

## RESEARCH

# 'Ubuntu Bulamu' – Development and Testing of an Indigenous Intervention for Disability Inclusion in Uganda

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There is need to learn from indigenous knowledge and concepts when studying disability and inclusion in resource-constrained settings.

We describe the development and testing of the 'Ubuntu bulamu' intervention, a peer-to-peer support disability inclusion intervention, starting from indigenous interpretations of belonging and humanity. 'Ubuntu bulamu' is an accepted and consistent behaviour that signifies a shared set of values that promote well-being, togetherness, and unity.

The intervention was co-created and tested by a team of children, parents, teachers, disability rehabilitation workers, and academics in Uganda. It consists of training sessions, peer support meetings, and activities for children, parents, and teachers around the themes 'peer support', 'disability', and 'belonging'. Through qualitative participatory methods the feasibility and acceptability of the intervention was evaluated with 64 children, 64 parents, and 33 teachers in 10 communities in Wakiso district, Central Uganda.

**Keywords:** disability; inclusion; Global South; children; Ubuntu; community

## Introduction

### *Disability studies in the Global South*

Disability studies have been dominated by scholars from the Global North and predominantly use the disability language of 'international' normative frameworks such as the Convention of the Rights for Persons with Disabilities (CRPD) (UN 2006), and the Sustainable Development Goals (SDG) (UN 2015). Existing theoretical frameworks and interventions for persons with disabilities in the Global South are based mostly on these 'international' conventions and funded and implemented by private not-for-profit agencies (Alliansen 2017; AusAID 2015; DFID 2013; GIZ 2014; USAID 2017). Several frameworks include reference to the vicious cycle of poverty and disability, as well as stigma, and include persons with disabilities as one of the 'most vulnerable' groups in poverty alleviation in need of 'empowering' interventions (Baffoe 2013; Banks et al. 2017; Filmer 2008; Goffman 1963; Hoogeveen 2005; Loeb et al. 2008; Palmer 2011; Susman 1994; Wang 1992). The interventions often start from a theoretical framework of human rights, stigma, exclusion, and discrimination and aim to improve the medical, rehabilitative, and socio-economic situation of persons with disabilities. Whilst there is a general consensus that these conventions are designed to benefit persons with disabilities, several researchers have questioned whether theoretical disability models are transferrable across cultures (Grech 2011; Haang'andu 2018; Meekosha 2011; Miles 2003a; Soldatic & Grech 2014).

Scholars from the Global South are often employed as consultants for organisations from the Global North and write evaluations, based on international standards set by the funding agencies, which do not necessarily reflect their personal beliefs or theoretical frameworks. They are unlikely to question or criticize the funders (Katsui & Kumpuvuori 2008). Yet, without questioning the dominance of theories and power from the Global North in the disability field, generalized and simplified descriptions of disability experiences are created (Grech 2011; Haang'andu 2018; Ingstad 1999; Meekosha 2011; Whyte 1995). An example is the assumption of 'backward' socialization in 'developing' countries by persons in the Global North in which it is assumed that African societies hide, kill, stigmatize, and neglect all persons with disabilities (Grech 2011). These assumptions feed the charity model of disability and silence alternative critical frameworks.

Various authors have stated that there is a need to learn from indigenous frameworks and take into account local contexts, cultures, and economic and political factors when studying disability and inclusion in the Global South (Grech 2016; Phasha 2017; Seligman & Darling 2009; Whyte 1995). Meekosha (2011) has argued that there should be recognition of the cultural and political dominance of the North and called for participation in the intellectual decolonisation of the discourse about disability (Meekosha 2011). Phasha et al. (2017) emphasize the need to acknowledge social difference, identity, power, and culture when studying inclusion and inclusive schooling, and to look at difference as a strength. They argue that there is a need to look at the example of African indigenous education, which is about inclusion and embracing cultural knowledge.

In this paper we describe our attempt to offer an alternative disability discourse starting from the central Ugandan concept 'Ubuntu bulamu'. We describe the development and testing of the 'Ubuntu bulamu' intervention based on and named after this indigenous concept.

### **'Ubuntu bulamu' – The conceptual framework**

African scholars have suggested looking at family, poverty, cultural conceptions of disability, and the notion of *ubuntu* ('I am because we are') as an alternative disability discourse (Berghs 2017; Chataika & McKenzie 2013; Oppenheim 2012). 'Ubuntu bulamu' is a concept closely related to the South African Ubuntu philosophy ('humanity to others') which has been embraced, and also carefully criticised, as African humanism (Chataika & McKenzie 2013; Hailey 2008; Matolino & Kwindigwi 2013; Mugumbate & Nyanguru 2013).

An African model of disability that encapsulates *ubuntu* is closely related to disability activism, decolonisation, violence, and oppression (Berghs et al. 2019; Mji et al. 2011; Opini 2016). Berghs emphasizes the effect education, employment, corruption, violence, and poverty have on disability activism. She stresses that when using *ubuntu* as a model 'we can ask why the social responsibilities of ethical actions are enabled or disabled individually, socially, by the state or structurally' (Berghs 2019: 6).

