

## DOWN SYNDROME IN UGANDA: IDENTIFYING BARRIERS AND MAKING RECOMMENDATIONS TO INCREASE ACCESS

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### ABSTRACT

**Background:** Developing countries such as Uganda often struggle to create realistic action plans to ameliorate inequalities that impact people with disabilities. Inequalities may take many forms and may cross many areas of life, including medical care, education, and social inclusion, and may further vary based on disability and geography.

**Objective:** The report seeks to map available resources and identify gaps in medical care and education, and describes the unique challenges facing children and adults with Down syndrome in Uganda. We conclude by making specific recommendations on how to address these gaps.

**Methods:** This research used convenience sampling and snowball sampling to conduct 50 semi-structured interviews with people with Down syndrome and their families, local and international experts, community advocates, local and national public health workers, and key leaders in Uganda.

**Results:** Results from this report include four key recommendations: creating a word in Luganda for Down syndrome, improving in-country medical training related to making an earlier diagnosis of Down syndrome and to providing care for commonly occurring co-morbidities, creating inclusive education opportunities by increasing teacher training, and advancing this work in Uganda in a more coordinated and collaborative approach across public, private and nonprofit sectors.

**Conclusions:** This research may help set Uganda on a path for the full inclusion of individuals with disabilities, including those with Down syndrome. The approach recommended could inform how other developing countries respond to persons with disabilities.

**Keywords:** Down Syndrome, Trisomy 21, Uganda, Intellectual & Developmental Disability, Healthcare, Education, Stigma, NGOs, Advocacy, Medical Training.

### 1.0 INTRODUCTION

Down syndrome, also known as Trisomy 21, is a condition whereby an individual is born with three copies of chromosome 21 instead of two. It is the most common cause of developmental and intellectual disability in the world. The average global prevalence is estimated to be one out of every 1,000 live births, with variance across populations of roughly 25%.<sup>1</sup> In the last 30 years, medical care, opportunities, and inclusion of people with down syndrome has been significantly improved as evidenced in many countries around the world. However, global progress remains uneven, and developing countries such as Uganda have struggled to address and ameliorate inequalities that impact people with disabilities, including people with Down syndrome. In Uganda, people with Down syndrome experience widespread cultural stigma, which further complicates addressing their basic needs, such as access to health care and education.

This research employed convenience sampling and snowball sampling to conduct semi-structured interviews coupled with over 500 hours of archival research to identify documents, key organizations, key leaders and in-country policies relevant to this study. Interviews took place between August 2017 and May 2019. The 50 semi-structured and content-specific interviews further informed the study on existing resources available to people with Down syndrome, existing gaps in services and misperceptions and challenges confronting families and children with Down syndrome. The Global Livingston Institute (GLI) conducted these interviews with international and local experts, people with Down syndrome and their respective families, community advocates, local and national public health workers, and key leaders in Uganda. A content analysis of the existing documents related to persons with Down syndrome included policy documents from government institutions, global and country-specific statistics, education system reports, and academic research on Down syndrome and people with disabilities in Uganda.

## 2.0 ASSESSING THE PREVALENCE OF DOWN SYNDROME IN UGANDA

It is difficult to determine the number of individuals with Down syndrome in Uganda as the Ugandan government does not currently (at the time of this research) collect nationwide statistics on the prevalence of Down syndrome, and many parents of children with disabilities do not register them. Under the Births and Deaths Registration Act, all children born in Uganda must be registered with the Registrar General.<sup>2</sup> However; the Committee on the Rights of the Child has found that children with disabilities are disproportionately vulnerable to non-registration at birth.<sup>3</sup> According to the African Child Policy Forum's 2011 report, Children with disabilities in Uganda: The hidden reality, in Uganda it is estimated that less than half of the children with disabilities are registered.<sup>4</sup>

