

Teachers' and Parents' Perspectives on Inclusive Education for Children with Spina Bifida in Uganda

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Abstract

Introduction: Despite all the policies in place implementation of inclusive education remains limited at grass root level in Uganda. This paper explores accessibility and inclusion of children with spina bifida in primary schools with parents and teachers.

Method: Qualitative semi structured interviews and school observations were combined and conducted with 63 parents and 30 teachers in Uganda's central region. The Index of Inclusion was used as a guide in the interviews with parents, students, and teachers, and the Trip Chain concept and drawings of the Ugandan Accessibility Standards were used to measure accessibility.

Findings: Children with spina bifida with poor physical and cognitive functioning from families with a low household income were less likely to be in school compared to children with better functioning scores and a higher household income. Physical accessibility to schools for children with spina bifida is very limited. Classroom participation is affected by lack of space, materials, knowledge and experience of teachers to use diversified teaching methods. Education performance is rated lower by teachers than parents. Inclusive policies to include the children and prevent bullying are in place but lack implementation.

Conclusion: To achieve inclusive education for children with spina bifida, awareness rising to reduce discrimination, training and on job mentoring to support teachers and schools, and earmarking funds for inclusiveness in schools for children with disabilities is required.

Keywords: Inclusive education; Spina bifida; Uganda; Disability; Africa; Primary school; Teachers

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Introduction

Children with spina bifida in Uganda

Spina bifida is a congenital disability and neural tube defect; the spinal cord and vertebrae do not form completely and the neural tube fails to develop normally. The worldwide incidence of spina bifida varies between 0.17 and 6.39 per 1000 live births [1-4]. Incidence and prevalence rates in Uganda may be higher due to inadequate folate consumption by pregnant women [5, 6], lack of pre-natal care, absence of secondary prevention services [7], and higher exposure to environmental risk factors such as dioxins [8] and fumonisins intake [9-11]. No national data are available

in Uganda. Warf et al. estimate that 1,400 children are born with spina bifida in Uganda annually [12] and 66% of children with spina bifida develop hydrocephalus [13].

For children with spina bifida participating in daily activities is challenging as the majority have some degree of paralysis, which affects mobility as well as bowel and bladder control [14-16]. Most children with spina bifida need surgery to close the back to prevent infections; children with progressive hydrocephalus need endoscopic third ventriculostomy (ETV) or placement of a ventriculo-peritoneal (VP) shunt to drain cerebral spinal fluid and prevent secondary impairments [17].

Surgery and rehabilitative care is expensive and inaccessible for

many children born with a physical disability in Africa. In East Africa efforts are made to provide basic services at community level for children with spina bifida, but largely remain funded by international donors and charities [18]. In Uganda the initial surgery (closure of the spine) at the time of this study was only available in two public government funded hospitals (Mulago National Referral Hospital in Kampala and Mbarara Regional Referral Hospital), and one private specialized neuro-paediatric hospital (CURE Children's Hospital) in Mbale, eastern Uganda. In north, west, and central Uganda three rehabilitation centers, funded by international donors and charities offer occupational therapy, physiotherapy, continence management, and social support services for children with spina bifida and their families.

Children with spina bifida have intelligence in the normal range, tending to be in the low normal range. They have a specific cognitive phenotype with functional assets and deficits in timing, attention, movement, perception, language, literacy, and numeracy [19]. The neuropsychological profile of children with spina bifida and hydrocephalus is often more impaired. Shunting, shunt infections, revisions, and history of seizures predict poorer memory, meta-cognitive abilities, executive functioning and cognitive health. In Uganda infants not requiring treatment for hydrocephalus had significantly better neurocognitive outcomes than those who did require treatment [20]. In Uganda children with spina with better motor function outcomes have better cognitive outcomes and are more likely to be in school [21].