The overall meaning of *ubuntu* as humanness is found in various East and southern African countries; each language has its own specific version and meaning of the concept. In South Africa and other southern African countries *ubuntu* is called upon as a unifying vision of how to behave and respond to others (Hailey 2008). In central and western Uganda and northern Tanzania 'Ubuntu (bulamu)' refers to the human characteristics of generosity, consideration, and humaneness towards others in the community (Hailey 2008). In Uganda 'Ubuntu bulamu' is described as an accepted and consistent behaviour that signifies a shared set of values that promote well-being, togetherness, and unity (Karlström 1996; Otiso 2006).

In an earlier article we described the concepts 'missing parts', 'the ability to manage', belonging, and 'being given a chance' as key concepts in disability inclusion for children (and adults) with disabilities in Uganda, and proposed the 'Ubuntu bulamu' framework with belonging at its core to give a more culturally embedded and relevant starting point for disability inclusion interventions (Bannink et al. 2019). We proposed this framework because inclusion of children with disabilities in communities, especially schools, is still lacking in Uganda despite the implementation of various (imported) inclusion programs and policies (DANIDA 2005; Ministry of Education and Sports 2019; UNICEF 2014). One of the imported methods from the Global North was the introduction of learner- or child-centered pedagogy in the early 2000s, which was initially received with enthusiasm but not implemented despite the provision of teachers training (Altinyelken 2010). This method was viewed as contradicting communal cultural values (Altinyelken 2010; Bannink et al. 2019) and did not match with the focus of annual school examinations, so a lack of implementation followed.

The 'Ubuntu bulamu' framework starts with recognition and belonging. The emphasis is upon the importance of belonging (the attachment to people and places in a person's life) before being (who the person is) and becoming (things the person does through life) can take place (Bannink et al. 2019; Brown 2003; Woodill et al. 1994).

Belonging in this framework is closely tied to recognition of the child by his or her family and community, whilst being is about interdependency between the child, family, school, and community members enabling the child to 'become' (Bannink 2017). Belonging to a family and clan has social and financial implications for the mother of the child and the support the child receives (Roscoe 1965). For example, in the patrilineal system among the Baganda in central Uganda, the father's clan is expected to give the child a clan name. Once the child is given that name, the father's family must 'provide' food, shelter, and school fees. If the father does not recognize the child, these 'provisions' mentioned above are not made, and the mother must fend for the child herself (Bannink 2017). Being is closely attached to one's role and the mutual obligations in the family and community (Asiimwe, 2002). In East Africa the decision to regard a child as disabled is often related to the child's ability to carry out age-appropriate chores and tasks (Mutua & Swadener 2011; Bannink et al. 2019). The emphasis on 'being able to manage' – including the ability to carry out chores and tasks and participate in social events – has a deeper meaning than participation and is again linked to being 'because we are'. For example, a child who has hearing difficulties is considered 'disabled' as (s)he has a 'missing part' (the ears 'do not work'), and the child can carry out some age-appropriate chores and tasks but not all, as a number of these tasks in the community involve verbal communication. Despite being unable to carry out an age-appropriate task using verbal communication, the child can still be given 'a chance'. This 'chance' suggests a sense of reciprocity and duty, to all present at home, at school, and in communities, valuing mutual obligations between family members and community

members to include children with disabilities (Bannink et al. 2019). In this article we describe the development and testing of an intervention based on the 'Ubuntu bulamu' framework.

### **Children's voices**

Participatory methodologies that include children in the research process have emerged over the past decades (Goodley 2013; James & Christensen 2000; Richards & Clark 2018). Researchers have argued for a combination of traditional research methods used with adults – such as participant observation and (activity-based) interviews, and techniques considered to be more suitable for use with children (e.g., drawing, photographs, co-narration, and activity worksheets) (Eisen et al. 2019; Punch 2002; Stafford 2017) – and to re-think the use of the narrative approach with children with intellectual disabilities (Flynn 2019; Stafford 2017).

Whilst progress has been made in including children's narratives in research both in the Global North and 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) narratives of children with disabilities in the Global South remain absent in most disability literature (Curran & Runswick-Cole 2014). Studies with families with children with disabilities have mostly given voice to parents. The narratives portrayed have often emphasized deficits and linear narratives and explanations (Goodley 2007; Traustadóttir 2006). Some authors have explored alternative parental and child narratives (De Schauwer et al. 2009; Fisher & Goodley 2007; Mortier et al. 2011). Others have developed measures specific to children with disabilities to understand their health-related quality of life (Baars et al. 2005). In sub-Saharan Africa, disability studies have largely focused on adults with disabilities and caregivers of children with disabilities; these studies have primarily been conducted in South Africa (e.g., Coomer 2013; Greeff & Nolting 2013; Greeff, Vansteenwegen & Gillard 2012).

To deconstruct static meanings of families with family members with disabilities, Mazzei (2016) suggests shifting thinking from distributed voices to look at voice as a process of connections, and 'the forces at work producing voice as an entanglement' (Mazzei 2016: 153). This closely links to the 'Ubuntu bulamu' framework which inherently complicates the production of individual voices but considers the forces producing voice within a complex web of interdependent relationships.

In our work, in the development and testing of the 'Ubuntu bulamu' intervention, we aimed to give voice to unheard processes, forces, and families' and children's voices using artistic and academic research processes. Disability researchers have explored integration of artistic processes and academic research to narrate adult and children's experiences in childhood and disability studies without focusing on individual voices (Van Hove et al. 2015; Vandecasteele 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 film has been used as a research (dissemination) method; for example, in a study on enhancing support for young carers and families affected by HIV in Uganda and Tanzania, Evans (2016) used video performances of children to communicate research findings to communities, local leaders and non-governmental organisations, and students in the United Kingdom. In the development and testing of the 'Ubuntu bulamu' intervention, children and families used visual and oral narratives to describe their world and used these to challenge stereotypical views of disability in and outside Uganda.

