A Methodological and Desk Review Evaluation of the RHF and IF Supported Regional Programme for Early Intervention, Treatment and Rehabilitation of Children with Spina Bifida and/or Hydrocephalus in Eastern, Central and Southern Africa Regions (2009-2014)

FINAL REPORT
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Acknowledgments

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## Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>ADD</td>
<td>Action for Disability</td>
</tr>
<tr>
<td>ANC</td>
<td>Antenatal Clinics</td>
</tr>
<tr>
<td>ASBAHT</td>
<td>Association for Spina Bifida and Hydrocephalus Tanzania</td>
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<tr>
<td>BK</td>
<td>Bethany Kids Hospital</td>
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<td>CBM</td>
<td>Christian Blind Mission</td>
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<td>CBOs</td>
<td>Community-Based Organizations</td>
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<tr>
<td>CBR</td>
<td>Community-Based Rehabilitation</td>
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<tr>
<td>CDC</td>
<td>Centre for Disabled Children</td>
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<tr>
<td>CIC</td>
<td>Clean Intermittent Catheterisation</td>
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<tr>
<td>CSF</td>
<td>Cerebrospinal Fluid</td>
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<tr>
<td>CSOs</td>
<td>Civil Society Organizations</td>
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<tr>
<td>CT scan</td>
<td>Computed Tomography Scan</td>
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<tr>
<td>CU</td>
<td>Central Uganda</td>
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<tr>
<td>CU-SBH</td>
<td>Central Uganda Spina Bifida and Hydrocephalus Network</td>
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<tr>
<td>DPOs</td>
<td>Disabled People’s Organizations</td>
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<tr>
<td>DRC</td>
<td>Democratic Republic of Congo</td>
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<tr>
<td>ETV</td>
<td>Endoscopic Third Ventriculosomy</td>
</tr>
<tr>
<td>EU-SBH-NET</td>
<td>Eastern Uganda Spina Bifida and Hydrocephalus Network</td>
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<tr>
<td>FA</td>
<td>Folic Acid</td>
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<tr>
<td>FGDs</td>
<td>Focus Group Discussions</td>
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<tr>
<td>GDPU</td>
<td>Gulu Disabled Persons’ Union</td>
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<td>GROW</td>
<td>Gulu Referral and Orthopaedic Workshop</td>
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<tr>
<td>H or HIC</td>
<td>Hydrocephalus</td>
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<tr>
<td>HIV/AIDS</td>
<td>Human Immunodeficiency Virus</td>
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<tr>
<td>IDI</td>
<td>Individual Interview</td>
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<tr>
<td>IF</td>
<td>International Federation for Spina Bifida and Hydrocephalus</td>
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<tr>
<td>IFAD</td>
<td>International Fund for Agricultural Development</td>
</tr>
<tr>
<td>IGAs</td>
<td>Income-Generating Activities</td>
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<tr>
<td>KCH</td>
<td>Katalemwa Chesire Home</td>
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<tr>
<td>KII</td>
<td>Key Informant Interview</td>
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<tr>
<td>M&amp;E</td>
<td>Monitoring and Evaluation</td>
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<tr>
<td>MoH</td>
<td>Ministry of Health</td>
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<td>MoU</td>
<td>Memorandum of Understanding</td>
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<td>NBI</td>
<td>Nairobi</td>
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<tr>
<td>NCD</td>
<td>National Council for Disability</td>
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<tr>
<td>NGO</td>
<td>Non-Governmental Organization</td>
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<tr>
<td>NORAD</td>
<td>Norwegian Agency for Development Cooperation</td>
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<tr>
<td>NTDs</td>
<td>Neural Tube Defects</td>
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<tr>
<td>NUDIPU</td>
<td>National Union for Disabled Persons in Uganda</td>
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<tr>
<td>OURS</td>
<td>Organized Useful Rehabilitation Services</td>
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<tr>
<td>PASHL</td>
<td>Parent Association for Spina Bifida and Hydrocephalus Limited</td>
</tr>
<tr>
<td>PSG</td>
<td>Parent Support Group</td>
</tr>
<tr>
<td>QECH</td>
<td>Queen Elizabeth Central Hospital</td>
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<tr>
<td>RAPCD</td>
<td>Rwenzori Association of Parents with Children with Disabilities</td>
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<tr>
<td>RHF</td>
<td>Ryggmargbrokk-og hydrocephalus foreningen [Norwegian Association for Spina Bifida and Hydrocephalus]</td>
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<tr>
<td>SACCCOs</td>
<td>Savings and Credit Cooperatives</td>
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<td>ASBAHT</td>
<td>Association for Spina Bifida and Hydrocephalus Tanzania</td>
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<td>SBFA</td>
<td>Spina Bifida Federal Association</td>
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<tr>
<td>Abbreviation</td>
<td>Full Form</td>
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<tr>
<td>SBH</td>
<td>Spina Bifida and Hydrocephalus</td>
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<tr>
<td>SHAK</td>
<td>Spina Bifida and Hydrocephalus Association Kenya</td>
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<tr>
<td>SHA-U</td>
<td>Spina Bifida and Hydrocephalus Association Uganda</td>
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<tr>
<td>SHIA</td>
<td>Swedish Organization of Persons with Disabilities International Aid Association</td>
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<tr>
<td>SHIP</td>
<td>Spina Bifida and Hydrocephalus Interdisciplinary Programme</td>
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<tr>
<td>TBA</td>
<td>Traditional Birth Attendants</td>
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<tr>
<td>TOTs</td>
<td>Training of Trainers</td>
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<tr>
<td>UNDP</td>
<td>United Nations Development Programme</td>
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<tr>
<td>UNICEF</td>
<td>United Nations Children’s Emergency Fund</td>
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<tr>
<td>UTI</td>
<td>Urinary Tract Infection</td>
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<tr>
<td>VHT</td>
<td>Village Health Teams</td>
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<tr>
<td>WHO</td>
<td>World Health Organization</td>
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<tr>
<td>ZAHSB</td>
<td>Zambia Association for Hydrocephalus and Spina Bifida</td>
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Executive Summary

Background
For the last 14 years, the International Federation for Spina Bifida and Hydrocephalus/Ryggmargsbrokk-og Hydrocephalus Foreningen [Norwegian Association for Spina Bifida and Hydrocephalus](IF/RHF) Regional Programme has been receiving annual funding from the Norwegian Agency for Development Cooperation (NORAD) and Atlas Alliance under its long-term agreement. Under its mission to reduce the prevalence and improve the quality of life of persons with spina bifida and hydrocephalus (SBH), the programme has disbursed funds to its network partners in six African countries. These include Uganda, Kenya, Tanzania, Sudan, Malawi and Zambia. The partnership is essentially aimed to complement existing efforts by building on what has already been achieved by parents and the existing service delivery systems. However, it also covers both the medical and lifelong follow-up mechanisms jointly designed by all local NGO stakeholders – the service providers and members of the Disabled People Organizations (DPOs). Through this continuous process, IF/RHF has over the decade long period been able to augment the ‘Solidarity in the South’ slogan by translating the latest knowledge of the North into realistic care for its local partners in the South.

Objectives of the evaluation
This evaluation aimed at assessing the relevance, effectiveness and sustainability of the programme. Its specific objectives included the following:

- Assessing the relevance and clarity of the objectives of the programme related to the challenges of the target group and the strategies and working methods for reaching these objectives, including gender equality strategies
- Determining the impact of the programme on the local DPOs and their members
- The impact of the local DPOs on the individuals and communities in which they operate.
- The sustainability of the results achieved and interventions being implemented by the DPOs.
- Documenting lessons learnt from the implementation of the programme.
- Providing recommendations that IF and RHF can use to improve the design and implementation of the programme.

Evaluation methodology
This evaluation exercise was undertaken basing on the design and approach tailored to achieve its specific objectives outlined in the terms of reference (TOR). It employed a qualitative approach that involved desk review of country narrative reports, activity plans by the local partners, online questionnaires, Skype-based interviews and field site visits. In terms of primary data collection, personal (in-depth) interviews, focus group discussions (FGDs), key informant interviews (KII) and telephone-based interviews were used. The range of respondents interviewed for the evaluation included executive members of the DPOs, parents and guardians/caretakers of children affected by SBH, children and youth affected by SBH, and SHIP coordinators and other healthcare workers in SBH service organizations. A semi-structured (in-depth) interview guide was the main instrument for collecting data for this exercise, supplemented by a FGD guide. Although the evaluation team faced limitations such as inadequate time and financial resources to facilitate the sampling of respondents from a wide geographical scope, memory loss and poor communication by some of the children and youth interviewed and a slow and generally low response rate by the online respondents, the process can – by and large – be considered a success.
Evaluation findings

Relevance
The evaluation exercise found that the programme is relevant to all the local stakeholders who are targeted by its activities. Specifically, the programme’s relevance is grounded in its pioneering role as not only the first to address SBH conditions in eastern and southern Africa but also the only civil society initiative to provide awareness, treatment and rehabilitation to the children and youth affected by SBH. Secondly, the programme has changed the past trend that saw almost all the children born with SBH either die immediately after birth or die afterwards for lack of treatment and rehabilitation. Thirdly, the programme has created accessibility to services for the target groups in the community, a move that has not only addressed their needs but also improved their quality of life and dignity. Finally, the programme’s relevance is also underpinned by the range of sensitization and advocacy initiatives that have created awareness about these two critical conditions and the efforts to fight varying forms of stigma and discrimination against parents, the affected youth and children.

Effectiveness and impact
Based on the assessment of the achieved observable or recorded outcomes of its interventions with reference to its set objectives, the programme has been found to be not only effective in some respects but also of profound impact on its individual beneficiaries and the community in general. The highlights of the effectiveness and impact include:

- **Prevention:** There is now an increased level of knowledge and understanding of the causes, prevention and management techniques of SBH. There are also adequate and reliable supplies of folic acid for all expectant mothers. The DPOs and service providers are also effective in undertaking follow-up home visits to ensure that the folic acid supplied to the expectant mothers is utilised according to the instructions.

- **Treatment and rehabilitation:** The DPOs have been effective in mobilizing communities to ensure that more children affected by SBH receive treatment and rehabilitation. Many affected children and youth have also been able to acquire assistive devices such as wheelchairs to enable them to move more conveniently from one place to another.

- **Networking and collaboration:** Most DPOs have been effective in trying to establish networks with government, the private sector and civil society organizations. Through these networks, they have been able to leverage their operations to supplement IF funding. However, the evaluation revealed that the concept of networking is not well understood by some DPOs/support groups. For example, some of them regard organizations or individuals who give them one time donations and grants to be their partners.

- **Training in continence and bowel management:** It was revealed that many parents with children affected by SBH have received training in the biomedical management of continence and bowel management. In some countries the training initiatives are undertaken by the DPOs in conjunction with the service providers. But in others it is initiated mainly by the service providers.

- **Support groups:** All the six countries have established support groups with a burgeoning membership. For example in Uganda the support groups which are organized at varying levels of leadership, comprise between 200 and 550 members in each of the regions. The situation is nearly the same in the other countries involved in the evaluation exercise except for Malawi where the support groups in Blantyre and Zomba do not have many members as such.
Sensitization and advocacy: The DPOs have – through the use of the media, leaflets and other public forums have – effectively been able to sensitize the community about the causes, treatment and management of SBH and HC in all the six countries.

DPO administration: All the DPOs have been able to elect executive committees to steer their activities. Although some of them are still working under the wings of the established service providers, it is evident that the administrative structures that have been put in place are making it possible for them to fulfill most of their objectives.

Sustainability
- The DPOs have, to some extent, integrated SBH and HC into existing structures at the different levels. In Uganda and Kenya for instance, some DPOs have in conjunction with the service providers, been able to pioneer efforts to integrate services through engagement with nurses at the antenatal clinics in the hospitals.
- The close interaction and partnership between service providers and DPOs were perceived by DPOs as positively impacting on the capacity building of their members and structures.
- Some DPOs have engaged in a sustainability initiative by collaborating with the local government administrations in their localities to incorporate some components of their funding needs into the latter’s annual budgets.
- There are some signs that members of the support groups in almost all partner states have started responding positively to making contributions to self-sustainability of the support groups by for example; paying membership fee, getting involved in income generating activities, having monthly group savings and other contributions. Although these contributions are nominal, this is a strong indication of commitment to sustain these nascent structures.

Key challenges
- Looking after children affected by SBH requires a lot of financial resources to purchase the required materials and equipment, which most parents do not have. In addition, it also takes a lot of time for one to clean a child affected by SBH, which has made it difficult for some parents to engage in gainful employment. Other parents have had to resign from their formal jobs to stay at home and look after such children.
- Although some DPOs have lobbied national referral hospitals to incorporate the treatment and rehabilitation of SBH and HC children in their units, the latter have not been forthcoming mainly because of the assumption that the two conditions are not as widespread among children as the other forms of disability.
- Some youth still fear to come out in public and participate in the anti-stigma and other sensitization campaigns for fear of being identified as SBH patients, which is still undermining the efforts to eliminate the conditions.
- Most DPOs have a large proportion of illiterate or semi-literate members, which makes it difficult for them to fully execute their sensitization campaigns.
- All the DPOs reported a lack of adequate financial resources to purchase office logistics such as computers, printers and scanners, which are important for their operational activities, such as record-keeping.
- Most DPO members live in poor conditions and cannot afford to pay for regular visits to the service providers – including surgical operations when required.
- The DPOs reported a shortage of qualified/skilled health care providers such as neurosurgical doctors and nurses, psychologists, social workers, physiotherapists,
occupational physiotherapists and psycho-social counselors, which makes them spend several hours/days waiting to be served by the service providers.

- Some women do not take folic acid because they lack adequate knowledge of when it should be taken. Some mothers also reported that they found taking folic acid repulsive due to its foul smell.
- The poverty levels among most parents make it difficult for most DPO members to provide the basic needs for their families – including their children affected by SBH.

Lessons learnt

- The provision of folic acid and mobilization of expectant mothers to improve nutrition have been critical in the primary prevention of SBH and HC.
- The lives of many children affected by SBH can be saved through effective prevention and management interventions.
- The current programme initiatives can greatly benefit from the integration of SBH services with the services of the Ministry of Health (MoH) and other government, private sector and civil society projects.
- Research – which is currently not a mainstream component of the programme – can add more value and impetus to the ongoing initiatives as it would further provide evidence of local solutions.
- DPOs need to get more involved in monitoring and evaluating the activities of the programme.
- Sensitization and advocacy might not necessarily be the magic bullets to eradicate SBH in the six countries but they are the key to creating awareness, removing stigma and improving the quality of life.
- The future of the programme depends on the development of strong sustainability initiatives for the DPOs.

Key recommendations

- Sign language communication and translation services should be introduced for children who cannot communicate using normal speech and language processes owing to their condition. The evaluation revealed that communication was a big challenge for some children and yet the DPOs/support groups did not have any qualified person/staff in sign language.
- There is need to start training of trainers (TOTs) to empower the parents and children/youth to train their counterparts in continence and bowel management. This will not only reduce the burden/shortage of health workers involved in such training activities but will also reduce the transport costs incurred by the parents from their respective homes to the DPO/service centres for training purposes. It is also our considered recommendation that the presence of such TOTs in the local communities will encourage more parents with SBH-affected children to disclose their conditions to the DPOs.
- DPOs in Uganda and other countries should be encouraged to follow the example of their counterparts in Tanzania and Sudan by targeting female students in universities and other institutions of higher learning in their SBH sensitization and advocacy campaigns. This will help in disseminating information about the need to take folic acid and other relevant information about the two health conditions before the females get pregnant.
- There is need to streamline networking and collaboration between the DPOs and the village health teams (VHT), traditional birth attendants (TBAs), community leaders
and other institutions/professionals, especially with regard to community sensitization regarding SBH, the use of folic acid, identifying children with SBH for treatment and outreach visits.

- There is need to introduce mobile vans to sensitize the rural communities about the SBH conditions.
- IF should consider providing seed funding to enable parents and youth to start income-generating projects to improve their livelihoods.
- There is need to consider establishing a vocational training institute for the youth who were not given a chance to go to school owing to their health condition and are now suffering with the double jeopardy of SBH and lack of education/skills.
- There is need for more competence-building or training of health providers, staff, children, youth, parents/caregivers of children with SBH and other stakeholders in the community in order to enhance their knowledge about SBH issues and also improve the quality of health delivery services.
- There is need to streamline sensitization through exchange visits by the various DPOs and workshops and seminars for sharing their experiences.
- There is need to integrate SBH training into the health workers’ curriculum.
- Where possible, the number of service providers should be increased to enable more parents/guardians/caretakers and youth to access SBH treatment and rehabilitation services near or within their communities.
- Schools, health centres and other public facilities should set up facilities and the necessary equipment for children with SBH to enable them to utilize their services.
- IF should consider funding exchange visits for parents’ support associations (inter- and intra-country visits) to enable the sharing and exchange of knowledge and experience regarding managing SBH.
- There is need to develop more strategies for involving the youth, parents and care providers in the planning and implementation of the programme activities.
- There is need to develop strategies for encouraging men to be involved in the programme activities.
- There is need to build on the current internal resource strategies to expand them into more sustainable income-generating activities managed on a private sector model to generate profits that can be ploughed back into offering services.
- There is need to build on the current efforts by DPOs and service providers to strengthen the integration of SBH care, treatment and psycho-social support into health services offered at various levels of health services delivery.
- There is need to build the capacity of DPOs in resource mobilization. Each DPO should be facilitated to develop a resource mobilization strategy as part of their strategic planning processes.
- Many parents cannot read and write. Therefore it is important to use pictorial aid for awareness creation and during training.
- Research, monitoring and evaluation components should be established or improved. The evaluation revealed that there is a lot of information and data which DPOs can document through action research.
1 Introduction and Background

1.1 Introduction

This is a report of an evaluation of the Norwegian Association for Spina Bifida and Hydrocephalus (RHF) and the International Federation for Spina Bifida and Hydrocephalus (IF) supported Programme for Early Intervention, Treatment and Rehabilitation of Children with Spina Bifida and Hydrocephalus (SBH) in the East, Central and Southern Africa Regions (2009-2014). The Programme is implemented by RHF/IF partners in six African countries, namely Kenya, Malawi, Sudan, Tanzania, Uganda and Zambia. The RHF/IF Regional Programme has been receiving annual funding since 1998 as part of its long-term agreement with Norwegian Agency for Development Cooperation (NORAD) and Atlas Alliance. This report provides an evaluation of the relevance, effectiveness and sustainability of the interventions which address the needs of children with SBH, their parents and care providers. The evaluation focused on efforts to prevent and to provide pre- and post-care services to children/youth with SBH, their parents and caregivers. It also looked at knowledge and ownership of the programme by persons with SBH and their families. Lastly, the evaluation explored the lessons from the partnerships in order to serve as a basis for making decisions regarding future work and strategies of RHF’s and IF’s engagement in target countries in the South.

1.2 Background and context

There are between 785 million and 975 million people with various types of disability in the world and this represents between 15.6% and 19.4% of the global population. Eighty per cent of the people with disabilities in the world live in developing countries (WHO and World Bank, 2011). The majority of the persons with disabilities have limited or no access to basic services, including rehabilitation facilities, owing to prevailing high levels of poverty (www.who.int). Lack of health care, illnesses and injuries often lead to lasting disabilities. For the same reason, existing disabilities easily deteriorate, or new disabilities are added. Studies conducted in a number of southern African countries by SINTEF, for example, indicate that the living conditions of persons with disabilities in Malawi have shown that illness and injuries/accidents constitute the major causes of disability (see Loeb and Eide, 2004). The causes of disability include communicable diseases (e.g. meningitis, tuberculosis and measles), poor per-natal care, malnutrition/associated vitamin deficiencies and neural tube defects, a rise in chronic diseases, injuries, car accidents, falls, violence and ageing (2). Children with disabilities living in poor countries are especially vulnerable: only a few attend school and approximately 50% of the 120 million children who do not go to school have a disability (Norad, 2002). Also in Africa, disability is a major public health problem: there are approximately 35 million persons with disability in Africa. In Africa most of the persons with disability are found in rural areas where services for prevention and rehabilitation are either limited or totally unavailable.

However, although in Africa the delivery of health services is generally poor, the situation is several times worse for services for disabilities. Some studies (e.g. Loeb and Eide, 2004) found that while persons with disabilities are aware of available health services and that they need these services, a significantly lower proportion access such services. Access to health services especially for neurological conditions and severe disabilities is an enormous challenge. There is a tendency for disability to exclude the concerned persons from the rest of the community because of negative attitudes, unsuitable facilities or physical and social barriers, among other challenges. Public institutions often do not have strategies for dealing with disability and ensuring that the rights and needs of persons with disabilities are met.
1.3 Objectives of the evaluation
The main objective of the evaluation was to assess the relevance of the programme, the effectiveness of the programme and the sustainability of the programme. In this programme IF has been working with local DPOs and their members. This evaluation was, therefore, also aimed at determining the impact of the programme on these local DPOs and their members in the six focus countries and the impact of the local DPOs on the local situation. The study further explored the sustainability of the results achieved and interventions being implemented by the DPOs. Furthermore, the evaluation aimed at documenting the lessons learnt and to provide recommendations that the project partners, IF and RHF can use to improve the design and implementation of the programme.
A Description of Spina Bifida and Hydrocephalus

2.1 Spina bifida
One to two in a thousand live born children have spina bifida and 80% of them develop hydrocephalus in most parts of the world (M. Miles, 2006). ‘Spina bifida’ comes from the Latin word for ‘split spine’. It is one of the serious birth defects called neural tube defects (NTDs). This involves damage to the bony spine and the nervous tissue of the spinal cord. Some vertebrae of the spine fail to close properly during development and the spinal cord nerves fail to develop normally. This defect occurs within the first four weeks after the mother becomes pregnant. The exposed spinal cord nerves can be further subjected to more damage. Spina bifida occurs in varying degrees such that nerve signals to most parts of the body located below the ‘split spine’ are damaged, resulting in a wide range of muscles, organs and bodily functions being affected. This condition can occur at any place along the spine. The exact cause is not completely understood but it appears that a combination of genetic, nutritional and environmental factors is responsible.

Research shows that this condition occurs partly owing to lack of absorption of folic acid before and during the first weeks of the pregnancy. Folic acid can prevent up to 70% of spina bifida cases if taken daily from two months before and until three month after conception. The recommended dosage is 400 micrograms (see Centre for Disease Control and Prevention, 1992). Additionally, natural foods such as asparagus, spinach, oranges, bananas, legumes etc., which are rich in foliate, are recommended for inclusion in the diet of the pregnant woman. Spina bifida cannot be cured, though medical interventions mean that many people with the condition now live into old age and have a good quality of life. There are three types of spina bifida, namely: Spina bifida occulta, meningocele and myelomeningocele (Mile, 2002).

Spina bifida occulta: A mild form of spina bifida in which the spinal cord and the surrounding structures remain inside the body, but the back bones in the lower back area fail to form normally. There may be a hairy patch, dimple, or birthmark over the area of the defect. Other times, there may be no abnormalities in the area.

Spina bifida meningocele: With this type of spina bifida, a sack is visible on the child’s back. This sack contains cerebrospinal fluid (CSF) and membranes which surround the spinal cord. CSF is the fluid which circulates in the cavities (ventricles) inside the brain. The spinal cord stays in its proper place, and the nerves are usually not damaged. This is the least common form of spina bifida.

