#### FULL-LENGTH ARTICLES

# The 'Obuntu Bulamu' Visual Narratives: Participatory Research and Film Making About Inclusion of Children With Disabilities in Uganda

Femke Bannink Mbazzi<sup>1,2</sup>, Elizabeth Shalom Kawesa<sup>1</sup>, Ruth Nalugya<sup>1,3</sup>, Janet Seeley<sup>4</sup>

<sup>1</sup> Disability Research Group, MRC/UVRI & LSHTM Uganda Research Unit, <sup>2</sup> International Centre for Evidence in Disability, London School of Hygiene & Tropical Medicine, <sup>3</sup> Spina Bifida and Hydrocephalus Association of Uganda, <sup>4</sup> Global Health and Development, London School of Hygiene & Tropical Medicine Keywords: participatory film, disability, children, inclusion, Africa, Uganda

https://doi.org/10.35844/001c.123887

Journal of Participatory Research Methods Vol. 5, Issue 4, 2024

> In the Global South children with disabilities have often been left out of research projects. A method which has the potential to increase inclusion of children with disabilities in research is participatory photography and video.

In this participatory research project 32 children with disabilities and their peers aged 8 to 14 living in Central Uganda, were asked to describe their daily life experiences through drawings, photos, and films. The project was nested within a larger intervention study which aims to improve inclusion, which used an African childhood disability studies framework with Afrocentric methods, involving the children's family and community networks. In five participatory workshops, each followed by home and school follow up visits, children cocreated 3 short films and 1 documentary film together with their peers, family members, teachers, and communities.

The short films and documentary were shared with stakeholders and have been utilized by civil society organizations and organizations of persons with disabilities in advocacy and training initiatives on disability inclusion in Uganda and abroad. Participants felt positive about the outcomes, going forward they suggested making more short films featuring the experiences of children with different types of impairments to build the confidence of children with disabilities, reduce stigma and advocate for family and community support.

Participatory film is a feasible and meaningful way of including children with disabilities in research in the Global South when we acknowledge the importance of interdependence, step away from predefined ideas, reflect on voice and hierarchy, make ethical considerations, and allow space and time for a nonlinear and complex process.

#### Introduction

Despite efforts to ensure children and young persons with disabilities have the same opportunities as their peers, they still have poorer health, education and social outcomes (Kuper et al., 2014; United Nations Children's Fund, 2022). In the Global North researchers have increasingly developed and used participatory methodologies that include children in the research process (Goodley, 2013; James & Christensen, 2008; Richards & Clark, 2018). Whilst progress has been made in including children's narratives in research in the Global South, in Uganda especially in the field of children's rights,

HIV, and war trauma-related research (Bernays et al., 2015; Vindevogel et al., 2015; Witter & Bukokhe, 2004), inclusion of narratives of children and young persons with disabilities remain limited (Curran & Runswick-Cole, 2014). A recent scoping review on participatory research with children and youth with disabilities in low income countries by Schlebusch et al. (2020) which included 20 studies including 6 from Sub-Saharan Africa, confirmed this, and specifically pointed out the lack of involvement of children with chronic health conditions. To involve children with disabilities in research there is a need to provide space for children to express their views, facilitate their voices, ensure an audience to listen to their perspective and mobilize action (Lundy et al., 2011). In a paper critically reflecting on the International Centre for Evidence in Disability's participatory research projects, Kuper et al (2021) described that successful participatory research with persons in low income countries can be equitable and respectful if a shift in power from researchers from high income countries to people with disabilities and researchers in low income countries is made and participation is measured using appropriate tools. To achieve this, the authors state, there is need for 'commitment, planning and adequate resourcing' (Kuper et al., 2021, p. 335).

In research with children, it is common to combine traditional research methods used with adults, such as participant observation and (activitybased) interviews, and techniques considered more suitable for children. These may include drawing, photography, videography, co-narration, and activity worksheets (Eisen et al., 2019; Punch, 2002; Stafford, 2017). The method of participatory photography and film, with reasonable modifications depending on the child's needs, has been documented as an effective qualitative research method to learn about the experiences of children with disabilities (Eisen et al., 2019).

In the past visual ethnographies were used by anthropologists and filmmakers to describe cultural practices, ways of living, and belief systems in the Global South. More recently disability researchers have explored integrating photo and film in academic research to document children's experiences in disability studies (Benjamin-Thomas et al., 2019; Vandecasteele et al., 2019; Vandenbussche et al., 2020; Wickenden & Kembhavi-Tam, 2014). Participatory photo and film can provide a space for children with disabilities in which they can voice their perspectives to a larger audience beyond their own communities and influence societal change (Lundy et al., 2011; Wickenden & Kembhavi-Tam, 2014).

Participatory video or filmmaking is a process in which community members use cameras to document, explore and engage with their environment and create a film that communicates information, reveals hidden social relationships and stimulates community action (Gubrium et al., 2015). There is no fixed way of conducting participatory film making, but broadly the steps include brainstorming ideas, getting to know the equipment, storyboarding, shooting the films, watching, and reflecting on the films and the process and dissemination. In India for example, Benjamin-Thomas et al (2019) created a short film with 6 boys with disabilities aged 10 to 17 years to explore the perspectives from children with disabilities on participation in everyday activities, the barriers and the ways to overcome those barriers and give support.