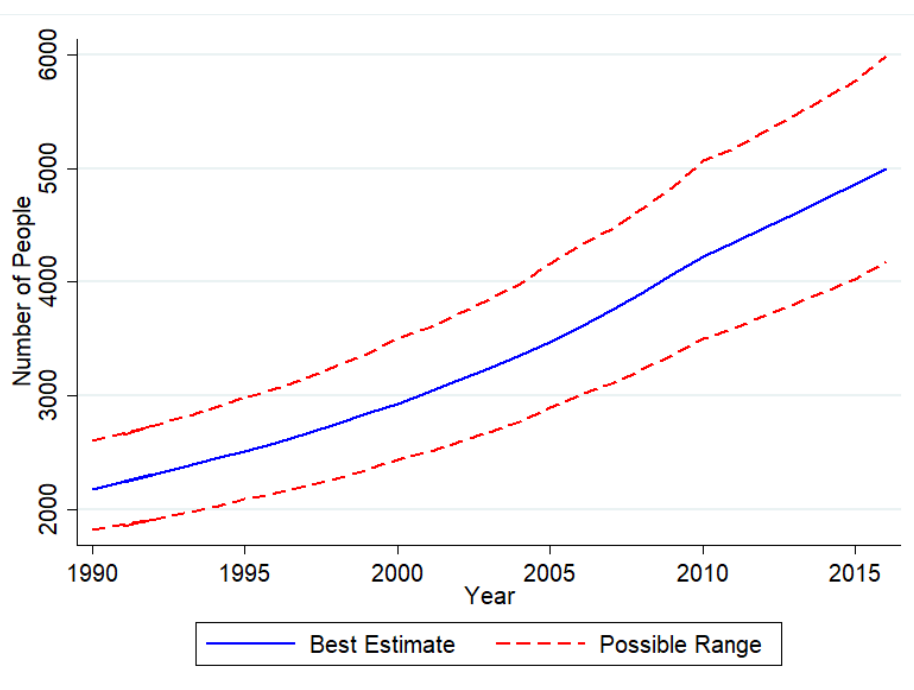
There are many barriers to registration at birth, including financial hardship, use of non-traditional birthing centres, and for children with disabilities, parents may also be encumbered by familial shame or a lack of a diagnosis.

Registration is critical to quantify the prevalence of Down syndrome in Uganda, which could be used to demonstrate the need for medical, educational, and social services available for this population.

Until national data is available, the assessment of the number of individuals with Down syndrome is determined by sampling and estimates based on international trends. The Global

The burden of Disease (GBD) estimates that there are 5,000 people with Down syndrome in Uganda. This number has steadily risen in tandem with Uganda’s total population over the years, from around 2,000 in 1990 as indicated by Figure 1. Additionally, in a sample of 2,365 infants born between April 2003 – November 2005 at Entebbe General Hospital, four infants were born with Down syndrome.<sup>5</sup> This suggests the prevalence of Down syndrome at birth is generally consistent with the global trend, but without formal statistics quantifying prevalence, people with Down syndrome in Uganda lack presence for advocacy at almost every level. Although the GBD can be used for nation-wide estimates, it does not provide information on where people with Down syndrome live in Uganda, which is a critical question for understanding the best ways to help address their needs given that geography is a key determinant of resources.<sup>6</sup>

**Figure 1: Number of People with Down syndrome in Uganda from 1990-2016** <sup>7</sup>



### 3.0 MAPPING EXISTING BARRIERS FOR PEOPLE WITH DOWN SYNDROME IN UGANDA

#### 3.1 Cultural Barriers & Stigmas

Because data specific to Down syndrome is scarce on the national level and the terminology is often vague, our researchers found it is useful to examine the broad category of “disability” in Uganda as it relates to cultural barriers and stigma. The social stigma against Down syndrome in Uganda, as in other countries, is evident even in the everyday language. Although the English term “Down syndrome” is used in official documents and in professional settings, there is no specific word for Down syndrome in Luganda, Uganda’s most widely spoken local language. Medical professionals and community health workers may use the English term Down syndrome. However, lack of education and cultural awareness create a stigma such that children with disabilities in the community are likely to

be referred to by pejorative terminology in Luganda, such as 'stupid' (kasilu) or 'unable' (kateyamba). As one mother interviewed for this research explained based on her experience with her son who has Down syndrome, "they can't associate with other children—they are called 'mad,' but I am very proud of my child." These labels foster continued discrimination and support the misconception that individuals with Down syndrome are less than their peers and are not valued members of the community.