Spina bifida myelomeningocele: This is the most common and most serious form of spina bifida. The sack has CSF, nerve tissues and part of the spinal cord is also present. This means that the spinal cord is damaged and not properly developed and the result is weakness in the lower limbs, abnormality of the feet, and urine and stool incontinence, depending on the location of the sac on the child’s back. Owing to nerve damage that occurs, children with spina bifida do not have normal senses of feeling and pain in their bodies, legs and feet. In some children, there may be total lack of feeling below the level of the sac, while others may lack feeling just around the toes.

2.2 Hydrocephalus
‘Hydrocephalus’ comes from the Greek words hydro which means ‘water’ and cephalus which means ‘head’. This condition is sometimes referred to as ‘water on the brain’ (RHF/IF,
Hydrocephalus is a result of too much CSF causing an increase in pressure within the skull. Normally there is a balance between the production and the absorption of CSF. If the drainage pathways are obstructed, which is the case when hydrocephalus develops, the fluid accumulates in the brain ventricles, resulting in compression of the surrounding tissue. The condition can be present at birth, and in premature babies, children and adults. There are many other causes of hydrocephalus besides obstruction of the normal CSF pathways caused by abnormal brain anatomy, as is the case with spina bifida. Among others, it can also be the result of meningitis, tumors, cysts, trauma or intracranial bleeding, which occurs more frequently following premature birth. Hydrocephalus is much more common in Africa owing to post-natal infections (Warf and the East African Neurosurgery Research Consortium, 2010). Approximately 2-3 out of every 1,000 newborns, or even a higher number when there is contamination of foodstuffs with fumonisin, will have hydrocephalus (IF, 2012). More than 60% of the children with spina bifida also have hydrocephalus. However, even in old age, one can get hydrocephalus.

The symptoms of hydrocephalus can be observed by measuring the size of a baby’s head. If the head is growing too quickly, then a doctor should be contacted. Other signs are large veins on the scalp and the baby appearing to look downwards, drowsiness, fits and vomiting. In some conditions, no treatment is required, while in others treatment is short-term. Most often hydrocephalus requires long-term treatment and follow-up. Surgical treatment is the usual course of action and this involves the insertion of a shunt to drain excess fluid from the brain and prevent the condition from worsening. A shunt is a small plastic tube that passes from the brain under the skin to the abdomen, remaining completely inside the body. It allows the head and brain to grow normally when well-functioning. In addition to shunting, endoscopic third ventriculostomy (ETV) is an alternative surgical intervention which was further developed by Dr Warf, a renowned neurosurgeon during his tenure at CURE Children’s Hospital in Uganda. ETV involves making with an endoscope a natural bypass of the fluid in the head, thus eliminating the use of a shunt. This procedure has shown good results and is considered more appropriate for use in resource-poor settings.

Spina bifida and hydrocephalus are some of the disabilities that have been largely ignored. This is most likely due to the absence of experts such as neurosurgeons, pediatricians, nurses and social workers and specialized treatment and rehabilitation which would act as a support to assist parents in coping with the burden of bringing up a child and the child’s inclusion in society. These two conditions are disabilities which need an appropriate and adequate approach and lifelong follow-up care. To achieve this, information and training are needed. The multidisciplinary approach makes it a pars pro toto for the whole health care system. With the right approach, people with spina bifida and hydrocephalus (SBH) can become active members of society.

Nevertheless, without correct and timely treatment, the prognosis of children with spina bifida and/or hydrocephalus is very poor. Their condition worsens, secondary disabilities such as blindness and cognitive impairment develop and children risk dying. The disastrous outcome of untreated and incorrectly treated children contributes to the downward spiral where negative outcomes lead to further loss of hope and belief in the future of children with spina bifida and hydrocephalus (SBH) by health care workers, parents and society in general. Where there is no hope and belief, health systems and governments stop looking for solutions to improve the care for children with SBH. Without solutions, more children will become victims of a failing health system and end up with a poor diagnosis, confirming the image of negative outcome for children with SBH.
2.3 Responding to the SBH problem
There are a number of organizations which have been established to contribute towards responding to the SBH problem as described below.

The International Federation for Spina Bifida and Hydrocephalus (IF)
The International Federation for Spina Bifida and Hydrocephalus (IF) is the worldwide umbrella non-governmental organization (NGO) for spina bifida and hydrocephalus organisations. It was created in 1979 by national organisations of people with these impairments and their parents. Today IF’s members consist of 55 regional and national umbrella organisations for spina bifida and hydrocephalus. The mission of IF is: (i) to improve the quality of life of people with spina bifida and hydrocephalus; and (ii) to reduce the prevalence of spina bifida and hydrocephalus by primary prevention. IF fulfils its mission by spreading knowledge, following the medical and scientific evolutions on the treatment of spina bifida and/or hydrocephalus, stimulating exchange and encouraging contact between parents, families, individuals, professionals and volunteers involved in the SBH field and people with spina bifida and/or hydrocephalus. IF’s work for international solidarity is steered by a group of experienced experts, volunteers, donors and members of staff. This working group consults and involves experts and professionals on different specific areas.

The Norwegian Association for Spina Bifida and Hydrocephalus (RHF)
The Norwegian Association for Spina Bifida and Hydrocephalus (Ryggmargsbrokk-og Hydrocephalus foreningen [RHF]) is a national organization for people with spina bifida and hydrocephalus and their families. RHF was founded in 1973 and has active local groups in almost every county of Norway. RHF started as a small parent group and has developed into a strong user organization which improves and influences the services for the target group in Norway. As a parent and user organization, RHF has contributed to improved treatment and health care for children and adults with spina bifida and/or hydrocephalus and the inclusion of their members in society. The strategy of RHF’s international solidarity work is to use this potential and capacity to strengthen and build support groups and organizations in countries which receive support through the programme. RHF sees peer support as key to the development of the programme. In 2000 RHF became a member of the Atlas Alliance, an umbrella organization consisting of Norwegian organizations of people with disabilities, parents and patients which are involved in international work. RHF is an important part of the IF network as it was one of the founding members and has always been represented on its board.

Solidarity in the South
Since 1998 RHF and IF have been involved in the joint regional programme pertaining to the early intervention, treatment and rehabilitation of children with spina bifida and hydrocephalus in six African countries. The programme is mainly supported by NORAD, followed by SHIA. This is an ongoing process in which IF/RHF is trying to translate the latest knowledge of the North into realistic care for the South. The objectives of the programme are as follows:

- To improve quality of and access to medical and lifelong care
- To increase awareness and knowledge about SBH
- To improve ownership and leadership of people with SBH and their caretakers; and
- To increase preventive measures
The overall strategy to achieve these objectives is to complement existing efforts by building on what has already been achieved by parents and existing service delivery systems. In view of this strategy IF, RHF and its local partners have developed a programme called the Spina Bifida and Hydrocephalus Interdisciplinary Programme (SHIP). This programme is a coordinated and multidisciplinary approach to individualised care where the person with SBH and his/her needs are at the centre. It covers both medical and lifelong follow-up and aims at involving all stakeholders on an equal footing, including the families and DPOs. Networking with other stakeholders and partners in the country/district is, therefore, an important part of the SHIP programme and it comes with various tools, such as the framework for the standardisation of care and the passport for better coordination and communication.

**IF/RHF’s DPO partners in the South**

**Tanzania: Association for Spina Bifida and Hydrocephalus Tanzania (ASBAHT)**
The Association for Spina Bifida and Hydrocephalus Tanzania (ASBAHT) is a national association and has seven branches in Tanzania. These branches are in Dar es Salaam, Arusha, Moshi, Morogoro, Musoma, Tanga and Dodoma. In 2014 a national board was elected to oversee all national activities. IF/RHF’s partnership in Tanzania started in 1998.

**Kenya: Spina Bifida and Hydrocephalus Association Kenya (SHAK)**
The Spina Bifida and Hydrocephalus Association Kenya (SHAK) has 12 chapters covering all of Kenya. A national office was officially registered in 2013. The various SHAK branches are supported by and work closely with Bethany Kids at Kijabe Hospital and Bethany Relief and Rehabilitation International (international NGO). The hospital started its collaboration with IF in 2005 when it took over the collaboration from AIC Bethany Crippled Children’s Centre of Kenya which had been collaborating with IF/RHF since 1999. SHAK is an official member of IF.

**Malawi, nationwide: Parent Association for Spina Bifida and Hydrocephalus Ltd (PASHL)**
In Malawi the Parent Association for Spina Bifida and Hydrocephalus Ltd (PASHL) was established on 17 June 2009. It is registered as a company but the administrators are now trying to have it registered as an NGO. The main objective of establishing this group was to motivate families with children/youth with SBH and to teach them how to take care of their children. It is active in Blantyre and has established a small branch in Zomba. Owing to financial strains, the association is only able to reach a few parents, but it has an active youth group. It works closely with Queen Elisabeth Central Hospital, which aspires to be the centre of excellence of tertiary health care through the provision of specialized services, such as neurosurgery, to children with spina bifida and hydrocephalus. The hospital collaborates with district hospitals where clinical officers are trained to insert shunts. The hospital is responsible for neurological care and follow-up of children with these conditions. Initially PASHL used to hold meetings with the hospital but since Jan 2015, the group become independent and it now holds its own meetings once every two months. These meetings are important in supporting and encouraging parents in managing their children with SBH.

**Zambia, national: Zambia Association for Hydrocephalus and Spina Bifida (ZAHSB)**
The Zambian Association for Hydrocephalus and Spina Bifida (ZAHSB) was established in 2005 and consists of five support groups based in Lusaka, Kitwe, Ndola, Chipata and Livingstone. It has a national coordinator, who works closely with the hospitals and CBR centres such as Cheshire Homes, CBM and Beit CURE Hospital. Cheshire Homes is a rehabilitation centre for children with physical disabilities. Cheshire Homes collaborates with
the University Teaching Hospital in Lusaka for neurosurgery. The collaboration between ZAHSB and IF started in 2000 and in 2008 Beit CURE Hospital took over and started providing pediatric orthopedic surgery and neurosurgery. To-date about 500 people with SBH have been reached in Zambia. The ZAHSB is involved in the following activities:

- Sensitize women of child-bearing age about the importance of taking folic acid, especially in severely SBH-affected regions such as the southern province of Zambia.
- Sensitize pregnant women about the importance of taking folic acid.
- Sensitize health workers with regard to giving women folic acid in the first trimester of pregnancy.
- Providing mobility aids, because most children have mobility challenges
- Mitigating continence challenges by providing training to teachers on how to manage children with SBH.

**Sudan, Khartoum: Spina Bifida Federal Association (SBFA)**
The Khartoum Spina Bifida Federal Association (SBFA) in Sudan was created as a parent support group in 2002 within the Khartoum Cheshire Home for Rehabilitation. SBFA is now an independent, registered NGO established in 2007 that covers Khartoum and that has plans to expand to other regions.

**Uganda: The Spina Bifida and Hydrocephalus Association Uganda (SHA-U)**
SHA-U is a national umbrella organization which was started by the four existing and independent DPOs in central, northern, eastern and western Uganda (see below). All regional DPOs have a seat on the national board. However, SHA-U has not yet been registered as an NGO by the Uganda NGO Board though it submitted an application.

**Central Uganda Association for Spina Bifida and Hydrocephalus (CU-SBH)**
The Central Uganda Spina Bifida and Hydrocephalus Network (CU-SBH) was created as a parent support group within the Katalemwa Cheshire Home for Rehabilitation. However, CU-SBH is now an independent, registered NGO covering the central region of Uganda. CU-SBH is also an official member of IF. As for Katalemwa, it is a rehabilitation centre for disabilities and, among other things, it specializes in technical aids, producing wheelchairs, sitting aids etc. Katalemwa brings parents together and teaches and empowers them. The organization has, thus, continued to be a service provider to CU-SBH. The organization is registered as an NGO and it signed an MoU with IF in 1998.

**Mbale: Eastern Uganda Spina Bifida and Hydrocephalus Network (EU-SBH-NET)**
The Eastern Uganda Spina Bifida and Hydrocephalus Network (EU-SBH-NET) was formed on 30 July 2010 and is registered as a community-based organization (CBO). It is supported through CURE Children’s Hospital and currently the network consists of seven different support groups in Mbale in eastern Uganda. CURE Children’s Hospital is the main referral hospital for spina bifida and hydrocephalus in Uganda. It works closely with other health facilities in Uganda for the referral and follow-up of children. The hospital provides world-class expertise in neurosurgical care for children with spina bifida and hydrocephalus. It has also become an expert in alternative surgery of hydrocephalus with ETV, making with an endoscope a natural bypass of the fluid in the head. CURE Children’s Hospital signed an MoU with IF in 2000.
Mbarara: God Cares Parents Group Association for Spina Bifida and Hydrocephalus
This DPO started working in 2006 and currently has over 400 members and runs local groups in more than 10 different districts. It works very closely with OURS, which is IF’s community-based rehabilitation (CBR) partner in Mbarara.

Gulu: Spina Bifida and Hydrocephalus Parent Support Group-North
This group is based in Gulu, and is being supported by IF’s local partner, AVSI. It is gradually attracting members in the northern region of Uganda.
3 Evaluation methodology
The evaluation exercise was undertaken between 15 June and 26 July 2015 basing on the design and methods specifically tailored to achieve its specific objectives outlined in the TOR. Given that the evaluation was to be based on a qualitative research approach, the tools used to collect the data and the techniques used to analyse it were premised on this ‘paradigm’ school of social inquiry. As provided for in the TOR document, the methodology applied in this evaluation included desk review of policy and project documents including semi-annual and annual reports, evaluation reports, work plans and activity reports. Parents/care providers, children/youth and health providers who participated in the evaluation were identified by DPO administrators.

3.1 Sampling procedures
Participants in this evaluation exercise were selected for inclusion in the study sample either purposively or randomly basing on their role in the programme activities. The number of participants in the evaluation exercise from the six countries are summarised in Annex 1. Overall, the following categories and number of participants were interviewed using various techniques to provide the evaluation data:

3.1.1 Children and youth with SBH
A total of 11 children and youth were purposively sampled from Uganda and Malawi for individual interviews on the relevant issues of the evaluation exercise and programme. In addition, a total of 18 children/youth were also purposively sampled from Uganda and Malawi for FGDs. In sampling, the evaluation team and the local partner programme coordinators considered a range of issues such as the variations of the spina bifida and/or hydrocephalus conditions, gender, age, willingness and ability to participate in the discussion and consent of the parent/caregiver. As for the age bracket, participants below 18 years of age were considered to be children and those between 18-30 years of age were deemed to be youth and young adults.

3.1.2 Professional/medical caregivers of the children/youngsters with SBH
A total of 8 professional/medical caregivers of the children/youngsters were purposively sampled as one category of key informants (KIs) from each of the local partners in Uganda and Malawi. In selecting the professional/medical caregivers, specific attention was paid to the centrality of the role played by those individuals in the day-to-day activities relating to the prevention, treatment and management of SBH in the region.

3.1.3 Parents/caretakers of children affected by SBH
A total of 12 parents were randomly selected from Uganda for individual interviews on the issues covered under the evaluation exercise. As for FGDs, 45 parents were selected for the evaluation from Uganda and Malawi. When selecting participants for IDIs and FGDs, the evaluation team and local programme coordinators paid specific attention to the gender differences of the parents/caretakers of the children/youngsters in order to ensure gender representation in the sampling process. Also considered for the selection of participants were the variations in the spina bifida and/or hydrocephalus condition of their children, income level, marital status and geographical representation of the local partner operational region, among other factors.
3.1.4 DPO/support groups project/programme managers
A total of 18 local DPO management officials were purposively sampled as KIs from all the partner countries in the South except Zambia and were interviewed on a range of issues covered by the evaluation exercise. These largely included the programme/project managers or any other senior managers of the DPOs involved in the day-to-day running of the SBH programme. As insiders in the programme, it was envisaged that the selected officials would not only serve as vital sources of information but also offer insights into the other issues that significantly enhanced ownership of the findings of the evaluation exercise by stakeholders.

3.1.5 RHF/IF management officials
In order to obtain the perspective of the RHF/IF management on the operations of DPOs under evaluation, a face-to-face interview was conducted with one of the coordinators of RHF in Oslo, Norway by the evaluation team leader. During the interview, the RHF/IF management official provided key insights into RHF’s involvement with IF in the South, the role of youth role models in dealing with the challenges faced by children affected by SBH and the role of research and information sharing among the DPOs.

3.2 Data collection methods
A range of methods were used to collect data for the evaluation exercise, as explained below:

3.2.1 Desk review of IF and partner documents
Prior to the commencement of the fieldwork, the evaluation team reviewed a series of documents provided by IF and RHF. Specifically, the team reviewed the half-year IF narrative reports for Uganda, Kenya, Sudan, Tanzania, Malawi and Zambia. Also reviewed were various printed materials giving IF background details, IF’s MoU documents with its partners, field operational manuals and the IF-RHF evaluation report for the period 1998-2009. It was largely on the basis of the desk review of these documents that the different evaluation tools were developed. Desk review remained a continuous process throughout the evaluation process as the team constantly reviewed local partners’ annual reports, minutes of support groups, literature on the prevention and treatment of SBH and annual IF-local partner funding agreements (where available) to cross-check with baseline indicators.

3.2.2 In-depth (semi-structured) interviews
These were the primary means of collecting data from parents/caregivers, children and youth, KIs and professionals/medical caregivers. These interviews were conducted by well trained and experienced researchers using guiding questionnaires. Through in-depth interviews, it was possible for the evaluation team to gather and document narratives on the perceptions and experiences of dealing with SBH at individual, household and community levels.

3.2.3 Focus group discussions (FGDs)
These were held to complement data gathered through desk review and in-depth interviews. The use of this data collection method was justified by the need to capture individual/community perspectives on children/youth’s and parents’/caretakers’ perceptions and experiences of living with and caring for persons affected by SBH. The
FGDs were conducted with the help of FGD guides blended with varying forms of gender and trend analysis, among other things. In addition to reinforcing the triangulation of data collection methods, the use of FGDs also reinforced the validity and reliability of the data gathered using other methods.

3.2.4 Online questionnaires
The evaluation team used online questionnaires to collect data from partners in the countries included in the TOR for the evaluation exercise as provided by the IF office. Specifically, online questionnaires were sent to DPO coordinators so that they could distribute them to other DPOs/support groups as follows: Kenya (9), Tanzania (5), Sudan (2) and Zambia (2). The response rate was, however, low despite several reminders (by cell phone calls and emails) over a period stretching to two months. The response to online questionnaires is summarised in the table below:

<table>
<thead>
<tr>
<th>Country</th>
<th>Number of DPO officials who responded to online questionnaires</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kenya</td>
<td>4 (2 males and 2 females)</td>
</tr>
<tr>
<td>Tanzania</td>
<td>2 (1 female and 1 male)</td>
</tr>
<tr>
<td>Sudan</td>
<td>2 (2 males)</td>
</tr>
<tr>
<td>Total</td>
<td>8</td>
</tr>
</tbody>
</table>

3.2.5 Skype and telephone interviews
Given the limited time within which this evaluation exercise was undertaken, the evaluation team tasked one of its members to initiate and follow up on some respondents with Skype and/or telephone interviews. This was especially done for the IF local partner management officials in Sudan, Kenya and Tanzania.

3.3 Data analysis
Data collected using the above technique was transcribed within 24 hours after every interview. The transcripts were then edited and harmonised in preparation for a debriefing meeting held at the end of the fieldwork. The analysis process was done thematically in line with the core aims of the evaluation, namely relevance, effectiveness and sustainability of the IF and RHF supported programmes in the countries covered by the evaluation.

3.4 Ethical Issues
Verbal or written consent was sought from all participants and they were informed of the objectives of the study. Consent was sought from parents/caretakers for participants who were below 18 years old before they took part in the evaluation. In addition, we assented with the children themselves. Participants were informed that this was a voluntary exercise and they were, therefore, free to decline participation in the evaluation exercise or to answer certain questions without any adverse consequences. Participants were also informed that their real names would not be mentioned in the report without their permission. The confidentiality of all the information gathered was strictly to be protected. Recording equipment and materials such as tape recorders and notebooks were treated with strict confidentiality.
3.5 Methodological limitations
The evaluation team encountered a set of methodological limitations during the exercise as outlined below:

(i) Recruitment of children and youth for IDIs and FGDs: Owing to the limited time schedule within which the evaluation was to be conducted, in Uganda it was quite challenging to mobilize the children and youth for FGDs in the various regions. The situation was also compounded by the fact that these children and youth live geographically far from each other. Therefore, mobilizing them for an FGD would not only require more financial resources but also a longer time than the period allocated for this exercise. Also, because the evaluation was conducted before schools closed for holidays, the inclusion of a large number of children/youth in the evaluation was practically impossible since many of them were in school. The situation was the same in Malawi. However, in spite of these challenges the team was able to conduct one FGD with some children in a school in Mbale, eastern Uganda and one FGD with some youth in Malawi.

(ii) Memory loss and poor communication by the children and youth: Some of the children and youth targeted for the evaluation exercise suffered memory loss and could not express themselves well during the interviews. This greatly affected both the quantity and quality of the data collected from them. Largely attributed to their SB and HC conditions, the children and youth could not readily recall the trend of events related to the health condition (such as treatment, surgery and advocacy programmes). Some of them struggled to express themselves fluently while a few found it difficult to sit through a 45-minute or one-hour interview. Faced with this problem, the evaluation team, therefore, chose to only focus on particular sets of questions for this category of respondents, thus not completing the entire set of questions as originally designed.

(iii) Failure to visit all local DPOs in case study countries: Although this evaluation exercise could have largely benefited from visits and longer stays at all the offices of the DPOs targeted, this was not possible. Once again, time and financial resources for the evaluation proved inadequate. This explains why the evaluation team only managed a handful of interviews with the various officials of the DPOs. In some cases, email and telephone interviews were used to gather data from the DPOs but these were not as effective as desired or expected owing to the lack of physical contact that could have fostered better rapport and probing for more detailed information. Also, some of the officials of the DPOs, for example those from eastern Uganda, were very difficult to reach on the phone for follow-up so that they could provide us with the additional information/data that we wanted from them.

(iv) Low response rate by online respondents: Originally envisaged to target at least 18 online respondents from the DPOs in the focus countries, the evaluation team received less than half of the projected feedback from these countries. Despite several regular email reminders and telephone follow-up to the respondents in these countries, there was quite a disappointing response from them. The most difficult was Zambia where the contact person did not take any telephone calls neither did he respond to any mails and data collection tools that were sent to
him from Kampala and Norway. The evaluation team, therefore, had to use the limited data provided by the few DPOs that responded to inform this report.

(v) **Large catchment area:** Some DPOs provide services to a very wide geographical area, therefore it became very difficult to draw representative samples of participants from the entire catchment area. We suppose that including parents, children and youth from the various DPOs/support groups in different districts could have impacted on the data gathered. Also, time and financial resources made it difficult for the team to cross-check the validity of the data that was collected because follow-up through repeated interviews with the participants was not possible.

(vi) **Participants’ social categories:** Owing to limited time and finances, many participants did not have all the social categories – e.g. geographical representation etc. – which the evaluation team and project coordinators had set from their participation in the evaluation exercise. Concerning the age bracket for the youth, this was very challenging because a few parents/care providers were also within the same age bracket although, as parents, they did not have SBH disability. In such a situation, the evaluation team had to use parenthood and having a child with SBH disability as a basis for one to qualify to belong to the parent group.
4 Findings
This section presents the team’s findings highlighting the relevance of the programme, the effectiveness and impact of the implemented activities, sustainability, overall assessment issues, challenges and limitations and the lessons learnt.

