

Publisher



African Journal of Social Work

Afri. j. soc. work

© National Association of Social Workers Zimbabwe/Autor(s)

ISSN Print 1563-3934

ISSN Online 2409-5605

Licensed under a Creative Commons Attribution-Non-commercial 4.0 International License

Indexed & Accredited with: African Journals Online (AJOL) | University of Zimbabwe Accredited Journals (UZAJ) | SCOPUS (Elsevier) | Directory of Open Access Journals (DOAJ) | Society of African Journal Editors (SAJE) | Asian Digital Library (ADL) | African Social Work & Development Network (ASWDNet) | Department of Higher Education and Training (DHET) - South Africa | SJR | CNKI - China | Journal Publishing Practices & Standards (JPPS) | EBSCO | DOI

‘My sister is my everything’: A qualitative explorative study of social participation by youth with disabilities in Wakiso District, Uganda

Slivesteri SANDE, E. S. KAWESA, H. MUYINDA, F. B. MBAZZI and DIY Youth Researcher team

ABSTRACT

Approximately $\frac{3}{4}$ of the Ugandan population is below 30 years and 12% have a disability. Youth with disabilities continue to face barriers in social participation due to poor infrastructures, stigma, and limited support networks. Despite the national and international policy frameworks promoting inclusivity, these obstacles continue to impede their participation in education, employment and social participation. Using qualitative life histories, we explored the social participation experiences of youth with disabilities in Wakiso District, Uganda. Employing a peer-to-peer model, 14 youth researchers with and without disabilities were trained in qualitative research and collected life histories from 31 youths with disabilities (18-30 years) from Wakiso district. Data was transcribed and analyzed using thematic analysis. A validation meeting was held with the youth participants. Family support, peer networks, self-esteem, and institutional accommodations are critical facilitators of social participation, while physical inaccessibility, financial constraints, and societal prejudice remain significant barriers to social participation. The findings emphasize the need for systemic changes to promote accessibility and inclusivity in low-resource settings, recommending increased investment in infrastructure, supportive policy implementations, and community sensitization to counter negative societal attitudes. These efforts are essential to create environments that enable youth with disabilities to participate fully and equally in society.

KEY TERMS: Peer-to-peer model, Life histories, social participation, Youth with disabilities, Barriers and facilitators

KEY DATES: Submitted: March 2024; Reviewed: April 2025; Accepted: August 2025; Published: October 2025

KEY DECLARATIONS: Funding: None | Conflict of Interest: None

AUTHOR DETAILS

- Sande Slivesteri, Disability Research Group, Medical Research Council/Uganda Virus Research Institute and London School of Hygiene & Tropical Medicine Uganda Research Unit, Entebbe, Uganda
- Kawesa Elizabeth Shalom, Disability Research Group, Medical Research Council/Uganda Virus Research Institute and London School of Hygiene & Tropical Medicine Uganda Research Unit, Entebbe, Uganda
- Muyinda Herbert, Child Health and Development Centre, Makerere University, Kampala, Uganda
- Mbazzi Femke Bannink, International Centre for Evidence in Disability, London School of Hygiene & Tropical Medicine, London, United Kingdom
- Nalikk Aisha, Kamusiime Ronald, Akwii Betty, Omara Jonathan, Tukasingular Adong Naume, Sakwa Wycliffe, Agea Tonny, Luzinda Richard, Mwinganiza Joseph, Okello Charles, Kengonzi Prossy, Mulyenzi Tonny, Nabagesera Rebecca, DIY youth researchers

Current and previous volumes are available at:

<https://ajsw.africasocialwork.net>



HOW TO REFERENCE USING ASWDNET STYLE

Sande S., Kawesa E.E., Muyinda H., Mbazzi F. B. And the DIY Youth Researcher Team. (2025). ‘My Sister Is My Everything’: A qualitative explorative study of social participation by youth with disabilities in Wakiso District, Uganda. *African Journal of Social Work*, 15(5), 1-13. <https://dx.doi.org/10.4314/ajsw.v15i5.1>

INTRODUCTION

Youth with disabilities in Uganda face persistent challenges that limit their ability to fully engage in society. Although policies exist to promote inclusion, many continue to encounter physical, social, and economic barriers in everyday life. These challenges often begin at home and extend through school, work, and community spaces, where stigmas and inaccessible environments are common. In Wakiso District, a growing population of young people with disabilities remains largely excluded from meaningful participation in education, employment, and social life. This study sets out to understand their lived experiences by exploring how they navigate these challenges and what factors support or hinder their involvement in society.

BACKGROUND

People with disabilities face barriers to inclusion and participation in society worldwide (Griffiths et al., 2020). Despite attempts and commitment to improve participation of people with disabilities in society, long-standing stereotypes, discrimination, and structural inequalities continue to exist, affecting their full social participation in daily life (Polat, 2011; Trani et al., 2020). Individual characteristics, like the nature and severity of the impairment, plays a significant role in social participation (Awsumb et al., 2022). External factors, including societal attitudes, infrastructure accessibility, availability of social support services influence the participation of youth with disabilities in education, employment, and social engagement (Egan et al., 2022; Shahin et al., 2020; WHO, 2023). The social life of youth with disabilities is often controlled and influenced by parents, guardians, or caregivers who determine where, how and whom they socialize with (Werner & Chabany, 2016).

