

Lived Experiences of Children with Disabilities as They Try Accessing Inclusive Education in Emergency/Refugee Communities, Kyaka II Refugee Settlement, Southwestern Uganda

Alex Magezi¹, Atuhumuze Faith²

¹War Child International, Kampala, Uganda

²Institute for Research and Development, Marseille, France

Received on: June 23 2022 Accepted on: June 12 2024

ABSTRACT

Purpose: This study sought to understand and bridge the research gap on the lived experiences of Children with Disabilities (CWD) in Kyaka II refugee settlement as they seek for inclusive education. Also, the study accessed the inclusivity of the settlement's schools. **Methods:** Key informant interviews were used to collect data primary from 36 respondents across the settlement. These included, CWD (n=9), parents of CWD (n=14), local leaders/ Refugee Welfare Committee (RWC) (n=7), and head teachers (n=6). Observations were also conducted on the settlement's Primary schools. **Findings:** This study revealed: (1) majority of the CWD are not schooling; (2) majority of the CWD live in single and yet female-headed families; (3) CWD still support with domestic work; (4) CWD also have games they enjoy playing; (5) families with CWD are mainly faced with stigma/ discrimination, abuse (physical and emotional) and increased expenses; (6) in the community and schools CWD are mainly faced with stigma/ discrimination, abuse (physical & emotional), movement difficulties, distress, writing difficulties and difficult in accessing some school structures; (7) schools in the settlement are not fully inclusive. **Conclusion:** This study is insightful to the policymakers, funders and organisations responding to disability inclusion and inclusive education, also, more funding is recommended.

Keywords: Disability, inclusive education, emergencies, refugee communities, Kyaka II refugee settlement

INTRODUCTION

Globally, over one billion people are living with some form of disability and 80% percent of them are in low-and-middle income countries (Jahan, et al., 2020). Similarly, In Uganda, about 13% of the population have one or more forms of disability (Oketch, Yuwono, & Abdu, 2021). In the same tone, over 10 million refugees globally, possess a disability (Bešić & Hochgatterer, 2020). Disability is defined as any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions) (Centers for Disease Control and Prevntion, 2020). Therefore, disability inclusion is ensuring that all people with disabilities are given equal access and chance, eliminating judgment and racism (Centers for Disease Control and Prevntion, 2020; Inclusion me,

2020). On the other hand, inclusive education is a system or a form of education, where students or pupils with different special needs (like different forms of impairments etc), access quality education from the same classroom and school environment, with children without special needs (Karsidia, Kartonob, & Wulansaric, 2017). However, there are many obstacles faced by young persons with disabilities, as they try accessing education, in refugee settings (Odech, Jones, Pincok, & Malachowska, 2021).

Disability inclusion is of great importance. For instance, it reduces the vulnerability of Children with disabilities (Uddin, 2020). In emergency settings people with disabilities need help the most, as they are faced with increased risks ranging from violence to exploitation or abuse (Perry, 2019). Also importantly, inclusive education enables all learners, irrespective of their diversities, to achieve optimum growth and development, ranging from physical to mental, intellectual, emotional and social (Karsidia, Kartonob, & Wulansaric, 2017).

Some things need to be done to create inclusive education. Assistive technologies (ATs) help the creation of disability inclusion by removing challenges persons with disabilities face (Jahan, Barbareschi, Austin, & Holloway, 2020). Also, in order to create inclusive education, school structures or human resources, school policy, curriculum, testing, management,

*Corresponding Author's Email: navyalex@rocketmail.com

Cite as: Ojekere, S Mkpandio D. (2024). Magezi, A., & Faith, A. (2024). Lived Experiences of Children with Disabilities as They Try Accessing Inclusive Education in Emergency/Refugee communities, Kyaka II Refugee Settlement, Southwestern Uganda. *Journal of Disability Studies*, Epub.

facilities, and reception of new students should not be left behind (Karsidia, Kartonob, & Wulansaric, 2017).

Prior research evidences that being a child with disabilities negatively affects one's quality of life (Karsidia, Kartonob, & Wulansaric, 2017). Whereas the number of Children with Disabilities, who are school going has been ascertained (With reference to data bases of NGOs like Finn Church Aid, Humanity & Inclusion, Save the Children, War Child International and Window International, who are implementing education programmes in the Kyaka II refugee settlement), the exact data and information on refugees with disabilities, more especially the non-schooling children with disabilities, is not known (UNDESA, u.d.). In addition, there is limited published research on Children with Disabilities in emergencies (Stough, Ducey, & Kang, 2017). Then, for case of Kyaka II refugee settlement, there isn't any existing published research at all. This study therefore sought to understand the lived experiences of children with disabilities in Kyaka II refugee settlement as they try to access inclusive education. Also, the study accessed the inclusivity of the primary schools in Kyaka II refugee settlement (located in South Western Uganda), by accessing the inclusivity of the school structures, human resources and school policies (Karsidia, Kartonob, & Wulansaric, 2017).

LITERATURE REVIEW

Overview of Disability

Over one billion people, globally are living with some form of disability and 80% percent of them are in low-and-middle income countries (Jahan, et al., 2020). Similarly, in Uganda, about 13% of the population have a disability (Oketch, Yuwono, & Abdu, 2021). In the same tone, over 10 million refugees globally, possess a disability (Bešić & Hochgatterer, 2020). Disability takes different forms; hearing disability, visual disability, physical disability, speech disability and mental disability (Uddin, 2020; Centers for Disease Control and Prevention, 2020) etc. Children with disabilities make up one third or around 14 million of the 58 million out of school children (Saebones, 2015). In addition, refugee children with disabilities are among the most disadvantaged persons (Bešić & Hochgatterer, 2020).

