DISABLED REFUGEES STUDENTS INCLUDED AND VISIBLE IN EDUCATION: CHALLENGES AND OPPORTUNITIES IN THREE AFRICAN COUNTRIES: UGANDA CASE REPORT

A project funded by The British Academy Learning in Crises Programme

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September 2022

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Executive summary

This report is a representation of the Uganda Case Study. It is written in 5 sections. In the first section we detail the social context of Uganda, including relevant policies. In the second section, we provide an account of the research approach and methods that were used, including a timeline. In the third section, we present the data according to the perspectives of the various stakeholders and around particular themes that have emerged from the broader research questions. In the fourth section, we analyse the data according to a social ecosystem model, and in the fifth section we provide a conclusion with future directions, including dissemination and research impact.

This report is based on empirical evidence from a qualitative study in three refugee hosting districts in northern Uganda. A total of 103 participants including disabled refugee children and their families, NGOs, and education officials (including teachers and ministry officials) participated in the study. The study findings indicate significant relevant legislation on educational access for children with disability, and for refugee children, however, there are limitations in the policy implementation because of intersectional challenges. The study also highlights a lack of learning opportunities provided for parents and caregivers of children with disability. Most of these are women who are taking care of large households on their own. Narratives of stigma about families and students with disabilities requires problematization in relation to normative and essential assumptions. Education NGOs' contribution to educational access for refugee children with disability has given opportunity for education opportunities and is appreciated by the parents and caregivers. However, there remains a need for strong public education systems with qualified teachers and small class sizes with the necessary equipment to work with the various needs of students with disabilities. There is also a need to develop pathways and transitions for secondary schools and further opportunities for students with disabilities to pursue meaningful lives. The study recommends developing stronger informal and integrated spaces and forums for children with disabilities and their families to direct policy and learning opportunities.

Section 1: Ugandan context

At the end of 2021, over 82.4 million persons were forcibly displaced worldwide, of these, 42% are children below 18 years of age (UNHCR, 2022). As of November 2021, Uganda hosts the third largest population of refugees in the world and is a key site of South-South migration with 66.8% of refugees coming from South Sudan (UNHCR, 2022). Uganda has the unique approach of integrating refugees in settlements alongside host communities and allowing them mobility within and outside the gazetted settlements in the country as they choose, rather than segregating them to camps. The South Sudanese refugees are settled in the northern part of Uganda (the location for this research), bordering South Sudan to the south. West Nile districts including Adjumani, Obongi and Lamwo in the Acholi sub-region are in the northern parts of Uganda, on the southern border with South Sudan. The communities on both sides of the border are similar in cultural practices and language, a social construction that enhances settlement and adaptation. Ethnic similarity enhances settlement and adaptation of the migrant population. (Fielden, 2008). In the context of educational policy on access, ethnic similarity has enhanced educational access and promoted mobility for a section of South Sudanese Luo speakers in Ugandan schools, in northern Uganda. The educational policy for primary schools in Uganda promotes the use of mother tongue as a language of instruction in lower primary education, with positive results (Kaahwa, 2011). A 2016 UNICEF study on Language and learning found positive links between using the child's home language and learning outcomes, and contributing to education quality for refugee children in northern Uganda. However, there are several students (undocumented) who speak languages that are different from the Luo or Madii languages of northern Uganda.

Additionally, 80% of the refugee population are women and children (UNHCR, 2022). The available data shows that over 18,000 refugees have disability-specific needs, with girls more affected (UNHCR 2022; Disability Rights Fund, 2018). In the case of Acholi and Madi of Uganda and South Sudan, the cultural practices that see children as a labour force and girls as wives persist. These practices have a direct impact on educational access and transition (Justice & Reconciliation Project, 2015). Refugee girls with disabilities in Uganda face multiple barriers with their educational transition (Walton et al., 2020; Beibet et al., 2020).

Uganda is signatory to the Global Compact on refugees; a demonstration of political will and responsibility to share the management of the social-economics of displacement (UNHCR, 2018). The 2006 Refugee Policy of Uganda and the refugee regulatory framework fit within this agenda as far as commitment to the protection of refugees is concerned (Government of Uganda, 2006). Within this policy, Uganda upholds key rights including freedom of movement and access to social services such as education. Educational access for all children, including refugee children, are enshrined in the Constitution of Uganda and in the Education Act (Government of Uganda, 1995; Uganda Government Gazette, 2008). The Education Response Plan for Refugees (ERPR) (Ministry of Education and Sports, 2018) is the main implementation guideline for refugee children's education in Uganda, and it is aligned with the other policy frameworks. The ERPR mandates local governments and education partners to set up and operate schools in refugee settlements in Uganda.

Uganda has also ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (UN, 2022), binding itself to its international commitments in relation to inclusive

education for all. A Uganda education and disability policy review (Walton et al., 2020) observed good legislation around general educational access for all children. However, limitations with policy implementation were also observed, especially at the school and community levels, due to system constraints, resources limitations, and negative attitudes. This is consistent with the observation of Mac-Seing et al. (2021) that implementation and enforcement of pro-disability policy and legislation in Uganda is problematic. Central to this problem is a lack of enforcement mechanisms and widespread lack of awareness and training on disability issues among policy executors. Policy gaps with the Uganda Primary Education implementation leads to school dropout (Nakanyike et al., 2002). In the case of disabled children in northern Uganda, barriers to educational access are compounded by policy implementation gaps observed in inadequate provision of skilled teachers and learning materials in most schools, access to health care, gender-based violence and sexual harassment, tuition costs, and lack of inclusive schools.