Special needs and inclusive education in Uganda

Although inclusion of children with spina bifida in normal schools is common in high and middle income countries, this remains a challenge in low income countries [22]. Implementation of inclusive education is affected negatively by non-supportive attitudes of parents and community members, distance to school, not conducive school environment (access, materials, equipment), and lack of trained special needs teachers. In South Africa, physical access, transport, medical information, and training and support of teachers to respond to particular learning disabilities were identified as key areas that need to be addressed to allow children with disabilities to participate in the existing education system. A study in Uganda shows that children with disabilities are admitted without proper assessment of their educational needs and the resources are not available to provide them with an appropriate range of experiences.

In Uganda Persons with Disabilities (PWDs) are represented in the national and local governance structure. Through the National Council for Children and the National Action Plan for PWD, strategies have been developed to cater for children with disabilities. In 1955, special needs education began with the creation of a school for children with visual impairments by the British, followed by education for children with hearing impairments in 1958. In 1965 the International Labour Organisation (ILO) conducted the first Sub-Saharan National Census of the Disabled and urged government to be more vigilant and active in the provision of education for PWD. In 1973 a special education department was created in the Ministry of Education [23], now called the Special Needs and Inclusive Education department. Since 1991, primary school teachers and

other professionals have been trained at the Uganda National Institute for Special Education (UNISE). In 1992, a nationwide network of centres at district level started to address and coordinate special needs education locally [24]. In 1997 Uganda endorsed the Universal Primary Education policy, and in line with the Education for All initiative the target group of children with disabilities expanded to including orphans, traumatised children, HIV positive children and others with special needs. A new Basic Education Policy for Disadvantaged Children was endorsed in 2002, which increased the demand for training of staff at all levels [25]. Uganda signed the UN Convention on the Rights of Persons with Disabilities in 2008. In 2010 the Uganda National Action on Physical Disability (UNAPD) and the Ministry of Gender Labour and Social Development (MoGLSD) launched the Accessibility Standards, which provide guidelines for a barrier-free environment [26]. The Ministry of Education has an inclusive education policy in draft for inclusion of children with special needs in primary schools [27]. Despite all the policies in place implementation of inclusive education remains limited at grass root level [28]. According to a UNICEF report only 9% of children with disabilities in Uganda attended school in the period 2009–2011, and only 6% completed primary school and went to secondary school [29].

In this paper we describe the primary school setting for children with spina bifida in the central region of Uganda and explore accessibility and inclusion with parents and teachers.

Methods

Study design

The sample for this study was selected from a larger study population of 139 children with spina bifida in Uganda for which purposeful sampling was used in rehabilitation centres throughout the country to recruit families of children with spina bifida aged 4 to 14 years. For our study we selected all 63 children from the central region of Uganda from the database with 139 children. Of the 63 children, 41 children were schooling. Basic demographic data, motor functioning, continence management, and cognitive functioning data were earlier collected in the larger study of all 63 children and families. In addition we collected school specific information for the 63 children. The parents of the 41 children were approached for permission for a school visit, interview with the teacher, and classroom observation, and 36 accepted. In total 30 schools and teachers consented to participate. Qualitative semi structured interviews and school observations were combined and conducted with 30 parents and teachers between June 2011 and December 2014.

Ethical considerations

Ethical approval and research clearance were obtained from Ghent University, Belgium, the Uganda Virus Research Institute, and the Uganda National Council for Science and Technology. Informed consent was obtained from all parents and teachers, and assent from children and siblings of 8 years and above where possible.

Selected measures

The Index of Inclusion [30] was used as a guide in the interviews with parents, students, and teachers. No full questionnaires were administered or scale scores calculated, as some of the items were not applicable in the Ugandan setting. Instead the overall themes of inclusive cultures, policies and practices were explored in semi-structured interviews appropriate for the school setting. Questions about relationships and respect between students and teachers were unmerged and rephrased to fit the cultural setting.