Disability is defined as any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions) (Centers for Disease Control and Prevention, 2020). On the other side, a Child With a Disability (CWD) means a child having mental retardation, a hearing impairment (including deafness), a speech or language impairment, a visual impairment (including blindness), a serious emotional disturbance (referred to in this part as "emotional disturbance"), an orthopaedic impairment, autism, traumatic brain injury, and other health impairment, a specific learning disability, deaf-blindness, or multiple disabilities, and who, by reason thereof, needs special education and related services (IDEA Partnership, 2004).

Over view of Disability Inclusion

Inclusion is simply ensuring that everyone has equal access and chance without judgement and racism (Inclusion me, 2020).

Therefore, disability inclusion is ensuring that all people with disabilities are given equal access and chance, eliminating judgment and racism (Centers for Disease Control and Prevention, 2020; Inclusion me, 2020). Disability inclusion is of great importance. Disability inclusion reduces the vulnerability of Children with disabilities (Uddin, 2020). Also according to the disability inclusion guidelines set by United Nations Relief and Works Agency (UNRWA) (2015), disability inclusion is important in different ways: firstly, persons with disabilities are entitled to similar rights as all others; secondly, disability inclusion ensures effective development assistance and humanitarian action; thirdly, persons with disabilities represent a big percentage of the world (about 1 billion); fourthly, persons with disabilities are faced with risks and forms of vulnerabilities; then lastly, disability inclusion creates economic sense. Similarly, in refugee settings, people with disabilities need help the most, as they are faced with increased risks ranging from violence to exploitation or abuse, stigma and discrimination (Perry, 2019). Therefore, these advantages and more are missed if there is disability exclusion.

There is call for effort to create disability inclusion in various ways. Assistive technologies (ATs) help in removing Challenges faced by persons with disabilities (Jahan, Barbareschi, Austin, & Holloway, 2020). In addition, changing of people's thoughts towards persons with disabilities, creates inclusion (Mantey, 2017). Further, environmental changes are needed in addressing vulnerabilities of people with disabilities (Stough, Ducey, & Kang, 2017). In the refugee settings, there is need for adequate involvement of persons with disabilities in the Humanitarian Action Planning (HPC) (Perry, 2019). Perry (2019) still puts forward that this eliminates specific risk factors and barriers to equitable access to protection and assistance, that persons with disabilities would be getting. Similarly, to archiving effective project communication (Magezi, Abaho, & Kakooza, 2021), persons with disabilities must be considered as key stakeholders and also engaged in the humanitarian action planning, accountability and protection mainstreaming (Perry, 2019).

Overview of Inclusive education

Education in emergencies is a form of education, which is undertaken by people who have been affected by conflicts (Sinclair, 2001). There is no specific definition for inclusive education. However inclusive education can be looked at as a system or a form of education, where students or pupils with different special needs (like different forms of impairments etc), access quality education from the same classroom and school environment, with children who do not have special needs (Karsidia, Kartonob, & Wulansaric, 2017). Therefore, inclusive education is ensuring that children with special needs are accessing quality education without separating them from others (Monika, 2018). Similarly, inclusive education also looks at eliminating the differences in ethnicity, social class, gender, culture, religion, immigration history or other attributes, from the education system (Kauffman, 2007). However, there are many obstacles that face young persons with disabilities as they try accessing education, in refugee settings (Odech, Jones, Pincock,

& Malachowska, 2021). Therefore, if challenges facing CWDs are not eliminated, they may not fully benefit from education (Mantey, 2017).

Even though some stake holders in Uganda are less committed to the implementation of inclusive education (Oketch, Yuwono, & Abdu, 2021), inclusive education is of great importance (Karsidia, Kartonob, & Wulansaric, 2017). Inclusive education enables all learners, irrespective of their diversities, to achieve optimum growth and development, ranging from physical to mental, intellectual, emotional and social (Karsidia, Kartonob, & Wulansaric, 2017). On the other hand, with exclusive education, majority of the Children with Disabilities may not be able to enjoy their right of education (Wapling, 2016). In addition, CWD will be stigmatized, in an education exclusive environment (Donaghue, Deacon, & Stephen, 2020). Further, with exclusive education, CWD face a challenge of being discriminated by their colleagues, teachers and non-teaching staff (Mantey, 2017). Furthermore, global and national education goals can never be attained, unless there is inclusive education (Hussain, Shahzadi, & Khan, 2020). Further to add, compared to developed countries, in the developing and low-income countries (Hussain, Shahzadi, & Khan, 2020), disability exclusion increases the vulnerability of Children with disabilities (Uddin, 2020). Therefore, if disability inclusion is not given attention, CWD end up going through painful childhood experiences (Donaghue, Deacon, & Stephen, 2020). Also, they face many vulnerabilities as they try to access education (Inclusion me, 2020).

Even though the Implementation of inclusive education has only been carried out at a lesser extent (Oketch, Yuwono, & Abdu, 2021), in order to create inclusive education, school structures or facilities, human resources, school policy, curriculum, testing, management, and reception of new students should not be left behind (Karsidia, Kartonob, & Wulansaric, 2017). Equally in emergencies, there is must be a minimum accessibility standard of all schools (Saebones, 2015). The schools require effective and right measures in the form of provision of resources and capacity building to cope with the education of the disabled population (Hussain, Shahzadi, & Khan, 2020). To ensure inclusive education, alternative writing and reading skills which are inclusive in nature, need to be considered (Donaghue, Deacon, & Stephen, 2020). Also, positive teachers' attitude is vital in creating inclusive education (Saloviita, 2020). Seabones (2015) still lists possible ways of creating inclusive education; firstly, investing in teachers' training that equips all teachers to respond to diversity and disability inclusion in the classroom, secondly, ensuring availability of learning materials/resources in accessible formats and are easily adaptable, thirdly, investing in assistive technology and devices for children with disabilities, lastly, ensuring participation of Disabled People's Organisations in education planning and monitoring. As still brought forward by (Guo-Brennan & Guo-Brennan, 2019) to create inclusive education there is a need to engage community stakeholders, including educators, students, parents, governments and community organizations and agencies.

