

THE INTERSECTION OF MIGRATION, MOTHERHOOD AND DISABILITY: REVISITING THE ROLE OF A MOTHER IN THE LEARNING CONTINUATION OF DISABLED REFUGEE CHILDREN IN UGANDA



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Introduction

Inclusive Education is a human right, and is recognised as a means to achieving an inclusive society (UN, 2016). Several international and national legal frameworks (Walton et al., 2020, Steigmann, 2020, UN, 2016) exist in support of legislation, policy and advocacy for educational access for persons with disabilities.

But there are gaps in implementation. Although cognisant of the gaps in attaining inclusive education for disabled children, particularly refugee children in rural settlements, and the inconsistencies between theory and practice, our point of departure is that parents/caregivers are a decisive aspect on whom prospects of inclusive education could depend (Steigmann, 2020). This article centres on the role of mothers as inclusive educators and views structural gaps in inclusive educational access as an opportunity for meaningful participation in the education of children, especially those children with special needs.

Parents play a huge role in the care and development of their children, providing overall physical care, the development of healthy habits, physical development, and the “development of their intellectual affinities, as well as creation for a better moral values and convictions and attitudes” (Ceka & Murati, 2016:

61). Parents are “direct leaders as well as supporters” (Ceka & Murati, 2016: 61) in the implementation of the education of children, partly owing to the fact that parents potentially maintain awareness and are familiar with the rules for the child’s physical and psychological development. These are “fundamental factors of influence in a child’s ability to learn” (Ceka & Murati, 2016).

Essentially, parents enable the child’s protection and the development of a total personality for the child. They are the “other educators” in the child’s education journey, alongside school teachers (Good, 1998 in Ceka & Murati, 2016: 62), Referencing the proverb, “mother is the first and best teacher”, Ceka & Murati (2016: 62) argue that the child-mother relationship is often intense and crucial to the development of a child’s identity and the “feeling of being a mother to the woman is more powerful than being a father of given child for the husband”.

This article argues that this special connectedness of mothers to their children plays a pivotal role in the possibility for learning continuation and educational access for children with disabilities.

Role of caregivers in advancing education for children with special needs

The article also explores the support role of social networks and caregivers in enabling educational inclusion of children with special needs. Bešić and Hochgatterer (2020) highlight evidence of ‘good practice’ with caregiver organisations at the



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intersection of migration and disability. Social networks and caregivers are conceived as key to inclusive education, with social networks being key partner organisations and important staff working directly with families and children with disabilities. In the Ugandan refugee context, it is largely education non-governmental organisations (NGOs) who serve the educational needs of refugee children on behalf of the United Nations High Commissioner for Refugees (UNHCR).

Caregiving is defined as the “responsibility of providing care” (Cooper, 2020: 77). An online caregiver identity construction study identified various caregiver identities including companionate caregiver which focuses on the “relational aspects of providing care” (Cooper, 2020: 77). Through this article, we reflect on the contribution of NGO workers involved in the identification of families and children with disabilities within the refugee and host community settlements in the research sites, as well as those foster families and guardians providing care to children with disabilities who participated in the study.

How do parents support education for refugee children with disabilities?

It is vital to understand the ways in which social networks, caregivers and parents are key to the support of education for refugee children with disabilities because of the barriers these children face in accessing inclusive education, especially in the Global South. Despite the existence of both international and national frameworks (the United Nations Convention on the Rights of the Child, 1989; the World Declaration on Education for All, 1990; the United Nations Standard Rules on Equalization of Opportunities for Persons with Disabilities, 1993; and the Salamanca Declaration and Framework for Action, 1994 and national policies including the Special Needs and Inclusive Education policy of Uganda; the 1995 Uganda Constitution; the National Council for Disability Act, 2003; the Education Act, 2008; and Persons’ with Disability Act, 2006), children with disabilities still struggle to access the rights contained in these laws and policies, owing to systems constraints, resource limitations, policy implementation gaps and negative attitudes of communities and families of children with disabilities (Steigmaan, 2020). Against this background, we envision a positive contribution by mothers, caregivers and social networks in changing the stories of these children.

The study adopted a social ecosystem model (Hodgson & Spours, 2016). It explores the dynamics of the social world and the interconnectivity and inter-dependence of human relations. The social ecosystem emphasises the potentiality in social collaboration and process adaptation that could result in a more resilient and sustainable humankind. Social ecosystem thinking “gives back to us the ideal of a future that we can shape and develop” (Hodgson & Spours, 2016:2).