In this paper, we describe the participatory film making process with children with disabilities who participated in the 'Obuntu bulamu' intervention study in Uganda. The 'Obuntu bulamu' study uses an African Childhood Disability studies framework (Chataika & McKenzie, 2013). Whilst it has links to the social and right based models of disability, the framework emphasis is on mutual responsibility towards persons with disabilities, interdependence versus independence, and places the social and cultural understandings and concepts of disability first. African childhood disability studies which use this framework engage families and communities as key persons in care, participation and research and give a strong focus on the intersection with poverty (Chataika & McKenzie, 2013; Owusu-Ansah & Mji, 2013). We explored children, their peers, families, teachers, and community members views on inclusion at home, in school and in the community. In our approach the child's voice, as amplified in research in the Global North (Lundy et al., 2011), is important and key to the visual narratives created, but exists and is developed with the persons they are interrelated to and interdependent with (Mkabela, 2005; Owusu-Ansah & Mji, 2013).

In this paper, we use the United Nations Educational, Scientific and Cultural Organization's (UNESCO's) description of inclusion as made in the Cali commitment to equity and inclusion in education in 2019:

Inclusion is a transformative process that ensures full participation and access to quality learning opportunities for all children, young adolescents, and adults, respecting and valuing diversity, and eliminating all forms of discrimination in and through education. The term inclusion represents a commitment to make schools [...] and educational settings, places in which everyone is valued and belongs, and diversity is seen as enriching.

We will focus on inclusion specifically whilst considering African knowledge systems and intersectional lines of difference such as gender, religion, and socio-economic status (Chataika & McKenzie, 2013; Owusu-Ansah & Mji, 2013; United Nations Educational Scientific and Cultural Organization, 2021).

## Methods

## Ethical considerations

Ethical approval was obtained from the Uganda Virus Research Institute, Research Ethics Committee (GC/127/18/02/633). Research clearance was received from the Uganda National Council for Science and Technology (HS SS4557). All parents and teachers gave written informed consent to

participate in the study and specifically agreed to the visual narrative drawing, photo, and film activities and sharing of outcomes in the public domain. Where possible children assented to participate; adult consent was received on behalf of children with moderate to severe neurocognitive impairments, who could not assent to participate by themselves. Consent was received from the heads of schools where photo and film footage was taken and workshops took place. The heads of schools informed the school community and asked parents if they had any objection to have their children filmed as part of main character's classroom and school setting. The filmmaker obtained permission from the relevant authorities to film in public spaces, such as markets, following Ugandan local policies and guidelines. Reasonable accommodation was made to promote participation of children who required an aid to communicate and others who required an aid to support mobility. The measures to accommodate these needs included sign language interpretation, provision of easy read and picture materials were provided during the consenting and data collection process. Most of the aid at home and during the workshops were provided by parents or siblings, whilst peers or teachers often took on the role of an aid in the filming in the school setting. Participants and persons providing aid received reimbursement for their time as well as a transport refund where meetings took place away from their home and school locations, following national guidelines for compensation (Uganda National Council of Science and Technology, 2014, 2022).

Specific attention was paid to explaining the possible benefits and risks of participating in film making and sharing of visual materials with a wider audience. The discussions with the children, families, teachers, and community members in the consenting process included privacy, sensitivity of footage, and possible responses of others when watching the film. These included both positive (for example being known and raising profile) and negative responses due to stereotyping and misunderstanding of impairment related needs (for example discussing incontinence and difficulties in learning).

## Study setting

The *Obuntu bulamu* intervention is a peer-to-peer support disability inclusion intervention, which aims at improving participation and inclusion of children with disabilities in Uganda, East Africa. It was co-created by a team of Ugandan children, parents, teachers, disability rehabilitation workers, and academics. The intervention uses indigenous interpretations of belonging and humanity which are closely linked to the *Ubuntu* philosophy and emphasises the capabilities of community and society, building solidarity and support (Bannink et al., 2020; Bannink Mbazzi, 2023). The Ubuntu philosophy of humanness has been described as an African framework which could change and improve disability inclusion in low-income countries (Berghs, 2017). In Central Uganda, it represents an accepted and consistent behaviour that signifies a shared set of values, which promote well-being, togetherness and unity (Karlström, 1996; Otiso, 2006). The intervention consists of training sessions, peer support meetings and activities for children, family members, and teachers (Bannink Mbazzi et al., 2020). It was developed, tested and evaluated using a mixed methods approach in which the research team immersed themselves culturally and socially with the children, parents, and teachers who were part of the project, something which has earlier been described as Africentrism by Mkabela (2005) and Owusu & Mji (2013).

The intervention training sessions and activities were initially developed and piloted (2017-2019) by a multidisciplinary team of rehabilitation workers, psychologists, education specialists, parents, teachers, and children. After the pilot showed good feasibility and acceptability of the co-created intervention, we commenced testing the intervention in a cluster randomized control trial in 20 schools and communities in Wakiso and Masaka district in Central Uganda (2020 – 2024).

The participatory film narratives were developed during the pilot testing phase and are utilized in training in the intervention group in the randomized control trial.

## Study participants

A group of 15 children with disabilities, 15 peers, 30 parents, and 5 teachers were purposively selected from the larger *Obuntu bulamu* pilot participants, taking into account impairment type, age, gender, school and community location, and social-economic status with the aim to ensure an equitable representation. Of those invited to participate, 11 children with a disability, 11 peers, 22 parents, and 4 teachers accepted. The children with disabilities aged 8 to 14 years (5 male, 6 female) had different impairments including visual and hearing impairments, neuro-disabilities, intellectual disabilities, and autistic spectrum disorder. In the study each child was matched with a peer of their choice. The children, their peers and parents took part in 4 participatory workshops, engaged in data collection at home between workshops, and a feedback meeting. In addition, another 22 children with disabilities, 22 peers (of which 2 also had an impairment), 44 parents, and 24 teachers involved in the larger project attended the fourth workshop in which the rough cuts were displayed and discussed.

