

A young girl with spina bifida is sitting on a red bicycle in a rural village setting. She is wearing a blue patterned shirt and black pants. A man in a white tank top is sitting on a tire next to her, possibly assisting her. In the background, there are other people, including a man in an orange shirt and a woman in a white shirt, and some animals like cows. The scene is outdoors on a dirt path with simple buildings and trees in the background.

**Mobility, incontinence,
and social functioning of children
with spina bifida in Uganda**

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UGANDA

- ⊙ National capital
- Town, village
- ✈ Airport
- International boundary
- - - District boundary
- Main road
- - - Secondary road
- Railroad

The boundaries and names shown and the designations used on this map do not imply official endorsement or acceptance by the United Nations.



Republic of Uganda

- Population: 32 million
- Language: English and local languages
- Capital city: Kampala
- Life expectancy: 52.3 years
- Fertility rate: 7.2
- Growth rate: 3.6%
- 17 Bantu and Nilotic tribes
- War in northern region from 1984 - 2006

Spina Bifida



Spina bifida in Uganda

- 1-2 in 1,000 live births; estimated 1,400 / year (*Warf, 2011*). Approximately 10% of these receive neurosurgical care. The remaining most likely dies.
- Prevention: poor feeding, malnutrition, lack of folic acid intake, poor antenatal care (*Miles, 2006*)
- Barriers to treatment: lack of knowledge (*Mertens and Bannink, 2012*), negative attitudes and beliefs (*Bannink, Idro, van Hove 2013*), poverty (*Miles, 2006*).

Study population

- Part of a larger quality of life study, looking at daily, social, cognitive, and family functioning
- 132 parents of children with spina bifida aged 4 to 14 years
- Recruitment through rehabilitation centers and tracing in communities
- In 5 locations in Uganda



Methods

- Semi structured interviews
- Vineland Adaptive Behavior Scales – daily and social functioning subscales
- Strengths and Difficulties Questionnaire – pro-social behaviour, and relationships with peers
- SPSS was used for data analysis.
- NVIVO was used to analyze qualitative data from interviews.

