

CONCEPT NOTE FOR SPINABIFIDA & HYDROCEPHALUS AWARENESS NETWORK (SHYNEA –UGANDA) 2016-2017

1. ORGANIZATION BACKGROUND

The Organization is called Spinabifida and Hydrocephalus awareness network, Uganda (SHYNEA- UGANDA). The Organization is fully registered according to the laws of the Republic of Uganda; registration number- 1128 and provides equal opportunities regardless of an individual's race, creed, ethnic origin, political belief, gender, disability.

The Organization offices are located at Mengo, Musajja'lumbwa Zone, Kampala central Division in the Republic of Uganda.

Vision:

A platform where every individual with Spinabifida & Hydrocephalus (SBH) realizes their full potential and put to use the available resources for better health and development.

Mission:

To create and foster a co-operative network of various social agencies; to effectively influence policies, programmes and practices of government in order to holistically meet the needs of children with spinal bifida and hydrocephalous and support their care takers.

Objectives:

1. To Raise public awareness and advocate for rights of children with SBH to become more visible and to understand what life is like for people with SBH and their care takers
2. To create and foster a co-operative network of various social agencies as change agents to address the challenge that people with Spinabifida and Hydrocephalus meet
3. To promote empowerment and participation of people with Spinabifida and Hydrocephalous in expression of their needs, concerns, aspirations and condition management.
4. To ensure availability of a comprehensive pool of relevant resources for stakeholders through information, education, and communication.
5. To support SBH children and their care takers to receive holistic care that is physical, emotional, spiritual and legal.

Core Values

- Value and Respect for every person with or without SBH
- Work for excellence
- Accountability and transparency
- Positively influence society perception of our members
- Use resources ethically, considerately and sensibly

2. WHAT WE DO

- Creating awareness in the general population on SBH through campaigns, partnership and networking, seminars, workshops and media.
- Advocating for effective and sensitive policies for provision of quality services for children with SBH.
- Promoting interventions on; disability Counseling, Nutrition Education, home Based Health Education, Psychosocial Support and Resource Mobilization and Capacity Building.
- Emphasising on viewing SBH psychosocial support as a right to all individuals, families and communities affected by the condition.
- Supporting optimum child development by increasing knowledge, demonstrating good management techniques and facilitating, movement, play and skill development.
- Giving advice for referrals and also do home visits/follow up to ensure that children are well integrated to reach their full potential.

Our target groups

- Our primary target is children, and families affected by spinabifida and Hydrocephalus, followed by communities, government & non-government organisations, medical support systems, education and human rights institutions as the secondary target.

3. SITUATIONAL ANALYSIS:

Despite the Private and Government's effort to reduce infant mortality rate, an estimated 1,400 children are born with spinabifida in Uganda annually [Warf BC, et al 2011). Incidence and prevalence rates in Uganda are probably higher due to absence of foliate (Folic acid) consumption by pregnant women, lack of pre-natal care, and absence of secondary prevention, higher exposure to environmental risk factors such as dioxins and fumonisins intake and high birth rates. (Miles M. 2006; Frey L and Hauser WA. 2003; Safi J, et al 2012; Hendricks K. 1999. Most children born with spina bifida need surgery to close their back in order to prevent infections. Children with spina bifida and progressive hydrocephalus also often need surgery to prevent secondary impairments (IFSBH, 2014). Children with spina bifida experience mobility challenges and incontinence which affect their participation in daily activities, and require the use of assistive devices and continence management (Abresch, McDonald, Widman, McGinnis, & Hickey, 2007; Andren & Grimby, 2000; Danielsson et al., 2008; Jansen, Blokland, de Jong, Greving, & Poenaru, 2009). Surgery and rehabilitative care is expensive and inaccessible for many children born with a disability in Africa. Their families are often their main source of care and protection (Guyer, 1981). Families living in poverty often struggle to find resources to provide this care and protection (Miles, 2002) as external and government support is limited (van der Mark & Verrest,2014).

Children in Uganda suffering from hydrocephalus & neural tube defect have little hope for a productive future. If left untreated, infant hydrocephalus leads to significant brain damage, severe developmental delay, blindness, and ultimate death. Such children have continuously remained subject to various forms of discrimination and marginalization due to negative attitudes, superstition, neglect, social norms and practices, and poor recognition of their rights (UNICEF, 2013, WHO,2011). According to our experience, when children with disabilities are denied their basic rights, such as access to health care, education, and rehabilitation, their ability to develop to their full potential is severely compromised.

Majority of the Ugandan population are not familiar with the causes and management of spinaBifida and hydrocephalous despite the attempts for example Cure Hospital to subsidise on the treatment cost. Families do not seek for treatment because of the negative perceptions and stigma around the conditions. They are concerned about costs, have little or no access to

management centres, or don't realize that conditions in early infancy can lead to permanent disability yet the condition may be treated/reversible.

Spinabifida & Hydrocephalus coupled with chronic poverty and inadequate psychosocial support services have placed enormous stress on families and communities in Uganda.

Households with Spinabifida/Hydrocephalus affected children require extensive care and attention. Care takers who are able to work find their incomes insufficient to pay for their children's medical and rehabilitation needs and other needs, while the majority are barely able to afford any treatment at all.

In many communities, stigmatization compounds the problem, as SBH persons are isolated and avoided. Many families keep to themselves rather than meeting other people to talk about their common problems and concerns.

With the long duration of the condition, multiple complications associated with the disease, high cost of treatment and management, SBH patients and their families suffer a lot of psychological, social and economic trauma.

Therefore, creating awareness about SBH and sourcing support for the individuals and families affected by Spinabifida/Hydrocephalus is an urgent intervention in Uganda.

5. Proposed activities and expected outcomes:

- Facilitate creation of awareness about SBH condition preventive and management measures as well as demystify myths against SBH
- Mobilize SBH children and affected families to advocate for attention and prioritization of their wellbeing by the concerned stakeholders.
- Promote family and community dialogues to enhance adequate family support and care among SBH affected families.
- Mentor cadres of psychosocial support promoters in and around Kampala to offer ongoing support, transfer essential nursing skills and coordinate with the National platform.
- Scale up access to meaningful counseling to enhance the resilience of SBH affected families and thrive all through the stages.

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- Facilitate SBH persons and their immediate family members with social economic support skills for survival with the children's health as a priority.
- Develop appropriate SBH IEC psychosocial support materials e.g. Memory books among SBH affected families
- Scale up fundraising drives to enhance the well-being of SBH persons and sustain the delivery of our services.
- Facilitate the translation of findings of biology investigation into social application to deal with the health problem and treat the social part of the situation with objectivity.
- Scale up efforts to facilitate the professional development of our frontline team through capacity building initiatives to deliver quality services.
- Facilitate annual institutional audit

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