Relevant internal & local legislations on disability & inclusion

The idea of inclusive education holds its grass root from the Salamanca statement (Monika, 2018). To quote the Salamanca statement (1994) governments are encouraged to *"adopt as matter of have or policy, the principle of inclusive education, enrolling all children in regular schools unless there are compelling reasons for doing otherwise"*. In Uganda the national disability-inclusive planning guidelines have also clearly put forward, how to create disability inclusion (National Planning Authority, 2017). These guidelines also share the messages with Article 32 of the 1995 Constitution of the Republic of Uganda (National Planning Authority, 2017).

METHODOLOGY

Research Design: This qualitative study used snow ball sampling technique due to its suitability for studying respondents with; rare characteristics, hard to find and may only be gotten using the referral system (Goodman, 1961). In this study parents/ care givers of Children With Disabilities, Children with Disabilities, local leaders and teachers were mainly gotten using the referral system.

Sturdy Population: Key informant interviews were used to collect data primary from 36 respondents from the 6 zones the refugee settlement (Bwiiriza,, Bukere, Sweswe, Mukondo, Byabakoora and Kaborogota). Detailed observations were also conducted the 6 Primary schools of ; Bwiiriza, Bukere, Sweswe, Mukondo, Byabakoora and Bujubuli to measure their inclusivity. The Key informant interviews comprised of Children With Disabilities, aged 6-19 years (n = 9), Parents of Children With Disabilities (n = 14), local leaders / Refugee Welfare Committee (RWC) (n=7), and teachers (n=6). The children with Disabilities that took part in the study were of primary school going age, 6-19 years. In addition, equal representation of the majority of the zones/villages in the refugee settlement was ensured. Key informant interviews were used because they allow the researcher to get deeper information and understanding of what the target respondent knows, why they behave like that, and the reasons behind their behaviors and attitudes (Kumar, 1989). This inline the objectives of this study. Also, these specific respondents were selected because they are the actors of Disability Inclusion and inclusive education (Krischler, Powell, & Ineke, 2019; Pantic & Florian, 2015).

Data Collection: Through key informant interviews, the primary data was collected in the period of December 2020 to January 2021. Key informant interviews were recorded on audio media. The key informant interviews focused on the areas of:

- Significant Back ground information of Children with Disabilities
- Activities engaged in by children with disabilities
- Challenges faced by children with disabilities and their families, at home and in their communities
- Challenges faced by children with disabilities to, fro and while at school

- The suggested solutions for challenges faced by children with disabilities
- Inclusivity of the primary schools in the settlement

An observation check list/ questionnaire was used to observe and measure the inclusivity of the primary schools in the settlement. This questionnaire was developed according to the works of Oketch, Yuwono and Abdu (2021); Zwane and Malale (2018); Sobel (2019) and Mantey,(2017)

Data Analysis and Presentation: The interviews were transcribed following verbatim and translated into English, where needed data was coded, categorized and themes were developed. This was done by the help of Microsoft excel while following a thematic approach. Thematic approach was used because it allowed analysis of the qualitative data, by pattern identification and reporting of the identified patterns (Braun, Clarke, Hayfield, & Terry, 2018).

Data on inclusivity of the primary schools was tabulated, analyzed and presented using Microsoft Exel.

Validity and Reliability: Data from the first 5 key informants was first analyzed. This helped the researcher to refine the questions and better prob for information from the respondents. Saturation was ensured, by conducting more and more key informant interviews. Saturation was ensured by interviewing more and more respondents, till no new data was being collected. Saturation was ensured to guide when sufficient data has been collected (Glaser & Strauss, 1967). Also equal representation of the majority of the zones/ villages in the settlement was ensured.

Ethical Statement: This study was permitted by the Office of the Prime Minister (OPM). In addition, informed consents were obtained from the parents of children with disabilities, the local leaders and the primary school head teachers. Furthermore, confidentiality and anonymization all the data were ensured throughout the entire study.

FINDINGS AND DISCUSSIONS

Back ground information of the children with disabilities

Table 1 Background information on children with disability (CWD)

| Variable | | % |
|--------------------------------------|----------------------------|-----|
| Average no of children in the family | 6 | NA |
| Parenting status | Both Parents | 43 |
| | Father Only | 0 |
| | Mother Only | 100 |
| When the Disability was gotten | From the country of origin | 57 |
| | After reaching | 36 |
| | Born with it | 36 |
| | After birth | 64 |
| Disability Duration | >5 years | 36 |
| | ≥5 years | 71 |
| Schooling status of the CWD | Schooling | 17 |
| | Not schooling | 39 |
| Reasons for are not schooling | Lack of fee | 6 |
| | Disability | 25 |
| | Others | 11 |

The study found out the following background information on the Children with Disabilities and their families that took part in the study:

There are averagely 6 children, including those without disabilities, in the families of Children With Disabilities. This finding gets supported by (World Vision International, 2017), whose livelihood report show that refugee families have 6-10 members per household. However, this report was conducted in Rhino Camp and IMVEPI refugee settlements, leaving out Kyaka refugee settlement.