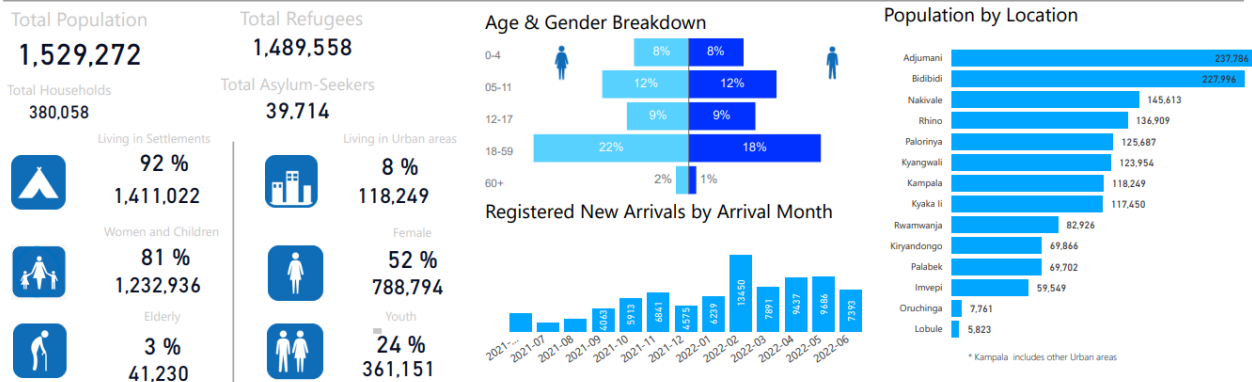
We use this theoretical lens to envision a more inclusive society where children with disabilities are supported by a social network of parents and caregivers in ways that change their stories. Within this thinking, we conceive the role of mothers, guardians and caregivers as potentially decisive for improved access to inclusive learning for refugee children with disabilities. The study explores the inclusive educational practices in a conceptual space that is impacted by vertical facilitatory mechanisms such as international, national and local policy regulations, resource allocation, etc. against the horizontal connectivity’s such as interactions and relationships between local actors/social networks and how these influence practices of inclusion and/or exclusion.

Study context

The UNHCR’s Global Trends Report 2021 indicates that up to 89.3 million persons were forcibly displaced around the world. Of these, 83 percent are hosted in low and middle-income countries like Uganda (UNHCR, 2021). Uganda is the third largest refugee-hosting country in the world (after Turkey with 3.8 million refugees and Columbia with 1.8 million refugees). Uganda hosts more than 1.5 million refugees, mainly from neighbouring South Sudan (60 percent), the Democratic Republic of Congo (30.2 percent) and other countries including Somalia, Eritrea, Rwanda, and Burundi (UNHCR, 2021). The Ugandan refugee statistics indicate that 81 percent of refugees are women and children and 92 percent of the refugee population live in rural settlements with very limited access to inclusive education and or special schools for children with disabilities. Of the Ugandan refugee community, 72,523 are persons with disabilities; 85,120 are women at risk and 48,138 are children at risk (UNHCR, 2022). Around the world, children account for 30 percent of the world’s population; and 41 percent of the forcibly displaced (UNHCR, 2021).

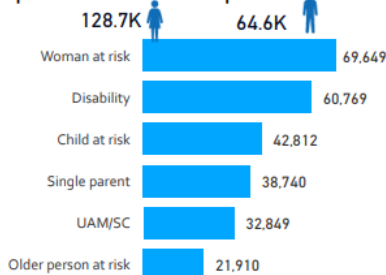


Uganda - Refugee Statistics June 2022



Source: UNHCR Uganda Portal 2022

Specific Needs - Top 6



Source: UNHCR Uganda Portal 2022

Education offers significant protection for vulnerable children, including refugee children and children with disability (Crea et al., 2022). It offers protection from military conscription, sexual exploitation and child marriages. Many refugee children face challenges in accessing education, but refugee children with disabilities are especially vulnerable to educational exclusion (Crea et al, 2022).

Children with special needs in Uganda's refugee settlements

A zoom into the Special Needs Education (SNE) assessment reports from two refugee settlements in West Nile in Uganda show that over 50 percent of the children had special learning needs; 44 percent of teachers got some training on SNE and 75 percent of schools did not have Braille (ECHO/FCA, 2018). Essentially, even

though the children with disabilities access school, there was no guarantee that they would stay in school, and actually learn. Most of the accessible schools in the settlements did not have specialist teachers and appropriate facilities. There is still a mismatch between the policies on SNE and its implementation, as the infrastructure for an inclusive education and learning environment remains elusive. Additionally, the focus, advocacy and campaigns appear to be more towards primary level education, with very little, if any, for the post primary education, as if to suggest that disabled students are not expected to go beyond primary education. The policy and practice environments have validated these assumptions. It is also worth noting that the 2011 policy on Special Needs and Inclusive Education of Uganda is still in draft form 11 years later. Emong and Eron (2016) report discrimination and exclusion of students with disability in higher education institutions owing to a lack of disability support services. They recommend the institutionalisation of policies and guidelines on support services in higher education in Uganda.

