



Social inclusion,
care, and belonging
of children with
spina bifida
and their families
in Uganda

Femke Bannink Mbazzi

Dr. Richard Idro

Prof. dr. Geert van Hove



Children with Spina Bifida and Hydrocephalus in Uganda

INTRODUCTION

Spina Bifida



Spina bifida occurs in 0.17 to 6.39/1,000 live births, estimated 1,400 per year in Uganda

(Warf, Wright & Kulkarni, 2011)

Hydrocephalus



In Uganda 66% of children with spina bifida develop hydrocephalus

(Warf & Campbell, 2008)

Research questions

- 1) What is the knowledge, attitudes about, and perception of children with spina bifida in Uganda?
- 2) Which health and rehabilitative care services do children with spina bifida and their parents access?
- 3) Which factors promote social inclusion and belonging of children with spina bifida?
- 4) What is the role of the family in social inclusion, care, and belonging of children with spina bifida?



Study population and design

METHODS

Study population

- Random sample selection from CURE files, 56% survival rates (*Warf, Wright, and Kulkarni, 2011*)
- Recruitment through rehabilitation centers and tracing in communities (home visits)
- In 5 CURE clinic locations in Uganda



Average age children 6.4

(range 4 to 14 years)

Average age siblings 7.8

(range 4 to 14 years)

Average age parents 32.9

(range 24 – 46)

66 (47.4%) urban

53 (52.6%) rural areas

Average household size is 6.5,
ranging from 2 to 13 members

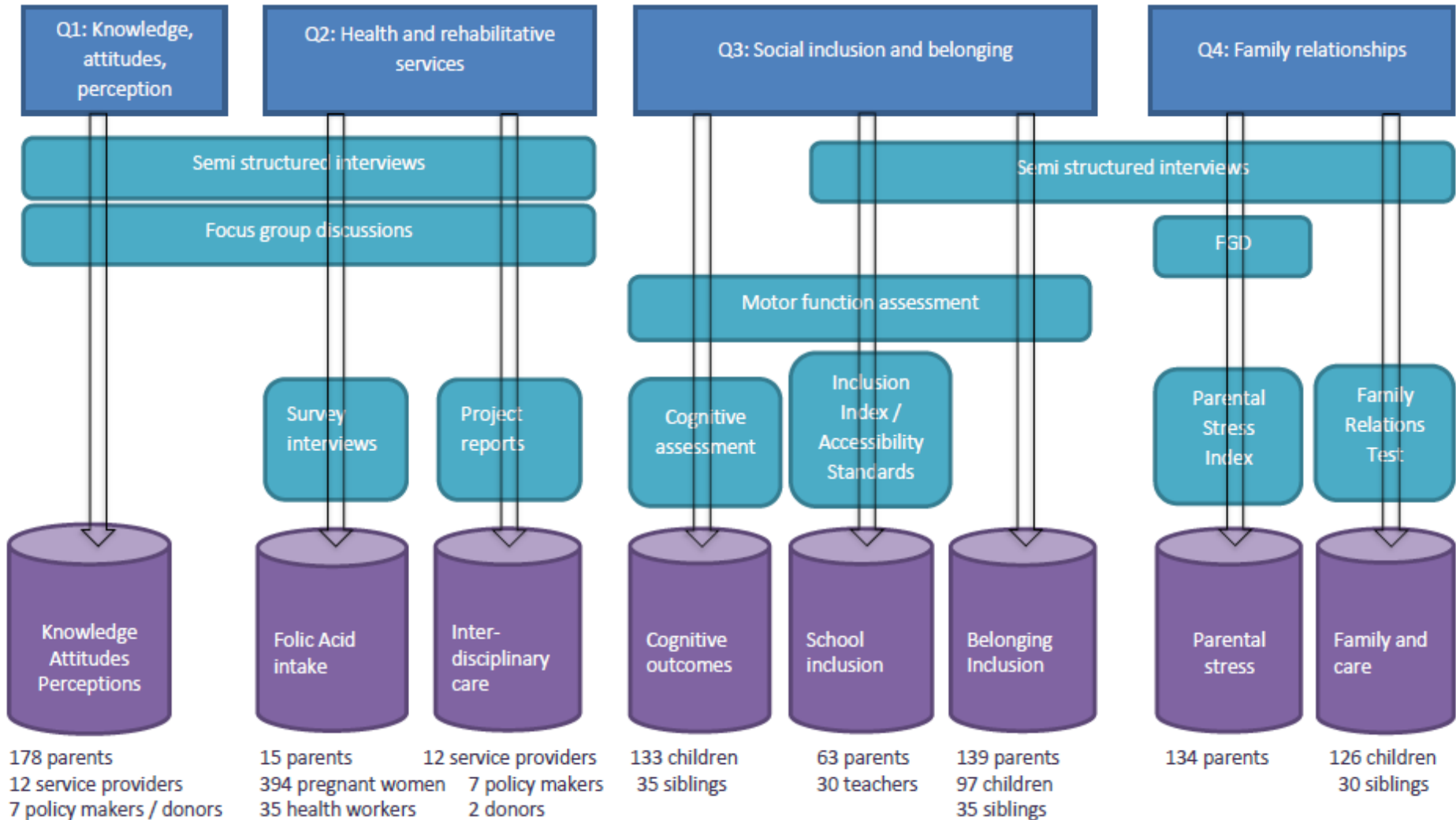
Average household income is
82 euro / month

