrating, accepting change, behavior control, and making friends loaded on factor 1 (Motor and cognition), while anxiety and depression loaded on factor 2 (Mood) (Table 2.3).

Reliability

Cronbach's alpha for the overall C-DAS was 0.899, showing good internal consistency. Cronbach's alpha for each extracted factor was excellent – 0.904 for motor and cognition, and 0.902 for mood. The Cronbach's alpha for the overall Module A was 0.742, showing acceptable internal consistency.

Face validity

No major modifications were made in C-DAS as a result of its translation and back-translation. During the pre-test, none of the participants reported any difficulty in understanding the questions and answer responses.

Concurrent validity

Spearman's rank correlation between overall C-DAS and Module A scores was 0.51 (p-value <0.001), showing a positive correlation. The overall mean C-DAS score was 2.47±3.82 out of 39 and 0.5±1.48 for Module A out of 14. (Figure 2.5). The mean score for Mood (1.35±1.42) was higher compared to Motor and Cognition (1.12±3.06). Table 2.4 compares Likert responses between C-DAS and Module A and shows that the percent agreement greater for "cannot do at all." However, agreement for "some difficulty" and "a lot of difficulty" was around 70%. The observed overall percent agreement between C-DAS and Module A was 48.02% and kappa was 0.219 (standard error: 0.014), showing minimal agreement between the two tools.

Discussion

To the best of our knowledge, this is the first study that adapted and assessed validity and reliability of C-DAS in Uganda. The analysis shows that the questions listed in the tool represent the underlying construct of disability through two factors – Motor and cognition, and Mood— and 13 domains - vision, hearing, walking, self-care, communication, learning, remembering, concentrating, accepting change, controlling behavior, making friends, anxiety, and depression – all of which focus on functional disability and, hence, show that the tool is unidimensional. The Washington Group/UNICEF tool for 5-17-year-old children was validated in school settings in Fiji in 2015 with the objective to determine if the UNICEF/Washington Group tool can be used by teachers to identify children at risk of disability for timely referral for further assessment and interventions. That study conducted diagnostic accuracy testing to determine optimal cut-offs of scores to predict impairment in seeing, hearing and walking and found that "some difficulty" has optimal level of sensitivity and specificity compared to "a lot of difficulty" to assess disability status of children [49]. The analysis in the Fiji study is presented at domain level. It does not present results related to adaptation of the tool in Fijian context [49]. However, this study shows that C-DAS as a complete tool can be adapted into Ugandan context and is valid to assess level of functioning in children.

C-DAS showed good overall internal consistency and excellent factor-level internal consistency. Its correlation with Module A was moderate, while kappa agreement was minimal. This could be because C-DAS includes additional domains related to cognition (learning, remembering, concentrating, accepting change, controlling behavior, making friends, anxiety, and depression) which are not covered in Module A. In addition, Module A assess upper body mobility, which is not assessed in C-DAS. However, C-DAS is well-suited for implementation within the Ugandan context. This has great implications for furthering the current discussion around lack of comparable disaggregated disability data at national, regional and global levels to monitor disability-related SDGs [12, 17, 30]. Disability has many manifestations, and each type of disability can be assessed separately. However, for effective interventions at the community level, it is important to understand the overall burden of disability and account for multiple disabilities in an individual. The focus of C-DAS is on assessing physical disability in children and is not applicable to children with intellectual disabilities due their unique needs.

Field testing of the initial version of UNICEF/WG tool for children 5-17 years of age was conducted in two rounds in several different settings, including India, Belize, Oman, Montenegro, and the USA, resulting in development of a final version that was used for this study [14, 31, 50, 51]. Like this study, the main respondents of the tool during field testing were caregivers of children [52]. A study from South Africa has used the UNICEF/Washington Group tool for 2-4 years old children in its 2011 General Household Survey and National Census to generate epidemiological evidence on child disability and to identify types and extent of disabilities [53].

Disability is considered to be on a spectrum – from mild to severe. In order to use disability as an outcome variable, several different recommendations have been put forward which suggest using disability as a binary or categorical outcome [18, 49]. Categorization of disability into binary categories may result in loss of important information. It is important to understand the concept of heterogeneity associated with disability measurement. People with different degrees and types of disability may face different degrees and types of barriers. Combining all people into one group of "people with disabilities" can mask different impacts [2]. Changing the cut-off will change the measured impact. Most severe cut-offs will show the biggest difference in outcome between children with and without disabilities, while the opposite is true for less severe cut-offs, which will raise prevalence but show the smallest difference in outcome [50]. This has practical implications where interventions are planned, implemented and monitored for their impact and usefulness. This is even more crucial in LMICs, where limited resources hamper efforts to address needs of individuals with disabilities.

Using a binary outcome could help in identifying more severe cases of disability and thus allow targeted use of limited resources towards interventions for those who need them the most [31, 50]. But unlike a binary outcome, a Likert scale – as used in C-DAS - provides a more accurate picture of the spectrum of disability in the population. This study shows that the greatest agreement between C-DAS and Module A scores was for the most severe category. In addition, it is noticed that there tends to be greater agreement between C-DAS and Module A for severe disability category. This may reflect that for assessment of severe disability, either tool could be implemented for assessment at the community level. Children with disability may have different experiences over their lifespan. Considering disability as a categorical outcome variable will also allow the investigation of the changes that children experience in their level of disability and monitoring the impact of interventions on these children, especially during their development phase.

Some of the advantages of C-DAS are as follows. First, it does not need clinicians to administer it and can be implemented easily by field staff or community workers [53]. Second, having a standardized and validated tool for settings like Uganda is very much needed for good quality, reliable, and accessible data to help with monitoring of SDGs. C-DAS has the benefit of use by multiple sectors – health, finance, education, and transport – to ensure inclusion of children with disability. Third, C-DAS was implemented as an electronic, tablet-based data collection system in a semi-urban/rural setting, which allowed for timely, efficient data entry and transfer. There were built-in validation mechanisms that allowed data quality checks. Such systems ensure timely availability of data, which can be shared with relevant stakeholders for planning purposes. Fourth, C-DAS is specific for children and allows for proxy responses from mothers/caregivers. The questions are structured such that they account for the growing needs of children and age-appropriate activities by asking questions like, “in comparison with children of the same age….” This also helps to consider local context [14, 31]. Fifth, the translation process and feedback from IM-HDSS and participants of the pre-test did not require many changes in the question structure and understanding of words and response options. No challenges in a respondent’s understanding and administration of C-DAS were reported. This favors the use of a standard tool across different contexts to collect internationally comparable disability data.

Some limitations of the study are as follows: First, this was a cross-sectional study and doesn’t allow an assessment of changes in disability level over time. This is a crucial consideration in disability research and needs data systems that have the capacity to follow-up on children with disabilities to assess their growing needs along with their disability-specific needs. Second, merely collecting data on children with disability using Module A and C-DAS is not enough. This study lacked resources to have clinical follow-up on children identified as having disability. This needs to be addressed in future work at IM-HDSS in order to provide liaison mechanisms between IM-HDSS and the local district health office and healthcare facilities. Third, C-DAS tends to identify children with disability as early as possible so that interventions can be implemented earlier to allow inclusion of these children. Fourth, comparison between C-DAS and Module A was performed for the overall score. Domain level comparison was only possible for seeing, hearing, walking, self-care and communication. Both C-DAS and Module A were developed with the goal of assessing disability as a whole. However, since each domain has separate interventions, it is important to consider overall as well as domain-specific analyses. Fifth, C-DAS lacks questions on upper-limb mobility as was also noted by Sprunt et al [49]. Perhaps future work can add this as one of the domains. This is an important domain to consider due to its implication on fine and gross upper-limb movements and opportunities for learning and education for these children. Sixth, there may be bias in how caregivers responded to questions if their child had disability [31]. This might have influenced their interpretation of the question, or they might have changed their responses to a more desirable option with the hope for monetary support or some gain in case the child is shown to have disability. In addition, for questions mentioning comparison to "other child of same age…," the caregiver could have either compared to other children with disability or to other children without disability, which could results in biased responses based on disability status of the child [31].

Developing polices and interventions to address the needs of disabled children is possible using reliable data, and such data can be a means of understanding the needs of disabled children based on their gender and age, ensuring their appropriate integration within their environments like home, school, and work [16, 17]. Such data are also useful to identify children in need of clinical and rehabilitation support for their disability. Sustainable Development Goal 17 (SDG) also emphasizes the importance of high quality, reliable and timely availability of disability data to monitor the progress of other disability-related SDGs [54, 55]. Such a standard validated tool can be used for comparisons across context and is important for obtaining disaggregated data on variables like gender, quintile, education, and employment. It also allows for monitoring of programs and policies, program implementation and larger monitoring of SDGs [14, 31].

Conclusion

C-DAS is a unidimensional, two-factor, valid and reliable scale for assessing disability in Uganda. It is an easy-to-administer tool that helps in deeper understanding of context-specific burden and type of disability in children between 5-17 years of age. This standardized tool can be used at national and sub-national levels for collecting longitudinal data in a timely manner to generate evidence for policy-makers, and for monitoring and evaluation of interventions.

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Tables

Table 2.1: Demographic characteristics of children (n=1,439)

Child characteristics n (%)	
Average age in years (mean ± SD)	11.06 ± 3.59
Age groups	
5-10 years	657 (45.66)
11-14 years	467 (32.45)
15-17 years	315 (21.89)
Sex	
Male	739 (51.36)
Female	700 (48.64)
Immunization status	
Complete	557 (38.71)
Not complete	790 (54.90)
No vaccination done	92 (6.39)
Currently in school	
Yes	1,272 (88.39)
No	167 (11.61)
Have a primary caregiver (yes)	1,239 (86.10)
Family system	
Single parent	138 (9.59)
Nuclear	743 (51.63)
Joint	555 (38.57)
Household wealth quintile (n=1,389)	
Poorest	389 (28.01)
Poorer	299 (21.53)
Poor	325 (23.40)
Less poor	248 (17.85)
Least poor	128 (9.22)

Table 2.2: Demographic characteristics of primary caregivers (n=1,239)

Caregiver characteristics n (%)	
Caregiver relation with child	
Mother	770 (62.15)
Father	164 (13.24)
Sibling	13 (1.05)
Uncle/Aunt	58 (4.68)
Grandparent(s)	173 (13.96)
Others	61 (4.92)
Average age (mean ± SD)	41.15 ± 11.69
Sex	
Male	219 (17.68)
Female	1,020 (82.32)
Education level	
None	168 (13.56)
Primary	731 (59.00)
Lower secondary	250 (20.18)
Upper secondary	12 (0.97)
Other (university/vocational)	78 (6.30)
Occupation	
Farmer	679 (54.80)
Shopkeeper	281 (22.68)
Housewife	120 (9.69)
Professional	55 (4.44)
Boda boda driver	13 (1.05)
Unemployed	30 (2.42)
Others	61 (4.92)

Table 2.3: Factor loadings and uniqueness of Child Disability Assessment tool

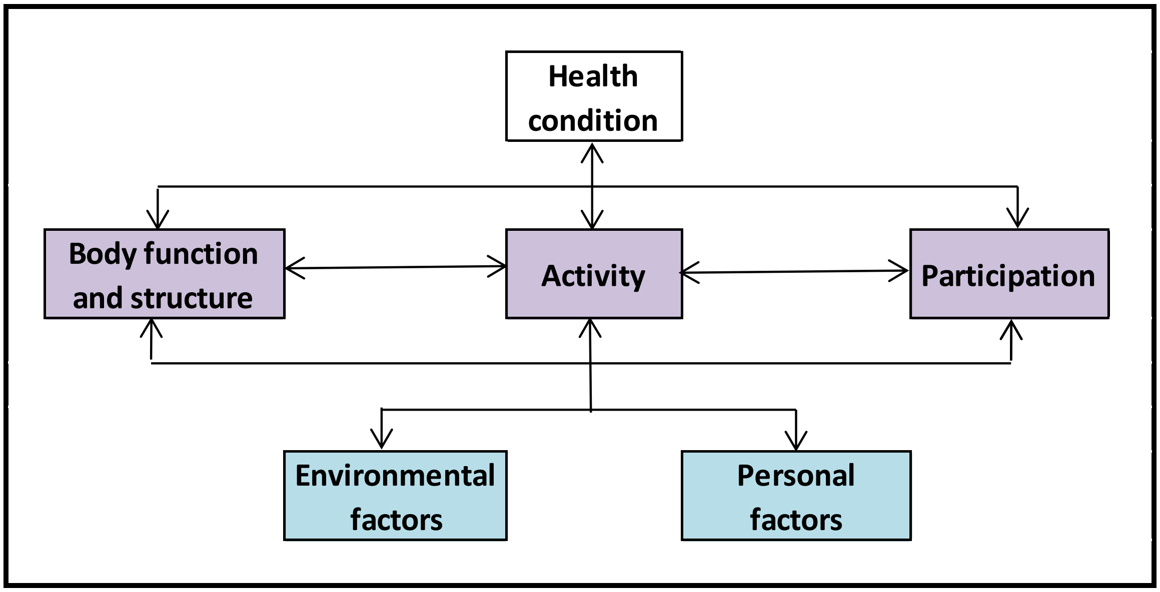
Domains	Factor 1: Motor and cognition	Factor 2: Mood	Uniqueness
Vision	0.30		0.91
Hearing	0.54		0.73
Walking	0.71		0.45
Self-care	0.79		0.21
Communication	0.88		0.14
Learning	1.00		0.10
Remembering	0.99		0.15
Concentration	0.95		0.05
Accepting change	0.93		0.12
Behavior	0.87		0.16
Making friends	0.86		0.08
Feeling anxiety		0.86	0.22
Feeling depression		1.00	-0.00

Table 2.4: Comparison between Module A and Child Disability Assessment tool

C-DAS	**Module A**				
	None	**Some**	**A lot**	**Cannot do at all**	**Total**
None	458 (41.04)	4 (1.75)	0	0	462
Some	521 (46.68)	162 (70.74)	9 (12.68)	0	692
A lot	125 (11.20)	53 (23.14)	49 (69.01)	1 (4.35)	228
Cannot do at all	12 (1.08)	10 (4.37)	13 (18.31)	22 (95.65)	57
Total	1,116	229	71	23	1,439

Figures

Figure 2.1: Conceptual Framework for the International Classification of Functioning



Source: [5]

Figure 2.2: Flow chart of translation process of Child Disability Assessment tool

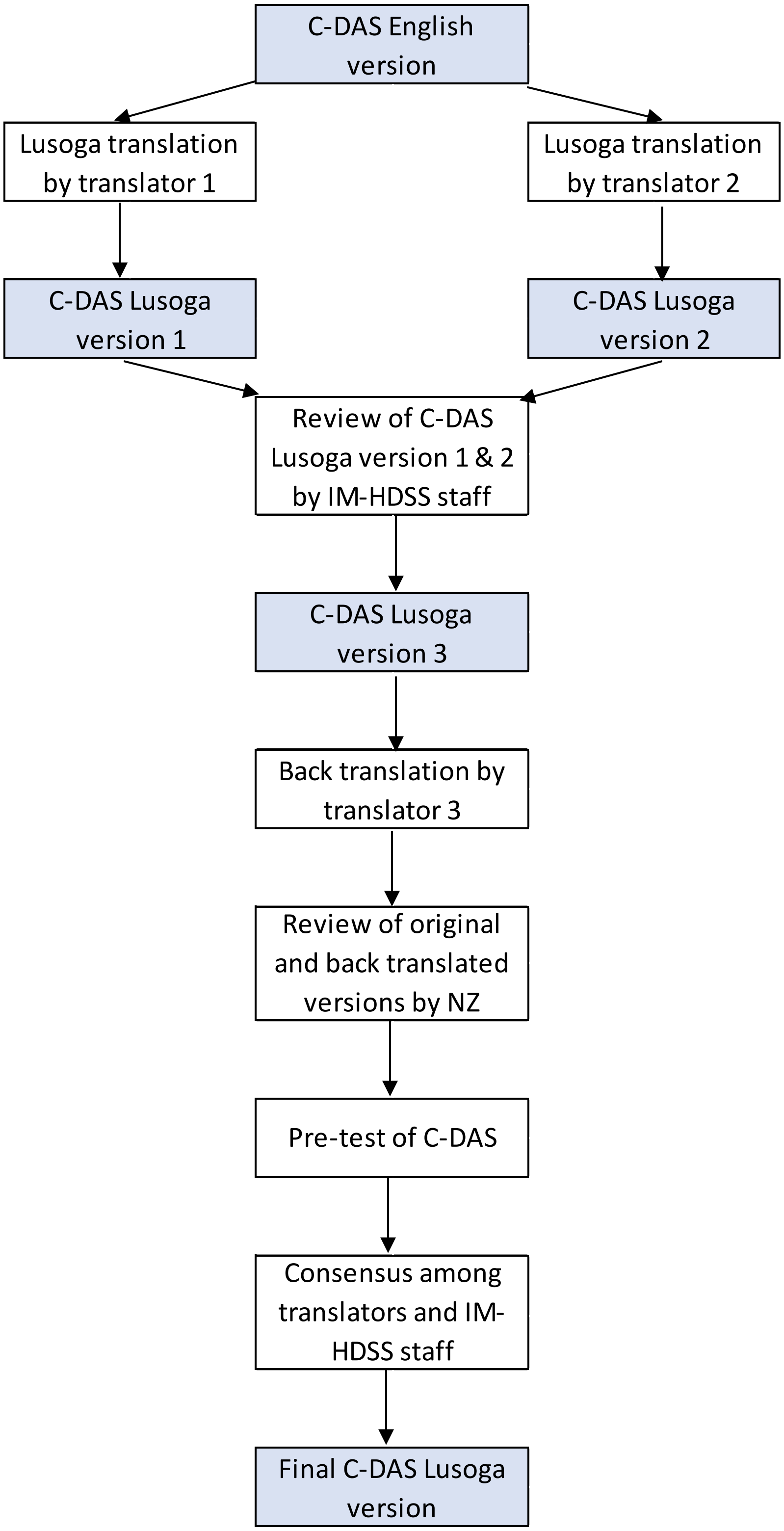


Figure 2.3: Flow chart of caregiver enrollment for Child Disability study

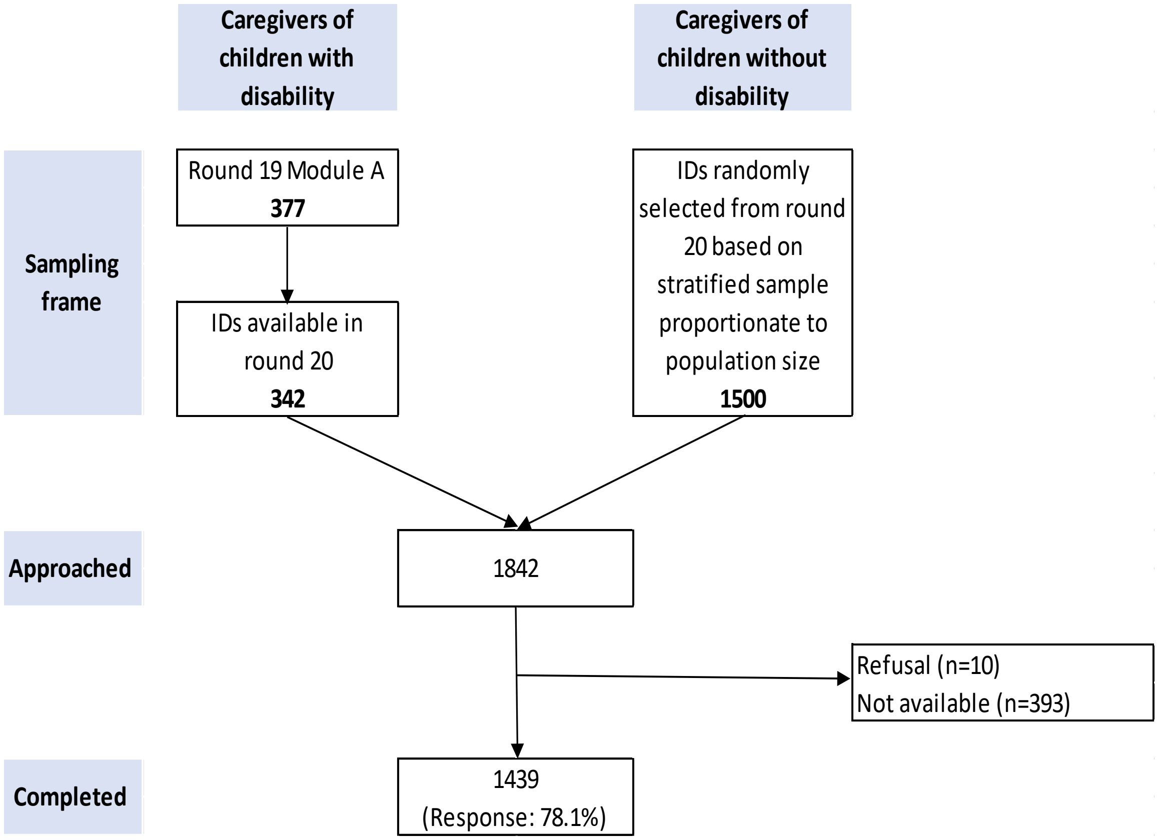


Figure 2.4: Scree plot based on exploratory factor analysis for selection of retained factors

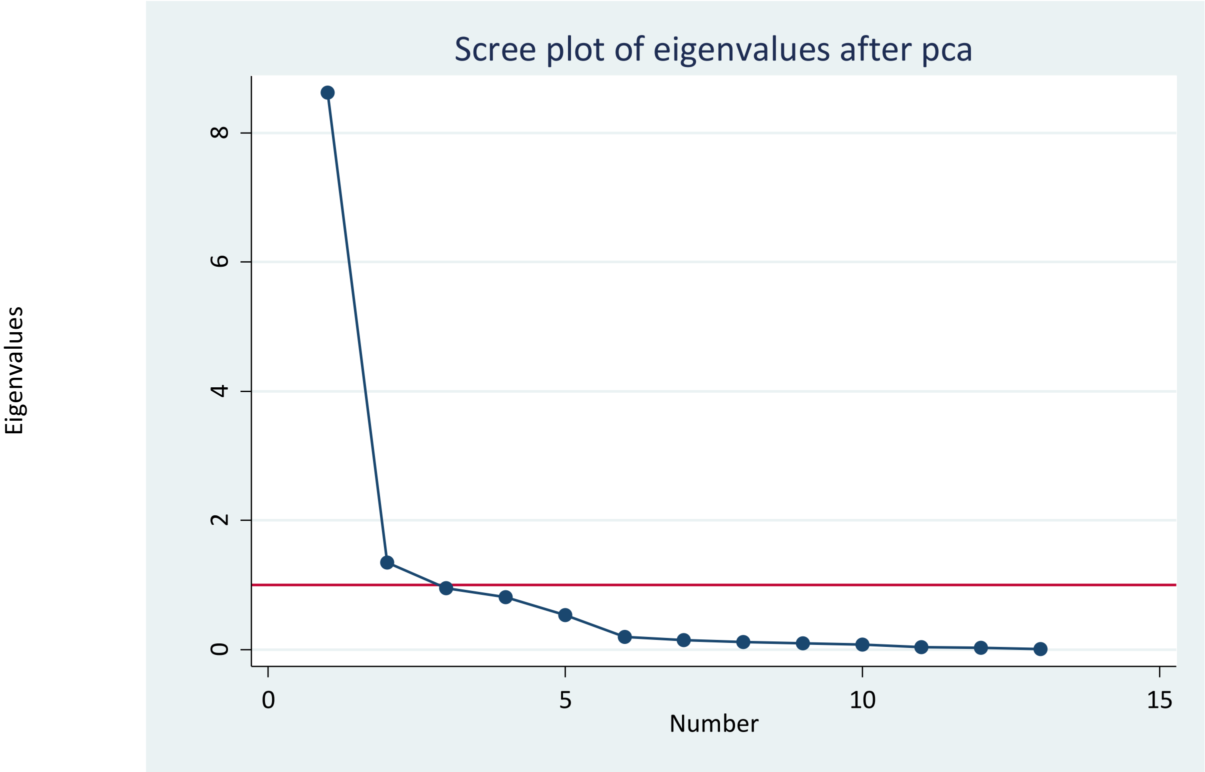
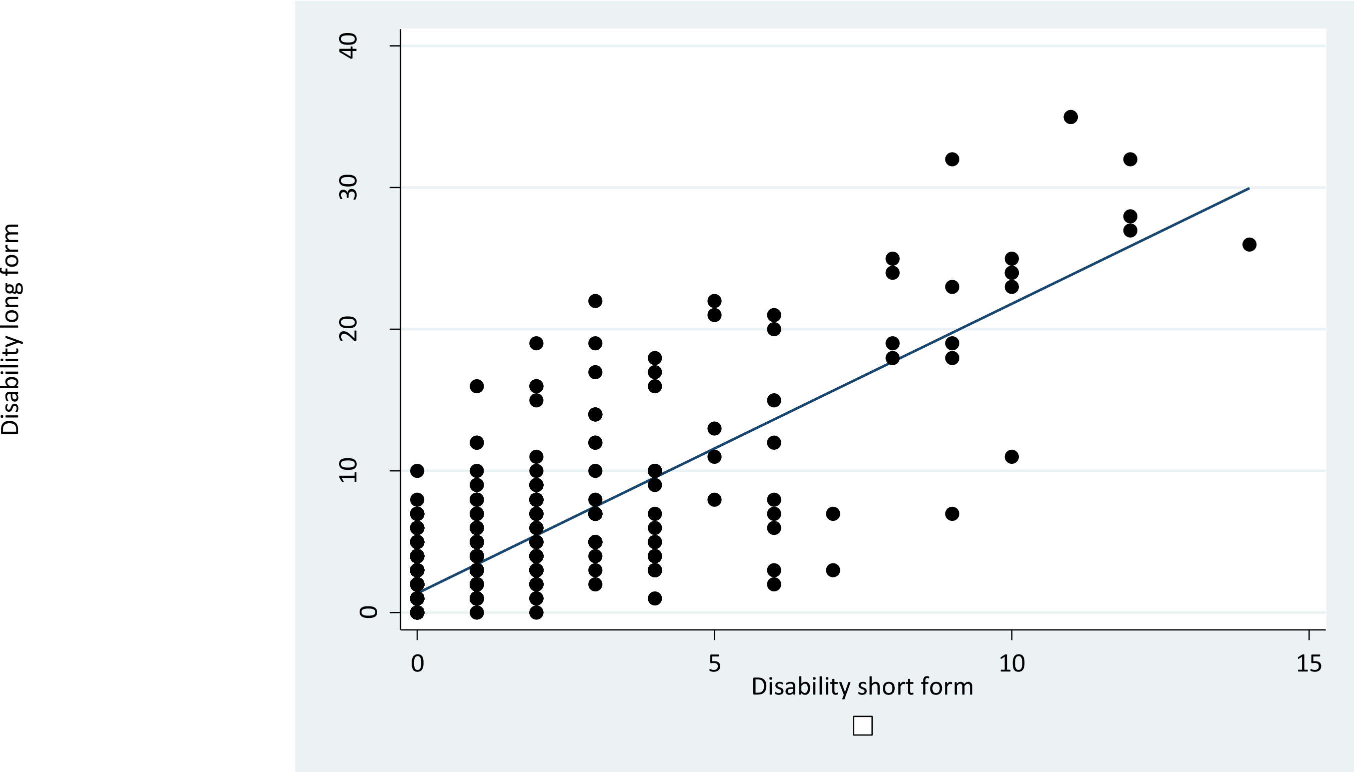


Figure 2.5: Scatterplot showing monotonic relationship between scores of Child Disability Assessment tool and Module A



Chapter 3: Measuring child functioning: assessing correlation and agreement between caregiver and child responses at the Iganga-Mayuge Health and Demographic Surveillance Site in Uganda (Paper 2)

Abstract

Introduction: Measuring child disability is complex. One contributing issue is whom the respondent for questionnaires should be for attempting to capture disability among children. Children and their caregivers may have different perceptions. Understanding how these perceptions differ is a key step in identifying the best approach to measure the degree of correlation and agreement between children and their caregivers. The aim of this study was to assess responses of the child disability assessment tool (C-DAS) between children (11-17 years old) and their caregivers at the Iganga-Mayuge Health and Demographic Surveillance Site (IM-HDSS) in Uganda.