We used the Trip Chain concept and drawings of the Ugandan Accessibility Standards [26] to measure accessibility in schools. A Trip Chain is defined as 'the sum of all parts of movement from one place to another which must be accessible in order to ensure a barrier-free environment' in the Accessibility Standards. In the case of the children in this study, this included the ability to independently: 1) walk or wheel from home to school on a sidewalk or pathway or use public transport 2) enter the school compound, offices, and classrooms (e.g. ramps available for wheelchair users) 3) manoeuvre within the school buildings and compound (e.g. corridors, inside classroom, sports field) 4) use the toilet facilities 5) use boarding facilities.

Data management and analysis

Basic demographic data were registered during assessments, and entered into a database after completion. The semi structured interviews were transcribed, translated, coded and analysed using thematic analysis in NVivo version 10. Descriptive statistics were calculated from observations and the index questions on school accessibility using SPSS16.

Results

Study population

The study population consisted of 63 parents of children with spina bifida; 30 teachers (22 female, 8 male) of children with spina bifida. The children's average age was 5.97 (SD 2.20) years. In total, 41 children were schooling, and 22 were not. Of the schooling children, 26 were in nursery school, 11 in primary, and 4 in secondary school. All children with spina bifida had undergone surgery to close their spine (myelomeningocele closure) earlier in life. 22/27 children who had both spina bifida and hydrocephalus had surgery for hydrocephalus. The parent's average age was 33.3 (SD 5.17) years.

The majority (over 80%) of the families was Christian, 18% was Muslim. **Table 1** describes the demographics and impairment characteristics of the study population divided into the families of children who were and were not schooling.

In total 30 primary school teachers were interviewed at nursery and primary schools where children with spina bifida were enrolled. Children (18 male, 12 female) were observed in class, and parents/caregivers (27 mothers, 1 father, 1 foster parent, and 1 elder sister) were interviewed. In total 16/30 children in school could walk without assistive devices; 6 children used crutches, and 8 used a wheelchair to ambulate. Fifteen had spina bifida, and 15 spina bifida and hydrocephalus. 24 practiced CIC, 1 used

pampers, 5 were continent of urine. The teachers were the child's class teacher and interacted with the child on a daily basis. The class levels varied from lowest level nursery school ('baby class') to primary school level 5 ('P5'). The class size varied between 28 and 69 children.

School enrolment

The demographics and interview data showed that children with spina bifida with better gross and fine motor skills, continence management, cognitive outcomes, higher household incomes, and higher levels of parental support were more likely to be in school than those with lower outcomes on these variables. Parents described this as following: 'I went to 5 different schools but none of them would accept him, they said they cannot manage with a wheelchair and his continence management needs'; 'I have 6 children and cannot afford to send all to school. As she has some difficulties in understanding, I decided to send the other ones first'. Parents whose children were not in school indicated this was due to insufficient income (12/22), the child not being able to go to school due to poor physical and cognitive functioning (8/22), and the child still being young (2/22). The latter was only mentioned for children of 4 years of age. The sample was too small to carry out reliable statistical testing. All children who were schooling were in private schools. Only 4 parents had tried enrolling their child in a public school, but the children had not been welcomed and were bullied, after which parents tried to secure funds for a simple private school: 'I had no money, I had to send him to a government school, but the other children abused him, and the teacher was not interested in helping him, so I took him out after 1 term'.

Physical accessibility of school facilities

In total 24/30 parents and 17/30 teachers felt the school was accessible for their children, 24 parents felt it was, compared to 17 teachers. In the school observations, we noted that parents and teachers rated the school accessible if their child could enter their classroom without help. We observed that only 7 out of the 30 schools had classrooms which were accessible for wheelchair users and children using crutches using the Accessibility Standards. In two (2/30) of the schools cemented ramps were constructed, three (3/30) had installed wooden ramps, and two had a marram ramp (which was not functional in the rainy season). Parents paid for the wooden ramps.

None of the classrooms had space to manoeuvre a wheelchair in. The other school offices, libraries, and sports fields were not accessible according to the Accessibility Standards. In 5 out of the 30 schools children could practice continence management and had accessible toilets. Parents explained practicing Clean Intermittent Catheterization (CIC) was a major challenge, as the schools only had normal latrines which were generally unclean and have no place or seat to put the CIC materials and practice CIC. However in 3 of the schools the children used the teacher's toilets, in 2 schools actual bars and ramps were constructed to make the student latrines accessible.