(range 12 to 604 euro)

70% < 100 euro / month

Variable	Number	%
<u>Gender child</u>		
Male	82	59.0%
Female	57	41.0%
<u>Type of disability child</u>		
Spina bifida	76	54.0%
SB & hydrocephalus	63	46.0%
<u>Location / region where family lives</u>		
Central	65	46.8%
East	26	18.7%
West	29	20.9%
North	19	13.7%
<u>Relationship parent to child</u>		
Mother	119	66.7%
Father	30	16.7%
Grandmother	20	11.1%
Other	9	5.5%
<u>Marital status parent</u>		
Single	18	9.9%
Married	127	71.1%
Separated	14	7.9%
Widowed	19	11.1%

Study Design



Knowledge, attitudes, perceptions

Health and rehabilitative services

Social Inclusion and belonging

Family relationships and care

RESULTS

“Everyone told me my child will die.
Now she is 7 years old and goes to
school. They are all surprised.”

Mother of an 8-year-old girl with spina bifida and hydrocephalus

Knowledge, attitudes and perceptions

- Spina bifida was most commonly believed to be caused by witchcraft, bad luck, and the use of family planning methods
- Search to undo the curse – it was often believed the mother did something wrong, which resulted in ‘this’ misfortune
- A child with a ‘*swelling on the back*’ will die, anticipation and response including neglect and dropping them in the river
- Regional and individual differences in practices
- Recent social and cultural change in survival and response
- Complex play of traditional society and cultural values and globalization and access to biomedical care.

Health and rehabilitation services

- Poor access to general health services, and difficulties accessing specialized health services for neurosurgery and rehabilitation
- Limited knowledge and rejection by health workers in public facilities
- Good relationships between children and health / community based rehabilitation workers of specialized centres. Good adherence and CBR follow up in IF supported projects.
- Low cost interventions are an option and make a big difference, e.g. using cheaper shunts, providing CIC training with buckets and reusable catheters.
- Low intake of and knowledge about folic acid (8%) and lack of mandatory food fortification hampers prevention



Social inclusion and belonging

- The family is the place where children belong
- Participation in household activities: children are included at home if their motor function is ok
- Mobility, continence and parental support are key to social inclusion
- Bullying and exclusion in community settings reduces after the child starts participating in daily life and the family and clan shows the child belongs
- *Ubuntu* 'I am because we are' and *obuntu bulamu* 'the way people behave (human kindness)'