The 2017 Uganda functional disability survey reported an overall disability prevalence of 16.5%. Among children aged 2-4 years, the prevalence was 3.5%, while it was 7.5% for those aged 5-17 years, and 16.5% for adults (Uganda, 2021; UNFPA, 2019). The United Nations Educational, Scientific and Cultural Organization (UNESCO), reports the literacy rate among youth with disabilities at 31%, lower than the 78% literacy rate of their non-disabled counterparts. (Howgego et al., 2014; Wapling, 2016). Moreover, the unemployment rate for people with disabilities is 9.7% in working-age adults with disabilities compared to 9.0% of their non-disabled peers (Lindsay et al., 2019; Ministry of Gender, 2020).

The Convention on the Rights of Persons with Disabilities (2006) defines disability as an evolving concept. It results from the interaction between a person's long-term physical, mental, intellectual, or sensory impairment and environmental, attitudinal, and other barriers that limit their full and equal participation in society (Hendriks, 2007; Márton et al., 2013; Sabatello & Schulze, 2013). Uganda's regulations and policies, including the Persons with Disabilities Act (2020), adopt and reinforce this definition of disability, recognizing that it arises from dynamic interactions rather than just individual impairments (Katsui & Kumpuvuori, 2008; Wahitu & Guzu, 2022).

Youth with disabilities have mostly participated as subjects in research about them but rarely take part as (co-)researchers. Their involvement is essential to better understand disability and build an inclusive research culture (Lundy et al., 2011). In this study we explored social participation of youth with disabilities with a group of researchers with disabilities in Uganda.

METHODS

Ethical considerations

The study received ethical approval from the Uganda Virus Research Institute Research Ethics Committee (Ref: GC/127/964), the London School of Hygiene & Tropical Medicine Research Ethics Committee (Ref: 29531), and clearance from the Uganda National Council for Science and Technology (Ref: SS1706ES).

Youth researchers were trained in research ethics, Good Clinical Practice, and data protection, following the project's safeguarding policy.

Reasonable accommodation was provided for youth researchers and participants with disabilities. Informed consent forms were available in English, Luganda, and Braille. Information was read aloud for those with visual impairments or unable to read Braille. A sign language interpreter supported those with hearing impairments, and simplified information sheets were provided for participants with cognitive challenges. Written consent was obtained, and two youth with cognitive and communication difficulties assented with caregiver consent.

Study design

The MRC/UVRI & LSHTM Uganda Research Unit in collaboration with the Child Health and Development Centre, Makerere University, Uganda National Council for Persons with Disabilities, and Youth Research Academy of THRU ZIM implemented the African Human Rights Consortium-funded Disabled Youth

Investigates project. Its goals were to develop youth-led disability research, create employment for youth with disabilities in research, and promote knowledge exchange and awareness led by youth.

Using a peer-to-peer model, seven pairs of youth researchers, each pair including one youth with a disability and one without, were recruited and trained in qualitative disability research. (Strand et al., 2022)(Neille, 2021; Simbaya et al., 2019). They received mentorship and internship placements on various projects. The researchers collected life history data from youths with disabilities in Wakiso district, focusing on their experiences in education, employment, social participation, and research involvement.

Collected through interviews or autobiographies, life histories are detailed narratives of an individual's life, focusing on significant events, personal development, relationships, and the social and historical contexts in which they lived (Tierney and Lanford 2020). Life histories were collected by pairs of youth researchers.

Study participants

Between August 15 and September 2, 2023, participants were purposely sampled and recruited based on gender, age (18–30), type of impairment, education, and employment status. Thirty-one youth with disabilities were recruited from Wakiso district, central Uganda, with support from Organizations of Persons with Disabilities including Kireka Rehabilitation Center, Uganda National Association of the Blind, Uganda National Association of the Deaf, and the National Council for Persons with Disabilities.

Participants were screened using the Washington Short Set of Questions {Weeks, 2021 #2}, which defines persons with disabilities as those at greater risk than the general population of experiencing difficulties completing tasks like walking, seeing, or hearing due to limitations in basic functioning (Weeks et al., 2021). This categorizes impairments into visual, hearing, mobility, cognition and self-care with responses on a four-point scale: no difficulty, some difficulty, a lot of difficulty, or cannot do at all (Boggs, Kuper et al. 2022). Participants who reported a lot of difficulty and cannot do at all in any of the categories were selected for the interviews. (Bannink Mbazzi et al., 2024; Kahonde & Mji, 2024)

Since this tool does not cover some disabilities like albinism and short stature, we also applied the Uganda Disability Act (2020). The Act defines disability as a significant limitation in daily activities caused by impairments and environmental barriers, resulting in restricted participation in society on an equal basis with others (Ministry of Gender 2020). The Act outlines categories including physical, sensory, intellectual, psychosocial, visual, persons with short stature, people with albinism, deaf blind individuals, and hearing disabilities. We therefore ensured participants from these additional categories were included in the screening process by using both the Washington tool and the broader definitions provided by the Uganda Disability Act. The participants consisted of 15 male and 16 female youths aged 18-30 years with a mean age of 25.6 years.

DATA COLLECTION

Using interview guides and voice audio recorders, pairs of youth researchers with disabilities conducted life history interviews. Life histories involve in-depth interviews that focus on the individual's personal experiences and the broader socio-cultural contexts that shape their lives (Jessee, 2019). Through this method, researchers aimed to understand the unique perspectives and trajectories of individuals over time, providing valuable insights into their lived experiences and challenges (Goodson et al., 2016; Plummer, 2001).

Interviews were held in English or Luganda, the local language commonly spoken in the study area, or sign language, depending on the participant's preference. The focus of the interviews was on youth with disabilities' participation in daily activities, social life, education, employment, and research.

