



Review

“Will I Be Celebrated at the End of This Training?” Inclusive Research in Kenya

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Abstract: The development and practice of inclusive research with people with intellectual disabilities is complex, revealing challenges and lessons that inform innovative and novel methodological approaches. In Africa, inclusive research still lags for various reasons. First, due to societal misconceptions that portray people with intellectual disabilities as unable to self-advocate or as lacking agency and self-determination; second, due to a lack of trained researchers and ethics committees on inclusive research practices. This paper critically reflects on and discusses the strategies and methods used to conduct an inclusive research study in Kenya. The focus was on the methodological approach of including people with intellectual disabilities as researchers in Kenya. Two people with intellectual disabilities were trained as research assistants. This paper describes the experiences with Institutional Review Boards, the processes and experiences while training this research assistants using a UK-developed curriculum, and fieldwork experiences while piloting interview guides, conducting interviews, and conducting focus groups with this research assistants. This study findings indicate the need to culturally adapt co-researcher training, the importance of working with support personnel who empower researchers with intellectual disabilities, and the need for greater advocacy to change negative attitudes towards people with intellectual disabilities that hinder their participation in research.

Keywords: inclusive research; Africa; intellectual disabilities

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1. Introduction

People with intellectual disabilities have historically been underrepresented in conducting research as researchers (Fulton et al. 2021; Harrison et al. 2021; Zarb 1992). Additionally, research methods have traditionally been developed and implemented in inaccessible ways that prevented people with intellectual disabilities from being researchers and instead were only researched (Oliver 1992; Nind et al. 2016). Disability studies scholars and activists with and without disabilities have advocated for people with intellectual disabilities to have a voice in the ways their experiences are collected, analyzed, interpreted, and represented (Bourke 2009; Goodley 2018; Zarb 1992). This requires people with intellectual disabilities to be part of research processes that investigate their experiences (Nind et al. 2016; García Iriarte et al. 2014).

The aim of the field of inclusive research has been to produce knowledge with and by people with intellectual disabilities, enabling them to shape their narratives in ways that are relatable to their experiences and realities (Bigby et al. 2014; O'Brien et al. 2014; Nind et al. 2016; Purcal et al. 2019).

Inclusive researchers have been collaborating with people with intellectual disabilities to develop accessible research and dissemination methods (Bigby et al. 2014; Bigby and Frawley 2015; Dowse 2009; O'Brien et al. 2014). The field of inclusive research also addresses issues of power dynamics between researchers with and without intellectual disabilities and supports the empowerment and representation of people with intellectual disabilities

in research, as well as their fair remuneration (Di Lorito et al. 2018; Fletcher-Watson et al. 2019; Nind and Vinha 2014; Walmsley et al. 2018; Woelders et al. 2015). Reflecting on how people with intellectual disabilities have participated in inclusive research and consequently improving their level of engagement has made the field's output more meaningful, relatable, and utilizable for people with intellectual disabilities (Bourke 2009; García Iriarte et al. 2014; Hacker 2013; Nind 2014; Strnadová et al. 2016).

Inclusive research practices have steered the field in a direction where it becomes possible to imagine an intellectual disability epistemology informed by people with intellectual disabilities themselves (Walmsley and Johnson 2003). In this paper, intellectual disability epistemology refers to the knowledge and perceptions that emanate from the meanings that people with intellectual disabilities make of the world. The exclusion of people with intellectual disabilities from knowledge production strengthens ableism (Friedman and Owen 2017; McDonald et al. 2023) and contributes to the erasure of intellectual disability as part of human diversity. It becomes difficult and complex to imagine an intellectual disability epistemology when ableism is normalized. An intellectual disability epistemology is essential to the pursuit of social justice for people with intellectual disabilities (Purcal et al. 2019; Walmsley et al. 2018; Ouellette 2011). This is because they continue to be negatively impacted by the systemic devaluation of what it means to exist and live with an intellectual disability (Wilson 2022). People with intellectual disabilities experience disparities in access to health care, education, employment, leisure activities, civic participation, and basic needs such as food and shelter, and these can be compounded by race, ethnicity, nationality, and gender (Elder 2015; Kabia et al. 2018; Moyi 2017; Opoku et al. 2017).

Situating and affirming inclusive research as the dominant and expected approach to research with people with intellectual disabilities can promote an intellectual disability epistemology, one where people with intellectual disabilities are reshaping the knowledge about their identities and disabilities as a part of human diversity, not as a problem or limitation. The work of reimagining knowledge production together with people with intellectual disabilities has gained traction in most Western countries but has barely begun in non-Western countries (Kahonde 2023). In Africa, this is in part due to the negative attitudes, medicalization, and infantilization of people with intellectual disabilities (Bunning et al. 2017; Kahonde 2023; McConkey et al. 2016). Additionally, Kahonde (2023) notes that African researchers and ethics committees may lack knowledge on how to conduct research inclusively. Intellectual disability is poorly understood in Kenya. Census reports indicate varied conceptualizations of intellectual disability in Kenya (Global Disability Rights Movement 2020; Kenya National Survey of People with Disabilities 2008; Kenya Population and Housing Census 2009; Status of Disability in Kenya: Statistics from the 2019 Census 2019). Efforts to conduct inclusive research are often undermined by the negative attitudes and gatekeeping of ethics committees, governments, disability organizations, researchers, parents, and guardians, leading to a challenging environment in which to develop, practice, and promote inclusive research.