None of the roads to school were accessible for children using assistive devices: 22 out of the 30 children were brought to school by their parent(s), a 'boda boda' (4, local motorbike transport),

Table 1 Demographic and impairment characteristics of the study population (N=63 children with spina bifida).

Variable	Child in school (N=41)	%	Child not in school (N=22)	%
Gender child				
Male	26	63.4%	10	54.5%
Female	15	36.6%	12	55.5%
Type of disability				
Spina bifida	23	56.1%	13	59.1%
Spina bifida and hydrocephalus	18	43.9%	9	40.9%
Child is continent/uses CIC				
Child practices CIC	36	87.8%	17	77.3%
Child does not practice CIC	5	12.2%	5	22.7%
Child gross motor skills				
Cannot walk, has no assistive devices	8	19.5%	8	36.4%
Can walk with assistive devices	12	29.3%	6	27.3%
Can walk without using assistive devices	21	51.2%	8	36.4%
Child fine motor skills				
Average score	15.85	(SD=3.53)	11.7	(SD 4.88)
Child cognitive score				
Average score	-.57	(SD=0.26)	-2.09	(SD 1.23)
Relationship parent/care-giver				
Mother	36	87.8%	19	86.4%
Father	1	2.4%	2	9.1%
Other	4	9.8%	1	4.5%
Education level parent				
None	2	4.9%	3	13.6%
Primary	18	43.9%	9	40.9%
Secondary	12	29.3%	5	22.7%
Vocational	4	9.8%	3	13.6%
University	5	12.2%	2	9.1%
Marital status parent				
Single	5	12.2%	1	4.5%
Married	32	78.0%	18	81.8%
Separated	1	2.4%	2	9.1%
Widowed	1	2.4%	1	4.5%
Monthly household income				
<30 euro	0	0%	4	18.2%
30-60 euro	7	17.1%	5	22.7%
61-90 euro	10	24.4%	2	9.1%
>90 euro	22	53.7%	9	40.9%
Parent has support from another adult on a daily basis				
Yes	26	63.4%	11	50.0%
No	15	36.6%	11	50.0%
Occupation parent				
Finance/administration	5	3.8%	2	5.9%
Small scale private business	30	22.7%	7	11.8%
Teacher/education	9	6.8%	3	8.6%
Medical/paramedical	5	3.8%	0	0
Civil service/government	2	1.5%	0	0
Peasant farmer	65	49.2%	19	62.9%
No occupation	6	12.1%	3	8.6%

or their sibling pushing their wheelchair (2). The other two could walk to school by themselves. None of the children using

assistive devices could ambulate to school on their own without assistance.

None of the children was in boarding school. The school with boarding sections had no accessible entrances to the dormitories, no accessible bathrooms, and insufficient space to manoeuvre in.

Classroom participation

All teachers were solely responsible for their class and had no teaching assistants. All schools were private schools and had desks, chairs, and a blackboard in the classrooms. Some of the more expensive private schools had a variety of toys and books available in the nursery section. In primary schools, textbooks were not available in class for children, 8 schools had a library where children could access the books. In the primary schools and most nursery schools, children copied notes from the blackboard or transcribed what the teacher was reading out. Teachers did not have tools or materials to offer diversified teaching activities. None of the children who were using assistive devices (14) participated in physical education/sports lessons.

The teachers felt they try their best to teach all children in class, and expressed to find it difficult to find enough time to help each child individually. This makes it harder to teach the child with spina bifida well they say, as they often need more attention and time.

Most teachers (24/30) felt they included the child by making sure the child sat in front of the classroom: 'so I can see her well and check if (s)he is following', spending some extra time to make sure they understood the exercises and work given: 'I check if he has copied the assignment well and understands it', and discussing their physical needs with the parents: 'I told his mother she needs to buy a table desk for his wheelchair'.