## Data collection

The participatory film making followed the general preparatory, participatory research, and action phases (Benjamin-Thomas et al., 2019) with 4 participatory workshops to ensure co-research and joined efforts to create content and share this with a larger audience (Lorenz & Kolb, 2009) and evaluation meetings.

In the preparatory phase we worked with children, parents and teachers and researchers involved in the *Obuntu bulamu* project to brainstorm about how best we could develop a visual narrative with the cohort of children that were enrolled in the project. The research team had already built rapport with the participants through the co-creation of the *Obuntu bulamu* intervention

Workshop	Activities
1	<ul> <li>Rapport building activities and objectives setting.</li> <li>Visual narrative creation through drawings and audio recordings.</li> <li>Follow up: continue with drawings and audio narratives at home with support of peers and family members and research team.</li> </ul>
2	<ul> <li>Summarize observations from the drawings and oral narratives.</li> <li>Identification of most important concepts and areas of inclusion.</li> <li>Training on the use of instant still photo cameras and film cameras.</li> <li>Follow up: participants take photos at home and school.</li> </ul>
3	<ul> <li>Feedback meetings about the photos, audios and footage collected.</li> <li>Each child displayed and discussed their photos and audio or film clips.</li> <li>Training on story boarding: who, what, when, where, and why.</li> <li>Drafting of storyboards in pairs and presentation to the group.</li> <li>Selection of 3 three stories to be filmed by a professional filmmaker.</li> <li>Follow up: shooting through various home, school and community visits.</li> </ul>
4	<ul> <li>Display of 3 draft film narratives for feedback with participants.</li> <li>Discussion of and drafting script for documentary narrative.</li> <li>Follow up: shooting of documentary and editing of 3 short narratives.</li> </ul>
5	<ul> <li>Discussion of draft documentary in 3 groups (due to COVID-19 outbreak).</li> <li>Planning dissemination strategies.</li> <li>Follow up: finalize films, share online and on DVDs with all participants.</li> </ul>

Table 1. Content of participatory workshops in the 'Obuntu bulamu' film making process

earlier in the project. The participatory visual narrative creation built on these relationships. In the participatory phase we identified and prioritized the focus of the narratives: inclusion and participation at home, in school and communities. We trained children on handling the camera and held feedback meetings about the data collected. In between workshops, home and school visits were conducted to follow up on each child individually. As part of the community action phase, we met to discuss the dissemination strategies and shared the film narratives with national and international stakeholders and included some of the film narratives as training material in the *Obuntu bulamu* intervention. The film was shown to local stakeholders to elicit discussion and action to address some of the participation barriers raised in the film and shared at various international research and public events.

#### Participatory film-making process

The children, peers, and at least one parent or older sibling were asked to participate in four participatory workshops over one year before the COVID-19 pandemic, followed by a fifth workshop 18 months later, after the peak of the COVID-19 pandemic and the easing of containment measures. Home and school follow up visits and phone calls were conducted in between the workshops (Table 1).

In the first workshop, children described their daily lives through drawings and oral narratives. They were asked to continue making drawings about their daily life experiences at home and were provided with materials which they would bring back in the second workshop or hand over to the study staff during a home follow up visit. Children with visual impairments were asked to record voice messages instead and with the support of their peers provided visual information to illustrate their messages. In the second workshop, a summary of the observations from the drawings and oral narratives was given after which participants formulated important concepts and areas of inclusion they wanted to be photographed or filmed. The workshop consisted of various practical assignments in which parents and children took photos and filmed shots of their environment and one another. Children were given and trained in the use of instant still photo cameras and film cameras and were followed up at home and in school by a member of the research team. Children were asked to take photos of what is important to them in their daily lives, what they enjoy, and what they dislike or find difficult. These were earlier defined as ways to elicit inclusion and participation with the larger study population.

The photos and film clips were discussed in a third workshop. Each child displayed their photos and film clips and discussed why they took these. Peers and parents provided support for children who were unable to verbally express themselves or required support in describing the visual images due to their impairment. Each child then developed an idea for a film script together with their peer about their daily lives. They were explained how story boards are used in film making and asked to mention what they thought should be the story of their film, who should feature in the film, and which experiences should be included. After drafting the storyboards, the children shared and discussed their ideas with their parents, teachers, and members of the research team for input. Peers played an important role in describing the inclusiveness of the schools, especially peers of children with severe neurocognitive or multiple disabilities. From the ideas presented, the children, parents, and research team members selected three stories to be scripted and filmed by a professional filmmaker. The filmmaker and research team worked together with the three selected children and families to further develop the storyboards and film them in their homes, schools, and communities, with the permission of all those involved. This involved regular home, school and community visits including different film shoots and drafts which were discussed with the families. There was a constant dialogue between the team members in the co-creation of the film with very regular feedback on rough cuts during the filming process.

The three draft film narratives were shared in a fourth workshop in which the participants as well as other children, parents, teachers, and research team members involved in the *Obuntu bulamu* project gave feedback. Comments and suggestions were captured and further adjustments to the films were made. In this meeting, a suggestion was made to create a documentary describing the *Obuntu bulamu* intervention and activities that all participants were part of with a specific focus on inclusive education. Participants believed that this could be used as an advocacy tool for inclusion in schools and communities and could be shown in conjunction with the case studies, which they too felt were not only a research outcome but equally an awareness raising tool to give voice to children with disabilities and advocate for inclusion. A script for the documentary was co-developed with the workshop participants, filmmaker, and research team. The films of the three short narratives were shared with the participants on DVDs and were made accessible <u>online</u>.