In the spirit of no one being left behind, there is a need to explore what inclusive research would look like from an African perspective since contextual differences may impact and influence the practice. There may be differences in the lived experiences of people with intellectual disabilities, cultural practices and beliefs, academic practices, and government policies, or lack thereof, in Africa compared to Western countries. To ensure that Africans with intellectual disabilities also have a voice, it is important to create spaces where knowledge about intellectual disabilities is being co-created with people with intellectual disabilities in the African context.

This paper contributes to the global discourse on inclusive research by describing the lessons learned from the implementation of an inclusive research study in Kenya conducted in 2023. The primary investigator of this study, though currently living in the United States (U.S.), is Kenyan. Additionally, they have worked with and lived with people with intellectual disabilities for eight years in the setting where this study was conducted.

This ethnographic qualitative study facilitated the participation of Kenyans with intellectual disabilities as research assistants in this study's data collection and dissemination.

The aim of this study was to explore the support needs of people with intellectual disabilities and caregivers of people with intellectual disabilities in Kenya through a combination of interviews and focus groups. This paper describes the complexity of developing and conducting this inclusive research study. The focus is on the innovative methodological approach of inclusive research in Kenya, including the implementation of this study, particularly the process of obtaining ethical approval for this study, the recruitment and training of this research assistants with intellectual disabilities, the collaboration with a local Kenyan disability service organization, and the completion of fieldwork. This paper offers reflections on what lessons were learned to better inform and prepare future inclusive research teams in non-Western contexts.

2. Background of This Study

This project was a qualitative ethnographic study with the aim of determining the services needed by people with intellectual disabilities and their families in Kenya. Three research assistants with intellectual disabilities were trained. A total of twenty people were interviewed: 10 people with intellectual disabilities and 10 caregivers. Key findings about the support and service needs of people with intellectual disabilities and caregivers in Kenya will be reported in a future publication. Preliminary analysis indicates that people with intellectual disabilities and caregivers in Kenya hope for greater visibility and information about available services. Additionally, people with intellectual disabilities want to get more involved in advocacy and decisions about services provided to them. This study is one of the first known attempts to develop and implement an inclusive research project in Kenya. This study was a new experience for Institutional Review Boards (IRBs), the local disability service organization, Kenyans with intellectual disabilities, and caregivers. Since Kenyan IRBs are not well informed about people with intellectual disabilities conducting research, implementing this study was challenging. This section below describes the steps involved in obtaining IRB approval for this study and this study procedures.

2.1. Navigating Institutional Review Boards

A primary challenge that this research project experienced came at the genesis of this study, with multiple barriers in obtaining Institutional Review Board (i.e., ethical) approval to conduct this study. This included the perceived "vulnerability" of this study population, language and training barriers, and discordant perspectives on inclusive research. The ethics of involving people with intellectual disabilities as research participants and researchers has been an area of attention and ongoing research (Dalton and McVilly 2004; McDonald and Kidney 2012; McDonald et al. 2013; Stack and McDonald 2014). Conducting research with people with intellectual disabilities as researchers has been a new frontier for ethics committees to consider (McDonald and Kidney 2012). According to the Helsinki declaration, people with intellectual disabilities have been considered a vulnerable population requiring research protections (General Assembly of the World Medical Association 2014). These protections have sometimes placed limits on the opportunities for self-determination and autonomy of people with intellectual disabilities, preventing them from taking on roles as participants and co-researchers in research projects (Friesen et al. 2023; Ouellette 2011).

In addition to challenges to the inclusion of this population in research, there were practical barriers. For example, the Institutional Review Board (IRB) at the authors' U.S.-based university required all research personnel to complete the CITI training (CITI Program n.d.). This training lacks a Swahili version and hence cannot be completed by Kenyan research assistants (RAs) with intellectual disabilities who do not speak English. Additionally, at the time of this study, the content of the CITI training was not available in an accessible language for people with intellectual disabilities (see next section for further discussion on training of RAs). This study was approved by the U.S. IRB with the assurance that RAs would work with and be supervised by the primary investigator. Research personnel with

intellectual disabilities were not allowed to independently hold responsibility for any of this research activities.