Methods: This was a cross-sectional study conducted between September 2018 – January 2019 at IM-HDSS. Respondents were children between 11 to 17 years of age and their caregivers. Both caregiver and child versions have 24-questions corresponding to 13 domains. The responses were recorded on a 4-point Likert scale. Descriptive analyses of the child and caregiver responses were conducted. Correlation (Spearman's rank correlation) and agreement (Bland-Altman plot, percentage agreement and Cohen's Kappa) between caregiver and child responses were assessed.

Results: Of the 217 caregiver and child pairs eligible for this study, 181 pairs agreed to participate (83.4%). The mean age of children was 13.9 ± 1.9 years, and 56.4% were males. Cronbach's alpha was 0.892 and 0.886 for the caregiver and child versions of C-DAS respectively, showing good internal consistency in both. The overall mean score was reported to be 5.36 ± 5.63 out of 39 for caregivers and 5.45 ± 5.34 for children, showing significant overall agreement between scores within caregiver and child pairs. Spearman's rank correlation between caregiver and child scores was 0.806, showing strong positive correlation. The difference in the paired score between the caregiver and child was not statistically significantly different from zero (Wilcoxon signed-rank test, p-value 0.969). Bland-Altman plots for C-DAS scores showed greater agreement between caregiver and child at lower scores. Percentage agreement between caregiver and child for overall disability was greater for mild (83.53%) and moderate (79.37%) categories as compared to the severe (66.67%) category. There was substantial agreement (kappa 0.623) for overall disability between caregiver and child responses.

Conclusion: This study indicates that there is significant correlation agreement between self-reported caregiver-child pair responses. This was observed for both overall and domain-specific disability.

Introduction

Disability is a complex phenomenon and, based on the International Classification of Functioning, Disability and Health (ICF), is a result of interactions between impairments at the body level, in the context of the health condition of an individual, as well as the contextual factors specific to the environment in which the individual lives [1]. Disability has devastating effects on individuals, their families and the society. It is regarded as a cause and consequence of poverty [2]. In many LMICs, disability is still highly stigmatized and can lead to social exclusion and discrimination. For children with disability, this often means a life in isolation and exclusion from education and future employment opportunities, as well as lack of access to health services [3-7].

Child development occurs in the context of their family and social environment, where the family and living circumstances play an important role in shaping their functional and social adaptation [8]. One aspect of these environmental interactions is the level of functioning that children with disability have with respect to various functional domains, for example, vision, hearing, mobility, and self-care [9]. Functioning is a spectrum that can range from no difficulty to severe difficulties with implications for development and growth, and these are influenced by a child's immediate environment and their ability to accommodate. However, there is scarcity of data from LMICs on functioning for children with disability, as well as their interaction with their environment [10].

Population-based disability assessment is a challenge due to the complex nature of disability [8, 11, 12]. Prevailing socio-cultural norms in LMICs make it even more challenging to assess disability [1, 6]. In addition, the shift in thinking from the medical to biopsychosocial model of disability has had a direct implication on population-based assessments of disability. Furthermore, measurement tools developed in high-income countries (HICs) may not be directly applicable to LMICs due to differences in context within which disability is assessed [1, 8, 11-15].

The United Nations Children's Fund (UNICEF) and the Washington Group on Disability Statistics (WG) have collaboratively developed a set of questions to assess disability in children based on the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) framework [9, 16]. They developed two tools – one for children between 2-4 years and another for those between 5-17 years. These tools cover thirteen domains: vision, hearing, walking, self-care, communication, learning, remembering, concentrating, accepting change, controlling behavior, making friends, anxiety, and depression [17-19]. The tools are not applicable for children under 2 years of age due to the challenge associated with assessing developmental delays in such young children. In addition, cultural norms vary across different contexts and can influence a child's developmental milestones during infancy [9, 20].

The UNICEF/WG tool is designed to be administered to primary caregivers of children, and this is considered an appropriate approach for younger children. However, in cases of older children, it is important to get their own input on perceptions of functioning. This is because the perceptions of children and their parents/caregivers may differ about the child's disability [21]. In order to reduce any bias introduced through just interviewing parents/caregivers, perhaps interviewing children, when possible, is appropriate. Not only does this approach allow children to self-report their limitation, but it also validates caregiver responses. Child interviews should be supplemented with parent/caregiver interviews to get the perspectives of children as well as their parents/caregivers [18]. Although there is no official child version of the UNICEF/WG tool, UNICEF and WG have conducted cognitive testing in the US to assess differences in caregiver and child responses. It showed that the level of agreement between caregiver and child was highest for physical domains, like vision and hearing, probably because these are easy to observe. The agreement was lowest for learning, concentration, accepting change, making friends, anxiety, and depression, probably because these cannot be observed directly [21].

Since the pilot study by UNICEF/WG was done in the US only, there is lack of empirical data on how the child version of the UNICEF/WG tool would work in other settings, especially LMICs such as Uganda. To address this gap, the child version of the child disability assessment tool (C-DAS) was implemented at the Iganga-Mayuge Health and Demographic Surveillance Site (IM-HDSS). The aim of this study was to determine correlation and agreement of C-DAS between responses of children (11-17 years old) and their caregivers at the IM-HDSS in Uganda. More specifically. this study explores overall and domain-level agreement for caregiver-child pairs. It further assesses caregiver-child pair agreement based on specific characteristics: child sex, child age group, child school enrollment status and household wealth quintile.

Methods

Study site

Iganga-Mayuge Health and Demographic Surveillance Site (IM-HDSS) is located in Eastern Uganda and covers the districts of Iganga and Mayuge. The site is part of International Network for the Demographic Evaluation of Population and Their Health Network (INDEPTH) and was established in 2005 as a field research site for Makerere University [22-24]. About 38% of the IM-HDSS is peri-urban and is located mostly around Iganga Town; females comprise about half of the population [23].

IM-HDSS follows over 89,000 individuals living in about 18,000 households. Over 18,000 of these individuals are between 11-17 years of age. It conducts census-level data collection two times a year on births, deaths, pregnancies and their outcomes, and in- and out-migrations [24]. In addition, IM-HDSS also periodically collects data on access to health services, causes of death, relevant socioeconomic and education data, non-communicable diseases and injuries [25]. Since 2005, 21 rounds of data collection have been completed as of June 2019 [22].

This study was nested within an ongoing parent study to pilot electronic data collection for injuries and disability in IM-HDSS. The parent study focused on using innovative ICT approaches to collect, manage, and analyze data on injuries and disability. These modules were implemented in paper format during a previous study conducted at IM-HDSS between 2008 – 2009 and subsequently were integrated into IM-HDSS and data was collected in three rounds [25, 26]. The IM-HDSS relies predominantly on paper-based data collection, [27, 28] and the process from data collection to entry into a database and analysis involves multiple steps [29]. However, the site is now transitioning to electronic data collection for efficient and timely availability of data for analysis. A pilot using tablet-based data collection was conducted in round 19 (April – June 2017). Data collected in round 19 was used as sampling frame (see sampling frame section below) for the current study on child disability.

Study tool: Child Disability Assessment tool (C-DAS)

This study utilizes a detailed Child Disability Assessment (C-DAS) tool developed by the UNICEF/Washington Group on Disability Statistics [9]. C-DAS focuses on everyday activities and has an expanded set of questions to assess functioning of a child. It can be administered at the national level and allows for comparisons across time and countries. The primary respondent of C-DAS are caregivers of children [9]. It is comprised of 24-questions with responses on 4-level Likert scale (0=no difficulty, 1=some difficulty, 2=a lot of difficulty and 3=cannot do at all). These questions cover 13 domains: vision, hearing, walking, self-care, communication, learning, remembering, concentrating, accepting change, controlling behavior, making friends, anxiety, and depression. The total score ranges from 0 – 39, and the higher the score, the greater the disability. It takes about 20-25 minutes to complete C-DAS [16].

The child response version of C-DAS caters to children between 11-17 years of age [21]. The C-DAS tool was translated and back-translated to Lusoga using standardized approach [30]. The language was kept at the level of understanding of children (grade 5) and was revised based on input from a pre-test and field staff.

Study design and respondents

This was a *cross-sectional study* conducted between September 2018 – January 2019. Respondents were children between 11 to 17 years of age and their caregivers; an effort was made to administer C-DAS to the child and caregiver in the same visit. However, in instances when the child was not available, three attempts were made to interview the child. All child interviews were conducted after completion of caregiver interviews and after receiving oral parental permission and child assent, which was recorded during tablet-based data collection.

Sampling frame and sample size

Sampling frame for this study was drawn from household and individual listings available from the latest IM-HDSS rounds, round 19 and round 20. Data from a pilot conducted as part of round 19 served as the basis for identifying children with disabilities who were between 5-17 years of age. A total of 377 children between the ages of 5-17 were identified in round 19 (April - June 2019) in IM-HDSS. The IM-HDSS data management team then confirmed active status of their IDs in round 20, which had been completed four months (May 2018) before the beginning of this study (September 2018). Based on the data check, 342 children out of 377 from round 19 were found to have active IDs in round 20; 29 children were more than 17 years, one had died, four had moved to another location within IM-HDSS, and one had moved out of IM-HDSS. Active IDs mean that these children were present at the IM-HDSS site as of round 20. Caregivers of these 342 children with disabilities were approached for participation in this study. Of these 342 children, caregivers of 308 children agreed to participate in the study. However, only 217 of the 308 children were between the ages of 11-17 years and were eligible for this study. Only one child per household was selected. Figure 3.1 summarizes the sampling frame and flow of enrollment of caregiver and child pairs.

Data collection and management

Parental or caregiver oral consent and child's assent were taken before face-to-face interviews were conducted using two separate tablet-based versions (caregiver and child) of C-DAS that were developed, pre-tested, and validated based on available local resources (local staff and data management team, tablets) at the IM-HDSS. The tablets included English and Lusoga versions of questions, which were developed in Microsoft Excel .xls format and uploaded to KoBoToolbox (https://www.kobotoolbox.org/) for data collection. Questions had corresponding check box and free-text entry formats to input responses. Questions were designed to allow skip patterns where appropriate, and mandatory fields were also marked to ensure that there were no missing data. Caregiver and child versions of the forms were uploaded separately for data collection. The Kobo app was downloaded to android tablets to allow for data collection using user-specific passwords. These forms were used in the field during data collection and did not require internet or Wi-Fi connection to fill them. Once an interview was completed, the form was saved on tablets. Field supervisors checked saved forms at the end of the day, and the completed forms were uploaded daily using IM-HDSS Wi-Fi connection to a cloud server. The electronic forms were submitted to a secure, encrypted cloud server with no copy left on the tablet. The server was only accessible to authorized study team members at IM-HDSS and JHSPH. This ensured data confidentiality and security. Data were downloaded daily from the server in MS Excel (.xls and .cvs format). Using unique study IDs, caregiver and child data were merged at the end of data collection.

Data analysis

Descriptive analysis

Descriptive analyses were conducted to depict the demographic characteristics of children and their caregivers. Binary and categorical variables are reported in percentages and mean with standard deviation as well as median and interquartile range (IQR) are reported for continuous variables.

Internal consistency of C-DAS

The internal consistency of caregiver and child versions of the C-DAS was calculated using Cronbach's alpha. Cronbach's alpha of ≥0.9 is excellent, ≥0.8 is good, ≥0.7 is acceptable, ≥0.6 is questionable, ≥0.5 is poor and <0.5 is unacceptable [31].

The child-caregiver responses were examined by using tests of distribution of response pairs (*Wilcoxon signed-rank test)*, correlation (*Spearman's rank correlation coefficient*), and agreement (*Bland-Altman plot*, *Percent agreement and Cohen's Kappa*). Wilcoxon signed-rank test, Spearman's rank correlation coefficient and Bland-Altman plot used C-DAS scores (details provided below), while Likert scale responses were used for calculation of percent agreement and Cohen's Kappa (details provided below).

Tests performed using C-DAS scores

Row totals were calculated to assess individual scores and their distribution. The differences between paired caregiver and child scores were also calculated. Total disability score was categorized into four categories: no disability, mild disability, moderate disability and severe disability. No disability was defined if "none" was marked for all 13 domains. Mild disability was defined if "some difficulty" was marked for any one of the 13 domains, moderate disability for "a lot of difficulty" on any one of the 13 domains, and severe disability for "cannot do at all" on any one of the 13 domains. The *Shapiro-Wilk test* was conducted to assess the normality of the distribution of caregiver and child scores, as well as the difference between the scores; it tests the null hypothesis that a continuous variable is normally distributed [32].

The *Wilcoxon signed-rank test* is a non-parametric test and was conducted to test the null hypothesis that there is no difference in the distribution between paired caregiver and child scores [33]. It does not assess relation between responses of child-caregiver pairs; therefore, association between caregiver and child scores was assessed using *Spearman's rank correlation coefficient*. Its value ranges between -1 to +1, and values are interpreted as "very weak" for values between 0.00-.19, "weak" for 0.20-0.39, "moderate" for 0.40-0.59, "strong" for 0.60-0.79, and "very strong" for 0.80-1.0 [34, 35]. The *Bland-Altman plot* for difference between caregiver and child scores, and average of caregiver and child scores was developed to evaluate agreement between caregiver and child scores and to assess any over-reporting or under-reporting of functional disability by either caregivers or children [36]. This test was performed because correlation between scores of child-caregiver pairs does not specify agreement.

Tests performed using Likert-scale responses

In addition to assessing correlation and agreement based on caregiver and child scores, overall and domain-specific percent agreement and kappa statistic between caregiver and child responses were also calculated for the 4-point Likert scale disability severity categories. *Percent agreement* was calculated as the number of pairs with caregiver and child pair agreement divided by the total number of caregiver and child pairs [37]. *Cohen's Kappa* was also calculated and is reported when the outcome variable is categorical and is preferred when the respondent pair is selected purposively (as was the case in this study) [37,

[38]. The advantage of Cohen's Kappa over percentage agreement is that it accounts for chance agreement between raters. It varies from -1 to 1, where 0 reflects chance agreement and 1 reflects perfect agreement. Values between 0.1 – 0.20 show slight agreement, 0.21 – 0.40 fair agreement, 0.41 – 0.60 moderate agreement, 0.61 – 0.80 substantial agreement, and 0.81-0.99 is near perfect agreement.

Cohen's Kappa assumes that responses of raters are independent. However, in this study, this assumption may be violated because the caregiver and child with disability are related and their responses may not differ in most of the domains in the C-DAS. Thus, it is advisable to report both percentage agreement and Cohen's Kappa [37]. One example of chance agreement between the caregiver and child is when a question is not understood by the respondent or if the respondent is answering a question quickly to rush through the survey. All analysis was conducted in STATA 14.

Ethical approval

The study was approved by the institutional ethics committees of the Johns Hopkins Bloomberg School of Public Health, USA and both Makerere University School of Public Health and the Uganda National Council for Science and Technology.

Results

Descriptive analysis

Of the 217 caregiver and child pairs that were eligible for participation in this study, 181 pairs agreed to participate (83.4%). The mean age of children was 13.9 ± 1. 9 years; 56.4% were males. Over 80% had a primary caregiver, and about half of the children lived in a nuclear family system. Mothers were the primary caregivers for 60% of the children. About 65.4% of the primary caregivers had received primary education, and over 50% worked as farmers. (Table 3.1 and 3.2). Comparison of disability categories based on respondents showed that children reported higher percentage of mild (child: 51.4% and caregiver: 47.0%) and moderate (child: 38.1% and caregiver: 34.8%) disability, whereas the percentage reported for severe disability was 8.3% by children and 11.6% by caregivers (Figure 3.2).

Internal consistency of C-DAS

Cronbach's alpha was 0.892 and 0.886 for the total disability scores for the caregiver and child versions of C-DAS respectively, showing good internal consistency.

Tests performed using C-DAS scores

The overall mean score was reported to be 5.36 ± 5.63 out of 39 for caregivers and 5.45 ± 5.34 for children, showing significant overall agreement between scores within caregiver and child pairs. Interestingly, median scores reported by children (Median: 14; IQR: 7-23) were higher for severe disability compared to those reported by caregivers (Median: 18; IQR: 8-23). (Table 3.3).

Caregiver and child scores were also compared based on child sex, age group, school enrollment and household wealth quintile. Means and medians of caregiver and child scores did not vary based on child sex, age group, school enrollment and household wealth quintile and showed similar trend. Higher scores were observed for 15-17-year olds compared to 11-14-year olds. Scores were also higher for children not enrolled in schools. Caregiver and child pairs in the least poor quintile had higher scores compared to other quintiles. (Table 3.4). The overlap between caregiver and child scores showed that there was no statistical difference between the child and caregiver pair scores.

Wilcoxon signed-rank test was not statistically significant and failed to reject the null hypothesis that the median of difference equals zero (p-value 0.969). Spearman's rank correlation between caregiver and child scores was 0.806 (p-value), showing very strong correlation between scores. (Figure 3.3). Bland-Altman plot for C-DAS scores showed greater agreement between caregiver and child at lower scores; in addition, the majority of the agreement was within the 95% limits (Figure 3.4).

Tests performed using Likert-scale responses

Overall percentage agreement between caregivers and children was 76.80%. Percentage agreement between caregiver and child for overall disability severity categories showed that the percentage of agreement was greater for mild (83.53%) and moderate (79.37%) categories compared to the severe (66.67%) category. (Table 3.5).

Domain-specific percentage agreement showed that agreement was greater than 90% for severe disability in the domains of hearing, self-care, learning, and making friends, and over 80% for walking, communication, and depression. However, percentage agreement was less than 70% for anxiety. This was observed for overall agreement for females, for 15-17-year olds, for children in school and for children belonging to the “less poor” and “least poor” wealth quintile (Table 3.6).

Likert scale disability severity categories for caregivers and children were also assessed based on child sex, child age group, school enrollment and wealth quintiles and showed that caregiver and child responses were each statistically associated with school enrollment, with a greater percentage of severe disability reported for children not enrolled in school (Figure 3.5).

There was substantial agreement (kappa 0.623) between caregiver and child responses for the overall disability scores. The kappa statistic was substantial for all domains except for controlling behavior (0.533), anxiety (0.542) and depression (0.593). The kappa statistic based on child sex, age group, school enrollment and wealth quintile were moderate to substantial except for the poor quintile (kappa 0.833), which was near perfect. For specific domains, the kappa statistic for child sex, age group, school enrollment and wealth quintile were in the same range as the overall agreement. However, there were variations based on wealth quintiles. For example, for hearing, the agreement was substantial across all characteristics except for the poor, which was near perfect (kappa 0.826), and less poor, which was moderate (kappa 0.525). For concentration, the agreement was substantial across all characteristics except for the less poor, which was near perfect (kappa 0.919), and least poor, which was moderate (kappa 0.402). For anxiety, the agreement was moderate to substantial across all characteristics except for the less poor (kappa 0.396) and least poor (kappa 0.333) quintiles, which were fair. (Table 3.6).

Discussion

To the best of our knowledge, this is the first disability study conducted at the Iganga-Mayuge Health and Demographic Surveillance site (IM-HDSS) in which children between 11-17 years of age were interviewed in addition to their caregivers. It assessed responses of caregiver and child pairs for child's disability and level of functioning. This study explored both total scores and Likert categories for caregiver and child responses using multiple statistical tests to assess correlation and agreement between caregiver-child pair responses. Correlation was assessed to determine the association between child and caregiver responses -- if child score goes up, caregiver score goes up as well. However, this does not assess level of agreement between responses. There is a possibility that child and caregiver scores are correlated but may also have a large difference in their level of agreement. In such instances, it is recommended to assess both correlation and agreement between scores [39]. Based on these approaches, it was found that the responses did not differ significantly between caregivers and their children. This means that community-based assessment of child functioning and disability could be done by interviewing either caregivers or children with disability. However, disability assessment needs to be contextualized, and it is important to understand relevant caregiver (education, occupation), household (wealth quintile, income) and social (family structure) factors that may impact a child's disability. Given that caregivers are more informed about such factors and the impact these have on their child, family and household, it is probably important to interview caregivers in addition to child interviews to obtain a better understanding of contextual factors [40].

The agreement between caregiver and children was more for mild and moderate disability compared to severe disability. This could reflect that children with severe disability adapt to their limitation and are able to cope with functional limitation and ability to participate. Hence, their perception of disability might be less severe compared to the perception of their caregivers. This may also imply the underlying issue related to how caregivers perceive extent of disability in their children. Therefore, it is important to consider both child and caregiver perspectives to get a better understanding of level of disability among children [41].

In addition, it was also interesting to note that agreement for domains like anxiety was less compared to other physical domains like vision and hearing. This was also observed by Massey et al [21]. This is an interesting observation with several different explanations. First is related to understanding of words anxiety and depression. In most Western countries, these words are traditionally used for clinical diagnosis of these conditions, however, in many LMICs, the expression of these words is more to express underlying mood of an individual for example feeling anxious before starting school [42]. This area needs further exploration through administration of clinical assessments for anxiety and depression and qualitative assessment to understand mental health well-being of these children. The expression of being anxious or depressed could also be associated with other types of disabilities that a child may have, or it could be an expression of parental anxiety and depression associated with child's disability and its impact on the parents. These are important areas to explore in pediatric mental health and well-being and need further exploration in this population.

Exploration of the distribution of disability scores based on selected child characteristics showed that scores did not vary based on the child's sex. This observation is specific to IM-HDSS, and it may differ if the same study is conducted in other parts of Uganda or other LMICs. Reporting any physical limitation is considered a taboo in many parts of the world, especially when the child is a girl [6]. Social norms and culture have a major influence on how "disability" is perceived in many parts of the world, especially LMICs where individuals with disability are isolated from society [6]. C-DAS is thus designed in a way to avoid using the word "disability" in its questions; it focuses more on assessing limitation rather than labeling children with disability [19].

This study showed that scores were higher for older children, probably because older children are more aware of their limitation and, hence, are able to communicate with their caregiver about their disability [43]. In addition, C-DAS covers both functional and developmental domains, and since older children have mostly achieved their developmental milestones, the level of disability or limitation is better assessed in older children [43]. However, this theory needs to be explored in other contexts and through longitudinal studies.

Higher scores were also reported for children not enrolled in school. This was consistent across caregiver and child responses; this possibly indicates that the severity of the level of disability hampers enrollment of these children into school. Although this study did not conduct environmental assessment within schools, it does indicate the need to understand factors that prevent school enrollment of children with disabilities. Potential reasons may include lack of accommodations (trained teachers, books in braille, ramps etc.) in schools for children with disabilities [44]. Another potential reason could be the attitude of teachers and peers, which act as a barrier to integration of students with disabilities into the school environment [44]. In addition, this study did not collect data from teachers and school administration to assess the factors associated with lack of enrollment among children with high disability scores. This is an important area of future work and needs to be considered to ensure a holistic approach to addressing disability in children. Children with physical disability can receive education in mainstream schools, and the C-DAS tool has been shown to provide useful information regarding disability severity [45].

Some strengths of this study include that this is the first time that child interviews were conducted at IM-HDSS. Disability is considered a taboo, and until recently, many caregivers had not registered their disabled children with the IM-HDSS staff. However, over the past few years, IM-HDSS has worked to collect routine data on these children. Combined with the C-DAS tool, the core IM-HDSS data has the potential to identify needs of these children and guide the local district health office to develop and implement strategies to improve the health and well-being of children with disabilities at the IM-HDSS. Second, administration of C-DAS did not require field staff to have medical and clinical knowledge and background. This supports the broad application of C-DAS in communities, especially in LMICs where standardized methods to assess disability are lacking and thus lead to data scarcity. Third, translation of the child version of C-DAS did not require any changes in the questions and was at the level of understanding of children 11-17 years of age. This shows that the wording of questions and their framing were easy to follow in the translated version. This is reassuring as it helped in implementation of C-DAS without major changes in questions and will help in making comparisons with different contexts in future studies on disabilities. Fourth, this study utilized different statistical tests to assess correlation and agreement between responses of caregiver and child pairs to get a better understanding of association between responses [39].

One of the limitations of the study is that the results of this study may not generalize to the whole of Uganda and other LMICs. Disability needs to be contextualized based on individual, family, household and social factors. These findings may vary if the study is conducted again at the IM-HDSS because disability is a dynamic process and perception of disability among caregiver-child pairs may change as the child learns to cope with their disability or recovers from their disability. Second, the major issue with child interviews was the non-availability of children during daytime and weekdays. The team approached these children during evenings and weekends and made up to three attempts to complete child interviews. Third, interviews with children have their own ethical issues since the issue of disability may cause anxiety among children. Therefore, C-DAS has questions which do not mention the word “disability”; instead, the questions assess limitations for the 13 domains, which are less likely to cause anxiety in children. Fourth, this study did not have a follow-up using clinical assessment method to verify the information shared by caregiver-child pairs. However, significant agreement on most domains show that the self-reported limitations by caregivers and children were similar. Fifth, selected characteristics were explored in this study; however, due to time constraints, lived experiences of caregiver-child pairs were not recorded to explore various aspects of disability and their impact on their daily living.

Perception about disability is developed through family interactions and surrounding environment. It impacts and shapes a child’s ability to receive education and employment opportunities later in life. Therefore, it is important to understand the lived experiences and environment at home and school for holistic understanding of a child and their level of disability. It is thus important to get multiple perspectives to assess child functioning. One is the *insider perspective,* which means how a child perceives their level of functioning. This is based on their own experience of living with disability. Second is the *outsider perspective,* which means how caregivers perceive their child’s disability and level of functioning and is based on household and social factors [41]. For example, a school-going child with lower limb disability uses a wheelchair to go to school. This child has learned to manage his commute to school despite his limitation and has the opportunity to get an education. However, from the caregiver perspective, sending a child to school in a wheelchair might have required mobilization of financial resources to ensure that the child has access to school. Thus, it is important to give children the opportunity to report their functioning. This helps to empower children as reporters of their health and well-being. Their understanding of their health can form the basis of community-based interventions, giving these children the voice to help them integrate in to their society.