### **'Methodology' – The 'Ubuntu bulamu' peer-to-peer support intervention**

The main objective of this study was to co-create a culturally appropriate intervention for disability inclusion based on the 'Ubuntu bulamu' framework and test this intervention in 10 communities in Uganda.

The intervention was developed by a research team consisting of Ugandan representatives of families with children with disabilities, adults with disabilities, children with disabilities, parents' support groups, rehabilitation workers, policy makers, and Ugandan(-based) academics. It started out as a group of persons who had met each other at different disability-related research and development cooperation events over the past 10 years. They had been involved in other disability inclusion interventions, mostly interventions adapted from the Global North, and felt that these did not sufficiently address disability and inclusion in accordance with Ugandan culture and the education system (e.g., only 9% of children with disabilities in Uganda go to school [UNICEF 2014] despite years of investment in special needs education and inclusion by international agencies [DANIDA 2005; Government of Uganda 2019]). The group met at least every quarter over a period of three years during the development and testing of the intervention (2017–2019). The team members also held smaller group consultations with different sets of team members to provide inputs on developed intervention drafts during the process. The development process is documented with inputs from all team members and described below.

The intervention was tested in 10 communities in Wakiso district in Central Uganda. We purposely selected children aged 8 to 14 years with different impairments, with different levels of household income and familial support, and who were enrolled in primary schools in the 10 communities with on average three children with disabilities per community. Participants were selected by the research team in collaboration with parents' and district education office representatives.

Ethical approval for this study was obtained from the Uganda Virus Research Institute, Research Ethics Committee (GC/127/18/02/633). All adults 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 who could not assent to participate by themselves. Research clearance was received from Uganda National Council for Science and Technology (HS SS4557).

To test and evaluate the use of different data collection methods, we piloted both culturally adapted 'international standards and tools' (also described as Adaptive Evaluation Approach by Carden & Alkin 2012 and Chilisa et al. 2016), as well as more qualitative and 'Afrocentric' methods (Mkabela 2005). To provide sufficient indicator data for the 'international framework' and funder we evaluated whether the intervention improved 'participation', 'inclusion', and 'quality of life', as measured by culturally adapted and translated versions of the Child and Adolescent Scale of Participation (adapted from Bedell 2009), the Index of Inclusion (adapted from Booth 2002), and the KIDSCREEN-10 quality of life scale (adapted from Ravens-Sieberer 2010).

In this paper we describe the development and testing of the intervention using qualitative and 'Afrocentric' data collection to understand if the 'Ubuntu bulamu' intervention has the potential to offer a culturally relevant alternative to imported disability inclusion interventions.

Baseline, midline, and endline interview and focus group discussion data were collected from 64 parents and 33 teachers who participated in the testing of the intervention. Interview and focus group discussions focused on the perception and evaluation of the intervention. Observational data from the home and school setting, as well as visual narrative data, including drawings and photo narratives, were collected with the 32 children with different disabilities and 32 peers. Two 'participatory action research meetings' with all participants to co-create, test, and evaluate the 'Ubuntu bulamu' intervention were held.

The research team consisted of community members, participants, researchers, and decision makers. Team members tried to collect data consistent with the value of 'Ubuntu bulamu', emphasizing oneness. Rather than keeping a scientific distance, the research team immersed themselves culturally and socially with the children, parents, and teachers who were part of the project, something which has previously been described as Africentrism by Mkabela (2005) and Owusu and Mji (2013). For some team members this came naturally, others – especially the academics in the team – struggled with closing the gap in power relations between the 'researcher' and 'the researched' as they were often seen as more knowledgeable by participants and were sometimes expected to provide information on 'how things should be done'. We attempted to minimize this distance by ensuring that most data collection was conducted by persons from the research team who participants felt closer to, in terms of educational and social background (including masters' students with disabilities and parents of children with disabilities). The team members frequently met with participants at home, in community meetings, and were in touch with each other on the phone. Some research team members were already or became part of the peer support group that the 'Ubuntu bulamu' intervention promotes and are still in touch with the participants.

Data from the development and testing phases were reviewed following a thematic approach using framework analysis, a matrix-based system for organizing, reducing, and synthesizing data (Ritchie et al. 2013). A codebook was developed by three study team members and imported into NVivo 12. The thematically organized data were reviewed and synthesized. Meaningful themes and quotes were selected to highlight, explain or describe relevant themes. Identified themes were discussed and checked with the participants in follow up meetings.

## **Findings**

### **Developing the 'Ubuntu bulamu' peer-to-peer support intervention**

The research team members had a shared interest in developing and testing an intervention for inclusion based on the 'Ubuntu bulamu' framework (Bannink et al. 2019). This was something that could start from within Uganda and was – only to a limited extent – influenced by research priorities set in the Global North. In the development of the intervention, the research team members considered the 'Ubuntu bulamu' framework by sharing and collectively owning the opportunities, responsibilities and challenges as much as possible. Whilst we faced some challenges in holding on to this principle during the development of the content of the intervention, as team members tended to focus on 'their area of specialty' (e.g., teaching methods, parental wellbeing, and child development), often influenced by the postcolonial education they had had, we were able to collectively agree on the intervention as it was drafted. The inputs of children were especially important in linking the different 'areas' to each other, as they had not (yet) been exposed to the same structures and categories as the adult members of the team were prone to think in.