Due to the illness of the filmmaker and the COVID-19 outbreak, the originally planned fifth workshop to discuss the draft documentary had to be postponed until 2021. At that time, due to the restrictions on large meetings during the COVID-19 outbreak, the draft documentary film was shown for feedback and input in three small groups: to children and parents, teachers, and stakeholders separately. As with the three short films, changes were made based on the inputs of the participants and a final version was developed and published <u>online</u>.

## Data analysis

All workshop and home visit discussions were audio recorded, and some parts were video recorded. Summary reports were written after the meetings and shared with participants and research team members. The research team members took field notes during all activities and kept a log of reflections about the process during the project. All recorded and handwritten data was transcribed and analysed manually using a thematic analysis approach (Braun & Clarke, 2006). We used an interactive and informal process with feedback from the various participants along the way on interpretations and observations from the visual and narrative data collected.

Based on the messages and topics in the films listed by the children during the process (making the storyboards) and retrospectively after having watched the films, the research team developed a codebook. The research assistants who worked most closely with the children, families and teachers developed the codebook, which was reviewed by the study coordinator and investigators. After coding, themes were derived by the research team. The codes and themes were discussed and checked with the children, their peers, family members, teachers and community members, following the Afrocentric method of close collaboration and cultural and social immersion in the lives of the study participants. In addition to the analysis of the narrative content, we evaluated the participatory process with the participants through informal evaluation discussions with individual participants and all participants together after display of the films to stakeholders. These data were analysed thematically by the research team and checked with the participants.

## Findings

## Themes in the films and documentary

Three short films and one documentary were created. Descriptions of the films are outlined in Appendix I. Themes identified in the film narratives, drawings, and photos were friendship; play; belonging to a family; parents' (mostly mothers') care and resilience in looking after and loving their child with a disability despite negative attitudes from relatives and community members; poverty; lack of services; and inaccessibility of schools and other



Figure 1. Photo made by a child, theme '(in)accessibility'

public places. Whilst some themes were disability or impairment specific, such as the social stigma of persons with disabilities, as well as difficulties in access to buildings for children with mobility difficulties (Figure 1), the majority of narratives focused on relationships with family and friends. These themes were similar for children with disabilities and their non-disabled peers: the importance of play (Figure 2); having a friend; and having someone who cares for you and supports you (Figure 3). The wider themes of poverty and lack of health and social services for all (often more pronounced for children with disabilities) were identified through descriptions of daily challenges and desires. These were occasionally mentioned as direct challenges in the films but literally appeared as background in all of them.

#### Use of the films in training and advocacy

The short films and documentary were displayed to various audiences to invite scholars, policymakers, and implementers to listen to the voices of children, parents and teachers and embrace African descriptions and models of inclusion and belonging in disability inclusion policy and practice. Table 2 summarizes the different training and advocacy initiatives the film narratives contributed to.

First, a dissemination meeting was held with participants and stakeholders including the Ministry of Education and Sports, discussing the potential of the *Obuntu bulamu* training manuals and films in advocacy and training. As a result, the *Obuntu bulamu* team was requested to contribute to the development and review of the national Continuous Professional



Figure 2. Drawing by child, theme 'importance of play'



Figure 3. Still image of film narratives, theme 'care and support'

Table 2. Summary of use of Obuntu bulamu film narratives in training and advocacy

Contributions of the Obuntu bulamu film narratives in training and advocacy:

- Contributed to the National Continuous Professional Development training manual for primary school teachers on inclusive education in Uganda
- As training and advocacy materials by parent groups and organizations working in disability inclusion in Africa and South America
- As educational materials in lectures for academic students at the London School of Hygiene and Tropical Medicine and Ghent University
- In sharing study findings and raising awareness on international conferences and film festivals in Europe and Africa.

Development training for primary school teachers on inclusive education. Large parts of the *Obuntu bulamu* training manuals and films were adopted in the development of the national training manuals.

Secondly, the participatory films were included as training materials in the *Obuntu bulamu* training manuals, which were uploaded on the <u>Ubuntu hub</u> of the London School of Hygiene and Tropical Medicine. Interested civil society and government organizations from different countries in Africa and South America have used the training materials in their setting. The short film of James was adopted by the <u>Baby Ubuntu</u> project in their training manual on togetherness and belonging. Within Uganda parents' groups and teachers have utilized the films to advocate for the inclusion of children with disabilities.

Thirdly, the films were advertised to an academic audience through the university websites of the London School of Hygiene and Tropical Medicine and <u>Ghent University</u>. Both universities have utilized the films in academic teaching for master students on disability inclusion in low-income countries. The films were displayed at various international scientific conferences, advocating for including alternative, indigenous concepts of belonging and inclusion in disability and inclusive education research, e.g. at the AfriNEAD conference in Cape Town, South Africa in 2023.

Lastly, the *Obuntu bulamu* documentary was selected for display at the Africa Film Festival in Ghent, Belgium in 2022. Three of the authors travelled to Ghent to introduce the film and have a panel discussion about the making of the film, including the mother of a child with a disability who features in the documentary, the research team coordinator who worked with the children throughout the process and the study team lead who designed and guided the co-creative process.

## Experiences from film-making process

The process of creating the films itself was an experience in which a web of connections was made visible. From the start, children included their peers, parents, teachers, and community members. The film scripts were focused on telling 'their' story in the plural: children asked parent(s) to talk about their early years, their experiences with hospitals and schools, and asked their teachers and peers to talk about school. The voices were entangled, children described their lives from a perspective of 'we', our home, our school, our church. When speaking about 'I' they shifted to individual achievements in school, and what they would like to do in future. Each child returned to the 'we', describing how in future they would take care of their parents, and be part of their community. In all photos and films interdependence rather than autonomy dominated the narratives and was interlinked with the collective responsibility and duty of care values of *Obuntu bulamu*.