Conclusion

This study shows significant agreement in self-reported caregiver-child pair disability score using the C-DAS tool. This was observed for both overall and domain-specific disability scores. This means that children can report their limitations using a standardized tool like C-DAS. However, in order to contextualize disability within a child's environment, it is recommended to also interview caregivers, as they can provide more information on family and household-related factors of which a child may not be aware. This will provide a better and deeper understanding of disability in children.

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Tables

Table 3.1: Demographic characteristics of children with disability between 11-17 years of age (n=181)

Child characteristics n (%)	
Average age in years (mean ± SD)	13.91 ± 1.89
Age groups	
11-14 years	108 (59.67)
15-17 years	73 (40.33)
Sex	
Male	102 (56.35)
Female	79 (43.65)
Immunization status	
Complete	66 (36.46)
Not complete	105 (58.01)
No vaccination done	10 (5.52)
Currently in school (yes)	141 (77.90)
Have a primary caregiver (yes)	162 (89.50)
Family system	
Single parent	21 (11.60)
Nuclear	92 (50.83)
Joint	68 (37.57)
Household wealth quintile (n=173)	
Poorest	54 (31.21)
Poorer	29 (16.76)
Poor	42 (24.28)
Less poor	35 (20.23)
Least poor	13 (7.51)

Table 3.2: Demographic characteristics of primary caregivers of children (11-17 years of age) with disability (n=162)

Caregiver characteristics n (%)	
Caregiver relation with child	
Mother	109 (60.22)
Father	23 (12.71)
Grandparent(s)	15 (8.29)
Uncle/Aunt	5 (2.76)
Sibling	2 (1.10)
Others	8 (4.42)
Average age (mean ± SD)	42.16 ± 11.07
Sex	
Male	30 (18.52)
Female	132 (81.48)
Education level	
None	24 (14.81)
Primary	106 (65.43)
Lower secondary	26 (16.05)
Upper secondary	1 (0.62)
Other (university/vocational)	5 (3.09)
Occupation	
Farmer	95 (58.64)
Shopkeeper	42 (25.93)
Housewife	12 (7.41)
Professional	5 (3.09)
Boda boda driver	2 (1.23)
Unemployed	1 (0.62)
Others	5 (3.09)

Table 3.3: Mean, median, minimum and maximum scores based on disability severity category

Disability categories	Caregiver					Child				
	n	Mean ± SD	Median (IQR)	Minimum score	Maximum score	n	Mean ± SD	Median (IQR)	Minimum score	Maximum score
Overall	181	5.36 ± 5.63	4 (2-7)	0	35	181	5.45 ± 5.34	4 (3-6)	0	32
None	12	0 ± 0	0 (0)	0	0	4	0 ± 0	0 (0)	0	0
Mild	85	3.05 ± 1.72	3 (2-4)	1	9	93	2.96 ± 1.61	3 (2-4)	1	10
Moderate	63	6.16 ± 3.63	6 (3-7)	2	18	69	6.64 ± 3.93	6 (4-7)	2	21
Severe	21	15.43 ± 9.11	14 (7-23)	3	35	15	16.87 ± 8.82	18 (8-23)	5	32

Table 3.4: Mean, median, minimum and maximum scores by child sex, child age category, school enrollment status and wealth quintile

Characteristics	n	Caregiver				Child			
		Mean ± SD	Median (IQR)	Minimum score	Maximum score	Mean ± SD	Median (IQR)	Minimum score	Maximum score
Child sex									
Male	102	5.41 ± 5.31	4 (2-7)	0	25	5.41 ± 5.33	4 (2-6)	0	29
Female	79	5.30 ± 6.03	4 (2-6)	0	35	5.49 ± 5.38	4 (3-6)	0	32
Child age group									
11-14 years	108	4.75 ± 5.01	3 (2-6)	0	26	4.99 ± 5.08	4 (2-6)	0	29
15-17 years	73	6.27 ± 6.35	4 (3-7)	0	35	6.12 ± 5.67	4 (3-7)	0	32
School enrollment									
Yes	142	3.93 ± 2.78	3 (2-5)	0	14	4.14 ± 2.59	4 (2-5)	0	12
No	39	10.59 ± 9.24	7 (3-18)	0	35	10.21 ± 8.97	6 (3-18)	1	32
Wealth quintile									
Poorest	53	4.43 ± 4.63	3 (2-5)	0	26	4.43 ± 4.34	3 (2-5)	0	25
Poorer	28	5.04 ± 4.59	3 (2-7)	0	18	5.43 ± 4.49	4.5 (3-6)	0	19

Characteristics	n	Caregiver				Child			
		Mean ± SD	Median (IQR)	Minimum score	Maximum score	Mean ± SD	Median (IQR)	Minimum score	Maximum score
Poor	41	5.37 ± 4.66	4 (3-7)	0	24	5.32 ± 5.15	4 (3-5)	1	29
Less poor	31	6.03 ± 7.67	4 (1-7)	0	35	6.19 ± 6.99	4 (2-7)	0	32
Least poor	13	8.23 ± 8.00	5 (3-9)	1	25	7.85 ± 6.56	5 (3-12)	1	22

Table 3.5: Agreement between caregiver and child response by the overall functional disability category

Child response	**Caregiver response**				
	None	**Mild**	**Moderate**	**Severe**	**Total**
None	4 (33.33)	0 (0)	0 (0)	0 (0)	4
Mild	7 (58.33)	71 (83.53)	12 (19.05)	3 (14.29)	93
Moderate	1 (8.33)	14 (16.47)	50 (79.37)	4 (19.05)	69
Severe	0 (0)	0 (0)	1 (1.59)	14 (66.67)	15
Total	12	85	63	21	181

p-value <0.001

Table 3.6: Overall and domain specific agreement between caregiver and child based on child sex, child age group, child school status and household wealth quintile

Domains	Overall	Child sex		Child age (years)		Child in school		Wealth quintile				
		Male	Female	11-14	15-17	Yes	No	Poorest	Poorer	Poor	Less poor	Least poor
Overall												
Observed agreement (%)	76.80	75.49	78.48	80.56	71.23	78.01	72.50	73.58	71.43	90.24	70.97	69.23
Expected agreement (%)	38.51	36.67	41.24	38.63	38.43	43.18	31.87	46.92	35.71	41.64	30.18	36.09
Kappa statistic (Standard Error)	0.623 (0.054)	0.613 (0.069)	0.634 (0.085)	0.683 (0.069)	0.533 (0.085)	0.613 (0.067)	0.596 (0.107)	0.502 (0.108)	0.556 (0.129)	0.833 (0.124)	0.584 (0.109)	0.519 (0.196)
Vision												
Observed agreement (%)	90.61	91.18	89.87	93.52	86.30	89.36	95.00	90.57	92.86	82.93	93.55	92.31
Expected agreement (%)	58.37	59.41	57.03	58.89	57.59	56.95	64.00	53.68	75.51	56.93	52.13	54.44
Kappa statistic (Standard Error)	0.774 (0.068)	0.783 (0.091)	0.764 (0.101)	0.842 (0.087)	0.677 (0.107)	0.753 (0.077)	0.861 (0.142)	0.796 (0.123)	0.708 (0.189)	0.604 (0.129)	0.865 (0.163)	0.831 (0.273)
Hearing												
Observed agreement (%)	85.08	85.29	84.81	87.96	80.82	85.11	85.00	83.02	85.71	92.68	74.19	84.62
Expected agreement (%)	47.93	50.98	44.43	48.47	47.42	48.64	45.62	46.24	39.67	58.00	45.68	52.66
Kappa statistic (Standard Error)	0.714 (0.057)	0.700 (0.078)	0.727 (0.084)	0.766 (0.072)	0.635 (0.094)	0.710 (0.067)	0.724 (0.112)	0.684 (0.105)	0.763 (0.141)	0.826 (0.127)	0.525 (0.125)	0.675 (0.208)
Walking												
Observed agreement (%)	88.95	87.25	91.14	90.74	86.30	90.78	82.50	92.45	96.43	82.93	83.87	92.31

Domains	Overall	Child sex		Child age (years)		Child in school		Wealth quintile				
		Male	Female	11-14	15-17	Yes	No	Poorest	Poorer	Poor	Less poor	Least poor
Expected agreement (%)	54.25	49.30	61.85	58.26	48.92	62.99	33.19	74.65	52.17	48.96	46.31	39.64
Kappa statistic (Standard Error)	0.759 (0.052)	0.749 (0.070)	0.768 (0.081)	0.778 (0.068)	0.732 (0.082)	0.751 (0.062)	0.738 (0.101)	0.702 (0.104)	0.925 (0.149)	0.666 (0.114)	0.700 (0.119)	0.873 (0.178)
Self-care												
Observed agreement (%)	94.48	94.12	94.94	95.37	93.15	95.74	90.00	96.23	96.43	97.56	93.55	76.92
Expected agreement (%)	72.75	69.90	76.89	75.79	68.89	83.01	45.44	76.29	62.24	88.34	71.28	56.80
Kappa statistic (Standard Error)	0.797 (0.059)	0.805 (0.084)	0.781 (0.080)	0.809 (0.073)	0.800 (0.102)	0.750 (0.074)	0.817 (0.112)	0.841 (0.109)	0.905 (0.153)	0.791 (0.120)	0.775 (0.125)	0.466 (0.211)
Communication												
Observed agreement (%)	95.03	93.14	97.47	96.30	93.15	97.87	85.00	96.23	96.43	97.56	96.77	92.31
Expected agreement (%)	76.33	75.25	77.89	82.68	67.63	91.79	39.81	90.85	74.62	77.63	79.08	52.66
Kappa statistic (Standard Error)	0.790 (0.052)	0.723 (0.073)	0.886 (0.078)	0.786 (0.070)	0.788 (0.080)	0.741 (0.073)	0.751 (0.107)	0.588 (0.094)	0.859 (0.151)	0.891 (0.109)	0.846 (0.122)	0.838 (0.206)
Learning												
Observed agreement (%)	83.98	85.29	82.28	87.04	79.45	85.11	80.00	83.02	85.71	87.80	87.10	69.23
Expected agreement (%)	51.23	52.61	49.74	54.66	46.86	58.41	35.00	56.67	50.51	52.35	50.35	41.42
Kappa statistic (Standard Error)	0.671 (0.059)	0.690 (0.077)	0.647 (0.090)	0.714 (0.076)	0.613 (0.091)	0.642 (0.079)	0.692 (0.102)	0.608 (0.114)	0.711 (0.149)	0.744 (0.129)	0.740 (0.127)	0.475 (0.194)
Remembering												
Observed agreement (%)	85.08	82.35	88.61	87.04	82.19	87.23	77.50	83.02	85.71	87.80	93.55	92.31

Domains	Overall	Child sex		Child age (years)		Child in school		Wealth quintile				
		Male	Female	11-14	15-17	Yes	No	Poorest	Poorer	Poor	Less poor	Least poor
Expected agreement (%)	55.38	56.74	53.82	59.91	49.60	63.28	35.75	62.23	55.87	54.02	53.80	39.64
Kappa statistic (Standard Error)	0.666 (0.059)	0.592 (0.076)	0.753 (0.092)	0.677 (0.076)	0.647 (0.092)	0.652 (0.081)	0.650 (0.100)	0.550 (0.117)	0.676 (0.151)	0.735 (0.124)	0.860 (0.125)	0.873 (0.200)
Concentrating												
Observed agreement (%)	88.95	86.27	92.41	88.89	89.04	90.07	85.00	88.68	85.71	87.80	96.77	69.23
Expected agreement (%)	66.65	63.28	71.08	69.56	62.54	76.67	41.88	79.35	59.95	65.73	60.04	48.52
Kappa statistic (Standard Error)	0.669 (0.058)	0.626 (0.076)	0.737 (0.085)	0.635 (0.075)	0.707 (0.090)	0.574 (0.084)	0.742 (0.108)	0.452 (0.110)	0.643 (0.151)	0.644 (0.132)	0.919 (0.130)	0.402 (0.203)
Accepting change												
Observed agreement (%)	90.61	92.16	88.61	93.52	86.30	92.91	82.50	96.23	92.86	90.24	90.32	76.92
Expected agreement (%)	69.91	68.80	71.29	75.24	62.71	80.95	42.50	76.65	74.49	68.95	66.39	50.89
Kappa statistic (Standard Error)	0.688 (0.059)	0.749 (0.078)	0.603 (0.090)	0.738 (0.077)	0.633 (0.092)	0.628 (0.083)	0.696 (0.113)	0.838 (0.123)	0.720 (0.149)	0.686 (0.131)	0.712 (0.125)	0.530 (0.177)
Controlling behavior												
Observed agreement (%)	86.74	88.24	84.81	87.04	86.30	90.78	72.50	92.45	89.29	85.37	83.87	92.31
Expected agreement (%)	71.64	70.07	73.71	76.10	65.47	82.62	43.19	82.34	80.10	68.53	64.41	52.66
Kappa statistic (Standard Error)	0.533 (0.061)	0.607 (0.076)	0.422 (0.101)	0.458 (0.081)	0.603 (0.092)	0.470 (0.082)	0.516 (0.111)	0.573 (0.104)	0.462 (0.136)	0.535 (0.125)	0.547 (0.131)	0.838 (0.206)
Making friends												

Domains	Overall	Child sex		Child age (years)		Child in school		Wealth quintile				
		Male	Female	11-14	15-17	Yes	No	Poorest	Poorer	Poor	Less poor	Least poor
Observed agreement (%)	95.03	95.10	94.94	96.30	93.15	97.16	87.50	96.23	96.43	92.68	96.77	92.31
Expected agreement (%)	78.66	76.74	81.19	84.26	70.95	94.42	40.00	85.76	80.48	75.55	76.69	62.72
Kappa statistic (Standard Error)	0.767 (0.053)	0.789 (0.071)	0.731 (0.082)	0.765 (0.067)	0.764 (0.085)	0.492 (0.057)	0.792 (0.104)	0.735 (0.107)	0.817 (0.161)	0.700 (0.109)	0.862 (0.139)	0.794 (0.231)
Anxiety												
Observed agreement (%)	69.61	74.51	63.29	71.30	67.12	68.79	72.50	77.36	71.43	70.73	58.06	53.85
Expected agreement (%)	33.60	32.68	35.23	33.84	33.91	35.46	29.13	39.62	37.63	32.72	30.59	30.77
Kappa statistic (Standard Error)	0.542 (0.049)	0.621 (0.065)	0.433 (0.074)	0.566 (0.065)	0.503 (0.074)	0.517 (0.059)	0.612 (0.095)	0.625 (0.099)	0.542 (0.124)	0.565 (0.101)	0.396 (0.110)	0.333 (0.164)
Depression												
Observed agreement (%)	73.48	75.49	70.89	76.85	68.49	73.05	75.00	75.47	82.14	65.85	70.97	69.23
Expected agreement (%)	34.83	32.62	39.42	34.33	37.08	38.25	26.00	36.74	43.49	33.55	30.07	42.60
Kappa statistic (Standard Error)	0.593 (0.05)	0.636 (0.066)	0.519 (0.075)	0.648 (0.065)	0.500 (0.078)	0.564 (0.060)	0.662 (0.090)	0.612 (0.096)	0.684 (0.140)	0.486 (0.101)	0.585 (0.113)	0.464 (0.175)

Figures

Figure 3.1: Sampling frame and enrollment of caregiver and child pairs (n=181)

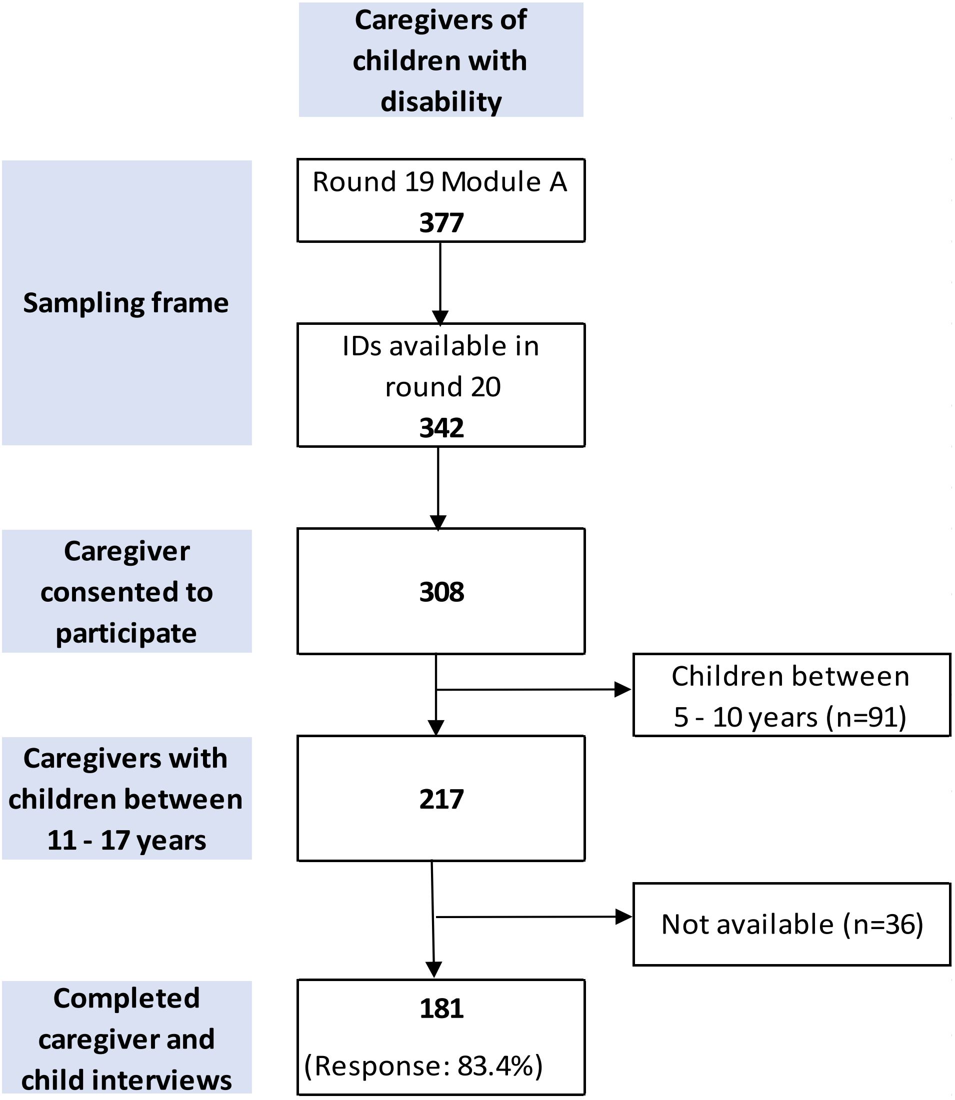


Figure 3.2: **Distribution of disability categories based on caregiver and child responses**

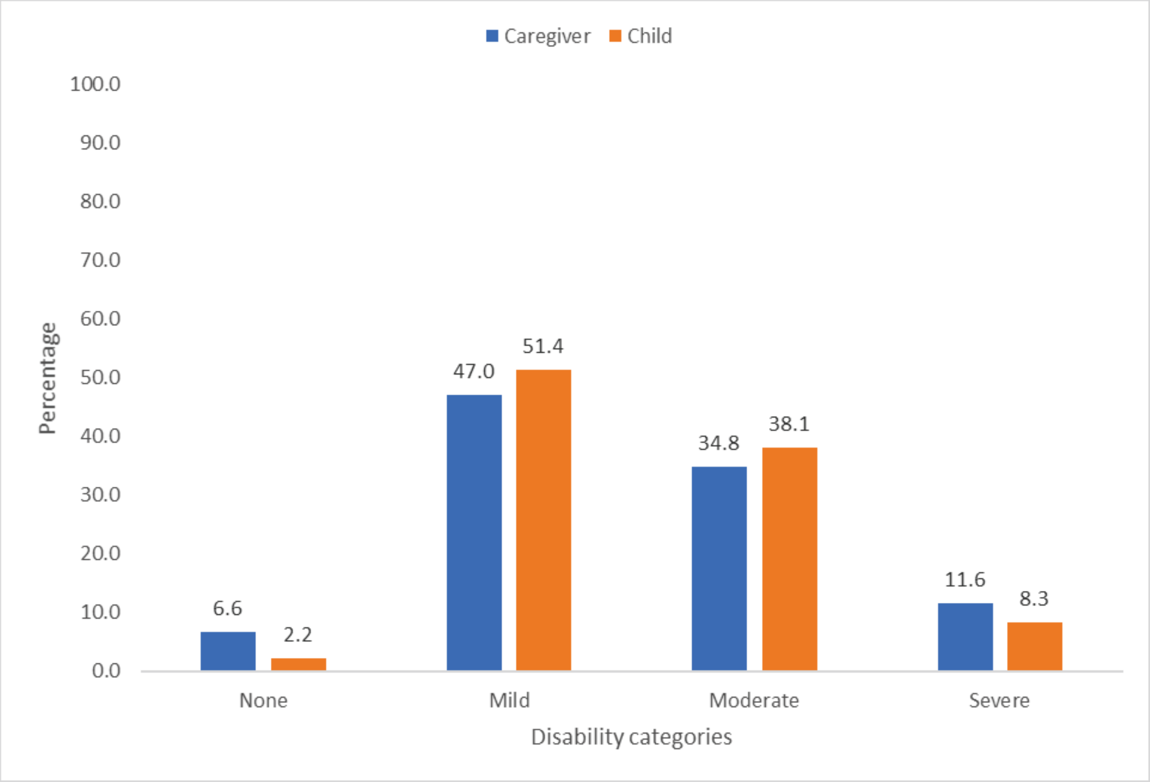


Figure 3. 3: Scatter plot of caregiver and child disability scores

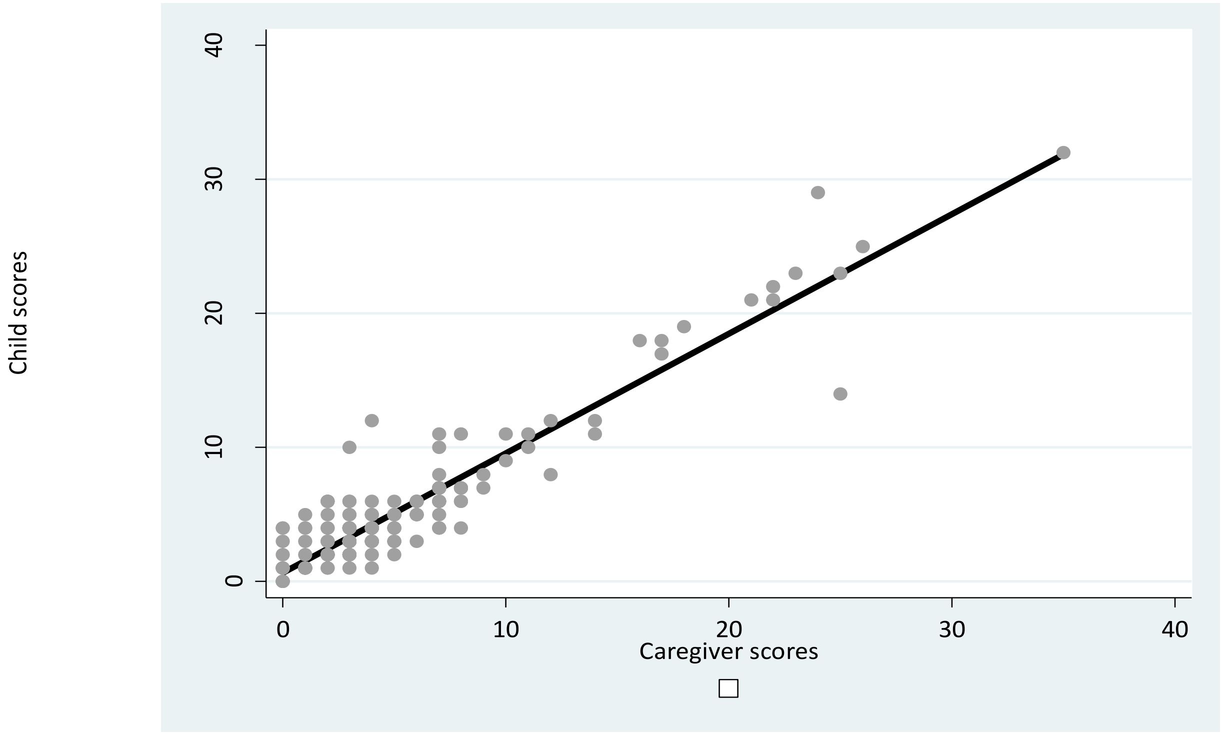


Figure 3.4: Bland Altman plot of difference between caregiver and child disability scores versus the average of the caregiver and child scores