The interviews were conducted in participants' homes and lasted between 40 to 60 minutes with an average of 45 minutes per interview. All interviews were audio-recorded, whilst interviews conducted in sign language were video recorded for participants with hearing impairments.

Data management

Life history data was recorded on encrypted tablets, and laptops. The audio and video recordings were transferred to password-protected computers immediately after the interviews, anonymized and permanently deleted from the original devices.

The audio and video recordings were transcribed by the youth researchers, and transcripts were translated from Luganda to English if interviews were conducted in Luganda and to English when conducted in sign language. The anonymized transcripts were then transferred to the secure project data file on the data server at the MRC/UVRI and LSHTM Uganda Research Unit.

Data analysis

We used thematic analysis (Braun & Clarke, 2006) (Beail & Williams, 2014; Veta, 2025) following the six-step approach described by Braun & Clarke (Braun and Clarke 2006). We familiarized ourselves with the data by repeatedly reading the transcripts and taking initial notes. We generated initial codes by applying both deductive and inductive approaches, using a codebook that was collaboratively developed.

Fourteen youth researchers with disabilities and the study coordinator coded the data in NVivo 14. To ensure reliability, transcripts were double-coded, and discrepancies resolved by the team. Codes were grouped into themes, which were reviewed and refined to accurately reflect the data. Themes were then defined and analyzed line-by-line in MS Word, with analytical memos written to merge themes and guide this manuscript.

RESULTS

Thirty-one youth with disabilities participated in life histories in-depth interviews. We recruited 16 female and 15 male youth, aged 18-30 years, with a mean age of 25.6 years (SD=2.1 years). In total 23% (n=7) had hearing impairment, 29% (n=9) visual impairment, 10% (n=3) with albinism, 10% (n=3) cognitive impairment, 26% (n=8) physical impairment and 3% (n=1) multiple impairments. Almost half (45%) were unemployed, 19% had informal jobs, and 35% formal employment. Furthermore, the vast majority (94%, n=29) were single.

The findings identify facilitators and barriers to participation among youth with disabilities. Facilitators include family support, positive self-esteem, flexible work, assistive devices, and peer and teacher support. Barriers include inaccessible infrastructure, discrimination, financial limits, and communication gaps.

Facilitators to social participation

Family support

Youth with disabilities reported family support and acceptance as a facilitator to their participation in social life, education, and employment. The participants described how family support helped them to navigate societal stigma and stereotyping that comes with having a member with a disability as they show them love, making it easy for them to engage in different aspects of life.

“Their attitude remained positive towards me, because I remember that whenever my brothers and sister went to play, they used to call me, and we played together. They would teach me how to play new games. My mother used to take me to different places in Kampala, and even my father” (Female, 23 years, hearing impairment).

Youths with disabilities reported the support extended to them by the family members through pushing wheelchairs for those with physical impairment and guiding those with visual impairment which helped them to participate in social life.

“...Because I was a person who needed help, pushing me on the wheelchair, putting my clothes on the hang-line, it also helped me improve my communication skills” (Male, 25 years, physical impairment).

Financial support by family was reported to be fundamental in facilitating access to assistive devices that supported their participation in education.

“.... I am a person who grew up in a family where my grandmother raised me...so my only hope was in my grandmother but at that time she had no money. Therefore, she borrowed money and brought a bicycle. It was a normal bicycle, and my brothers started taking me to school. (Male, 28 years, physical impairment).

Youth with disabilities emphasized the vital role their families played in accessing education. Some relied on home-based learning during early childhood, supported by their families. Others shared how families arranged alternative transport like using bicycles to get them to school when wheelchairs were unaffordable.

“....my school was a bit far in the village and now walking from there to the school was always hard, so they used to get someone with a bicycle to ride me there and pick me up which was a problem.... as you know that village schools don't have boarding sections (Male, 26 years, physical impairment).

Peer support

Youth with disabilities highlighted the important role of peer support, especially in school settings. Those with

physical impairments relied on peers for help with mobility and self-care. Youth with visual impairments shared that classmates assisted with reading notes, guiding services, and engaging in discussions. Similar support was also reported in workplace settings.

“Life was okay both academically and socially because those girls helped us in academics; they helped to read for us what the teacher had written on the blackboard, and they guided us about accessibility and reading handouts. They really helped us in many things; life became really very easy.” (Male, 25 years, visual impairment).

Support from peers played a critical role in their engagement in sports, music and social activities. They reported that their friends were instrumental in facilitating their participation, with peers hosting and interpreting for those with hearing impairments during sports events, for example some watched football together.

“...my friends outside work do guide and give me information on important issues, which I might have missed. I love football so much but sometimes I have no place to watch from so I could sit with friends who can hear from the radio, and they can also help to interpret for me to understand what is going on...” (Male, 24 years, hearing impairment).

Additionally, they highlighted the importance of enjoying the company of their peers in various social settings such as going to beaches, parties, and having lively conversations, which further enhanced their participation in social activities.

“.....now I am close to like three friends from my former school. They are even proud of me now because I am doing sports, they see me on TV and am even in some groups of old girls and boys, I even go and attend those alumni parties, the get-together parties.” (Female, 30 years, physical impairment)

Teacher support

Support from teachers played a key role in the inclusion of youth with disabilities in education. Some participants shared that teachers made extra efforts to provide reasonable accommodation. Youth with physical disabilities noted that lessons were sometimes moved to accessible classrooms, while those with visual impairments mentioned special math sessions held separately from the main class.