The Majority of the interviewed Children With Disabilities, got the disabilities while still in their countries of origin, whereas a few got the disabilities after reaching the host nation (Uganda). Take an example of the response from **parent 5**;....*She (CWD) came when she already had the disability, before I reached this side..* No prior literature was found on this.

The majority of the interviewed Children With Disabilities got their disabilities after birth compared to those born with the disabilities. Fore instance as responded by **parent 4**: ..*She has spent 10 years because now she is 16 years but she got the problem when she was 6 years...* This is in line with the works of (Thwala, Ntinda, & Buyisile, 2015), who bring forward that some children with disabilities contracted disabilities after birth. However, this prior research was not conducted in refugee communities and was in Switzerland.

The majority of the interviewed families with Children With Disabilities are single parent families. In addition, they are female headed. Eg in the interview with **RWC8**:...*You find most of the families having one parent.....mama only...* This is still in line with the report of (World Vision International, 2017), who report that majority of the families are female headed. However, The weakness with this report is being conducted in other settlement in Uganda, excluding Kyaka II refugee settlement. To add more, the works of (Zahaika, Daraweesh, Shqerat, & Halaweh, 2021) also share that majority of the care givers for children with disabilities are mothers. However, these works of were conducted in Palestine and not a refugee community.

Also, to add, the majority of the separation of the parents happened when they were still in their country of origin. Although a few separated after reaching Uganda. Forex ample as responded by **RWC8**: .. *....you find the issue is coming from the country which you came from....they kill the man and the woman stays with the children alone.* No prior literature was found on this particular finding.

The Majority of the CWD have spent 5 years and more with the disabilities. For example as shared by **Parent 6**: ...*He (the Child With Disabilities) has spent like 5 years. He got it when he was like 7 years ...because now he is having 12 years*". No prior literature was found to on this finding

The majority of the interviewed Children With Disabilities were not schooling. Fore instance after asking **RWC1**:.. *me like the chairman, what i know, most of them (Children With Disabilities) are not schooling....* The reasons shared for not schooling are: firstly, the severeness of the disability; secondly, negative attitude of the society towards educating a CWD;

thirdly, lack of sufficient attention & care by the teachers; lastly, inability to afford school fees and bills. However, it should be noted that children with disabilities, including those in emergencies, also have a right to education (Veriava & Paterson, 2020). This specific finding is backed by the research of (Saebones, 2015), who shares, that Children with disabilities make up the majority of out-of-school children. Although, the shortfall with Saebones' research is that it was conducted in Norway and outside the refugee settings. It also does not share the various reasons for not schooling.

Activities are engaged in by children with disabilities at school and home

The interviewed Children with Disabilities are involved in domestic work, at home, whereas at school they are mainly involved in outdoor games more than indoor games. Forexampel as shared by CWD4: *....I like skipping the rope at school...then at home, I help my parent in like; washing plates. Looking for water and like looking for firewood"*

From the above finding and assertion, some children with disabilities in the Kyaka II settlement, are still helpful (both at home and school) and active despite the disability status.

Challenges faced by Children with Disabilities and their families

Table 2. Challenges faced by families & Children with Disabilities

| Area Challenges | % |
|---|----|
| Challenges faced by families with CWDs | |
| Stigma / Discrimination | 43 |
| Abuse (Physical & Emotional) | 40 |
| Increased expenses (especially medical) | 37 |
| Challenges at home and in the Community | |
| Difficulty in movement | 67 |
| Stigma / Discrimination | 77 |
| Abuse (Physical & Emotional) | 77 |
| Distress (self-neglect, over fighting, not happy about themselves) | 57 |
| Challenges to & fro & at school | |
| Difficulty in movement | 67 |
| Stigma / Discrimination | 70 |
| Abuse (Physical & Emotional) | 70 |
| Distress (self-neglect, over fighting, not happy about themselves) | 64 |
| Difficulty in writing | 27 |
| Difficult in accessing school structures (e.g. toilets, class rooms) | 27 |

Challenges faced by the families of CWD

The interviewed families with children with disabilities are faced with various challenges, explained as below.

Majority of the interviewed families of children with disabilities mentioned the challenge of being Discriminated/ stigmatized. Eg as shared by **Parent 5...** *now you find I am sited there, then you find someone abusing me that I produced a lame person*. However, with stigma, such families struggle to strike a balance for earning a living to take care of their children with disabilities (UNICEF, 2018). This particular finding is supported by findings of a similar study, where families with CWDs were found being discriminated (Lekholetova, Liakh, & Zaveryko, 2020). However, their works lack a focus of the situation in emergencies in Uganda. Also the works (Song, Mailick, & Greenberg, 2018) of sill share that parents of children with disabilities face more stigma and discrimination than other parents. To dad further, the works of (Perry, 2019), still forward that people with disabilities in emergencies are faced with stigma and discrimination.

Nearly half of the interviewed families, shared the challenge of abuse (mainly physically and emotionally). Eg as eaired shared by **Parent 5...** *now you find I am sited there, then you find someone abusing me that I produced a lame person* In turn, this negatively affects their psychological wellbeing (Mitter, Ali, & Scior, 2019). However, it should be noted that the better the mental health of a care giver, the better the care he/she will give (Zahaika, Daraweesh, Shqerat, and Halaweh, 2021). This finding is similar to the works of Stough, Ducey, & Kang (2017), where CWDs and their families are physicall and schocologically volunabel. In Addition, the finding of (Lekholetova, Liakh, & Zaveryko, 2020), also show that these families are faced with psychosocial problems. Although all these prior studies were outside Uganda and refugee settings.