Teachers explained they often ask other students to help the child with spina bifida to go outside, or copy notes for them if writing is difficult or slow, or the child has missed class. They would not ask the child with spina bifida to help another child.

Of all the children who practiced CIC teachers mentioned the challenge in practicing CIC during the normal school day: 'she needs to go to the bathroom during the lesson at certain hours and it takes long, then she misses a lot of what we are doing in class'; 'his mother comes to take him out to urinate, but when she cannot come, he smells of urine and the other children complain'. When asked if teachers could assist five (5/30) teachers explained a teacher or school nurse is assisting the child, but most felt it was the child and parent's responsibility to organize CIC in school.

During the classroom observations, it was noted that children with spina bifida were called to answer questions and participate in class activities. It was observed that the children often sat in front of the class, closer to the blackboard. In most schools teachers explained that this was due to vision or ambulation problems, e.g. 'he has difficulties seeing, so it is better to sit close to the blackboard' and 'there is little space for the wheelchair in the back, here in front it is better for her'.

Educational performance

We asked parents and teachers to rate the child's performance as poor, fair, or good. Whilst 11 parents felt their child performed well, only 7 teachers did; 11 parents and 10 teachers felt the

child performed fair; and 8 parents and 13 teachers felt the child performed poorly.

The majority of teachers said the children are slow learners compared to the other children in class. When asked about performance in different subjects or tasks most class teachers responded 'it is not so good' or '(s)he needs to improve'. Some were dismissive in whether or not this child would be able to complete school and pass examinations, especially in those with hydrocephalus. One teacher felt it was not useful to send the child to school 'it is a waste of money, he does not understand most of what we teach, I think he will stop after P2 [primary 2, second year of primary school]'. Only 4 out of the 30 teachers felt the child would be able to complete secondary school, and only 2 said they felt the child could go to university: 'it will be difficult to complete A-level [secondary examinations to qualify for university admission], but maybe she can try, she is bright'.

Parents were concerned about their child's performance and felt there was no room to adjust or understand their child's difficulties in reading or processing information. None of the children had received any cognitive assessments prior to this study nor had families been informed about possible cognitive deficits and assets related to spina bifida. Five (5/30) parents said to have meetings with the teachers regularly and felt the school informed them about their child's development and needs adequately; these were parents whose children were enrolled in more expensive schools which had more facilities and teachers available.

Inclusive school policies

The teachers interviewed explained their school follows the regulations and curriculum of the Ministry of Education and Sports. This includes giving children with disabilities a place to study. However they explained that despite these policies being in place it is often difficult for the children to participate as the number of children in class is very high, and the school have very limited resources in making their buildings accessible and teaching materials available.

Teachers said they expect the children with spina bifida to participate in class like any other child. They said they are not expected to participate in physical education if they cannot walk. Homework expectations are the same as for the other children. Homework instructions are copied from the blackboard or in a few occasions given on a piece of paper and are usually expected to be handed back the next day. No extra time is provided for examinations whether or not the child appears to have learning difficulties. Report cards are based on the national curriculum and marking system. There are no individualized score cards, education plans, or appraisal systems.

Teachers explained that whilst bullying is discouraged it often happens as children can be rude to each other. Half of the teachers felt it was part of their role to prevent bullying and take action if the child with spina bifida was bullied in class. The other teachers felt it was the school management and parents to make sure that they dealt with such behaviour. Some said it is the parents fault: 'if you [parent] send your child here and he cannot walk and has no wheelchair they will make fun of him when he is crawling'.

Parents explained their child is sometimes bullied in school. Most of the bullying was centred on their physical appearance and slow learning. Some tried to address the bullying through talking to the school administration without much result. Almost a third (9/30) of the parents changed school at least once because of bullying. Parents did mention that if children are in school for a longer time, the bullying reduces as children get used to them.

