International Conference On
CHILD PROTECTION
IN AFRICA

From Vulnerability to Resilience, Innovation and Evidence

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Enabling Environment for children living with spinabifida & hydrocephalus

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AVSI Foundation: Origin, Vision and Mission

**AVSI Foundation** is a non-governmental organization born in 1972.

**AVSI** works for a world where every person, aware of her value and dignity, is the main protagonist of her own integral development and that of her community, even in crisis and emergency contexts.

**AVSI** implements cooperation projects in various sectors with a preferential focus on education, meaning that the person is accompanied towards self-discovery and recognition that the other person is a good for me. Each project is conceived of as an instrument to promote this awareness in all persons involved, carries in itself a need for communicating and sharing, and creates an impact capable of generating positive change.
Sectors
- Education+ ECD
- Food security and Nutrition
- Agriculture
- Health
- Protection
- Psychosocial care
- Family strengthening
- Economic strengthening
- WASH
- Energy and environment
- Urban development
- Emergency
• Spina Bifida and/or Hydrocephalus is one of the most common Neural Tube Defects.

• It is more common in low income countries due to lack and/or late start of intake of folic acid.

• Spina bifida is one of the commonest Neural Tube Defects (NTD) affecting 1/1000 life birth globally (Warf, Write & Kulkarni, 2011).

• Majority of children with Spina bifida develop hydrocephalus.

• However, Post Infectious Hydrocephalus (PIH) is more common than congenital hydrocephalus.

• Complications: Feecal and urinary incontinence, Urinary Tract Infection, Renal system Organ failure, pressure wound and physical dysfunctions due to damages caused to the nerves.
• Estimate: SBH incidence rate is 2-4 per 1,000 births; translating to 5,000 to 6,000 new cases of hydrocephalus per year including both congenital and post-infectious hydrocephalus and 800-to-1,000 new cases of Spina Bifida. (CURE Children’s Hospital, 2016).

• The project is being funded by IF Global; 2009 to date.

• The project aims at improving the quality of lives of children with SB/H in Northern Uganda.

• Annually the project sees over 400 children with SBH; 3.5 years.

• The project site is at Gulu Regional Rehabilitation Centre in Gulu Regional Referral Hospital Northern Uganda.

• The Centre was built by AVSI during the war in 1998 using donor funding.
Enabling Environment (1/2)

Both Functional and environmental

- Community Dialogue (schools and villages)
- Family mediations
- Parents Support Group
- Psychological support (individual, couple, group)
- Home Based care/Community Based Rehabilitation
- Encourage enrolment in inclusive schools (exception special needs)
- Disable friendly structures e.g. access ramps, latrine, home environment
Enabling Environment (2/2):

Both Functional and environmental

- Intake increased from 51 children in 2009 to 509 in 2018
- Average Referral to CURE from 10 to 54 annually
- PSG: from 52 to 140
- 18 /96 youths knowledgeable/maintain hygiene
- 20 children in regular schools
- Cases of family friction reducing
Replicability: Enabling Environment

- Assessment (conditions, areas for intervention/referrals)
- Ask share experiences/fears etc
- Encourage active participation of caregivers/parents (support group)
- Work together on agreed intervention
- Encourage meaningful participation by children
- Duties & responsibility of child
- Partnership with other stake holders
- Follow up
Scalability: Enabling Environment

- Group therapy to handle increasing demand.
- Empowerment of support group (advocacy, lobbying, management)
- Support groups – government programmes in community
- Experience sharing across geographical regions, cultures
Lessons learnt: Enabling Environment

- Community involvement is vital for any project success (ownership)
  - Selection
  - Planning
  - Implementation

- Use of locally and low cost materials are culturally acceptable
Recommendation: Enabling Environment

- Community champion testimonies – change societal attitude /stigma around disability.
Our contacts

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