Factors influencing social functioning

Variable	Social functioning
Motor skills	33.04***
Use of assistive devices	2.41*
Practices CIC	10.45***
Schooling	2.39
Parent is a member of a support group	5.63*
Geographical location (east, west, central)	4.56**

F-scores * $p < .05$; ** $p < .01$; *** $p < .001$

“I always push my sister to school. It’s heavy and the dust makes it hard to push her [in the dry season]. But the rainy season is worse, sometimes she has to stay home, because the wheelchair cannot pass the road.”

12 year old sibling of a 9 year old girl with spina bifida

“I would like to go with my sisters and collect water, but it is not possible, they go and I am left at home, I cannot meet others on the road and talk about secret things like they do because I am always home.” *12 year old girl with spina bifida*

“I like to play outside but when I have a wound [pressure sore] I am not allowed to crawl and play outside, then I watch them from the house.” *5 year old boy with spina bifida*

Mobility and assistive devices

57.6% (80) of the children interviewed need assistive devices for mobility:

- 31.3% (25) use a wheelchair (2 of them on their own)
- 20.0% (16) uses crutches
- 3.7% (3) use walking frames
- 45.0% (36) crawled due to lack of access or use of a device. Almost all these children have pressure sores, mostly on their feet



Impaired bodily experiences: inaccessibility

Incontinence and CIC

- 89.2% (125) children are incontinent, and practice bowel wash out (70.5%) and clean intermittent catheterization (75.8%)
- 15.9% practices CIC, and 4.9% practices bowel management on their own
- 15.2% can practice at school



“I have 7 children and I can afford to send 4 to school. I cannot send her [the child with spina bifida], I have to add transport for her too as she cannot walk to school, and it is unlikely someone will give her job when she completes school.”