The team agreed that the 'Ubuntu bulamu' framework is a relevant and culturally appropriate framework promoting support for each other, togetherness and unity, and 'good' or 'inclusive' behaviour in the central region, and felt that children and adults need to be supported to promote this behaviour and help community members remember children with disabilities equally belong to and can participate in their communities. This support according to children and adults in the team could best be given by a 'peer' or 'friend' who had more knowledge of resources or ideas for activities children and adults could employ to feel more supported at school or home.

Whilst parents and teachers suggested matching the children with disabilities with a peer who was a 'good performer', children suggested that older siblings or any peer in class that was friendly to them could support them, in addition to their teachers and parents. Parents also explained that siblings were helpful peers at home and school and should be included in the peer support model.

Furthermore, in the development of the intervention, parents felt they would benefit from support from 'focal' or 'peer' parents in their community. These peers could give them information and training, but also just be there to listen to them and support them emotionally. Ideally these peers would be part of the community to help them raise awareness and address other issues linked to disability, such as poverty and sometimes marital issues. Most parents felt they required more support from their children's teachers to ensure inclusion in school, which they described as 'being given a chance to participate'.

Teachers, on the other hand, felt they required more knowledge and skills to be able to include children with disabilities in school and requested for practical 'in-school training' and support from experts as well as support from their head teachers. In developing the intervention, teachers also requested more tools and materials to use in class.

There was no clear number of 'support' people set by participants, but the idea of having at least one peer for the child, one for the parent, one for the teacher, and then group support meetings, was suggested as a 'minimum' support group. This group would then link to other relevant persons and organisations in their communities.

The assumption underpinning the intervention is that in 'Ubuntu bulamu' everyone has a responsibility in caring for the other, and that all are interlinked. We found that the participants did not think that 'peer-to-peer' support consisted of dyadic support between two persons but felt that the various linkages created a small group of people around the child who would advocate for and show that the child indeed belongs in their community. This shared 'behaviour' would make the child belong and 'be given a chance'.

Another factor that spoke to the development phase was the absence of in-country funding for the development and testing of the intervention. Whilst most members were happy to volunteer their time in the developmental phase, funds were required to obtain ethical approval for the study, travel to the communities, compensate for study participants' transport and time, and eventually pay a percentage of team members' salaries as they mostly depend on grants for their income during the testing phase.

Without compromising the initial plan to implement an indigenous intervention, the research team approached an international funder who has been keen on funding Ugandan-led parent groups for families with children with disabilities and had shown an interest in critical disability studies. To access the funds, the team attempted to creatively merge the original idea with concepts of other peer-to-peer support approaches linked to international accessibility and Community-Based Inclusive Development (CBID) standards. Benefiting from the previous grant-writing experience of some team members for funders in the Global North, we were able to fit our idea in the standard objectives and indicators of the funder and were awarded a grant. This was later supplemented by another grant from a funder in the Global North that specifically had capacity building of local research institutes on its agenda. In order not to reduce our original intervention to imported terms and methods, we made clear distinctions between the reporting language we were required to use, and the original language of 'Ubuntu bulamu' and reflected on this at various stages in the project.

#### Testing the 'Ubuntu bulamu' peer-to-peer support intervention

To test the 'Ubuntu bulamu' intervention in school and home settings, the research team explored the use of the peer-to-peer support model in 10 schools and communities in Wakiso district. The district surrounds the capital city Kampala and has a mix of peri-urban and rural communities.

The intervention designed consisted of a two-year peer-to-peer training and support package for children, parents, and teachers. Each participant received three days of training together with their peer.

The themes of the three training sessions were 'peer support', 'disability, and 'belonging'. Each concept was explored at an age and role appropriate level with a group of children, parents, and teachers separately first, and joined together at the end of each training day. Culturally appropriate activities which are part of day-to-day life in Central Uganda were included; storytelling, singing, games for children, and group discussions for adults were part of the training methods. After each training, peer-to-peer support was provided in each community, and day-to-day support needs were identified and addressed within the peer-to-peer child and adult dyads or groups. All meetings were geared towards enhancing belonging and togetherness in children's homes, schools, and communities.

In the testing phase the children's training sessions focused on ways to support each other at home and in class and creating a positive and inclusive environment for all children. The children were also supported in initiatives they would develop further which promoted togetherness in school, such as organizing music performances, drama skits, or talks during assemblies at school or in church.

Parents of the same children received training from focal parents, who were trained by members of the research team (including members with a disability or members with a child with a disability) on providing peer-to-peer support and offering practical support to daily life challenges parents might be facing when looking after a child with a disability. During the training, parents were encouraged to discuss difficulties and come up with solutions to increase belonging in families and communities that would exclude them. During the peer support that was carried out in between the training, parents often tried to solve practical issues. For example, they could jointly go to meet with (head) teachers or would raise awareness about their child's condition and need to belong in different community meetings. Trained peer parents would also teach other parents simple locally appropriate methods to care for children with specific impairment-related needs.