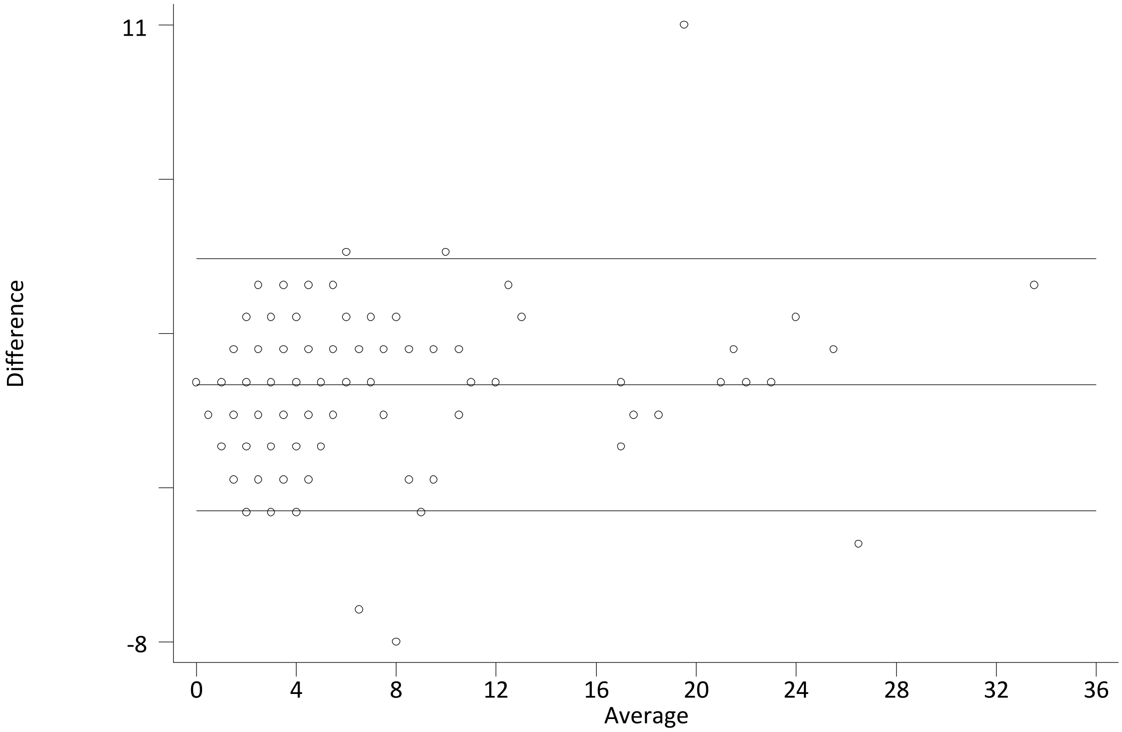
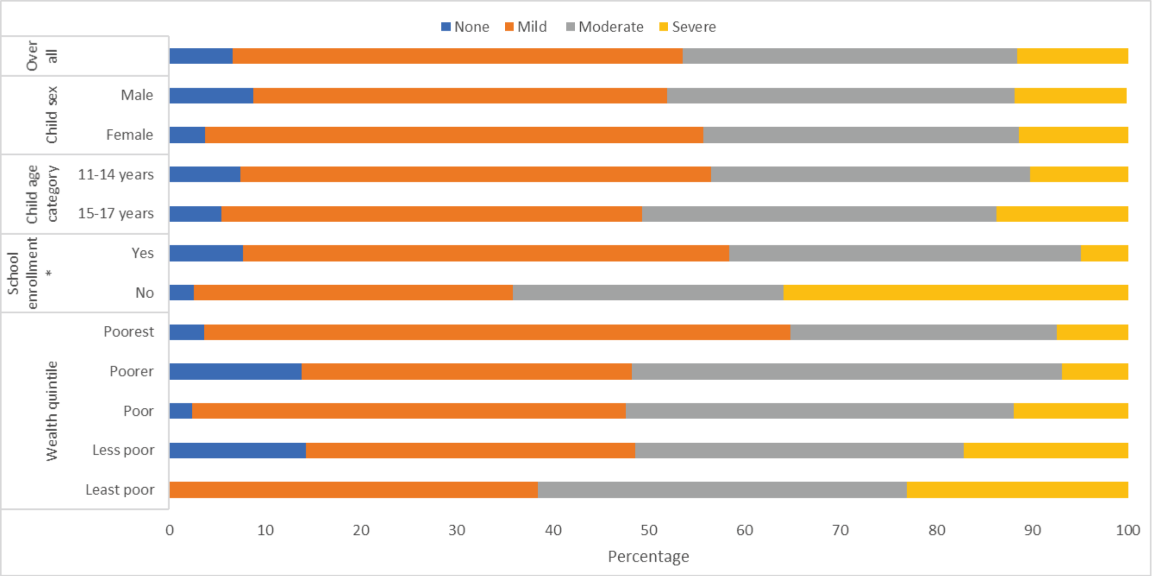
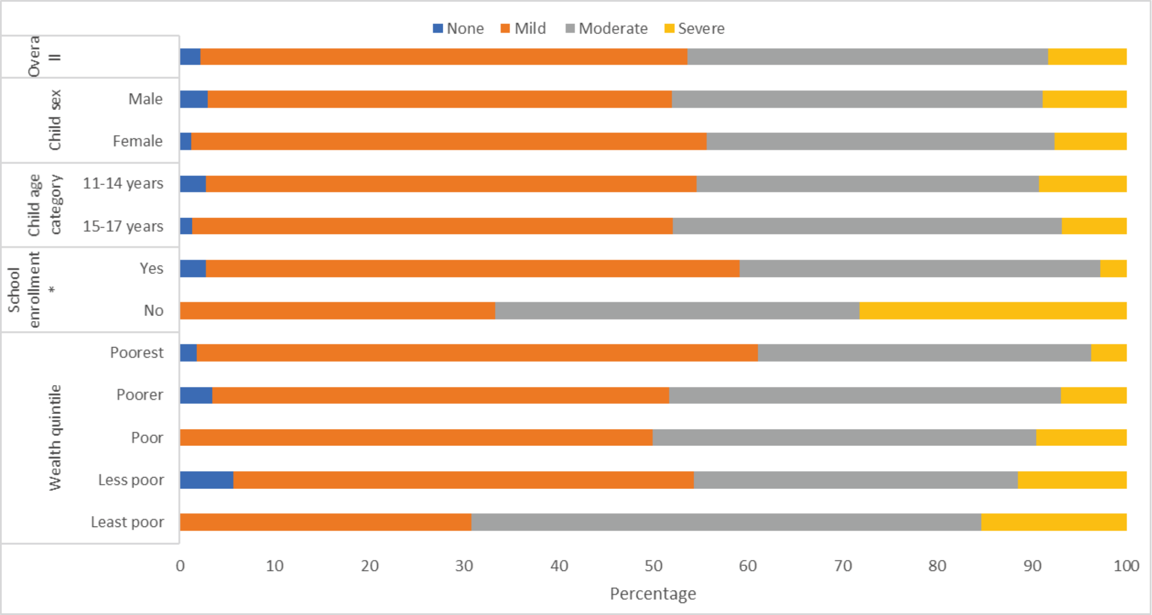


Figure 3.5: Caregiver and Child Likert disability categories overall and stratified by child sex, child age category, child school enrollment and wealth quintile

a) Caregiver responses



b) Child responses



*p-value <0.001

Chapter 4: Factors associated with child disability at the Iganga-Mayuge Health and Demographic Surveillance Site in Uganda (Paper 3)

Abstract

Introduction: There is scarcity of data on children with disabilities living in low-and-middle-income countries, including Uganda. This study describes disability prevalence by disability categories and explores factors associated with different disability categories. It highlights the value of using a standardized, easy-to-use tool to determine disability in children and contextualizing disability in children in light of their developmental needs.

Methods: A prospective cross-sectional study was conducted between September 2018 – January 2019 at the Iganga-Mayuge Health and Demographic Surveillance Site in Uganda. Respondents were caregivers of children between 5 to 17 years of age and were administered an in-depth child disability assessment (C-DAS) tool, which recorded responses on a 4-point Likert scale, with scores ranging from 0 to 39. The outcome variable, disability, was defined as an ordered categorical variable with three categories – mild disability, moderate disability, and severe disability. Generalized ordered logit model was applied to explore factors associated with disability categories. The independent variables included in the model were the child’s age, sex, immunization status, school enrollment, primary caregiver status, age of mother at child’s birth, family system, family size and household wealth quintile.

Results: Out of 1,842 caregivers approached for the study, 1,439 (response: 78.1%) agreed to participate in the study. Out of these 1,439, some level of disability was reported by 67.89% (n=977) of caregivers. Of these 977 children with disability, 48.01% (n=692) had mild disability and 15.84% (n=228) had moderate disability, while 3.96% (n=57) had severe disability. The mean (SD) score for mild disability was 2.22 ± 1.17, with a median of 2. The mean and median for moderate disability was 5.26 ± 3.28 and 4 (3-6), and for severe disability, they were 14.23 ± 9.51 and 12 (6-22). The most common disabilities reported were depression (54.83%) and anxiety (50.87%). According to the generalized ordered logit model, completion of immunization status and school enrollment were statistically and significantly associated with disability when controlled for a child's age, sex, having a primary caregiver, age of mother at child's birth, family system, family size and household wealth quintile.

Conclusion: This study suggests association between incomplete immunization status and school enrollment for children with disability. This is an area for further exploration.

Introduction

The World Health Organization (WHO) and United Nations Children's Fund (UNICEF) regard disability as a human rights issue. Across the globe, disability is considered a major development priority, especially in low-and-middle-income countries (LMICs) [1, 2]. Five out of 17 Sustainable Development Goals (SDGs) specifically focus on disability: Goal 4 focuses on inclusive education; Goal 8 on equal and inclusive employment opportunities; Goal 10 on social, economic and political inclusion of individuals with disabilities; Goal 11 on accessible cities, transport services and public spaces; and Goal 17 emphasizes the importance of high quality, reliable and timely availability of disability data to monitor the progress of other disability-related SDGs [3, 4].

Disability is a complex phenomenon. Based on the International Classification of Functioning (ICF), disability stems from dynamic interactions between impairments at the body level, within the context of an individual’s health condition and environment, and limitation in an individual’s ability to participate and perform activities [5]. However, measurement of disability at the population level has been particularly problematic due to the complexity of the disability phenomenon [6-8]. Furthermore, assessment of disability among children becomes even more complex, as it is complicated by their growth and developmental issues. As a result, disability among children is not well understood in LMICs from a public health perspective. The WHO modified the ICF framework and adapted it for children and youth (ICF-CY) to better understand the needs of children with disability as they grow [6, 8]. The framework was proposed in 2007 to account for disability in children, which differs from adults in terms of their anatomy and body functioning. The needs and requirements of children change as they go through the various stages of development, especially during early years of life.

One of the main problems in measuring disability among children has been the lack of standardized, easy-to-use instruments that could be used to measure child disability [9, 10]. This has led to the lack of comparable burden estimates and hampers the development and evaluation of appropriate policies and programs to address the needs of children with disabilities [9]. To address this gap, UNICEF and the Washington Group (WG) developed a disability tool for assessing child functioning [11]. The tool is based on the ICF-CY framework and assesses child functioning among children 5-17 years of age through 24 questions across 13 domains: vision, hearing, walking, self-care, communication, learning, remembering, concentration, accepting change, behavior control, making friends, anxiety and depression [12, 13]. The Washington Group/UNICEF tool for 5-17-year-old children was validated in school settings in Fiji in 2015, with the objective to determine if the UNICEF/Washington Group tool can be used by teachers to identify children at risk of disability for timely referral for further assessment and interventions [14, 15].

Estimates from the WHO put the global prevalence of disability at 15%, or one in seven people in the world; globally, there are about 93 million (one in 20) disabled children less than 15 years of age living with moderate or severe disability [1, 2]. About 90% of these children live in LMICs [1, 2, 8, 10, 16]. The estimated prevalence of moderate to severe disability in the African region is 15.3% [10]. The main causes of disability in the African region include infectious diseases such as polio and leprosy; noncommunicable diseases like congenital malformation and cerebral palsy; injuries such as road traffic crashes; and health-services errors such as inappropriate treatment [17]. However, it is important to point out that the World Report on Disability acknowledges that these numbers are an underestimation and that reliable data on disability – prevalence, type, and causes- are lacking for most LMICs [10].

Uganda is a nation of 42.8 million people located in East Africa [18]. The population of the country is young, with a median age of 15.8 years and life expectancy of 65.7 years at birth [19, 20]. The burden of disease in children between 5-19 years of age is still mainly attributed to communicable diseases like HIV, malaria, and diarrhea. However, non-communicable diseases like skin diseases and asthma, injuries from road crashes, drowning and falls are also contributing to the disease burden [19]. This "triple burden" of diseases is crippling for a fragile economy when people must pay for their own healthcare. Furthermore, in countries with disabilities occurring in youth with a lack of public rehabilitation facilities, the burden of care falls on families.

The 2002 Uganda Population and Housing Census estimated that there are about 2% disabled children in Uganda, and according to the 2014 census, 12.5% of individuals in Uganda have at least one type of disability. Estimates from the UNICEF and the Ministry of Gender of Uganda put this number at 2.5 million disabled children (13% of the population) in the year 2014 [21-23]. Specific to the disabled population in Uganda, as per the 2002 census, 30% of the disabled population comprised of children between 0-17 years of age, and about 42% of these had a physical disability [24]. Previously, researchers in Uganda developed and applied instruments to assess disability among adults at the Iganga-Mayuge Health and Demographic Surveillance Site (IM-HDSS) [25, 26]. To overcome socio-cultural issues impeding the identification of individuals with disability, the Washington Group on Disability Statistics' approach was used to identify individuals with specific limitations in key areas of functioning such as vision, hearing, upper and lower limb mobility, self-care, and communication [25-27]. Through this approach, the prevalence of disability in adults was found to be 9.4% in IM-HDSS, with difficulty in vision being the most common type of disability. Being male, older age, and lower socioeconomic status (SES) were associated with physical disability [25]. Disabled adults were found to have greater difficulty in getting around, completing life activities, and participating in society [26]. One interesting finding from this study was that many of these limitations had been life-long, implying that they began in childhood; this study will expand such measurement efforts to children and will generate data to address the gap that exists in disability studies in LMICs.

The overall goal of this paper is to estimate childhood disability prevalence by disability category and assess factors associated with disability in children between 5-17 years of age living at IM-HDSS. More specifically, the study describes overall and domain-specific functioning assessed using the child disability assessment tool (C-DAS) and examines the prevalence and extent of disability in this child population by various child, caregiver and household characteristics. The hope is to understand the burden of disability among children living at IM-HDSS and examine child and household-level factors associated with disability among children.

Methods

Study site

IM-HDSS is in Eastern Uganda and covers the districts of Iganga and Mayuge. IM-HDSS is part of the International Network for the Demographic Evaluation of Populations and Their Health (INDEPTH) and was established in 2005 as a field research site for Makerere University [28-30]. IM-HDSS follows over 89,000 individuals living in about 18,000 households. It conducts census-level data collection two times a year on births, deaths, pregnancies and their outcomes, and in-and out-migrations [30]. In addition, the site also periodically collects data on access to health services, causes of death, relevant socioeconomic and education data, non-communicable diseases and injuries [25]. Since 2005, 21 rounds of data collection have been completed as of June 2019 [28].

This study was nested within an ongoing parent study to pilot electronic data collection for injuries and disability in IM-HDSS. The main aim of the parent study was to strengthen local capacity to employ cutting-edge information and communication technology (ICT) for research and training on trauma, injuries, and disability. The purpose of the parent study was to pilot electronic versions of injury and disability data modules. These modules were implemented in paper format during previous studies conducted at IM-HDSS between 2008 – 2009 and subsequently were integrated into IM-HDSS. So far injury and disability modules have been implemented in three IM-HDSS rounds [25, 26]. The IM-HDSS relies predominantly on paper-based data collection, [31, 32] and the process from data collection to entry into a database and analysis involves multiple steps [31-33]. However, at the time of data collection, the site was transitioning to electronic data collection for efficient and timely availability of data for analysis. A pilot using tablet-based data collection was conducted in round 19 (April - June 2017), and this provided the sampling frame for the current study on child disability.

Study tool

Two tools were implemented as part of this study. Their details are provided below:

Short set questions on disability (Module A)

This study used a modified version of the Washington Group short-set (Module A) [25, 34]. It has 6 questions intended for a brief disability assessment of individuals 5 years and older. Each question uses a 4-level Likert scale (0=no difficulty, 1=some difficulty, 2=a lot of difficulty and 3=cannot do at all), with scores ranging from 0 – 18, such that the higher the score, the greater the difficulty. It focuses on activity limitations to identify individuals with disability and covers six domains: vision, hearing, walking, upper body mobility, self-care and communication. Previous studies conducted at IM-DSS and elsewhere found that it takes approximately 10 minutes to administer, and the questions are well understood by respondents [25, 27, 34, 35]. The main purpose of this tool is to identify individuals who are at potential risk of limitation in their basic life activities (e.g., walking, hearing, and vision). The WG previously administered Module A during field testing of C-DAS in Serbia [36].

It is important to note that Module A had already been translated into the local language, Lusoga, and was implemented at IM-HDSS for disability assessment in individuals 5 years and above at the household level [25, 26]. Module A was first introduced at the IM-HDSS in 2009, and since then it has been implemented three more times (2011, 2014 and 2017). Currently, only adults (18 years and older) identified to have disability based on Module A are followed-up using a more detailed disability assessment tool to further characterize the implications of their activity limitation on different life domains. The WHO Disability Assessment Schedule 2.0 (WHODAS 2.0) is used for this purpose and was first implemented at the IM-HDSS in 2011, with another round conducted in 2017 [25, 26].

The data collection in round 19 (April – July 2017) was the first time IM-HDSS piloted electronic data collection of Module A and WHODAS 2.0. Since the WHODAS is only applied to individuals over 18 years, disability among children has not been previously studied at the IM-DSS. The current study focuses on children between 5-17 years of age and is therefore an extension of the current disability work being done at IM-HDSS to allow for a better understanding of disability in this younger age group. Data from Module A was used for validating C-DAS (see Paper 1 for details).

Child Disability Assessment tool (C-DAS)

This study utilizes a detailed Child Disability Assessment (C-DAS) tool developed by the UNICEF/Washington Group on Disability Statistics [12]. C-DAS focuses on basic, everyday activities and has expanded its set of questions to assess functioning of a child. It can be administered at the national level and allows for comparisons across time and countries [12]. It comprises 24 questions, with responses on a 4-level Likert scale (0=no difficulty, 1=some difficulty, 2=a lot of difficulty and 3=cannot do at all). These questions result in 13 domains, with scores ranging from 0 – 39; the higher the score, the greater the disability. It takes about 20-25 minutes to complete [13]. The 13 C-DAS domains include vision, hearing, walking, self-care, communication, learning, remembering, concentration, accepting change, behavior, making friends, feeling anxiety, and feeling depression [13].

Additional data collected during this study included information on household head and members, household wealth quintile, child and caregiver demographics (age, gender, education), caregiver education and employment status, child birth, vaccination, sibling information, school and work history, and health seeking practices. The C-DAS and additional questions were translated to Lusoga and back translated to English.

Study design and respondents

This was a *cross-sectional study* conducted between September 2018 – January 2019. Respondents were caregivers of children between 5 to 17 years of age. At the time of the study, there were 35,062 children between the ages of 5-17 years who were residing in the IM-HDSS.

Sampling frame and sample size

Sampling frame for this study was drawn from household and individual listings available from the latest IM-HDSS rounds - round 19 and round 20. Data from a pilot conducted as part of round 19 served as basis for identifying children with disabilities who were between 5-17 years of age. This was done using data from Module A that was administered at the household level. A total of 377 children between the ages of 5-17 years were identified to have some form of disability based on round 19 Module A data. Their IDs were then confirmed for active status in round 20, which had been completed four months (May 2018) before the beginning of this study (September 2018). Based on the round 20 check for active IDs, 342 children out of 377 from round 19 were found to have active IDs (29 children were more than 17 years, one had died, four had moved to another location within IM-HDSS, and one had moved out of IM-HDSS). Active IDs mean that these children were present at the IM-HDSS as of round 20; hence, all 342 children were included in this study.

In addition to children with disability, a sample size of 1,273 was computed assuming the ability to observe a difference in disability prevalence of 1% between two groups. Other parameters included alpha of 5% and power of 80%. Thus, the total sample required was 1,615: 1,273 children without disability and 342 with disability. However, to account for non-availability, refusals, and out-migrations from the site, sample for non-disabled was increased to 1500. At the time of this study, 35,062 children (excluding 342 with disability) were residing at the IM-HDSS. A stratified (based on sex of child) sample proportionate to population size of children without disability was drawn from the list of 35,062 children. The formula used for the stratified sample size calculation was:

$$\left(\frac{\text{Total sample size required}}{\text{Population size}}\right) \text{ x } \text{Stratum size}$$

Table below gives sample size calculation for each stratum.

Sample size calculation	**Male**	**Female**
Total sample size	1,500	1,500
Population size	35,062	35,062
Stratum size	17,216	17,846
Calculation	(1,500/35,062) * 17,216	(1,500/35,062) * 1,7846
Stratified sample	737	763

A random list of IDs was drawn from each stratum using STATA version 14 [37]. Thus, the sample for this study included 342 children with disabilities and 1,500 children without disabilities, giving a total of 1,842 children whose caregivers were approached to participate in the study. Only one child per household was selected. A unique study ID was assigned to all 1,842 children included in the sample.

It is important to note that the distinction between children with disability and without disability was made for sampling purpose to ensure that sample for this study does not miss children with disabilities. The analysis for this study was conducted on the pooled sample of individuals who agreed to participate in the study. Figure 4.1 depicts enrollment of caregivers.

Data collection and management

After obtaining oral informed consent, data were collected through face-to-face caregiver interviews using a tablet-based platform that was developed and pre-tested based on available local resources at the IM-HDSS. The platform included English and Lusoga versions of questions, which were developed in Microsoft Excel .xls format and uploaded to KoBoToolbox (https://www.kobotoolbox.org/) for data collection. Questions had check box and free text entry formats to input responses. Questions were designed to allow skip patterns where appropriate, and mandatory fields were also marked. This ensured that there were no missing data for Module A and C-DAS. In order to reduce the workload related to entry of IM-HDSS IDs, each unique study ID was linked with IM-HDSS IDs at the back end. This helped to address issues related to errors in ID entry. The Kobo app was downloaded to android tablets to allow for data collection using user-specific passwords. These forms were then accessible in the field during data collection and did not require internet or Wi-Fi connection to complete them. Once an interview was completed, the form was saved on a tablet. Field supervisors checked the saved forms at the end of the day, and completed forms were uploaded daily using office Wi-Fi connection to a cloud server. The electronic forms were submitted to a secure, encrypted cloud server with no copy remaining on the tablet. The server was only accessible to authorized study team members at IM-HDSS and JHSPH. This ensured data confidentiality and security. Data were downloaded daily from the server in MS Excel (.xls and .cvs format).

Data analysis

Outcome variable

The outcome variable of interest was disability and was categorized into four groups, no disability, mild disability, moderate disability, and severe disability, using 4-point Likert responses of C-DAS. “No disability” was defined when “no difficulty” was marked on all C-DAS questions. “Mild disability” was defined when “some difficulty” was marked as the highest response for any one of the C-DAS domains. “Moderate disability” was defined when “a lot of difficulty” was marked as the highest response for any one of the C-DAS domains. “Severe disability” was defined when “cannot do at all” was marked as the highest response for any one of the C-DAS domains. The total C-DAS score ranged between 0-39. Scores for mild disabilities ranged between 1-13, moderate disability ranged between 2-26, and severe disability ranged between 3-39. This classification was used for further analysis including regression analysis.

The work done during field testing of the UNICEF/WG tool defined disability using several different binary cut-off levels [38]. Therefore, sensitivity analysis was also conducted for the purpose of reporting disability prevalence. Disability was categorized into the same four categorizes mentioned above; however, the definition of none and mild disability was changed. “No disability” was defined when “no difficulty” was marked on all C-DAS questions or “some difficulty” was marked as the highest response on only one of the C-DAS domains. “Mild disability” was defined when “some difficulty” was marked as the highest response on two or more of the C-DAS domains. The definitions for moderate and severe disability were the same. Based on this classification, scores for mild disabilities ranged between 2-13, moderate disability between 2-26, and severe disability between 3-39. Table 4.1 summarizes the two classifications.

Descriptive analysis

Descriptive analysis was conducted to calculate the prevalence of disability based on disability categories. Child, parent, primary caregiver and household characteristics were explored by level of disability categories. Binary and categorical variables were reported in percentages and mean with standard deviation as well as median and interquartile range (IQR) are reported for continuous variables. Chi square tests were conducted to assess relationships between categorical variables [39]. To assess the relationship between non-normally distributed continuous variables and the ordered categorical disability variable, Kruskal Wallis tests were conducted. This is a non-parametric test comparable to ANOVA, which compares medians of two or more groups [40].

Regression analysis

For regression analysis, disability outcome variable with three categories – mild, moderate and severe – were considered. Since the outcome variable "disability" was categorical and ordered, the first choice of regression analysis was ordinal logistic regression. This model is based on the proportional odds or parallel-regression assumption, which means that the value of odd ratios in the model remains the same across various categories of the dependent variable [41, 42]. For example, the odd ratio between mild to moderate is the same as between moderate to severe. The proportional odds assumption was tested using two methods. The first is a *likelihood ratio test,* which tests the null hypothesis that there is no difference in the coefficients between models [43]. The second test is the *Brant test of parallel regression assumption,* which checks the proportional odds assumption [44]. The null hypothesis for each of these tests is that of proportionality; rejecting the null hypothesis provides evidence against using the ordinal logistic regression [43]. When the results of these tests are statistically significant, the proportional odds assumption is violated, and an alternate model called generalized ordered logit model may be used.

Generalized ordered logit model relaxes the proportional odds assumption and allows estimation of a partial proportional odds model [41, 42]. Furthermore, it presents results by dichotomizing the categorical outcome variable. For generalized ordered logit regression analysis with three categories, there are two panels of odd ratios. The first one compares mild disability with combined moderate and severe, and the second panel compares combined mild and moderate disability with severe disability. This approach allows the relationship with independent variable to vary based on different dichotomization of the categorical outcome variable [41, 42]. Independent variables considered in the regression models included the child's age, sex, immunization status, school enrollment, primary caregiver status, age of mother at child's birth, type of family system, family size and household wealth quintile. All analysis was conducted in STATA 14 [37].

Ethical approval

The study was approved by the institutional ethics committees of the Johns Hopkins Bloomberg School of Public Health, USA and both Makerere University School of Public Health and the Uganda National Council for Science and Technology.

Results

Descriptive analysis

Disability prevalence and scores

Out of 1,842 caregivers approached for the study, caregivers of 1,439 (response: 78.1%) children agreed to participate in the study (Figure 4.1). There were 10 refusals, while 393 caregivers were not available for interview. Out of these 1,439, some level of disability was reported by 67.89% (n=977) caregivers. Of these 977 children with disability, 48.01% (n=692) had mild disability, 15.84% (n=228) had moderate disability, and 3.96% (n=57) had severe disability (Table 4.2). The mean score for mild disability was 2.22 ± 1.17 out of 13, with a median of 2. The mean and median for moderate disability was 5.26 ± 3.28 out of 26 and 4 (3-6), and for severe disability, they were 14.23 ± 9.51 out of 39 and 12 (6-22). (Table 4.2). Second classification method defined for sensitivity analysis showed that caregivers of 840 children reported some disability (58.37%). Among these 840 children, 38.57% had mild disability.

Based on the sampling frame, out of 342 caregivers of children with disability, 308 (90.06%) agreed to participate, while out of 1,500 caregivers of children without disability, 1,131 (75.4%) participated in the study. The overall mean scores for 308 children was 5.57 ± 6.30. Of the 308, 10.39% (n=32) were reported to have no disability, 44.16% (n=136) had mild disability (mean ± SD: 3 ± 1.81), 32.79% (n=101) had moderate disability (mean ± SD: 6.38 ± 3.84), and 12.66% (n=39) had severe disability (mean ± SD: 17.03 ± 9.16). The overall mean score for 1,131 children was 1.62 ± 2.11. Of the 1,131, 38.02% (n=430) did not have any disability, 49.16% (n=556) had mild (mean ± SD: 2.03 ± 0.86), 11.23% (n=127) had moderate (mean ± SD: 4.37 ± 2.42), and 1.59% (n=18) had severe disability (mean ± SD: 8.17 ± 7.31) (Figure 4.2).

Supplementary table 4.1 compares child, caregiver, and household characteristics of the sampling frame groups.

Overall, the most common disability was depression (54.83%), followed by anxiety (50.87%) and remembering (12.2%). The least reported disability domains were communication (4.52%), making friends (4.52%), and self-care (4.31%). (Figure 4.3). Based on the disability categories, more than 90% of the children did not have any disability related to vision, hearing, walking, communication, concentration, accepting change, behavior, and making friends. No disability in learning and remembering was reported for 88% and 87.8% of the children respectively (Figure 4.4). However, the reported disability related to anxiety or depression was much higher than that of other domains. Overall, 38.3% had mild disability related to anxiety, while 42.0% had mild disability related to depression. Similarly, 10.7% had moderate disability related to anxiety, while 10.9% had moderate disability related to depression.

Demographic characteristics

The mean age of children across the disability categories was similar (Figure 4.5). Most of the children with mild disability were between 5-10 years of age (n=314, 45.38%), while the distributions of children in the moderate and severe disability groups were almost similar for the 5-10 years age group and for 11-14-year olds. The distribution of children based on child sex varied across the disability groups, with more males (64.91%) in the severe disability group. (Figure 4.54). Being severely disabled was associated with the lowest percentage of completed immunization (29.41%) (p-value <0.001) and not being enrolled in school (47.37%, p-value <0.001) (Table 4.3). The respondents identified a primary caregiver for children, with the highest percentage of primary caregivers for children with severe disability (94.74%) compared to those with mild (88.87%) and moderate (94.30%) disability (p-value <0.001) (Table 4.3).