The U.S. IRB also required approval from a local Kenyan IRB since this research was being conducted in Kenya. This research study plan was submitted to a local Kenyan IRB. After their review, the Kenyan IRB recommended changes to this research study plan that were antithetical to the philosophical and epistemological foundations of inclusive research. The recommendations were grounded in traditional approaches to research, which were highly medicalized and individualized, drawing on positivist frameworks of research. For example, a description of the primary researcher's positionality in this research was labeled "unscientific", the primary investigator was asked to include the "medical causes of intellectual disability", and a demand was made to remove the role of research assistants with intellectual disabilities from this research study plan, arguing that they were "not trained academically".

A rebuttal was submitted to the Kenyan IRB with explanations of the principles of inclusive research, including an articulation of the value of Kenyans with intellectual disabilities having a voice in research that is about them. After extensive follow-up and attempted engagement with the Kenyan IRB and no response, this study was unable to continue with the approval process. The U.S. IRB instead collaborated with the local disability service organization where this study was to be conducted. The service organization provided a letter of support and signed an IRB authorization agreement, which meant that the organization would rely on the review, approval, and continued oversight of the U.S. IRB. The multiple challenges in obtaining an IRB created significant delays in starting this research project.

2.2. Recruitment and Consent Procedures

This study was conducted in collaboration with a disability service organization in Kenya that employs 13 staff members who support 357 people with disabilities through a variety of residential and nonresidential services. Partnering with an on-site organization that was familiar with people with intellectual disabilities was critical to the success of this study. This section describes the recruitment process and the support this study received from the disability organization staff.

Once this study was approved, recruitment of study participants was conducted in conjunction with the local disability service organization. The organization's director and human resource manager provided permission for this research to be implemented in collaboration with the organization's staff and provided a support person for the RAs. The social workers of the organization helped to share information about this study with potentially suitable participants. All individuals who were approached by the social workers expressed interest in participating and contacted the primary investigator, who set up individual meetings to introduce this research team, explain this study, and obtain informed consent.

Although the primary investigator presented all potential participants with accessible information sheets written in Swahili, which included bullet points and pictures illustrating this research, they seemed to rely more on the verbal explanations of this research provided by the primary investigator and research assistants. Given that this was the first time these individuals were engaging with research, they were curious about its benefits. Despite the fact that the primary investigator described this research as having mostly indirect benefits, such as informing services and policies on intellectual disabilities in Kenya, the participants still expressed a willingness to participate and contribute information. All participants gave their consent to participate in this study. Guardians of participants with intellectual disabilities who did not require support during interviews were made aware of this study, but they did not participate in the interviews or focus groups. In addition to individual consent, guardians of participants with intellectual disabilities who required and requested the support and presence of their guardians during the information meetings, interviews, and group meetings also signed consent forms. In such instances, the

person with intellectual disabilities had to approve having their guardian present during interviews and group discussions.

2.3. Data Collection Procedures

Once recruitment was completed, data collection started. This research team agreed to start fieldwork at 9 a.m. each day and that the primary investigator would bring lunch and water for the team. The support person ensured this research assistants' parents and work supervisors were aware of the fieldwork schedule and that they had permission to be away on the required days. The majority of this research activities were conducted in Swahili and Kikuyu. Swahili was understood by all participants, but some individuals were more articulate and comfortable communicating in Kikuyu.

The primary investigator and the RAs with intellectual disabilities (see section below on training and engagement with RAs) jointly conducted interviews with 10 people with intellectual disabilities and 10 caregivers who later participated in the four focus groups. The people with intellectual disabilities and caregivers who participated in this study were not related or recruited as dyads. All interviews took place in the participants' homes and lasted an hour on average. A five-minute break was included halfway through interviews because the RAs found one-hour interviews to be lengthy. Several participants with intellectual disabilities required support from their guardians to participate in this study due to their physical mobility and communication needs. Each RA asked three questions they memorized from the interview guides, while the primary investigator asked the remainder of the questions. After the interviews were complete, the primary investigator did a preliminary analysis of the interviews and presented the themes to the RAs.

This research team worked together to identify and develop three common themes from the interviews, which were used to develop focus group questions. Two focus groups were then conducted with people with intellectual disabilities (five participants per group) and two focus groups with caregivers (also five participants per group). The focus groups took, on average, two hours. Breaks were taken as needed. The RAs were included in all aspects of the focus groups, including by asking questions and facilitating discussion. The primary investigator supported the RAs to co-facilitate by providing prompts and follow-up questions as needed. Participants received a stipend for transportation costs as well as refreshments during the interviews and focus groups. The RAs were essential to the successful completion of the focus groups. This was especially visible in the focus groups, where the RAs were viewed as insiders, which encouraged free and open dialogue. This helped address the power dynamic between the researchers and research and was one of the benefits of the design of this inclusive research study, similar to others reported in other studies (Purcal et al. 2019; Walmsley et al. 2018).