Also nearly, half of the respondents brought out the challenge of, increased family expenses. These were mainly medical expenses to take care of the disability of the child. The findings of the the works by (Lekholetova, Liakh, & Zaveryko, 2020) indicate that families of children with disabilities are having medical, financial and economic problems. Similarly, the works of (Zahaika, Daraweesh, Shqerat, & Halaweh, 2021) highlight financial challenges as one of the challenges faced by parents of Children with Disabilities.

Therefore, the above findings, assertions, discussions and explanations imply that having a Child With Disabilities brings extra challenges and misery to the family, in the Kyaka II refugee settlement

Challenges faced by children with disabilities at home and in the community

The psychological and emotional abuse of children with disabilities was shared by the majority of the study respondents. Take an example of **CWD2:** *....In the community, these neighbors don't want me ... they keep telling like you, you talk! do you think that you are a human being?*. Also, as shared by **CWD8:** *..I normally go to the way, like when I have been sent bring something , then people sometimes grab the things from me, because I am not able to defend myself...* However, it should be noted that everyone has equal rights and deserves to be treated well despite their disability status (Szmuker, 2019).

This study finding is backed by the prior works of (Stough, Ducey, & Kang, 2017), who earlier discussed that children with disabilities are psychologically and physically vulnerable. However, these prior works lack a focus on the situation of the refugee communities of Uganda.

Stigma/discrimination of the children with disabilities was a challenge still shared by the majority of the study respondents. Still to quote a response from **CWD2**: *.. they (people in the community) keep telling me, like you, you talk! do you think that you are a human being?*. However, with stigma/discrimination one is associated with higher levels of overall mental health problems, burn-out, daily mood problems, anxiety, depressive symptoms, psychological distress, and lower life satisfaction and psychological well-being (Song, Mailick, & Greenberg, 2018).

This finding is backed up by the works of (Odech, Jones, Pincock, & Malachowska, 2021) who put forward that young persons with Disabilities face stigma as a disability related problem. Even this prior research was conducted in a refugee community, it was conducted in Jordan, not Uganda.

The Distress in children with disabilities was a challenge shared by more than half of the respondents. The mostly shared signs and symptoms of distress were; self-neglect, over-fighting, not happy about oneself. Taking an example of the response by **parent 6**: *..you find that the boy Child with one eye is not doing good things, like when sited there, he is always feeling like fighting, like when this Ka-child (the younger sister of the Child With a Disability) talks about him, he feels like also removing the eye so that they can be the same...like recently he had a knife and told her I remove your eye also!* Sadly however, distress and its related issues like stress negatively affects brain development in children (EcEwen, 2011).

This is in line with the works of (Stough, Ducey, & Kang, 2017) who put forward that persons with disabilities are characterized with challenges of distress and other psychological issues. Although this prior research was about the situation in emergencies, it was conducted out of Uganda.

The above findings, assertions and discussions, therefore imply that Children With Disabilities in the Kyaka II settlement are always battling with several challenges in their homes and communities. This in turn, negatively affects their growth and development (Karsidia, Kartonob, & Wulansaric, 2017).

Challenges/ Problems encountered by CWD to and from, also while at school

The study found out, when going to, coming from and while at school, Children with disabilities are still faced with challenges of; Abuse (physical and emotional). Eg as responded by **parent 6**: *...the problem with the child with one eye, when he goes to school and plays with other children.. you find them fighting him and telling him that they will also remove the remaining eye. The problems are many but you find a child with a disability, you find other children not giving him respect as a normal child.* However, it should be noted that abuse negatively affects a child and the entire society, psychically and psychologically (Children's Bureau, 2017). This finding gets its backing from the work of (Mantey, 2017), whose findings are that children with

disabilities are discriminated by the colleagues, teachers and non-teaching staff, at school. The shortfall with prior research is that it was conducted in Ghana and outside their emergency /refugee communities.

Distress was also mentioned by more than half of the respondents as a challenge, Children with Disabilities face while going to, at and from school. This is supported by the works of (Chan, Singer, & Naido, 2020), whose findings indicate that children with disabilities, are faced with distress at school. Chan, Singer, & Naido (2020) still share, is due their inability to take part in some activities, like playing with fellows. It should be noted that distress negatively impacts the life of children with disabilities (Chan, Singer, & Naido, 2020). However, their research was conducted in South Africa and not in emergency communities.

Stigma/Discrimination of children with disabilities while going to, at and from school was mentioned by three quarters of the study respondents. Eg as responded by **CWD2**: *...“there where I am studying from, I don't think they can stop abusing like “look at that lame”!”. Maybe if they can change the school for me* This is gets it striking from the works of (Barbareschi, Carew, Johnson, Kopi, & Holloway, 2021), who put forward, stigmatizing attitudes on persons with disabilities limits their access to education. Although this prior research was conducted in Kenya and not in emergency communities.

Difficult in movement is also mentioned by more than half of the respondents as a challenge, being faced by Children with Disabilities as they try accessing education. For example taking the response of **Parent 6**: *... most of them (Children with Disabilities), what disturbs them is they find challenges in trying to reach school ..* This is backed by the works of (UNICEF, 2018) who share that movement challenges faced by children with disabilities, isolates them from social activities and participation in their communities.

Difficult in accessing some school structures, was shared by a quarter of the study respondents, as a challenge faced by children with disabilities, while at school. Eg as **CWD5** responds *....the steps over disturb us because we have to climb up..* However, it should be noted that accessibility is very crucial in creating inclusive education (Hayes & Bulat, 2017). This finding is similar to the works of (United Nations DESA, n.d.), who bring forward those persons with disabilities in emergencies are faced with inaccessible structures. The shortfall with prior research is that it was conducted outside emergency communities.