Teachers received training in how to stimulate peer support between children in the classroom, focusing on togetherness and belonging to a class and school community. They also exchanged ideas and methods to support children with disabilities in the classroom during the training, linked to the teaching plans they make within the national curriculum which guides their teaching. Under supervision of two members of the research team (one of whom has a disability), trained peer teachers (one of whom is a parent of a child with a disability) carried out on-the-job training and mentoring for teachers in schools, aimed at including all children in their classroom teaching and diversifying methods using locally available materials and teaching methods.

During the testing phase, funds were allocated for small interventions at home and in school. These were funded and labelled as 'CBID accessibility and rehabilitation' activities in the grant. To refrain from imposing measures from the framework of the Global North, children, parents, and teachers were asked to discuss areas in which they would like to see change in their lives which required infrastructural interventions. Some of the responses included the creation of ramps and provision of assistive devices. However, most children suggested putting more play materials in their school and communities, fixing potholes in roads, and improving the toilets and bathrooms. Parents often made requests for renovations of their home toilets and bathrooms, whilst teachers mostly requested teaching materials.

Implementing and testing the intervention was an interesting mixture and constantly shifting process between the peer-to-peer support as originally planned, influenced by indicators and numbers to show our model had 'worked' according to what had been agreed for the grant. The implementers were influenced by their own educational and family background when relating to participants and stressed different aspects of the model in the training: those with a teaching background focused on learning objectives and lesson plans, social scientists focused on developmental milestones and behaviour change, parents of different backgrounds focused on helping children and families achieve household tasks, creating new business ideas, and community participation and responsibilities. An interesting mix of indigenous interpretations and imported 'systems of inclusion' emerged during the implementation of the 'Ubuntu bulamu' intervention. Some used Luganda proverbs to describe the need to include children with disabilities, such as 'Awali omulema tewafunyirwa lunwe' – meaning 'one should not offend a person with a disability', whilst others referred to religious beliefs, such as 'we need to love all children as they were all created by the same God', or called upon the government to provide the necessary services – 'government should make sure all children can go to school, also those with disabilities'. Some would start 'counting' the number of teachers who would give children with disabilities a turn in class or looked at whether educational performance had improved, whilst others focused on looking at whether the children appeared happy and were engaging with others.

Also in relation to the testing phase, it should be noted that the intervention was not a linear process in which training sessions were followed by school, home, and community activities on the exact training theme, but a process in which co-creation was the norm. The training sessions were informed by the peer support activities and vice versa. The intervention did not consist of a detailed training and implementation manual for facilitators, but rather addressed the broader themes mentioned above in interaction with the participants' daily lives and experiences and co-created a sense of togetherness and peer support.

To ensure fidelity to this not 'predefined' and 'manual-focused' intervention, emphasis was put on activities which enhanced the 'we'. On training and meetings days all children, parents, and teachers were invited in 1 of the 10 project schools to work on the particular training theme of that day. Whilst some sessions were held for the different groups to address different needs and questions, joint sessions were always part of the program to enhance dialogue and further develop action plans as a group. The activity location rotated amongst schools and included (exchange) visits to other schools and joint activities in the communities so that all had a responsibility in and were part of the organisations of the intervention activities.

#### Evaluating the 'Ubuntu bulamu' peer-to-peer support intervention

In this section we describe how participants perceived the intervention, what they felt was useful, and what they think still needs to be changed. The outcomes of the intervention are beyond the scope of this paper and will be described elsewhere.

Parents, teachers, and children described 'Ubuntu bulamu' as an intervention for all which promotes unity and togetherness. Some said 'Ubuntu bulamu' makes children with disabilities and peers become a family. They said that the intervention teaches people to include persons with disabilities as they are inherently 'one of us':

'The project [intervention] has promoted unity and togetherness among children' (mother of a child with a disability).

'The project [intervention] promotes love for each other' (teacher of a child with a disability).

The relationship to others was mentioned as the key element of the 'Ubuntu bulamu' intervention by parents and teachers. Parents emphasized the importance of relatives, neighbors, and community members in their child's daily life and care, and gave examples of how peer support works in their homes:

'Myself, my wife, the sisters, the relatives at home and even the neighbours help her if in case she [the child with a disability] is out of the house and something happens' (father of a child with a disability).

'Other parents support us; when we tell them about our children's conditions they understand them and learn how to love them [...] I work at night, it's my neighbours who help me while I am away' (mother of a child with a disability).

Children with disabilities and their peers described the 'Ubuntu bulamu' intervention as an intervention in which people are kind to each other. They talked about friendships and not bullying children in school and the community through photos and drawings. They also spoke about having teachers who help them and do not beat them. In a number of the photos children described the 'Ubuntu bulamu' intervention as an intervention about friendship, sharing, and working together.