4.1 Relevance of the regional programme
Relevance refers to how important or necessary the programme interventions or activities are or have been in addressing the needs of the target groups or community. This includes exploring the added value and/ or impact of these activities in relation to these needs, and how the programme is in line with the policies governing the thematic areas that the programme activities are directed to. Therefore, in view of the above definition, the RHF/IF Regional Programme is relevant to the needs and priorities of the target group (children/youth with spina bifida and hydrocephalus, their parents and primary caregivers, and to the professionals working with spina bifida and hydrocephalus) as follows:

4.1.1 Pioneer programme
The RHF/IF Regional Programme represents pioneer work in the six African countries where it has been active since 1998. The programme started in Tanzania in 1998 and it was later extended to other countries. Currently the RHF/IF programme is one of the programmes which is implemented in collaboration with a few other organizations, provides rehabilitation and other services such as free shunts to children with SBH in these countries. The programme has given parents/caregivers, children with SB and/or hydrocephalus and professionals a platform where they can voice their concerns, learn more about the SBH conditions and bridge the gap between service providers and the clients. For example, in Malawi both parents and youth with SBH mentioned that, while previously they did not know much about the conditions, all the youth and parents interviewed were now able to describe spina bifida and hydrocephalus, which are locally known as chotupa cha pa msana and mutuwaukulu. In Uganda many children from South Sudan are also benefiting from these services, which have been initiated and financed through this programme. In addition, the project targets special cases, not just general disability as other projects do.

4.1.2 Contribution to people with SBH
The programme is greatly contributing to people with spina bifida and hydrocephalus. In the past the opportunity for survival was limited to children from rich families. This trend has, however, changed through the implementation of the IF/RHF programme. The programme has offered hope of life to the children and youth with SBH. Thus in the MoUs signed between RHF/IF and its partners in the South, RHF/IF’s vision is to provide appropriate and specialized affordable services to all patients with spina bifida and hydrocephalus, including poor families in rural areas.

In view of this, RHF/IF agreed to be the donor, i.e. mobilizing funds via partners and donor networks, and providing, free of charge, medical supplies and equipment such as shunts, oxybutynin capsules etc., which are not readily available in partner countries. RHF/IF partners must ensure that patients with SBH, regardless of their socio-economic status, religion and other social categories, receive appropriate treatment, with specified budgets for activities such as the training of staff, providing support to parent groups etc.

The budgets are reviewed annually and MoUs renewed according to performance. For example, in all the six countries, women get free folic acid, and when children are referred for surgery RHF/IF pays their transport costs and those of the parents/care providers. Parents
and youth in Malawi mentioned that the payment for transport is not made only during the time they undergo surgery but transport is also paid for during CIC training, when they come for support group meetings which are held once in every two months and during neuro-days, which fall on 25 October of each year. But parents do not get transport refund when they come for medical follow-ups.

However, in Uganda it was mentioned that when parents come for training or capacity-building from the service providers, they no longer get transport as noted below:

“They used to give us transport for taking us back to our homes but then when it stopped, it affected the attendance, people have now stopped coming. They now just give us lunch and no transport” (IDI, parent, Gulu)

In reference to the services of RHF/IF programme in the South, there is need to examine how, today, children are surviving and living in a meaningful state within their families as a result of the interventions supported by the programme. For example, according to information from Uganda, Kenya, Malawi and Sudan, the number and age of new cases referred from antenatal are reducing, while the number of cases which people in the communities had not reported before is increasing. A decrease in the number and age of new cases referred from antenatal and an increase in the number of cases which people in the communities had not reported before, highlight that interventions, e.g. sensitization, awareness creation, advocacy, capacity-building etc., which the DPOs and service providers are engaged in, are yielding a positive impact.

This points to a number of things. First, more women are taking folic acid, thus impacting on the number of children born with SBH. Second, many professionals who have been trained are now able to identify SBH, treat infections, make immediate referrals to other professionals and institutions, and give advice to SBH children, their parents and the community about the available services. As one parent noted:

“I was operated (caesarean) for the child to come out. And I think that the doctor who operated on me did not have knowledge about SBH. But when the child fell sick, they took us to the ward at Gulu Hospital and the doctor saw it and told me that this can be healed, just have a strong heart, the hospital where it is done is in Mbale” (IDI parent)

Third, some parents having children with SBH in the community have acquired knowledge and information about SBH and about where they can get help and/or treatment. Today such parents no longer hide and reject their children or feel very devastated as they did before. One key informant from Tanzania stated:

“This project is also relevant because the communities are now aware of the SBH. Many before used to hide their kids. Others used to abandon them yet now they love them and stay with them because they are aware that it is not their fault that the child is what they are at the moment. Actually if I am given an option of taking away anything from the project I would not manage because all the activities are relevant” (KII, ASBAHT)

In Uganda one parent stated:

“When I knew that my child had hydrocephalus, I felt bad and mentally I became so desperate because it was something that had never happened to anybody close to me. People kept on advising me to seek help from witch doctors but I refused until I got treatment from CURE Hospital” (IDI, parent, Gulu)
Similar statements were made by some parents in Malawi. Another parent stated:

“I felt very bad when I knew that my child has hydrocephalus. But because my last sister is lame but our parents were able to raise her and even take her to school, so I said let me try and treat this child. So I took him to the hospital saying if I fail, and the child dies, I will bring him back and bury. But today my child is alive” (IDI, parent, Mbale)

4.1.3 Accessibility to services and improved quality of life

In all the six target countries in the South the project has created accessibility to services for the target groups in the community and this has not only addressed their needs but also improved their quality of life and dignity. For example in most of them, outreach clinics and follow-up are organized. As a result of increased care and treatment more children are surviving and becoming youth and more children are mobile and are now attending regular schools, unlike in the past, and others move freely in the community. As some respondents noted:

“There have been changes on my child. Two years ago he used not to sit. But now he crawls, sits, reads and understands. His life has greatly changed; I didn’t think he would even be able to understand small things but today he does” (IDI, parent, Eastern)

“Two weeks after my son was born, we noticed that his head was swelling but because his sister was stubborn we thought that she could have hurt him. So we decided to first take him to the hospital for a medical examination. At the hospital we were told that our child has hydrocephalus but it can be corrected from CURE Hospital and that if we had the money, the hospital could write a letter of referral for me to Mbale. We told them to give me one week to look for the money. Then when we got the money, I went and picked the referral letter. At Mbale, I was told more about the disease, and that is when I got scared, weak and worried. However, I was told that the only option for him to live was to put a tube called shunt or do what they called the ETV. They started with ETV but after two weeks it failed. So they put a tube and they told me that the tube was the only way for treating my son because the water should be drained. Today I am a very happy father because my son is six years old and at school in Primary One like other kids and he can even ride on a bicycle. All this is because of the free shunts IF gives to Mbale” (IDI, parent, Mbarara)

However, in some countries, such as Malawi, the follow-ups are mainly done when patients visit the clinics because outreach services and home visits are rarely conducted owing to the shortage of staff and financial resources. But the chairperson of PASHL reported that from January 2016 there will be enhancement in a number of activities including home visits.

For many parents the burden of looking after these children all the time has slightly been reduced. This enables them to get engaged in other activities which are necessary for the social and economic survival of their families. Therefore, social inclusion for the children should not be an undertaking of their families alone but needs holistic and multi-sectoral
approaches or efforts at different levels, including at local government level. Nevertheless, now that the medical aspects are increasingly being addressed for many children with SBH, it is also necessary to step up efforts aimed at addressing the increasing need for their education and household income so that parents are able to bring their children for treatment etc.

In Kenya it was reported that:

“For our children catheter is free of charge also shunting and closure is also free but parents have to pay transport, for example from Mombasa to Kijabe which is KSh. 5,000 and they cannot afford it. Some come from very poor families and others are single parents” (KII, SHAK)

4.1.4 Stigma and discrimination

Stigma and discrimination are universal, occurring in every society in different forms and levels, such as in social/professional interaction, at the workplace, at school, in the family, in public places, in health institutions etc. Stigma and discrimination are caused by cultural norms and values, beliefs, fear related to illness and death, lack of understanding and information, prejudice etc. Generally stigma creates social boundaries between those who claim to be normal and the stigmatised. Thus, the stigmatised are doomed to ‘eternal stigmatisation in their own eyes as well as those of society’ (Albon, 1981. p. 8). There are two main forms of stigma: felt or self-stigma and enacted stigma.

Felt-stigma relates to the feelings which individuals harbour about their condition and the likely reactions of others. These include feelings of shame, denial, self-hatred etc. Self-stigma makes those who are labelled different wish to avoid situations where their difference may be problematic for themselves and others. As Goffman (1963) notes, these individuals tend to accept the norms that actually disqualify them from comfortable and equal participation in social interaction.

Enacted stigma refers to experiences of stigmatisation or sanctions which significant others either individually or collectively apply to people with a condition. The discrepancy between what is expected in a normal individual and what is actual in a stigmatized individual ‘spoils’ the social identity that is important in social interactions and limits the level of social acceptance that s/he might expect from significant others (Alonzo and Reynolds, 1995).

This evaluation revealed that in all countries stigma and discrimination against SBH children/youth and their parents/care providers exist at different levels and in the environment, and are a big challenge to address. In Malawi a youth with hydrocephalus said that ‘due to the appearance of most children with this condition, most of these children are being discriminated in their communities and even insulted by community members’.

During an FGD with youth in Malawi one participant with hydrocephalus reported that her mother used to hide her inside the house and it was only after her death and after her aunt adopted her that she was taken to QECH where she started receiving treatment.

However, currently the services, training, advocacy, awareness creation, sensitization etc. which are provided through this programme have to a certain extent reduced these negative attitudes. For example, in all the focus countries it was reported that some children with spina bifida revealed that in the past they were discriminated against because of the incontinence problem and strong smell that they had but that now this had changed after they received treatment and the training in CIC. Also, although support groups are formed by parents who
have children with SBH, anyone who wants to be a friend of these groups is free to join. It was revealed that allowing others to be members has been relevant and contributed to reducing stigma as well as enhancing cooperation and integration of children with SBH and their parents with other children and people in the community. Overall, in all the countries many participants reported that the perception of the public is changing and many actors appreciate the project interventions.

### 4.2 Effectiveness/impact of the DPO interventions

This section examines the effectiveness of the various activities or interventions undertaken by the DPOs and service providers in implementing the programme objectives. It also highlights the impact of the selected activities for evaluation on the intended beneficiaries. In evaluating the effectiveness of the programme, the evaluation team focused on assessing the achieved observable or recorded outcomes of its interventions with reference to its set objectives. In other words, the findings presented in this theme of the evaluation report highlight the extent to which targets were or are being met while also detecting the factors that either facilitate or hinder the realisation of the set goals and objectives set by the DPOs. On the other hand, impact refers to the outcome or results achieved through the activities/interventions being implemented in relation to the programme objectives. Such results might include either tangible issues the number of lives saved or a change in perceptions about the particular intervention which could be positive, negative, expected or unexpected. By choosing to combine effectiveness and impact in this section, the evaluation team sought to present a more in-depth understanding of the programme than just a review of its achievements during the period under review.

#### 4.2.1 Prevention

If prevention is, better than cure, then the DPOs and various service providers covered under this evaluation have set the right tone for this intervention. The activities covered under this component hinge on the need to raise the level of knowledge of the causes, prevention and management of SBH – largely through improved nutrition. On this front, CU-SBH’s involvement has led the way in ensuring that effective measures are in place to prevent new cases. In central Uganda, for instance, CU-SBH, in collaboration with Katalemwa Cheshire Home (KCH), which is a service provider, ensures that there are adequate and reliable supplies of folic acid for all expectant mothers. The KCH team and officials from CU-SBH, led by the SHIP co-ordinator, also undertake follow-up home visits to ensure that folic acid supplied to the expectant mothers is utilised according to the instructions.

“We also place much emphasis on improved nutrition. Women are advised to eat fruits and vegetables and also not to over-prepare/overcook their greens to limit the depletion of natural nutrients from them” (IDI, KCH SHIP coordinator)

Such preventive interventions could not, however, have been anywhere close to being described as effective if it was not for the efforts of the central Uganda DPO. Founded in 2010 to largely bring together parents with children affected by SBH in the region, the DPO now has a membership of 527 in eight districts in central Uganda. Key among its effective activities is the prevention aspect:

“As a DPO, we have taken the folic acid gospel to another level. Although folic acid is available in pharmacies and all health centres where women seek antenatal services, there was very limited awareness about its role among expectant mothers. But we have taken the information to many places – in open markets, churches and even the major hospitals. The new SBH cases in the areas where we have emphasised the use of folic acid have reduced” (KII, CU-SBH)
Analysis of the data from the other regions in Uganda shows that preventive efforts are equally effective. In the western region, the OURS God Cares Support Group has effectively taken to preaching the folic acid gospel.

“Our members and the general community are encouraged to eat foods that contain vitamin C such as carrots and vegetables. These should either be half-cooked or cooked in low temperatures” (Health professional, OURS)

Although encouraging women to eat foods which contain folic acid is very important, the above statement, however, highlights what seems to be a widespread misconception that foods that contain vitamin C can be equated to folic acid in nutritional value (especially when half-cooked). But this is not scientifically proven and there is, therefore, need for more sensitization of the population – especially the expectant mothers – that the best way to prevent SBH is to use folic acid before or during the first four weeks of the pregnancy.

Members of the Eastern Uganda SBH Network have also – in conjunction with CURE hospital Mbale – effectively warmed up to not just the use of but also the sensitisation of the community to the use of folic acid by expectant mothers to prevent SBH cases.

“For us, these conditions are only caused by the lack of folic acid, nothing else. So, we are using that as the most effective intervention to prevent new cases” (KII, EU-SBH.NET)

In northern Uganda, AVSI and GROW – the two leading SBH service providers – have also worked effectively with the network of DPOs at village, sub-county and district levels to promote the use of folic acid in order to prevent new SBH cases. For a region that experienced two decades of insurgency, the regular and steady supplies of folic acid to expectant mothers is now worth highlighting – a view aptly expressed by the AVSI team leader:

“Our focus on the use of folic acid may appear ordinary but it is a significant indicator of effectiveness since there was none during the times of the civil war”

In Tanzania, ASBAHT has used its network of branches in Moshi, Arusha, Tanga, Morogoro, Dodoma and Musomato to promote the use of folic acid.

“On the World Spina Bifida Day, we, for instance, distributed folic acid free of charge to mothers and all the women who came to attend. We also encourage people to access and use fortified foods supplied by AZAM food supplier who agreed to fortify all its food products” (KII, ASBAHT)

In Kenya, SHAK Nairobi and SHAK Mombasa/Coast have also – in collaboration with the Bethany Kids and Kenyatta National Hospitals – been effective in providing folic acid to expectant mothers. In Sudan, ‘folic acid is provided to all females, especially those who are marrying’ (KII SBFA). In Malawi, it was reported that mothers and women who are of reproductive age are encouraged to take folic acid. However regarding providing leaflets and teaching material on folic acid to women, it was reported that these are not provided to them but women are taught about folic acid during CIC training weeks and then reinforce it at the clinics. The reason for not providing these leaflets etc is because most parents cannot read.

**Impact:** Although there is no proper research evidence/data suggesting that the combined DPOs/service providers’ efforts towards the prevention of SBH have led to reduced numbers of children being born with the two conditions, it is clear that the initiatives have not only created awareness about the biomedical causes and prevention methods but also increased the use of folic acid. Through such initiatives, parents and relatives of SBH-affected children who initially had no
answers to why it happened to them and what they ought to do to prevent similar conditions in future, now have a clue as to what to do.

4.2.2 Treatment and rehabilitation

Efforts by the DPOs have been fundamental to the success of the treatment and rehabilitation initiatives for children affected by SBH. Although DPOs lack the medical expertise to treat and rehabilitate the affected individuals, they are often effective mechanisms to identify those who need treatment and rehabilitation. In fact, there is adequate empirical evidence to demonstrate that there are many parents who would have never benefited from the treatment and rehabilitation services of biomedical providers without the intervention of the support groups.

“A couple of weeks ago, I saw a woman seated on a ‘boda boda’ motor cycle holding a baby who I suspected had a unique problem. I followed them and on close inspection, I noticed that the baby had signs of SBH. I counselled the mother and referred her to Katalemwa. She is now getting treatment and rehabilitation” (KII, CU-SBH)

Another parent added:

“Our association has successfully changed the mindset of some parents who used to think that they could use local herbs and the incision procedure to treat HC. They also stopped taking their children to churches and traditional healers for healing purposes. They now seek treatment from professional health providers like CURE Hospital and Katalemwa Cheshire Home” (IDI, parent)

In northern Uganda, IF co-funding has made it possible for AVSI – the local partner in the region – to provide SBH treatment and assistive devices, such as wheelchairs, to children undergoing rehabilitation. Whereas the multi-layered DPOs in the region continue to mobilise the parents to take their affected children to seek treatment, Gulu Hospital has effectively established itself as one of the institutions offering post-care treatment and rehabilitation facilities to children/youth with SBH in the region, and also serving Uganda’s neighbours, Democratic Republic of Congo (DRC) and South Sudan. And it is at this hospital that Gulu Regional Orthopaedic Workshop Centre (GROW) is stationed.
In Sudan, the SBFA is valuable in identifying children who need treatment for SBH and referring them to the biomedical service providers.

“We refer all such cases to the doctors in the hospitals and physiotherapy centres. Most patients come to Khartoum but there are surgeries now in Medani in central Sudan, Port Sudan in the east and Atbara in River Nile State in the north. We also supply them with shunts” (KII, SBFA)

In Kenya, the DPOs have been of use in treatment initiatives for SBH-affected children.

“The parents groups always bring the children. Sometimes someone intimates to you that so and so has a child with the SBH condition. So we explain to the person the need to seek professional medical help and also inform them to take the children to Kijabe Bethany Kids” (KII, chair, SHAK Mombasa/Coast)

In Malawi, the effectiveness of the treatment and rehabilitation programme can be measured by the increase in the number of SBH patients receiving surgical treatment at QECH and the Kamuzu Central Hospital in Lilongwe.

“A number of youth with SBH are now in various secondary schools and they are performing well in school. There is an estimated 40-50% increase in the number of patients receiving treatment from these two hospitals” (Health professional, QECH)

However in Malawi identifying and referring of SBH cases for treatment and rehabilitation by the DPO/support group has not been effective. This is because the support group has not been involved in awareness creation, home visits, and outreach activities in the community where most of the children/youth with SBH live. Nevertheless as already noted the hospital has been involved in such activities but at a very small scale due to lack of funds and man power. Therefore most SBH cases have been identified and/or referred for treatment through the health service delivery system and individual contacts.

**Impact:** The combined efforts of the DPOs and the service providers in identifying and making referrals have greatly impacted on the treatment and rehabilitation of SBH-affected children – both qualitatively and quantitatively. In central Uganda, for instance, an estimated 60% of the SBH cases received social rehabilitation services at Katalemwa Cheshire Home in 2014, compared to about 45% in 2009. Similarly, a total of 6,347 surgeries were carried out at CURE Hospital in eastern Uganda between 2009 and 2014. The hospital also treated and rehabilitated 27,242 out-patients. Other impact indices related to this intervention include the increase in the number of children attending school after seeking treatment.

### 4.2.3 Networking and collaboration

One of the key areas in which some of the DPOs are trying to achieve effectiveness is in the way they set up networks and collaborations. DPOs acknowledged that collaborating with other organizations and individuals has enabled them to get to where they are and the people in the community have started recognizing the work that they are doing.

In Kenya, SHAK Nairobi and SHAK Mombasa/Coast have – in partnership with the service provider Bethany Kids Hospital – set out to network with a host of partners, especially in its efforts to create more awareness about SBH in the country. Such partners include the African Inland Church, Naivasha and K-Rep Banks etc.

“As a group, we visit churches for creating awareness on disability issues. We move from church to church talking about spina bifida and hydrocephalus. We are invited to churches to share our experiences and successes as parents and we use this chance to talk to the congregations about these two conditions” (KII, SHAK Nairobi)
Other partners with whom the DPO collaborates include the Global Alliance for Improving Nutrition and the local leading newspapers which feature reports and human interest articles on SBH issues. The chair of SHAK Mombasa/Coast also provided an insight into the effectiveness of DPO’s collaboration intentions and set up.

“The National Council of Persons with Disability gave us KSh.50,000, while the Kenya Maritime provided us with milk for our children. The county government also provided us with the venue where we can hold our Spina Bifida and Hydrocephalus Day activities without charging. A few other organisations also gave us chairs to use on the day” (KII, SHAK Mombasa/Coast)

The situation is not so different in Tanzania. Over the last four years, ASBAHT has forged effective collaborations with Shivyawata, Friends of Children and My Right Tanzania. Other partners include the Ministry of Health and the Roman Catholic and Lutheran churches – all geared to reaching out to children with SBH in remote areas in Musoma, Mwanza and Bukoba provinces.

“My Rights Tanzania organises leadership trainings for the ASBAHT executive members. Our patron Dorcas, a wife to one of the prominent politicians in Tanzania, donated 50 shunts to us recently” (KII, ASBAHT)

Although the DPOs/support groups in northern Uganda are structured at varying levels – at district, sub-county and village levels – they have also formed a host of partnerships/collaborations. Through this collaboration, some parents have, for instance, been able to secure school fees funding for their SBH-affected children from the Liliane Foundation. The DPO has also been able to collaborate with World Vision, St. Joseph’s Centre (Kitgum district), Gulu Disabled Persons Union, which gives vocational training and apprenticeship to some children with SBH, Watoto Church, and the local government administrations in Gulu and Lira districts to co-fund community sensitisation campaigns.

Similarly, the central Uganda DPOs and support group network includes CURE children’s hospitals where all surgery cases are referred to, CoRSU Hospital (Entebbe) where those with deformities are referred to and the Joy Children’s Trust, a local NGO.

"Our partnership with Katalemwa and the other specialised service providers is quite effective. Now our focus is on working with the local government administrations at Kira town and others in the region to create synergies in our operations” (KII, CU-SBH)

In eastern Uganda EU-SBH-NET referred to partnerships with the local governments and the media.

“We partner with Step Television and the Monitor newspaper. We also effectively work with various community development officers from various districts in the region” (KII, EU-SBH-NET)

In the western region, OURS God Cares Support Group is also in partnership with the local governments of the districts of Mbarara, Rukungiri and Kabale to integrate their work plans into their local governments’ strategic plans – even if this is yet to translate into funding.

“The collaboration with local politicians and private sector investors has so far yielded 20 wheelchairs to support movement of children affected by SBH in the last couple of years. We also partner with the police, churches, schools, the Christian Blind Mission (CBM), Liliane Foundation and the Light for the World” (KII, OURS God Cares)
In Sudan, the SBFA has established effective networking and collaboration with a number of NGOs/CBOs such as Nile College, Sudan UN, Nieleen, Azhary, Shariah El hwadth, Umbda and Rabat universities.

“We have now established a good working relationship with the United Nations Development Programme (UNDP), UNICEF Sudan and the private sector to create more awareness about SBH in Sudan. We also have inter-sectoral institutions” (KII, SBFA)

In Malawi, the main organization that PASHL networks and collaborates with is CURE Orthopaedic Hospital. Through this hospital contacts have made with Innerworld a charity organization and a local church to secure some funds for school fees for two youth who attend secondary school. However it was reported that since PASHL is now independent, from year 2016 it intends to establish more networking and collaborating contacts.