The presence of RAs with intellectual disabilities also sparked interest, especially among caregivers who did not think it was possible to involve people with intellectual disabilities as researchers. In some instances, the caregivers interrogated the RAs about their experience as researchers. Although well intended, sometimes the interrogation came off as if doubting the capabilities of the RAs as researchers. This was evidenced in the caregivers' tone and attitudes when they spoke to the RAs in a belittling manner. In such instances, the primary investigator stepped in to affirm that the RAs were trained and were continuing to learn through the process.

2.4. Findings and Dissemination

The dissemination of this research was a key component of this study, as the aim of inclusive research is to leave sustainable change on the issues being addressed in research (Walmsley et al. 2018). There were initial plans to hold a town hall with the key stakeholders in disability services. The host disability organization asked for stipends to be provided to prospective attendees of the town hall. This request presented a clear gatekeeping challenge, both practically in terms of the unavailable study budget and philosophically in that this study results should be freely distributed and received as part of a commitment

to further understanding of the issues facing people with intellectual disabilities. It did not seem ethical to pay people to listen to the findings because it would attract attendance for the sake of pay, but not because the stakeholders were interested in or cared about the issues affecting people with intellectual disabilities.

Instead of hosting a town hall, findings were disseminated to the host organization and through outreach activities that were already planned by organization staff, such as a parents' fundraising meeting and a teachers' training. Accessible handouts were provided to all attendees at these events. The host organization was in the process of developing a new strategic plan, and so the findings of this research were welcomed to help inform this process. Attendees at the events welcomed this research findings, which they found to be informative and empowering for families and people with intellectual disabilities.

3. Working with Research Assistants

As noted above, there are a multitude of complexities in developing, practicing, and promoting inclusive research in Kenya. Barriers to the implementation of inclusive research in Kenya have resulted in a lack of opportunities for Kenyans with intellectual disabilities to participate in research training or to do research. Scholars in the field of inclusive research have attempted to bridge the gap of exclusion of people with intellectual disabilities from research by developing research trainings, implementing research together with people with intellectual disabilities, drawing lessons from their experiences, and sharing them with other inclusive researchers (Di Lorito et al. 2018; García Iriarte et al. 2014; Nind et al. 2016; O'Brien et al. 2014; Tuffrey-Wijne et al. 2020; Strnadová et al. 2020; Walmsley et al. 2018). However, this work is typically limited to Western countries and has not been conducted in Africa. This next section describes the processes that were involved in recruiting and training RAs with intellectual disabilities in Kenya. The training consisted of ethics and research methods using the training materials available at the time of this study.

3.1. Recruitment of Research Assistants

Inclusive research teams experience challenges in recruiting and training RAs with intellectual disabilities and receiving approval from ethics committees to include them in research projects (Ghaderi et al. 2023; McDonald and Kidney 2012). The U.S. IRB considered people with intellectual disabilities a "vulnerable population", and additional approval measures and caution were required to avoid coercion and ensure the voluntary participation of the RAs. The primary investigator worked closely with the disability organization staff, who recruited two suitable candidates to fill the RA positions. The demographics of the RAs included one male, 25 years old, and a female, 28 years old, and they had been attending day programs at the host organization for more than three years. The RAs were required to meet the following criteria to be part of this research team: be willing to be an RA and represent other people with intellectual disabilities; be able to communicate verbally; concentrate on a task for at least 15 min; work collaboratively; and learn how to do research. Once two RAs were selected, the organization's staff provided ongoing logistical support to the RAs, such as by providing reminders during trainings and fieldwork activities, by communicating and coordinating schedules with guardians, and by explaining unfamiliar words used during training to the RAs.

During initial training, it became evident that one RA was unable to complete foundational tasks to co-lead this research. This RA had difficulties understanding and retaining the training content, despite the primary investigator and support person using familiar words, phrases, and figures of speech. This RA also had a hard time remembering what to say to introduce herself, recall questions, or comprehend sentences with more than three words. Although she completed this research training with the support of the primary investigator and support person, the RA expressed that she felt she was unable to ask questions during data collection. The primary investigator requested that the disability service organization recruit an additional RA who also received training. The new RA was female and 24 years old. She had been attending day programs at the host organization for

two years. Training the third RA followed a similar process and curriculum used during the onboarding of the first two RAs (described in detail below).

The two RAs who conducted fieldwork each received USD 50 per month for the eight months they were involved in this study engaging in training and fieldwork (\$50 is an equivalent of 5000 Kenya shillings, which is a competitive local rate for part-time employment). The RA who did not participate in fieldwork received pay for the time spent on ethics and research training. Additionally, all three RAs were included as presenters for an online international webinar on inclusive research where they shared their experiences with this study.

Given the extended time spent on training, it would have been better for the primary investigator to request for an additional RA as soon as they noticed that one of the RAs was struggling with training.