The overall objective of the research was to understand the dynamics of educational inclusion and exclusion of disabled refugee children in three refugee hosting countries (Uganda, Zimbabwe and South Africa) where their historical and ongoing experience of crises impacts learning, and to use this understanding to advocate for change in policy and practice. The three cross-country study was guided by the following research questions:

- 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?
- What are the experiences of disabled refugee students (disaggregated by gender), and their families with educational access and success in the host country?
- 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?

The findings we share in the next section are only for the Uganda Case Study.

Methodology

The Uganda Case Study was carried out in three refugee hosting districts in northern Uganda in 2021-2022. The study sites were Lamwo (Palabek settlement); Adjumani (Ayilo 1& II; Nyumanzi and Maji) and Obongi (Palorinya settlement). The study was carried out with children from both refugee and nearby host communities, with children who are in and out of school, boys and girls with disabilities and their families, and with education officers and stakeholders at district and national levels.

Qualitative data was collected from 95 research participants. Fourteen (14) were children with disabilities



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from families of the host community; 25 were refugee children with disabilities; 17 education officials; and 39 parents/caregivers of the children who participated in the study. The education officials were local district education officers and staff from the ministry of education. NGO workers in the settlements were also involved. As part of this case study, semi-structured interviews were conducted with participants. Case study methods allow the researcher in-depth investigation of a phenomenon within its real-life context (Yin, 2003). Participants and their families were anticipated to be potentially traumatised by previous and current crises, and therefore interactive and collaborative methods were used. These included art (drawing by children), photography, life grids and narration by the children and their parents/guardians. To understand how education officials and NGO workers perceive the educational challenges and opportunities of disabled refugee students, semi-structured interviews were conducted. Data analysis was done thematically by identifying and matching patterns to create meaning.

Ethical approval was sought from Nottingham University and from Gulu University Research Ethics committee (GUREC). The committee reviewed and approved informed consent and



accent requests for children, parents/guardians and other categories of research participants. Locally, the research team, comprised of the advisory board, sought permission to access the refugee settlement and families to conduct the interviews. Data reliability and validity was ensured through pre-test and refining of the data collection tools. The use of sign language interpreters and language translators improved data accuracy. However, the travel limitations owing to the COVID-19 country wide lockdown narrowed the participant sample scope - only those settlements and villages that were accessible were reached. This could have had an impact on the overall data narrative and its representativeness. Additionally, being a qualitative study, the sample size was limited, thus the level of representativeness of the opinion of study participants is equally limited.

Findings and discussions

Biographic data of study participants

From the primary data, 18 of the children with disability were girls, 10 were in schools outside the settlement; eight were boys - six in schools outside the settlement and two who were out of school. As noted earlier, the schools at and around

the settlement lack special needs teachers and facilities. As a result, parents had to look for alternative schools outside the settlement which could accommodate their children's learning needs. Some of the families, especially refugee families, received support from education NGOs working in the settlements, but host community families who participated in the study did not receive any external support. More girls than boys with disabilities were out of school. These findings are consistent with the Special Needs Education assessment report (ECHO/FCA, 2018) from two refugee settlements in West Nile, where this study was partly conducted. The report showed that over 50 percent of the children had special learning needs and would need support to access education from outside the settlements, as there are no special needs schools within the settlements. Parents appeared more reluctant to send girls with disabilities to special needs schools far from home. This perhaps explains why more girls than boys with special needs were not in school.

Nine out of 14 interviews with families were done with mothers of children with disabilities. In all the cases, fathers were absent (not present) in the life of the children. In two of the cases where fathers were present, their role in the care and support of the children with disabilities to access education was not very apparent and/or remained unaccounted for.

Educational inclusion for refugee children with disabilities: Challenges and opportunities

From the UNHCR refugee portal report, up to 81 percent of the 1.5 million refugees are women and children and more than 90 percent of all refugees live in rural settlements of Uganda (UNHCR, 2022). By implication, the majority of the refugee population category who live in remote settlements, with limited access to social amenities, are women and children. Access to social amenities like special needs schools, assistive devices and disability sensitive infrastructure enhance educational inclusion. This information is consistent with the observation of Crea et al (2020) that refugee children with disabilities who live in remote areas are doubly constrained. Empirical evidence from our primary data shows that there are no special needs schools within the research settlements for 'severe' disability types such as blind, deaf and cognitive disabilities. The disability report for West Nile (ECHO/FCA, 2018) reported that 50 percent of learners had special learning needs. Learners with such disabilities are often supported by the education non-governmental organisation to access special schools, several kilometres outside the settlement. We view this social-educational collaboration between children with disabilities, their families and the education NGOs, amidst infrastructure and resource gaps, as an opportunity supportive of educational inclusion for children with disabilities.