Section 2: Research Methods

The research reported here is part of a wider project that seeks to understand the dynamics of educational inclusion and exclusion of disabled refugee students in three African host countries: Uganda, South Africa, and Zimbabwe. This report draws on empirical data from Uganda.

At the heart of the research is an attempt to centre the perspective of the core stakeholders: the students and their families. We, therefore, focused our data generation on eliciting the lived experiences and life-wide stories of refugee students living with disabilities and their families, though we also conducted interviews with teachers, NGO officers working directly with disabled refugee students, Ugandan education officials at the district, and national levels, policymakers, and indigenous leaders from the host community.

The research team obtained ethical approval from the University of Nottingham and local approval from Gulu University Research Ethics Committee (GUREC). The ethical boards mandated consent forms in local languages and with appropriate level of language. It also mandated engagement with families with provision to minimise risk of harm. The approved provisions, which were followed, included informing settlement administrators about the research and requesting permission to do research, ensuring that translators (including for sign language and braille) were present where needed, that participants fully understand the research and use of the research, consent forms signed, and interviews and focus groups take place in locations that are comfortable with the participants. Interviews with refugee students all took place with permission and within visibility of caregivers. Interviews took place at a location (usually sitting outside in the homestead) suggested by interviewees in prior meetings. Where requested (and often), caregivers and siblings sat with the student and participated in the interview. Prior to the interviews, site visits with local officials, parental education committees, families and NGOs were conducted. Interviews were recorded using security protected recording devices. An advisory committee of contextually experienced stakeholders guided all the interview procedures.

Privacy and anonymity were always adhered to. All members of the research team who participated in interviewing, translating or transcribing data signed non-disclosure agreements. Interviews were recorded and uploaded at the earliest possible instance into individualised private folders on Microsoft teams. Only the co-investigator had access to all the folders.

Interviews were transcribed by hand and all identifying data retracted prior to placing them in a secure shared research folder accessible to the broader research team for coding and analysis. A code was given to each interview to identify the type of participant (i.e., teacher, refugee student, education official, NGO worker). A file was created identifying the code with the participant, in case the participant requested to be removed from the research (which has not yet occurred). The file is secure in Microsoft teams and available to the Co-Investigator and research assistant alone.

In addition to the formally mandated privacy and engagement procedures, the team engaged in ethics processes recommended by community engagement and participatory research theory and guidelines.

We used White's (2019) guidelines which emphasise developing long term relationships, accountability to the communities that are being researched, and conducting research that matters to the community, and has impact in the community/ with the stakeholders and participants.
The lead established a core team of research advisors who have existing relationships with participants and their context. The advisory team of 7 is composed of people from government, academia, parent associations, and NGOs working with refugees. The team was selected based on their expertise, experience, and influence in working with refugees and students with disabilities in Uganda. Following a participatory approach, the advisory board was actively involved in all stages of the research process. Monk et. al. (2020) demonstrated how participatory approaches enhance the quality (including asking the right questions) and impact of research. In a study of community learning networks in South Africa, Lotz-Sisitka (2004) demonstrated that participatory approaches are valuable to generate effective partnerships for sustainable development. We worked through the advisory networks to identify key issues and access stakeholders. We held regular sessions with our advisory team, reflecting on the literature, reviewing the research questions, deciding on the points of entry for participants and deciding and revising the scope of the research.

Three changes were made based on regular reflection sessions. First, we realised that we did not have anyone with a disability on our team, and this was having an impact on our research conceptualisation. We therefore recruited a relevant advisor to our team. Similarly, we recruited a teacher and parent to our team, who was instrumental in guiding our research direction, and connecting us to families who were not receiving aid from NGOs. Finally, we had to adjust our interview teams to better reflect gender. The NGO field officers we were working with were all men, and there was a noticeable difference in the responses of the children and their families between interviews conducted by women and those conducted by men. In some cases, we went back and re-interviewed participants, and as we progressed, we made certain that our female team members were present in as many interviews with women as possible. These adjustments were made possible because of the nature of participative qualitative research processes that require regular reflection and adaptation to the research. Additionally, as it became obvious that there was not much thought or opportunity beyond primary school, we returned to the field and conducted some interviews related to vocational education.

The participants were spread over three settlements in Northern Uganda and their environs, with the majority from one larger settlement. Participants were identified and selected together with

our advisory group and in consultation with their related connections to NGOs working in refugee settlements. We conducted 65 interviews with 103 participants including: 43 disabled refugee students and their families, (14 of the participants were families from host communities), 3 district education officers, 11 head teachers and teachers of selected primary schools, 1 National representative for special needs education from the Ministry of Education and Sports, and 7 NGO field officers. Additionally, 2 focus group discussions were conducted with 4 teachers, 6 NGO field officers and one disabled students' Parents Association representative.

Coding and Analysis were performed collaboratively and were ongoing through iterative and reflexive sessions with the advisory committee and with the international research team. When we decided to close the data collection, we asked our advisors to all go through anonymised transcripts and identify themes that emerged for them, these were placed in a shared excel file. We then had a series of reflective discussions based on the themes generated. We used a jam board to place the themes on a grid according to a social ecosystem model borrowed from Wedekind et. al (2021). The themes were colour coded according to the stakeholder to capture, compare, and contrast the diverse perspectives and power of the various stakeholders. These themes were then analysed according to the various participants' perspectives, and cross referenced to the ecosystem jam board where themes were compiled according to horizontalities and verticalites. Drawing on complexity theory and power, we focused on relations and structures. The themes were then shared in a larger google Jam board in initial cross case analysis with the two other case sites. Finally, the research assistant and the co-investigator used the generative themes compiled to analyse the data according to the research questions. A representative group of participants were invited to a policy brief and research dissemination forum to verify, reflect on (and add to) the research findings.