Parent of a 5 year old girl with spina bifida

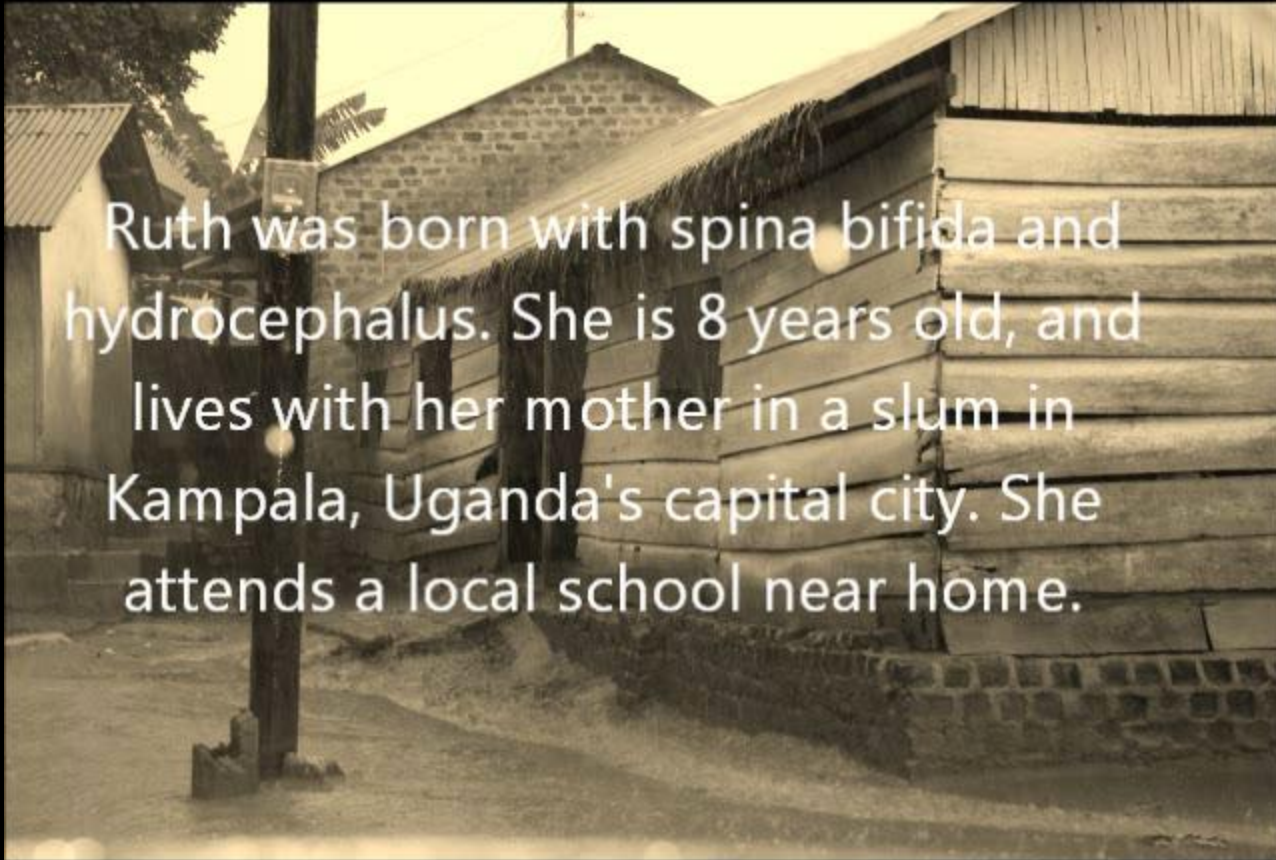
Schooling

Variable	Children with spina bifida	Siblings of children with spina bifida
Nursery school	36.8% (50)	
Primary school	16.2% (22)	25.7% (9)
Secondary school	2.9% (4)	74.3% (26)
Not schooling	44.1% (60)	

- 55% of children with spina bifida in school vs 83% nationally
- Approximately 1 year behind



Going to school



Ruth was born with spina bifida and hydrocephalus. She is 8 years old, and lives with her mother in a slum in Kampala, Uganda's capital city. She attends a local school near home.

Inclusive education

- Reluctance of public and private schools heads
- Physical accessibility to schools is very limited
- Incontinence management is difficult in school
- Classroom participation is affected by lack of space, materials, knowledge and experience of teachers to use diversified teaching methods
- Inclusive policies to include the children and prevent bullying lack implementation

Cognitive outcomes

- Cognitive outcomes siblings > children with spina bifida
- Cognitive outcomes are predicted by:
 - Age
 - Presence of hydrocephalus
 - Parent receiving support from another adult
 - Motor skills level
 - Schooling
- Surgical procedures and membership of a parent support group did not have a significant effect on cognitive outcomes

The importance of CBR and parental support



Family relationships: parents

- Parents of children with spina bifida experience high levels of stress. Parental stress was higher if a child:
 - could not walk and had no assistive device ($\beta=-.248$)
 - had poor incontinence management ($\beta=-.468$)
 - parent had no adult to support ($\beta=-.228$)
- Parents in northern Uganda had significantly higher scores compared to parents in other regions

PSI-SF Parental Distress $F=5.467^*$

Parent Child Dysfunctional Interaction $F=8.815^{**}$

Difficult Child score $F=10.489^{**}$

Parent Support Groups

- 41.8% (56) parents are members of parent support groups (self help groups)
- 47.0% (63) have support from another adult in the care for their child



“When I attended the first time, I was so surprised and happy I was not the only one with a child like mine. There were children who could not even sit. The other parents were so encouraging; they gave me hope and a lot of information and ideas on how to help my child and myself.”

Parent of a 7 year old daughter with spina bifida and hydrocephalus in central Uganda

“Here [in the north] people think our children’s disability is contagious, they fear us, they avoid us. In the PSG we can work together, we understand each other. We bought goats for the group, and when they produced we all got a goatlet. We started planting maize in the last rainy season together too.”