“The teachers were so good, that one I would say they were good for example to some teachers if the classes are upstairs, at least they would tell students that, “you know what, today let’s get some chairs and go and study under that mango tree”, toto ensure that I am also catered for. I would always be given front seats not to burden me, even in church, and they would help me. (Male, 25 years, visual impairment)

Institutional support

Youth with disabilities emphasized the importance of institutional support in social gatherings. They valued sign language interpretation services and ramps at churches to allow full participation. These accommodations help overcome communication and mobility barriers for those with hearing and physical impairments. Institutions also offer counseling to emphasize the importance of including youth with disabilities in family and community activities.

“.....I love meeting my friends and going to a certain church [...], there, sign language interpreters are available. At first, I used to go to nearby churches, but I would just sit and could not understand anything, I will never go back to that church.” (Male, 25 years, hearing impairment).

Organizations of people with disabilities and rehabilitation centers were reported to have played an important role in imparting youth with disabilities with self-advocacy skills through mentorship. As a result, they became confident enough to voice their own opinions in social spaces, eventually enhancing their social participation.

“Looking back where I was and were I am today I think with time I will be fine because these days I fit in people, and I speak with responsible people, and they listen to me, so I have that love. The action of organizations visiting us and talk to us empowers us persons with disabilities and it shows that they are people who care for us.” (Male, 23 years, intellectual impairment).

Organizations embracing Equity, Diversity, and Inclusion policies, as reported by youth with disabilities,

facilitated their social participation at work. They reported that their social interactions were an opportunity for them to sensitize coworkers about disability, which aided their social participation.

“In the Accounts office, we have a policy that demands all accountant officers to be cooperative and supporting each other instead of leaving someone behind. So, if you are stuck, you don’t have to keep quiet, you can seek for help from your colleagues like the cashier officer, accountant, senior accountant officer and any other....” (Female, 26 years, hearing impairment).

Furthermore, institutions also supported youth with disabilities by awarding scholarships and bursaries. Youth reported institutions like schools, government, charitable organizations and churches were instrumental in providing guides, scholastic materials which promoted participation and access to education for youth with disabilities.

“My father stopped paying my school fees when I was in primary three, so I studied on sponsorship since primary three to university. Being a clever student in class, I always got bursaries and in my senior five I got a Mastercard sponsorship and then government sponsorship at university because of my good performance I never found challenges with tuition” (Female, 29 years, with albinism)

Reasonable accommodation

Flexible working schedules and extra time to youth with disabilities are reported considerations allowing them to work from home and complete their work-related tasks.

“Therefore, they also give you the liberty of you not going to office every day, because it might be costly if you go to office every day. Therefore, they give you that allowance of you staying at home and only going to the office when you need it.” (Male, 25 years, physical impairment).

Youth with disabilities indicated instances where their families recognized and appreciated their abilities, making efforts to ensure reasonable accommodation. They reported families making efforts to include them in family activities by utilizing alternative communication means like local gestures and writing for family members with hearing impairments.

“They always try to use sign language and if I fail to understand they write for me. This happens especially when they are giving me some guidance like stopping moving at night. I interact with my mother as well as my brothers, but my sister doesn’t know sign language.” (Male, 29 years, hearing impairment)

“...they had to bring me to a school e [...]. It is a primary school where I first sat in a wheelchair. I had never used a wheelchair, and I felt happy. Sometimes, my brother would carry me on a bicycle and occasionally throw me down. All that would make me fear but the fear stopped because I was given a wheelchair, a very clean one, that I would sit and push myself.” (Male, 28 years, physical impairment)

Self-esteem

Self-esteem among some youth with disabilities was reported as a key facilitator to their participation. This self-esteem was reported to have been nurtured mainly through the acknowledgment of their unique strengths. In instances where the youth accepted and appreciated their disability, it was reported to be easier for them to engage in community events such as leadership, sports, and clan meetings.

“I wouldn’t say that it is a showstopper. I do believe that when you realize that you have a challenge, you have to find a way of living with it. I believe this has been an opportunity for me to showcase my talents, to become a disability rights activist.” (Male, 25 years, physical impairment).

In schools, self-esteem emerged as a critical facilitator in empowering youths with disabilities to assert their rights and protect themselves from bullying both at school and in their communities. They reported how self-esteem helped them overcome stereotypes that once hindered their social participation. Despite facing stigmatization, including hurtful name-calling like "full stop" for individuals with short stature, they found strength to confront such insults.

“At first, it used to affect me. If I was going, somewhere and somebody called me “Full stop”, that could mark the end of my journey at that moment. I could go back home and start crying. However, one day,

while I was listening to the radio, I was encouraged, and I realized that everyone must be talked about in the world. I became strong and even if someone comes and tells me that, "full stop, how are you?", I do not answer them badly. I tell them that I am fine but that is not my name; my name is [...]." (Female, 20 years, short stature, and physical impairment).

Youth with disabilities reported demonstrating work competences, attributing it to increased self-esteem. They expressed that as their self-esteem grew; they felt more capable in their roles. By showcasing their abilities, they challenged stereotypes held by employers and others, which also led to improved social interactions.

"... whenever I am among people without disability, I sometimes forget that I have a disability. I usually relate with people freely without isolating myself and at the same time I ensure that I look good[...].and if I am to work I bring out my inner ability, so I exceed people's expectations and they become overwhelmed and they say such people also have different talents like she has and that is how I have managed to overcome such challenges of discrimination." (Female, 29 years, with albinism).

Barriers to participation

Overprotection by family members

Youth with disabilities mentioned that overprotection from their families hindered their social participation. They reported that their families often restricted their independence, worrying that they might get lost, be taken advantage of, or exploited, as noted especially by youth with a hearing impairment. This was reported to have resulted into families closely controlling their movements, decisions and social interactions which impeded their personal autonomy.