In Uganda, individuals with disabilities, including Down syndrome, can be perceived as a curse or a lifelong financial and social burden to their families, according to multiple parents interviewed for this research. Families report that children with Down syndrome in Uganda face alienation in their communities and that they are often segregated from peers. Disproportionately, mothers of children with disabilities may be blamed for their child's disability, which is viewed as a punishment for past bad behavior.<sup>8</sup> This cultivates shame within families and fosters rejection from the community. After her child with Down syndrome finally received a diagnosis of 'mongolism,' one mother shared, "It ultimately caused my marriage to break up, as the father abandoned us, but I can say that right now, I am in a good place with my child."

Examples of stigma can be found in many sectors of the community. As will be shown throughout this research, there are documented instances of general health providers in Uganda who refuse to treat people with certain disabilities or conditions like Down syndrome.<sup>9</sup> Additionally, access to education is limited for those who have a disability, and even more difficult to access for individuals with an intellectual developmental disability like Down syndrome. The stigma that begins with language is evident in medical care and education and prevents people with Down syndrome in Uganda from being included in society.

### 3.2 Healthcare

Access to health care is a challenge for many Ugandans, with a disproportionate burden felt by people in rural areas and people with disabilities, including those with Down syndrome. A 2010 study by Joseph Konde-Lule which mapped 445 facilities in Uganda found that 95.7% of mapped facilities were privately funded, and of those, 77.1% of private providers were "informal," which the study defined as, "unqualified providers without formal training."<sup>10</sup>

This suggests that any attempt to affect or improve healthcare in Uganda, for people with or without Down syndrome, will have limited effect if only public, formal medical facilities like hospitals are targeted. People with Down syndrome have specialized medical needs. For example, in babies born with Down syndrome, an estimated 1% will develop leukemia, 18% will have thyroid disease, 75% will have hearing impairments and 50% will have congenital heart defects, most of which will require surgery.<sup>11</sup> According to our interview with pediatric cardiologist Dr. Judith Namuyonga, the Uganda Heart Institute is the only facility in Uganda that is equipped to perform cardiovascular procedures. However, even the Heart Institute lacks equipment and training for more severe heart defects.

The reported experience of parents interviewed by our research revealed that most of their children were not given a diagnosis of Down syndrome prenatally or at birth. One mother told our interviewer her concerns were dismissed by medical providers. "After a few months,

I started to realize that she looked different. I asked a doctor and he said that was normal and it would disappear. It was (not) until 4 years ago when I joined The Uganda Down syndrome Association that I learnt that it was Down syndrome.”

In addition to a lack of education about the condition among the traditional and non-traditional medical providers, medical doctors interviewed for our study reported prenatal care is not routinely accessed by expecting mothers. Furthermore, the blood test necessary to confirm the presence of trisomy 21 called karyotyping requires a machine many small clinics do not have and the test, our researchers were told, is unaffordable for the average family in Uganda. Without an early and clear diagnosis, key pediatric care considerations can go unchecked for years, which can negatively impact the child’s future development and health.

In addition, many of the recommended medical screenings and specialized care procedures are limited to urban areas. With few specialists to address the health needs of people with Down syndrome in Uganda and international travel too costly for the average family, individuals with the condition often go without care. Through improved access to life-changing and, in many cases, life-saving medical care, children and adults with Down syndrome can lead healthier lives which can reduce the stigma that they are burdens on their families by affording them opportunities to participate in many aspects of society, including education.

### 3.3 Education

Children with disabilities, including Down syndrome, are often alienated from the education the system in Uganda. A 2010 report from UNESCO states that “disability is one of the least visible but most potent factors in educational marginalization. Beyond the immediate health-related effects, physical and mental impairments carry a stigma that is often a basis for exclusion from society and school.”<sup>12</sup> The 2002 Census concluded that 19% of children with disabilities in Uganda aged seven to 16 had never attended school, compared to 10% of typical children of the same age.<sup>13</sup>

In examining inclusion efforts as they related to individuals with Down syndrome, one area that continues to be challenging is that schools in Uganda often lack special education professionals trained to address the unique learning needs of children with Down syndrome. Much like the specific medical needs, children with Down syndrome also have specific learning needs. A 2006 study of 15 special schools for children with disabilities across Uganda showed that the specific needs of children with disabilities were assessed in only a few circumstances<sup>14</sup> and there were no assessments related specifically to Down syndrome. With a broad categorization of “disability,” the unique educational needs of children with Down syndrome remain unmet as there are few educators with the necessary expertise and resources to individualize education plans.

