

# **Assessment of community perceptions, beliefs and societal-traditional practices toward disability that inhibit Occupational Therapy intervention and rehabilitation for children with Spina Bifida and Hydrocephalus in Northern Uganda**

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# Acronyms

- 1) **AVSI**: International Services of Volunteers' Association
- 2) **GROW**: Gulu Regional Orthopedic Workshop
- 3) **SB/H**: Spina Bifida and/or Hydrocephalus
- 4) **IFSBH**: International Federation for Spina Bifida and Hydrocephalus
- 5) **PIH**: Post Infectious Hydrocephalus – Acquired Hydrocephalus
- 6) **FGDs**: Focuss Group Discussions
- 7) **NIH**: National Institute of Health
- 8) **NPHC**: National Population and Housing Census
- 9) **UBOS**. Uganda Bureau of Statistics
- 10) **MoH**: Ministry of Health
- 11) **CCHU**: Cure Children Hospital of Uganda

# Introduction

- Spina Bifida and/or Hydrocephalus are major global health burden and causes of disabilities *(Colin Kennedy MD, Jim Stevenson PhD, Department of Psychology, University of Southampton, Southampton, UK.)*
- But currently under-recognized by government healthcare systems especially in developing countries.
- They occur at a range of 0.5–10 or more in 1,000 live births worldwide
- Globally, it is estimated that approximately 300,000 babies are born each year with NTDs (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4827875/>)

# Introduction cont...

- Prevalence estimates vary widely in the World Health Organization (WHO) regions and World Bank income classifications
- Uganda has no clear data about SB/H but its estimated that more than 1.5 /1000 births are born with Spina Bifida
- and 3-5/1,000 live births are born with or acquire Hydrocephalus (*CCHU 2016*)
- 10% of the total population in Uganda live with disability (*World bank and NPHC, UBOS 2014*)

# Definition

- Spina bifida, '*a cleft spine*'
- It is a neural tube defect characterized by incomplete development of Brain, Spinal cord and /or Meninges.
- The defect occur during the first trimester
- It can occur at any point along the spinal column.



# Definition cont...

- Hydrocephalus
- Excessive accumulation of cerebrospinal fluid (CSF) in the brain ventricles.
- Not merely increased size of the head
- But accumulation of CSF which is characterized by increased intracranial pressure (ICP)



# Background

- ✓ AVSI Foundation, is an international not for profit non-governmental organization
- ✓ Has been working in Northern Uganda since **1984** providing health care, education, social economic and development services.
- ✓ AVSI began her collaboration with IF in the year **2008**, by referring **51** SBH clients for surgery
- ✓ The number has increased exponentially to currently **509** clients in the follow up program
- ✓ The mean age of clients in follow up program is 3.5 years
- ✓ Annually, AVSI refers 54 SB/H for Neurosurgery

# Study approach and objectives

- ✓ Qualitative approach was used to:
  - i. Assess socio-cultural practices of communities in Agago district in addressing health needs of children living with SB/H
  - ii. Dispel myths about SB/H and scale up preventive and rehabilitative awareness
  - iii. Dialogue with the community