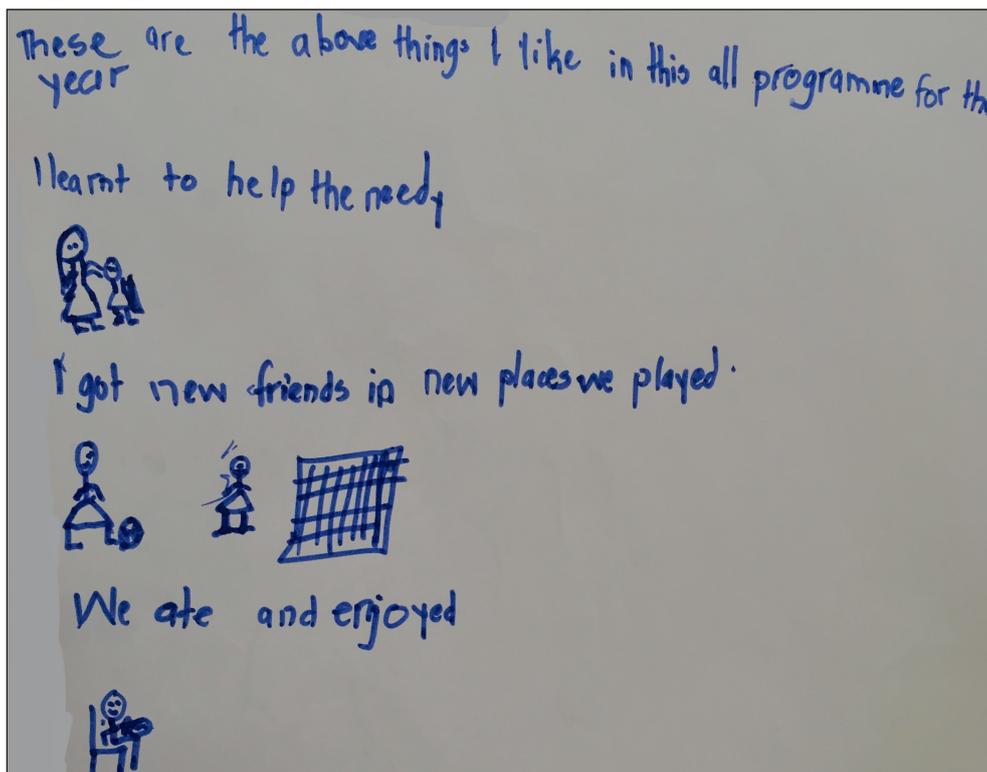
Teachers mostly emphasized that the 'Ubuntu bulamu' intervention stressed the need to love all and give all students a chance and allow them to participate in mainstream education. They often translated 'Ubuntu bulamu' as 'good behavior'.

'We have to include all, even children with disabilities and help them to learn like others' (teacher of a child with a disability).

Participants provided positive feedback on the 'Ubuntu bulamu' intervention activities which were tested. Children with disabilities mostly found the intervention fun, as it involved peers from their schools and communities, which helped initiate and strengthen existing friendships and support. The children with disabilities and their peers felt that inviting them together to the training sessions and planning activities together was very good. They all expressed their enjoyment of the training sessions and follow up activities. **Image 1** shows a drawing of the things one of the children liked about the intervention.

The non-disabled peers particularly enjoyed the games in which they could support their friends and carry out shared tasks. Participating in the data collection methods of storytelling, drawing, and taking photos and videos of their day-to-day life made the children feel they were important and changed the interaction between them and the persons around them.

The child peer-to-peer support was also valued highly by parents and teachers, who felt it was helpful to invite peers to the meetings, as children with disabilities often do not mix with their non-disabled peers. Parents of peers mentioned the inclusion of their children and themselves as parents in all training sessions and activities was the most important aspect of the intervention, as this created relationships between the children and parents.



**Image 1:** Child's drawing of the positive aspects of the 'Ubuntu bulamu' intervention.

'The first time I came for the training I was wondering why I had been invited, I saw children with disabilities and I don't have one. But later I started to get to know the other parents and understood more about disability and moving together' (parent of a peer child).

In one of the feedback meetings, a Commissioner of the Ministry of Education and Sports was invited and observed the interaction between the children, parents, and teachers, and applauded the fact that the intervention did not only look at the school and teacher-child relationships, but also at the parents and community, creating an inclusive environment for all.

Overall, parents and children felt the training was sufficient and follow-up support and activities were tailored to their needs. All appreciated the approach of involving peers and having focal persons to speak to in case of any concerns. The parents appreciated the follow-up by peer parents at home too and explained this helped them share any concerns they might have not been able to share or show the peer during the group training sessions and meetings. It also made them feel closer to the team member as they had come home and might then have a better understanding of their living situation and challenges.

'I am happy you came to visit us, you have seen how we are. Now you know our home, you can come again' (parent of a child with a disability).

On a sad note one father died, and in another family a mother lost a baby during the period in which the intervention was tested. Two members of the team visited the families to pay their respects, which was very much appreciated; this is also part of what 'Obuntu bulamu' means – to care for and look after each other as a community, respecting cultural values.

Parents said the training sessions were very practical and had low-cost solutions on how to care for and parent their children. Training days were mostly held during the school holidays and/or on weekends, which parents appreciated. During some of the training sessions persons with disabilities spoke as peer role models. This was appreciated by parents and teachers:

'We are motivated by people with disabilities who give us trainings and share their life experiences' (teacher of a child with a disability).

Teachers felt that the training sessions had been useful as they were given by Ugandan teachers who were conversant with the education system and able to practically think of solutions to challenges they face in including all students in class. The teachers appreciated that the training sessions were held over the weekend so that these did not interfere with their day-to-day job. All teachers were very appreciative of the peer support in class in the form of on-job mentoring on a termly basis.

'When you come to our school, you can see how we manage, what is easy and what we can still improve. When we work together in the class we can make things better' (teacher of a child with a disability).

Teachers said the support of other teachers in their schools was one of the most important components of the intervention when describing positive aspects. Teachers also appreciated the exchange visits that were held between the schools. The teachers said that they appreciated the involvement of (focal) parents in school to help them to take care of children with disabilities, and they valued the improved relationships with children, parents, and teachers.