As part of this research, one of Uganda’s few special needs educators, Ms. Jennifer, was interviewed. Her school, Bishop’s Primary School Mukono West, had five students with Down syndrome enrolled at the time this research was being conducted. Ms Jennifer highlights another barrier to education for children with Down syndrome; even when they are enrolled in school, the curriculum is not modified and adapted to be developmentally appropriate or accessible to a child with Down syndrome. She noted that most of her students

with Down syndrome do not graduate or advance from her Primary 1 class to Primary 2 due to poor performance, and thus they repeat Primary 1 until they are of age for vocational training.

The Ugandan government has created laws addressing education inclusion for people with disabilities, but the setback today lies in implementing and enforcing these policies. Uganda relies on non-governmental organizations (NGOs) to implement and monitor policy, however there are only a few NGO advocacy groups with this capacity and the government resources to support these initiatives are scarce. There is also no international framework mandating inclusive education programs.<sup>15</sup>

#### **4.0 RECOMMENDATIONS TO INCREASE ACCESS FOR PEOPLE WITH DOWN SYNDROME IN UGANDA**

As we conducted this research the intention was not to put forward a publication but to better understand how communities were responding to the needs of children and adults with Down syndrome in Uganda and to determine if there were ways that community organizations could better coordinate and deliver services. These are solutions that could be implemented today with public will and cooperation. That said, there is also a very clear need for investment and resources to address issues of access and health care that are vital to ensuring every person with Down syndrome has an opportunity to live and thrive in a safe and healthy community environment.

##### **4.1 Advocacy**

Providing a proper translation of Down syndrome in Luganda is essential so that families and communities have a shared language to refer to the condition that does not further alienate or stigmatize Down syndrome. Enacting a comprehensive advocacy and awareness campaign involving the Ministry of Education, the Ministry of Health, and the NGO community to provide families, practitioners and policymakers with updated and accurate facts about Down syndrome is also important. This campaign should target parts of the country and socioeconomic strata where negative stigma against people with disabilities is most prominent. This effort could remove barriers to care by reducing misperceptions that people in Uganda have about Down syndrome.

##### **4.2 Health Care Training**

Establishing a national plan to train medical professionals to diagnose Down syndrome earlier should reduce the frustration and rejection families feel when they are unsure why their child is different from their peers and may help families' access resources and supports sooner. The Ministry of Health and public entities like the Uganda Heart Institute should work together to prioritize what medical specialties and specific training is needed in-country to diagnose and provide care for people with Down syndrome. Medical training programs should focus on diagnostic instruction and treatment for commonly co-occurring conditions of Down syndrome. More successful interventions would involve medical experts traveling to Uganda and training providers on-site as well as increasing access to supplies and equipment. These services could save lives and reduce costs incurred by sending people out of country for expensive treatment.

## 4.3 Education Opportunities

Children with Down syndrome require individualized supports in the classroom; Ugandan educators should be trained to provide such modifications. Uganda should use existing research on teacher training to develop a modular curriculum highlighting the universal design best practices, which could benefit all students, including those with disabilities. An alternative approach would be to create a parallel program functioning within the same school as typical children, with a different teacher trained in special education.

## 5.0 DISCUSSION & CONCLUSIONS

Over the course of the study, four key areas for making countrywide improvements in the lives of people with Down syndrome in Uganda were identified based on both content analysis and participant interviews and observations:

- I. Creating a word in Luganda for Down syndrome and launching a national awareness and advocacy campaign;
- II. Improving in-country medical training to better diagnose and treat co-occurring conditions common in individuals with Down syndrome
- III. Fostering inclusive education opportunities with special education teacher training and individualized learning plans for students with Down syndrome; and
- IV. Advancing this work in Uganda in a coordinated and collaborative approach across public, private and nonprofit sectors.