3.2. Training of This Research Assistants

3.2.1. Ethics Training

When working at a university, anyone who engages in research requires training and awareness about ethical considerations during research. Ethics training is conducted with researchers with intellectual disabilities as well, so they understand the necessary protections of human subjects during research (Nind et al. 2016). The absence of accessible ethics training for researchers with intellectual disabilities approved by the U.S. IRB revealed power dynamics that exist between researchers with and without intellectual disabilities. Researchers without intellectual disabilities have the upper hand in understanding ethical considerations in research and then informing researchers with intellectual disabilities about them. It is not yet clear how balancing power regarding ethical considerations in research could impact how inclusive research is implemented. For now, researchers with intellectual disabilities need ethics training that they can understand, access, and possibly interrogate (Wolbring 2003; Milner and Frawley 2019; Ouellette 2011).

For this study, the primary investigator used an IRB-approved training developed by the Johns Hopkins School of Public Health (JHSPH) (2010), the Human Subjects Research Ethics Field Guide. This training is designed to be used in rural and community contexts and consists of written modules. The training does not include audiovisual materials, as this format cannot always be supported locally. The training is not tailored for people with intellectual disabilities, but it had a Swahili translation conducted by Mohammed and Kitale (2011) (Johns Hopkins School of Public Health (JHSPH) (2010)), the language spoken by this research assistants. For accessibility, pictures were added to the training handouts to facilitate the understanding of the material by the RAs.

The ethics training covered topics related to data integrity and ethical interactions with human subjects. To account for fatigue and information access, the training took place virtually in two-hour sessions daily for five days. This consistency helped retain and build on the information from the previous day. Each day, the RAs engaged in a review, a discussion, a Q&A, and an opportunity for practice. For example, one RA explained that she did not discuss with anyone what her friend had shared with her and that this was an example of keeping confidentiality. The other RA reported that instead of having everyone speak up at the same time in a meeting he had attended, he suggested that people wait for their turn to speak. At the end of the training, the RAs were provided with certificates. Modifications to the training in terms of delivery modes, formats, time, and practical skill building were necessary to ensure this study remained inclusive. However, systemic barriers to inclusive research remain. IRB-approved ethics trainings need to be developed that are accessible to researchers with intellectual disabilities and available in languages other than English (McDonald and Kidney 2012; McDonald et al. 2022).

3.2.2. Research Training

Research shows that developing congeniality and trust can promote success in inclusive research and communities of practice (O'Brien et al. 2014; Strnadová et al. 2020). This

research training of the RAs was extensive and required consistent in-person engagement with an initial focus on team building. The RAs joined for research training from 10 a.m. to 1 p.m. each day for two weeks and shared lunch together, which was provided by the primary investigator. Having a meal together was an opportunity to build relationships and cohesion within the team. It also ensured that the RAs had a meal since the support person informed the primary researcher that the RAs may not always have access to food.

Trainings for inclusive research have mostly been developed by adapting conventional research methods to make them easy to read and understand (Strnadová et al. 2020; Tuffrey-Wijne and Lam 2019). This has been conducted using pictures, plain language, easy-to-read formats, and pre-written scripts (Nygren 2022). Given that inclusive research has not been practiced in Africa with the intentionality it has received in Western countries and that no locally created research training exists, this research study adapted an existing research training course for people with intellectual disabilities developed by Kingston University and St. George's University of London (Tuffrey-Wijne and Lam 2019). The training was adapted for the Kenyan context and local people with intellectual disabilities. The adaptations consisted of adding Swahili translations and making the pictures and examples used more relatable, fitting, and culturally applicable to the Kenyan setting.

The training covered topics related to both qualitative and quantitative research, along with practical interviewing activities. This research assistants did not read or write. Using a traditional classroom set-up where we sat in a semi-circle holding conversations and projected the topics of discussion on the wall did not elicit the anticipated level of engagement. One of the RAs was unable to concentrate for more than five minutes. It became evident that holding conversations about research was not empowering the RAs in the same way as practicing research activities. The primary investigator then decided to adapt much of the training further into short activities. During these activities, RAs learned how to introduce themselves to participants, how to explain accessible information and interview guides to participants, how to gain informed consent, how to record interviews, how to ask questions, how to listen actively, how to facilitate group discussions, and how to respond to questions others would ask about this study. On each training day, the RAs took home a practice activity and discussed their feedback with the team the following day. Practicing these skills paid off during the implementation of fieldwork when the RAs demonstrated they were well prepared. As part of their preparation for fieldwork, the RAs were introduced to the actual interview guides used in this study. Each RA memorized three interview questions to ask participants during the fieldwork.