<table>
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<tr>
<th>Impact:</th>
<th>Even if most forms of partnerships referred to in this evaluation are quite informal with no Memoranda of Understanding (MoUs) signed between the DPOs and their partners, there is substantial evidence to prove that they have created varying forms of impact. First, partnerships between the DPOs and the service providers have been the foundation of all SBH prevention, treatment and management interventions.</th>
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<td>“Our partnership with Katalemwa and CURE Hospital in Mbale has resulted in saving the lives of children born with SBH in Uganda. In the past, they used to either neglect them until they died or even kill them” (KII, CU-SBH)</td>
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In Kenya, one of SHAK’s projects is the House of Hope Parents’ Guesthouse in Kijabe funded by a Belgian NGO to help to accommodate parents who come from very far-off regions to seek treatment at the Bethany Kids Hospital.

“One once our parents are discharged from the hospital and a follow-up is to be done in a few days or weeks, they stay at the guesthouse very close to the hospital where the children are monitored. The parents are trained by fellow parents who have older children with SBH and the parents can go back to Bethany Kids for review. Staying at CURE Hospital or Guest House at Kijabe also serves as a platform where parents from different regions meet and exchange ideas or learn from each other” (KII, S HAK Nairobi).

In addition, the varying forms of partnerships are yielding some material and financial support for some poor families having children with SBH. Thus education for their children is paid for by the partner organizations. This has led to improved levels of education and better quality of life for these children.

4.2.4 Training and capacity-building

Some DPOs, individual parents/caregivers, children and youth have received training on capacity-building in various areas such as leadership and disease management, child care management skills, counselling aimed at changing people’s perceptions about SBH and the actors affected, home economics, income-generating activities etc. For example, the SHIP coordinator in Gulu stated that:

“A two days non-residential training was conducted for the DPO/parent support groups titled ‘capacity-building training’ for the spina bifida and hydrocephalus parents’ support group leaders was conducted at Gulu Disabled Persons’ Union (GDPU). The core of the training was to equip the PSG board members with the basic principles of the group dynamics and group leadership/management” (KII, Gulu)

The methods used included workshops and seminars through which lectures and group discussions/sharing of experiences are organized. The skills that DPOs and/or individual
stakeholders acquire through capacity-building are enabling them to alleviate some of the life-threatening as well as more difficult aspects of living with the effects of SBH. For example, the training and information offered have enhanced the knowledge of children, parents/care providers about SBH issues, health-seeking behavior and other infections. This has saved the lives of many children and also prolonged the live span of others.

**Continence and bowel management:** Efforts to treat and live with SBH conditions cannot succeed without effective continence and bowel management training practices. During the period under evaluation, the DPOs and the service providers have been involved in training activities to promote social continence and bowel management practices. In Sudan, for instance, the Spina Bifida Federal Association (SBFA) organises its members to attend training in continence management on a regular basis under the direct supervision of medical assistants and nurses at Soba and Khartoum hospitals. In Kenya, it was reported that initiatives to train parents and the youth affected by SBH in continence and bowel management have been relatively effective, as noted below:

“Our relationship with the health workers at the local service providers has made it possible for our DPO members to acquire the necessary knowledge and skills in CIC and bowel management” (KII, SHAK)

“The CIC and bowel management programme has improved the lives of our children. It gives them confidence to deal with the challenges of life” (KII, SHAK)

“We were taught how to keep hygiene because for these children, the urine keeps passing out, you have to bathe him in the morning and then after 30 minutes, you have to keep changing his clothes. And the things used to drain urine should always be clean because if it is not clean, it can bring diseases to him” (KII, SHAK)

In Tanzania, too, training in continence and bowel management has been effective.

“ASBAHT trains parents (mothers) and the youth/children in CIC. They also teach them specialised physical exercises” (KII, ASBAHT).

In Uganda, OURS God Cares in Mbarara reported that their efforts to mobilise their members to undergo training in continence and bowel management have been effective. As one of the parents narrated in FGDs:

“All our members now know how to handle the catheters, use soap, KY Jelly and clean tissue”. (KII, OURS God CARES)

Similarly, the central Uganda-SBH has in conjunction with Katalemwa Cheshire Home – been effective in involving the youth and children in continence and bowel management training.

“Many of the youth who are affected by SBH can do CIC and bowel management on their own, thanks to the training organised by the parents group at Katalemwa” (IDI, 27-year-old participant living with SBH)

In eastern Uganda, one key informant from EU-SBH-NET summed up the effectiveness of this particular intervention thus:

“In our parent support group we normally come together, and invite health professionals from CURE Hospital who come and teach parents to carry out CIC or bowel management. Today, the parents are now experienced in handling CIC and bowel management and are now teaching their children how to do it on their own” (KII, EU-SBH-NET)
In northern Uganda, training in CIC and bowel management has been effective. In an individual interview, a parent in Gulu stated ‘both the parents and youth now know what to do with CIC.’

“Most times parents come every month for continence management and they access it free of charge. We provide them with continence management material, our staff trains at least one parent or caregiver in continence management and it is our occupational therapist who handles all this. Our team also encourages parents to train at least one other person in the family on continence management. We also sensitise parents on nutrition aspects of caring for children with spina bifida.” (KII, Gulu)

In Malawi training on CIC is done at the hospital for children, youth, parents and care providers for a total of four weeks in a year and it also focuses on other issues. For example, participants discuss what is MMC and hydrocephalus, they learn what is an anatomy, risk of renal damage, how to identify UTIs, need for CIC, use of oxybutinin, prevention of MMC, need to use folic acid, reasons for bowel washouts, and they go through practical training for CIC and bowel washouts. Each time a training session is organized, the support group leaders are supposed to attend. However the chairperson reported that when the support group gets its own location, most of the capacity building interventions will be conducted from there.

In addition, through this programme, regional conferences/training are arranged. For example, continence management training was carried from 18 to 20 March 2013 at Katalemwa Cheshire Home. In total 10 IF partner staff from Kenya, Malawi, Sudan, Tanzania, Zambia and Uganda came together to learn more about continence for spina bifida patients. This means that, in addition to the skills that the participants acquired, the conference was a platform for them to share other experiences and the lessons learnt from their countries.

However, although this training has been relevant and effective, some participants feel that they now need more knowledge than what they have already achieved as a KII notes:

“Training and transfer of knowledge has been effective especially when our neuro nurses come to the level of understanding of parents. Medical matters are very complex and these trainings offer a situation where we bridge the gap between service providers, parents/caregivers and children. However, sadly I would say that this training has been so monotonous, same facilitators, same venue and topics. I have attended several of these trainings and it has always been same old version and there is nothing new. Currently the most viable added value is that new parents who have never undergone this kind of training get to learn so much. But for those of us who have been trained over and over again we yearn for something new. Therefore these trainings should act as refresher courses” (KII, SHAK)

The above statement calls for an evaluation of the methods, materials/tools and type of information being used and offered during the training.

**Impact:** The DPOs’ initiatives to provide training and capacity-building, including continence and bowel management, to parents and children/youth have created a noticeable impact on the lives of the affected individuals. By improving general hygiene among children and families in most homes, there has been a noticeable reduction in the number of opportunistic infections such as urinary tract infections (UTIs) recorded among such individuals and families. Overall, this has significantly improved the quality of life in such families. The fact that since some of the youth have now been trained in injecting themselves with oxybutinin saves some of the parents’ time which, in turn, allows them to concentrate on their jobs to earn a living for the family.
The evaluation also revealed that, although involving children/youth in SBH activities is still a challenge, on individual and personal levels a number of them have become inspired and are positive about issues related to SBH and how to deal with the conditions. In addition, training parents/care providers in IGAs etc. will improve their skills and economic survival for the families because most of them are from very poor homes.

4.2.5 Information dissemination, sensitization and advocacy

The evaluation revealed that during sensitization and awareness creation the most common information given is about: a) what spina bifida and hydrocephalus are and what their main causes are; i b) the available services/treatment and encouraging parents/care providers having children with condition to make use of them; c) continence management; d) encouraging people to change their perceptions towards children/youth with SBH; e) practical and psychological coping with the effects of SBH; f) the importance of eating foodstuffs which are rich in folic acid; g) advising women/girls to start using folic acid before and after getting pregnant; and h) cooperation among couples etc.

During sensitization, awareness creation and advocacy, multi-sectoral approaches are used and these include: a) the distribution of IF leaflets and other materials with information about SBH; b) conducting radio and TV talk shows involving parents, youth, health workers, IF service providers etc.; c) seminars and workshops; d) community mobilization involving different stakeholders in the community, e.g. local leaders, religious leaders, cultural leaders etc.; e) organizing sessions at antenatal clinics – which has helped to increase the consumption of folic acid tablets among women of child-bearing age; f) during sensitisation, as parents move around the communities they give testimonies about the improvements among their children with SB/H; g) using home visits and outreach clinics; h) when parents/care providers and children/youth visit hospitals like CURE, BK etc. for treatment they are counselled/given information about SBH; i) during national celebrations, e.g. World SBH Day, j) parent support groups; and k) visiting schools and other institutions. For example, in Sudan, the SBFA conducts sensitisation and advocacy campaigns using lectures, seminar presentations, brochures, posters and videos. For effectiveness, the DPO often solicits the expertise of the service providers such as physiotherapists, nurses and social workers in driving home the SBH messages to the target audience.

“Our target groups are the general community but we concentrate on universities because students are from all corners of Sudan and can spread the message about the disease and prevention widely. The schools for the midwives are also good at sensitising the people in the rural areas. Other effective methods are by using volunteers and FM radio stations. We also use television stations to sensitise the community” (KII, SBFA)

In Kenya, SHAK Nairobi has – since 2012 – printed and distributed over 500 brochures and leaflets on SBH which have been distributed in Nairobi city as part of its sensitisation and advocacy campaigns. In Tanzanian, ASBAHT has teamed up with another local partner NGO to produce a seven-minute educational video about folic acid and food fortification which has been shared with other rehabilitation units in and around Dar es Salaam.

“The video has since proved an effective tool in sensitising the community on SBH and HC in the city and the neighbouring areas”( KII, ASBAHT)

In central Uganda, CU-SBH holds effective joint media – largely television and radio – sensitisation and advocacy campaigns on SBH.
Our media strategy involves using the youth to explain to the public their experiences of treatment and living with SBH. To some extent, this has been effective although we still have incidences in which some of the adult youth are more reluctant to appear on television for fear of being identified by the general public as having SBH. (KII, CU-SBH)

In eastern Uganda, the support groups and CURE Hospital not only mobilise the community to mark the annual SBH World Day on 25 October but also jointly hold talk shows on radio and television.

“We held a talk show on Step Television station last month and have monthly programmes on a local radio station in Mbale during which the parents and health workers from CURE Hospital interact with the listeners on various issues related to SBH conditions” (KII, EU-SBH-NET)

In western Uganda, God Cares Support Group has also effectively used Radio West talk shows to sensitise the community to SBH in the region.

“We held 3 radio talk shows were conducted in 2014. In addition, we held two workshops on stigma and discrimination and two community meetings conducted between January and July 2015” (KII, God Cares)

In Malawi the youth have come up with a play which they intend to use for sensitization in the communities, schools and during functions such as the SBH World Day. The play is about how parents should not take children with SBH to witchdoctors but to hospitals.

The evaluation revealed that the most effective methods are: radio talks and TV, home visits and outreach clinics, testimonies, meetings at antenatal clinics, community mobilisation etc.

However in Malawi, although in the narrative report of July-December, 2014 it is reported that there is contact or networking with capitol radio where interviews and awareness raising messages have been broad casted, during an FGD with youth it was mentioned that they had heard about different types of disability being discussed on radio but they had never heard of a programme being aired on radio or TV on SBH and that such issues were mainly discussed during their meetings. Owing to this there is, therefore, need to disseminate information on spina bifida and hydrocephalus using all channels of communication.

Nevertheless, although information about services and SBH may not be adequate, it has been relevant and also enabled many families to take decisions regarding children affected by the condition instead of giving up and basically waiting for their children to die without trying to cope with practical difficulties as best they can.

“When I gave birth to this child, I did not know what causes this condition but now that I am staying with it, the knowledge I have is that it is because of lack of enough nutrients when one is pregnant. We were told that this condition occurs during the first three weeks of pregnancy up to three months and this is because during this time the mother was not eating a balanced diet or not taking this medicine called folic acid that they give from the hospital. There are certain nutrients that you don’t get in foods but if you take those medicines, it helps” (IDI, parent)

In the western region of Uganda, it was revealed that the traditional method of treating hydrocephalus has always been using local herbs when they see the head of a child expanding in size. One of the local herbs used is called omuhanga. It is applied through cutting the skin on the head in a form of okushandaga and then smearing the juice obtained from the herb. It is believed that with treatment the size of the head can be reduced.
However, owing to sensitization, awareness creation and training directed at SBH in various communities, traditional methods of treating hydrocephalus are reducing. Thus when parents or parent support groups identify a child with signs of SBH, they bring or refer him/her to OURS, where action is taken as stated below:

“Today, SBH cases are promptly referred to OURS God Cares in Mbarara which then diagnoses and, if need be, refers them to CURE Hospital in Mbale for surgery” (KII, OURS God Cares)

On the contrary, in Tanzania a key informant from ASBAHT stated:

“I don’t think that the information dissemination, sensitisation and awareness creation have been so effective as we had expected. I say so because every day one sees children being born with spina bifida and hydrocephalus. It seems people are not taking folic acid. In the branches of ASBAHT, we have mothers who have children with hydrocephalus and we tell them what to do yet even with that they still give birth to another child with the same defect. So I think they do not follow what we tell them and they don’t take in the folic acid” (KII, ASBAHT)

In the views of the evaluation team, the above statement indicates that people involved in providing information or awareness creation, for example, the key informant who made the above statement and many others too, need more information and proper knowledge about the causes of SBH. Thus they seem to think that not taking folic acid is the cause of spina bifida and hydrocephalus.

**Impact:** Increased sensitization and advocacy have, like all the other forms of interventions covered in this section of the report, had an impact on the lives of the children affected by SBH and their families. The sensitization of communities about to the causes, prevention, treatment and management of the two conditions has obliterated the traditional – often mythical and superstitious – beliefs in which the overall construction of SBH was anchored. People have started accepting that the two health conditions are not caused by family planning pills, witchcraft or a punishment from God. Also demystified is the use of stones and local herbs that were previously administered to the affected children through the incision method using razor blades. A youth in central Uganda aptly summed up the impact of sensitization and advocacy to the perception that children born with HC are part of ‘deformed’ twins – one of whom was never born.

“Our neighbours and the entire community who used to think that my mother was supposed to produce twins but failed and my twin sibling passed on his or her head to me have since abandoned such beliefs. They now have a lot of information about the conditions due to the sensitization and advocacy by the parent groups and the service providers”.

**4.2.6 DPOs/support groups’ administration structures and operations**

Generally DPOs, whether operating under the wing of service providers or not, have administration structures or a chain of command with office bearers whose roles are defined. For example, GROW has a project manager, two social workers/counsellors, one occupational physiotherapist, one physiotherapist, shoemakers for the physically impaired, a multipurpose technician to assemble the wheelchairs, hostel attendants and cleaners. Others, for example OURS God Cares, ASBAHT, SHAK, EU-SHB-NET, PASHL etc., have elected board members/office bearers comprising a chairperson, vice chairperson, secretary, vice secretary and treasurer and additional board members, as noted below.

“In Nairobi we have an advisory board which comprises of a university lecturer; a head teacher to a primary school with a resource centre for children with special needs, a gospel artiste, an administrator at a children’s home and a disability advocate with peer educators and youth. The parent is I and a youth living with spina bifida. Our board has been in existence since 2009 and we conduct our elections after five years. A member can stay in office for up
to two terms but if the performance from any member is deemed good and influential to the members, then the said member can run for third or fourth term. We allow all members within the parent group to vote and it is done by secret ballot. For me I have been a leader, and every time I have tried to leave the position, the members have always elected me back. I think there are some characters that members see in someone and they realise that such a person is competent to get the group from point A to point B” (KII, SHAK)

However, in most countries, for example in Uganda, DPOs like EU-SBH-NET, OURS God Cares, and CU-SBH, have support groups in different districts or locations which, according to their organizational structures, operate under them. Such support groups also have their own secretariats or administrative boards comprising of a chairperson, secretary, treasurer etc. who are elected from among registered members and they are volunteers. Some of these support groups are registered as CBOs in the districts where they operate but others are not. For example, the support group in Gulu is registered with the district community development officer (DCDO) as a CBO. Other groups are also registered at sub-county level, e.g. the support group in Bobi sub-county was registered in June 2014. It was reported that on the DPOs/support groups’ administration committees, children/youth are represented.

In terms of effectiveness, the establishment of DPOs/support groups and their active involvement in a number of activities count among the most significant achievements of the IF/RHF funding to SBH programmes in the countries covered under this evaluation. The DPOs have not only been effective in providing a platform for parents/health care providers to meet and share their experiences but also proved to be the major catalysts to the other forms of intervention for the conditions.

In Tanzania, ASBAHT has steadily evolved from a home cell that comprised a handful of parents to a network of over 200 members in its network of branches.

“Our biggest success is that now we have an office and people know our address where they can come to get information about SBH” (KII, ASBAHT).

In Sudan, the Spina Bifida Federal Association (SBFA) has been effective in providing shelter to affected families without accommodation, training in CIC and bowel management and providing a forum for sharing experiences.

In Kenya, support groups are the chain link between the children affected by SBH and IF through the service provider Bethany Kids.

“As the DPO leaders, we listen to the opinions of the ordinary members who in turn identify with the group. We hold six meetings in a year-funded by IF – to devise ways of dealing with our unique challenges in raising our children” (KII, SHAK, Nairobi)

Similarly, SHAK Mombasa/Coast region has – despite being a new support group – set up a small ranch for rearing and chickens. In addition, they have started table banking.

“The parents are doing table banking and home visits to know each other, and also keep encouraging one another to take their children to the clinics ”(KII, SHAK, Mombasa)

The central Uganda-SBH support group is one of those effectively involved in mobilizing parents and other stakeholders towards the cause of SBH children. Since its inception in 2010, the DPO – headquarter in the suburb of Kampala has so far registered 527 members in eight districts of central Uganda. Through IF funding, the DPO has galvanised parents’ efforts to bring a smile to the faces of the hundreds of children and youth affected by SBH. The parents support group now has a direct working partnership with IF, a factor that greatly
facilitates the rate at which it implements its activities. In addition to its routine group activities, the DPO has also spearheaded the ‘Know Your Rights’ campaign aimed at lobbying the government ministry responsible for persons with disabilities to incorporate the promotion of rights of persons affected by SBH into its annual work plans. It is also responsible for the provision of counselling and psycho-social support to members and children/youth affected by SBH. It also keeps minutes of all its executive and general meetings. The DPO chairperson summed up the effectiveness of IF funding on their successes as follows:

"F funding has pushed us from zero to the level at which we are now. We have managed to mobilise parents to form and register the association. We are also mobilising the youth to start income-generating activities like chicken rearing. Using IF funds, we are able to organise parents’ meetings. Our presence is now felt within the disability movement in this region”  
(KII, CU-SBH)

The Eastern Uganda SBH Network is also steadily proving to be an influential and effective network of parents with a network of branches in Tororo, Budaka, Kibuku, Sironko, Iganga, Jinja and other districts. Over the years, a total of fifteen multi-level support groups have been playing an influential role in mobilising parents for project activities.

“The support groups consist of members of all age groups, with the oldest being 62 years. They are involved in advocacy, the protection and promotion of rights of children with SBH”  
(IDI, eastern Uganda)

Similarly, the God Cares support group – located at the OURS health centre in Mbarara – is effective in promoting knowledge sharing. The DPO is now actively involved in mobilizing members to form Savings and Credit Cooperative Organisations (SACCOs) to improve their livelihoods and meet the needs of their SBH-affected children.

In northern Uganda, the multi-level support groups that were started under AVSI/GROW (Gulu) are steadily becoming influential in training in overall care for the children affected by the two conditions.

“The support groups have also mentored many affected youth and promoted networking among them”  
(IDI, Gulu)

In Zambia, Beit Cure Hospital and the parents association successfully lobbied the government to enact a new law against discrimination against persons living with disability in 2013. It should be noted that the youth with SBH are aware of the existence of the support groups and they are also aware of the roles that such groups play. Some members of the support groups personally support the youth groups. For example, a youth with hydrocephalus in Malawi mentioned a woman who was a member of the parents’ support group who supported their youth as well as parent groups with food during neuro-days as well as during meetings. The youth groups, if well-organized are important as members encourage one another to attend school and regarding how to address the other challenges that they experience.

Although DPOs plan and implement their activities in cooperation and collaboration with the support groups which are under them, it was reported that it is common for support groups to also plan and implement activities in the communities without directly involving the DPOs while periodically reporting to the project coordinator. This is noted below:
“There are some activities which the parent groups (executive committee) plan or implement without involving the project coordinator but they do report to the coordinator periodically. Some of these activities include support group meetings, IGAs, parents-to-parents’ home visits, distribution of shunt leaflets and folic acid, village savings and loan association (VSLA) activities etc. They are now even able to identify SBH cases in the community and refer them to the coordinator for further assessment and treatment planning” (KII, GROW)

Although the DPOs/support groups’ activities are financially supported by IF, owing to the inadequacy of funds, the groups are also trying to finance them out of their own avenues generated through membership fees, monthly contributions, table banking, income generating activities etc. However it was noted that the support groups in Malawi do not have any of these initiatives though the chairperson revealed that from year 2016, there are plans to start some of them.

On the other hand, in view of the support groups’ independent involvement in some activities, the evaluation revealed that there is a strong need for qualified TOTs in support groups and/or communities because these will improve the members’ skills and also strengthen the support groups’ strategies, methods and quality in their operations.

**Impact:** IF funding to DPOs/support groups is probably the most fundamental component of this programme. The reality is that this component has had a great impact. Using IF funding, the DPOs/support groups are actively involved in the identification of new SBH cases, mobilisation of parents and youth for CIC and bowel management and providing psycho-social support where and when it is needed. In most rural areas, they have taken on the task of distributing shunt leaflets, folic acid, pampers and other necessities. They are also involved in economic empowerment through table banking, chicken rearing and soap making – among other activities. They are also helping some parents in coping with divorce challenges – especially, the single mothers who are struggling to raise the children alone. Generally, the DPOs/support groups are the fulcrum that keeps the SBH alive.

4.3 **Sustainability**

This section focuses on sustainability in terms of what DPOs have achieved and accomplished, as highlighted in the sections on relevance and effectiveness. The assessment has adopted the IFAD definition of sustainability, which focuses primarily on ensuring that the institutions supported through projects and the benefits realized are maintained and continue after the end of the project lifespan (IFAD, 2007).¹

4.3.1 **Capacity-building of human resources**

The capacity-building efforts of most DPOs have been supported and conducted by key partner organizations or implementing partners. For example, CURE Children’s Hospital in Mbale, OURS in Mbarara, Katelemwa Cheshire Homes in Kampala, CURE Orthopedic Hospital in Malawi as well as AVSI in Gulu have trained a number of health providers and social workers in the secretariat on SBH prevention and management. Much as these are not staff from DPOs, they have been instrumental in training and building the staff of DPOs. The close interaction and partnership between service providers and DPO structures were perceived by DPO as positively impacting on the capacity-building of members of DPOs. For example, the training targeting the support groups have contributed to creating awareness, as well as enhancing knowledge, skills and appropriate attitudes of parents, children and youth regarding SBH prevention and management. Also discussing and sharing of experiences among parents as part of training have been important. For example, one participant in Gulu

noted that ‘discussing and sensitizing parents about SBH, have improved how parents treat their children’ (IDI, Parent, Gulu).