The mean age of mothers at the time of birth of their child was around 25 years, which was slightly higher for mothers of children with severe disability (Table 4.3). The percentage of uneducated parents was higher for children with severe disability (mother: 17.54%, father: 8.77%), while it was much lower for mild (mother: 6.94%, father: 2.17%) and moderate (mother: 4.39%, father: 3.51%) disability groups, although over 50% of mothers and over 40% of fathers had received primary education. About 18% of primary caregivers of children with severe disability were uneducated, but almost 70% had received primary education (Table 4.3).

About 12.28% of children with severe disability lived with single parents, while 7% of children with mild and moderate disability had single parents (Table 4.3). Children with mild to moderate disability had a higher percentage living in nuclear and joint family systems compared to those with severe disability (p-value <0.001).

Regression analysis

This study analyzed factors associated with disability using generalized ordered logit model. The decision was based on statistically significant findings of the Brant test, which indicated that the proportional odds assumption was violated for the ordinal regression model and depicted that the relationships between disability and independent variables in the model vary across the different disability categories.

According to the results of the generalized ordered logit model, completion of immunization status and school enrollment were statistically and significantly associated with disability when controlled for the child's age, sex, primary caregiver status, age of mother at child's birth, type of family system, family size and household wealth quintile. (Table 4.4).

Mild disability versus combined moderate and severe disability

After controlling for the independent variables in the model, comparing children in mild disability group to higher disability categories showed that the children with higher disability were 38% less likely to have incomplete immunization (aOR = 0.58; 95% CI: 0.42 – 0.80). Comparing children in mild disability category to higher disability categories showed that children in higher categories were 1.60 times more likely to be not enrolled in school (aOR = 1.60; 95% CI: 1.01 – 2.53). The adjusted odds of not having a primary caregiver were 60% less for children with mild disability (95% CI: 0.21 – 0.79) (Table 4.4).

Mild and moderate disability versus severe disability

After controlling for the independent variables in the model, comparing children in mild and moderate disability groups to those in the severe disability category showed that children with severe disability were 2.36 (95% CI: 1.12 – 4.95) times more likely to have incomplete immunization. Comparing children in mild and moderate disability groups to the severe disability category showed that children with severe disability were 11.01 times more likely to not be enrolled in school (aOR = 11.01; 95% CI: 5.15 – 23.56).

Discussion

To the best of our knowledge, this is the first study conducted at IM-HDSS to assess prevalence of disability among children and factors associated with disability among children between 5-17 years of age. Depending on how disability is defined, it was found that between 58.37% - 67.89% children living at IM-HDSS have some form of disability. Previous studies done to estimate disability prevalence in different context report different percentages based on disability definition. For example, prevalence was reported to be 63.3% based on the most inclusive definition of disability ("some difficulty" in one of the C-DAS domains); however, it was reported to be 42.0% when disability was defined as "some difficulty" in two of the C-DAS domains, 8.9% for moderate and 0.7% for severe [45]. The same study reported that at least 34.5% of the children in India had some form of disability [45]. While another study reported this prevalence to be at 46.3% for Mexico, 9.8% for Samoa, and 25.2% for Serbia [38].

It is important to note that the distribution of disability categories followed a positively skewed distribution, with more children found to have mild disability and a very small number with severe form of disability. This has implications for developing and implementing targeted interventions. According to recommendations by UNICEF/WG, disability is categorized as a binary variable, and several different cut-offs are suggested

[36, 38]. However, for this study, disability was categorized based on Likert-responses to allow assessment of factors without losing granularity in the data. This analysis shows that while the definition of moderate and severe disability is clear, defining mild disability is a challenge. Based on the sensitivity analysis, it was found that by changing the definition of mild disability, disability prevalence for this category changed by 10%. This means that disability prevalence in this population might be overestimated for children at IM-HDSS. Thus, caregiver responses that place children into the "some difficulty" category needs careful consideration. This could be due to some behavioral changes that the child is going through instead of actually having disability [36]. This may have increased false positives and, thus, overestimated disability prevalence. But at the same time, it provides an in-depth assessment of children at the community level. This is vital for early identification of disability and for monitoring the progress of these children in case an intervention is implemented.

The factors considered for association with disability included selected child, primary caregiver and household characteristics. Incomplete child immunization status and lack of school enrollment at the time of the study were found to be associated with disability. It is important to note that due to the cross-sectional study design, this study only shows association of disability with immunization status and school enrollment. It does not give casual relation between disability and these variables. Disability can have devastating effects on individuals, their families and the society. It is regarded as a cause and consequence of poverty. In many LMICs, disability is still highly stigmatized and can lead to social exclusion and discrimination. For children with disability, this often means a life in isolation and exclusion from education and future employment opportunities as well as a lack of access to health services [2, 10, 16, 46-48].

An important finding in this study is the association of disability with completion of immunization. It was noticed that children with mild disability seemed to have higher odds of incomplete immunization compared to children in higher disability categories. This is an interesting finding; it may reflect that children with moderate and severe disability have greater access to health services and, thus, are able to receive these immunizations. However, when children with mild to moderate disability were compared to those with severe disability, children with severe disability were less likely to have had completed their immunizations. This opposing trend may be driven by how children with moderate disability are placed and could also be due to the small number of children with severe disability. However, the study highlights the importance of providing preventive measures for vaccine-preventable diseases and the need to address access to immunization [49]. There may be several contributing factors, including lack of vaccines, trained healthcare providers, and ramps for wheelchairs for children with disabilities at the designated immunization centers and facilities; or the burden on the family and caregiver to take the children for vaccination perhaps due to the high cost associated with transportation; or the attitude of providers even if the child is taken for vaccination. Stigmatization and lack of trust in the healthcare system coupled with lack of resources could be a reason for incomplete immunization [49, 50].

School enrollment for children with mild and moderate disability was higher as compared to those with severe disability. In Uganda only 9% of children with mild and moderate disability attended primary school, and 6% attended secondary school [21]. Of the children with disabilities in Uganda, only 10% have access to schools that meet their needs, and only 5% of disabled children going to public school receive specialized education [23]. These estimates are worrisome and underscore the significant impact that disability can have on the development and future life opportunities for these children. Another report from Uganda, however, shows that about 62% of disabled children between 9-17 years of age are enrolled in school [24]. With relatively high enrollment reported at the IM-HDSS, the focus should be on training teachers to teach children with disabilities and providing accommodations to receive education. This may include having accessible school transportation, ramps within school buildings, accessible toilet facilities, and study aids for children with visual and hearing impairments [51].

In addition to assessing overall disability, all 13 specific domains were also assessed for disability categories. Higher percentages of disability were reported for anxiety and depression compared to other domains. This finding is consistent with Massey et al work in the US [47]. This could be due to lack of understanding of questions by caregivers, or it may depict an underlying feeling of sadness and unhappiness as perceived by caregivers [52]. How caregivers perceive level of anxiety and depression among their children may be a reflection of their own level of anxiety and depression, which might be projected in their responses to the questions related to anxiety and depression[53]. In either case, this is an interesting finding which needs further exploration using in-depth clinical assessments for anxiety and depression to ensure that children receive proper treatment and therapy. This approach can also help to identify at risk population of children who might be influenced by adverse household and social factors like loss of a parent or being marginalized [52].

Some strengths of this study are: it is the first study at IM-HDSS and Uganda that has assessed disability in children and its associated factors. This is a priority area for the local district health office and will help in developing, implementing, and monitoring relevant interventions. Second, C-DAS assesses physical as well as developmental limitations in children, thus acknowledging growth and developmental needs of children with disability. Third, the tool is validated in Ugandan context (see paper 1 for details) and can be administered in a community setting by non-clinical staff to assess the burden of disability in the community. The IM-HDSS staff works very closely with the local district health office and can use data from the child disability module to ensure integration of children into the education and healthcare systems. Fourth, the tool asks for level of difficulty associated with C-DAS domains but does not label children as "disabled." This helps to avoid stigmatization of children with disabilities and reduces any level of discomfort a caregiver might have faced during the interview. Fifth, the analysis assesses the relationship between disability utilizing Likert-scale responses and associated factors in bivariate analyses and accounted for ordered responses during the multivariable regression analysis. Sixth, this study does not report specific causes of disability; instead, it focuses on domains which, according to the ICF framework, constitute activities and ability of children to function in their daily life. However, future work should explore specific causes of disability and their association with the disability categories.

This study explored factors associated with disability only for children living at the IM-HDSS; these factors may differ from other regions in Uganda and in other LMICs. It is, therefore, not possible to generalize findings from this study to the Ugandan context, but the results provide an understanding of disability burden at the site as well as an opportunity for data sharing with the local district health office to plan inclusive interventions in the districts. Second, disability categorization into mild, moderate and severe may have overestimated disability prevalence at the IM-HDSS. However, this allows opportunity for early identification and intervention for children with mild disability who may progress to moderate or even severe disability without any intervention. Third, this study enrolled children with and without disability. This might have also contributed to overestimation of disability prevalence at the IM-HDSS, but it also shows that disability is a dynamic process and that children who were previously reported to have disability did not report disability during this study and vice versa. Thus, it is important that longitudinal studies are conducted to understand the dynamic disability process and its impact on growth and development of children. Fourth, the study highlights that children with disability lack opportunities related to education and healthcare access. However, due to the inherent limitations of the cross-sectional study design, it was not possible to explore the causal relationship between immunization and disability, and between school enrollment and disability. Future work needs to focus on exploring limitations related to school and healthcare access. Fifth, C-DAS assessed 13 domains comprising physical functioning and developmental aspects. However, there was no clinical assessment done to verify limitations reported by caregivers. It is important that C-DAS is implemented as a tool in the community to facilitate early identification of children with disabilities so that they can be referred for clinical assessment and intervention in a timely manner. Sixth, since C-DAS is a self-reported tool, there is a possibility of bias in caregiver responses prompted by perceived gains, for example in terms of enrollment into intervention studies. However, the structure of questions in C-DAS allows an assessment of the level of difficulty without labeling children as disabled. Future work should allow longitudinal data collection to determine change in disability status of children and possible adaptations as a result of their disability. Seventh, disability was categorized by considering highest responses on the Likert-scale and did not consider potential combinations of disability. This was complemented by reporting scores within each category instead of reporting cut-offs defining disability categories. This approach provides one way for reporting disability without categorizing disability into a binary outcome. Eighth, due to time and resource constraints, collecting information on the experiences of caregivers and children with disabilities was not possible. This is an important area of future work to understand local context to generate data that can help monitor interventions and SDGs to include individuals with disabilities within education and work opportunities.

Conclusion

This study provides an insight into factors associated with disability in children 5-17 years of age living at IM-HDSS and uses C-DAS as a standardized tool for assessment within communities. This study concludes that the lack of complete immunization and school enrollment are statistically and significantly associated with disability among children. This does not imply causal relation due to cross-sectional study design and requires further studies to get a better understanding of social issues related to access to education and health services by children with disabilities.

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Tables

Table 4.1: Definition of disability categories

	Classification 1*	Classification 2
None	“no difficulty” marked on all domains	“no difficulty” was marked on all C-DAS questions or “some difficulty” was marked as the highest response on only one of the C-DAS domains
Mild	“some difficulty” was the highest response for any one domain	“some difficulty” was marked as the highest response on two or more of the C-DAS domains
Moderate	“a lot of difficulty” was the highest response for any one domain	
Severe	“cannot do at all” was the highest response for any one domain	

*used for further analysis

Table 4.2: Mean, median, minimum and maximum C-DAS scores based on disability categories (n=1,439)

Disability categories	n (%)	Mean ± SD	Median (IQR)	Minimum	Maximum
Overall	1,439	2.47 ± 3.82	2 (0 – 3)	0	35
None	462 (32.11)	0	0	0	0
Mild	692 (48.09)	2.22 ± 1.17	2 (0)	1	10
Moderate	228 (15.84)	5.26 ± 3.28	4 (3-6)	2	19
Severe	57 (3.96)	14.23 ± 9.51	12 (6-22)	3	35

Table 4.3: Distribution of child, parent, primary caregivers, and household characteristics by disability categories (n=1,439)

Characteristics	None (n=462)	Mild (n=692)	Moderate (n=228)	Severe (n=57)	Total (n=1,439)
Child Characteristics					
Average age in years (mean ± SD)*	10.52 ± 3.49	11.12 ± 3.71	11.83 ± 3.40	11.47 ± 3.03	11.06 ± 3.59
Age groups*					
5-10 years	237 (51.30)	314 (45.38)	83 (36.40)	23 (40.35)	657 (45.66)
11-14 years	147 (31.82)	218 (31.50)	79 (34.65)	23 (40.35)	467 (32.45)
15-17 years	78 (16.88)	160 (23.12)	66 (28.95)	11 (19.30)	315 (21.89)
Sex					
Male	241 (52.16)	347 (50.14)	114 (50.00)	37 (64.91)	739 (51.36)
Female	221 (47.84)	345 (49.86)	114 (50.00)	20 (35.09)	700 (48.64)
Immunization (completed)*	211 (49.18)	223 (34.31)	108 (49.77)	15 (29.41)	557 (41.35)
Currently in school (yes)*	425 (91.99)	624 (90.17)	196 (85.96)	27 (47.37)	1,272 (88.39)
Siblings (yes)	442 (95.67)	670 (96.82)	221 (96.93)	55 (96.49)	1,388 (96.46)
Have a primary caregiver (yes)*	355 (76.84)	615 (88.87)	215 (94.30)	54 (94.74)	1,239 (86.10)
Parental Characteristics					
Mother alive (yes)	446 (96.54)	674 (97.40)	218 (95.61)	53 (92.98)	1,391 (96.66)
Mother's age at child's birth in years (mean ± SD)	25.72 ± 6.37	25.28 ± 6.40	25.49 ± 7.00	26.54 ± 7.46	25.50 ± 6.53
Mother's education level*					
None	58 (12.55)	48 (6.94)	10 (4.39)	10 (17.54)	126 (8.76)
Primary	263 (56.93)	396 (57.23)	149 (65.35)	37 (64.91)	845 (58.72)
Lower secondary	89 (19.26)	176 (25.43)	49 (21.49)	4 (7.02)	318 (22.10)

Characteristics	None (n=462)	Mild (n=692)	Moderate (n=228)	Severe (n=57)	Total (n=1,439)
Upper secondary	4 (0.87)	3 (0.43)	1 (0.44)	-	8 (0.56)
Other (university/vocational)	48 (10.39)	69 (9.97)	19 (8.33)	6 (10.53)	142 (9.87)
Mother's occupation*					
Housewife	52 (11.26)	104 (15.03)	22 (9.65)	12 (21.05)	190 (13.20)
Farmer	241 (52.16)	321 (46.39)	125 (54.82)	32 (56.14)	719 (49.97)
Shopkeeper	100 (21.65)	167 (24.13)	60 (26.32)	8 (14.04)	335 (23.28)
Professional	17 (3.68)	29 (4.19)	8 (3.51)	2 (3.51)	56 (3.89)
Unemployed	8 (1.73)	22 (3.18)	5 (2.19)	-	35 (2.43)
Others	28 (6.06)	24 (3.47)	5 (2.19)	1 (1.75)	58 (4.03)
Father alive (yes)	431 (93.29)	649 (93.79)	207 (90.79)	54 (94.74)	1,341 (93.19)
Father's education level*					
None	32 (6.93)	15 (2.17)	8 (3.51)	5 (8.77)	60 (4.17)
Primary	196 (42.42)	308 (44.51)	108 (47.37)	37 (64.91)	649 (45.10)
Lower secondary	105 (22.73)	236 (34.10)	71 (31.14)	4 (7.02)	416 (28.91)
Upper secondary	12 (2.60)	21 (3.03)	8 (3.51)	1 (1.75)	42 (2.92)
Other (university/vocational)	117 (25.32)	112 (16.18)	33 (14.47)	10 (17.54)	272 (18.90)
Father's occupation*					
Farmer	153 (33.12)	186 (26.88)	86 (37.72)	19 (33.33)	444 (30.85)
Shopkeeper	131 (28.35)	248 (35.84)	68 (29.82)	17 (29.82)	464 (32.24)
Professional	44 (9.52)	37 (5.35)	16 (7.02)	3 (5.26)	100 (6.95)
Boda boda driver	41 (8.87)	87 (12.57)	25 (10.96)	7 (12.28)	160 (11.12)
Unemployed	5 (1.08)	2 (0.29)	2 (0.88)	-	9 (0.63)

Characteristics	None (n=462)	Mild (n=692)	Moderate (n=228)	Severe (n=57)	Total (n=1,439)
Others	72 (15.58)	116 (16.76)	26 (11.40)	10 (17.54)	224 (15.57)
Primary caregiver characteristics					
Caregiver relation with child*					
Mother	196 (55.21)	407 (66.18)	133 (61.86)	34 (62.96)	770 (62.15)
Father	64 (18.03)	71 (11.54)	20 (9.30)	9 (16.67)	164 (13.24)
Grandparent(s)	61 (17.18)	76 (12.36)	31 (14.42)	5 (9.26)	173 (13.96)
Uncle/Aunt	10 (2.82)	31 (5.04)	14 (6.51)	3 (5.56)	58 (4.68)
Sibling	7 (1.97)	4 (0.65)	2 (0.93)	-	13 (1.05)
Others	16 (4.51)	26 (4.23)	15 (6.98)	3 (5.56)	61 (4.92)
Average age (mean ± SD)*	41.91 ± 12.17	40.31 ± 11.60	42.17 ± 11.54	41.56 ± 9.65	41.15 ± 11.69
Sex					
Male	68 (19.15)	106 (17.24)	32 (14.88)	13 (24.07)	219 (17.68)
Female	287 (80.85)	509 (82.76)	183 (85.12)	41 (75.93)	1,020 (82.32)
Education level*					
None	71 (20.00)	70 (11.38)	17 (7.91)	10 (18.52)	168 (13.56)
Primary	196 (55.21)	353 (57.40)	143 (66.51)	39 (72.22)	731 (59.00)
Lower secondary	60 (16.90)	144 (23.41)	43 (20.00)	3 (5.56)	250 (20.18)
Upper secondary	3 (0.85)	6 (0.98)	3 (1.40)	-	12 (0.97)
Other (university/vocational)	25 (7.04)	42 (6.83)	9 (4.19)	2 (3.70)	78 (6.30)
Occupation					
Farmer	200 (56.34)	314 (51.06)	130 (60.47)	35 (64.81)	679 (54.80)
Shopkeeper	78 (21.97)	144 (23.41)	48 (22.33)	11 (20.37)	281 (22.68)

Characteristics	**None (n=462)**	**Mild (n=692)**	**Moderate (n=228)**	**Severe (n=57)**	**Total (n=1,439)**
Housewife	25 (7.04)	78 (12.68)	12 (5.58)	5 (9.26)	120 (9.69)
Professional	19 (5.35)	28 (4.55)	7 (3.26)	1 (1.85)	55 (4.44)
Boda boda driver	3 (0.85)	6 (0.98)	3 (1.40)	1 (1.85)	13 (1.05)
Unemployed	11 (3.10)	12 (1.95)	6 (2.79)	1 (1.85)	30 (2.42)
Others	19 (5.35)	33 (5.37)	9 (4.19)	-	61 (4.92)
Household Characteristics					
Family system*					
Single parent	64 (13.85)	51 (7.37)	16 (7.02)	7 (12.28)	138 (9.59)
Nuclear	242 (52.38)	364 (52.60)	110 (48.25)	27 (47.37)	743 (51.63)
Joint	155 (33.55)	277 (40.03)	101 (44.30)	22 (38.60)	555 (38.57)
Family size (mean ± SD)	7.77 ± 2.93	7.88 ± 3.10	8.13 ± 3.65	8.09 ± 3.69	7.89 ± 3.16
Household wealth quintile					
Poorest	122 (27.23)	189 (28.51)	63 (28.25)	15 (27.27)	389 (28.01)
Poorer	93 (20.76)	137 (20.66)	58 (26.01)	11 (20.00)	299 (21.53)
Poor	108 (24.11)	151 (22.78)	51 (22.87)	15 (27.27)	325 (23.40)
Less poor	85 (18.97)	121 (18.25)	33 (14.80)	9 (16.36)	248 (17.85)
Least poor	40 (8.93)	65 (9.80)	18 (8.07)	5 (9.09)	128 (9.22)

* p-value <0.05

Table 4.4: Factors associated with disability in children living at the IM-HDSS, Uganda (Generalized ordered logistic model)

Characteristics	Mild versus combined moderate and severe	Combined mild and moderate versus severe
Age groups		
5-10 years	Reference	Reference
11-14 years	**1.57*** (1.11 – 2.25)	1.33 (0.64 – 2.75)
15-17 years	1.41 (0.94 – 2.09)	0.49 (0.21 – 1.14)
Sex		
Male	Reference	Reference
Female	0.91 (0.67 – 1.24)	0.57 (0.30 – 1.10)
Immunization status		
Completed	Reference	Reference
Not completed	**0.58*** (0.42 – 0.80)	**2.36*** (1.12 – 4.96)
Currently in school		
Yes	Reference	Reference
No	**1.60*** (1.01 – 2.53)	**11.01*** (5.15 – 23.56)
Primary caregiver		
Yes	Reference	Reference
No	**0.40*** (0.21 – 0.79)	0.70 (0.15 – 3.18)
Mother's age at birth		
14 – 20 years	Reference	Reference
21 – 30 years	0.89 (0.62 – 1.28)	0.73 (0.33 – 1.61)
31 – 40 years	1.02 (0.64 – 1.62)	1.37 (0.59 – 3.19)
41 – 50 years	1.22 (0.50 – 2.95)	0.45 (0.08 – 2.47)
Family system		
Single parent	Reference	Reference
Nuclear	1.14 (0.64 – 2.06)	0.56 (0.19 – 1.63)
Joint	1.54 (0.83 – 2.88)	0.50 (0.16 – 1.58)

Characteristics	**Mild versus combined moderate and severe**	**Combined mild and moderate versus severe**
Family size	1.01 (0.97 – 1.06)	1.08 (0.99 – 1.18)
Household wealth quintile		
Poorest	Reference	Reference
Poorer	1.24 (0.81 – 1.88)	0.67 (0.27 – 1.68)
Poor	0.97 (0.63 – 1.48)	1.61 (0.67 – 3.88)
Less poor	0.88 (0.54 – 1.44)	1.62 (0.58 – 4.49)
Least poor	0.86 (0.48 – 1.53)	1.04 (0.33 – 3.27)

*Statistically significant at p-value <0.05

Supplementary table 4.1: **Demographic characteristics of sampling frame groups (n=1,439)**

Characteristics	**Children with disabilities (n=308)**	**Children without disabilities (n= 1,131)**	**p-value**
Disability severity			**<0.001**
No disability	32 (10.39)	430 (38.02)	
Mild disability	136 (44.16)	556 (49.16)	
Moderate disability	101 (32.79)	127 (11.23)	
Severe disability	39 (12.66)	18 (1.59)	
Child Characteristics			
Average age in years (mean ± SD)*	12.03 ± 3.09	10.79 ± 3.67	**0.0003**
Age groups			**0.001**
5-10 years	112 (36.36)	545 (48.19)	
11-14 years	115 (37.34)	352 (31.12)	
15-17 years	81 (26.30)	234 (20.69)	
Sex			0.206
Male	168 (54.55)	571 (50.49)	
Female	140 (45.45)	560 (49.51)	
Immunization status			0.581
Completed	115 (39.93)	442 (41.74)	
Not completed	173 (60.07)	617 (58.26)	
Currently in school			**<0.001**
Yes	245 (79.55)	1,027 (90.80)	
No	62 (20.13)	104 (9.20)	
Siblings			0.419
Yes	299 (97.08)	1,089 (96.29)	
No	9 (2.92)	41 (3.63)	
Has a primary caregiver			0.052
Yes	278 (90.26)	961 (84.97)	

Characteristics	**Children with disabilities (n=308)**	**Children without disabilities (n= 1,131)**	**p-value**
No	30 (9.74)	170 (15.04)	
Parental Characteristics			
Mother alive			
Yes	300 (97.40)	1,091 (96.46)	0.660
No	8 (2.60)	40 (3.54)	
Mother's age at child's birth in years (mean ± SD)	25.85 ± 6.84	25.41 ± 6.45	0.213
Mother's education level			
None	32 (10.39)	94 (8.31)	**0.047**
Primary	198 (64.29)	647 (57.21)	
Lower secondary	54 (17.53)	264 (23.34)	
Upper secondary	1 (0.32)	7 (0.62)	
Other (university/vocational)	23 (7.47)	119 (10.52)	
Mother's occupation			
Housewife	41 (13.31)	149 (13.17)	**0.050**
Farmer	166 (53.90)	553 (48.89)	
Shopkeeper	73 (23.70)	262 (23.17)	
Professional	8 (2.60)	48 (4.24)	
Unemployed	3 (0.97)	32 (2.83)	
Others	5 (1.62)	53 (4.69)	
Father alive			
Yes	284 (92.21)	1,057 (93.46)	0.661
No	23 (7.47)	69 (6.10)	
Father's education level			
None	19 (6.17)	41 (3.63)	**0.008**
Primary	159 (51.62)	490 (43.32)	
Lower secondary	79 (25.65)	337 (29.80)	
Upper secondary	7 (2.27)	35 (3.09)	

Characteristics	**Children with disabilities (n=308)**	**Children without disabilities (n= 1,131)**	**p-value**
Other (university/vocational)	44 (14.29)	228 (20.16)	
Father's occupation			0.172
Farmer	104 (33.77)	340 (30.06)	
Shopkeeper	100 (32.47)	364 (32.18)	
Professional	13 (4.22)	87 (7.69)	
Boda boda driver	33 (10.71)	127 (11.23)	
Unemployed	3 (0.97)	6 (0.53)	
Others	51 (16.56)	173 (15.30)	
Primary caregiver characteristics			
Caregiver relation with child			0.125
Mother	187 (67.27)	583 (60.67)	
Father	39 (14.03)	125 (13.01)	
Grandparent(s)	27 (9.71)	146 (15.19)	
Uncle/Aunt	13 (4.68)	45 (4.68)	
Sibling	4 (1.44)	9 (0.94)	
Others	8 (2.88)	52 (5.41)	
Average age (mean ± SD)	41.28 ± 10.41	41.11 ± 12.05	**0.003**
Sex			0.144
Male	54 (19.42)	165 (17.17)	
Female	224 (80.58)	796 (82.83)	
Education level			**0.004**
None	39 (14.03)	129 (13.42)	
Primary	185 (66.55)	546 (56.82)	
Lower secondary	42 (15.11)	208 (21.64)	
Upper secondary	4 (1.44)	8 (0.83)	
Other (university/vocational)	8 (2.88)	70 (7.28)	
Occupation			**0.012**