The lessons learned are in line with previous inclusive research process findings that there is a need to allow sufficient time for RAs to understand and practice for them to grow confident as researchers (Johnson et al. 2014; Walmsley et al. 2018). Team building helped the RAs, the support person, and the primary investigator get to know each other and learn how to work together (Fudge Schormans et al. 2019; O'Brien et al. 2014). The presence of a support person who knew the RAs well during training was instrumental because they sometimes helped to organize practice sessions and offered phrases and examples that the RAs were familiar with (Conroy et al. 2021; García Iriarte et al. 2023).

It was necessary to adapt training materials beyond increasing accessibility by using familiar language and cultural teaching tools (Mikulak et al. 2022).

3.2.3. Piloting the Interview Guides

To give the RAs an opportunity to practice the skills they had learned, pilot interviews were incorporated into this research training. The RAs conducted interviews with one parent and one individual with intellectual disabilities in collaboration with the primary investigator. During each interview, the RAs practiced asking the questions they had memorized, while all other questions were asked by the primary investigator. The RAs found asking follow-up questions challenging, so the primary investigator took care of this task.

The interview with the parent lasted an hour, while the interview with the person with an intellectual disability lasted forty-five minutes. Both participants were satisfied with the length of the interviews and provided feedback that the questions and pictures in the interview guides helped them speak about their experiences. The parent who participated in the pilot interview expressed joy to see people with intellectual disabilities interviewing her and participating in research. The participant with an intellectual disability expressed gratitude for being asked to share their experiences and needs. Both interviewees received a transport refund.

The RAs practiced recording the interviews with the support of the primary investigator. After the interviews, this research team listened to the recordings to ensure that they were saved correctly and captured clearly. The primary investigator determined that the questions were effective in eliciting responses from the participants. The RAs received feedback that they had asked their questions well and in the right order, according to the interview guide. They were reminded to always introduce themselves to participants. The RAs commented that the pilot interviews were a good learning experience for them since they learned it is important to listen to participants actively to be able to ask appropriate follow-up questions. The RAs told the primary investigator that they needed time to observe the primary investigator asking follow-up questions during interviews before they would feel comfortable doing so themselves. To complete the training, the primary investigator explained this study's research procedures for the interviews and focus groups to the RAs in detail while awaiting IRB approval for this study.

RAs articulated feeling proud and accomplished for completing the training and for being researchers. Although the RAs found research to be complicated, they were happy to be included in it and hoped they would continue to learn through practice. One RA asked if they could be celebrated for having completed the training. This research team agreed to recognize the accomplishments of the RAs at the end of fieldwork. The celebration consisted of a small party at the disability service organization and a meal out.

The challenges in including people with intellectual disabilities as RAs in this study were the result of both systemic barriers and practical and study-specific barriers. Systemic barriers included challenges to securing IRB approval and a lack of formal education for the RAs. Practical barriers included the RAs being unfamiliar with research in general and needing extended time to complete training. Study-specific barriers included challenges in identifying suitable RAs and the lack of culturally adapted research training. Despite these barriers, this study was successful in recruiting, training, and involving RAs with intellectual disabilities in inclusive research in Kenya.

4. Discussion—Pushing Boundaries When Conducting Inclusive Research in Kenya

Inclusive research is scarce, if present at all, in Kenya. This study employed a novel approach to conducting inclusive research with RAs with intellectual disabilities, local people with intellectual disabilities, and their family members. Conducting an inclusive research study in Kenya and supporting people with intellectual disabilities to serve as RAs was a new endeavor. People with intellectual disabilities, their parents and caregivers, the host disability service organization, and the local IRB did not expect people with intellectual disabilities to complete training and conduct research. Numerous interrelated complexities were present throughout the development and implementation of this inclusive research study, which impacted the participation of people with intellectual disabilities in this research process. Two primary barriers experienced in this study included: (1) internalized oppression of the RAs due to stigma stemming from superstitious beliefs, medicalization, systemic discrimination, and a negative perception of intellectual disabilities; and (2) research processes and training methods were not adequately adapted to the context. These barriers and their implications are discussed in detail below.

4.1. Effects of Stigma and Negative Perceptions of Intellectual Disabilities in Inclusive Research in Kenya

Kenyan with intellectual disabilities are excluded from much of public life and are denied equal access to formal education and work opportunities (Chomba et al. 2014). This is mainly caused by negative perceptions and the medicalization of intellectual disability (Gona et al. 2018), which gives rise to stigma, low self-esteem, and internalized oppression (Bunning et al. 2017). Low self-esteem and internalized oppression become barriers for people with intellectual disabilities to participate in research studies, either as researchers or participants.

People with intellectual disabilities are already an excluded and invisible group in Kenya (Bunning et al. 2017; Gona et al. 2018). The lack of services and policy frameworks that ensure that people with intellectual disabilities are participating in the same way as their non-disabled counterparts is discriminatory (Kahonde 2023). The involvement of people with intellectual disabilities as participants and as researchers in this study was an opportunity to improve their visibility. Additionally, it created a platform for people with intellectual disabilities to express their voice and shape knowledge about intellectual disability in Kenya. During this study, people in positions of authority at times acted in ways that were disempowering to people with intellectual disabilities. For example, the suggestion by the Kenyan IRB to remove researchers with intellectual disabilities from this study was removing power from them. In such instances, authority contributes to the exclusion, silencing, and oppression of people with intellectual disabilities in Kenya.