Another participant stated:

“I was trained on how to remove urine and now I have no problem while removing urine. I know the procedures followed and it includes getting warm water to wash the catheter, then put the catheter inside me to drain the urine, then I put it in the bucket and throws it to the toilet” (IDI, male youth, 20, Mbarara)

There are positive indications that capacity building at family level to continue with the practices and strategies promoted by the project are likely to continue even after its lifespan.

There is also increased participation of the parents and children/youth in the programme activities and this is a positive strategy for sustainability. For example, OURS God Cares reported that parents participate in different group activities and that, depending on their level of awareness and literacy, they engage in the sensitization of their communities. For instance, around 40 parents participate in mobile clinics. Thirteen parents participate in management and two children in designing, planning, implementing and monitoring of the programme, and they also do the follow-up of their parents. Two youth are involved and they were reached through their parents. There is a children’s committee comprising of six members, two male and four female. When these members meet, they plan and select ideas that can be translated into practical activities.

In Tanzania, it was observed that some DPOs were benefiting from training organized by the umbrella bodies of people with disabilities and their partners. These are examples of positive inroads towards sustainability.

“The My Rights organization organizes leadership training for the executive members. Actually the organization has four board members and they include the treasurer, the secretary, the chairman and one youth”.

In Malawi it was reported that when the support group gets its own premises, capacity building of children/youth with SBH and their parents/care providers is going to be one of the main activities.

However, these positive aspects notwithstanding, the evaluation team noted with concern that most DPOs did not have their own skilled and competent human resources to provide prevention, care and treatment services for children and youth with SBH conditions. For example, most DPOs did not have their own trained health providers, social workers or administrative staff in their respect secretariats. This means that DPOs and support groups were largely dependent on the skills and competence offered by service providers and other institutions from the partners. This was noted to be a critical gap in terms of technical sustainability that needed urgent attention.

4.3.2 Level of integration of SBH activities into the existing structures

The integration of SBH into existing structures at all levels is limited. For example, there have been efforts to integrate services through engagement with nurses at the antenatal clinics in Mbarara Hospital’s outpatient department and this has helped to disseminate the preventive awareness messages to 300 expectant mothers who come for antenatal care and immunization services. However, this is happening in a quite sporadic rather than systemic manner.
Similarly, in Kenya, there was evidence that SBH activities were being integrated into existing structures, especially the faith-based structures. DPO and support group members were reported to visit churches and integrate their messages into the church activities. DPOs are also members of existing structures such as the Disability Awareness Movement in Kenya. SBH issues have also been integrated into the Kenya Ministry of Health National Folic Acid Supplementation Programme. These are positive steps towards sustainability that could be replicated in other settings. The Ministry of Health in Kenya has also integrated issues of food fortification into antenatal and post-natal clinics. DPOs and support groups have been brought on board to serve as key players in pushing for food fortification. Remarks below from KIIIs with the National Association in Kenya provide more context-specific details.

“In my presentation, I talked about the iron and folic acid food supplementation programme by the Ministry of Health. When I met the Global Alliance for Improving Nutrition, they wanted to work with us because they said these are the people who can push for food fortification in Kenya. So the Ministry of Health gives out this medication in antenatal and postnatal clinics. They used to charge but now they give them out free of charge so now what we do as DPOs, we tell the parents/mothers not only to use the medication only when they are pregnant but do it regularly. This we say based on the knowledge that not many people know how spina bifida and hydrocephalus happen unlike for us in the group who are now aware” (KII, SHAK, Nairobi)

At national level, there is no systematic evidence to suggest that SBH issues and concerns have been reflected in the national development plans, national health policies, other sector-specific policies and programmes in the various partner states. Similarly, few umbrella organizations working on disability at national and local levels have incorporated SBH into their strategic plans. For example, in Uganda national disability agencies such as the National Union for Disabled Persons (NUDIPU), Action for Disability (ADD), the Centre for Disabled Children (CDC) and the National Council for Disability (NCD), are aware about SBH but they have not seriously taken it up and integrated it into their strategies and plans. Similarly, although VHTs are a crucial structure at the community level and at Health Centre 1 level, they have not been mobilized and trained to support the implementation of the programme.

The national curriculum for training various categories of health care providers has not been reviewed and revised to take into account SBH conditions and dynamics. This has contributed to health providers fearing or being reluctant to provide the correct diagnosis and treatment.

“The health providers fear to do medical check-up or treatment on our children who are affected by SBH even if it is just fever and they don’t want to write in SHIP passport” (Male participant in FGD)

“There are few doctors who are knowledgeable about the conditions of SBH. They will refer even simple illness which be treated elsewhere in any health centre” (Health provider at CURE)

4.3.3 Partnerships
In Uganda, DPOs are working with a number of partners supporting their work. Some of the key partners include CURE Children’s Hospital, Katalemwa, OURS partnering with CSO, local SBS for brain CTC scan, among others, Liliane Foundation which supports children with school fees and Parents with Children with Disabilities (RAPCD) for mobilization, identification and counselling.
“We have CSO that we partner with. For instance, nine children are supported by local SBS for brain CTC scan, among others. We also have Liliane Foundation which supports inclusive education, for example five children are being sponsored by Liliane Foundation in their education. We also collaborate with churches. For example, every year, the cathedral gives us a contribution to support children” (KII, OURS)

"Others support us in the work of mobilization, identification and counselling. Rwenzori Association of Parents with Children with Disabilities (RAPCD) supports us with money for transport and brain CTC scan. CBM supports some of the community work, staffing and the management, especially in the day-to-day management as well as paying the administration costs” (KII, OURS)

Partners have played a crucial role in administrative and financial management and accounting. For example, CURE Children’s Hospital, OURS and AVSI are engaged in providing administrative support. However, there were concerns among DPOs that they are rarely involved in financial planning and management decisions. This has to some extent denied them opportunities to build their capacities in financial planning and management, which are crucial for sustainability.

In Tanzania, interviews with DPOs indicated that they have established alliances with some leading politicians. For example, one of the patrons of the DPOs (Dorcas)\(^2\), a wife to one of the leading political figures in Tanzania, was reported to have played a key role in creating a supportive environment in schools for children affected by SBH. She was also reported to have made financial and material contributions to the DPOs.

“We have our patron called Dorcas, who works with us. She goes to schools and encourages the children to boost their morale. She is the wife to one of the politicians who contested in their party to become the nominee for the office of the president of Tanzania. Actually last month, she even donated to us 50 shunts and this was a good boost to our cause” (KII, ASBAHT, Tanzania)

As already highlighted, DPOs in Kenya are working in partnership with and is part of the Disability Awareness Movement. They are also working in partnership with the Ministry of Health and the Global Alliance for Improving Nutrition. These partnerships are crucial for networking and sustainability. They also have the potential to improve advocacy and the mobilization of resources.

4.3.4 Financial sustainability

Financial sustainability is a major challenge for almost all national associations. In Uganda the efforts to outsource funding or grants from the district local governments have been ongoing but none of the organizations have successfully applied for these grants. To-date, no proposal from these associations has been funded. This is an indication that capacity-building in resource mobilization, especially project proposal writing and building partnerships, is needed to enhance the capacity of most DPOs to engage in local and external fundraising. This further underscores the need for networking to get into consortiums that can be used to attract more resources.

“We have been writing proposals to secure funding for them but we have not secured them apart from IF. There are also limited resources to handle the overwhelming number of people. For example, we have children who are on waiting list for wheelchairs for two years. We can

\(^2\)She has a son with HC.
only be able to buy eight wheelchairs per year out of many children who need them because the wheelchair costs 600,000" (KII, OURS)

However the parents of children affected by SBH are running income-generating activities (IGAs) and SACCOs as means of boosting their incomes as noted below:

The parents and children support groups are gradually being strengthened to sustain the management and sustainability. These are being sustained through income-generating activities which are being run by parents. Each parent contributes around six thousand which is still not enough to help sustaining the project. (KII, OURS)

We are trained in IGAs by the experts and the hospital staff. We can save some little money and life is better now. The first time I came here at CURE I had only one gomesi (dress) given to me by the grandmother but now you see me...I look a person because of CURE and IF. (Parent, FGD, Mbale)

In addition there are some signs that members in the support groups in almost all partner states have started responding positively to making contributions to ensure the self-sustainability of the support groups. Although what is paid is nominal, it is a strong indication of commitment to sustain these nascent structures. Remarks from KIIIs help to put this in context.

“In Nairobi we have a membership fee which is Sh. 100 per month and Sh. 50 annual registration. This money is used for the welfare of the contributing parents. If a child gets admitted, upon discharge the committee gives the contributing parent Sh. 1,000 as a consolation fee. When a contributing parent loses a member of the nuclear family then the committee gives this bereaved parent Sh. 2,000 as consolation fee. These are the very funds that help older children access annual kidney ultrasound. We also use these funds for other activities like renewal of the group certificate, and buying stationery for the group” (KII, SHAK Nairobi)

In Malawi PASHL does not have any ongoing financial strategy for its sustainability though it was revealed that in future the group intends to:

a) To seek for financial help from other charity organizations
b) Assist youth and parents to acquire some small loans and engage in business activities
c) Start various income generating and skill training activities

Already indicated although at organizational and at family levels, there are promising attempts aimed at generating resources to complement those received from IF, the evaluation team noted that there is limited capacity-building for enabling communities, especially parents of SBH children, to acquire the ongoing financing needed to sustainably maintain IGAs that have been initiated. Also the funds generated cannot sustain them to manage demands associated with children affected by SBH.

4.3.5 Organizational structure

There are some viable structures which form a good foundation to build on for further organizational development processes. The team noted that DPOs/support groups in various countries are at different levels in terms of organizational development. For example in Kenya, there were indications that SHAK and its sister organs are more functional having advisory boards comprising of highly qualified professionals. In western Uganda one participant stated:
“God Cares Support Group was formed so that they can mobilize resources to support us. But they have not yet secured funding to become any better. These support groups bring us together. They normally meet few times in a year like once for the general meeting and three time for the local parents support groups to discuss the concerns regarding our conditions and income generating activities. It’s a combination of all men and women and their views are always forwarded up to OURS management for immediate action” (IDI God Cares Support Group, Mbarara)

However, we noted that underinvestment in institutional strengthening and capacity development of the board, secretariat of support groups etc. may undermine organizational development processes and, therefore, sustainability. For example, it was observed that in a number of DPOs/support groups, the secretariat is not fully functional owing to limited office space, limited skilled manpower and lack of funds for operations.

“We do not have funds or skilled personnel to manage the office work and even the office is small as you can see it. Can three people sit here? We need a full functioning office but this needs funds. We are doing good work on local radio talk shows once in a month and these radio talk shows have great significance in the communities but we need money for that service” (KII, EU-SBH-NET)

Participation and ownership: With respect to ownership as an indicator of sustainability, the review found that the DPOs and support groups have to some extent started to appreciate the importance of participation of members in planning processes. This is a good step towards increasing the participation of support groups. However, there were concerns that the level of participation by member of support groups is sub-optimal. For example, some KIIIs noted that participation in planning and also in activity implementation by the DPO/support group members is a major challenge and yet it is important for sustainability, and project ownership. The team noted that most DPOs appreciate autonomy but they also appreciate that this should come gradually as their capacity is built by service providers to run the organizations on their own. Key to this is having the required knowledgeable and skilled human resources to handle the technical aspects of SBH prevention, and response as well as in resource mobilization and management.

However, it was noted that DPOs, for example EU-SBH-NET, SHAK and OURS that are run under the wing of service providers have little say on financial allocations and on administering the budget. This is different from more autonomous DPOs in Malawi, Zambia, Sudan, and Tanzania, and also others like AVSI and CU-SBH that have greater participation and control over their funds. This is an achievement for these DPOs and IF. Therefore there is need to organize exchange visits for DPOs that are still under the service providers to learn from other DPOs which are independent. At the same time training in organizational development is also required to build the capacity of these DPOs in establishing systems and institutions that can facilitate them to become more autonomous in future to run their plans and budgets.

The review team also noted that inadequate attention is given to the formulation of viable exit strategies yet these are very important for the sustainability of projects’ benefits and structures.
4.4 Overall assessment
This section provides an overview of specific evaluation issues which are: financial management and reporting; research strategies; gender equality; monitoring and evaluation; working methods and communication between IF/RHF and partners; relevance of training tools and methods; and added value of the stakeholders.

4.4.1 Financial management and reporting
Owing to the limited time available for the evaluation exercise, obtaining all the relevant information on the detailed financial management and reporting systems and clearly evaluating their relevance, effectiveness and sustainability was difficult. Nonetheless, all the key informants from the DPOs interviewed and the desk reviews pointed to a streamlined system that poses no major obstacles to the transfer of funds from IF, accounting and audit processes. It was clear that the DPOs that are not under the wing of service providers do financial reporting direct to IF.

Transfer of funds to local partners: The evaluation team found that IF remits the funds directly to the DPOs or service providers in accordance with the MoU on which the working relationships are based. Overall, the evidence available at all the DPOs and service providers’ offices showed that none of them has encountered problems related to the transfer of funds from IF – a view emphasized by the SHIP coordinator, Katalemwa Chesire Home:

”In terms of transfer of funds, we have not had any major hurdles to overcome. Over the last four years, it was only during 2012 when the funds came late. Otherwise, the transfer process has been incident-free for us” (SHIP coordinator, CU-SBH)

In Tanzania, it was reported that funds are remitted by IF to the ASBAHT bank account and the same was reported in Sudan.

However, in Mbarara OURS mentioned delays in receiving funds as being one of the challenges they were facing because delayed receipt of funds slows down the implementation of project activities.

In Malawi too it was reported that the service provider’s delay in processing funds for the activities was one of the reasons why PASHL decided to become independent.

“We can now make our own budget which we send to IF. The money is remitted directly to our account and we start implementing the activities. But in the past when everything had to go through the hospital and we had to wait for a long time” (KII, PASHL)

It was also noted that DOPs which are still under the service providers have little say on financial allocations and on administering the budget. For example, in Kenya, a key informant stated

“Our funding from IF and RHF are centralized through our partners Bethany Kids who then disburse it to the existing parent groups across Kenya but we are not aware of the total amount which is given to Bethany Kids by IF/RHF” (KII, SHAK)

In eastern Uganda, the secretary of EU-SBH-NET referred to the predicament of the DPO’s lack of financial autonomy thus:
“The budgeting of our activities is done by CURE Hospital. Actually with our finances, we don't know anything completely which affects the effectiveness of our implementation. We are not involved at all, so even as I talk now, we don’t know how much funds that come for the parent support groups and we don’t know how much we spend and how much remains” (KII, EU-SBH-NET)

Bank accounts: All the local partners operate bank accounts in various commercial banks in line with the procedures spelt out in their respective MoUs with IF. Funds related to SBH are deposited in separate bank accounts and such funds cannot be mixed with other funds or used for other projects. Requisition for funds for particular activities follows the normal procedures; it involves the generation of a request by the SHIP coordinators or other relevant accounting officers under the approval of the local partner executive director or other authorized person. At OURS, which is a service provider, the SBH bank account is run by the association through four signatories, namely the chairperson, secretary, treasurer and opinion leader. As one key informant explained:

“Money available on the account can only be withdrawn for a planned activity based on the minutes as agreed to during either the Board or general meeting”

Accounting and auditing procedures: The DPOs/service providers follow standard international accounting procedures. Under these partnership agreements, the local partners are obliged to report to IF at least twice a year on a schedule agreed to by both parties – and this includes programmatic and financial reporting. Annual audits are done in the first 1-3 months following the end of the annual budget agreement. Records at all the DPOs visited during the evaluation exercise showed that they all procure qualified and authorized auditors to undertake the process. At Katalemwa Cheshire Home, OURS and AVSI, the evaluation team was shown copies of audit certificates. There was also evidence of stringent account bookkeeping, expenditure receipts for the various activities and bank statements. Over the period under evaluation, there was no evidence of violation of the national accounting and audit laws and procedures. In Tanzania, it was reported that the financial procedures of ASBAHT are carried out through reporting formats sent by IF.

However, DPOs which are still under the service providers submit their reports to IF through them, as noted below:

“Since I started leading the Nairobi support group, I have never submitted any report directly to IF. In Kenya the local partner submits its audit reports to BK, which in turn submits it to IF” (KII, SHAK)

Surplus funds: Although the MoUs seen by the evaluation team clearly state that any part of the project funds unutilized according to the budget of a particular financial year must be returned to IF, there was no evidence to suggest that any of the local partners had ever recorded unutilized or surplus funds during the period under evaluation.

In all the countries, the key informants reported that there had never been a case where the funds had not been spent. In fact, they had always had shortages. Therefore, returning unutilized funds to IF was out of question for them.
4.4.2 Research strategies

Although the MoUs between IF and the local partners do not provide any funds for research on SBH, in the IF narrative report format there is a component for research. This means that indirectly IF/RHF have an interest in conducting research on various socio-cultural issues related to these two conditions. However, the evaluation revealed that it is only the service providers that have ever been involved in research but not the DPOs. For example, in Uganda:

a) Katalemwa Cheshire Home, in partnership with AVSI, in 2012 conducted a study on ‘the impact of service delivery on the lives of children affected by SB and HC in Uganda’.

b) In 2013, research was conducted at Beit Cure Hospital by Prof. Ben Warf on ‘the possible causes of hydrocephalus and spina bifida treatment options and their effects’. It was based on secondary data from the records at CURE hospitals and outreach centres in Zambia. In addition, Prof. Ben Warf published a number of papers based on secondary data from the records at CURE Hospital at Mbale.

In Malawi, a provider mentioned a number of studies which had been done by students from the College of Medicine of the University of Malawi and these studies include:

- b. *A retrospective cohort study comparing the outcomes of endoscopic third ventriculostomy (ETV) and ventriculoperitoneal shunting in the treatment of paediatric hydrocephalus in Malawi*. (2014/15 MBBS Year 4 student project) – Dr Kamalo was the student project supervisor.
- c. *A retrospective audit to determine the outcomes of surgical treatment of myelomeningocele (hydrocephalus) at QECH*. (2013/14 MBBS Year 4 student project) – Dr Kamalo was the student project supervisor.

The studies which have been conducted by students of College of Medicine of the University of Malawi have, among other things, compared outcomes of treatment of hydrocephalus at QECH. Apart from the above-mentioned studies, there was no evidence of any other completed or ongoing research activity either by the DPOs or service providers.

Given the importance of research in providing local perspectives on the prevention, management, achievements and challenges of coping with SBH conditions, it is imperative that IF consider funding some specific areas of research within their partner organizations. It is important that the research should include a focus on financial challenges, networking and collaborations, sustainability in terms of what has been achieved and coping with increased numbers of people accessing services and their demands, and public health especially on issues related to mental health challenges of the parents/caregivers and that of the children/youth with SBH.

4.4.3 Gender equality

A lot has been written about how social relations, including disease and disabilities, affect men and women differently but, of course, women are usually more vulnerable and have more responsibilities than men. In the case of SBH, the situation is no different. Interviews with parents, health providers and other key stakeholders, revealed how gender equality is a
big challenge. Basically, having a child with SBH has led to divorce and separation in some families. Men either ran away from responsibilities or put the blame for producing such a child on women, or both. Not many of the men accept children with SBH. In Mbale, some men relate SBH to family planning. Therefore, a child with SBH is said to belong to the mother because she might have used family planning. One parent remarked:

“This condition has separated many homes. Some men refuse the women claiming that this is a disease or curse they have come with it from their homes. It is mostly the mothers of the children who are suffering a lot because the father will simply say that for such a thing, we don’t have it in our home so you go back to your home” (IDI with a parent)

One of the dedicated male parents stated:

“There are many broken families due to SBH. Like for my child in just two weeks the condition was showing. So for parents with weak minds, the husband keeps on blaming the woman that you have produced a bad omen in our house and it is not there in our family. They end up chasing away the mother of the child. So when the mother is left alone struggling with the child and has nothing much, then it is hard for her to take the child for treatment. But when people from CURE come to visit they give us more knowledge on how as parents we should treat and take care of these children. Even our coordinator Isaac moves a lot in the communities counseling parents that they should continue staying together because children with SBH keep on falling sick and when they fall sick, they need to be taken to the hospital immediately. Therefore the cooperation and solidarity of the parents is important for the survival of these children” (IDI, parent, Gulu)

In all the countries, because of men’s negative attitude towards children with SBH, it was reported that in most support groups there were fewer men than women. Furthermore, the few men who were members had little patience so they ended up dropping out of the groups, leaving only their wives as members. For example, in Zambia the support group ZAHSB had fewer male members than female members, hence there was unequal participation in its activities in terms of gender. Some single parents in Zambia – especially male ones – did not show any interest in therapy for patients. The groups had, however, embarked on a sensitization campaign to encourage male parents and/or guardians of SBH children and youth to participate in its activities. In Blantyre in Malawi the support group had 38 members, of whom only one is male. In one youth group there were 11 participants, and out of these only three male. In another youth group there were eight girls and three boys. In Zomba the group had only one man whose wife ran away leaving him with a child having spina bifida. But alsoin Malawi, in one youth group, there was a good mix of young males and females. And in the 2014 narrative reports to IF the situation was summed up by one of the group members as follows:

“We have one very motivated father who was trained in CIC. This father helped us to teach the other parents (he actually supervised) CIC at our training session in August 2013. He is a brilliant teacher”.

Nevertheless, the evaluation revealed that, except for community sensitization, advocacy and awareness creation aimed at changing people’s attitudes towards SBH and the children who have it, DPOs/support groups have no solid strategies for engaging men in SBH interventions. Therefore there is need for the local partners to come up with strategies for involving more men in various SBH-related activities, including taking part in parents support groups.
Regarding treatment and other services which are given to girls and boys with SBH, in all the countries it was revealed that patients receive equal treatment. The service providers do not draw lines based on gender. Also, in all the countries it was revealed that both boys and girls with SBH experience similar challenges of being stigmatised and discriminated against by community members. However, in Uganda, Kenya, Tanzania and Malawi, actors from different DPOs/support groups revealed that it is important to take into consideration the unique needs of males and females with SBH – for example girls with hydrocephalus reach puberty earlier than most girls; this should be considered when providing services. Also in Uganda a key informant said that often it is difficult to involve female youth in advocacy activities. They fear that nobody will marry them if boys know that they have SBH. In Malawi it was suggested that having a male nurse involved in CIC training is very important for the male youth.