The social ecosystem model emphasises adaptation and longer-term research and learning processes. This is synergistic with our participatory research approach that attempts to build relationships and communities of learning, and to sustain and maximise practical research impact. As a component of this research, we have engaged several stakeholders to think more deeply about education for disabled refugees, particularly girls. The process has therefore begun to develop a community of learning and practice that we hope to sustain through Gulu University initiatives. As a component of the research dissemination, we brought core stakeholders together-including research participants, government officials and policy makers, National and local disability unions representatives, NGO directors and academics- In an expanded policy brief forum. In the forum, we presented the research findings, analysis, and policy recommendations. We facilitated a reflexive discourse on the research, policy brief, and practical steps forward. The result has been the initiation of a formative and transdisciplinary community of practice, facilitated by the co-I and located at Gulu University, with an action agenda of reviewing the full research report along with the official report from the policy brief forum, which was documented by a rapporteur team. At Gulu university, we have already started to act on some of the recommendations. One key finding was the lack of trained special needs teachers- with only one university in Uganda offering formal diploma programs in inclusive education. Gulu University has engaged in two dissemination workshops with more than 500 students and staff in the Faculty of Education. This has in turn led to the development of a curriculum for special needs education at Gulu University, which contains courses related to the case of refugees. The process has been approved by the Faculty Board, although with some concern about the costs of purchasing equipment. Having the Vice Chancellor as an active

advisor who helped with data collection, analysis and site visits has been instrumental in moving this program forward, but also in orienting future directions for research: Gulu university has recognized the refugee population as a core area requiring attention, and is positioning itself to meet the needs of this community, not just with education but in the fully entangled social ecosystem. The impact of this research is therefore already substantial and will continue to be so.

Section 3: Findings

The goal of this study was to investigate the dynamics of educational inclusion and exclusion of disabled refugee students in three settlements and host communities in northern Uganda. To do this, the researchers interviewed disabled refugee and host community children, in and outside the settlements; their families and caregivers; Education officers in the 3 research districts and NGO workers. Specifically, the study set out to: 1). identify relevant policies available and needed in the Ugandan context, and identify what local and international policies are relevant; 2). explore the experiences of disabled refugee learners and their families in educational access; and 3). explore how Education Officials (at institutional, district and department level) and NGO workers perceive the educational challenges and opportunities of disabled refugee students, with a particular focus on girls. We present the findings according to the research questions below.

Question1

What data about the education of disabled refugee students is available and needed in the three contexts and what local and international policies are relevant? Collecting data is important for policy formulation and eventual monitoring the impact of interventions. But collecting these data is difficult because of different understandings of disability. Also, refugee populations may not wish to disclose disability and disabled people may be reluctant to disclose refugee status. We also need to know about where and how the education of disabled refugee students is in national policy and legislation, to give an understanding of needed policy change and educational response.

The Uganda refugee statistics 2021 (UNHCR, 2021, 2022) data on children with disability is very scanty. The 2021 statistics lists disability as one of the top 6 special needs of refugees, with 23,025 persons. The data is not disaggregated, either by gender or age. UNHCR is the largest generator of refugee statistics. The data on education for refugees with disabilities is even more scanty (Jamall and Sera, Okot -Oyal, 2017 in Walton et al., 2020) even for organisations that work with refugee children. During the literature reviews for this study, there was little accurate data on education for refugees with disability in Uganda. What is needed is a comprehensive national study on children with disability and their access and transition in education and further research and documentation on refugee children with disabilities. Indeed, in the policy brief and dissemination forum, stakeholders requested for stronger quantitative data related to refugee students with disability in and out of school and the nature of the disability. Our study found some data on inclusive education but not refugee children with disabilities. As a part of the research process, we came across several families in settlements who had students out of school, and who had not been identified by NGOs or education officials, and who needed support because of impairments.

Local and international policies

The national policies that framed refugee education in Uganda are the Comprehensive Refugee Response framework (CRRP), the Education Response Plan for refugees in Uganda (ERPR). The common thread in all these policies is the 2006 Refugee Act and the 2010 Refugee Regulations, driven by development partners, NGOs, and the education partners. The CRRFP framework is the commitment to harness the whole of society's approach to responding and funding solutions to the refugee crisis, including educational access and quality. These policies build on the existing initiatives to ensure access to the same social services for refugees as the host communities. The refugee policies jointly emphasise provision of equitable, inclusive, quality education and to strengthen educational systems for refugees and host communities; boys and girls.

Uganda's Special Needs and Inclusive Education policy is rooted in the Salamanca statement and Framework for Action on special Needs education (UNESCO, 1994). The Salamanca statement, an international policy framework is in consonance with the 1995 Uganda Constitution, and the subsequent Persons with Disability Act of 2006. The related policies on Inclusive Education emphasise the right of education for all children; for inclusive schools and classrooms; quality meaningful education; and the right to attend school, including those with temporary and permanent needs for educational adjustments. None of the policies is explicit on educational access for refugee children with disabilities. None the less, the policy frameworks contributed to further development of minimum standards and guidelines in school infrastructure development, school management and, the overall achievement of the education for all agenda. However, the study found gaps in the education policy on access. Some schools did not have facilities and resources to accommodate children with special needs. A ministry official explained in relation to policy,

> People with disabilities have a right to be included, and special action must be taken to include them- even in political positions……when you talk of refugees it is like a child with a disability. If there is a meeting in the ministry without a representative for refugees or children with disabilities, then there is no mention of their needs but the meeting is always cautious, once a representative is in that meeting, their issue is catered for.