Difficult in writing, by children with disabilities, while at school was shared by a quarter of the study respondents. Take an example of **CWD6**: *yes we feel pain when writing... the way I can be helped is like if I could get something to help in writing, like a computer or phone...* This is in line with the works of (Kholi, Sharma, & Padhy, 2018), who bring forward that some children with disabilities are faced with difficulty in writing. They still share that this may negatively affect their academic performance. Although the shortfall with their prior research is that it lacks a special focus of the situation in Uganda and emergency communities.

The above findings, assertions and discussions imply that going to school is challenging and possess extra challenges to the Children With Disabilities in the Kyaka II refugee settlement. Then, this negatively affects their growth and development (Karsidia, Kartonob, & Wulansaric, 2017).

Suggestions to overcome the challenges/problems faced with CWD

The study respondents suggested some solutions for challenges of CWD and their communities. These are discussed below.

Construction and equipping a resource center for the CWD. Take an example of the response by **Teacher 1**: *..the other suggestion which I had, the resource centre, plus the equipment. Because for these teacher at least they have some ka-Knowledge. They Know what it means by inclusive education.* This in line with the works of (Lekholetova, Liakh, & Zaveryko, 2020), who stress out the need for rehabilitaiton equipment as one way of helping childlren with disabilities. However, this research was conducted in Ukriane and outisde emergency settings.

Availing children with disabilities with assistive devices. Fore instance as shared by **CWD1**: *..movement devices are good, they can help me..* This in agreement with the research of (Inclusive City Maker, 2021), who share that, that globally 75million people need wheel chairs. However, this literature is not focused in situation of children with disabilities in emergency settings.

Change of attitude by the society and schools towards Children With Disabilities. Fore example as shared by **CWD5**: *...we (children with disabilities) now want the masters (School teachers) to change the behaviors of the children at school.* This is supported by the research of (Bannink, Hove, & Idro, 2016), who bring forward that there is a need to strengthen the reduction of stigma for children with disabilities. The shortfall this prior research is that it was not conducted in emergency communities and was also outside Uganda.

Economic assistance to the Children With Disabilities and their families. Eg as shared by **Parent 7**: *..the problems are many because you cannot do anything else with the CWD, but If I have like something, like a small business ... but in case you have a CWD but having money , you cannot fail to take care..* This finding is backed by the work of (WHO, 2011) who put forward that persons with disabilities have financial challenges and need to be supported. Although these works lack a special focus on the situation on emergencies and Uganda.

Being re-allocated to schools and places for CWD only. Eg as responded by **CWD2**: *...“there where I am studying from, I don't think they can stop abusing like “look at that lame”!. Maybe if they can change the school for me . .* However, inclusive education disagrees with this as it promotes exclusive instead of inclusive education (Andrienko, et al., 2017; Hayes & Bulat, 2017)

Medical assistance. Eg as responded by **Parent 13** *... “Me like the parent I pray to God to get doctors to treat her (a girl child with a disability) and she also becomes okay..* This is in line with the works of (Mattson & Kuo, 2019) who bring forward that,

children with disabilities require more medical compared to normal children. Hower, this prior research was conducted outside Uganda and lacks a focus on the life in refugee communities.

Other forms of support (like being given play materials, clothes etc), were share by the least of the study respondents. As earlier discussed, this lends support from the works of (WHO, 2011), who report that persons with disabilities need several forms of support.

Inclusivity of the primary schools in the refugee settlement

The study found out that the local school rules and regulations were completely silent (av score = 1) when it came to disability inclusion and inclusive education. Yet Putting in place such relevant rules and policies helps in promoting inclusive education (Oketch, Yuwono, & Abdu, 2021). Similarly, the works of (Mantey, 2017) point out lack of sufficient planning, interms of policy and programming for persons with disabilities. However, the shortfall with their works is; lack a special insight on the local school rules and regulations, being conducted in Ghana and outside humanitarian settings.

Therefore, the above finding, assertion and discussion imply that lack of inclusive school rules and regulations is one the contributors to the high number out of school children with disabilities in the Kyaka II refugee settlement.

Inclusivity of the schools' structures/building in the Kyaka II refugee Settlement

The study discovered that averagely the school structures are not inclusive in nature (average score =1.33). For instance, observations showed: most of the entrances were too narrow and rarely had accessible ramps with rails; there were no specialized equipment inside classrooms to assist the children with disabilities; etc This finding is in line with the research of (Oketch, Yuwono, & Abdu, 2021) who shares that most schools in Uganda are not inclusive and there is a need for ensuring that classrooms are inclusively well setup and there accessible ramps in school structures, in order to achieve inclusive education. Although this study was conducted in Uganda, it does not focus on the situation in refugee communities

The above therefore implies that non-inclusivity of the majority of the school structures, are some of the reasons why children with dishabilles in the Kyaka II settlement are not going to school.

Inclusivity of the human resources of the primary schools in the Kyaka II refugee Settlement

The study found out that the teachers were somehow aware and try to implement inclusive education practices (average score = 1.8). However, they are still below the required standards for inclusive education (an average score = 3). To mention a few: they lacked sufficient training in disability inclusion and inclusive education; non-teaching staffs had never received any training on disabilities inclusion and inclusive education; etc. This finding is backed by the works of (Zwane & Malale, 2018) who bring forwards some barriers to inclusive education, to mention a few: insufficient teacher development and training in inclusive education; lack of facilities to support inclusivity and teacher's incompetence in identifying children that need special

support. The short fall with this research it was conducted in the secondary schools of Switzerland and outside emergency/refugee set up.