The exclusion of people with intellectual disabilities from knowledge production contributes to the misconceptions around intellectual disabilities in Kenya. These misconceptions form the basis of decisions such as the exclusion proposed by the Kenyan IRB. This further silences people with intellectual disabilities in Kenya, who have a handful of platforms where they can be seen and heard. This ultimately causes barriers to improving their lives through services and supports.

4.1.1. Medicalization of Intellectual Disabilities

Medicalization of disability situates the 'problem' of disability within the individual (Patsavas 2018). The dominant view in Kenya is that intellectual disability is a medical problem. This view was upheld by the Kenyan IRB members, who were of the opinion that people with intellectual disabilities should not hold active roles in conducting research and that the etiology of intellectual disability should be described in this research study plan. Including medical causes of intellectual disabilities in this inclusive research study would shift the focus away from societal barriers (Barnes 2019; Oliver 2013) that negatively impact the lives of Kenyans with intellectual disabilities and hinder the implementation of inclusive research. The primary investigator was keen to have individuals self-identify as people with intellectual disabilities because it shifts power to the individuals to decide how they are represented and cultivates self-determination (Siebers 2017).

Medicalizing intellectual disability paves the way for people who do not have lived experience with intellectual disability to develop biased knowledge about intellectual disability. This detracts from opportunities to develop an intellectual disability epistemology from the perspective of those with an embodied experience of living with an intellectual disability. It was therefore necessary to refuse to adhere to the requests of the Kenyan IRB, since the purpose of this research was to dismantle ideologies that are harmful to the intellectual disability community (Wilson 2022). In the future, the Kenyan IRBs would benefit from information regarding the usefulness of including people with intellectual disabilities in research.

4.1.2. Internalized Oppression Due to Stigma

Internalized oppression is a common challenge for people with intellectual disabilities (Watermeyer and Gørgens 2013). In this study, stigma seemed to perpetuate the internalized oppression of people with intellectual disabilities, which hindered their ability to advocate

for themselves. As a consequence, they often looked up to their caregivers and staff for approval.

Empowering the RAs through extensive training and support did not materialize into instant advocacy because years of keeping people with intellectual disabilities subjugated impacted their self-esteem. Collegiality did not seem sufficient to dismantle years of internalized negative rhetoric and low self-esteem within the short research period. For example, one RA believed that they were possessed by evil spirits because their parents had told them these spirits caused their disability. This RA shared that their parents had taken them to church on several occasions to be prayed over for deliverance. Other researchers have also reported that intellectual disability is commonly seen as a result of witchcraft or a curse in Kenya (Bunning et al. 2017; Gona et al. 2018; Munyi 2012). The negative beliefs about intellectual disabilities had a negative impact on the RAs development of the confidence required to carry out research tasks. This played out during fieldwork, where the RAs barely spoke unless it was necessary, such as when asking their interview questions or when asked to do something by someone else.

RAs and participants with intellectual disabilities had a number of “learned responses” to adhere to how they thought people without intellectual disabilities wanted or expected things to be. Because people with intellectual disabilities were perceived as people who lacked agency, they were infantilized by caregivers and by staff in the organization where they received services. For example, the primary investigator observed during field trips that the support person told the RAs where to sit inside the car and when to eat their snacks. The RAs always obliged without questioning the reasons behind the instructions they received. It was common to see the RA pause and wait for approval to take action or say something. On the other hand, the RAs were quite vocal when they were around their peers. Internalized oppression seemed to result in fear and a lack of trust in anyone besides those with whom they shared an insider-embodied experience.

Self-advocacy laid the foundation for inclusive research in Western countries (Bigby et al. 2014; Bigby and Frawley 2015; Walmsley and Johnson 2003), but there is no self-advocacy movement in Kenya as of yet. There is also a need to build trust in people with intellectual disabilities in Kenya for self-advocacy to develop. Building trust will require changes about how Kenyans think about and treat people with intellectual disabilities at individual and systemic levels. Before communities of trust come to be, there is a need to change narratives into rhetoric that affirms Kenyans with intellectual disabilities’ place and belonging in Kenyan society.