The official was also aware of the challenges with schools,

> …schools claim to be accessible, but are not fully. Example of bathrooms. Many bathrooms are not accessible. (Ministry Official)

> Parents cannot afford the needed tools- like wheelchairs (District Education Official)

Data about transitions

There is no data available for tracking education progression and careers for students with disabilities. District Education Officials and a few NGOs were only beginning to have conversations about secondary schools, and vocational training, however, data and policy do not address this. As one senior education official explained, there is

"no data on the number of refugees graduating."

Tracking and identification

Parents associations that we worked with were able to identify and bring us to students who were not being supported by NGOs. Our NGO partners were not aware of some of the families that we found, and these families were in situations of significant hardship. They spoke of attempting to seek out medical attention and support for accessing schools and livelihoods without success. This suggests that some families are falling through the cracks because of a lack of medical attention which prevents them from accessing school:

> Because of the gadget's that are not there many special needs students are not accessing schools, (District Education Official)

> ...Requesting for special help so that my daughter can study… (Caregiver)

Question 2

What are the experiences of disabled refugee students (disaggregated by gender), and their families with educational access and success in the host country? The perspectives and experiences of these students and their families offer 'insider knowledge' of the realities of accessing education and succeeding in learning in different contexts. In an era of big data, numbers can occlude the nuances of the workings of power and resistance in education access. Insights gained from these experiences will be available and needed in the three contexts and what local and international policies are relevant.

Differences between host communities and refugee settlements

There was a significant difference in the experiences of families who were sponsored by NGOs and those who were not. The students who were not sponsored were not in school, for a variety of reasons, including stigma, poor access and quality of learning and school fees. Students with disabilities who were supported were mostly in NGO supported inclusive schools- which were mostly boarding schools. Thus, avoiding the difficulties and dangers of getting to and from school- particularly for girls. Parents and caregivers who were supported saw benefit from their children's education in these schools. Children also had greater aspirations. Perhaps because of the quality of the education, supporting structures available and support in accessing services such as medical aid and counselling.

There was a significant difference brought to our attention between students with disabilities on settlements and off settlements. District education officers had a responsibility to care for and develop policy in schools both on and off settlements for refugees and non-refugee communities, however, most of the NGO programs were operating on settlements. We found families off settlements facing significantly greater challenges accessing and paying for quality education. The students with disabilities were less likely to attend schools and faced compounded challenges related to poverty, food security, and health care. Below are some anecdotes related to the perceived differences:

> ...Maybe she can be taken by well-wishers to a specialized school… (off settlement caregiver)

> ...Nothing, only waiting for help... (to go to special school)...(off settlement caregiver)

Refugee children get more help than those who are in the community...refugees receive aid and support and even teachers are trained, host do not. They are missing materials and resources in host community schools. (District Education official)

Tribal divisions

Students and their families reported cases of bullying and access to services along tribal lines in some instances. Students explained that they moved in the community together and with siblings to avoid being bullied and beaten. Children with disabilities were seen to be targets for violence from competing tribes. One caregiver explains:

They are always abusing him and sometimes they steal his things...They can abuse him because they are not his tribe (caregiver).

Families also spoke of access to services and goods as being a problem if the distributor or the person identifying families was from a different tribe. This included access to sponsorship and livelihood projects, medical services, farm land, and food rations. We found some families in vulnerable positions who were not getting the medical attention for their children that they required and as a result the students were not in school.

Caregivers

Caregivers were all women. There were very few men in the settlements, and women were mostly alone taking care of the families. Some examples:

(Translator): She says that since the father is very old (and in Sudan), and she used to manage them with the little she has, but she is together with 12 children. (Caregiver of child out of school)

We are here with my uncle's wife and if I do not have something nobody can buy for me because she is alone and unable. (Child with disability)

(Translator): What she wanted to tell you right now is as a single mother it is not easy to send a child to school alone, now she is requesting with the mercy from God if it may be possible with little support so that the boy can be sent to school. Because right now after seeing the results of the boy that day she was very happy but at night she started reflecting on how she will handle the boy's study ahead. I am giving time for your coming to save us. (caregiver)

Parents and caregivers really demonstrated the compounded challenges they face in trying to get an education for their children, while facing trauma and challenges of their own. For example:

A lot of difficulties with water sources, a lot of sicknesses as the place was new. While coming here there was a shortage of water, scared because of the war especially at night and thinking about those left behind in Sudan. (Caregiver)

Those that were not supported by NGOs spoke of travelling long distances and waiting in lines often without having a chance to meet people to register for programs both for school and for the interconnected medical attention required by their children:

> There are other challenges apart from the bad roads, payment in school and other requirements. Here in the settlement, there is limited farmland. We depend on the food ratio given. (Caregiver).

> (translator) They came but were told to wait for the other Dr…. the doctor did not come…When she goes to the hospital, they tell her to bring that person who is sick but She does not have money to hire the car to take her to the health centre. (Caregiver with bedridden child)

Parents demonstrated remarkable skill sets in terms of understanding and knowing their children and navigating systems to get the best for them that they could. Families not supported found it challenging to raise money for tuition to send their children to school. They had large families and we saw them prioritising education for boys without disabilities. There was a lot of fatigue, especially with families who did not have sponsorship. The following quotes from caretakers show their perseverance in attempting to educate their children:

> Is not easy, but there is no other alternative, there is nowhere I can even take them.