"... in most cases my family oppresses me, for example they say, most of my decisions are not right. And most of the time they are responsible for deciding for me, like they say some things I cannot do alone, for example buying a new phone, my mother can tell my brother to go with me, because people may cheat me and ask for a lot of money. I do not like it, now I can make decision on my own, but my parents do not believe it...." (Male, 24 years, hearing impairment).

Poverty

Reflecting on their education, many youths with disabilities emphasized how financial hardship limited their opportunities and affected other basic needs like healthcare, assistive devices, and transport. Some dropped out of school, while others pursued fields they were not interested in due to economic pressures.

".... I grew up with my grandmother who took care of me. She paid my school fees, and I think she got old and stopped. That is where I also stopped because I was supposed to sit for senior six, but I failed to because there was no money....." (Male, 27 years, visual impairment)

Negative attitudes

Negative attitudes towards people with disabilities was a reported barrier to social participation by the youths with disabilities. They recounted instances of discrimination, unpleasant treatment due to their disabilities by some people around them.

"...I really went through a lot given the condition I have, and the children used to laugh at me... I was in a girl's school, and we used cups with different colors like red, green, blue and purple. And my favorite color was blue. So, when we went for break tea in the school dining everyone was picking a blue cup so I did however, when I picked the blue cup, the students shouted 'to hell with the blue cups, I cannot use these cups. What if I use the very one, she used.' Some students even threatened to beat me. They suggested from now on I use blue cups only". (Female, 28 years, with albinism).

Participants also reported ongoing challenges related to societal perceptions of their appearance due to their disabilities. Youth expressed that they continue to face stigma and verbal abuse that makes them feel less human, limiting their social participation. These experiences highlighted persistent discrimination and its impact on their self-esteem and social interactions.

"Even up to now, I still get that problem of appearance. Someone would look at you and they begin

giving you nicknames, insulting you, and they end up calling you weird names that are not supposed to be called a human being.” (Female, 26 years, with Down syndrome).

Other youths reported that they find challenges with managing romantic relationships due to negative disability attitudes from either their partner, or partner’s family members.

“It happened to me at some point of my life. Before Covid-19, I had a boyfriend who loved and cared about me. He used to come and check on me every day; he used to buy me apples, and he used to bring me some other small things. At the beginning of the month, you could just see some new things like knickers, pads and others. However, his parents told him that we do not want a person with disabilities in our home. He told them that I was the one he loved. His father told him, “I told you that in my place, I do not want people with disabilities.” (Female, 20 years, short stature, physical disability)

Inaccessible infrastructure

Youth with disabilities reported that inaccessible infrastructure and underdeveloped public transport system greatly hampers their participation. They mentioned facing difficulties accessing offices, shopping malls, and lecture rooms due to the lack of ramps, often need assistance to navigate stairs or forgoing visiting such places altogether.

“...you can even go to the church, and you do not find a ramp, and you cannot access it or enter the church... I can reach a shopping hall and there are so many stairs that I cannot climb. I just stayed outside yet I had come to buy something. There are places that are so steep that you cannot easily access...” (Male, 28 years, physical impairment).

The nature of non-inclusive school activities was reported to have limited participation of youth with disabilities in school activities even when they wanted to.

‘...at school we get a lot of challenges because even in those games I never used to participate in those games since I am short-statured. I had desires to participate in them like in netball, I wanted to play netball, but I couldn’t reach those poles and jump like those people. (Female, 27 years, short stature).

Additionally, they noted sometimes being required to pay an extra fee for wheelchair usage when using public transport like taxis.

“The only problem that I have is with my transportation. Each time I want to go to town or Kampala, I have a problem with these taxis [public transport means]. People overcharge me because when they see my wheelchair they double the fee. When I tell them that I am going to XXX, instead of paying 5,000 UGX, I have to pay 10,000 UGX.” (28 male, 28 years, physical impairment).

Youth with visual impairments shared their challenges in crossing roads and moving along the streets due to unclear traffic conditions, merchandise, and crowds.

“.... Accessibility in movement from one place to another is the most challenging problem. ...” (Male, 25 years, visual impairment).

Communication is a major barrier for young people with hearing impairment, limiting their participation. They emphasized the need for sign language interpreters to engage in education, social life, and community events. Without this support, they often miss gatherings like church or family functions. In school, they rely on copying notes from peers or focusing on the blackboard, missing out on verbal teaching.

“It is not that easy to access all the information but only very few and at times they are not right. For example, getting life knowledge mainly while studying from hearing schools where we use the blackboard, but some form of teaching is verbal like in life skills and knowledge, and I never had a chance to understand them since I only understand what was written on the blackboard.” (Female, 26 years, hearing impairment)

DISCUSSION

Youth with disabilities explored the social participation experiences of other youth with disabilities in Wakiso

District, Uganda, their participation in education, employment, and social activities. The findings underscore the role of family support, self-esteem, and institutional accommodations in facilitating inclusion and active engagement of the youth in social life, education and employment.

The fundamental role of family support in facilitating social participation is consistent with findings by Arne et al. (2022), who explored the participation and inclusion of children and youth with disabilities in local communities in Norway. The study described family members as a source of encouragement and emotional support to social participation to youth with disabilities (Eide et al., 2022). Similarly, Mitra, et al. (2013) reported how family support significantly impacted educational and social participation, helping bridge gaps in systemic services for youth with disabilities for a multidimensional study on disability and poverty in Low Income Countries (Mitra et al., 2013). A study conducted by Hansen et al. (2014) in Zambia, examined the barriers to participation amongst children with disabilities, from the mothers' perspectives. The findings highlighted the significant role of mothers with children with disabilities they play in the child's social participation (Hansen et al., 2014).