The research team which was used to working closely together with children with disabilities in the project, reflected on the participatory filmmaking process, in particular the participatory and community action phases. In the design process the research team reflected on their own background and ideas about the films and importance of representation of impairment, gender, and social-economic background. For example, many had a list of areas they felt should be represented in the film if speaking about inclusive education, such as accessibility, inclusive methods including differentiation, school policies and teaching practices, yet children, parents and teachers did not necessarily raise these as the most important aspects they wished to share. Their focus was first and foremost on the relationship with others and 'being given a chance' to participate.

In the participatory phase the research team had to let go of predefined ideas on how best the films would describe the daily lives of children with disabilities as per 'international' ideals of what inclusive education looks like. To ensure the process was led by children and their family and community networks, the researchers carefully prepared and reflected on their roles in the film making process and evaluated how in each workshop issues of hierarchy and influence could be mitigated. The researchers deliberately refrained from giving directives and worked as collaboratively as possible, participants were given moderation roles in the workshops. Through this approach, participants who were first inclined to wait instructions and directions from the research team, would share their ideas and take ownership of the development process, which enabled a shift in power dynamics. The research team also allowed for various storyboards to be developed and filmed to ensure participants had sufficient footage to watch, experiment with, and choose from. The filmmaker was very generous with his time and edits to allow for this process to take place.

The researchers felt that the community action phase was inclusive and particularly successful in involving children in the dissemination to stakeholders in Uganda. It was more difficult to engage children in international meetings for practical and ethical reasons. Firstly, we did not want to interrupt their schooling or parents' work schedules. Secondly, planning international travel, even during holidays, is almost impossible for children and parents from low-income households due to international travel and visa restrictions for African minors.

The evaluation of the process and final product indicated that the participating children, peers, parents, teachers and community members were positive about the outcomes. They were happy with the way the stories were designed, their involvement and say in the process, and the final films. They felt the films represented their experiences well and involved the most important persons in their lives. The participants were proud about featuring in the films and participation (either in person or remotely) in the national and international community action events. The children were particularly excited about being 'film stars' and being able to 'show' others their home, friends, family, and community. Parents reflected on feeling that their child 'mattered' and they, their teachers and community members were 'important enough' to be filmed and their stories to be 'heard'. The teachers often took a 'teaching approach' in their participation, expressing the need to

share recommendations and best practices in the films. Community members were overall excited about being part of the film making, even if featured in the background. Some reflected to have acknowledged and supported children with disabilities and their families in their communities more after the engagement.

In discussing what might have been done differently retrospectively, participants mentioned that physical, communication and cognitive impairments were well represented, but felt additional short films about a child with hearing and a child with a visual impairment, as well as a child with albinism, would have been helpful from an advocacy perspective. Participants felt that this could help children with this type of impairment to identify more with the lead film character, which could build their confidence, reduce stigma and improve family and community support. Similarly, other films focusing on advocating for access to health care for children and youth with disabilities were suggested. Due to budget constraints, the project was not able to fund all these ideas.

### Conclusion

In this exploratory study, we used participatory film to describe the experiences of inclusion of children with disabilities, closely linked in with their peers, families, teachers, and communities.

The development of the photo and film narratives had many layers. Whilst the workshops and the activities in between can be described as a linear process in time, adjacent layers of influence of the research team, the filmmaker, and all participating were added in each phase of the project. All research team members are Ugandan or have been resident in Uganda for over 20 years but were taught in education systems in or based on the Global North's disability frameworks and were trained to use 'international' definitions and interpretations of disability and inclusion. The use of photo and film narratives helped to give more weight to interpretations of nonverbal narratives and reduce the use of imported terminology and language. It heightened our awareness of sensory perceptions of inclusion, including meaningful places, colours, and sounds. Earlier, Vandecasteele (2019) reflected in her visual narrative disability research on how using art and film opens up access to spaces in which words are inadequate, zooming in and out whilst researching moments over an over again, discovering new layers of meaning (Vandecasteele et al., 2019).

The children focused on the importance of belonging to a family, having a parent who cares, and changing negative attitudes: they communicated how friendship and interdependence make life worthwhile amidst poverty and lack of health and social services. The children too, felt proud to be the main characters in the films. Parents narrated the shifting attitudes and support they experienced over time and made suggestions for actions to inclusion, together with teachers and community members. Most of them saw the film as an advocacy tool. Parents too experienced a sense of recognition of their child and their family, and their voices in the process. This closely relates to the importance of 'being given a chance', earlier described in our theory of belonging in the development of the *Obuntu bulamu* intervention (Bannink et al., 2020; Bannink Mbazzi et al., 2020).

The children's oral, drawn, photographic, and film narratives showed how *Obuntu bulamu* makes it inherently impossible to produce individual voices: rather, *Obuntu bulamu* considers the forces producing voice in a complex web of interdependent relationships. This follows Mazzei's (2016, p. 153) suggestion to think of distributed voices and 'look at voice as a process of connections [...] and the forces at work producing voice as an entanglement' (Mazzei, 2016).

The process of the film creation is valuable in itself and can, together with the outputs and related challenges on participatory dissemination in the Global North, incite critical discussions on disability, childhood, ethnocentrism and post colonialism in the Global South.

Interaction between different subjects in creating the 'research outcome' was a chaotic, and complex process, influenced by colonial paradigms, the historicity of society, and power relations (Grech, 2011; Meekosha, 2011; Owusu-Ansah & Mji, 2013). When conducting 'participatory research' there is a need to reflect on these factors critically and accept that methods, including film, have an element of ethnocentrism (Ogunyemi, 2014; Owusu-Ansah & Mji, 2013), and power dynamics must carefully be navigated (Kuper et al., 2021).