Migration and disability intersection

The UNHCR report identifies six major special needs including persons with disabilities, single parents and women and children at risk and

unaccompanied minors and children. Nine out of 10 of the refugee families that participated in the study were women-led households. From the participants, the men had either "remained in South Sudan", "moved on to another wife", or were only "partially present" leaving the women to support the family. As a result, the protection risks for women and children with disabilities in refugee settlements is heightened. Women and girls with disabilities suffer double discrimination and vulnerabilities in displacement, and are more predisposed to dependency on others (Rohwerder, 2017). This notwithstanding, we found evidence of hope and strength against all odds among predominantly female caregivers in both refugee and host communities. In more than three families that participated in the study, mothers were more positive and hopeful than they believed fathers were:

[...] Maybe if she was a boy, the father would have loved him [...]

[...] The father said he will not waste his money to pay fees for [...]

At the intersection of migration and disability, we see a 'new' hidden population category - women, who are hardly reported on. Several studies (Burns 2017; Walton, 2020; Rohwerder, 2017 & Crea, 2020) underscore the lack of data on disability in migration. The lack of data is even more worrisome for women migrants caring for children with disabilities. UNHCR, the official refugee agency which oversees the reception and resettlement of refugees in Uganda, lacks disaggregated data on children and families with disability. Burns (2017: 7) also reports the "invisibility of disabled migrants in policy, research and practice". Our research highlights that migrant women with children with disabilities in Uganda are invisible in the data and calls for more rigorous research into the contribution of women at the intersection of migration and disability.

According to Trotter (2012: np), "being a migrant affects the experience of being disabled but being disabled also alters the experience of migration". The intersection of these experiences from a mother's perspective is the focus of this

article, but most especially how they externalise these experiences and still find the strength and hope to support their children and enhance their access to education. Within the social ecosystem model, we perceive these experiences and roles as facilitatory to practices that improve educational inclusion for children with disabilities.

Deconstructing motherhood

The English dictionary defines motherhood as the 'state of being a mother', literally referring to the female gender's reproductive roles and responsibilities. In 'Mandate of Motherhood', Ruso (1976) notes the centrality of the definition to the "adult female mandate to have children and raise them well". This motherhood identity focuses on the particularity and specificity of women as child bearers, and downplays the expanded roles that women have always taken on in the absence of fathers in most family situations. There is therefore an urgent need through research to disrupt these "sex-role stereotypes, mythologies, and sex-typed" (Ruso, 1976) views of motherhood. We seek to expand the motherhood mandate beyond just 'having children and taking care of them well'.

From the empirical primary data we collected, we noted mothers as 'experts' taking care of the physical, health and psychological needs of their children with disabilities. They were always there, full time, to take care of the children whom fathers and society have written off; to find suitable schools for them and support them to stay in school and continue learning, while absorbing all the negative attitudes and connotations that a child with learning challenges suffers. Mothers stayed and took care of the child when the father absconded, they rejected the negative comments and advice of teachers against the child's potential to learn, and in some cases, the mother sat in class to encourage her child to complete promotional assessment tests.

This is the story of a mother with three children, one of whom has a disability:

[...] They told me she has to repeat for two times. I took her to a private school because in public



schools they refused to take her... Private (school) is expensive [...]

Running around, trying to find a school. She can mention words, but she cannot write. Her (younger sister and brother) also in P6 (caught up with her in the same class). When she was in P4, when I brought her to this private school, she was deteriorating, the brain was deteriorating...I failed to get the true sickness disturbing her [...]

[...] When they are doing examination, they could call me to go and sit with her (child) [...]

Story of another mother:

[...] I was every time in the hospital [...]

[...] I started doing their homework every time [...]

In this article we argue, from evidence, that mothers double as inclusive educators, disability assessors and the critical source of support for children with disabilities. This finding is consistent with Ceka's observation that parents are "direct leaders and supporters" of children in their development and learning (Ceka et al., 2016) and yet are not fully recognised as such.

Conclusion and recommendation

From the above discussion, we conclude that exploring the social interconnectivity and interdependency between families, caregivers and

existing social structures through awareness raising and capacity building might be a more sustainable and cost-effective measure for promoting inclusive education, amidst policy implementation gaps and limited resources, among other challenges.

The expanded role of mothers in care and support of children with disabilities remains a huge opportunity. However, more rigorous research into the contribution of women at the intersection of migration and disability is recommended. Additionally, the popularisation and acceptance of the 'new' hidden population category - women - in the migration-disability discourse needs to happen soon.

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