'The project has really helped us by bringing focal parents who have been talking to the teachers [...] earlier the teachers didn't know [...] the focal parent [...] can inform the teacher how to approach the child. I really thank the project [intervention] for involving the parents' (head teacher).

Participants mentioned they liked the intervention as it was, they did not recommend to reduce it in size or remove any activity; however, they did recommend paying more attention to poverty reduction. They also recommended taking the intervention to other schools, including secondary schools.

'If given chance I would train parents how to help themselves out of poverty because things are usually hard when you have no money' (parent of a peer).

'If given chance, I would add more schools in the project so that more children with disabilities are helped because they are many' (parent of a child with a disability).

Children emphasized that they would like to see higher enrolment of children with different disabilities in their schools and thought the intervention could try to help enrol more children in their schools.

'I would want that more children with disabilities join the school with other differences or other disorders from mine so that the other children become more aware of other disabilities' (child with a disability).

Parents of children with disabilities and peers, as well as teachers, also requested that the project is rolled out in more communities and involves local leaders more:

'This project has helped us a lot and I am suggesting we also involve our community leaders because every local council has a leader for persons with disabilities. It is important to train these leaders and have them as members in the project' (mother of a child with a disability).

The research team included the feedback received from the participants in the reworking and drafting of the 'Ubuntu bulamu' intervention guidelines. The intervention was presented and well received by the Ugandan Ministry of Education and Sports, and intervention guidelines will be published and used in a four-year study in 20 communities in two districts in Central Uganda, which started in 2020.

## Discussion

In this paper we described the development and testing of the 'Ubuntu bulamu' intervention, which is based on the 'Ubuntu bulamu' alternative disability framework to 'improve disability inclusion'.

The intervention development process was distinctive as it was a co-creative process that emerged over a longer period of time and built on experiences of persons with disabilities, families of children with disabilities, and academics and rehabilitation workers from the Ugandan disability field. It started from the assumption that there are indigenous concepts that can provide alternative frameworks for inclusion in the Global South and was further developed over a period of several years.

We found that participants perceived that the 'Ubuntu bulamu' intervention promotes unity and togetherness and is a culturally acceptable intervention to promote inclusion in communities, and more specifically schools. Participants spoke in a language of kinship using descriptions of 'shared blood', 'brother and sisterhood', when emphasizing peer-to-peer relationships and support. They appreciated this support, and the role each person could play in supporting one another to achieve a more inclusive environment for all.

Poverty and the absence of government support for families with children with disabilities was mentioned by our participants during home visits and training sessions and was emphasized as an area the intervention should include further in the future. Parents and teachers appreciated the peer support, including the low-cost practical solutions that were shared during the intervention. This is in line with Grech's notion of factors which influence disability experiences such as poverty, the absence of a welfare system and dependence on natural resources for livelihoods (Grech 2011).

Berghs raised the question as to whether disability 'needs to be about ensuring greater *ubuntu* in society in a wider sense of diversity than impairment' (2017: 6). Participants in our study described that the intervention created greater *ubuntu* for all children. The focus was on peer-to-peer support, and togetherness. In this process 'disability' or 'impairment' moved to the background. Berghs (2007) follows her question on how to ensure greater *ubuntu* by querying what *ubuntu* and disability entail in urbanized areas. The communities in our study are located within a 40km range of Uganda's capital city and are mostly peri-urban areas. We noticed that while the 'Ubuntu bulamu' intervention was easily embraced and welcomed by participants, it too was something to 'go back to', something of a past in which social structures were more cohesive and supportive perhaps of all. Whilst it may be more complex to re-establish important and rich indigenous concepts such as 'Ubuntu bulamu', it is not unwelcome or impossible to do this in urbanized areas and apply it in the current context. Some customs related to 'Ubuntu bulamu' are still in place and were seen in our study, such as the importance of visiting a person at home to 'know' them more, as well as paying respect in case of a death. We are painfully aware of the negative interpretations or misinterpretations of *ubuntu*, which in the past has led to exclusion of persons with disabilities in different African communities (Ngubane-Mokiwa 2018). Ngubane-Mokiwa (2018), however, highlights a confusion about *ubuntu* and places *ubuntu* in context in which it is possible to renegotiate the meaning and application of *ubuntu* in communities. We believe this same negotiation is needed in 'Ubuntu bulamu'. Rather than seeing this as a static indigenous concept from the past, we believe it is a living concept that is applicable in urban, peri-urban and rural settings in the 21st century.

An interesting experience related to the topic of indigenous methods and globalization was the use of cameras. We faced the ethical dilemma of exposing children to a novel and fairly expensive tool (camera) which was then taken away again (Punch 2002). However, with more parents acquiring smartphones, especially in more urban areas of Uganda, children sometimes had the opportunity to take pictures. It was interesting to note that, whilst they sometimes took photos of themselves, they put greater emphasis on their wish to take group photos together with their friends and family. This supported our idea that the 'we' needs to be emphasized more than the 'I' in interventions in our setting. Using indigenous interventions does not exclude one from using modern technology.