This study shows, together with a few others (Benjamin-Thomas et al., 2019; Chappell et al., 2014; Walton, 2011; Wickenden & Kembhavi-Tam, 2014), that involving children with disabilities in co-creative participatory research using visual narratives in the Global South is feasible and indeed, required – even if complicated due to ethical considerations and power relations - if we want to develop more in-depth knowledge of childhood disability in the Global South.

## Acknowledgements

We express our gratitude to James, Josephine, Mercy, their parents, teachers, and peers for their active participation in creating the film narratives and documentary. Our sincere thanks extend to all the children, parents, and teachers who contributed to the *Obuntu bulamu* project. Special appreciation goes to Kitsha and his film crew, without whom the documentary would not have achieved its professional and compelling quality. We would also like to acknowledge the *Obuntu bulamu* study team of the MRC/UVRI & LSHTM Uganda Research Unit: Jane Nansamba, Esther Nassanga, Claire Nimusiima, and Harriet Nambejja for their dedication and support, and our partners Dr Patrick Ojok from Kyambogo University, Mr Bongole Wamala from the Wakiso District Education Office, and Dr Pamela Nizeyimana and her colleagues of the Special Needs and Inclusive Education department from the Ministry of Education and Sports for their inputs. Our gratitude extends

to Prof. Geert van Hove, Prof. Elisabeth de Schauwer, and Dr. Annelies Verdoolaege from Ghent University for their guidance and encouragement throughout the project and in the dissemination of the documentary at the Ghent Africa Film Festival.

## Funding

The Obuntu bulamu project (2017-2024) received funding from various sources, including the Flemish Interuniversity Council – University Cooperation for Development (VLIR-UOS) (Grant UG2018SIN235A103), the International Federation for Spina Bifida and Hydrocephalus, FIRAH (Grant Number AP2019\_029), Ghent University's Global Minds VLIR-UOS capacity-building and sensitization grants, Child-Help International, and Atlas Alliance (Grant Number GLO-3728 QZA-19/0256). The Principal Investigator's salary was supported by a post-doc fellowship from the Research Foundation – Flanders (FWO) (Grant 12V7120N). The funders were not involved in the study design, data analysis, or manuscript preparation. Disclaimer: The content of this article is solely the responsibility of the authors and does not necessarily represent the official views of the funders.

Submitted: February 04, 2024 EST, Accepted: May 17, 2024 EST



This is an open-access article distributed under the terms of the Creative Commons Attribution 4.0 International License (CCBY-4.0). View this license's legal deed at http://creativecommons.org/licenses/by/4.0/legalcode for more information.

## References

- Bannink, F., Nalugya, R., & van Hove, G. (2020). 'They Give Him a Chance'- Parents' Perspectives on Disability and Inclusive Primary Education in Uganda. *International Journal of Disability*, *Development and Education*, 67(4), 357–375. <u>https://doi.org/10.1080/1034912X.2019.1593326</u>
- Bannink Mbazzi, F. (2023). Translating the Ubuntu philosophy into practical disability inclusive interventions: The Obuntu bulamu experience from Uganda. In *Ubuntu Philosophy and Disabilities in Sub-Saharan Africa* (pp. 148–162). Routledge. <u>https://doi.org/10.4324/</u> <u>9781003343684</u>
- Bannink Mbazzi, F., Nalugya, R., Kawesa, E., Nambejja, H., Nizeyimana, P., Ojok, P., Van Hove, G., & Seeley, J. (2020). 'Obuntu Bulamu'–Development and Testing of an Indigenous Intervention for Disability Inclusion in Uganda. *Scandinavian Journal of Disability Research*, 22(1), 403–416. <u>https://doi.org/10.16993/sjdr.697</u>
- Benjamin-Thomas, T. E., Laliberte Rudman, D., Gunaseelan, J., Abraham, V. J., Cameron, D., McGrath, C., & Vinoth Kumar, S. P. (2019). A participatory filmmaking process with children with disabilities in rural India: Working towards inclusive research. *Methodological Innovations*, 12(3), 2059799119890795. <u>https://doi.org/10.1177/2059799119890795</u>
- Berghs, M. (2017). Practices and discourses of ubuntu: Implications for an African model of disability? *African Journal of Disability (Online)*, 6, 1–8. <u>https://doi.org/10.4102/ajod.v6.292</u>
- Bernays, S., Seeley, J., Rhodes, T., & Mupambireyi, Z. (2015). What am I 'living'with? Growing up with HIV in Uganda and Zimbabwe. *Sociology of Health & Illness*, *37*(2), 270–283. <u>https://doi.org/10.1111/1467-9566.12189</u>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <u>https://doi.org/10.1191/1478088706qp0630a</u>
- Chappell, P., Rule, P., Dlamini, M., & Nkala, N. (2014). Troubling power dynamics: Youth with disabilities as co-researchers in sexuality research in South Africa. *Childhood*, *21*(3), 385–399. https://doi.org/10.1177/0907568214525427
- Chataika, T., & McKenzie, J. A. (2013). Considerations of an African Childhood Disability Studies. In T. a. K. R.-C. Curran (Ed.), *Disabled Children's Childhood Studies: Critical Approaches in a Global Context* (pp. 152–163). Palgrave. <u>https://doi.org/10.1057/9781137008220.0019</u>
- Curran, T., & Runswick-Cole, K. (2014). Disabled children's childhood studies: a distinct approach? *Disability & Society*, *29*(10), 1617–1630. <u>https://doi.org/10.1080/</u>09687599.2014.966187
- Eisen, I., Cunningham, B. J., & Campbell, W. (2019). Conducting participatory photography with children with disabilities: a literature review. *Disability and Rehabilitation*, 41(16), 1943–1954. https://doi.org/10.1080/09638288.2018.1457089
- Goodley, D. (2013). Dis/entangling critical disability studies. *Disability & Society*, 28(5), 631–644. https://doi.org/10.1080/09687599.2012.717884
- Grech, S. (2011). Recolonising debates or perpetuated coloniality? Decentring the spaces of disability, development and community in the global South. *International Journal of Inclusive Education*, *15*(1), 87–100. <u>https://doi.org/10.1080/13603116.2010.496198</u>
- Gubrium, A., Harper, K., & Otañez, M. (2015). *Participatory visual and digital research in action*. Routledge. <u>https://doi.org/10.4324/9781315422978</u>
- James, A., & Christensen, P. M. (2008). Research with children: Perspectives and practices (2 ed.). Routledge. <u>https://doi.org/10.4324/9780203964576</u>