> When they are doing the examination, they could call me to go, that I go, I sit with (the child) …

> I could teach her even at home, I struggle with her, I want her to learn

> I struggled to do little farming where I sold the produce and used the money to enrol her (daughter) to school but currently there is not good yield and like you see when you arrived, I was harvesting groundnuts and I am worried whether she will get the amount of groundnut to be sold to get my daughter to school.

Families recognized in general that the conditions of education in Uganda were better than the ones they had in their home countries. Caregivers of sponsored children valued education and were seeking out the best opportunities for them. One caregiver explained that,

> The school here is better (than South Sudan), they were in school but with a lot of interference.

Students differentiated between the quality of the inclusive schools supported by NGO programs and those that were not:

> If it is me, I will change my school, teachers do not treat well even if one is sick.

> 2015 I was in [name of school A], but the next year 2016 I joined [name of school B (NGO supported school)] up to date. Is better in [school B] than [school a] Because when they are teaching, I can understand them.

Some families travelled to nearby cities to get better education for their children. This was particularly the case for students with more severe conditions because there were no local schools to meet their needs. For those that were out of school, there was a mixed perception in terms of the value of schools. The public schools were described as inaccessible and overly crowded. Paying tuition costs were another challenge, and often families did not see the financial value of sending their children to a school that could not accommodate them.

Parents also were often uncomfortable with the capacity of regular schools to understand and work with their children. They worried about the personal safety of their children both travelling to school and within the schools themselves. This was particularly the case for girls, who faced higher risk of violence and sexual harassment. The distance and conditions of the footpaths and roads to get to schools were also challenges and boarding schools were preferred

> She loves the school and reads books when she is at home, I wish she could be put at boarding school so that the problem of bad road could be avoided.

> [name] has enrolled in a school with a very high population and I think that if the pupil were small in class, the teachers could manage and [name] will become a lawyer through that school.

In some cases, parents worried that their children would not have the medical care required should something occur- particularly regarding epilepsy which was a common condition.

> On top of this physical handicap, she is also epileptic and made her drop out of school. by that time even the teachers said she would not continue with her study because the malaria was so much disturbing. By that time, if you ask her, she could not answer your question. By then when she was stopped from study. We did not take a step to look for another school because the mid was so disturbed by then if we were to look for school for her, there was no one to care for her. The mind is so disturbed. (Caregiver)

> The problem is, she cannot be handled by someone else apart from us especially if the malaria starts (Caregiver)

Schools were seen as important places of socialisation and students that were in schools stated that they liked going to school in order to meet and play with friends. Doing homework together and playing games together was an important part of their lives especially for students with disabilities who had fewer opportunities for integration outside of school or more trouble making friends.

> my best friend is called [name]. After finishing homework, my friend will call me so we go have our personal studies, sometimes [name] calls on me so we go and play netball with other friends (student).

For children who were not in schools we saw a significant amount of social isolation. They were confined to their households. This was especially the case for girls who were forced to

undertake household chores around the house and not given an opportunity to go out and interact with other children of their age either because the parents were afraid for their security or they had too much work to do at home.

> when the children go to school and she remain at home, she just staying the way she stays, if there is a parent at home, they just talk with her. (caregiver)

> They (friends) now only come to greet and go (out of school child)

> (Translator) he feels bad and offended when he might be seeing some of his friends, progressing with their studies but for him he is not at school. (out of school child)

> (translator) Now the mother was the one who was pushing the wheelchair, because she can even fear when she is in the wheelchair that she may fall also, the mother was the one pushing. (caregiver)

Capabilities to dream

The students with disabilities that we spoke with had dreams and often their families around them supported them and recognized what they were good at. Many students wanted to enter some type of caregiving role such as doctors or nurses or teachers to help other people like them and have an impact on their community. Again, those that were supported by NGOs and who were in school had greater capacity to dream but all the students that we spoke with aspired and hope to achieve them through education.

> If I can be helped even, I can go up to the University

> If I study, I may also change the situation in my country and may even stop the war in Southern Sudan

> I want to be a laboratory doctor and check people's health

A teacher explained that,

> We need to tell students with disabilities that they matter.

Care

We observed that children with disabilities played a crucial role in caring for and bringing hope to the people around them. Families around them cared for the children as well, although where there was no support, it was with very few exceptions coming from fathers who were not interested in supporting a child with disabilities to go to school. Children with disabilities were performing the regular familial chores in the household, and were proud to be contributing:

> (translator) Every day she wakes up in the morning and helps her mother, then prepares water for the chicken. She can dig sometimes and she can go with her mother. She likes growing groundnuts and maize. The problem is the garden is far from home. (Out of school child)

Transitions and pathways

Some NGOs sponsor secondary school education in cities close by. However, in most cases there is not really an opportunity to attend secondary school. There is an assumption that students with disabilities will not make it through primary school. There were not a lot of career trajectories in place for students with disabilities. So, while we heard students talk a lot about their dreams, when asked about next steps, their answers were less clear. There were not a lot of graduates from primary school, with many students leaving because they felt too old, or simply giving up because they felt that they were not being successful. There was some development of vocational Education and Training programs, which at least offers some reduction of dependency for the children. However simply having the VET programs is not helping students to develop their interests and life aspirations and goals. The VET schools that we spoke with were not aware of education policy for students with disabilities or refugees, did not have professional teachers to identify or teach people with disabilities and there are no provisions for exams and assessment. It was the same with the few secondary schools. A lot more can be done in relation to developing and supporting viable career options. Refugees explained:

> She is saying she is so much interested in joining tailoring school (out of school child)

> He said that if they want to sponsor him, he will continue beyond secondary (student)

Question3

How do education officials (at institutional, district and department level) and NGO workers perceive the educational challenges and opportunities of disabled refugee students, with a particular focus on girls? This question is important because education officials create and mediate policy and have insight into the systemic pressures at play in the education of disabled refugees. NGO workers will yield insights about the context, challenges and extent of support faced by disabled refugee students.