4.4.4 Monitoring and evaluation (M&E)

Monitoring and evaluation tools provide a way to determine if programmes are achieving what they are intended for. Both M&E tools should be an integral part of the programme from its beginning. Thus they can be used to improve the current activities and future planning, programming and decision-making. However, M&E is always a weak programme component and it remains a continual challenge. In this evaluation, according to desk reviews and interviews with SHIP coordinators/project managers, local partners compile reports on project operations and share them with IF/RHF on a half-yearly basis. Nevertheless, it is difficult to trace evidence showing that they adequately monitor and evaluate their operations. For example, partners could not provide evidence on how adequately they follow up on the referrals they make or how the information in their possession is used. Although local partners submit narrative reports outlining activity achievements, it is not clear how IF/RHF verifies or cross-checks the impact of these activities beyond what is written in the submitted reports. This is evident in the contextual presentations in the reports the evaluation team reviewed. For example, in the narrative reports from Kenya for the year 2014 there are many claimed achievements and activities which were implemented. The same goes for narrative reports from OURS in Mbarara. In this regard, the evaluation team was concerned about how IF can verify the validity of the claimed achievements.

Also, in the narrative reports submitted through the service providers the information/data is presented in a manner which implies that the reported achievements and/or activities were mainly implemented by the service providers. Thus the role and/or participation of the DPOs/support groups in the implemented activities somehow diminish and are only highlighted on a very limited scale (see narratives reports from Kenya, Mbole, OURS and Malawi). In addition, in some components of the narrative report format, some DPOs/support groups simply give their answers as ‘YES’ or ‘NO’ without elaborations. Others, however, provide detailed answers and even elaborate on their implemented activities. The evaluation team finds this to be more useful because it enables IF to know more about what has been accomplished and/or achieved by the DPO.

Concerning participatory monitoring and evaluation, in all the countries it was not mentioned how individual members in the DPOs are involved in monitoring and evaluation mechanisms). In addition although DPOs/support groups reported process effectiveness and/or achieved impact, in most of their interventions, for example increased knowledge and change of attitude due to massive sensitization, none of them had evidence that baseline studies had been conducted prior to activity implementation. In M&E it is necessary to have baseline data.
Regarding the prevalence/incidence data on SBH in focus countries, none of the DPOs had it. In Malawi one key informant stated that:

“The hospital keeps records of our patients but we do not know the true incidence as many patients do not make it to the hospital. Also we have no compiled data from different hospitals, clinics and the Ministry of Health for the reported cases except for those that are referred to us” (KII, PASHL)

Generally, DPOs need to strengthen M&E in their interventions.

4.4.5 Working methods and communications between IF/RHF and partners
The key informants interviewed and the literature reviewed revealed that communication between IF and local partners have mainly been through email and evaluation visits by RHF/IF officials. The partners submit bi-annual reports on activities (operations, financial and management reports). The format is provided by IF. According to the participants, this has worked well, but we suppose that with Sudan, owing to language barriers, the situation is a little bit different. Even the evaluation team encountered some problems with Sudan with regard to the English language.

4.4.6 Assessment - relevance and effectiveness of the tools, materials and methods used in training and follow-up of the projects which are provided by IF to partner organizations
According to the information gathered the tools are useful and posters are helpful in using different techniques. They feel that although IF’s materials are of international standard, they fit well with the African settings. The training which they offer to support groups and partners using these tools and materials has been very relevant and beneficial to them. One parent remarked:

The programme is good especially for CIC training. It improves the lives of our children and gives confidence of life of the children and parents. (IDI, parent OURS God Cares)

The informants commented that the knowledge and skills gained from IF’s training has contributed to the formation of other support groups and enabled group members to do advocacy work effectively. However, some health providers, e.g. the physiotherapist at GROW in Gulu, admitted that they do not use IF medical guidelines but instead those of WHO and they expressed the view that the contents are the same. On the other hand, in Sudan one of the key informants reported that some of the tools and materials are not considered effective and relevant because of availability of few trained nurses and medical doctors and also owing to lack of sufficient training methods. In addition, the evaluation revealed that none of the DPOs in all the countries had ever tried to develop its own training material or update the ones provided by IF/RHF. When asked, none of the informants had any suggestions to this effect.

In Malawi it was reported that the SHUNT leaflets are not used to inform parents because they are not translated in the local language. Also the leaflets/teaching materials on FA are not provided to women but during the training on CIC they are taught about FA and this is reinforced at the clinics.
4.4.7 Assessment – Value added of RHF/IF as partners and donors

RHF and IF have dedicated, committed and experienced volunteers whose vision and interests are to build the capacity of their partners in the South and putting spina bifida and hydrocephalus high on the agenda of the collaborating partners. RHF being a strong organization in Norway brings its expertise in working with parents, youth and their support groups and shares it with other support groups in the South. As already noted, IF spreads knowledge about SBH and follows the latest medical and scientific findings in the field, which it shares with its partners in the South who have limited resources and access to such information. It also mobilizes resources from other donors, such as NORAD, to support its programme in the South. RHF/IF have leveraged their partners’ expertise in the medical treatment and rehabilitation of children with SBH and linkages to the health systems to achieve the objectives of Regional Programme (see also IF evaluation report, 2009).

This means that IF/RHF add value in terms of funding the partners’ project activities, training, and transfer of knowledge/competence to its partner organizations. According to the literature reviewed, and interviews with stakeholders, the support from RHF/IF has been vital in pioneering the work related to the treatment and rehabilitation of children with spina bifida and hydrocephalus in the South. Stakeholders in the support groups expressed their gratitude to RHF/IF as partners and donors for enabling them to acquire knowledge, exchange experiences with other parents and health personnel in their respective countries and, above all, for their determination in aiming at saving and improving the quality of life of children with SBH. It is through the RHF/IF regional programme that support groups which have functioned as arenas for emotional support to many parents and their children have gradually been established in these countries. During an FGD one parent commented:

“IF has a specific mandate and knowledge on SBH which is helpful for us to use and focus on this group of children within our wider disability programmes “(FGD, CU-SBH)

And a key informant remarked:

"IF’s contribution has made the public to and appreciate our work as a group and today we have a louder voice, especially on advocacy, lobbying and awareness creation than before. With time due to numbers, we shall use our strength, powers, and ability to access support as a group which one cannot access individually” (KII, CU-SBH)
4.5 Challenges and limitations

4.5.1 DPO/support groups’ lack of financial resources
Reports from participants and desk reviews in all countries reveal that lack of funds is a big challenge for them, as noted below:

“We used to get enough funds from IF between 2007 and 2013, then the problem started. Today most of the time we find ourselves complaining because of cutting down of funds, lack of funds for action plans etc. and yet the parents keep on increasing. When health providers from Bethany Kids at Kijabe Hospital visit us and we inform them about the importance of home visits they say there is no money for that” (KII, SHAK Mombasa/Coast)

In all countries, lack of funds is a cross-cutting challenge which is affecting the programme activities such as outreach and mobile clinics, home visits and follow-up clinics, capacity-building, horizontal/vertical networking and collaborations, training in continence management, effective advocacy and awareness creation etc. For example, in Malawi DPOs said that outreach clinics and home visits are not conducted mainly because of lack of finances.

4.5.2 Poverty in the community
It was revealed that many parents do not go for follow-up clinics and others do not take their children to hospital for operations because they live very far away from the health facilities and they have no money for transport. For example, although all the DOPs in Uganda reported that they pay the parents’ transport costs when they take their children to CURE Hospital for operations, in Kenya it was reported that DPOs do not pay parents’ transport costs to Bethany Kids (BK). So in Kenya some parents from distant regions are not able to bring their children to BK for operations because, for example, it costs Kenya Shillings 5000 to travel from Mombasa to Nairobi and many parents cannot afford this. In Malawi transport is also a challenge; some study participants, such as youth, mentioned that, owing to poverty, parents cannot afford to take their children to district hospitals for treatment as well as follow-up. A youth with hydrocephalus, for example, said that some patients who had been seen at Queen Elizabeth Central Hospital came from Mangochi and other far-away places, so it was difficult for them to find transport money. Because of this, they failed to take their children to hospital for proper treatment and check-ups.

In addition in Uganda, Kenya and Tanzania etc. parents must pay for the operations of SBH and some of the post-operative care costs. Because of this, some parents default and decide not to come for clinical follow-ups. Therefore, poverty and lack of facilities and equipment in nearby hospitals affect the children’s quality of life as they become vulnerable to different infections. But at Mbarara Regional Referral Hospital SBH children undergo free operations through collaboration with Prof. David Kitya. However, some children/parents who need CT scan must pay Uganda Shillings 200,000 (US$ 70) and this is a lot of money for many parents. Also, owing to lack of money for transport, many (parents/youth) are frequently not able to attend various meetings, including capacity-building meetings which are organized by DPOs/support groups. However, some support groups provide transport money for the members who cannot afford it out of membership contributions or any other income generated by the support group.
4.5.3 Lack of knowledge and cultural beliefs about SBH

Some parents seek for help very late because they had no idea about the availability of the services. Besides the lack of easy access to services, and financial challenges, there is lack of awareness and knowledge about SBH in the community. Because of this, some relate SBH to witchcraft. For example, in northern Uganda (Gulu), SBH is known as ‘two rubanga’, loosely translated as ‘disease of the gods’, and people think that it can be sent from one family to another by using supernatural powers. Most of the people find the disease quite strange because it is not something that happens to everybody and that is why people associate it with evil spirits. Children with hydrocephalus are given names like Ojok if it is a boy or Ajok if is a girl; these names mean ‘they are of the spirit’. One parent narrated:

“When my son was born with hydrocephalus disability, most people thought about it differently but they never told me directly. Instead they would tell my parents that I should just change the name of my child to Ojok and the condition will be go away. My father came and told me to do so but I told him that he should not bother because I am a born-again Christian and I can’t practice those things. I told him that I had already taken my child to the hospital. Other people were saying that I have a lot of money otherwise if I was a poor person I would not waste the little I have by travelling to Mbale and spending money on treatment. They would say that it was better for me to leave the kid to die. But I always put my things in prayer and as I talk now, I am a happy man” (IDI, parent, Gulu)

In Mbale, the husband of a woman who gave birth in a car on her way to hospital blamed the driver of the car for having caused bodily harm when it was discovered that the child had SB. As already stated in the section on information dissemination and sensitization, such perceptions demonstrate that people do not understand SBH and as a result, they seek treatment from traditional healers who may not be able to give proper treatment. Delayed seeking of care either as a result of going to traditional healers or prayers may result in the worsening of these children’s conditions. One youth in Malawi said that before going to Queen Elizabeth Central Hospital for treatment, his mother used to call people to pray for him. In addition to this, in Malawi one youth with hydrocephalus said that after he underwent a surgical operation he had been experiencing loss of memory and he forgot things quite easily. He narrated that he was experiencing challenges in his family, especially with his father who perceived him as impolite because sometimes when his father told him to do something he easily forgot. It is important, therefore, that parents and other community members understand the challenges children with hydrocephalus experience.

While people may lack knowledge about the disease, it should also be noted that they may not even know where to seek treatment. In the focus countries there are facilities which are providing treatment for SBH but not everyone knows about the existence of such facilities because they are available only in certain places and regions. Therefore, there are many children or people with these conditions who do not have access to effective treatment. For example, a youth participant with hydrocephalus in Malawi gave the example of a woman with hydrocephalus who sought assistance from well-wishers to help her travel to South Africa to seek treatment, which demonstrated that she was not aware of the fact that treatment for her condition was available in Malawi. Also in Malawi, it was reported that people were not aware of any organization that deals with spina bifida and hydrocephalus. In these focus countries there is, therefore, need for information about the availability of SBH services to be disseminated extensively and also for these services to be expanded nationwide so that more people can have access to them.
4.5.4 Shortage of human resources
In all countries it was noted that there was a shortage of qualified/skilled health care providers, such as neurosurgical doctors and nurses, psychologists, social workers, physiotherapists, occupational physiotherapists and psycho-social counselors. For example, in western Uganda there was only one neurosurgical doctor. In Malawi, at Queen Elizabeth Central Hospital there was only one doctor who specialised in surgical management of ETV. So there is a heavy workload on certain health care providers. Also, in Sudan it was reported that no support or financial incentives are given to the nurses, and that full-time coordination of the programme is absent. So staff turnover is very high for economic reasons. In Mbale it was reported that one of the major challenges DPOs/support groups were facing was that members were money-minded and were, therefore, not willing to work on a voluntary basis. In Kenya one key informant stated that “we need more staff so that they can reach everywhere especially in rural areas but they need incentives which we do not have”. Another one said, “In our group we do not have any members employed formally by IF or RHF. So the workload is challenging”. The shortage of human resources, including those with requisite skills, has affected the achievement of sufficient effectiveness and impact through the programme interventions. Therefore, there is need for more staff and more training of those who are already in place so that they can serve more people, including those in remote rural areas.

4.5.5 Shortage of supplies
In Malawi it was reported that most of the materials that, for example, children with spina bifida use are quite expensive. In some cases the hospital runs out of these materials. Hence patients experience a lot of challenges. Patients also experience challenges if they are given catheters and plastic bags which are not appropriate for their age. One male patient aged 28 actually reported that when he is given material which is not appropriate for his age he experiences a lot of pain in the stomach. This man reported that when the hospital runs out of materials he improvises and uses a two-liter plastic bottle, which some patients do not like. It is quite clear that these are challenges which DPOs cannot easily handle but they can lobby for assistance in order to address them.

4.5.6 Hygiene and domestic work
The evaluation revealed that children with SB need constant hygiene and/or follow-up but, although their parents receive information and training in continence management, they are so poor that they lack the means to implement continence management and to bring the children to clinics for follow-up. Also, maintaining or cleaning of CIC and managing bowel movements is a continuous process, so some parents/caregivers get tired and just ignore it. Generally, it was reported that many mothers cannot bring their children to hospital and/or pay attention to their hygiene because of the workload at home, especially when there is growing demand to care for other children and for gardening. For example, parents reported that it was difficult for them to spend many hours away from home doing garden work. If they did so they would find that the children had soiled themselves. This is very challenging because without cultivation there will be a shortage of food in the home. Therefore, many parents are forced to leave their child unattended to regardless of the hygiene consequences that they may experience.

However, children with SBH and who have no mental disorders learn how to do self-catheterisation either at the centre or in their homes. Nevertheless, they also tend to drop the practice when they get tired of long-term management or join schools owing to pressure from peers, lack of supervision, lack of privacy and attitude-related factors. Therefore, some of
these children die of UTIs and other infections which go untreated because of poor hygiene caused by lack of soap, disinfectants etc. A parent commented that:

“There was a condition of the child that arose where pus had filled the stomach and in the hospital they said that it was because of poor hygiene due to the fact that the mother was not removing the child’s stool and urine. The child was then operated and the pus was removed and up to now, they are still in the hospital” (IDI, parent, Gulu)

The evaluation revealed that owing to poor hygiene, it is common that when some children with SBH are taken for treatment, health providers refuse to treat them because they smell foul.

4.5.7 Challenges in taking folic acid

i) Although women are advised to take folic acid before they get pregnant, such as three months earlier, for many of them this is not possible because they do not know when they should get pregnant. Some of these women, therefore, do not take folic acid during the early stages of their pregnancies. In Malawi, for example, some women deliver without being given folic acid partly owing to stock-outs of folic acid. In all the focus countries, it was revealed that most pregnant women seek antenatal care very late in their pregnancy, for example when they are six months pregnant, and at such a time it is not conducive to use folic acid.

ii) There is a problem with adherence to folic acid. Thus some women stop using folic acid because of its taste which makes them to vomit while others stop because of long-term daily use. Therefore, some parents suggest that pills which can only be taken once a month should be produced. Some women refuse to take folic acid because either they or their husbands think that these are pills for family planning or HIV/AIDS. In Kenya and Uganda, it was noted that mothers who have no access to folic acid or to facilities where they can get it, use dried clay, a substitute which is not hygienic and may cause deformities. So there is lack of awareness about the FA itself, when it should be taken and why it is important. Therefore, more sensitization is needed. However, it was reported that sometimes the actors who sensitize women to the importance of using folic acid in different communities also face challenges. The comment below bears this out:

"When we go out for sensitization, some people do not believe us since we do not have a medical education and background. There was a time I was pressed to verify the source of the information of urine reflux in kidneys due to incontinence. Also many women cannot easily understand the relationship between folic acid and SBH, especially when a mother has some other children who are not having this condition” (KII, SHAK)

In Sudan, all women below marriage age get FA. However, its utilization is affected by poor logistics, awareness, media as well as the implementation of the fortification programme in country.
4.5.8 Difficulties in involving children and youth with SBH

Although there are youth representatives in the support groups and committees, and also in the narrative reports it is indicated that youth groups exist, the evaluation revealed that generally involving them in daily activities is a challenge because they are scattered and it is difficult to bring all of them together. Furthermore, even if it was possible to bring them together, some of them would not be willing to turn up because of self-stigma. In addition, the evaluation revealed that most DPOs/support groups do not have well defined strategies for involving the youth, although in a number of DPOs/support groups, they are represented. One of the reasons is that in the past most children with SBH died before becoming youth or adults. Therefore, the focus has always been on survival and improvement of quality of life for the children. But now that many children are becoming youth and even adults, there is need for the DPOs to strategize their involvement, to have role models among them who will encourage others and also be living examples to the public that people with SBH can live a normal life and that SBH is not related to witchcraft. For example, in Malawi, the support group does not have youth representatives because the youth have their own group and therefore they meet separately. However besides the play which they have up with for advocacy purposes, there are no other viable activities which the group is involved in.

In addition, DPOs/support groups should come up with plans to address their various material, social, and public health needs. For example, a 16-year-old girl with hydrocephalus and who was interviewed in Gulu said:

“There should be many more groups for children/youth where we can share issues to do with education, coping strategies/experiences and also counseling”.

Although for survival and sustainability reasons DPOs/support groups talked of initiating or carrying out income-generating activities, nothing was mentioned regarding how the youth in these groups are, or would be involved in IGAs.

4.5.9 Composition of support groups

As already noted, although support groups are now widespread in all the six countries in the South, the evaluation revealed that in most of them members are parents/care providers of low economic status or low social class. The rich parents do not join these groups and hardly interact with other parents, even those of the same status. Instead, they keep their children at home and take them to private hospitals for clinic follow-up. However, in Nairobi it was reported that the groups consist of poor parents/care providers from the slums, the middle class who are in formal and informal employment and the rich. Nevertheless, as indicated in the table below from Gulu, most members are women and, therefore, often it is they who
attend these support group meetings because they are the ones who are close to the children and who bear the burden of caring for them. A similar situation was reported in all other DOPs/support groups in the focus countries.

Table 1: Meeting held with PSG (the group started in 2012)

<table>
<thead>
<tr>
<th></th>
<th>General meeting</th>
<th>Executive meetings</th>
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<tbody>
<tr>
<td></td>
<td>1st meeting</td>
<td>2nd meeting</td>
<td>1st qtr</td>
<td>2nd qtr</td>
<td>3rd qtr</td>
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<td>M  F</td>
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<tr>
<td>2012</td>
<td>11 36</td>
<td>19 38</td>
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<tr>
<td>2013</td>
<td>26 40</td>
<td>21 50</td>
<td>5  4</td>
<td>5  4</td>
<td>5  4</td>
<td>5  3</td>
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<tr>
<td>2014</td>
<td>28 56</td>
<td>35 73</td>
<td>7  4</td>
<td>7  5</td>
<td>8  4</td>
<td>8  4</td>
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</table>

4.5.10 SHIP passport

According to the records from different regions, health workers were educated on the SHIP passport. However in Uganda, in spite of such massive sensitization, it was reported that many health workers in different health centres refuse to fill in the SHIP passports. In some cases, clients are completely denied treatment when they present SHIP passports to the health workers. They are told either to access treatment without SHIP passports or to go to health centres where these passports are accepted. Partly this is because these health workers lack sufficient knowledge about SBH so they do not want to commit themselves in case they make mistakes with treatment, as noted below:

"Doctors and nurses here in Gulu referral hospital fear to treat children with hydrocephalus so even for simple cases they refer them to Mbale" (KII, Gulu)

Therefore, in some health centres SHIP passports cause stigma and discrimination against children with SBH conditions. Also, not using the SHIP passports causes gaps in the follow-up and quality control of the treatment being given. This means that there is need for more sensitization of the health workers.

4.5.11 Education for children and youth with SBH

In spite of integration policies, most schools find it difficult to accept children with SBH because of their condition. For example, OURS God Cares reported how one child was denied access to school in Buwhezu, Ntungamo, Isingoma and Rukungiri because of his SHB condition but there many others who are in a similar situation.

Schools that can accept them are not many and they are expensive because they handle them in a special way. For example, it was revealed that in Uganda there is only one school for children with SHB – it is called Over Comers and it is located in Mbale. However, the research assistants who visited the school during the evaluation commented that owing to financial constraints, this school also lacked adequate facilities for children with SBH. One of the parents from northern Uganda whose daughter goes to Over Comers also reported the same to the evaluation team.

Also as stated earlier, there are many low- and high-class parents who keep their children away from the public eye. For the poor parents/care providers, such behavior deprives these children of access to education. In addition many children with SBH cannot go to school because their parents have no money and because they also need mobility.
The evaluation revealed that lack of education denies the children with SBH and their parents the opportunity to read and understand the contents of the leaflets etc. It also affects capacity-building for support group members because some of them cannot read and write even though the leaflets and other materials may be translated into the local language. But in Malawi as already noted owing to insufficient funds leaflets e.g. “SHUNT leaflets” were not translated into local languages or distributed. In terms of manpower in the DPOs/support groups, it was revealed that there were a number of parents who wanted to volunteer but they could not do so owing to their reading and writing limitations. It was also revealed that the implementation of CIC at home can be difficult and challenging because some of the parents are illiterate.

4.5.12 Referrals
When DPOs/support group members go out on home visits, community mobilization, outreach clinics etc. and happen to identify a child with SBH, they refer her/him to the right professionals and/or institutions for treatment or to access services. Also, during training and capacity-building and parents/youth meetings, some parents/care providers come with SBH children/youth. So when DPOs identify any cases which need attention, they immediately make referrals. This also happens when patients come for rehabilitation, e.g. at GROW rehabilitation centre. Serious cases that are identified are referred. In Uganda, it was reported that CURE Children’s Hospital Uganda (CCHU) sends letters to health professionals about referrals and appeals to them to treat children with SBH for common infections instead of sending them to Mbale and thus risking their lives through delays when these infections, such as malaria, could be treated like in any other children.

However, it was revealed that if the referrals are not followed up, clients take very long without being served, and that no priority is given to them. In addition, it was revealed that although identified cases may be referred or parents advised to take their children to the hospital, owing to cultural beliefs, many of them decline to do so. This was noted by a parent who is a member of an outreach team and whose child got a shunt from CURE Hospital:

"One month ago, I came across a mother from Palaro whose child was developing hydrocephalus but it was not bad as yet. I advised her to go to AVSI in Gulu Main Hospital, where she would be supported with some small transport money and take the child to CURE Hospital. I thought that she had taken my advice. But when I met her again in town, she told me that the child’s grandmother is a witch doctor and that they would first take the child there to be treated before going to the hospital. I told them her that she was wasting time. There is nothing that can treat that child unless she goes to the hospital” (IDI parent, Gulu)

In all countries it was noted that culture has had a big effect because people have different beliefs and therefore they interpret SBH differently.

4.5.13 Stigma and discrimination
Although in all the countries to some extent awareness raising activities have helped quite a Lot in addressing stigma and discrimination, during interviews held with children, youth, parents, care providers and even service providers, it was highlighted that stigma and discrimination still exist against children with SBH in schools, communities and health facilities. For example, self- and enacted stigma makes some children with SBH drop out of school or not to desire to go to school. As a 16-year-old girl remarked:
“My life is okay. I find everything okay except that at school, the children keep making fun of me, they abuse me, and the teachers too. This makes me feel uncomfortable and not part of the school community”

Some children have been nicknamed ‘kasilu’, meaning ‘dumb’, because of their inability to speak properly. The above statements highlight the need for more sensitization and advocacy in schools and other institutions too.