# Methodology

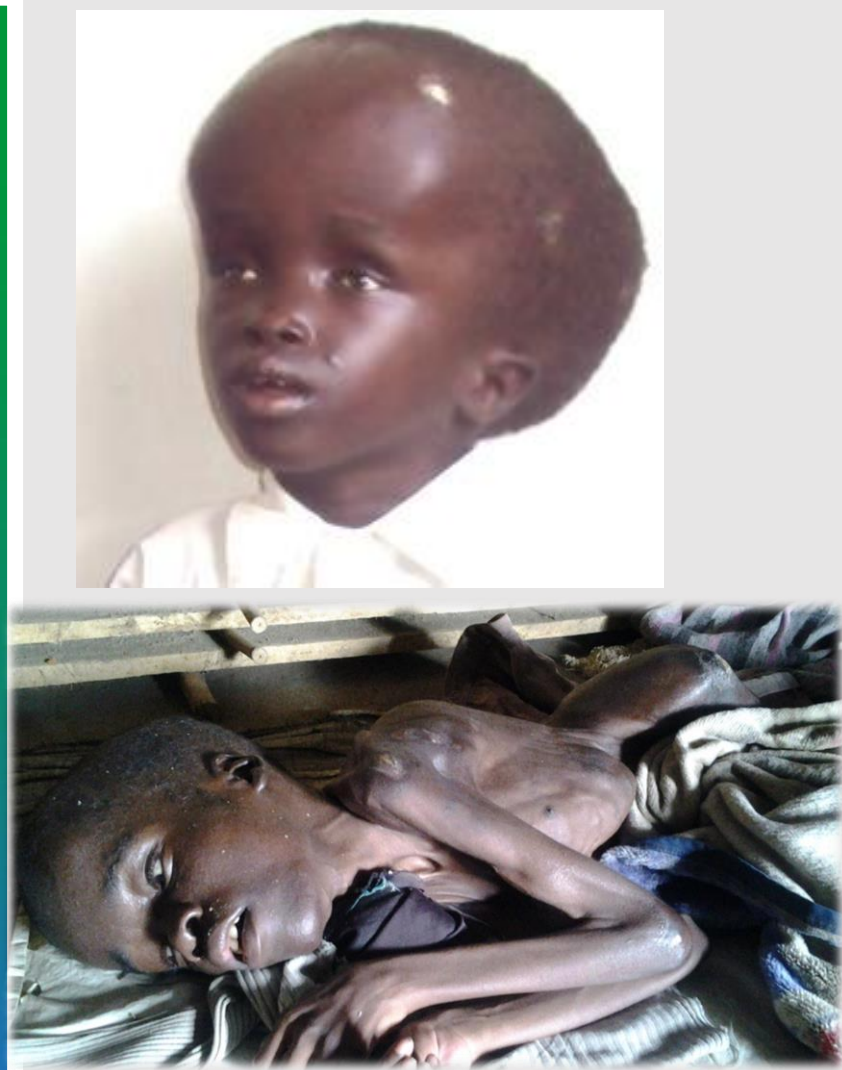
- ✓ Qualitative methodologies in this study include
  - Interviews with mothers during clinic visits
  - Focus Group Discussions
  - Dialogue with local leaders during a community outreaches.
  - Follow up of clients in the community

# Sample size and selection criteria

- ✓ Convenience/purposive sampling technique was used
- ✓ Krejcie & Morgan (1970) Table for sample determination was used to determine sample size.
- ✓ **Inclusion criteria:**
  - i. Children age 0 – 5 years, born with SB/H or acquired Hydrocephalus
  - ii. Under went Neurosurgery in 2012 – 2016.
  - iii. Defaulted follow up for rehabilitative Occupational Therapy interventions

# Interviews, FGDs and Community dialogue

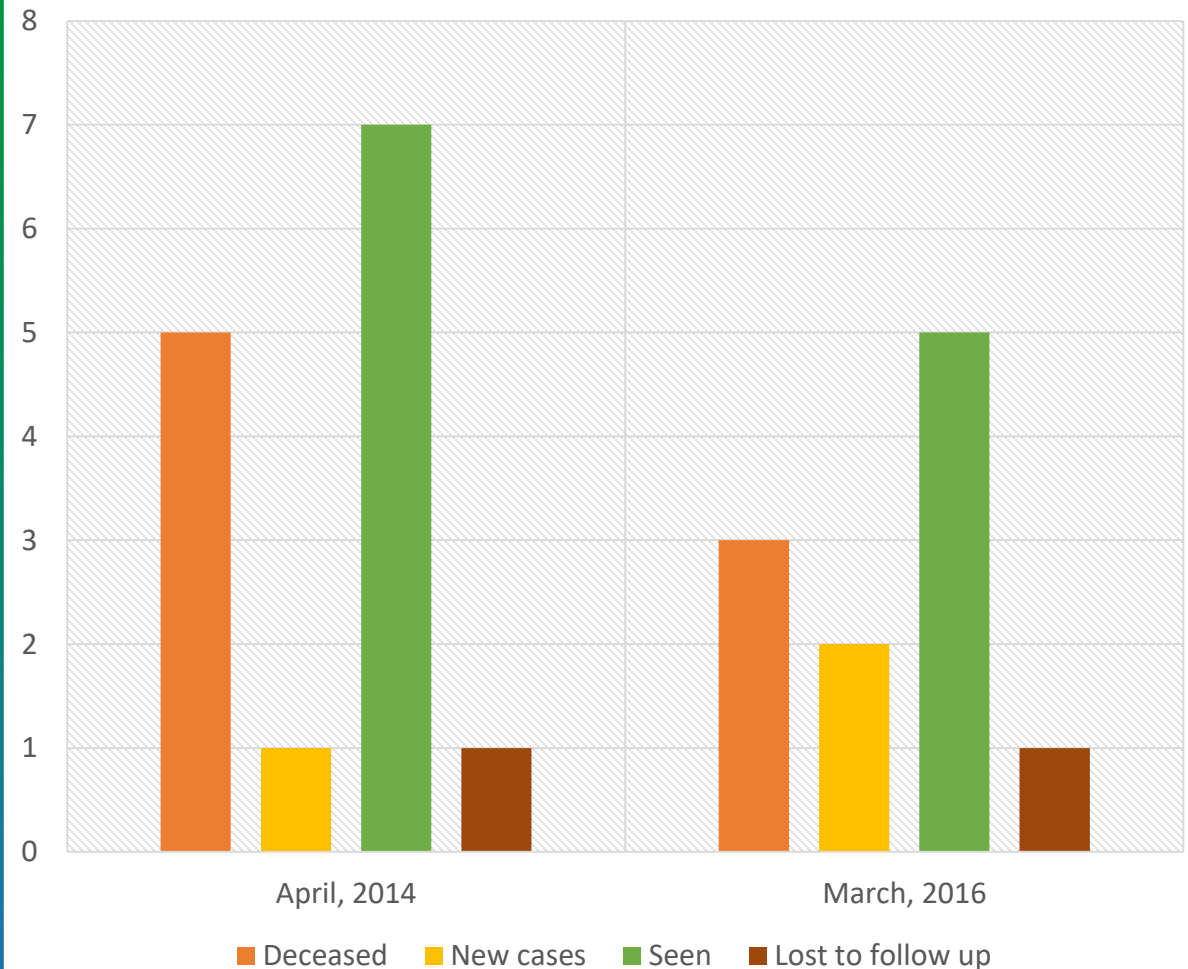
- SB/H is believed to be a misfortune and a punishment from *god*
- It is disgrace to a family
- They are kept indoor.
- they are either starved to death
- Or drawn in water
- If died, they are burried at the river bank