Policy awareness

District education officials were aware of specific policy and legislation- both international and national that guided their efforts in developing inclusive schools. NGOs working in the area were guided by international policy and standards. The teachers we spoke with did not know of any specific policies and do not have guidelines that frame their teaching practice in terms of working with students with disabilities beyond education for all frameworks.
 Some of the NGO programs included policy awareness for teachers and government officials, and there was an activist agenda for engagement about the rights of refugees with disabilities in the community.

> .. we conduct orientation programs for DEO's and inspectors about access to education for children with disabilities (Ministry official)

Coordination of efforts and communication

We found that there was a lot of coordination at the national level, with NGO working groups having regular discussions among themselves and with government policy makers. The long-awaited policy for disability education has been pushed and developed by these formal working

groups, and the emergency response plans which connect to refugees have regular meetings and working groups.

> My responsibility: coordinate with partners supporting disability education, the education task force weekly meeting for district with all partners (District Education officer)

Likewise at the district level, NGOs and district education officials have weekly meetings to discuss the needs and progress of broad education needs. Most of the implementation work is carried out by NGOs. The government does not have adequate funding, but they have the decision-making power. There is a big push to include special needs education, with funding coming from NGO programs.

> the number of students with disabilities are overwhelming the resources of the district… as a district we may be able to identify, but cannot support. appeal for help from funders, but it is limited. (District Education Officer)

Teacher training and resources

Teachers felt that they did not have resources or skills to instruct students with disabilities. Some of the teachers had undergone short training sessions sponsored by NGOs to learn some basic tenets for teaching special education, however it was recognized across the board that the training was not enough, and not enough people were trained. NGOs working with District special needs education officers were working to try and develop more capacity- through these short trainings, but a whole lot more needs to be done in this area.

> …when it comes to their access and participation because teachers are not able to acquire the required skills, at the same time you go to schools and find most of the children do not have materials or they do not have a teacher who knows braille so they end up not participating in for example a child with visual impairment (Ministry Official).

Accessibility

Likewise, teachers spoke about the accessibility of schools both in terms of school infrastructure and roads. In the rainy season, the roads become very muddy and those with physical disabilities do not attend because they are not able to get there. Some teachers spoke of schools that are not accessible. The conditions of bathrooms were emphasised, because ramps are often forgotten, and even where available we heard some vivid descriptions of students and teachers with disabilities crawling through unsanitary spaces to ease themselves. This was seen as another condition that kept students away from school. To contextualise this, one must know that bathrooms in Ugandan schools are all outhouses, with squatting toilets.

Stigma

Many teachers and education officials suggested that parents and community members did not see value in sending students with disabilities to school, and saw a need for engagement. A ministry official explained their strategies of engagement:

> … strategies of engagement: radio talk shows, sub county visits

School capacity

Schools were perceived as being overcrowded and under-resourced. Many teachers felt that they simply did not have the time to give the needed attention to students with disabilities learning needs, and often they were left to themselves. Teachers spoke of students with disabilities as being unruly and difficult to control. NGOs are working to support and build schools that are less crowded and which are oriented towards inclusive learning.

> Ok the challenges we have, is the classrooms are not enough for the learners. There are too many children in the school but few classes. Others come in the morning from far of places, we also have few latrines, some of the latrines do not have rums for the disabled and then the other roads from the community to the school are not okay especially if it rains it become impassable. (teacher)

Transitions

There was almost no preparation or provision for transitions beyond secondary school for students with disabilities. NGOs appear to have been focusing on students with disabilities' access to primary school.

> not enough secondary schools. only 2 in entire [name] district (NGO education officer)

> we need a specialised centre to handle transitions and secondary entrance (District Education Official)

> secondary school teachers do not have training in teaching for disabilities (Ministry Official)

> few partners support secondary (District Education Official)

> limited government intervention in secondary schools. Currently working with 2, one of which is for refugee students (ministry official)

> There is no specific programme targeting refugees with disabilities but we used to have a department offering career guidance and career pathways even students with disabilities attend. That is something I have been thinking about but I do not know how we are going to manage it. (Ministry official)

> It is very rare; it depends on the type of disability. At the settlement from my experience, I have not seen much transitioning by a disabled child where he leaves primary level and goes to secondary level. In the refugee settlement, the transitioning is very minimal (Senior Inclusive Education Official)

Understanding of inclusivity

Uganda has a dual process of integration and segregation when it comes to education for people with disabilities. The integration process is mostly related to students with lesser disabilities, and there is a push for inclusive schools. For students with more severe disabilities there are a few schools in the northern region where students are sent. For example, there are schools for the blind, and schools for the deaf. This is the same in the settlements. Speaking

with teachers and education officials we also came across several people who felt that inclusion meant segregating students with disabilities into special classes or into special schools. Others felt integrating students with disabilities into existing schools (to varying degrees) was inclusive:

> (Translator) He is saying that the school only consists of those children with disability. He is saying that he does not like that school, because even if he needs help from a colleague, they cannot even give help, because for them also they also need help, they all need help. (Student with disability)

> refugees and non-refugees learn together They have been integrated to learn together with the normal children of Uganda. and the school is up to, from P1 up to P7. (teacher)

Efforts for change

There are several programs that different NGOs are supporting. These include curriculum development, teacher training, student sponsorship, and building inclusive schools. In their sponsorship programs, the NGOs that we observed work closely with families and provide counselling and support through regular interactions with the families. There is also support for infrastructure development especially in primary schools in refugee settlements and districts hosting refugees.