Characteristics	**Children with disabilities (n=308)**	**Children without disabilities (n= 1,131)**	**p-value**
Farmer	167 (60.07)	512 (53.28)	
Shopkeeper	68 (24.46)	213 (22.16)	
Housewife	21 (7.55)	99 (10.30)	
Professional	6 (2.16)	49 (5.10)	
Boda boda driver	5 (1.80)	8 (0.83)	
Unemployed	5 (1.80)	25 (2.60)	
Others	6 (2.16)	55 (5.72)	
Household Characteristics			
Family system			
Single parent	35 (11.36)	103 (9.11)	0.164
Nuclear	170 (55.19)	573 (50.66)	
Joint	102 (33.12)	453 (40.05)	
Family size (mean ± SD)	8.04 ± 3.40	7.85 ± 3.10	**0.038**
Household wealth quintile			
Poorest	99 (32.78)	290 (26.68)	0.082
Poorer	55 (18.21)	244 (22.45)	
Poor	75 (24.83)	250 (23.00)	
Less poor	53 (17.55)	195 (17.94)	
Least poor	20 (6.62)	108 (9.94)	

* p-value <0.05

Figures

Figure 4.1: Sampling frame for child disability assessment at the Iganga-Mayuge Health and Demographic Surveillance Site

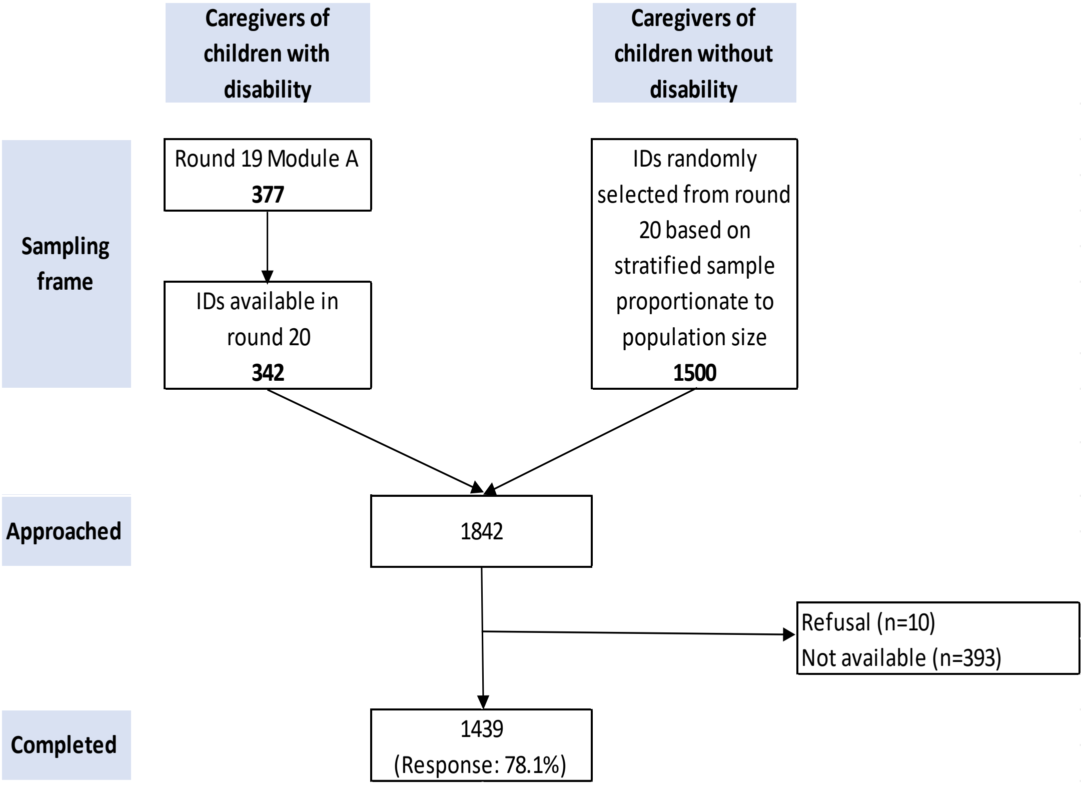
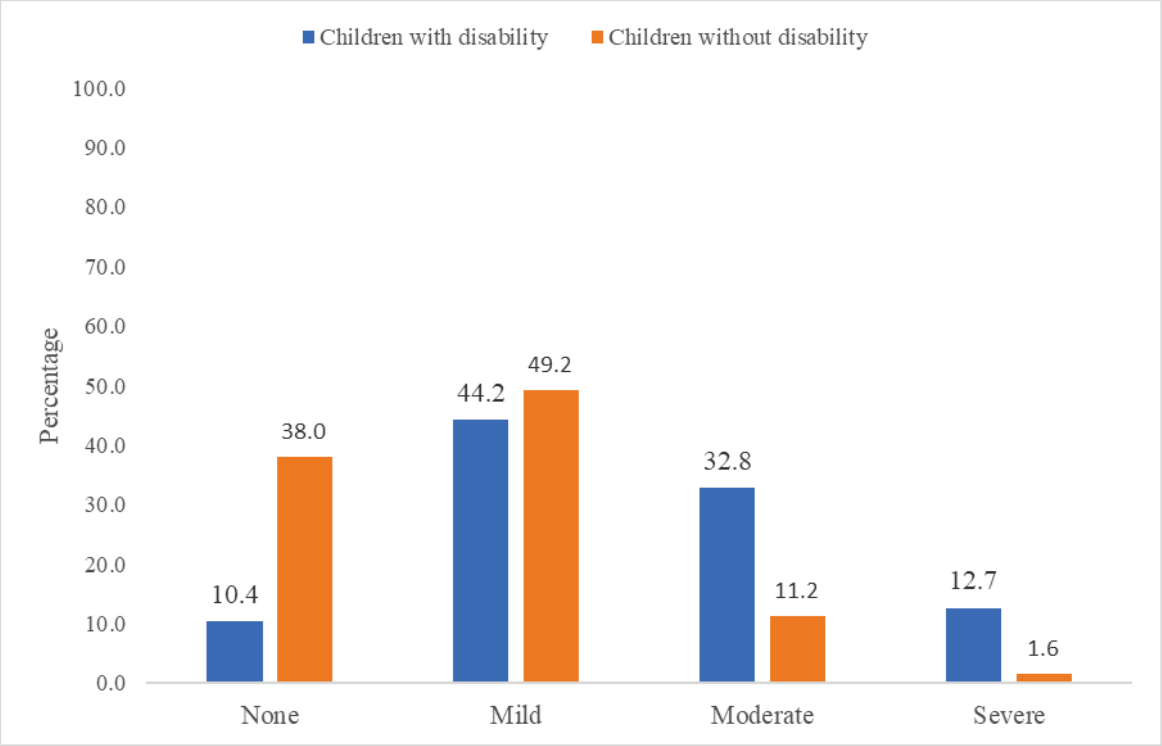


Figure 4.2: Percentage distribution of disability categories by sampling frame groups (n=1,439)



p-value <0.05

Figure 4.3: Percentage distribution of overall disability by C-DAS domains (n=1,439)

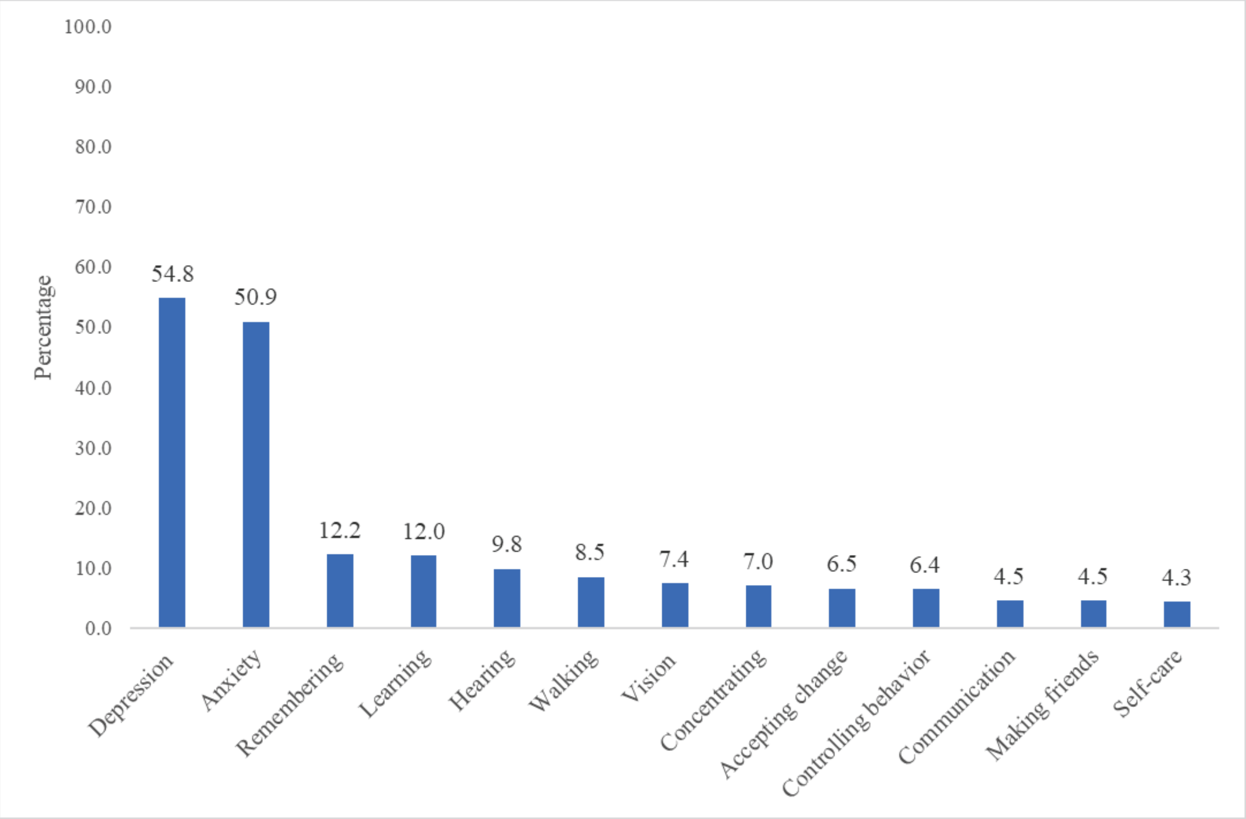


Figure 4.4: Percentage distribution of disability category by C-DAS domains (n=1,439)

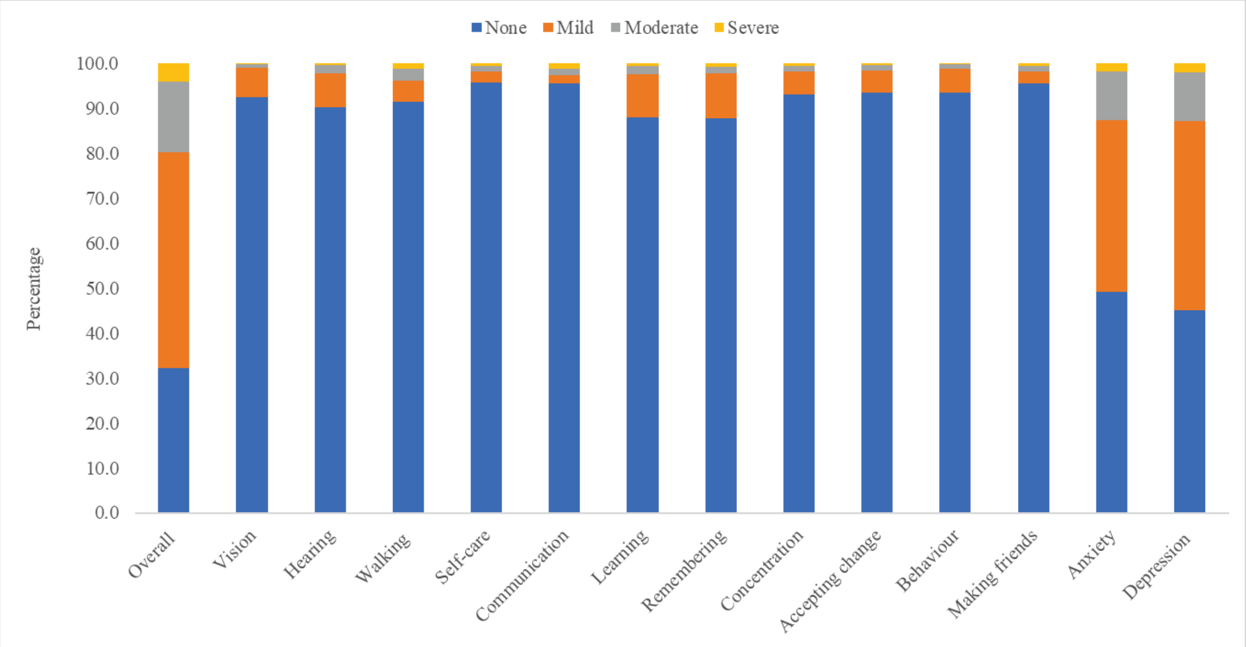
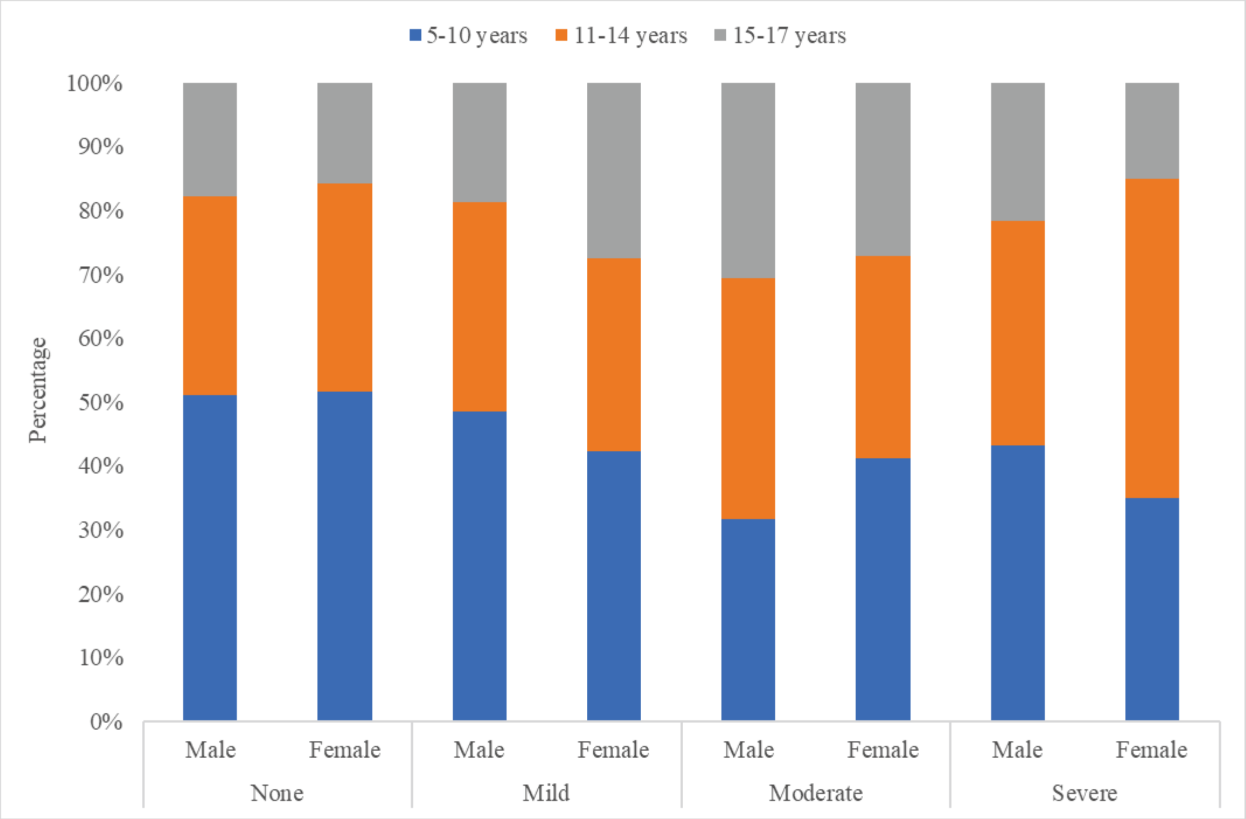


Figure 4.5: Percentage distribution of age category by disability category and sex of child (n=1,439)



Chapter 5: Conclusion

Goal 17 of Sustainable Development Goals (SDGs) emphasizes the importance of high quality, reliable and timely availability of disability data to monitor the progress of disability-related SDGs; Goal 4 highlights inclusive education; Goal 8 is for equal and inclusive employment opportunities; Goal 10 stresses social, economic and political inclusion of individuals with disabilities; and Goal 11 underlines accessible cities, transport services and public spaces [1, 2].

Disability is a complex phenomenon and based on the International Classification of Functioning (ICF), is a result of interactions between impairments at the body level, in the context of a health condition, as well as contextual factors specific to the environment in which the individual lives [3]. Availability of disability data is limited and is even more scare for children. Understanding disability among children is crucial to develop and implement interventions that account for their growth and development. In this regard, one of the main problems has been the lack of standardized, easy-to-use instruments that could be applied to understand child disability in different contexts [4, 5].

This study implemented a tool for measuring disability in children living at the Iganga-Mayuge Health and Demographic Surveillance Site (IM-HDSS) in Uganda. The tool called Child Disability Assessment tool (C-DAS) was applicable to children between 5-17 years of age, and this study was the first to implement C-DAS at IM-HDSS. C-DAS comprised of 24 questions covering 13 domains: vision, hearing, walking, self-care, communication, learning, remembering, concentrating, accepting change, controlling behavior, making friends, anxiety, and depression. The focus of C-DAS is on assessing physical disability in children and is not applicable to children with intellectual disabilities due their unique needs. Additional data related to child and caregiver demographics (age, gender, education), caregiver employment status, child birth, vaccination, sibling information, school and work history, child disability information (type, cause, duration, use of assistive devices), health-seeking practices, household members, and household asset were also collected. This study built upon previous disability work conducted at IM-HDSS [6, 7].

Key study points

C-DAS tool was translated to Lusago (a Ugandan language) and back translated to English. The tool was pre-tested to ensure that questions were clearly stated and comprehensible for respondents. The final version used for data collection was developed in consultation with IM-HDSS field coordinators and supervisor [8]. It took 20-25 minutes to administer C-DAS.

Paper 1 explored psychometrics properties of C-DAS. C-DAS showed good overall internal consistency. Its validation showed that it is a unidimensional, two-factor, valid and reliable scale for assessing disability among children (5-17 years) in Uganda. It was an easy-to-administer tool that helped in deeper understanding of context-specific burden and type of disability in children between 5-17 years of age. This standardized tool can be used at national and sub-national levels for collecting longitudinal data in a timely manner to generate evidence for policy-makers, and for monitoring and evaluation of interventions.

The main respondent of C-DAS were caregivers of children; however, one of the issues in measurement of disability is to understand who the best respondent for C-DAS is – child or their caregiver. Perceptions of children and that of their caregivers may differ about functioning and limitations. In *paper 2*, responses of child (11-17 years) and their caregivers were compared. This study explored both total scores and Likert-scale responses for caregiver and child pairs. Based on both these approaches, it was found that the responses did not differ significantly between caregivers and their children. This means that community-based assessment of child functioning and disability can be conducted by interviewing either caregivers or children with disability. Disability assessment needs to be contextualized, and it is important to understand relevant caregiver, household, and social factors that may impact a child's disability. Given that caregivers are more informed about such factors and the impact these have on their child, family and household, it is probably important to interview caregivers in addition to children to obtain a better understanding of disability and related factors.

Paper 3 assessed burden of disability among children living at IM-HDSS and also explored factors associated with disability. Of 1,439 caregivers interviewed, around 48.01% had children with mild disability, 15.84% with moderate disability, and 3.96% with severe disability. According to the generalized ordered logit model, completion of immunization status and school enrollment were statistically and significantly associated with the three disability categories when controlled for child's age, sex, a primary caregiver status, age of mother at child's birth, family system, family size and household wealth quintile. In addition, age group, having a primary caregiver, and family system were statistically and significantly associated with mild and moderate disability but not with severe disability.

Practical implications

Timeliness of data is crucial for monitoring interventions. Data collection was done using a tablet-based platform that was developed and pre-tested using tablets and server available at the IM-HDSS. Questions had check box and free text entry formats to input responses. Questions were designed to allow skip patterns where appropriate, and mandatory fields were also marked. This reduced data entry-related errors and missing data.

Interventions for children with disability cannot be implemented as "one size fit all"; these require individual catering to the specific needs of each child. C-DAS is administered using 4-point Likert scale response, which allowed analysis based on disability severity – mild, moderate and severe. Such distinction helps to plan and implement interventions according to children's needs. It also provides a more accurate picture of the spectrum of disability in the population.

Uganda has laws and policies which focus on individuals with disabilities; however, there is lack of their implementation. One of the potential reasons could be the lack of quality data. Implementation of C-DAS at IM-HDSS shows that it can be implemented for data collection at the sub-national level and can generate data that can be used by local district health offices to plan interventions catering to needs of children with disabilities, especially for education, employment and healthcare needs. These efforts can help in integration of individuals with disabilities and reduces their vulnerabilities. In addition to guiding development of interventions, data from C-DAS can be used for monitoring and evaluation of interventions, thus allowing policy-makers and local district health officials to assess value for money associated with these interventions.

C-DAS is a self-reported disability assessment tool that does not ask directly about disability. Instead, it assesses level of difficulty in performing activities. Respondents don’t need to know a cause of disability to be able to reply to C-DAS questions. This approach helps in identification of children within communities who might be at risk of disability and might benefit from intervention, if identified in a timely manner.

Way forward

Future work needs to focus on integration of C-DAS into core data collection conducted at the IM-HDSS; this will allow to study adaptation patterns of children with disabilities and their progress as they grow. C-DAS is a community-based tool and helps to identify children who have varying level of disability. It allows assessment of disability in 13 domains, providing in-depth data on children. There is need to develop mechanisms for clinical assessment of children, especially those in the mild disability category, to allow for timely interventions. There is a possibility that these children are able to overcome their disability, which otherwise may progress further, thus limiting their level of integration in society.

Developing polices and interventions to address the needs of disabled children is possible using reliable data, and such data can be a means of understanding the needs of disabled children based on their sex and age and ensure their integration within their environments like home, school, and work [9, 10]. Such data is also useful to identify children in need of clinical and rehabilitation support for their disability. Such a standard, validate tool can be used for comparison across context and is important for getting disaggregated data on variables like gender, quintile, education, and employment. It also allows for monitoring of programs and policies, program implementation and larger monitoring of SDGs [11, 12].

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Annexes

Annex 1

Child Disability Assessment Tool for Caregivers of Children (5-17 years)
Pilot study at the Iganga-Mayuge Health & Demographic Surveillance Site (IMHDSS)
Caregiver version

THE RESPONDENT MUST BE PRIMARY CAREGIVER OF THE CHILD BETWEEN 5-17 YEARS OF AGE. THE QUESTIONS ARE RELATED TO THE CHILD IDENTIFIED IN THE HOUSEHOLD. **Ayiramu ateekebwa okuba oyo alabirira omwana ali ghagati we myaka 5-17. Ebibuuzo bigemagana ku mwana alondebwa mu maka gano.**		
FA code: ____________________ **Date of Interview:** ____________________	**Study ID:** ____________________ **Interview visit:** First ☐ Second ☐ Third ☐	
Caregiver consent received Alabirira (Name) aikiriza okubuziibwa	1. Yes 2. No	
MODULE A: DISABILITY AND INJURY SCREENING TOOL **INSTRUCTIONS**: The following questions ask the caregiver about difficulties that the child (5-17 years old) may have doing certain activities because of a health problem. Nandienze okubuza obubuzo obugemagana kubukalubilivu (Name) bwayinza okubanabwo mukukola emirimo egyendawulo olwembera eyobulamubwe.		
MA1. Does the child have difficulty seeing, even if wearing glasses? (Name) aliku nobukalubilivu mukubona waile nga akozesa galubindi?	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	
MA2. Does the child have difficulty hearing, even if using a hearing aid? (Name) aliku nobukalubilivu mukuwulira wailenga akozesa ebyuma ebiyamba okuwulira?	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	
MA3. Does the child have difficulty walking or climbing steps? (Name) aliku nobukalubilivu mukutambula oba okunina amadala?	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	
MA4. Do the child have difficulty using hands & arms for pulling, pushing, reaching, throwing, catching? (Name) aliku nobukalubilivu mukukozesa emikono	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	

ne'ngalo mukusika, mukusindika, mukukanuga oba mukugema?		
MA5. Do the child have difficulty with self-care such as washing all over or dressing? (Name)aliku nobukalubilivu mukwelabilira nga mukunaaba, a okweyoleza oba okweyambaza?	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	
MA6. Using your usual (customary) language, does the child have difficulty communicating, for example understanding or being understood? (Name) Nga akosesa olimile olwa bulidho, aliku nobuzibu mukuwuliziganhia nga okutegera oba okutegerekeka?	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	
INSTRUCTIONS: The next questions ask the caregiver about injuries that the child may have had, which prevented the child from carrying out his/her normal daily activities for at least one day or for which you paid for any type of treatment. Ebibuzo ebilaaku bigemagana kubukosefu(Name) bwayinza okuba nga yafunaku, obwamulobera okukola emirimu gye egyabulidho okumala nga olunaku lulamba, bwemusasulira obwidhandhabi.		
I1. Did the child have any type of injury within the last four months? (Name) yafunaku obukosefu bwon bwona mumyezi ena egibise?	1. Yes 2. No	**2** ⇨ Next section
I2. What was the cause of injury? (Multiple options can be selected) Obukosefu bwava kuki?	1. Traffic 2. Unintentional fall 3. Burn 4. Gun shot 5. Stab 6. Blunt injury 7. Poisoning 8. Drowning 9. Dog, snake or other animal bite 10. Landmine 96. Unknown 97. Other (specify)	1 ⇨ I3
I3. What is the road user type for traffic injury? Omuntu yali kikaki eyafuna obukosefu ngali kukozesa oluguudo	1. Pedestrian 2. Car driver 3. Motorcycle or bicycle driver 4. Car passenger 5. Motorcycle or bicycle passenger 6. Vehicle occupant not otherwise specified 96. Unknown 97. Other (specify)	
MODULE C-DAS: CHILD IN-DEPTH DISABILITY ASSESSMENT		

CAREGIVER INFORMATION **AMAWULILE AGAGEMA KUALABIRIRA OMWANA**		**CI**
INSTRUCTIONS: The following questions are related to basic information of the caregiver. Ebibuuzo ebilaku bigemagana kumawulire agafa ku alabirira omwana		
CI1. What is your (caregiver) relationship with the head of household? Ayizemu ayetatya omukulu wamaka gano?	1.Self 2.Parent 3.Son/daughter 4.Cousin 97.Other (specify)	
CI2. What is the relationship of the caregiver with the identified child? (Name) ayefa atya amulabirira?	1. Mother 2. Father 3. Sibling 4. Uncle/Aunt 5. Grandparent(s) 97. Other (specify) 98. Don't know	
CI2. How old are you? Olina emyaaka emeka?	____________________	
CI3. What is the sex of the caregiver? Ekikula ky'ayizemu?	1.Male 2. Female	
CI4. What is the ethnic group of the respondent? Ayizemu wa ighangaki?	1. Basoga 2. Langis 3. Banyankole 4. Baganda 5. Bagwere 6. Bakiga 7. Karamajong 8. Bagisu 9. Itesot 10. Acholis 11. Lugubar 12. Japadhola 13. Samias 14. Banyole 97. Other (specify) 98. Don't know	
INSTRUCTIONS: The questions from here onwards are related to the child identified in the household. The respondent is the caregiver of the identified child. Ebibuuzo ebiiraku bigema ku mwana azuuliibwa nga ali n'obulemu mumaka gano. Ayiramu nalabirira omwana azuulibwa.		
CHILD DEMOGRAPHIC INFORMATION		**CD**

AMAWULIRE AGAGEMA KU MWANA		
INSTRUCTIONS: Following questions ask the caregiver about basic information of the child. Ebibuuzo ebilaku bibuuzibwa alabirira (Name) nga bigemagana ku mawulire aga mufaaku.		
CD1. What is the child's date of birth? (Name) yazaliibwa li?		
CD2. What is the age of the child in years? (Name) alina emyaka emeka?	____________________	
CD3. What is the sex of the child? Ekikula kya'(Name)?	1.Male 2.Female	
CD4. What is the religion of the child? (Name) wa idini ki?	1.Catholic 2.Protestant 3.Muslim 4.Pentecostal 5.SDA 6.Other Christian 7.No religion 97.Other (specify)	
CD5. What is the ethnic group of the child? (Name) wa ighanga ki?	1. Basoga 2. Langis 3. Banyankole 4. Baganda 5. Bagwere 6. Bakiga 7. Karamajong 8. Bagisu 9. Itesot 10. Acholis 11. Lugubar 12. Japadhola 13. Samias 14. Banyole 97. Other (specify) 98. Don't know	
CHILD BIRTH HISTROY **EBIFA KUKUZAALIBWA KWA (NAME)**		**CB**
INSTRUCTIONS: Following questions ask the caregiver about birth history of the child. In addition, ask if the caregiver has a birth card or birth certificate of the child, use the card to verify data for questions CB1-CB5. Ebibuuzo ebiiraku bibuuzibwa alabirira (Name) nga bigemagana ku kuzaalibwa kwe..Buuza oba alabirira omwana alin'ekipande kyona kyonqa ekilaga obuzaale bwe.		