In Uganda, the role of family extends beyond emotional support to include financial assistance, such as paying for school fees and transportation. This is crucial in contexts where public support systems are often lacking or inadequate (Tulibaleka et al., 2021). A study by Washington-Northey et al. (2021) on parental expectations for children with intellectual disability or autism in Ghana and Zambia, found that family acceptance boosted self-esteem, participation, education, and social integration (Washington-Northey & Serpell, 2021).

Peer-to-peer support models have increasingly been reorganized for their potential to increase social participation. Often centered on shared experiences and mutual encouragement, peer support models, systematic review by Allison et al. (2021) and other reports on how peer to peer support models significantly enhance self-esteem, social skills, and academic performance among youth with disabilities (Birnschein et al., 2021; Carter et al., 2016; Geffen et al., 2019). Studies in Kenya and South Africa have highlighted the role of peer support in fostering social inclusion and improving academic outcomes for youth with disabilities (Bunning et al., 2020; Cramm et al., 2014; Otanga et al., 2022).

Self-esteem also emerged as an important facilitator crucial for empowering the youth to assert their rights and participate actively in their communities (Yamada et al., 2021). In Uganda, Kimera et al. (2021) found that youth living with HIV often experience a boost in self-esteem when they overcome societal stigma, particularly in the context of HIV-related discrimination (Kimera et al., 2021). Bannink Mbazzi F., (2023) demonstrated that systemic support and anti-discrimination policies, such as inclusive education and disability services, play a major role in fostering participation (Mbazzi, 2023). Kim and Park (2023) showed that personal resilience and systemic factors interact to shape participation outcomes among adolescents with physical disabilities (Kim & Park, 2023).

Björquist and Tryggvason (2023) highlighted that the availability of institutional support, such as accessible infrastructure and inclusive services, is critical for the participation of youth with disabilities in Sweden (Björquist & Tryggvason, 2023). This study's findings on accessibility are consistent with research from Ethiopia, that indicated the lack of accessible educational facilities and transportation options form a barrier to school attendance for children with disabilities (Mergia, 2020; Negash & Gasa, 2022). In a scoping review by Shahin et al. (2020), they emphasized the need for systemic changes to ensure accessibility and inclusivity, echoing global calls for improved infrastructure and support services for young adults with brain-based disabilities (Shahin et al., 2020).

Nalubwama et al. (2022) highlighted that barriers such as lack of accessible infrastructure, financial constraints, and societal prejudices hinder the full participation of youth with disabilities in Uganda (Nalubwama et al., 2022). These barriers are not unique to Uganda but are prevalent in many low and middle-income countries (Hashemi et al., 2022). In India, children with disabilities experience inadequate school facilities, negative societal attitudes, and limited financial resources, which impede their educational and social integration (Math et al., 2019). Studies in South Africa and Brazil show poverty and discrimination greatly affect youth with disabilities. This emphasizes global challenges and the importance of global efforts for inclusion (Makwela & Smit, 2022; McKinney & Swartz, 2022; Trani et al., 2020).

STUDY STRENGTHS

This study breaks new ground by engaging youth with disabilities as co-researchers, centering the voices of those directly affected. Their direct role in data collection and analysis fosters inclusivity and enriches findings, as they draw on lived experience. The peer-to-peer model, pairing youth with and without disabilities, encourages mutual learning, builds capacity, and challenges social barriers. Using life histories enabled the team to explore participants' experiences in depth, offering a richer understanding of their lives.

Study limitations

The study was conducted in Wakiso district, which is a peri urban district in Central Uganda, therefore our results may not be generalized to rural populations. Another notable weakness is in the small sample size for some

impairment categories such as the cognitive impairments.

CONCLUSION

The results showed that family support, self-esteem, flexible work arrangements, and institutional accommodations are key to including youth with disabilities in education, employment, and social life. Governments and institutions should prioritize accessible infrastructure, inclusive education, and assistive devices to promote participation. Awareness campaigns should sensitize families and communities on the role of family in fostering self-esteem and hope for those acquiring disabilities later in life, and on reducing negative attitudes and perceptions.