4.5.14 Lack of space for CIC training
This problem was only mentioned in Malawi. A key informant belonging to a DPO mentioned that CIC training was only conducted at neuro-clinics at QECH, which was not all that conducive to such training as QECH did not have adequate space. Only a few participants can be trained at any one time. She, therefore, suggested that there was need for a permanent and spacious structure to be constructed specifically to cater for CIC training.

4.5.15 Networking and collaborations
Although DPOs are involved in networking and partnerships, for the purposes of project effectiveness, referrals, capacity- and competence-building, enhancement in project coverage, sustainability etc., this is one of the areas that need to be strengthened. Nevertheless, basically for many DPOs/support groups the concept of networking and/or partnership is not well understood and defined. For example, when some DPOs receive one- time financial support/ donation or material support e.g wheel chairs or try to lobby for financial help from organizations, they consider that to be networking or collaboration with these organizations. DPOs could not clearly explain whether they were involved in vertical or horizontal collaborations/partnerships. But even in situations where networking and collaborations are clear, much has not been achieved in terms of:

a) Providing a forum for sharing detailed information on activities, and developing a work plan or a strategic framework to ensure cohesiveness and minimizing duplication of activities in future.

b) Developing an advocacy plan for liaising with government authorities, donors, the media and other relevant actors.

c) Using a collaborating network for documentation and dissemination of information on successful practices and the lessons learnt in different DPOs/support groups’ interventions.

d) Engaging in multi-sectoral field missions to assess programme successes and challenges and to identify gaps in SBH programming

e) Active liaising with relevant sector/cluster working groups to ensure that SBH issues are integrated or mainstreamed into all humanitarian efforts.

f) Jointly identifying gaps to inform areas of intervention and to come up with a clear objective of packaging information and lobbying for policy influence that is geared towards the prevention of and response to sexual and gender-based violence.

4.6 Lessons learnt
a) It is important to use folic acid in the primary prevention of SBH.

b) Today, owing to the availability and accessibility to treatment, children/youth with SBH can live a normal life.
c) Although it takes a long time to build a therapeutic relationship and have parents involved, when this happens, children with SBH manage to cope well and become role models in their own communities and schools.
d) With regular follow-up on children with SBH in the community, many lives can be rescued and dignified.
e) Through home visits, one sees how families cope with children/youth who have SBH, the needs of these children, their mobility, appliances that they use both at home and in school and how continence management is followed.
f) Integrating SBH services with the services of the Ministry of Health (MoH) will ensure the sustainability of the programme.
g) More research is needed to understand the long-term effects of surgery and rehabilitation and prevention efforts.
h) It is important to involve parents/caregivers and persons living with SBH in the planning and monitoring of the activities.
i) Cooperation among support group members is very important for the groups’ survival and volunteerism among these members is crucial.
j) No individual institution can provide comprehensive services to children/youth with disabilities and their parents or care providers. Therefore, if effectiveness, impact and sustainability of the programme activities are to be achieved, there is need for combined efforts, collaborations and partnership among all stakeholders, civil society organizations, government and private institutions, and other actors in society.
k) In all regions, the SBH project is growing and is widely appreciated by the communities which it services.
l) There are negative attitudes towards SBH children and disability that is due to limited knowledge, but this can be changed with increased awareness, sensitization and improved quality of life for people with SBH.
m) Changing the mindsets and the perception of people is a gradual process. Therefore, project implementers and coordinators need to be patient about this social change.
n) The number of SBH children in need of services is ever increasing because there is more awareness and more of them are now surviving. This calls for additional financial and human resources to provide services for them.
o) We need to develop strong programmes for the sustainability of growing DPOs/support groups and the increasing number of children and youth with SBH.
5 Conclusions and recommendations

5.1 Conclusions

In spite of some challenges, the evaluation team found the interventions of the DPOs/support groups, including service providers, to be relevant, effective, and to have yielded great impact and that there is a level of sustainability which DPOs/support groups are trying to establish. Therefore, in this section the team highlights its major conclusions as follows:

a) The evaluation revealed that parents, children and youth are very positive about the programme because it has provided them with treatment, and this has been in terms of catheterization, shunting and back closure. For example children/youth with spina bifida narrated how the equipment they acquired from the hospital has helped them to be clean and dry all the time, unlike in the past when they had no control when they wanted to pass out urine or empty their bowels, and this resulted in a strong odour. Furthermore parents and children/youth have been trained in continence and bowel management and this has improved their hygiene. In addition, focus on surgical care for children with SBH has been widened to include rehabilitation and total care of the children. Because of health or life improvement of the children/youth, today more children are mobile, and are attending regular schools, and others move freely in the community, unlike in the past. A number of the parents even now have some time to engage in livelihood and income-generating activities.

b) DPOs/support groups and their partners, e.g. service providers, have contributed to empowering parents, children/youth with knowledge and life skills which they are currently using to take control of their lives. For example, today many parents are accepting their children with SBH conditions. This is due to effective sensitization, which is conducted through different modes. In addition, DPOs and partners train children/youth with SBH to be independent and try to involve them in organising meetings and seminars. This is contributing to enhancing their self-esteem and confidence.

c) Although patient follow-up is still a challenge, some improvements were reported. For example, the evaluation revealed that the SHIP passport is an important document/tool which is used to get feedback on treatment and follow-up both by the DPOs and individual parents. According to the IF/AVSI narrative report of January-June 2013, in the western region of Uganda sensitization of 200 health workers was carried out by OURS and some experienced members of DPOs participated in the facilitation. The SHIP passport was one of the documents which they were sensitized about. However, until now there are some health providers who refuse to fill in SHIP passports or to treat patients who come with them.

d) Through home visits, the outreach teams are able to know how families cope with children having SB and/or HC. They see how families practice continence management and what type of washrooms families use. They also observe the child’s mobility and the appliances the child uses, among other things. On the basis of what is observed, they advise the family accordingly. Home visits have also been useful in identifying and tracing defaulters and new cases which are always referred. Defaulters are those who have not been seen at the clinic for a number of months, who do not attend support group meetings and who do not attend therapy. The team carries some medical supplies (e.g. catheters) which are given to the parents/care providers.

e) All the DPOs/support groups and service providers complained about lack of funds. The evaluation team noted that lack of funds affected interventions at various levels. For example, the demands to care for children with SBH keep on increasing and yet the resources are
becoming less and less. IF was referred to as one of the donors which has gradually been reducing its support.

f) Many DPOs/support groups have been established at national, district and village levels. They have been beneficial for they provide a platform where parents, care providers, youth and even health providers meet to discuss and share experiences with one another. They are also involved in other activities, such as providing psycho-social support, training and capacity-building, income-generation, counselling, distribution of FA and leaflets etc., which have not only benefited the main target groups but also other categories of people in the community. The members pay a membership fee and in some places community members contribute financial support for poor families having children with SB and/or HC. This shows the impact on feelings and understanding about SBH that sensitization, advocacy and awareness creation are yielding among community members. However, it was noted that involving and/or establishing children/youth groups was very challenging. Owing to self-stigma, some of children/youth were not willing to discuss their condition freely, even among themselves. In addition, there was also a problem with horizontal networking and collaborations. Thus, although the DPOs/support groups operated in different districts/villages and environments, they hardly visited or exchanged experiences among themselves.

g) The evaluation revealed that community mobilization approaches are premised on the idea that impact and sustainable change are contingent upon the participation and commitment of community members themselves to design and implement change strategies. The approach also emphasizes wider participation, i.e. it presupposes that community change should be pursued through broad participation by a wide spectrum of people. Therefore, involving community leaders, religious leaders and other stakeholders in the community has yielded a good impact and results with reference to community mobilization, sensitization and awareness creation.

h) Regarding leaflets, these are distributed to mothers/guardians of children with SBH as well as to the community at large. Leaflets are perceived as useful by parents of children with SBH because they tend to change their perceptions and attitudes once they read them and learn that it was not their fault to have such children with special needs.

Concerning sustainability, DPOs/support groups mentioned different strategies, such as: building capacity for the members and people in the community; networking; raising funds through IGA; depending on donor community (IF); and applying for more funds from donors and local governments. However, in spite of the above-mentioned options, none of the DPOs/support groups had a viable exit strategy).

5.2 Recommendations
a. There should be networking and collaboration with VHTs and other stakeholders in the community, especially with regard to community sensitization concerning SBH, distribution of FA, identifying children with SBH, home visits and follow-ups etc. Also collaborations and networking between DPOs/support groups, and other institutions/individuals should be enhanced because at the moment it is limited only to conferences and workshops.
b. Since for many women adherence to taking FA is poor due to misconception that these are tablets for family planning or HIV/AIDS, there is need for more sensitization and encouraging them to take other nutrients.

c. There is need for more training of health providers, staff, parents/caregivers of children with SBH, and other stakeholders in the community. This will enhance health providers’ knowledge about SBH issues and also improve the quality of health delivery services. For example, it was revealed that at CURE Hospital all doctors and nurses are trained in SBH.

d. In Kenya, interview with a key informant revealed that at Bethany Kids Hospital nurses are leaving to get jobs elsewhere. So there is need for more nurses and volunteers who will be providing psycho-social support even when the children are at the wards waiting for surgery or just recovering.

e. Having skilled health providers will encourage and give hope to parents/care providers since they will know that if they seek medical help, their children’s conditions will be handled.

f. Organizing workshops and seminars and inviting professionals from different fields to come and share their experiences on SBH.

g. Integrating SBH training into the curriculum of health workers.

h. Empowering and also encouraging stakeholders to do more sensitization in the community and in other institutions. Thus, information dissemination through sensitization and awareness creation etc. will enable people in the community to accept children with SBH conditions as well as their parents. Some people don’t know about (SBH), and it is a shock when they finally get to know about it.

i. Most parents/care providers are very poor and lack adequate income. This affects their follow-up, attending DPO/support meetings, maintaining proper hygiene etc. Therefore, there is need to improve income-generating activities by building on the lessons learnt and successes already achieved.

j. Although in all the partner organizations, the youth and young adults have representatives on administration committees, there is need for strategies for involving them more in SBH programme work and activities. Thus, owing to self- and enacted stigma and other reasons, most of them are not willing to get engaged in these activities and yet the future sustainability and survival of the DPOs/support groups depends on their active involvement.

k. Generally, according to the desk reviews and interviews, parents and health workers from different countries highlighted the need for regular training and sensitization regarding continence management because as children keep on growing, their needs, medicines, and methods also change. For example, in Kenya one key informant stated that:

“Training on CIC is conducted during school holidays so we target three support groups per year. This will rotate among the 12 chapters so it will take at least four years before the CIC is done in group number one. Our Nairobi group had CIC training in December 2014 and most of the topics were similar to what we learnt in 2011” (KII, SHAK)
Nevertheless, in continence management it is important that parents, caregivers and youth are included in the planning of these programmes so that they can even be facilitators.

l. The services available for people with SBH conditions are few and centralized. So there is need for more of these services and they should be accessible to people who need them.

m. There should be facilities and equipment for children with SBH conditions in schools and other public places. For example, many children having this condition are languishing at home instead of being at school because they need special facilities, e.g. sanitation and care in schools, which are not available. In addition, many lack school fees but others are viewed by their parents as children without value or a future so they are neglected.

n. IF should consider funding exchange visits for DPOS/support groups (inter- and intra-country visits) to enable the sharing and exchange of knowledge and experience about managing SBH.

o. Supporting outreach services, physical infrastructure, supervision, home visits, and education for the children is necessary.

p. Although in hospitals and institutions that IF partners work with there are psychologists, social workers, doctors etc., there is need to address public health issues, especially mental health challenges of the parents/care providers and those of the children/youth with SBH.

q. Having rich and high status parents in the DPOs/support groups will contribute to economic strength and sustainability of these groups. Also, as in the case of HIV/AIDS, their influence would decrease the stigma and negative attitude that people have towards children and youth with SBH.

r. In the South, the IF/RHF programme is getting stronger and many DPOs/support groups are being established in different districts etc. and yet, owing to limited financial resources, manpower that is qualified to address the current demands is either inadequate or unavailable. It is, therefore, imperative that the strategy of having TOTs in the DPOs/support groups is given more focus.

s. In spite of the financial challenges that the DPOs face, enhancing follow-ups is necessary. Thus after treatment or an operation, as a result of various challenges, such as family problems, community problems, financial problems, psychological problems etc., many parents/care providers do not report back to the DPOs or health providers for follow-ups and therefore do not give any feedback. For example, in Dokolo district, in northern Uganda, through a follow-up which was conducted after a long time, it was discovered that out of nine children who had been operated on, three were still alive, four had died and two could not be traced.

In Tanzania, it was reported that;

“One of our biggest challenges is follow-up and the turn-out of parents. When these children are born and identified as having SB or HC, they are registered to become ASHBAT members. And when they are operated on, the parents are given dates to turn up for review, but they never turn up. And the hospitals keep calling us to ask about the patients but many times when we try to reach them on the contacts they left with us, we land on wrong numbers
or we are told that the number is not available. Even when we organise meetings only a few parents turn up and yet we keep seeing new faces but at the meetings very few are consistent” (KII, ASHBAT)

Without follow-up, the aim of saving and improving the quality of life of children/youth with SBH and their parents/care providers may in the long run not be achieved.

t. In order to enhance sustainability there is need to consider the following:

- Building on current internal resource mobilization strategies to expand them into more sustainable income-generating activities managed on a private sector model to generate profits that can be ploughed back into offering services.
- Building on current efforts by DPOs and service providers to strengthen the integration of SBH care, treatment and psycho-social support into health services offered at various levels of health services delivery.
- Building the capacity of DPOs in resource mobilization. Each DPO should be facilitated to develop a resource mobilization strategy as part of its strategic planning processes.

u. SBH has many social, physical, medical, psychological, mental and financial implications which are not well understood. It is, therefore, necessary that research studies are conducted into various themes related to SBH. This will provide guidance and support for the types of interventions to be implanted. For example, the evaluation revealed that the ongoing interventions in the South were started without the benefit of baseline studies.

v. In future it is important that an evaluation like this one is longer and is conducted as a case study in each of the countries being evaluated. This will enable the evaluation team to have more face-to-face interviews with many participants through which similarities and differences regarding achievements and challenges in each country will be highlighted.
References


Cure Children’s Hospital of Uganda: Guide for caretakers of children with either hydrocephalus and/or spina bifida.


IF: General DC Project Presentation NOV_2012 (Who are we?)


Norad’s policy on inclusion of disability in development cooperation 2002

RHF/IF’s final report (May 2009


WHO Afro site on Community Based Rehabilitation: http://www.afro.who.int/dpr/cbr.html


www.who.int, Oct. 2006
Annex 1: Table of Data Collection Methods and Participants

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<tr>
<th>Country/Region</th>
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<th>No. of IDIs (parents/gender)</th>
<th>No. of IDIs children/youth/gender</th>
<th>No. of KIIs (DPO project managers/gender)</th>
<th>No. of KIIs (health provider/gender)</th>
<th>No. of FGDs (children/youth)</th>
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<td>(2): 1(F) Director 1(M) secretary for mobilization and education. (both from CU-SBH)</td>
<td>(2F): One physiotherapist, one social worker (both from Katalemwa)</td>
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<td>Western Uganda</td>
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<td>3 F</td>
<td>2M (aged 15 yrs &amp; 20 yrs)</td>
<td>(3M) (1mobilizer, 1finance, 1 SHIP coordinator) from OURS, 1 secretary, from OURS God Cares</td>
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<td>(3):2F 1M</td>
<td>(4C): 2M and 2F (aged 16, 13, 11 and 23) One of the boys was a youth</td>
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<td>2M: 1(M) occupational physiotherapist, 1 (M) physiotherapist. From GROW</td>
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<td>Malawi</td>
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<td>1(8): 6F 2M All were youth</td>
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Note: M-male, F-female, Y-youth, C-children, PM-Project Manager
Annex 2: Evaluation Terms of Reference (TOR)

‘Programme Evaluation of Partner DPOs’

I. Evaluation title

Methodological and desk review evaluation of the RHF and IF supported regional Programme for Early Intervention, Treatment and Rehabilitation of Children with Spina Bifida and/or Hydrocephalus in East, Central and Southern Africa.

II. Purpose of the evaluation

This evaluation aims at assessing the relevance, effectiveness and sustainability of the programme supported by RHF and IF, and in particular the role of the local DPOs.

The evaluation should provide a view on the impact of the programme on the local DPO partners and their members, the impact of the DPOs on the local situation for people with spina bifida and/or hydrocephalus (SBH) and the sustainability of results (including capacity-building).

Further, the evaluation aims to review how RHF and IF contribute to achieving project objectives that are agreed with the local partners in the South – with a specific focus on choice of working methods, roles and responsibilities of all stakeholders and the value added of RHF and IF as donors and partners.

The evaluation also aims to document the lessons learnt and provide recommendations that project partners, IF and RHF can use to improve the design and implementation of the programme.

III. Project description

Spina bifida and hydrocephalus

Spina bifida is one of a group of birth defects known as neural tube defects (NTDs), which occurs within the first 25 days of pregnancy and affects 1-2 in every 1,000 live births. In addition to an obvious gap in the skin covering the spine, the vertebrae and the nervous system are damaged, leading to some degree of paralysis. Most children and adults have problems with bowel and bladder control. Spina bifida occurs as a result of lack of absorption of folic acid before and during the first weeks of the pregnancy: food quality can influence this, though other preventative measures may also be necessary. Spina bifida cannot be cured, though medical interventions mean that many people with spina bifida now live into old age and have a good quality of life. More than 60% of children with spina bifida also have hydrocephalus.

Hydrocephalus is the result of too much cerebrospinal fluid (CSF), the fluid that circulates in the cavities (ventricles) inside the brain, causing an increase in pressure within the skull. Normally there is a balance between the production and the absorption of CSF. If the drainage pathways are obstructed, which is the case when hydrocephalus develops, the fluid accumulates in the brain ventricles, resulting in compression of the surrounding tissue. In babies and infants the head can enlarge, but if the pressure is longstanding the brain is damaged. Drainage of the fluid with a device called a shunt or a natural bypass (ETV) is needed.
There are many other causes of hydrocephalus besides obstruction of the normal CSF pathways caused by abnormal brain anatomy as is the case with spina bifida. Among others, it can also be the result of meningitis, tumours, cysts, trauma or intracranial bleeding, which occurs more frequently following premature birth.

Spina bifida and hydrocephalus are two complex disabilities that require right and adequate approach and a lifelong care. To achieve that, information and training are needed. The multidisciplinary approach makes it a pars pro toto for the whole health care system: if a hospital is able to care for a child with spina bifida and hydrocephalus in a qualitative way, it will probably be able to work towards a qualitative approach of other diagnoses. With the right approach, people with spina bifida and hydrocephalus can become active members of society. Therefore, it is of utmost importance to sensitise and invest in qualitative care and training. Parents of children with spina bifida and hydrocephalus are probably the most important partners; this has been proven in the North and will be proven in the South. Therefore, they are key persons in the programme.

**Solidarity in the South**

The goal of our programme is to prevent spina bifida and hydrocephalus in the first place and, for those born with the conditions, to improve the inclusion of people with spina bifida and/or hydrocephalus in society and facilitate access to treatment, lifelong care and knowledge for people with spina bifida and/or hydrocephalus and their families. It is an ongoing process in which IF/RHF is trying to translate the latest knowledge of the North into realistic care for the South.

The objectives of the programme are:

- To improve the quality of and access to medical and lifelong care
- To increase awareness and knowledge of SBH
- To improve ownership and leadership of people with SBH and their caretakers
- To increase preventive measures.

The overall strategy to reach these goals is to complement the existing efforts, by building on what has already been achieved by parents and existing service delivery systems.

IF/ RHF and its local partners have developed a programme called SHIP, the Spina Bifida and Hydrocephalus Interdisciplinary Programme. SHIP is a coordinated, multidisciplinary approach to individualized care, where the person with SBH and his/her needs are at the centre. It covers both medical and lifelong follow-up, and aims to involve all stakeholders on an equal footing, including the families and DPOs. Networking with other stakeholders and partners in the country/district is, therefore, an important part of the programme.

The SHIP programme comes with various tools, such as the framework for the standardization of care and the passport for better coordination and communication.

**Stakeholders and partners**

The stakeholders of the programme are:

- Children and youngsters with spina bifida and/or hydrocephalus
The programme selected several good experts in eastern, central and southern Africa and shares its expertise and knowledge. These local partners consist of DPOs, CBR centres and hospitals. The vision of the programme is to complement the existing efforts, by building on what has already been achieved by existing service delivery systems. All partners care about treatment and rehabilitation of children with spina bifida and hydrocephalus and aim to include them in society. The selected partners for this evaluation are:

**Tanzania, national: Association for Spina Bifida and Hydrocephalus Tanzania (ASBAHT)**

ASBAHT has seven branches in Tanzania – Dar es Salaam, Arusha, Moshi, Morogoro, Musoma, Tanga, Dodoma. In 2014 a national board was elected to oversee all national activities.

https://www.facebook.com/groups/1540792392874042/

**Kenya, national: Spina Bifida and Hydrocephalus Association Kenya (SHAK)**

SHAK has 12 chapters covering all of Kenya. A national office was officially registered in 2013. The various SHAK branches are supported by and work closely with Bethany Kids at Kijabe Hospital.

SHAK is an official member of IF.

https://www.facebook.com/groups/510825368954511/

**Uganda, national: Spina Bifida and Hydrocephalus Association Uganda (SHA-U)**

This national umbrella organization was started by the four existing, independent DPOs in central, northern, eastern and western Uganda (see below). All regional DPOs have a seat on the national board. The national umbrella has been registered as an NGO since 2014.

**Uganda, Kampala: Central Uganda Spina Bifida and Hydrocephalus Network (CU-SBH)**

Created as a parent support group within the Katalemwa Cheshire Home for Rehabilitation, CU-SBH is now an independent, registered NGO covering the central region of Uganda.

CU-SBH is also an official member of IF.

**Uganda, Mbale: Eastern Uganda Spina Bifida and Hydrocephalus Network (EU-SBH-NET)**

Supported through CURE Children’s Hospital, the network currently consists of five support groups around Mbale district.

**Uganda, Mbarara: God Cares Parents Group Association for Spina Bifida and Hydrocephalus**

Started in 2006, this association now has over 400 members and runs local groups in more than 10 different districts. It works closely with OURS, our CBR partner in Mbarara.

**Uganda, Gulu: Spina Bifida and Hydrocephalus Parent Support Group-North**
The youngest of support group, this group is being supported by the local partner AVSI and is gradually growing into more members in Gulu district.

Malawi, nationwide: Parent Association for Spina Bifida and Hydrocephalus Ltd (PASHL)

The association is active in Blantyre and planning to establish a branch in Zomba. Owing to the high poverty level, the association is able to reach only a few parents. The parents have an active youth group.

Zambia, national: Zambia Association for Hydrocephalus and Spina Bifida (ZAHSB)

The Zambian Association consists of five support groups (Lusaka, Livingston, Kitwe, Chipata, Katete) with a national coordinator, who is working closely with the hospitals and CBR centres.