CB1. Where was the child born? (Name) yazaalibwa gha?	1. Home 2. Healthcare facility (hospital/clinic) 3. On the way to facility 4. At the place of TBA 97. Other(specify) 98. Don't know	
CB2. Who helped with the delivery? Ani eyamuyambaku mukuzaala?	1. Nobody/herself 2 Traditional birth attendant (TBA) 3. Nurse/midwife/doctor 4. Friend 5. Neighbor 6. Family member 97. Other (specify) 98. Don't know	
CB3. What was the mode of delivery of the child? Yamuzaala otya?	1. Normal 2. C-section 97. Other (specify) 98. Don't know	
CB4. What was child's birth weight in kilograms? (Name) yali waabuzito ki nga yakazaalibwa (Kgs)?	________________ 98. Don't know	
CB5. What was the age of biological mother at the time of the child's birth? Maama womwaana kenekene, yali wamyaka emeka gheyamuzaalira?	________________ 98. Don't know	
CHILD VACCINATION HISTROY **EBIGEMAGANA N'OKUGEMEBWA KWA (NAME)**		**CV**
INSTRUCTIONS: Following questions ask the caregiver about vaccination history of the child Ebibuzo ebiraku bbuziba alabirira (Name)kubigema gana n'o kukugemebwa kwe		
CV1. Was the child immunized? (Name) yagemebwa?	1. Yes 2. No 98. Don't know	
CV2. Do you have vaccination card for the child? Olina ekipande kyebaagemeraku (Name)?	1. Yes 2.No	1⇨CV3-11 2⇨CV12
CV3. Was the child given BCG at birth? Bamugema akakololo nga yakazalibwa?	1. Yes 2. No	
CV4. Was the child given polio 0 at birth? Bamugema walugono nga yakazalibwa?	1. Yes 2. No	

CV5. Was the child given DPT+HebB+Hib1 at 6 weeks? (Name) yafuna akapiso akokukismbi (DPT+HebB+Hib1)nga aghezeza wiiki omukaaga?	1. Yes 2. No	
CV6. Was the child given polio 1 at 6 weeks? Bamugema walugono asooka bweyagheza wiki omukaaga?	1. Yes 2. No	
CV7. Was the child given DPT+HebB+Hib2 at 10 weeks? Bamugema DPT+HebB+Hib2 bwe yagheza wiki eikumi?	1. Yes 2. No	
CV8. Was the child given polio 2 at 10 weeks? Bamugema walugono omulundi ogwokubiri bwe yagheza wiki eikumi?	1. Yes 2. No	
CV9. Was the child given DPT+HebB+Hib3 at 14 weeks? (Name) yafuna akapiso akokukisambi (DPT+HebB+Hib3)nga aghezeza wiki eikumi neina?	1. Yes 2. No	
CV10. Was the child given polio 3 at 14 weeks? (Name) bamugema walugono omulundi ogw'okusatu bwe yagheza wiki eikumi neina?	1. Yes 2. No	
CV11. Was the child given Measles vaccine at 9 months? (Name) bamugema olunkusense bwe yagheza wiki eikumi neina?	1. Yes 2. No	
CV12. Has the child got a BCG scar (given on right upper arm)? (Name) alina enkovu eyobugeme kumukono omusadha?	1. Yes 2. No 98. Don't know	
CV13. Has the child been given drops in the mouth? (Name) bamutoneza amatondo mukanwa?	1.Yes 2. No 98. Don't know	1⇨CV14
CV14. How many times were the drops given? Bamutonhiaamu emirundi emeka?	______________________	

CV15. Has the child received an injection on left upper thigh? (Name)yafuna akapiso kukisambi eky'omugulu omugedha?	1. Yes 2. No 98. Don't know	1⇨CV16
CV16. How many times was the injection given? Akapiso kano yakafuna emirundi emeka?	______________________	
CV17. Has the child received an injection on left upper arm? (Name) yafuna akapiso ku mukono omukazi?	1. Yes 2. No 98. Don't know	1⇨CV18
CV18. How many times was the injection given? Akapiso kano yakafuna emirundi emeka?	______________________	
CHILD SCHOOL & WORK HISTROY EBIGEMA KUKUSOMA KWA (NAME) NEMIRIMO		**CSh**
INSTRUCTIONS: Following questions are about the child's education and work. Ebibuzo ebiiraku bigema ku byendegeresa nemirimo gya (Name)		
CSh1. Is the child currently attending school? Buti (Name) asoma?	1. Yes 2. No 98. Don't know	2⇨CSh10
CSh2. What class is the child currently attending? Ali mu kibiina ki buti?	___________________	
CSh3. How does the child commute to school? (Name) atera kukozesa ntambula ki okuja ku isomero?	1. Private vehicle 2. Public transport 3. School van 4. Motorcycle (Boda boda) 5. Walk 97. Other (specify) 98. Don't know	
CSh4. Does someone accompany the child to school? Ghaliwo atera okumugherekera ku isomero?	1. Yes 2. No 98. Don't know	2⇨CSh6
CSh5. Who accompanies the child? Ani atera okumugherekera ku isomero?	1. Mother 2. Father 3. Sibling 4. Uncle/Aunt 5. Grandparent (s) 97. Other (specify) 98. Don't know	

CSh6. What school does the child go to? (Name) asomera ku isomer ki? *Note down name of the school.*	____________________	
CSh7. What is the approximate distance between child's house and school (in kilometers)? Mukugerageranhia waliwo buwanvu ki okuva awaka okutuuka ku isomero? (Km)	____________________	
CSh8. How much time does it take to reach school? Kitera kutwaala kiseera ki okutuuka ku isomero?	1. less than 15 minutes 2. 15 - 30 minutes 3. 31 – 45 minutes 4. 46 – 60 minutes 97. Other (specify) 98. Don't know	
CSh9. How much time does it take to return from school? Kitera kutwaala kiseera ki okuva ku isomer okutuuka waka?	1. less than 15 minutes 2. 15 - 30 minutes 3. 31 – 45 minutes 4. 46 – 60 minutes 97. Other (specify) 98. Don't know	
CSh10. Was the child ever in school? (Name) yali agileku ku isomero?	1. Yes 2. No 98. Don't know	2⇨CSh12
CSh11. What is the child's reason for leaving or not going to school? Nsonga ki (Name) gyaawa okulekera okusoma oba obutaja kwisomero?	1. School not suitable for children with disabilities 2. School refused admission to the child 3. Financial difficulties of the family 4. Bullying by other children in school 97. Other (specify) 98. Don't know	
CSh12. Does the child work to support his/her family? (Name) alina kyakola okuyamba ab'omumaka mwaaviira?	1. Yes 2. No 98. Don't know	2⇨CP3
CSh13. What type of work for income does the child do? Oba yii, akola mulimo ki?	1. Shop/business 2. Boda boda/taxi 3. Professional 4. Farmer/agriculture 5. Market vendor 6. Laborer (wage) 7. Mechanical work 8. Street vendor 9. Student	

	10. Unemployed 97. Others (specify) 98. Don't know	
CSh14. How long has the child been working for? (Name) amaze ibanga ki nga akola?	1. Days 2. Weeks 3. Months 4. Years	1⇨CP14a 2⇨CP14b 3⇨CP14c 4⇨CP14d
CSh14a. How many days has the child been working for? Ennaku imeka (Name) zamaze nga akola?	___________________	
CSh14b. How many weeks has the child been working for? Wiiki imeka (Name) zamaze nga akola?	___________________	
CSh14c. How many months has the child been working for? Emyezi emeka (Name) gyamaze nga akola?	___________________	
CSh14d. How many years has the child been working for? Emyaka emeka (Name) gyamaze nga akola?	___________________	
CSh15. What is the child's monthly income (in local currency)? (Name) afuna sente imeka omwezi?	___________________	
CSh16. What is the marital status of the child? (Name)mufumbo oba timufumbo? *Ask this question only from caregivers of children between 11-17 years of age?*	1. Single/never married 2. Married 97. Other (specify) 98. Don't know	
CHILD PARENTS' INFORMATION **AMAWULIRE AGAGEMA KU BAZAIRE BWA (NAME)**		**CP**
INSTRUCTIONS: Following questions are about the child's parents. Ebibuzo ebiraku bibuuzibwa alabirira (Name) nga bigemagana ku bazaire kenekene		
CP1. Is biological mother of the child alive? Maama wa (Name) kenekene akali mulamu?	1. Yes 2. No 98. Don't know	
CP2. Is biological father of the child alive? Baaba wa (Name) kenekene akali mulamu?	1. Yes 2. No 98. Don't know	
CP3. What is/was the age of biological mother?	1. Age in years 98. Don't know	

Maama wa'(Name) ali na/yali n'emyaka emeka/?		
CP3. Mention age of biological mother (Maama wa (Name) kenekene alin'emyaka/yali n'emyaka emeka?	____________________	
CP4. What is/was the age of biological father? Bbaba wa (Name) ali na/yali n'emyaka emeka/?	1. Age in years 98. Don't know	
CP4. Mention age of biological father (Bbaba wa (Name) kenekene alin'emyaka/yali n'emyaka emeka?	____________________	
CP5. What is/was the highest level of education of biological mother? Maama wa (Name) yakoma mukibiina ki?	1. No education 2. informal education 3. Upto grade 5 4. Upto grade 8 5. Upto Grade 10 6. Upto grade 12 7. Bachelors 8. Diploma 9. Professional education 97. Others (specify) 98. Don't know	
CP6. What is/was highest level of education of biological father? Baaba wa (Name) yakoma mukibiina ki?	1. No education 2. informal education 3. Upto grade 5 4. Upto grade 8 5. Upto Grade 10 6. Upto grade 12 7. Bachelors 8. Diploma 9. Professional education 97. Others (specify) 98. Don't know	
CP7. What is/was occupation of the biological mother? Maama wa (Name) akola /yali akola mulimo ki?	1. Shop/business 2. Boda boda/taxi 3. Professional 4. Farmer/agriculture 5. Market vendor 6. Laborer (wage) 7. Mechanical work 8. Street vendor 9. Student 10. Unemployed 11. Homemaker 97. Others (specify) 98. Don't know	

CP8. What is/was occupation of the biological father? Baaba w a (Name akola/yali akola mulimo ki?	1. Shop/business 2. Boda boda/taxi 3. Professional 4. Farmer/agriculture 5. Market vendor 6. Laborer (wage) 7. Mechanical work 8. Street vendor 9. Student 10. Unemployed 11. Homemaker 97. Others (specify) 98. Don't know	
CP9. Does the biological mother live in the same house with the child? Maama aba munhumba ndhala nhi (Name)?	1. Yes 2. No 98. Don't know	
CP10. Does the biological father live in the same house with the child? Bbaba aba munhumba ndhala nhi (Name)?	1. Yes 2. No 98. Don't know	
CHILD SIBLING HISTROY **EBIGEMA KUBAGANDABE/BAANINA BA (NAME)**		**CSi**
INSTRUCTIONS: Following questions are related to the child's siblings. Ebibuzo ebiiraku bibuuzibwa alabirira (Name) nga bigemagana bagandabe/baanina		
CSi1. Does the child have any siblings? (Name) alinaku mugandawe/mwaanina yenayena?	1. Yes 2. No 98. Don't know	
CSi2. How many biological siblings does the child have? Abaana bazalibwa nabo bali bameka?	____________________	
CSi3. What is the birth order of the child? (Name) yali waakumeka mukuzaalibwa?	____________________	
CSi4. Do any siblings of the child have disability? Kubaana baazaalibwa nabo ghaliwoku alina obulemu? *Note Name, age and sex (sibling with disability)*	1. Yes 2. No 98. Don't know	
CHILD DISABILITY HISTORY **EBIGEMA KUBULEMU BWA (NAME)**		**CDi**

INSTRUCTIONS: Following questions ask the caregiver about cause and duration of the child's disability. Ebibuuzo ebiraku bibuuzibwa alabirira (Name) nga bigemagana kunsonga eyaviraku obulemu bwe na ibanga ki lyamaze nabwo.		
CDi1. What was the main cause of this disability? KIki ekyasinga okuviraku obulemu bwa (Name)?	1. By birth 2. Injury (e.g. fall, road injury) 3. Infectious diseases (e.g. polio) 97. Other (specify) 98. Don't know	
CDi2. How long has the child had this disability? Obulemu buno bumumaazeeku ibanga ki?	1. Days 2. Weeks 3. Months 4. Years 94. Not applicable	
CDi2a. How many days has the child had disability for? Ennaku imeka (Name) zamaze nga akola?	______________________	
CDi2b. How many weeks has the child had disability for? Wiiki imeka (Name) zamaze nga akola?	______________________	
CDi2c. How many months has the child had disability for? Emyezi emeka (Name) gyamaze nga akola?	______________________	
CDi2d. How many years has the child had disability for? Emyaka emeka (Name) jamaze nhobukosefu?	______________________	
CHILD FUNCTIONING (AGE 5-17) **EMBEERA YA(NAME) - (EMYAAKA 5-17)**		**CF**
INSTRUCTIONS: Following questions ask the caregiver about difficulties the child may have. In the following questions, you will be asked to answer by selecting one of four possible answer choices. For each question, would you say that the child has: 1) no difficulty 2) some difficulty 3) a lot of difficulty 4) cannot do at all. Repeat the categories during the individual questions whenever the respondent does not use an answer category. Ebibuuzo ebiiraku bibuuziba alabirira (Name)nga bigemagana ku bukalubilivu bwayinza okuba nabwo. Ebibuuzo ebiiraku , oidha kusabibwa okwiramu, buli kibuzo, nga olondaku kirala kubino wamanga:		

1) Nzira bukalubirivu 2) Obukalubirivu butontono 3) Obukalubirivu bwamaanhi inho 4) Tisobola kukikola waire Ayiramu bwaba takwizemu,mwiriremu eby'okwiramu wamanga.		
CF1. Does the child wear glasses or contact lenses? (Name) avaala galubindi?	1. Yes 2. No	1⇨CF2 2⇨CF3
CF01. Check if the child wears glasses or contact lenses Kebera oba (Name) avaala galubindi?	1. Yes 2. No	
CF2. When wearing his/her glasses or contact lenses, does the child have difficulty seeing? Ghavaala galubindi afuna obuzibu mukubona?	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	
CF3. Does the child have difficulty seeing without glasses? (Name) akalubirizibwa okubona ghaba tavaire galubindi?	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	
CF4. Does the child use a hearing aid? (Name) alina byaakozesa mukuwulira?	1. Yes 2. No	1⇨CF5 2⇨CF6
CF04. Check if the child uses hearing aid Kebera oba(Name) akozesa ekimuyambaku mukuwulira	1. Yes 2. No	
CF5. When using his/her hearing aid, does the child have difficulty hearing sounds like peoples' voices or music? Gh'aba ali kukozesa ekimuyamba okuwulira, akalubirizibwa okuwulira amaloobozi ng'agabantu oba enhemba?	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	
CF6. Does the child have difficulty hearing sounds like peoples' voices or music without hearing aid? (Name) akalubirizibwa okuwulira amalooboozi ng'agabaatu oba enhemba gh'aba takozeisa bimuyambaku mukuwulira?	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	
CF7. Does the child use any equipment or receive assistance for walking?	1. Yes 2. No	2⇨CF12

(Name)alina ky'akozesa oba ayambibwaaku okusobola okutambula?		
CF07. Check if the child uses equipment or receives assistance for walking? Kebera oba (Name) akozesa ebimuyambaku okutambula oba afuna obuyambi okumusobozesa okutambula	1. Yes 2. No	
CF8. Without his/her equipment or assistance, does the child have difficulty walking 100 yards/meters on level ground? That would be about the length of 1 football field. (Name) gh'aba takozeisa kimuyambaku oba okuyambibwaaku, akalubirizibwa okutambula yaadi/mita 100 kumuseetwe. (Olwo olugendo luyinza kwaagayaga nekisaaghe ky'omupiira kirala *Note that category 'No difficulty' is not available, as the child uses equipment or receives assistance for walking.*	2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	3⇨CF10 4⇨CF10
CF9. Without his/her equipment or assistance, does the child have difficulty walking 500 yards/meters on level ground? That would be about the length of 5 football field. (Name) ghaba azira bimuyambaku oba okuyambibwaaku, akalubirizibwa okutambula yaadi/mita 500 kumuseetwe? (Olwo olugendo luyinza kwaagayaga nebisaaghe byamupiira bitaanu *Note that category 'No difficulty' is not available, as the child uses equipment or receives assistance for walking.*	2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	
CF10. With his/her equipment or assistance, does the child have difficulty walking 100 yards/meters on level ground? That would be about the length of 1 football field. (Name) gh'aba akozeisa ekimuyambaku okutambula oba okuyambibwa, akalubirizibwa okutambula yaadi/mita 100 kumuseetwe. (Olwo olugendo luyinza kwaagayaga nekisaaghe ky'omupiira kirala	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	3⇨CF14 4⇨CF14
CF11. With his/her equipment or assistance, does the child have difficulty walking 500 yards/meters	1. No difficulty 2. Some difficulty 3. A lot of difficulty	1⇨CF14

on level ground? That would be about the length of 5 football fields. (Name) gh'aba okozeisa ebimuyambaku oba okuyambibwaku, akalubirizibwa okutambula yaadi/mita 500 kumuseetwe? (Olwo olugendo luyinza kwaagayaga nebisaaghe byomupiira bitaanu (5)	4. Cannot do at all	
CF12. Compared with children of the same age, does the child have difficulty walking 100 yards/meters on level ground? That would be about the length of 1 football field. Bwogerageranhia (Name) n'abaana ab'emyakagye, akalubirizibwa okutambula yaadi/mita 100 kumuseetwe? (Olwo olugendo luyinza kwagayaga nekisaaghe kyomupiira kirala (1)	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	3⇨CF14 4⇨CF14
CF13. Compared with children of the same age, does the child have difficulty walking 500 yards/meters on level ground? That would be about the length of 5 football fields. Bwogelagelanhia (Name)n'abaana abandi ab'emyakagye, akalubirizibwa okutambula yaadi/mita 500 kumuseetwe? (Olwo olugendo luyinza kwaagayaga nebisaaghe by'omupiira bitaanu (5)	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	
CF14. Does the child have difficulty with self-care such as feeding or dressing himself/herself? (Name)alina obukalubirivu okwerabirira okugeza nga okweriisa oba okweyambaza?	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	
CF15. When the child speaks, does he/she have difficulty being understood by people inside of this household? (Name)ghaba ayogera, olina obukalubirivu abantu abandi aboomumakaage okutegeera byaali kukoba?	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	
CF16. When the child speaks, does he/she have difficulty being understood by people outside of this household? (Name) ghaba ayogera, ali n'obukalubirivu abantu abandi abatali bamukakage okutegeera byali kukoba?	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	
CF17. Compared with children of the same age, does the child have difficulty learning things?	1. No difficulty 2. Some difficulty 3. A lot of difficulty	

Bwogelegelanhia (Name)n'abaana ab'emyaka gye, ali n'obukalubirivu okweega ebintu?	4. Cannot do at all	
CF18. Compared with children of the same age, does the child have difficulty remembering things? Bwogelagelanhia (Name)n'abaana ab'emyaka gye, alina obukalubirivu okwidhukira ebintu?	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	
CF19. Does the child have difficulty concentrating on an activity that he/she enjoys doing? (Name) alina obukalubirivu okweenigira mukukola ekintu kyayendha einho?	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	
CF20. Does the child have difficulty accepting changes in his/her routine? (Name) alina obukalubirivu okwikiriza enkyukakyuka mumbeeraye eyabuliidho?	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	
CF21. Compared with children of the same age, does the child have difficulty controlling his/her behavior? Bwogerageranhia (Name) n'abaana ab'emyaka gye, afuna obuzibu okwefuga mungeri yeyebisamu?	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	
CF22. Does the child have difficulty making friends? (Name) alina obuzibu okukola emikwano?	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	
The next questions have different options for answers. The options will be read to you after each question. Ebibuuzo ebiiraku, birina ebyokwiramu byandawulo,nga biidha kusomebwa buli luvainuma lw'akibuuzo		
CF23. How often does the child seem very anxious, nervous or worried? (Name) atera li okweetya oba okweeghaliikira?	1.Daily 2. Weekly 3. Monthly 4. A few times a year 5. Never	
CF24. How often does the child seem very sad or depressed? (Name) atera li okunakughala oba nga tiimusanufu?	1.Daily 2. Weekly 3. Monthly 4. A few times a year 5. Never	
CHILD CAREGIVER INFORMATION **AMAWULIRE AGAGEMA KU ALABIRILA (NAME)**		**CC**
INSTRUCTIONs: Following questions ask the caregiver about caregiving for the child.		

Ebibuuzo ebiiraku bigema ku oyo alabirila omwaana		
CC1. What type of family system does the child live in? (Name) aba mu maka gaakikaa ki?	1. Single-parent family 2. Nuclear family 3. Joint family 97. Other (specify) 98. Don't know	
CC2. Does the child have a primary caregiver? (Name) alina amulabirira nga abaawo ekiseera kyona kyona?	1. Yes 2. No 98. Don't know	2⇨Next section
CC3. What is the relation of the child with primary caregiver? (Name) ayeta aatya amulabirila?	1. Mother 2. Father 3. Sibling 4. Uncle/Aunt 5. Grandparent(s) 97. Other (specify) 98. Don't know	
CC4. What is the age of caregiver? Amulabilila alina emyaka emeka?	________________	
CC5. What is the highest education level of the caregiver? Alabirila (Name) yakoma mukibiina kyakumeka?	1. No education 2. informal education 3. Upto grade 5 4. Upto grade 8 5. Upto Grade 10 6. Upto grade 12 7. Bachelors 8. Diploma 9. Professional education 97. Others (specify) 98. Don't know	
CC6. What is the occupation of the caregiver? Amulabirira akola mulimo ki?	1. Shop/business 2. Boda boda/taxi 3. Professional 4. Farmer/agriculture 5. Market vendor 6. Laborer (wage) 7. Mechanical work 8. Street vendor 9. Student 10. Unemployed 11. Homemaker 97. Others (specify) 98. Don't know	
CC7. Where does the caregiver live? Alabirila (Name) abaagha?	1. Same house as the child 2. Different house in the same village 3. Different village	

	97. Other (specify) 98. Don't know	
CC8. What are the caregiving requirements of the child? *Can mark more than one option* Alabirila (Name)yetaaga biki okulabilira omwaana?	1. Needs personal assistance 2. Needs help with eating 3. Needs help with selfcare 4. Needs with transportation 5. Needs financial support 97. Other (specify) 98. Don't know	
CC9. How frequently does the child need caregiving? (Name) yetaaga okulabirilwa buli luvainuma lwa ibanga ki?	1.Every day 2. Every week 3.Every month 97. Other (specify) 98. Don't know	
CC10. Do you, as a caregiver, have any support group? Nga iwe amulabirira, ofunaku okuyambibwa okuva mu kibiina kyona kyona?	1. Yes 2. No	2⇨CF12
CC11. Who is in that support group? Ani ali mukibiina ekyo ekikuyambaku?	1. Other family members 2. Caregivers of other disabled children 3. Professional like psychologists, pediatricians 97. Other (specify)	
CC12. Do you think you need a support group? Olowooza wetaaga ekibiina ekyobuyambi?	1. Yes 2. No 98. Don't know	
CC13. What are the things that you think you need to better care for the child with disability? *Can mark more than one option* Olowooza bintu ki byeweetaaga okusobola okulabirira obulungi omwaana alina obulema?	1. Education 2. Financial support 3. Home visits by local community workers 4. School for disabled children 5. Access to healthcare services 6. Access to rehabilitation services 97. Other (specify) 98. Don't know	
CHILD HEALTHCARE ACCESS **OKWEETUSAAKU OBWIIDANDHABI BWA (NAME)**		**CH**
INSTRUCTIONS: Following questions ask the caregiver about access to medical care and rehabilitation care for the child. Medical care includes any medical care that the child needed for their disability for example visit to the doctor, getting medicines for their disability. Rehabilitation care means any care received by the child to help cope with their disability for example physical therapy for making muscles strong.		