This particular finding therefore implies some children with disabilities are in the Kyaka II settlement are not school going due to several barriers to inclusive education at the schools in settlement.

Table 3 Summary of Inclusiveness of human resources

| Statement Source: Oketch, Yuwono and Abdu (2021); Zwane and Malale (2018); Sobel (2019) and Mantey,(2017) | Bwiriiza | Bukere | Sweswe | Mukondo | Byabakoora | Bujubuli |
|--|----------|--------|--------|---------|------------|----------|
| Teachers are capable of using sign language while teaching | 1 | 2 | 2 | 2 | 2 | 2 |
| Teachers are constantly trained on how to deal with CWD | 2 | 2 | 2 | 2 | 2 | 2 |
| Teachers are creative enough to cater for all learning needs of the CWD and other pupils | 2 | 2 | 2 | 2 | 2 | 2 |
| Teachers are always trying by all means to ensure other underlying problems (like cause of trauma, silence) of the CWDs are understood and addressed/reported. | 2 | 1 | 2 | 2 | 2 | 2 |
| Teachers possess and demonstrate support for all the children and their disability statuses. | 2 | 2 | 2 | 2 | 2 | 2 |
| Teacher have capacity to identify some disability amongst children. | 2 | 2 | 2 | 2 | 2 | 2 |
| There is at least a special needs teacher dedicated for the school | 2 | 2 | 2 | 2 | 2 | 2 |
| Non-teaching staffs know and implement inclusive education practices | 1 | 1 | 1 | 1 | 1 | 1 |
| Average | | | 1.8 | | | |
| Where by: 1=Not met, 2=Somehow met, 3=Fully met | | | | | | |

CONCLUSION

The lived experience of Children with Disabilities (CWD), in emergency communities are under researched. This is worse with the case of Kyaka II refugee Settlement. Despite the one's disability, children with Ddisabilities are also entitled to care and enjoyments of full rights, as children who do not require special attention. Funding gaps, lacking of the sufficient capabilities and capacities, exclusive school and community structures, exclusive laws and policies are a few reasons for disability exclusion and exclusive education. The study found out: majority of the children with disabilities are not schooling; majority of the children with disabilities live in single and yet female headed families; children with disabilities are involved in domestic work, at home, then,

outdoor games more than indoor games at school; families with children with disabilities are mainly faced with challenges of stigma/discrimination, abuse (physical and emotional) and increased expenses ; in the community and schools children with disabilities are mainly faced with the challenges of stigma/discrimination, abuse (physical &emotional), difficulty in movement, distress, difficult in writing and lastly difficult in accessing school structures; schools in the kyaka refugee settlement are not yet fully inclusive. Unless more efforts are allocated to the areas of Disability Inclusion and Inclusive Education, the Children With Disabilities in the Kyaka Refugee Settlement shall continue to suffer. This study therefore, recommends more funding in the areas of Disability Inclusion and Inclusive Education.

SOURCE OF FUNDING

This study did not receive any funding.

CONFLICT OF INTEREST

The Authors of this study declare to have no conflict of interest. In addition, the views in this study are entirely the authors' views not the views of their institutions of affiliation.

REFERENCE

- Andrienko, N. K., Gorbacheva, D. A., Skripkina, A. V., Lobejko, J. A., Trinistatskaja, O. G., Kovalenko, V. I., & Baboshina, E. V. (2017). Retraining of teachers of primary school for working with children with disabilities of health in the conditions of inclusive education. *Journal of Pharmaceutical Sciences and Research*, 9(10), 1668-1671.
- Anderson, D., Dumont, S., Phillip, J., & Azzaria, L. (2007). The personal cost of caring for a child with a disability: A review of the literature. Association of School of Public Health: SAGE Publications.
- Bannink, F., Hove, G. V., & Idro, R. (2016). Parental stress and support of parents of children with spina bifida in Uganda: Original research. *African Journal of Disability*, 5(1), 1-10.
- Bešić, E., & Hochgatterer, L. (2020, June 3). Refugee families with children with disabilities: Exploring their social network and support needs. A good practice example. *Frontiers in Education*, 5: 61. <https://doi.org/10.3389/educ.2020.00061>
- Braun, V., Clarke, V., Hayfield, N., & Terry, G. (2018). Thematic analysis. In P. Liamputtong (Ed.), *Handbook of research methods in health social sciences* (pp. 1-18). Springer.
- Centers for Disease Control and Prevention. (2020). Disability and health overview. Retrieved from [https://www.cdc.gov/ncbddd/disabilityandhealth/disability.html#:~:text=A%20disability%20is%20any%20condition,around%20them%20\(participation%20restrictions\).](https://www.cdc.gov/ncbddd/disabilityandhealth/disability.html#:~:text=A%20disability%20is%20any%20condition,around%20them%20(participation%20restrictions).)
- Children's Bureau. (2017). Long-term consequences of child welfare. Child Welfare Information Gateway. Retrieved from www.childwelfare.gov/pubpdfs/long_term_consequences.pdf
- Donaghue, J., Deacon, L. M., & Stephen, J. (2020). "What's wrong with you, are you stupid?" Listening to the biographical narratives of adults with dyslexia in an age of 'inclusive' and 'anti-discriminatory' practice. *Disability and Society*. 37(3), 406-426.
- EcEwen, B. S. (2011). Effects of stress on the developing brain. *Cerebrum: The Dana Forum on Brain Science*, 2011, 14. <https://doi.org/10.1002/wps.20584>