- Karlström, M. (1996). Imagining democracy: political culture and democratisation in Buganda. *Africa*, *66*(4), 485–505. <u>https://doi.org/10.2307/1160933</u>
- Kuper, H., Hameed, S., Reichenberger, V., Scherer, N., Wilbur, J., Zuurmond, M., Mactaggart, I., Bright, T., & Shakespeare, T. (2021). Participatory research in disability in low-and middleincome countries: what have we learnt and what should we do? *Scandinavian Journal of Disability Research*, 23(1), 328–337. <u>https://doi.org/10.16993/sjdr.814</u>
- Kuper, H., Monteath-van Dok, A., Wing, K., Danquah, L., Evans, J., Zuurmond, M., & Gallinetti, J. (2014). The impact of disability on the lives of children; cross-sectional data including 8,900 children with disabilities and 898,834 children without disabilities across 30 countries. *PLoS One*, *9*(9), e107300. <u>https://doi.org/10.1371/journal.pone.0107300</u>
- Lorenz, L. S., & Kolb, B. (2009). Involving the public through participatory visual research methods. *Health Expectations*, *12*(3), 262–274. <u>https://doi.org/10.1111/j.1369-7625.2009.00560.x</u>
- 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
- Mazzei, L. A. (2016). Voice Without a Subject. *Cultural Studies* ↔ *Critical Methodologies*, *16*(2), 151–161. <u>https://doi.org/10.1177/1532708616636893</u>
- Meekosha, H. (2011). Decolonising disability: thinking and acting globally. *Disability & Society*, 26(6), 667–682. <u>https://doi.org/10.1080/09687599.2011.602860</u>
- Mkabela, Q. (2005). Using the Afrocentric method in researching indigenous African culture. *The Qualitative Report*, *10*(1), 178–189. <u>https://doi.org/10.46743/2160-3715/2005.1864</u>
- Ogunyemi, O. (2014). The impact of ethnocentric news values on the framing of Africa: A case study of African diasporic press in the United Kingdom. *Ecquid Novi: African Journalism Studies*, 35(1), 9–24. <u>https://doi.org/10.1080/02560054.2014.886658</u>
- Otiso, K. M. (2006). *Culture and customs of Uganda*. Greenwood Publishing Group. <u>https://doi.org/10.5040/9798400636028</u>
- Owusu-Ansah, F., & Mji, G. (2013). African indigenous knowledge and research. *African Journal* of *Disability*, *2*(1), 30. <u>https://doi.org/10.4102/ajod.v2i1.30</u>
- Punch, S. (2002). Research with children: the same or different from research with adults? *Childhood*, 9(3), 321–341. <u>https://doi.org/10.1177/0907568202009003045</u>
- Richards, S., & Clark, J. (2018). Research with Disabled Children: Tracing the Past, Present and Future. In *Dis/abled Childhoods?* (pp. 187–209). Springer. <u>https://doi.org/10.1007/978-3-319-65175-0\_10</u>
- Schlebusch, L., Huus, K., Samuels, A., Granlund, M., & Dada, S. (2020). Participation of young people with disabilities and/or chronic conditions in low- and middle-income countries: a scoping review. *Developmental Medicine & Child Neurology*, 62(11), 1259–1265. <u>https://doi.org/ 10.1111/dmcn.14609</u>
- Stafford, L. (2017). 'What about my voice': emancipating the voices of children with disabilities through participant-centred methods. *Children's Geographies*, *15*(5), 600–613. <u>https://doi.org/10.1080/14733285.2017.1295134</u>
- Uganda National Council of Science and Technology. (2014). *Human Subjects Protection Guidelines*. UNCST. <u>https://www.uncst.go.ug/manage/files/downloads/</u> Human%20Subjects%20Protection%20Guidelines%20July%202014(1).pdf