Ebiibuuzo ebiraku bibuuzibwa alabirira (Name) nga bigemagana kukweetuusaaku obwiidandabi n'okubudabudibwa. Obwidhandabi obwekisawo butwaliramu okubona omusawo webyobulamu,n'okufuna obulezi. Okubudabudwibwa kutegeeza amagezi agaweebwa omwana okusobola okubaawo n'obulemu bwe nga okukola ebisaizi okugumya eningodhe.		
CH1. Does the child require medical care for his/her disability? (Name) yetaaga obwidhandhabi olw'obulemu bwalinabwo?	1. Yes 2. No 98. Don't know	2⇨CF9
CH2. How frequently does the child need medical care? Buli luvainuma lwa ibangaki(Name) weyeetaagira obwidhandhabi?	1. Every day 2. Every week 3. Every month 97. Other (specify) 98. Don't know	
CH3. Where is the child usually taken for medical care? (Name) mutera kumutwala gha okufuna obwidhandhabi?	1. Hospital 2. Health clinic/center 3. General medical practitioner 4. Community health worker 5. Traditional practitioner 6. Pharmacy 97. Other (specify) 98. Don't know	
CH4. What was the reason for last visit related to medical care? Nsongaki eyamutwaalisa mwilwaliro omulundi ogwasembayo?	1. Injury 2. Seizures 3. Medicine refill 4. Regular check-up 97. Other (specify) 98. Don't know	
CH5. How do you usually commute when the child needs medical care? Omwana gh'aba yetaaga obwidhandhabi mutera kukozesa ntambulaki?	1. Personal vehicle 2. Public transport 3. Taxi 4. Motorcycle (Boda Boda) 5. Ambulance 6. Walk 97. Other (specify) 98. Don't know	
CH6. What is the approximate distance (in kilometers) traveled to reach the facility for the last medical care received by the child? Bwogerageranhia, buwanvu ki (klms) (Name) bweyatambula okutuuka ku ilwariro omukuzi ogwasembayo?	____________________	
CH7. How long does it take to reach the facility for medical care? Kibatwaalira ibanga ki okutuuka kwilwaaliro waafunira obwidhandhabi?	1. Less than 1 hour 2. 1 - 2 hours 3. 3 – 6 hours 4. 7 – 9 hours 5. 10 – 12 hours	

	6. 13 – 24 hours 7. More than 24 hours 98. Don't know	
CH8. What was the cost of transportation to the facility for medical care (local currency) last time? Lwe mwasembayo okumutwaala mwilwaaliro mwaakozesa sente imeka?	___________________ 98. Don't know	
CH9. Does the child need rehabilitation care? (Name) yetaaga okubudhaabudibwa?	1. Yes 2. No 98. Don't know	2⇨CF11
CH10. What type of rehabilitation/correction is needed? Yetaaga kubudhaabudibwa kwa kika ki?	1. Mobility devices 2. Hearing aid 3. Vision glasses 4. Medication 5. Someone's assistance 6. Sign language 7. Surgical correction 97. Other (specify) 98. Don't know	
CH11. Why do you think the child doesn't need rehabilitation? Lwaki olowooza(Name) tiyetaaga kubudhaabudibwa?	1. Financial difficulties 2. Transportation difficulties 3. Rehabilitation will not improve child's disability 4. Not aware of a rehabilitation therapy that could benefit the child 5. Lack of trained rehabilitation staff 97. Other (specify) 98. Don't know	
HOUSEHOLD SES INFORMATION **AMAWULIRE AGAGEMA KUMBEERA N'EBYENFUNA**		**SES**
INSTRUCTIONS: Following questions ask the caregiver about the socioeconomic status of the household. Ebibuuzo ebiiraku bigemagana kumbeera n'ebyenfuna mumaka		
SES1. What is the approximate monthly household income (local currency)? Amaka gano gafuna sente nga imeka buli mwezi?	___________________	
SES2. What is the approximate monthly expenditure on the child with disability (local currency)? (Name) omusansanhiaku sente nga imeka bulimwezi kubulemu buno?	___________________	

SES3. How many people live in the house? Mu nhumba muno mubaamu abantu bameka?	____________________	
SES3a. Number of adults (older than 17 years) in the house Abantu abakulu (abaswika emyaka 17) bali bameka mu nhumba muno	____________________	
SES3b. Number of children (17 years and younger) in the house Abaana(abaweza emyaka 17 n'okwika ghansi), bali bameka mu nhumba muno	____________________	

Thank you for responding to the questions related to your child.

Webale okwilamu ebibuuzo bino

USE THE FOLLOWING TO TAKE PERMISSION FROM THE CAREGIVER TO INTERVIEW CHILD WITH DISABILITY IF AGE OF THE CHILD WITH DISABILITY IS BETWEEN 11-17 YEARS.

Now that you have completed the interview, we would like to talk to your child because the child is between 11-17 years and we would like to ask them a few questions as well. It will only take 20 minutes of their time. We will only talk to the child if you give us permission to do so. We will also take permission for interview from the child. The interview will only happen if we have permission from you as well as from the child.

If the child is close by, can you please ask the child to come for the interview? If the child is not with you now could we ask that you arrange for the child to return? If that is not possible, we can discuss a convenient time for us to come back.

KOZESA EBIGAMBO EBILLAKU OKUSOBOLA OKUFUNA OLUKUSA OKUVA ERI ALABIRIRA OMWANA ALINA OBULEMU BWABA NGA ALINA EMYAKA 11-17.

Buti nga bwomaze okwilamu ebibuuzo byaife. Nandyenze okwogeraku no mwanawo ali ghagati ghe'myaka eikumi nomulala n'eikumi n'omusanvu, nendha kumubuuzaku ebibuuzo bitontono.biidha kutwala dakika nga makumi abiri. Twida kwogera n'omwana nga omaze okutugha olukusa. Twidha kwiramu tufune olukusa okuva eli omwana oyo. Twidha kumubuza ebibuuzo nga mwembi mwikiriiza.

Omwana bwaba kumpi, mukobe aidhe tumubuuze. Omwana bwaba azilagho osobola okukola entegeka okubona lwanaira? ekyo bwekiba tikisoboka, tusobola okwikirizagania li lwe tunasobola okwira

Annex 2

Child Disability Assessment Tool for Children (11-17 years)
Pilot study at the Iganga-Mayuge Health & Demographic Surveillance Site (IMHDSS)
Child Version

FA code: ______________________ **Date of Interview:** ______________________	**Study ID:** ______________________ **Interview visit:** First ☐ Second ☐ Third ☐	
Caregiver permission received to interview child (11-17 years) Alabirira omwana owe myaka 11-17 aikiriza okumubuuza	1. Yes **2.** No	
Assent from the child between 11-17 years Olupapula olusaba okwikiriza kw'omwana ali ghagati we myaka 11-17 okubuuzibwa	1. Yes 2. No	
MODULE C-DAS: CHILD IN-DEPTH DISABILITY ASSESSMENT (CHILD VERSION)		
CHILD DEMOGRAPHIC INFORMATION **AMAWULIRE AGAGEMA KU MWANA** INSTRUCTION: Following questions ask about your basic information Ebibuuzo ebiiraku bigema kumawulire agagema kumwaana		**CD**
CD2. What is your age? Olina emyaka emeka oba wazaliba lii?	______________	
CD3. What is the sex of the child? Omwana wakikula ki?	1. Male 2. Female 1.	
CSh1. Are you currently attending school? Buti osoma?	1. Yes 2. No 98. Don't know 98.	
CSh2. What class are you in at school? Osoma kibiina kyakumeka?	______________	
CHILD FUNCTIONING (AGE 11-17) **EMBEERA EY'OMWAANA(EMYAAKA 11-17)**		**CF**
INSTRUCTION: Following questions are about difficulties that you may have. In the following questions, you will be asked to answer by selecting one of four possible answer choices. For each question, do you have: 1) no difficulty		

2) some difficulty 3) a lot of difficulty 4) cannot do at all Repeat the categories during the individual questions whenever the respondent does not use an answer category. Ebibuuzo ebiiraku bigema kubukaluubirivu omwaana byayinza okubanabyo. Ebibuuzo ebiiraku , oidha kusabibwa okwiramu, buli kibuzo, nga olondaku kirala kubino wamanga: 1) Nzira bukaluubirivu 2) Obukaluubirivu butono 3) Obukaluubirivu bungi 4) Tisobola kukyikolaku waire Ayiramu bwaba takwizemu,mwiriremu eby'okwiramu wamanga.		
CF1. Do you wear glasses or contact lenses? Ovala galubindi?	1. Yes 2. No	1⇨CF2 2⇨CF3
CF01. Check if the child wears glasses or contact lenses. Kebera oba omwana avaala galubindi?	1. Yes 2. No	
CF2. When wearing your glasses or contact lenses, do you have difficulty seeing? Ghoovaala galubindi ofuna obukaluubirivu mukubona?	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	
CF3. Do you have difficulty seeing without glasses? Okalubirizibwa okubona ghoba tovaire galubindi?	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	
CF4. Do you use a hearing aid? Olina ky'okozesa okuwulira	1. Yes 2. No	1⇨CF5 2⇨CF6
CF04. Check if the child uses hearing aid Kebera oba omwaana akozesa ekimuyambaku mukuwulira	1. Yes 2. No	
CF5. When using your hearing aid, do you have difficulty hearing sounds like peoples' voices or music? Ghoba olikukozesa ekikuyamba okuwulira okaluubirizibwa okuwulira amaloboozi nga agabantu oba eneemba?	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	
CF6. Do you have difficulty hearing sounds like peoples' voices or music without hearing aid?	1. No difficulty 2. Some difficulty	

Okaluubilizibwa okuwulira amaloboozi okugeza nga ag'abantu oba eneemba bwooba tokozeisa ekikuyambaku okuwulira?	3. A lot of difficulty 4. Cannot do at all	
CF7. Do you use any equipment or receive assistance for walking? Okozesa ekintu kyona kyona okutambula oba okufuna obuyambi okusobozesa okutambula?	1. Yes 2. No	2⇨CF12
CF07. Check if the child uses equipment or receives assistance for walking? Kebera oba omwaana akozesa ebimuyambaku okutambula oba afuna obuyambi okumusobozesa okutambula	1. Yes 2. No	
CF8. Without your equipment or assistance, do you have difficulty walking 100 yards/meters on level ground? (That would be about the length of 1 football field. Note that category 'No difficulty' is not available, as the child uses equipment or receives assistance for walking) Ghoba tokozeisa kikuyambaku mukutambula oba nga toyambiibwa, ofuna obukaluubirivu mutambula yaadi/mita kyikumi kumuseetwe? (olwo olugendo luyinza kwaagayaga nakisaaghe kyamupiira)	2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	3⇨CF10 4⇨CF10
CF9. Without your equipment or assistance, do you have difficulty walking 500 yards/meters on level ground? (That would be about the length of 5 football field. Note that category 'No difficulty' is not available, as the child uses equipment or receives assistance for walking.) Ghoba tokozeisa kikuyambaku mukutambula oba nga toyambiibwa, ofuna obukaluubirivu mutambula yaadi/mita bikumi bitaanu kumuseetwe? (olwo olugendo luyinza kwaagayaga n'ebisaaghe by'omupiira bitaanu)	2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	
CF10. With your equipment or assistance, do you have difficulty walking 100 yards/meters on level ground? (That would be about the length of 1 football field.) Ghoba okozeisa ekikuyambaku mukutambula oba nga oyambiibwa, ofuna obukaluubirivu mutambula	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	3⇨CF14 4⇨CF14

yaadi/mita kyikumi kumuseetwe? (olwo olugendo luyinza kwaagayaga nakisaaghe kyamupiira)		
CF11. With your equipment or assistance, do you have difficulty walking 500 yards/meters on level ground? (That would be about the length of 5 football fields.) Ghoba okozeisa ekikuyambaku mukutambula oba nga oyambiibwa, ofuna obukaluubirivu mutambula yaadi/mita bikumi bitaanu kumuseetwe? (olwo olugendo luyinza kwaagayaga n'ebisaaghe by'omupiira bitaanu)	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	1⇨CF14
CF12. Do you have difficulty walking 100 yards/meters on level ground? (That would be about the length of 1 football field.) Okalubirizibwa okutambula yaadi/mita 100 kumuseetwe? (Olwo olugendo luyinza kwagayaga nga nakisaaghe kyamupiira)	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	3⇨CF14 4⇨CF14
CF13. Do you have difficulty walking 500 yards/meters on level ground? (That would be about the length of 5 football fields.) Okalubirizibwa okutambula yaadi/mita 500kumuseetwe? (Olwo olugendo luyinza kwagayaga nga nabisaaghe byamupiira nga 5)	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	
CF14. Do you have difficulty with self-care such as feeding or dressing yourself? Olina obukaluubirivu mukweerabirira nga okweeliisa oba okweeyambaza?	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	
CF15. When you speak, do you have difficulty being understood by people inside of this household? Ghoba oyogera ofuna obukaluubirivu abantu ab'omumaka gano okukutegeera?	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	
CF16. When you speak, do you have difficulty being understood by people outside of this household? Ghoba oyogera ofuna obukaluubirivu abantu abatali baamumaka gano okukutegeera?	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	
CF17. Do you have difficulty learning things? Olina obukaluubirivu okweega ebintu?	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	

CF18. Do you have difficulty remembering things? Olina obukaluubirivu okwiidukira ebintu?	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	
CF19. Do you have difficulty concentrating on an activity that you enjoy doing? Olina obukaluubirivu okutaayo ebirowoozo kukyintu ky'oyenda eino okukola?	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	
CF20. Do you have difficulty accepting changes in your routine? Olina obukaluubirivu okwiikiriza enkyuukakyuuka mubintu by'okola buliidho?	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	
CF21. Do you have difficulty controlling your behavior? Olina obukaluubirivu mukufuga bweweebisa?	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	
CF22. Do you have difficulty making friends? Olina obukaluubirivu mukufuna emikwaano?	1. No difficulty 2. Some difficulty 3. A lot of difficulty 4. Cannot do at all	
INSTRUCTION: The next questions have different options for answers. The options will be read to you after each question. Ebibuuzo ebiiraku, birina ebyokwiramu byandawulo,nga biidha kusomebwa buli luvainuma lw'akibuuzo		
CF23. How often do you seem very anxious, nervous or worried? Luvainuma lwa ibanga ki lw'oboneka nga osuubiire inho, okutiire oba nga w'ewalikiiriire?	1. Daily 2. Weekly 3. Monthly 4. A few times a year 5. Never	
CF24. How often do you seem very sad or depressed? Luvainma lwa ibanga ki lw'oboneka nga olimunakuwavu inho?	1. Daily 2. Weekly 3. Monthly 4. A few times a year 5. Never	
THANK YOU FOR YOUR TIME.		

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Yu DS, Lee DT, Woo J. Issues and challenges of instrument translation. West J Nurs Res. 2004;26(3):307-20.

Curriculum Vitae

NUKHBA ZIA

QUALIFICATIONS

2015 – todate	**PhD candidate**, Health Systems program, Department of International Health, Johns Hopkins Bloomberg School of Public Health, Baltimore, Maryland, USA
2012 – 2013	Masters of Public Health (**MPH**) Johns Hopkins Bloomberg School of Public Health, Baltimore, Maryland, USA
2008	Education Commission for Foreign Medical Graduates (**ECFMG**) Certification
2000 - 2005	Bachelor of Medicine, Bachelor of Surgery (**MBBS**) Aga Khan University, Karachi, Pakistan

WORK EXPERIENCE

Sep 2015 - todate	Research Assistant, Johns Hopkins International Injury Research Unit, Department of International Health, Johns Hopkins Bloomberg School of Public Health, Baltimore, Maryland, USA
Oct 2016 – Oct 2018	Visiting Faculty, Department of Emergency Medicine, Aga Khan University, Karachi, Pakistan
Mar 2015 – Jul 2015	Senior Instructor Research, Department of Emergency Medicine, Aga Khan University, Karachi, Pakistan
Oct 2014 – May 2016	Consultant, Violence and Injury Prevention and Disability, World Health Organization Eastern Mediterranean Region Office pilot of Instrument to Profile for Trauma Care System
Aug 2013 – Feb 2015	Research Fellow, Department of Emergency Medicine, Aga Khan University, Karachi, Pakistan
Oct 2014 – May 2016	World Health Organization Eastern Mediterranean Region Office pilot of Instrument to Profile for Trauma Care System
Jul 2012 – Jun 2013	Research Assistant, Johns Hopkins International Injury Research Unit, Department of International Health, Johns Hopkins Bloomberg School of Public Health, Baltimore, Maryland, USA

Apr 2010 – May 2012	Research Associate, Department of Emergency Medicine Aga Khan University, Karachi, Pakistan
Oct 2009 – Mar 2010	Research Associate, Road Traffic Injuries Research Network (RTIRN) Secretariat, Department of Emergency Medicine, Aga Khan University, Karachi, Pakistan
Apr – Sept 2009	Teaching Assistant, Department of Biological and Biomedical Sciences, Aga Khan University, Karachi, Pakistan
Feb – May 2008	Voluntary Clinical Rotator Departments of Emergency Medicine, Cardiology and Family Medicine, University of Louisville Hospital, Kentucky, USA
Nov 2005 – Oct 2006	Internship, Departments of Emergency Medicine, Internal Medicine, Surgery and Obstetrics & Gynecology, Aga Khan University, Karachi, Pakistan

SCHOLARSHIP/AWARDS

- Student Assembly Fall Conference award, Johns Hopkins Bloomberg School of Public Health, Baltimore, Maryland, USA

- Health Systems Program Doctoral Award 2018, Johns Hopkins Bloomberg School of Public Health, Baltimore, Maryland, USA

- Graduate Student Employee of the Year Award 2018, 2nd position, Johns Hopkins University, Baltimore, MD, USA

- Global Health Established Field Placement award 2016 for project "Traumatic Brain Injury Across the Lifespan in Uganda" by the Center of Global Health, Johns Hopkins University, Baltimore, MD, USA

- Reed Frost Scholarship for Master of Public Health (MPH) from Johns Hopkins Bloomberg School of Public Health, Baltimore, Maryland, USA (2012 – 2013)

- Fulbright Scholarship for Master of Public Health (MPH) from Johns Hopkins Bloomberg School of Public Health, Baltimore, Maryland, USA (2012 – 2013)

GRANTS

May 2014 – May 2015	Principal investigator for "Evaluating disability in adult burn injury patients treated at a tertiary-care burn unit in Karachi, Pakistan: a longitudinal study using WHO Disability Assessment Schedule II". Collaborative Small Grants Program under JHU-Pakistan Fogarty International Collaborative Trauma and Injury Research Training Program.
Apr 2014- May 2015	Co-Investigator for "The South Asia Burn Registry (SABR) Project – a multicenter pilot study on burn injury epidemiology and registry development in South Asia". Johns Hopkins University.

PUBLICATIONS

Zia N, Mehmood A, Namaganda RH, Ssenyojo H, Kobusingye O, Hyder AA. Causes and outcomes of traumatic brain injuries in Uganda: analysis from a pilot hospital registry. Trauma Surg Acute Care Open 2019;4:e000259.

Zia N, Latif A, Mashreky SR, Al-Ibran E, Hashmi M, Rahman AKMF, Khondoker S, Quraishy MS, Hyder AA. Applying quality improvement methods to neglected conditions: development of the South Asia Burn Registry (SABR). BMC Res Notes. 2019 Jan 29;12(1):64. doi: 10.1186/s13104-019-4063-0.

Mehmood A, **Zia N**, Kobusingye O, Namaganda RH, Ssenyojo H, Kiryabwire J. Hyder AA. Determinants of emergency department disposition of patients with traumatic brain injury in Uganda: results from a registry. Trauma Surg Acute Care Open 2018;3:e000253. doi:10.1136/tsaco-2018-000253

Mehmood A, **Zia N**, Hoe C, Kobusingye O, Ssenyojo H, Hyder AA. Traumatic brain injury in Uganda: exploring the use of a hospital-based registry for measuring burden and outcomes. BMC Research Notes. 2018 May 15;11(1):299

Ahmad H, Naeem R, Feroze A, **Zia N**, Shakoor A, Khan UR, Mian AI. Teaching children road safety through storybooks: an approach to child health literacy in Pakistan. BMC Pediatrics (2018) 18:31

Bachani AM, Bentley JA, **Zia N**, Galiwango E, Lum J, Tuli G, Ho SE. Caregiving for Uganda's elders with disability: Using cross-sectional surveillance data to identify healthcare service gaps in low- and middle-income settings. Disability and Health Journal. 2017 Dec 31. pii: S1936-6574(17)30235-2. doi: 10.1016/j.dhjo.2017.12.011

Bachani AM, **Zia N**, Hung YW, Adetunji R, Cuong PV, Faried A, Jiwattanakulpaisarn P, Hyder AA. Speeding in urban South East Asia: Results from a multi-site observational study. Journal of the Australian College of Road Safety 2017. Volume 28 (2): 27-35

Siddiqui EU, Kazi SG, Habib MI, Khan KMA, **Zia N**. Pattern of relapse in paediatric acute lymphoblastic leukaemia in a tertiary care unit. Journal of Pakistan Medical Association 2016.Vol 66(8): 961-7

Fayyaz J, Wadhwaniya S, Shahzad H, Feroze A, **Zia N**, Mir MU, Khan UR, Iram S, Ali S, Razzak JA, Hyder AA. Pattern of fall injuries in Pakistan: the Pakistan National Emergency Department Surveillance (Pak-NEDS) study. BMC Emergency Medicine 2015, 15(Suppl 2):S3) doi:10.1186/1471-227X-15-S2-S3

He S, Lunnen JC, **Zia N**, Khan UR, Shamim K, Hyder AA. Pattern of presenting complaints recorded as near-drowning events in emergency departments: a national surveillance study from Pakistan. BMC Emergency Medicine 2015, 15(Suppl 2):S4) doi:10.1186/1471-227X-15-S2-S4

Siddiqui E, **Zia N**, Feroze A, Awan S, Ali AL, Razzak JA, Hyder AA, Latif A. Burn injury characteristics: findings from Pakistan National Emergency Department Surveillance Study. BMC Emergency Medicine 2015, 15(Suppl 2):S5) doi:10.1186/1471-227X-15-S2-S5

Khan UR, Hisam B, **Zia N**, Mir MU, Alonge O, Jamali S, Hyder AA and Razzak JA. Uncovering the burden of intentional injuries among children and adolescents in the emergency department. BMC Emergency Medicine 2015, 15(Suppl 2):S6) doi:10.1186/1471-227X-15-S2-S6

Khan IQ, Khan NU, Naeem R, Kerai S, Allen K, **Zia N**, Shahbaz S, Afridi SQ, Siddiqui E, Khan UR, Hyder AA, Razzak JA. Bomb blast injuries: an exploration of patient characteristics and outcome using Pakistan National Emergency Departments Surveillance (Pak-NEDS) data. BMC Emergency Medicine 2015, 15(Suppl 2):S7) doi:10.1186/1471-227X-15-S2-S7

Zia N, Shahzad H, Baqir SM, Shaukat S, Ahmad H, Robinson C, Hyder AA, Razzak JA. Ambulance use in Pakistan: an analysis of surveillance data from emergency departments in Pakistan. BMC Emergency Medicine 2015, 15(Suppl 2):S9) doi:10.1186/1471-227X-15-S2-S9.

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Ismail S, **Zia N**, Samad K, Naeem R, Ahmad H, Raza A, Baqir M, Khan UR. Prehospital airway management in emergency and trauma patients: a cross-sectional study of ambulance service providers and staff in a low- and middle-income country. Prehosp Disaster Med. 2015;30(6):1-7.

Bachani AM, Galiwango E, Kadobera D, Bentley JA, Bishai D, Wegener S, **Zia N**, Hyder AA. Characterizing Disability at the Iganga-Mayuge Demographic Surveillance System (IM-DSS), Uganda. Disabil Rehabil. 2015 Oct 12:1-9.

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Khan UR, Bhatti J, Shamim S, **Zia N**, Razza JA, Rashid J. Clothing-related motorcycle injuries in Pakistan: findings from a surveillance study. International Journal of Injury Control and Safety Promotion. 2015 Dec;22(4):308-13

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Fayyaz J, Rehman A, Hamid A, Khursheed M, **Zia N**, Feroze A, Khan UR. CT scan in children with acute bacterial meningitis: Experience from Emergency Department of a tertiary-care hospital in Karachi, Pakistan. Journal of Pakistan Medical Association. 2014. Vol. 64 (4)

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Khan UR, Chandran A, **Zia N**, Huang CM, Ramirez SS, Feroze A, Hyder AA, Razzak JA. Home injury risks to young children in Karachi, Pakistan: a pilot study. Achieves of Diseases in Childhood. 2013; doi: 10.1136/archdischild-2013-303907.

Razzak JA, Khan UR, **Zia N**, Azam I. A child an hour: burden of injury deaths among children under 5 in Pakistan. Achieves of Diseases in Childhood 2013;0:1–5. doi:10.1136/archdischild-2013-303654. Selected as one of the top global emergency medicine articles of 2013 by the Global Emergency Medicine Literature Review (GEMLR) Editorial Board.

Khan UR, Bhatti JA, **Zia N**, Farooq U. School-based injury outcomes in children from a low-income setting: results from the pilot injury surveillance in Rawalpindi city, Pakistan. BMC Research Notes.2013, 6:86.

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Hyder AA, Chandran A Khan UR, **Zia N**, Huang CM, Ramirez SS, Razzak JA. Innovations in Childhood Injury Prevention: Piloting a Community-Based Home Injury Risk Assessment in Pakistan. International Journal of Pediatrics Volume 2012

Bano S, Akhtar S, **Zia N**, Khan UR, Haq AU. Pediatric endotracheal intubations for airway management in the emergency department. PediatrEmerg Care. 2012 Nov;28(11):1129-31

Zia N, Khan UR, Razzak JA, Hyder AA, Puvanachandra P. Understanding Unintentional Childhood Home Injuries: pilot surveillance data from Karachi, Pakistan. BMC Res Notes. 2012 Jan 19;5(1):37

Saeed SA, **Zia N**, Qazi Y. Facilitation skills of basic sciences faculty and fresh medical graduates: An AKU experience. Procedia - Social and Behavioral Sciences 2010; 2(2):1316-1320

TEACHING ASSISTANT EXPERIENCE

Mar 2019	"Global Road Safety Leadership Course"; two-week course offered in Buenos Aires, Argentina by the Global Road Safety Partnership and Johns Hopkins International Injury Research Unit
Sep – Oct 2018	"Fundamentals in Global Health Practice"; Online Term 1 course offered as part of Online Programs for Applied Learning (OPAL) program, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, USA
Aug 2017	"Global Road Safety Leadership Course"; two-week course offered in Baltimore, MD by the Global Road Safety Partnership and Johns Hopkins International Injury Research Unit
Jun 2017 – Jun 2019	"Health Systems Summer Institute"; two-week institute with 11 courses offered onsite by the Department of International Health, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, USA
Jan 2017 - Mar 2019	"Health systems research and evaluation in developing countries"; Onsite Term 3 course offered by the Department of International Health, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, USA
Nov 2016 – Dec 2018	"Confronting the burden of injuries: A global perspective"; Online and onsite Term 2 course offered by the Department of International Health, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, USA
Sep - Oct 2016	"Introduction to International Health"; Onsite Term 1 course offered by the Department of International Health, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, USA
Sep 2016 – May 2019	"Health Systems program seminar series"; Onsite seminar series offered every term for one academic year by the Department of International Health, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, USA
Mar 2015 – May 2019	"Applying Summary Measures of Population Health to Improve Health Systems"; Onsite Term 4 course offered by the Department of International Health, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, USA

Oct – Dec 2014	“Injury Prevention and Control: Principles and Practice” master level course conducted by the Department of Emergency Medicine in collaboration with Health Policy and Management program offered by Department of Community Health Sciences at the Aga Khan University, Karachi

ADDITIONAL INFORMATION

Computer: SPSS & STATA (Statistical softwares), NVIVO 2, Microsoft Office
Languages: English, Urdu, Punjabi (spoken), Hindi (spoken)