Discussion

Schooling for children with spina bifida in Uganda is very challenging. Only 65% of the children in our study population were schooling. Nationally the net enrolment ratio in primary schools in the same period was 94.5% [31]. The main reasons for not being in school for children with spina bifida were poor physical and cognitive functioning, and lack of income to pay for school fees. Although public schools exist, none of the parents felt their child could be included in these. In earlier publications we found most children enjoy going to school, but parents indicated finding a school that will admit and include their child is challenging [32]. Parents in our study had to pay tuition fee for their child in the private schools, and a child had to often do an entrance examination. Earlier we found parents household income affected schooling [21] and parents would not prioritize sending their child with spina bifida to a private school if they did not have sufficient funds to send all children to school [16]. As schooling in turn will affect cognitive outcomes positively [21, 33], the chances to enrol into school later, e.g. when funds are available, may decrease even further as the gap between the child's development and those of their school going peers will enlarge, and the chance to pass the examination test reduces.

For those in school, physical accessibility of school facilities was very limited. Looking at the Accessibility standards, none of the children could walk or wheel from home to school on a sidewalk or pathway or use public transport; only a few could enter the school compound, offices, and classrooms (e.g. had ramps); none could manoeuvre within the school buildings and compound (e.g. inside classroom, sports field) and none could use boarding facilities. Toilet access and incontinence management was the main challenge for the children. Although some schools attempted to create accessible toilets to practice CIC, the majority did not have these facilities available. The physical impairment and physical access difficulties in education were emphasized by parents and teachers, more than cognitive difficulties or social inclusion.

Teachers did explain they were limited by the lack of materials, high numbers of students in class, and teaching methods. Nationally the pupil to classroom ratio is 57 and teacher to student ratio 45. Being inclusive in the classroom was mostly seen as ensuring the child could enter the classroom, offering him or her a position near the black board, and ensuring the child would be able to copy the notes. Teachers were not conversant with the

possibility of children's participation in physical education/sports whilst using assistive devices. Further support and activities to increase participation in sports are recommended. Private non profit organizations have started organizing sports days, and are promoting sports for children with disabilities [34, 35]. Knowledge of the effect of cognitive outcomes on inclusion was limited in the schools we visited. Although teachers and parents explained that the children are 'slow learners', none was aware that spina bifida comes with specific cognitive assets and deficits [19]. Some of the teachers who defined children as 'slow learners' tried to spend more time with them or break down tasks for them, however no clear strategies were in place to address learning difficulties. Educational and neuropsychological testing is very limited in Uganda. Bangirana et al. [36] have created a Ugandan validated test battery which is used to assess neuropsychological functioning in the national referral hospital Mulago in Kampala, the capital city. Earlier we noted children were unable to understand or complete a number of subtests from this battery due to their physical impairment [21]. We argue for awareness rising on the cognitive profiles of children with spina bifida and strategies to help them in learning in schools rather than individual testing of the child as a strategy to address their 'slow learning'. The International Federation for

Spina Bifida has sensitization materials available on inclusion of children with spina bifida in schools [37]. These could be adjusted and translated for use in low income countries. Bullying in schools is not well controlled and it is unclear if the responsibility for this lies with the parents or teachers. Awareness rising on the impairment, inclusive education, and more active implementation of child protection policies in school may help prevent and stop bullying. The Ugandan Ministry of Education and Sports, Ministry of Gender, Labour and Social Development in collaboration with international and national partners have implemented various child protection programs in schools over the past decade [38-40]. Further efforts are required to protect children with disabilities in schools and communities. E.g. training of teachers should be reoriented to give teachers the capacity to diversify teaching [28]. The schools in our study followed the national curriculum and did not offer diversified teaching, nor readers, scribes or extra time in examinations. To diversify teaching methods, a revision of the national curriculum and method of teaching may be required, as use of visual and image activities, play, art, and use of assistive electronic devices in schools is currently not available. Having embraced the Education for All objectives, there is need to critically look at the way children are involved and taught in class to enable teachers and schools to achieve this.

Conclusion

To achieve an inclusive education community, we recommend awareness rising to reduce discrimination, training and on job mentoring to support teachers and schools, and earmarking funds for inclusiveness in schools for children with disabilities.

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