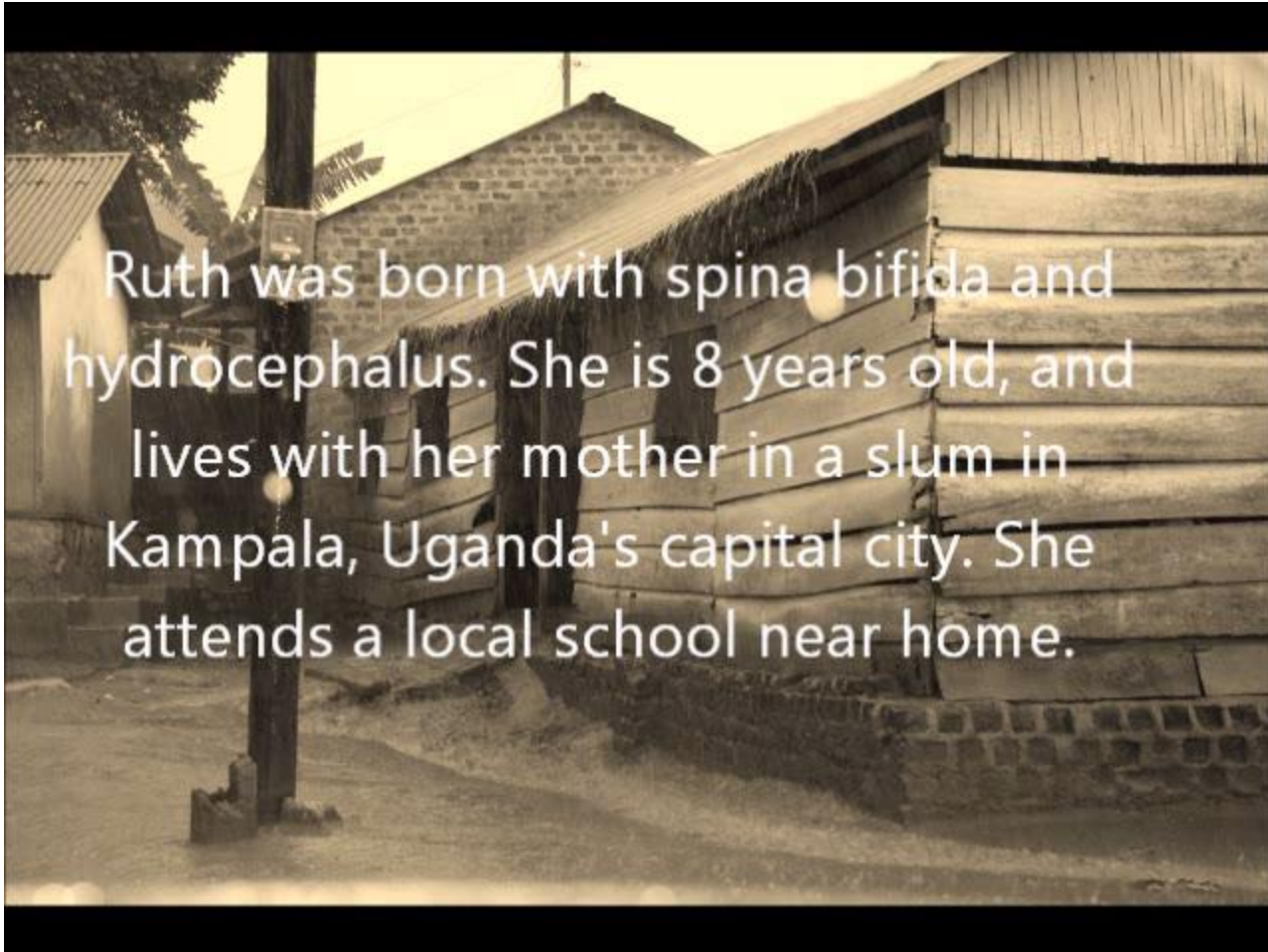
RESULTS	Demographics	
Sex child	56.8% (75) male 43.2% (57) female	
Age child	4 – 14 years, median 6.1 years	
Condition child	58.3% (77) spina bifida 41.7% (55) spina bifida with hydrocephalus	
Household size	\bar{x} = 6.6 persons in the household (2 – 13)	
Relationship caregiver	Mother 77.3% (102) Grandparent 7.6% (10)	Father 10.6% (14) Other 4.5% (6)
Marital status caregiver	Single 8.5% (11) Separated 8.5% (11)	Married 76.2% (99) Widowed 6.9% (9)
Location / region	Central 47.7% (63) East 19.7% (26)	West 21.2% (28) North 11.4% (15)

Results - Social functioning

Variable	Relationship with peers	Pro-social behaviour	Social communication
Daily functioning skills	2.18*	25.91***	33.04***
Lack of assistive devices	0.91	4.18*	2.41*
Incontinence	0.08	0.52	3.00
Practices CIC	2.11	13.38***	10.45***
Schooling	0.54	2.14	2.39
Parent support group	0.09	8.23**	5.63*
Region	6.93***	4.70**	4.56**

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

Daily functioning



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.