REFERENCES

- Awsumb, J., Schutz, M., Carter, E., Schwartzman, B., Burgess, L., & Lounds Taylor, J. (2022). Pursuing paid employment for youth with severe disabilities: Multiple perspectives on pressing challenges. *Research and Practice for Persons with Severe Disabilities*, 47(1), 22-39.
- Bannink Mbazzi, F., Hameed, S., Ganle, J. K., Shakespeare, T., & Polack, S. (2024). Participatory research with youth with disabilities: Experiences from sub-Saharan Africa. *African Journal of Disability*, 13, 1491.
- Beail, N., & Williams, K. (2014). Using qualitative methods in research with people who have intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 27(2), 85-96.
- Birnschein, A. M., Paisley, C. A., & Tomeny, T. S. (2021). Enhancing social interactions for youth with autism spectrum disorder through training programs for typically developing peers: A systematic review. *Research in Autism Spectrum Disorders*, 84, 101784. <https://doi.org/https://doi.org/10.1016/j.rasd.2021.101784>
- Björquist, E., & Tryggvason, N. (2023). When you are not here, I cannot do what I want on the tablet—The use of ICT to promote social participation of young people with intellectual disabilities. *Journal of intellectual disabilities*, 27(2), 466-482.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101.
- Bunning, K., Gona, J. K., Newton, C. R., Andrews, F., Blazey, C., Ruddock, H., Henery, J., & Hartley, S. (2020). Empowering self-help groups for caregivers of children with disabilities in Kilifi, Kenya: Impacts and their underlying mechanisms. *PLoS One*, 15(3), e0229851. <https://doi.org/10.1371/journal.pone.0229851>
- Carter, E. W., Asmus, J., Moss, C. K., Biggs, E. E., Bolt, D. M., Born, T. L., Brock, M. E., Catey, G. N., Chen, R., & Cooney, M. (2016). Randomized evaluation of peer support arrangements to support the inclusion of high school students with severe disabilities. *Exceptional Children*, 82(2), 209-233. <https://doi.org/https://doi.org/10.1177/0014402915598780>
- Cramm, J. M., Lorenzo, T., & Nieboer, A. P. (2014). Comparing education, employment, social support and well-being among youth with disabilities and their peers in South Africa. *Applied Research in Quality of Life*, 9, 517-524. <https://doi.org/https://doi.org/10.1007/s11482-013-9247-5>
- Egan, R., Wilson, R., Robertson, M., Scandiffio, J., Ross-White, A., & Coderre-Ball, A. M. (2022). Barriers and facilitators to education experienced by students with disabilities in low-and middle-income African countries: a systematic review of qualitative evidence. *JBI Evidence Synthesis*, 20(10), 2475-2511.
- Eide, A. H., Ofstad, D., Støylen, M., Hansen, E., & Høiseith, M. (2022). Participation and inclusion of children and youth with disabilities in local communities. *International Journal of Environmental Research and Public Health*, 19(19), 11893.
- Geffen, L. N., Kelly, G., Morris, J. N., & Howard, E. P. (2019). Geffen, L.N., Kelly, G., Morris, J.N. et al. Peer-to-peer support model to improve quality of life among highly vulnerable, low-income older adults in Cape Town, South Africa. *BMC Geriatr* 19, 279 (2019). *BMC geriatrics*, 19, 1-12.
- Goodson, I., Antikainen, A., Sikes, P., Andrews, M., & Sikes, P. J. (2016). *The Routledge international handbook on narrative and life history*. Routledge New York^ eNY NY.
- Griffiths, A., Bechange, S., Loryman, H., Iga, C., & Schmidt, E. (2020). How do legal and policy frameworks support employment of people with disabilities in Uganda? Findings from a qualitative policy analysis study. *Journal of International Development*, 32(8), 1360-1378.
- Hansen, A. M. W., Siame, M., & Van der Veen, J. (2014). A qualitative study: Barriers and support for participation for children with disabilities. *African journal of disability*, 3(1), 1-9.
- Hashemi, G., Wickenden, M., Bright, T., & Kuper, H. (2022). Barriers to accessing primary healthcare services for people with disabilities in low and middle-income countries, a Meta-synthesis of qualitative studies. *Disability and rehabilitation*, 44(8), 1207-1220.
- Hendriks, A. (2007). UN Convention on the Rights of Persons with Disabilities. *European Journal of Health Law*, 14(3), 273-298.
- Howgego, C., Miles, S., & Myers, J. (2014). Inclusive learning. *The Health & Education Advice & Resource Team (HEART)*. Retrieved from <https://www.heartresources.org/wp-content/uploads/2014/09/Inclusive-Learning-Topic-Guide.pdf>, 3, 2018.
- Jessee, E. (2019). The life history interview.
- Kahonde, C. K., & Mji, G. (2024). Disability research in African Network for Evidence-to-Action in Disability affiliated countries. *African Journal of Disability*, 13, 1517.
- Katsui, H., & Kumpuvuori, J. (2008). Human rights-based approach to disability in development in Uganda: A way to fill the gap between political and social spaces? *Scandinavian Journal of Disability Research*, 10(4), 227-236.