- Finn Church Aid Uganda. (2020). Kyaka II primary schools enrollment. Finn Church Aid Uganda.
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Aldine Transaction.
- Goodman, L. A. (1961). Snowball sampling. *The Annals of Mathematical Statistics*, 32(1), 148-170.
- Guo-Brennan, L., & Guo-Brennan, M. (2019, July 10). Building welcoming and inclusive schools for immigrant and refugee students: Policy, framework and promising praxis. In J. Daugard, B. Porter, D. Ikawa, & L. Chewi (Eds.), *Education, immigration and migration* (Studies in Educational Administration, pp. 73-93). <https://doi.org/10.1108/978-1-78756-044-420191006>
- Hayes, A. M., & Bulat, J. (2017). Disabilities inclusive education systems and policies guide for low- and middle-income countries. *RTI Press Publication No. OP-0043-1707*. <https://doi.org/10.3768/rtipress.2017.op.0043.1707>
- Hussain, S., Shahzadi, U., & Khan, I. (2020). Challenges to learners with disabilities in the higher education institutions in Pakistan: A review. *Research Journal of Social Sciences & Economics Review*, 1(3), 1-6.
- IDEA Partnership. (2004). Definition of child with a disability. Retrieved from [http://www.ideapartnership.org/topics-database/idea-2004/idea-2004-part-b/1396-definition-of-child-with-a-disability.html#:~:text=\(1\)%20Child%20with%20a%20disability,in%20this%20part%20as%20emotional](http://www.ideapartnership.org/topics-database/idea-2004/idea-2004-part-b/1396-definition-of-child-with-a-disability.html#:~:text=(1)%20Child%20with%20a%20disability,in%20this%20part%20as%20emotional).
- Inclusion me. (2020). What does inclusion mean? Retrieved from https://www.inclusion.me.uk/news/what_does_inclusion_mean
- Inclusive City Maker. (2021). Disabled people in the world in 2021: Facts and figures. Retrieved December 2021, from <https://www.inclusivacitymaker.com/disabled-people-in-the-world-in-2021-facts-and-figures/>
- Jahan, N., Barbareschi, G., Austin, V. P., & Holloway, C. (2020). Inclusion and independence: The impact of mobile technology on the lives of persons with disabilities in Kenya and Bangladesh. *ResearchGate*.
- Jahan, N., Barbareschi, G., Jan, C. A., Mutuku, C. M., Rahman, N., Austin, V., & Holloway, C. (2020). Inclusion and independence: The impact of mobile technology on the lives of persons with disabilities in Kenya and Bangladesh.
- Karsidia, R., Kartonob, D. T., & Wulansaric, A. (2017). The effect of signification, resource domination, and legitimacy and inclusive education legitimacy on inclusivity of elementary school in Surakarta City. *International Journal of Islamic and Civilizational Studies*, 4, 1-7.
- Kholi, A., Sharma, S., & Padhy, S. K. (2018). Specific learning disabilities: Issues that remain unanswered. *Indian Journal of Psychological Medicine*, 40(5): 399-405. https://doi.org/10.4103/IJPSYM.IJPSYM_86_18
- Kumar, K. (1989). *Conducting key informant interviews in developing countries*. A.I.D. Program Design and Evaluation Methodology Report No. 13.
- Lekholetova, M., Liakh, T., & Zaveryko, N. (2020). Problems of parents caring for children with disabilities. *International Scientific Conference, IV*, 268-278.
- Magezi, A., Abaho, E., & Kakooza, J. B. (2021, June). Effective project communication and successful consortia engagements. *International Journal of Innovative Science and Research Technology*, 6(6), 1474-1483.
- Mantey, E. E. (2017). Discrimination against children with disabilities in mainstream schools in Southern Ghana: Challenges and perspectives from stakeholders. *International Journal of Educational Development*, 54, 18-25.
- Kauffman J. M. (2007). Conceptual models and the future of special education. *Education and Treatment of Children*, 30, 241-258. <https://doi.org/10.1353/etc.2007.0024>
- Mattson, G., & Kuo, D. (2019). Psychosocial factors in children and youth with special health care needs and their families. *Pediatrics*, 143 (1): e20183171. <https://doi.org/10.1542/peds.2018-3171>
- Monika. (2018). Role of family in inclusive education. *International Journal of Academic Research and Development*, 3(1), 258-260.
- National Planning Authority. (2017). National disability-inclusive planning guidelines for Uganda. Kampala: National Planning Authority.
- Odech, K. B., Jones, N., Pincock, K., & Malachowska, A. (2021, September 15). 'I wish someone would ask me questions': The unheard voices of adolescents with disabilities in Jordan. *The European Journal of Development Research*, 33, 1328-1348. <https://doi.org/10.1057/s41287-021-00421-0>
- Oketch, J. B., Yuwono, I., & Abdu, W. J. (2021). Implementation of inclusive education practices for children with disabilities and other special needs in Uganda. *Journal of Education and e-Learning Research*, 8(1), 97-102.
- Pantić, N., & Florian, L. (2015). Developing teachers as agents of inclusion and social justice. *Education Inquiry*, 6(3), 27311. <https://doi.org/10.3402/edui.v6.27311>
- Perry, S. (2019). Guidance on strengthening disability inclusion in humanitarian response plans. ReliefWeb. Retrieved December 25, 2021, from <https://reliefweb.int/report/world/guidance-strengthening-disability-inclusion-humanitarian-response-plans>
- Saebones, A.-M. (2015). Towards a disability inclusive education. Background paper for the Oslo Summit on Education for Development. In R. B. Bieler, N. Baboo, L. Banham, N. Signal, C. Howgego, C. V. McClain-Nhlapo, & G. A. Danise (Eds.), *Oslo Summit on Education for Development*, 6(7).