> Since 1996 there has been a big change, people with disabilities are respected when they speak (Ministry Official)

> There is a very big difference; even yesterday we had a meeting discussing transition of disabled children from primary to secondary. Even when you look at performance, Primary is doing better than secondary so there is a little bit of difference, the reason is secondary teachers have not gone through training, very have attained special needs training and therefore they have no skills in training children with disabilities. Secondly in secondary school they get one teacher e.g., for biology so they teach as per time table but in primary teachers are there full time. Also, when you come to partners, there are very few who support children with disabilities at secondary level (senior government education official)

Section 4: Analysis and discussion

In this section we provide an analysis of the findings according to a social ecosystem model. This ecosystem mapping approach pays attention to power relations by examining facilitating verticalities and collaborative horizontalities. Wedekind et al. (2021) explain that verticalities reflect decision making hierarchies and mechanisms such as government and policy. They can become facilitating where top-down messages and initiatives support what is coming up from the ground. Wedekind et al. describe 'collaborative horizontalities' as the networks and collaboration between various actors at the local level. Mediation refers to the points of connection between these two dimensions.

On the vertical axis which represents the structures of power and decision making, we find binding international conventions driving policy in Uganda on paper. We see a distributed decision-making process when it comes to policy development, with a lot of NGO influence and regular working groups being consulted to develop implementation strategies. There are some discrepancies however in the policy arena. First there is no specific working group or policy that

covers refugees with disabilities education. There is an inclusive education policy- education for all, that has only minor discussion of education for people with disabilities, a disability act that has little attention to education, and there is a policy for refugees that includes education but does not refer to refugees with disabilities.

There are special needs representatives from the ministry of education and sports at the district level who are working in districts with refugees, and one of the core areas of refugee action in the working groups is in fact oriented towards inclusive education.

Policy is lacking, and policy implementation is not supported financially. Families get caught in between policies related to health, poverty, gender and education. They do not have access to policy development or implementation.

On the horizontal axis, we see local coordination, still formal. District Education Officers work closely with NGO Field officers to coordinate the needs of refugees with disabilities. Teachers in schools however remain with limited knowledge of policy or guidelines about rights, thus seemingly absent from decisions. Parents and their families have a range of knowledge about their rights, with the families supported by NGOs more aware. There does not seem to be a lot of networking or working among families or with schools outside of NGO involvement. The one exception we found was a parent's association for children with disabilities who operate both in settlements and host communities. This was primarily an advocacy organisation; however it had permission and contacts and considerable knowledge of conditions of families with children with disabilities. It also had formal contacts with camp administrators, however it lacked funding to help the families. Still, they played an influential role mobilising and engaging with particularly vulnerable families, and thus formed a network of families missed by NGOs.

NGOs play a mediating role. Their programs work closely with families and schools. They mediate government decisions with family needs, and appear to have close relationships with the families that they work with. Parents and families and students with disabilities do not have a lot of input into decision making policy outside of their contact with NGOs. Special needs officers are meant to play a mediating role between schools and policy and families, and they do, but their scope of operation is large both in and out of settlements, and their budget is not enough. They rely on NGO programs for implementation and as a result we find the gap between public schools and sponsored schools. This is not because of a lack of care or effort; the task just does not match the budget.

Absences

The core challenges remain in breaking the divide between public and sponsored schools. NGO field officers are doing a lot of work mediating the needs and caring for the families that they work with. They are also developing curriculum and sponsoring schools and basic teacher training in inclusive education. They are working together with the local government to coordinate activities, and understand the compounded difficulties facing families and fill gaps in schools. They provide significant care and support to families including with getting access to medical services and livelihood opportunities as well.

This outreach and engagement need to be a function of public schools. This will require significant investment in more schools to lower class sizes and improve infrastructure, more

training for teachers, and developing spaces for including parents and children with disabilities in decision making processes. Following the holistic model that is being developed in the NGO supported schools. The current public model of education is not meeting the needs of students with disabilities. This is a significant challenge, but it is not insurmountable. The expertise of district education officers is there, it is simply a matter of scaling up.

Another big gap that we have commented on already is the lack of secondary schools and a lack of further opportunities for students with disabilities. There are still many students with disabilities who are not in school, this is exaggerated within the host community, but applicable even to the NGO sponsored world. Exact numbers are absent however, teachers tell us that most students are not making it through Primary school. This is telling of the quality of education that is being provided. However, there are not a lot of opportunities to attend secondary schools in any case. Most focus to date has been on primary school access for children with disabilities. There are emerging livelihood discussions, through VET for people who are out of school, however there is no concerted attempt to develop career trajectories or life-opportunities for students. The Vocational and livelihood programs are simply attempts at scooping up the students who are leaving primary school, rather than address the problems of why they are leaving. The risk is that the problems will be the same in VET. A broader vision of understanding and helping to develop students' life goals needs to be done to provide them with an opportunity to flourish, find value, and be valued in their communities. Without the structures- starting in primary schools- to help them navigate their life pathways, it is difficult for them to realise, aspire or even imagine becoming doctors, nurses, and teachers like they say they want to be. Not doing this reflects a more deeply rooted imaginary that in fact students with disabilities cannot achieve such things, and impairs their ability to contribute meaningfully to their society.