- Kim, E., & Park, J. (2023). Structural Relationship among Disability Acceptance, Resilience, and Social Participation of Adolescents with Physical Disabilities. *International Journal of Disability, Development and Education*, 70(6), 1085-1100.
- Kimera, E., Vindevoegel, S., Engelen, A.-M., De Maeyer, J., Reynaert, D., Kintu, M. J., Rubaihayo, J., & Bilsen, J. (2021). HIV-related stigma among youth living with HIV in Western Uganda. *Qualitative Health Research*, 31(10), 1937-1950.
- Lindsay, S., Cagliostro, E., Leck, J., Shen, W., & Stinson, J. (2019). Disability disclosure and workplace accommodations among youth with disabilities. *Disability and rehabilitation*, 41(16), 1914-1924.
- Lundy, L., McEvoy, L., & Byrne, B. (2011). Working with young children as co-researchers: An approach informed by the United Nations Convention on the Rights of the Child. *Early education & development*, 22(5), 714-736. <https://doi.org/10.1080/10409289.2011.596463>
- Makwela, M. M., & Smit, E. I. (2022). Psychosocial challenges of children with disabilities in Sekhukhune District, Limpopo province of South Africa: Towards a responsive integrated disability strategy. *African journal of disability*, 11, 799.
- Márton, S. M., Polk, G., & Fiala, D. R. C. (2013). Convention on the rights of persons with disabilities. *USA: United Nations*.
- Math, S. B., Gowda, G. S., Basavaraju, V., Manjunatha, N., Kumar, C. N., Philip, S., & Gowda, M. (2019). The rights of persons with disability act, 2016: Challenges and opportunities. *Indian journal of psychiatry*, 61(Suppl 4), S809-S815.
- Mbazzi, F. B. (2023). Translating the Ubuntu philosophy into practical disability inclusive interventions: The Ubuntu bulamu experience from Uganda. In *Ubuntu Philosophy and Disabilities in Sub-Saharan Africa* (pp. 148-162). Routledge.
- McKinney, E. L., & Swartz, L. (2022). Integration into higher education: experiences of disabled students in South Africa. *Studies in Higher Education*, 47(2), 367-377.
- Mergia, A. T. (2020). Education of children and youth with disabilities in the Ethiopian school system. *Int J Sci Res Pub*, 10(4), 732-742.
- Ministry of Gender, L. a. S. D. (2020). *Situational Analysis of Persons with Disabilities in Uganda*. <https://www.developmentpathways.co.uk/wp-content/uploads/2020/09/Webready-DP1294-ESP-Disability-Uganda-Sept-2020.pdf>
- Mitra, S., Posarac, A., & Vick, B. (2013). Disability and poverty in developing countries: a multidimensional study *World Development*, 41, 1-18. <https://doi.org/https://doi.org/10.1016/j.worlddev.2012.05.024>
- Nalubwama, H., Blixen, C., Sewankambo, N., Sajatovic, M., & Katabira, E. (2022). A mixed-methods, cross-sectional study of perceived stigma among Ugandans with epilepsy. *African Health Sciences*, 22(1), 252-262.
- Negash, K. H., & Gasa, V. (2022). Academic barriers that prevent the inclusion of learners with visual impairment in Ethiopian mainstream schools. *SAGE Open*, 12(2), 21582440221089934.
- Neille, J. (2021). A qualitative inquiry into the ways in which space and place influence the lived experiences of adults with disabilities in rural South Africa. *Rural and Remote Health*, 21(4), 1-9.
- Otanga, H., Semujju, B., Mwaniki, L., & Aungo, J. (2022). Peer support and social networking interventions in diabetes self-management in Kenya and Uganda: A scoping review. *Plos one*, 17(9), e0273722. <https://doi.org/https://doi.org/10.1371/journal.pone.0273722>
- Plummer, K. (2001). *Documents of life 2: An invitation to a critical humanism* (Vol. 2). Sage.
- Polat, F. (2011). Inclusion in education: A step towards social justice. *International journal of educational development*, 31(1), 50-58.
- Sabatello, M., & Schulze, M. (2013). *Human rights and disability advocacy*. University of Pennsylvania Press.
- Shahin, S., Reitzel, M., Di Rezze, B., Ahmed, S., & Anaby, D. (2020). Environmental factors that impact the workplace participation of transition-aged young adults with brain-based disabilities: a scoping review. *International journal of environmental research and public health*, 17(7), 2378.
- Simbaya, J., Shakespeare, T., Nyariki, E., & Mugeere, A. (2019). Success in Africa: People with disabilities share their stories. *African Journal of Disability*, 8(1), 1-7.
- Strand, M., Rivers, N., Baasch, R., & Snow, B. (2022). Developing arts-based participatory research for more inclusive knowledge co-production in Algoa Bay, Curr. Res. Environ. Sustain 4 (2022). In.
- Trani, J.-F., Moodley, J., Anand, P., Graham, L., & Maw, M. T. T. (2020). Stigma of persons with disabilities in South Africa: Uncovering pathways from discrimination to depression and low self-esteem. *Social Science & Medicine*, 265, 113449.
- Tulibaleka, P. O., Nakalema, K., & Ndohtabi, D. E. (2021). Family Support and School-to-Work Transition: Perceptions and Experiences of University Graduates in Kampala City, Uganda. *Educational Research and Reviews*, 16(12), 428-437.
- UNFPA. (2019). Disability inclusion in Uganda: What you need to know. https://uganda.unfpa.org/sites/default/files/pub-pdf/disability_inclusion_-_factsheet_final.pdf

- Veta, O. D. (2025). Exploring participatory approach to community development projects in Africa: Toward an empowerment-participatory approach for sustainable development. *Journal of Social Work*, 25(3), 301-317.
- Wahitu, F. H., & Guzu, B. (2022). Disability and Workplace Inclusiveness; Regulatory and Structural Experiences from Developing Economies: A Case of Selected Organizations in Kampala Metropolitan, Uganda. *The African Journal of Governance and Development (AJGD)*, 11(2), 408-419.
- Wapling, L. (2016). Inclusive education and children with disabilities: Quality education for all in low- and middle-income countries. Retrieved from www@cbm.org.
- Washington-Nortey, P.-M., & Serpell, Z. (2021). Parental expectations for children with intellectual disability or autism in Ghana and Zambia: A concept mapping study. *Research in Developmental Disabilities*, 114, 103989.
- Weeks, J. D., Dahlhamer, J. M., Madans, J. H., & Maitland, A. (2021). Measuring disability: an examination of differences between the Washington Group Short Set on Functioning and the American Community Survey disability questions.
- Werner, S., & Chabany, R. (2016). Guardianship law versus supported decision-making policies: Perceptions of persons with intellectual or psychiatric disabilities and parents. *American Journal of Orthopsychiatry*, 86(5), 486.
- WHO. (2023). *Disability*. Retrieved 14/03 from <https://www.who.int/news-room/fact-sheets/detail/disability-and-health>
- Yamada, T., Sakisaka, K., Bermúdez Rodríguez, L. N., & Yamaoka, K. (2021). Self-esteem, socioeconomic status and social participation of persons with disabilities living in areas affected by armed conflict in Colombia. *International journal of environmental research and public health*, 18(8), 4328.