# Follow up

- Fourteen children with Spina Bifida/or Hydrocephalus in Agago district (Northern Uganda) were followed up in two years
- No clear evidence of the actual cause(s) of death
- Collateral informants stated that rituals were performed
- The rate of domestic violence and divorce is high
- Lost to follow up could have been due to fear to disclose the demise

Retrospective Follow up of Children with SB/H in Agago district in the years 2014/2016 respectively



# Factors influencing community practices

- The nearest Neurosurgical hospital is about **336km** from GROW
- GROW serves the entire region which is about **85,391km<sup>2</sup>** and has population of about **7,188,139** (NPHC, 2014)
- Majority of care givers to children living with SB/H are poor single mothers.
- Most of SB/H clients are left to be cared for by their grand mothers

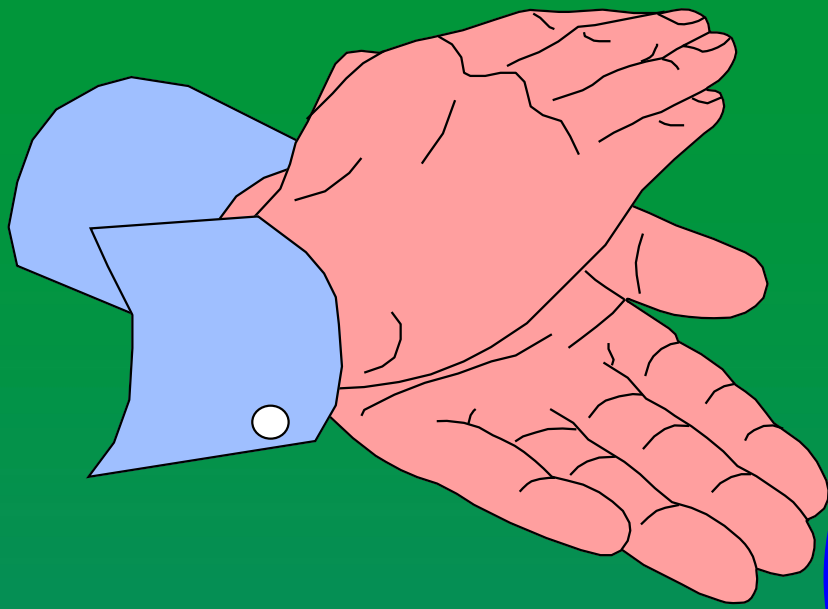
# Conclusion

- Health practices of the society are greatly influenced by traditional beliefs, Culture and norms and level of literacy.
- To some extent, political and Economic factors plays a role decision making.
- Revitalization of community based health care approaches is the immediate remedy.
- Community dialogue and health education and fundamental.



# Picture





***Thank You***

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