Participant interviews underscored the disconnect between public and non-governmental organizations and reinforced the importance of collaboration across sectors. According to UNICEF, "Partnerships could promote sharing of knowledge and techniques among professionals for teaching children with disabilities and enable a student transfer system between institutions."<sup>16</sup> Such strategic partnerships (IV) would help to reduce stigma by referring to Down syndrome in a culturally specific proper terminology, further improve in-country medical training and create more inclusive education opportunities (I-III). NGOs and local community organizations are making tremendous headway in developing programs and improving access to medical care for individuals with Down syndrome. However, this "bottom-up" approach will only work if there is an equally powerful "top-down" effort led by the government of Uganda and with community buy-in at all levels.

Limited sharing of knowledge coupled with a lack of coordinated resources that are already scarce, significantly compromises the ability to even make incremental changes. While comprehensive interventions are costly and will take time to implement, small coordinated steps with the combined efforts of the Ugandan government, NGOs, community leaders and advocates, hold the potential to significantly improve the lives of people with Down syndrome in Uganda.

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## REFERENCES

- Skotko B, Tenenbaum A. Down Syndrome. In: Rubin IL, Merrick J, Greydanus DE, Patel DR, editors. Health care for people with intellectual and developmental disabilities across the lifespan. Cham, Switzerland: Springer; c2016. p. 739–750.
- The Births and Deaths Registration Act Cap 309. Kampala, Uganda: 1973. 10 p.
- Committee on the Rights of the Child, General Comment No. 9, The rights of children with disabilities (Forty-third session, 2007), U.N. Doc. CRC/C/GC/9 (2007).
- African Child Policy Forum. Children with Disabilities in Uganda: A Hidden Reality. [Analysis in brief on the Internet]. 2011.
- Ndibazza J, Lule S, Nampijja M, Mpairwe H, Oduru G, Kiggundu M, et al. A description of congenital anomalies among infants in Entebbe, Uganda. *Birth Defects Res A Clin Molr Teratol*. 2011;91(9): 857–861.
- GDB 2016 Disease and injury Incidence and Prevalence Collaborators. Global, regional, and national incidence, prevalence, and years lived with disability for 328 diseases and injuries for 195 countries, 1990-2016: a systematic analysis for the Global Burden of Disease Study 2016. *Lancet*. 2017;390(10100):1211-1259.
- Institute for Health Metrics and Evaluation (IHME). Findings from the Global Burden of Disease Collaborative Network. Seattle Global Burden of Disease Study 2016 Results [Internet]. USA:2017.
- Chataika T, McKenzie J. Considerations of an African Childhood Disability Studies. In: Curran T, Runswick-Cole K, editors. *Disabled children's childhood studies*. London: Palgrave Macmillan; c2013. p. 152–163.
- Bannink F, Idro R, Van Hove G. 'I like to play with my friends': Children with spina bifida and belonging in Uganda. *Social Inclusion*. 2016; 4(1):127–141.
- Konde-Lule J, Gitta S, Lindfors A, Okuonzi S, Onama S, Forsberg B. Private and public health care in rural areas of Uganda. *BMC Int Health Hum Rights*. 2010; Nov 24;10(29)



Bull M. Committee on Genetics. Health supervision for children with Down syndrome. *Pediatrics*. 2011;128(2):393–406.

United Nations Educational, Scientific and Cultural Organization (UNESCO).

Reaching the marginalized. EFA Global Monitoring Report 2010. Oxford: Oxford University Press. p 181.

Riche N. Anyimuzala J. Research study on children with disabilities living in Uganda:

Situational analysis on the rights of children with disabilities in Uganda. UNICEF Uganda; 2014 May. 157 p.

Kristensen K. Omagor-Loican M. Onen N. Okot D. Opportunities for inclusion? The

education of learners with special educational needs and disabilities in special schools 3 in Uganda. *BJSE*. 2006;33(3):139–147.

United Nations Educational, Scientific and Cultural Organization (UNESCO).

Towards Inclusive Education for Children with Disabilities: A Guideline. [Analysis in brief on the Internet]. UNESCO, Bangkok. 2009. 154 p.

The Right of Children with Disabilities to Education: A Rights Based Approach to

Inclusive Education (2012) [Analysis in brief on the Internet]. UNICEF, 2012. 89 p.