As Kamenopoulou (2018) described in her case study on the meaning of inclusive education in Columbia, funding for research in Global South ethnographic studies to understand disability and inclusion is very limited, yet necessary to make inclusive education a priority in the Global South. She argues that inclusive education as a Global North-created

concept can acquire different meanings in contexts in the Global South. We have attempted to describe some of the difficulties in conducting research on concepts of inclusion in the Global South with funding from the Global North. One needs to fit in pre-established frameworks when writing a grant proposal and report back on standardized indicators. Many of our team members are used to 'bridging the gap between words and realities' as described by Miles (2003b) in his critical paper on the world-wide adoption of the Community-Based Rehabilitation model. This, when approached creatively does not exclude one from thinking critically and developing indigenous frameworks which can inform future projects and funding from the Global North. Miles argued to have 'people with a traditional heritage of concepts [...] delve into their folklore, art and drama, to uncover the positive and the ambivalent views of disability and assistance, and decide which are the authentic and valuable parts on which they will build' (Miles 2003b: 98). His argument is based on historical evidence that documents healing and other therapies, as well as self-organised groups and community practices with persons with disabilities in African countries (Miles 2003a). Many traditional ways of caring for persons with disabilities in communities were destroyed when colonial humanitarian models were introduced (Ingstad 1999; Miles 2003a). In our study we noticed how easily participants accepted and participated in an intervention that was based on an indigenous concept and appreciated how the research team members too became part of their lives, rather than staying as the distant investigator. New alternative Afrocentric approaches in conducting research have been proposed by various African scholars (Chilisa 2012; Mkabela, 2005; Owusu & Mji 2013). Chilisa and Malunga (2012) proposed an ideal community development evaluation framework consisting of five 'interrelated and complementary Ubuntu principles': sharing and collective ownership of opportunities, responsibilities, and challenges; the importance of people over things; participatory decision-making and leadership; loyalty; and reconciliation as a goal for conflict management and resolution. The development and testing process of 'Obuntu bulamu' followed these principles by emphasizing the importance of persons and communities and uniting persons from different backgrounds in the team. Whilst we did not specifically evaluate the intervention based on these principles, we feel they are inherently part of the intervention and the way the team co-created and evaluated the intervention. To show African scholars' attempts at 'decolonizing indigenizing, and envisioning new evaluation tools and practices that push the boundaries of international development theory and practice', Chilisa et al. (2016) developed an African evaluation tree metaphor. In selecting metaphors, cultural expressions of indigenous concepts are key. The 'Obuntu bulamu' framework uses a basket metaphor. Frameworks from the Global North are rarely receptive to alternative metaphors, which may not seem linear or causal enough to fit within results-based diagrams. In our intervention we tried to describe the intervention from an African basket perspective and translated this into a framework from the Global North to ensure compliance with funding requirements. Despite the challenges faced, the team felt it was possible to remain loyal to the original intervention and carefully chose ways to describe these in 'reporting terms' when necessary.

We found that whilst curious and interested in uncovering views of disability and inclusion, many of our team members did not feel comfortable questioning concepts from the Global North publicly. The epistemic freedom is bound by the way research is funded, if one is dependant for their income on grants from the Global North, will one question donor frameworks? Katsui and Kumpuvuori (2008) have described Ugandan Disabled Person's Organization as being pressured to produce results that are in line with the agenda set out by the donors. In addition, there is a tendency to value imported concepts from the Global North more highly than indigenous concepts, as those of the Global North are presumed to be more 'advanced'. With urbanisation, globalisation, and migration, these beliefs are further enhanced.

In her paper on the ethics of care in research, Evans (2016) notes that impact ranking of action research grants is largely determined by the influence the study has on policy, rather than benefits to the communities, and more so children. She argues that in evaluation research 'impact' in action-oriented research, especially in the Global South, should include the small things one does and benefits the research has in teaching and supervision. In our study, children participated in drawing, writing, mapping, photo- and videography, games, and drama and provided feedback on the themes identified by the adult researchers. They also participated in dissemination of the results in their video narratives and meetings with stakeholders. This was a 'small' thing, giving children a voice, not an individual voice, but voices as part of their families, schools, and communities. Despite their involvement in most of the research process, their involvement in the data analysis process was limited to what Coad and Evans (2008) call 'involving children to help verify the adult researchers' understandings of data' (42). The power balance between adults and children in the decision-making process during data analysis hence remained uneven (Coad & Evans 2008) and is a limitation in our study. We argue to not only involve adults when looking for indigenous knowledge frameworks. Children need to be included in this discussion, and preferably lead some of the discussions with adults. In 'Obuntu bulamu' there is reciprocity, the way one ought to behave might be different for each age group, but all behaviour is positive, conducive behaviour which will help individuals and the community. When children's perspectives change and children feel included from an early age, they are more likely to share positive examples with others during their lifetime and carry the unity and oneness forward into adulthood. The 'Obuntu bulamu' peer-to-peer support intervention addressed some practices that threatened humanity and injustice, as Berghs (2017) argued for.

In recent years, disability researchers have highlighted the importance of intersectionality and specifically argued to combine aspects of Critical Race Theory and Disability Studies into Disability Critical Race Studies or DisCrit (Connor et al. 2016). When studying disability in African countries, we argue for the need to cooperate with this approach looking

at the intersection of disability and race, post-colonialism, culture, poverty, and discrimination. We plan to further explore the relevance of the 'Ubuntu bulamu' intervention in other regions in Uganda, where the concept equally exists albeit in different languages and wording. More research is needed by various African scholars from different African countries to further develop and test interventions and evaluation methods relevant for our settings and populations.

### Competing Interests

The authors have no competing interests to declare.

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