Caregivers' education

Another absence we would like to highlight is the lack of learning opportunities provided for parents and caregivers. Most of these are women who are taking care of large households on their own. They are coming from spaces of significant trauma, many of them have disabilities themselves. They are trying to navigate foreign systems in a foreign language- often relying on their children for translation and direction for decision making. They do not have a lot of time, and appear to have sacrificed their own lives for those of their children. Many of them are learning informally about navigating systems and accessing services for their children. Learning, counselling, and career opportunities for these women- many of whom fit into a youth category- are missing and needed.

Gender and disability

We noticed most of the caregivers are women, and we wonder if this has any impact on their ability to contribute to decision making and access to services. We ask this, because we noticed that most of the decision makers, and even NGO field officers, were men. This causes a patriarchal tendency of women being told what to do. It also causes unbalanced decisions and the wrong questions being asked. In our own research, we realised how the responses were different according to who was asking. We also noticed that part of this was because of what questions were being asked. Likewise, we did not notice very many NGO officers identifying as having a disability. This was another area that we shifted in our own research, and which shifted the nature of the research as well. We noticed that parents who had disabilities had

more insight into the needs of their children. Authentic inclusion and participation are needed in decision making processes.

Stigma

We perceived a general narrative of stigma about families and communities' perceptions of students with disabilities. Teachers, government officials, NGO workers all suggest that there is a need for advocacy and engagement with families and parents of students with disabilities. The narrative is suggestive that parents do not value their children as much, or do not think they are as capable of success as other students. However, when we spoke with parents and their families, we did not see this. We saw caring families, who are working tirelessly to find ways to support their children. In some instances, they did not see a lot of opportunities for their children's success through education. There were a sizeable number of caregivers that felt their children could not succeed in school because of their conditions. Many of whom withdrew them because of safety and incidents that had occurred. These relate to struggles with class work and limited support from the school systems.

Our observations in this research suggest that in fact the parents are not overly wrong to be disenchanted by available opportunities. Given the conditions in schools and the challenges and costs of accessing them, it seems an insightful perspective that education in schools is not particularly effective when it comes to the learning needs of children with disabilities. The conditions are difficult for learning, tuition is expensive, the teachers are not trained, the class sizes are too large, bathrooms are unsanitary and inaccessible, their children are bullied and violated, they must travel long distances to get to school which are physically challenging and often unsafe, they do not have the required medical attention or learning aids. There children really can't learn in this situation.

We saw parents going to great lengths to seek out medical attention and education opportunities for their children with disabilities. We therefore counter the general narrative of parents and potentially even caregivers in communities as being prejudiced against students with disabilities. This is an over simplistic narrative which blames parents for conditions that are not really in their control. We therefore challenge this conception as being unsubstantiated. The parents who are receiving support, clearly believe in their Childrens' potential. What is needed is not a liberation of parents' minds about the value of their children, but a shift in structures that are limiting the opportunities for children, who likely will receive a better education from home. Here we agree that engagement is important. We need to change the structural boundaries that are making it dangerous and difficult for students with disabilities to learn and access quality education. Given a reason to dream and aspire, they will.

Policy

Finally, we must point out the most glaring absence of all: Government policy. Since the 2006 Act of Parliament requiring a national disability policy (and associated implementation guidelines and budget), there remains no policy. There has been a long series of consultations and regular promises made about policy forthcoming, but nothing has manifested, and there is no clarity about what or how the specific rights and needs of students with disabilities will be included. At present, they fall under three disparate and universal categories: People with disabilities, refugees, and people with the right to education. This does not connect with health, poverty, food security. Nor does budget provide for implementation. The intersectional and interconnected needs must be specifically addressed and funded.

Section 5: Conclusions

This research report is not the beginning nor the end of the real life needs for research and action in the constantly fluctuating lives of refugees with disabilities. The research offers an opportunity to reflect and adjust and continue to work with (not for) refugees with disabilities as we all seek to improve our communities together.

In general, the interventions that we observed seem to be positive and seem to be working well for the families of students with disabilities and for the students themselves. The students appreciated the quality of education that they were getting in the supported schools and the parents and caregivers also recognized and appreciated the value of the schools. Power and decision making is in fact well distributed with greater cooperation and coordination among NGO and government actors than is the case outside of refugee settlements in Uganda, where NGOs work more individually and competitively. Families, particularly women, need to be more involved in decisions about them.

There remains a need for strong public education systems with qualified teachers and small class sizes with the necessary equipment to work with the various needs of students with disabilities.

Within the social ecosystem we see some strong pillars that support and mediate needs. These committees of praxis are formed by government and NGO work and are important. One area we see that could be strengthened in the social ecosystem comes along the horizontal axis. Developing stronger informal and integrated spaces and forums for children with disabilities and their families to direct policy and learning opportunities would help communities to flourish in a more holistic way. Another obvious actor is Gulu University, and other higher education institutions close by, which can provide resources and transdisciplinary expertise through students, graduates, and researchers. The university needs to adapt their teacher education programs to include the intersectionalities in inclusive education. However, as we have seen, we cannot isolate education from deeply entangled social conditions, and available needs and aspirations of the students. The situation of refugees with disabilities requires a transdisciplinary, participative, and constantly adapting approach that can empower them to add value to their communities. This research has initiated-through strategic engagement of partners- a process to facilitate mechanisms for ongoing participative research and action in this field.

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