4.1.3. Systemic Barriers in Education

Although it is not a must for researchers with intellectual disabilities to have reading and writing skills (Nind et al. 2016), the lack of literacy skills by the RAs in Kenya was a result of discriminatory systems. Kenya has not yet put in place a legal mandate to educate people with intellectual disabilities, and the reasons for it are not clear (Chomba et al. 2014). Research shows that given the opportunities, some people with intellectual disabilities can gain literacy skills if supports, resources, and accommodations are provided (Luckasson and Schalock 2013; Thompson et al. 2009). The lack of a system that supports the education of people with intellectual disabilities in Kenya demonstrates that issues that matter to people with intellectual disabilities do not receive sufficient attention (Mercier et al. 2008). This makes it even harder for people with intellectual disabilities to advocate for their rights because of a lack of tools and support to do so. There is a great need to empower Kenyans with intellectual disabilities with the tools they need to advocate for their issues, including the right to receive formal education.

4.2. *Indigenizing Training and Research Together with People with Intellectual Disabilities*

Inclusive research methods and practices have mostly been developed in Western contexts. The methods may therefore lack the nuances necessary for the practice to work for populations in the global south that have not been exposed to research. This research

was new to the RAs, the disability service organization, and the participants. The primary investigator relied highly on written communication during training and fieldwork. The RAs found this approach challenging, especially because of their limitations in reading and writing. The presence of a support person with insider knowledge proved to be very useful because they were using phrases, figures of speech, and experiences that RAs were familiar with and that have been seen to work elsewhere (Carnemolla et al. 2022). In contexts such as Kenya, it will be useful for inclusive researchers to consider working with support people who have worked with or lived closely with the involved researchers with intellectual disabilities to facilitate their understanding of research. Support personnel need to be people who are keen to empower people with intellectual disabilities. Because of the level of engagement of the support person, it will be prudent to consider remunerating them for their time, work, and contribution towards making inclusive research possible.

Inclusive researchers in global South contexts will need to develop research trainings in collaboration with people with intellectual disabilities. Indigenizing research practice and training by embedding meaningful culturally appropriate approaches such as metaphors, songs, proverbs, and storytelling might be more relatable to local people with intellectual disabilities (Caxaj 2015). For example, the support person in our research team used this African proverb to help the RAs understand the concept of keeping confidentiality: "*Cia mucii ti como*", which translates to "*what is discussed at home stays within the home*". The phrase was catchy and easy to understand, and even months later, this research assistants reminded themselves of keeping confidentiality by just saying this proverb.

Developing research curricula for RAs with intellectual disabilities in global South contexts requires setting aside significant time to collect as many cultural and traditional tools as possible to adapt training. Additionally, it will be important to reflect on the meanings and harmony of the tools when applied to research methods of data collection and analysis (Geia et al. 2013; Somerville et al. 2021). Further research is indicated to determine methods of training and implementation of inclusive research procedures that can be easily understood by people with intellectual disabilities in contexts such as Kenya.

5. Conclusions

In continental Africa, inclusive research still lags because of misconceptions about the agency of people with intellectual disabilities and a lack of expertise around inclusive research. In this first known attempt to conduct inclusive research in Kenya, it was evident that the abilities of people with intellectual disabilities to participate as researchers and participants were stifled by internalized oppressions and external barriers such as limitations by IRBs. Additionally, research training was less adapted to the Kenyan context, which affected the effectiveness of implementing fieldwork. This was in part due to RAs lacking some form of formal education. As a result, the RAs lacked the tools to advocate for themselves. To achieve the level of advocacy where people with intellectual disabilities are actively engaged in inclusive research, they need to feel empowered and develop self-determination skills. The reflections in this paper are from non-disabled researchers only. Future research needs to include reflections on the RAs.

Historically, research methods have not favored the participation of people with intellectual disabilities as researchers (Lester and Nusbaum 2018). Adapting the research methods for use by people with intellectual disabilities in different cultures seems counter-intuitive. Since people with intellectual disabilities are most attuned to their local contexts and cultures, research methodologies that embed positive cultural aspects of their context might make better sense to them. For example, the use of materials written in plain and local language accompanied by pictures did not seem sufficient to help RAs in Kenya understand research. It is necessary for inclusive researchers in contexts such as Kenya to develop culturally competent, inclusive research materials. Reimagining inclusive research from a global south perspective will require the attention of researchers from a variety of disciplines, since the lives of people with intellectual disabilities span all aspects of epistemic and ontological imagination.

Upcoming inclusive researchers in Kenya have the arduous task of advocating for Kenyans with intellectual disabilities to take up their rightful place in society and shape their own futures. Junior and upcoming researchers need to reimagine research methods and procedures so they are a good fit for people with intellectual disabilities. Most importantly, they need to push back on patronizing attitudes and medicalization, which stand in the way of affording people with intellectual disabilities the justice they have been denied. As more people get involved in inclusive research in Kenya, narratives around intellectual disabilities and perceptions in academia are bound to change. People with intellectual disabilities may reconsider their beliefs about research participation and perceive different realities once they are able to successfully participate in knowledge production. Inclusive research will contribute to changing narratives around intellectual disabilities through evidence and advocacy.

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