- Uganda National Council of Science and Technology. (2022). *National Guidelines for Community Engagement in Research*. UNCST. <u>https://www.uncst.go.ug/manage/files/downloads/</u> <u>GUIDELINES%20FOR%20COMMUNITY%20ENGAGEMENT%20AS%20AT%209TH%20F</u> <u>EBRUARY%202022%20(3).pdf</u>
- United Nations Children's Fund. (2022). *Disability Inclusion Policy and Strategy (DIPAS)* 2022–2030. <u>https://www.unicef.org/media/134511/file/</u> <u>An%20inclusive%20world,%20starts%20with%20me,%20with%20you,%20with%20all%20of%20us</u> <u>.pdf</u>
- United Nations Educational Scientific and Cultural Organization. (2021). *Inclusion in education*. UNESCO. <u>https://www.unesco.org/en/inclusion-education</u>
- Vandecasteele, M., De Schauwer, E., Blockmans, I., & Van Hove, G. (2019). Research through a Camera Lens: A Rhizomatic Search for Lode's Code. *Critical Arts*, *33*(1), 30–43. <u>https://doi.org/10.1080/02560046.2019.1627473</u>
- Vandenbussche, H., De Schauwer, E., Vermeulen, E., Van de Putte, I., & Van Hove, G. (2020). Missing voices: a documentary practice about parents' and children's perspectives in inclusive education. In *Theory as resistance* (Vol. 3, pp. 82–100). Myers Education Press. <u>https:// biblio.ugent.be/publication/8712228</u>
- Vindevogel, S., Ager, A., Schiltz, J., Broekaert, E., & Derluyn, I. (2015). Toward a culturally sensitive conceptualization of resilience: Participatory research with war-affected communities in northern Uganda. *Transcultural Psychiatry*, 52(3), 396–416. <u>https://doi.org/10.1177/ 1363461514565852</u>
- Walton, E. (2011). "They discluded me": possibilities and limitations of children's participation in inclusion research in South Africa. *Perspectives in Education*, 29(1), 83–92. <u>https://doi.org/ 10.10520/EJC87605</u>
- Wickenden, M., & Kembhavi-Tam, G. (2014). Ask us too! Doing participatory research with disabled children in the global south. *Childhood*, 21(3), 400–417. <u>https://doi.org/10.1177/090756821452542</u>
- Witter, S., & Bukokhe, J. (2004). Children's perceptions of poverty, participation, and local governance in Uganda. *Development in Practice*, *14*(5), 645–659. <u>https://doi.org/10.1080/0961452042000239797</u>

## Appendix I Film narrative descriptions

## Short film 1 - Mercy

Mercy is 12 years old. When she was born, she got an infection and her head started to enlarge. Her mother had difficulties finding appropriate healthcare services to treat Mercy at the time, community members attributed her illness to witchcraft. Mercy's father left her mother when he noticed she had a disability. Mercy's mother received support from her mother, who encouraged her to show Mercy to the world. She eventually remarried, after establishing that her new husband would accept Mercy. Now Mercy goes to school and helps her mother in the market. She has friends she moves with to school and participates in the classroom activities, even if at times these are hard for her to understand. Her mother explains that if given time and repeated training, Mercy can learn and acquire new skills. Mercy feels cared for and loved by her mother, when she grows up, she would like to build her mother a house to make her happy.

## Short film 2 – Josephine

Josephine is 8 years old. She lives with her mother and siblings in Kampala. She loves playing and dancing. She uses crutches to move around and catheters to manage her bladder due to incontinence. Her mother explains she is a very happy and curious girl who is eager to try out anything that comes her way. She has a group of friends who play with her and support her when needed. When Josephine was young, others discouraged her mother from taking care of her, they said she would not grow, and she was wasting her time. Josephine's mother proved them wrong. She takes her to church, where she participates like others and argues with her teachers to include her in school. She explains the need for accessible toilets and the understanding and patience of teachers. Josephine's mother does worry that Josephine does not know her father and she is unable to provide Josephine with all that she needs. In the film, we see the 2 roomed house Josephine lives in with her mother and her siblings. Josephine's mother has dreams for Josephine: she would like her to become a doctor so that she can help other children with disabilities.

## Short film 3 - James

James is 13 years old. He is in his 5<sup>th</sup> year of primary school and lives in a semi-urban area outside Kampala. James is unable to walk due to a defect in his spine, he uses a wheelchair to move around. James' father and mother have always looked after him very well. James' father has said that he chose to love James because the doctors explained his disability. He explained that of all his children, James is special. He is able to learn, wash his clothes, and look after his younger siblings. James' mother explained that the counselling and training given to the family at the hospital was important. She said this comforted her and made her patient. James loves his mother more than anything else in the world. He thinks that other children like him deserve to go to school and that children can get used to people with disabilities if they would see more of them. He explained that they sometimes abuse children like him, or think he is not able, not out of hate but out of ignorance: "I would like to tell those who look down on us that we are not bad children, and we ask of them to love us like we love them too, so that it is easy for them to live with us". James' best friend is Abdul, they support each other in school and share everything. James always makes Abdul laugh. James' mother would like him to become a computer expert. His father advises all parents and teachers to take care of children with disabilities and to love them. James' teachers make sure he can access his classroom and sit close to the blackboard. They gave him turns to participate in classroom activities just like other children in his class and encouraged him to participate in school prefect elections. Although some children were unsupportive at first, James was elected by others. He spoke about disability and inclusive education in a school assembly. This helped other students and teachers to become more involved and supportive towards the education of children with disabilities.

### Documentary

The documentary gives a description of the Obuntu bulamu intervention and provides information about children with disabilities and inclusive education in Uganda. The film provides an account of the complexity of cultural beliefs and attitudes of community members towards young children with different disabilities, as well as the change that can occur over time when the child continues to grow with dedicated support, mostly from mothers. It shows the importance of peer-to-peer support and community for parents of children with disabilities and provides an explanation of how parent groups have been able to change attitudes and behaviour over time. While the narrative in the film acknowledges the challenges of raising a child with a disability with limited resources and support, there are also suggestions on how to make schools and communities more inclusive of children with disabilities. The visuals in the film show various situations of inaccessibility, exclusion of play and limited adaptations in learning, but also bring out the potential of peer support for children, parents, and teachers to explore belonging and togetherness. The documentary shows a glimpse of the film making process and gives voice to children, parents, teachers, and community members.