Mobility and assistive devices

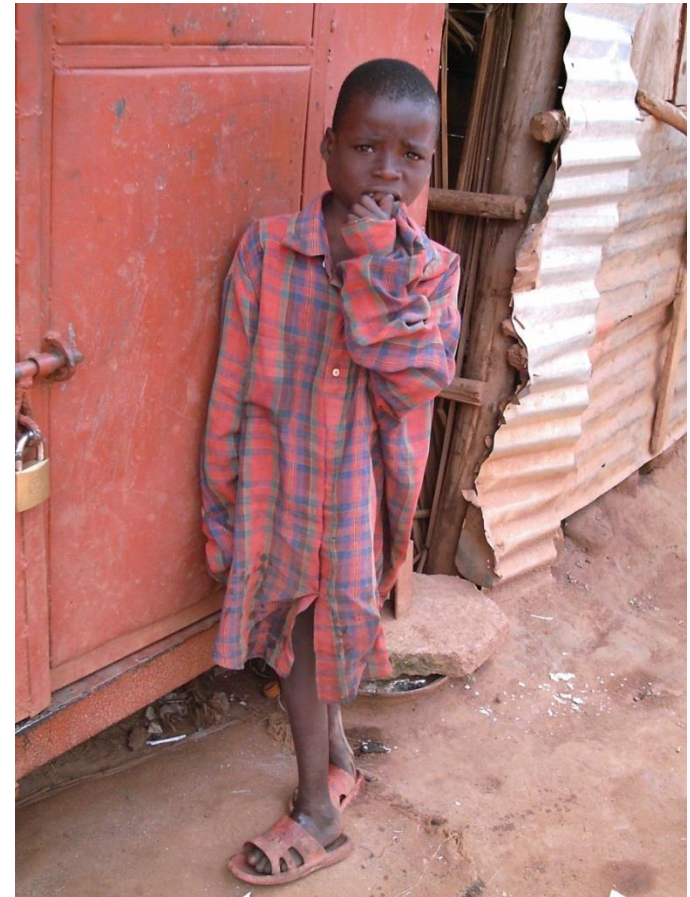
63.6% (84) of the children interviewed need assistive devices for mobility:

- 29.8% (25) use a wheelchair (7.6% of them on their own)
- 21.4% (18) uses crutches
- 6.0% (5) use walking frames
- 42.9% (36) crawled due to lack of access or use of a device. Almost all these children have pressure sores, mostly on their feet



Incontinence and CIC

- 89.4% (118) is incontinent, and practices bowel wash out (70.5%) and clean intermittent catheterization (75.8%). 15.9% practices CIC, and 4.9% practices bowel management on their own
- Practicing in school and public places is difficult due to lack of facilities and adults to. In school 15.2% can practice.



Schooling

Children with spina bifida	Total
Not schooling	58 (45.0%)
Nursery school	46 (35.7%)
Primary school	21 (16.3%)
Secondary school	4 (3.0%)



- 55% of children with SB in school vs 83% nationally
- Approximately 1 year behind their age mates
- Reasons for not schooling: inaccessibility, financial problems, incontinence, and bullying

Parent Support Groups

- 38.9% (51) parents are members of parent support groups (self help groups)
- 48.1% (63) have support from another adult in the care for their child



Geographical differences

Subscale scored	Sum of Squares	df	Mean Square	F	P-value
Vineland social subscale	129.926	3	43.309	4.562	0.005
SDQ peer subscale	67.542	3	22.514	6.934	<0.001
SDQ pro-social subscale	238.000	3	79.333	4.700	0.004

Children with spina bifida from the war affected northern region have lower social functioning scores compared to children from other regions.



Results – Predictors Social functioning

Predictors	Relationship with peers	Pro-social behaviour	Social communication
	β	β	β
Daily functioning skills	0.52**	0.57**	0.65***
Lack of assistive devices	-0.07	-0.03	0.04
Incontinence	0.10	0.07	0.14
Practices CIC	-0.07	0.24	0.15
Schooling	0.41*	0.16	0.21*
Parent support group	-0.11	0.20	0.14
Region	0.32*	-0.11	0.12

Multiple regression analysis * $p < .05$; ** $p < .01$; *** $p < .001$

Recommendations

- To improve social participation of children
 - improve daily functioning skills through early intervention and community based rehabilitation
 - use of catheterization at home and public places
 - support inclusion in schools
 - provision of relevant assistive devices
 - promoting participation in parent support groups
 - specific interventions in the war affected north
- Longitudinal studies to assess predictors and evaluate interventions to promote social functioning and inclusion over time

A young child with dark skin is sitting on a wooden step in the doorway of a building with thick, textured mud-brick walls. The child is wearing a light blue long-sleeved shirt and bright yellow pants. They are looking towards the camera with a slight smile. A white cloth hangs from the top of the doorway, and a striped fabric is visible hanging inside the room behind the child. The scene is brightly lit, suggesting daylight.

Thank you



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