Parent of a 4 year son with spina bifida and hydrocephalus in northern Uganda

Benefits of participating in Parents Support Group (N=56)	Number	%
Learning about taking care of child with SB	28	50.0%
Encouragement from other parents	8	14.3%
Sharing experiences, learning from each other	8	14.3%
Learning how to include my child in school	1	1.8%
Income generating activities / opportunities	7	12.5%
Don't know	4	7.1%

Reason for not participating in a PSG (N=78)	Number	%
Not aware of existence of PSG	48	61.5%
Not in their location / far away	23	29.5%
Does not have time	3	3.9%
Reason unknown	4	5.1%



Family relationships

- Highly dependent family care model in which mothers play a key role in the children's lives, dependency and care
- Fathers are relatively absent for both siblings and children with spina bifida
- Children with spina bifida have more interaction with their younger siblings and other household members than their typically developing siblings
- Children with spina bifida have more negative self-perceptions compared to their siblings
- Child neglect observed related to poverty and lack of support from another adult



belonging, being, becoming

CONCLUSION AND RECOMMENDATIONS

Conclusions

- Social inclusion in terms of schooling and society do not exist
- Interdependent families where all members belong do exist
- The concept of '*ubuntu*' is central, and starts with the family
- Poverty affects access to care, rehabilitation and schooling
- Low cost health interventions, parental support, and CBR improve motor skills, continence, and cognitive development
- Stigmatization and functioning worst in northern Uganda



Recommendations

- General health and education system reform: poverty alleviation and disability inclusive development
- IF program activities prevention, awareness raising, low cost surgical and incontinence management interventions, and CBR are helpful. Expand with:
 - Family support groups including siblings and househelps
 - Include an adult support system set up in CBR
 - Small scale livelihood activities to reduce poverty
- Research studies:
 - Focus on families and belonging rather than individual quality of life or rights awareness
 - Cohort study to understand the impact of intervention on mortality, survival, and development over time

Publications

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2. Bannink, F., Idro, R., and van Hove, G. (2015) Community knowledge, attitudes, and practices in caring for children with spina bifida in Uganda. *Journal of Disability, Development and Education* 62:2, 182-201, DOI: 10.1080/1034912X.2014.998174.
3. Bannink, F., Larok, R., Bauwens, L., Kirabira P., and van Hove, G. (2015) Prevention of spina bifida: folic acid intake during pregnancy in northern Uganda. *The Pan African Medical Journal* 20: 90. DOI: 10.11604/pamj.2015.20.90.533.
4. Bannink, F., Idro, R., and van Hove, G. (2016) Parental stress and support of parents of children with spina bifida in Uganda. *African Journal of Disability*, 5(1). DOI: 10.4102/ajod.v5i1.225.
5. Bannink, F., Idro, R., and van Hove, G. (2016) 'I like to play with my friends': children with spina bifida and belonging in Uganda. *Social Inclusion*, 4 (1). DOI: 10.17645/si.v4i1.630.
6. Bannink, F., Idro, R., and van Hove, G. (2016) Teachers' and parents' perspectives on inclusive education for children with spina bifida in Uganda. *Journal of Childhood & Developmental Disorders*, 2: 10. DOI:10.4172/2472-1786.100026.
7. Bannink, F., Fontaine, J.R.J., Idro, R., and van Hove, G. (2016) Cognitive abilities of pre- and primary school children with spina bifida in Uganda. *International Journal of Educational Psychology*. *International Journal of Educational Psychology*, 5(3), 249-280. DOI: 10.17583/ijep.2016.2075
8. Bannink, F., Idro, R., and van Hove, G. (in press) Family relationships, dependency and care: perspectives of children with spina bifida in central Uganda. *Knowledge Management for Development Journal*. *Special issue Knowledge for Disability Inclusive Development*.



Thank you

For more information:
femke.bannink@ugent.be