Sudan, Khartoum: Spina Bifida Federal Association (SBFA)

Created as a parent support group within the Khartoum Cheshire Home for Rehabilitation, SBFA is now an independent, registered NGO covering Khartoum with plans to expand to other regions.

SBFA is an official member of IF.

Facebook page 4

IF (International Federation for Spina Bifida and Hydrocephalus)

The International Federation for Spina Bifida and Hydrocephalus (IF) is the worldwide umbrella organisation (INGO) for spina bifida and hydrocephalus organisations. It was created in 1979 by national organisations of people with these impairments and their parents. Today IF’s members consist of 55 regional and national umbrella organisations for spina bifida and hydrocephalus.

Furthermore, IF has intensive contacts with regional and national organizations spread over five continents. IF’s activities are focused on the dissemination of information and expertise throughout the world to families, individuals, professionals and volunteers involved in the field of hydrocephalus and spina bifida.

The mission of the International Federation for Spina Bifida and Hydrocephalus (IF) is:

• To improve the quality of life of people with spina bifida and hydrocephalus
• To reduce the incidence of neural tube defects and hydrocephalus by primary prevention

The most important way to fulfil that mission is to spread knowledge, follow the medical and scientific evolutions on treatment of spina bifida and/or hydrocephalus, stimulate exchange and encourage contact between parents and people with spina bifida and/or hydrocephalus.

The work for international solidarity is steered by a group of experienced experts, volunteers, donors and staff. This Working Group International Solidarity consults and involves experts and professionals in different specific areas.
**RHF (Norwegian Association for Spina Bifida and Hydrocephalus)**

The Norwegian Association for Spina Bifida and Hydrocephalus (Ryggmargbrokk-oghydrocephalusforeningen RHF) is a national organization for people with spina bifida and hydrocephalus and their families. RHF was founded in 1973 and has active local groups in almost every county of Norway.

RHF is an important part of the IF network, as RHF was one of the founding members of and has always been represented on the IF board. Since 1998, RHF has been involved in the South, through the joint programme with IF.

RHF started as a small parent group and has developed into a strong user organization which improves and influences the services for the target group in Norway. As a parent and user organization, RHF has contributed to improved treatment and health care for children and adults with spina bifida and/or hydrocephalus and the inclusion of their members in society. The strategy of RHF’s international solidarity work is to use this potential and capacity in strengthening and building support groups and organizations in the countries that receive support through the programme. RHF sees peer support as important key to the development of the programme.

RHF is a member of the Atlas Alliance, an umbrella organization consisting of Norwegian organizations of people with disabilities, parents and patients that are involved in international work.

**IV. Objectives of the evaluation**

The overall objective of this evaluation is to assess the relevance, effectiveness and sustainability of the programme.

It is important to gain an overview of the impact of the programme on the target group, underlining the key results achieved and the progress made towards these achievements according to project plans. More specifically, the target group includes:

- Support groups as organizations/DPOs
- People with SBH and their families as a group of PWDs with specific needs and rights
- People with SBH and their families as individuals

Further, the evaluation aims to review how IF contributes to achieving project objectives that are agreed with the local partners in the South with a specific focus on IF/RHF’s underlying working methods, the roles and responsibilities of all local stakeholders and the added value of RHF and IF as donors and partners. The evaluation should consider the output of the programme with respect to input of human resources and available financial resources.

Based on the findings, the evaluation should give recommendations on how to improve the programme in order to ensure the achievement of agreed project goals and expected results, including long-term sustainability of the local partners.

This evaluation should offer a view on how IF/RHF can conduct its programme in the most professional way and will involve research of partner organizations to see whether IF/RHF’s methods can be improved.
This should be evaluated with respect to the partners’ objective views of the usefulness of the partnership.

The selected time frame to be assessed (2009-2014) refers to the five years following the last external evaluation, during which SHIP was developed and introduced.

The evaluation, together with other documentations and considerations, is expected to provide information, recommendations and lessons learnt in order to serve as a basis for making decisions regarding future work and strategies of IF’s and RHF’s engagement in the South.

V. Scope and focus

The evaluators shall elucidate and analyze the areas indicated below:

☐ Assess the relevance and clarity of the objectives of the programme related to the challenges and priorities of the target group and the strategies and working methods for reaching these objectives, including gender equality strategies.

☐ Assess the extent to which the objectives and expected results have been achieved for the target group and the partners included in this evaluation

☐ Assess the extent to which the target group is involved through project implementation

☐ Assess the role, relevance and impact of peer support in the programme and the benefits of this peer support strategy, both at individual level and as an organized group/DPO

☐ Assess the level of local ownership and sustainability of the programme and identify the factors that might stand in the way of sustainability, including organizational, financial and other management methods and structures

☐ Assess how cooperation between IF and its partners influence the outcome of the programme. Specifically, the evaluators shall assess:

1. Working methods: lines and methods of communication, relevance and usefulness of training, transfer of knowledge/competence to its partner organizations

2. Relevance and effectiveness of the tools and methods used in training and follow-up of the projects

3. Utilization of financial and human resources and capacity

4. Added value of all stakeholders, including IF and RHF

☐ Document lessons learnt and provide recommendations

The evaluator may further raise other issues of relevance and interest for IF and RHF. If any such an issue should constitute a major deviation from the scope of work according to these Terms of Reference, a prior approval is required of such alterations by RHF and IF.

VI. Methodology

The methodology applied in this evaluation shall include desk interview with all partners and desk reviews of policy and project documents including (semi-)annual reports, visiting reports, work plans and activity reports. Interviews can be conducted with IF, RHF, experts
and partners. Further, the evaluation will include one field visit for face-to-face interaction to two selected partners/countries (to be decided).

(a) Desk top review and consultation:

The team will carry out its task based on studies of relevant documents such as long-term plans, annual project plans, strategies, project documents, reports, printed materials and budgets. The team shall interview all local DPO partners as well as consult key actors, including representatives of IF’s Working Group International Solidarity, RHF and IF staff and representatives of the target group of the programme.

(b) Sampling through field visit:

A crucial part of the evaluation will be a one-week field visit to the selected projects. The aim of the field study is to assess the programme, goals and objectives from the perspective of the partner through semi-structured interviews with both board members as well as individual members (one-on-one and group). Interviews with the main partner(s) (hospital and/or CBR centre) of the selected DPOs will also be included.

Additionally, the evaluation should include a structured questionnaire to all others partners of the programme (see above – desk top consultation).

The review should, although independent of RHF and IF, be implemented in close cooperation with the organization. RHF and IF shall be invited to provide opinions and comments in the course of preparing the report. RHF and IF will welcome any alternative suggestions that the consultant might present in the tender document on approaches and methods to be applied in performing the assignment.

VII. Time schedule and evaluation team

The consultant team should have:

☐ Knowledge and experience of health and disability

☐ Documented experience of evaluations of NGOs/CSOs/DPOs engaged in development work

☐ Knowledge of interviewing and survey skills as well as participatory methods and techniques

☐ Good knowledge of the African countries involved; local evaluators are particularly encouraged

☐ Good understanding of organizational development and disability issues

☐ A good command of the English language

☐ Preferably understanding of development work of disabled people’s organizations (DPOs)

The consultant team should not consist of more than two persons

The evaluation shall be completed before 20 June 2015

It is estimated that the maximum time needed for the review is 4-5 full-time weeks, inclusive of travel days
VIII. Reporting and debriefing

A draft report should be presented to IF by 4 July 2015. IF and RHF should comment on the report within one week of its submission. After having received comments and remarks from IF and RHF, the final report should be prepared and presented before 20 July 2015.

The structure of the final report, which is to be written in concise and accessible English, should include:

(a) An executive summary

(b) Major recommendations, challenges and opportunities for the programme, including the gender component

(c) Relate the recommendations to the policy/development approach of RHF and IF, with a specific focus on sustainability

(d) Draw conclusions and state the relevant and priority areas which can be facilitated by IF and RHF’s support.

The report should not exceed 25 pages (excluding appendices).

IF will disseminate the final report to its donors and local partners and make it electronically available through its website.

IX. Budget

The budget for the evaluation should not exceed €12,000.

The consultant should submit a budget with a detailed breakdown of costs. Once agreed with IF and RHF, the budget will become part of the contract.

Proposals should be sent by 15 May 2015 to Ms. Katalijne van Diest, IF Programme Manager International Solidarity: katalijne.vandiest@ifglobal.org
Annex 3: Data Collection Guide for Key Informants (Project Administrators)

**Personal Information**
1. Name
2. Sex
3. Age (optional)
4. Place of birth (optional)
5. Present place of residence (optional)
6. Education
7. Current position in the organization
8. Marital status (single, married, divorced, widow/widower, co-habitation)
9. Number of children (biological, adopted)

**Information about the organization**
1. Name of the organization (DPO)
2. Date of establishment
3. Type of organization (CBO, NGO)

**Overall objectives of the organization**
1. What are the main objectives of the organization (DPO)?

**Target groups**
1. Who are target groups?
   a) Main target groups
   b) Other groups
2. Why are these groups targeted?
3. What is the geographical coverage? And numbers reached?

**Interventions**
1. What interventions or activities are you involved in and why?
   **Probe:** a) **Prevention** (advocacy, awareness creation, information dissemination, community mobilisation, nutrition, folic acid etc.)
   b) **Response** (health, CIC, surgery, psycho-social support, economic support, material support, security/shelter, training and capacity building etc.)
2. What strategies and methods do you use to implement your interventions and why?
   (Probe these strategies and methods being used, e.g. radio talk shows, community outreach, support groups, home visits etc.)

**Treatment**
1. Which treatment centres/hospitals are used to treat the children?
a) Children with HYDROCEPHALUS

1. What kind of treatment and care is available for these children?
2. Are these services accessible and used by all children affected by this condition?
3. What are the factors affecting and/or enabling access and utilisation of services by these children?

**Probe:** Barriers and how they are being addressed, enablers.

4. Quality control: In your opinion, do health providers follow the IF medical protocols and guidelines for management of hydrocephalus and shunting? YES/NO

**Probe:** If YES, probe how they are being used; and if NO, why?

5. Is the SHUNT leaflet used to inform youth/parents? YES/NO

**Probe:** If YES, probe how they are used; and if NO, why?

b) Children with SPINA BIFIDA

1. What kind of treatment and care is available for these children?
2. Are these services accessible and used by children affected by this condition? YES/NO (Explain).
3. What are the factors affecting and/or enabling access and utilization of services by these children?

**Probe:** barriers and how they are being addressed, enablers

4. Is the SHUNT leaflet used to inform parents or not? YES/NO

5. In your opinion, do health providers follow the IF medical protocols and guidelines for management of SB? YES/NO

**Probe:** If YES, probe how they are being used; and if NO, why?

**Continence management programme**

1. Describe the procedure(s) being used to implement the continence management programme for children with SPINA BIFIDA.

2. How are quality control and follow-up done in continence management programme?

**Probe:** 1) How training in continence management is organized for parents, children, youth and other participants, including the number of participants and dates if possible. 2) If new training materials have been developed or not.

3. What would you suggest regarding the improvement of the continence management programme?

**Pre- and post-operative care**

1. Overall, how is pre- and post-operative care organized?
2. Do you organize outreach clinics for children with SBH? YES/NO

If YES: Probe: How are they organized and how often? If NO, why?

3. What challenges do you face when organizing these outreach clinics?

4. Do you organize home visits? YES/NO

If YES: Probe: How they are organised and how often? If NO, why not?

5. Do you organize mobile clinics? YES/NO

If YES: Probe: How they are organized and how often? If NO, why?

Folic acid (FA)

1. Is folic acid available for women? YES/NO

If YES: Probe: Which women are provided with FA (target groups etc.)?

2. What are the factors affecting and/or enabling access to and utilization of FA?

Probe: barriers and how they are being addressed, enablers

3. Do you provide leaflets/teaching material on FA to women? YES/NO

Probe: a) The difficulties these women face in understanding these leaflets. b) To what extent are the leaflets useful to these women etc. If NO, why?

Feedback on Treatment and Follow-up

1. Do you have medical feedback on the provided medical treatment/material?

Probe: if YES/NO and what kind of feedback is given and from who?

2. Do you see a need for new or updated medical protocols/guidelines? YES/NO

Probe: Which guidelines should be replaced or updated?

3. Is there need for additional training for health workers, staff and caregivers in SBH management? YES/NO

Probe: Why the training is needed, type of training which is needed and for what category of staff/volunteers.

Project/administration staff

1. What is the al structure like?

Probe: a) al chart; b) office bearers and their responsibilities/roles, qualifications and skills; b) financial management; and c) Are the youth represented on the board or not?

2. What type of training do you offer to your project staff and what are the objectives for such training?

Probe: a) The themes addressed during the training. b) Who conducts the training? c) How they are d and how often they are conducted. d) What is the added value for such training to the project, the individual and the beneficiaries?
Support groups

1. What are the different support groups you have under this (DPO)?

Probe: The composition of these support groups in terms of gender, age and social categories.

2. Do you hold meetings with these groups and do you have minutes of the meetings? YES/NO

Probe: a) Objectives for these meetings. b) What is often discussed in these meetings. c) How often the meetings are held. d) Participants in these meetings. e) Added value/benefits of these meetings to the project and individuals.

3. Do you have training or capacity-building for parents, children, youth and/or other members in the support groups? YES/NO

Probe: a) What each target group is trained in. b) Objectives of training them. c) Who in the organization plans the trainings and how often are the trainings conducted? d) What training/information materials are used or available for the groups? e) The challenges experienced during the trainings. f) What the individuals have achieved from the trainings.

Participatory involvement of various actors and stakeholders in programme activities

1. How do you reach parents with SBH children and how are they involved in the project’s various activities?

Probe: a) How many parents are involved in these support activities? b) The activities they are involved and in what way. For example, project design, planning phase, implementation, monitoring and evaluation etc.

2. How do you reach the youth and young adults with SBH? And how are they involved in the various project activities?

Probe: a) How many youth are involved in these support activities? b) The activities they are involved and in what way. For example, project design, planning phase, implementation, sensitisation, monitoring and evaluation etc.

3. Are there parents/youth advocacy committees?

Probe: The composition of these committees.

4. How do you reach professional/health care providers of the children etc. and how are they involved in the various activities of the project?

Probe: a) Providing care/treatment. b) Making referrals. c) Participation in planning, prevention, advocacy etc.

5. Which other significant people/actors in institutions and community do you reach and how are they involved in the various project activities?

Probe: a) The advantages/disadvantages of involving these actors. b) The activities they are involved and in what way they are involved. For example, project design, planning phase, implementation phase, monitoring and evaluation etc.

Gender equality
1. How are issues related to gender equality addressed in the project?

Probe: a) Males and females in the administration. b) Strategies being used to ensure that male and female parents/care providers are involved in the various project activities at different levels. c) The challenges experienced in addressing gender equality. d) The advantages and added value to the programme and individuals in having gender equality etc.

Networking and collaborations

1. Which local, regional and international institutions and NGOs does the organization collaborate with?

Probe: a) Reasons for networking. b) What they collaborate on. c) The form of collaboration (vertical/horizontal) and how the collaboration is organized. d) The advantages of networking.

2) What challenges does the organization experience in collaborating with others?

(Probe the challenges and how they are dealt with)

Research, Monitoring and Evaluation

1. What research activities is the involved in?

2 How does the collect its data and also evaluate the challenges and progress in its activities?

Probe: a) The methodology for data collection. b) Who are the actors involved in data collection and evaluation? c) How often data is collected. d) Documentation. e) Indicators used to measure progress, failures etc.

Effectiveness or successes

1. In view of the programme objectives, do you think that the project/activities have been effective or successful? YES/NO

Probe: a) What makes the key informant to think that the project is effective? b) Which project activities have been effective or successful? c) To which actors have these activities been effective and what impact have they created in their lives? d) Why have some activities been effective but others not? e) What perceptions do the stakeholders and other actors in different institutions and community have about the effectiveness of these activities and what has been achieved by the project?

Challenges

1. What are the challenges which have affected the effectiveness and progress of your interventions?

Probe: a) financial, donor demands, limited skilled manpower, awareness creation, lack of knowledge about the disease, lack of care and treatment, increased number of children and care providers who need different types of help, poverty in the community, cultural beliefs, stigma and discrimination against the children with SBH and/or their parents within the family, institutions, and community.
Sustainability

1. What kind of help does this receive from different agencies?

Probe: Central government, local government, private, international community, local communities and their institutions, e.g. families, cultural and religious institutions etc.

2. If you are getting help from different donors:
   a) For what specific activities are these funds?
   b) How is the reporting done to these donors?
   c) Do the donors know each other?

3. How sustainable are your SBH interventions in reference to:
   a) Integration in existing structures for the prevention and management of SBH?
   b) Capacity-building?
   c) Project lifespan: What are the exit strategies (if any)?

Probe: The effectiveness of these exit strategies and how capacity has been built to sustain project interventions beyond lifespan.

4) How has ownership of the project interventions been effectively propagated?

Probe the participation of beneficiaries and stakeholders in:
   a) Project design
   b) Planning phase
   c) Implementation
   d) Monitoring and evaluation

5. What strategies do you have in relation to:
   a) Making sure that the effectiveness or impact the project has achieved are sustained?
   b) Addressing the challenges that the project is experiencing?

Suggestions

What specific personal and institutional suggestions/recommendations would you give for the future of this project?
Annex 4: Data Collection Guide for Key Informants (Health Providers)

Personal Information
1. Name
2. Sex
3. Age (optional)
4. Place of birth (optional)
5. Present place of residence (optional)
6. Education
7. Current position/years of service in the position and organization
8. Marital status (optional)
9. Number of children (biological, adopted)

Information about the organization
1. Name of the organization
2. Date of establishment
3. Type of organization (CBO, NGO) etc.

Overall objectives of the organization
1. What are the main objectives of the organization?

Categories of people/clients seeking help/services from this organization
1. What categories of people or clients seek help or services from you?
   a) Main category of people/clients
   b) Other categories
3. What is the geographical coverage? And the numbers reached?

Interventions/services offered
1. Generally, what services/activities is your involved in?
   a) Probe: Prevention (treatment, nutrition, folic acid, other informal means of prevention, advocacy, awareness creation, information dissemination etc.)
   b) Probe: Response (continence management [CIC], surgery, psycho-social support, counselling, referral to other institutions/professionals, follow-up of clients, economic support, material support, security/shelter, training and capacity-building etc.)
2. What services/activities are you as a health/care provider involved in?
   a) Probe: Prevention (treatment, nutrition, providing folic acid, advocacy, awareness creation, information dissemination etc.)
   b) Probe: Response (continence management (CIC), surgery, psycho-social support, counselling, referral to other institutions/professionals, follow-up of clients, economic support, material support, security/shelter, training and capacity building etc.)
3. What strategies and methods does your organization_and/or you use to implement the interventions or offer services and why?
Probe: Strategies and methods being used, e.g. radio talk shows, outreach clinics, community outreach, parent support groups, home visits, contacting patients who come to seek treatment at health facility.

Treatment

Which treatment or services do you offer the children?

a) *Children with hydrocephalus*

1. What kind of treatment and care is available or do you give to these children?
2. Are these services accessible to children affected by this condition? YES/NO

Probe: a) Factors that affect and/or enable access to and of services by these children, and how they are being addressed. b) Enablers.

3. Quality control

In your opinion, do you as a health/care provider follow the International Federation (IF) medical protocols and guidelines for the management of hydrocephalus and shunting? YES/NO

If YES: Probe: How they are being used; and if NO, why?

4. Is the SHUNT leaflet used to educate parents and other clients? YES/NO

If YES: Probe: How they are used; and if NO, why?

b) *Children with spina bifida (consider co-infection)*

1. What kind of treatment and care is available for these children?
2. Are these services accessible to children affected by this condition? YES/NO (explain your answer).
3. As a health/care provider, what factors affect and/or enable access to and of services by these children?

Probe: a) Barriers and how they are being addressed. b) Enablers.

4. Is the SHUNT leaflet used to inform parents? YES/NO

If YES: Probe: how they are used; and if NO, why?

5. Do you as a health/care provider follow the International Federation (IF) medical protocols and guidelines for the management of spina bifida and shunting? YES/NO (explain your answer)

**Continence management programme**

1) Do you provide continence management services? YES/NO

If YES, describe the procedures being used to implement the continence management for children with *SPINA BIFIDA*.

2) How is quality control and follow-up done in continence management?
a) Probe: i) How it is done at home; ii) in health facility and during outreach.

b) Probe: i) How training in continence management is organized for parents, children, youth and other participants, including the number of participants and dates if possible. ii) If new training materials have been developed or not. iii) Whether or not the health/care provider participated in developing these materials.

3) What would you suggest about the improvement of the continence management programme?

**Pre-and post operative care**

1. How do you organize pre- and post-operative care?

**Probe:** The strategies used to reach out to different categories of stakeholders and/or clients that the health provider or organization offers their services to.

**Outreach**

1. Do you organize outreach clinics for children with SBH? YES/NO

**If YES:** Probe how they are organized, how often and what is the health provider’s role in these outreach clinics. If NO, why not?

2. What challenges do you and the organization experience when organizing outreach clinics?

3. Do you organize for home visits? YES/NO

**If YES:** **Probe:** How they are organized and how often? If NO, why?

4. Do you organize mobile clinics? YES/NO

**If YES:** **Probe:** How they are organized, how often and what is the health provider’s role? If NO, why not?

**Folic acid (FA)**

1) Is folic acid available for expectant mothers and other women too? YES/NO (explain your answer)

2) Do you explain the importance of folic acid to the expectant mothers and other women too? YES/NO (explain your answer)

3) What are the factors affecting and/or enabling access to and utilization of FA?

**Probe:** Stock-outs, monitoring for compliance and barriers and how they are being addressed, and enablers.

4). Do you provide leaflets/teaching material on FA to women? YES/NO

**If YES:** Probe: 1) The difficulties these women face in understanding these leaflets. 2) To what extent are the leaflets useful to these women etc.?

5) As a health/care provider, what is your experience with mothers seeking antenatal care?

**Probe:** What time/stage of pregnancy expectant mothers come for antenatal care visit etc.
Feedback on treatment and follow-up

1. Do you get medical feedback from the beneficiaries on the provided medical treatment/material?

If YES: Probe: a) What kind of feedback do you get and from who? b) The feedback mechanisms being used.

2. As a health/care provider, do you see a need for new or updated medical protocols/guidelines? YES/NO

If YES: Probe: Which guidelines should be replaced or updated.

3. Do you think that there is need for training health workers, staff and caregivers in SBH management? YES/NO

If YES: Probe: a) Why the training is needed. b) Type of training which is needed and for what category of health workers/staff/volunteers.

Interaction with various actors, stakeholders and support groups in programme activities

1. What are the different support groups, including institutions, that you interact with and how do you reach them?

Probe: Composition of the support groups in relation to gender, age and other social categories, and the methods used to reach them.

2. Do you hold meetings with these groups and do you have minutes from the meetings? YES/NO

If YES: Probe: a) Objectives of these meetings. b) What is often discussed in these meetings. c) How often the meetings are held. d) Participation in these meetings. e) Turn up for the meetings. f) Added value/benefits of these meetings to you, the project, to them and other individuals, the relationship between you and them during the meeting and after. If NO, why?

3. Do you as a health/care provider participate in training or capacity-building for members in these support groups? YES/NO

Probe: a) What role he/she plays in these trainings. b) What each target group is trained in. c) Objectives of training them. d) Who plans for these trainings and how often the trainings are conducted. e) What training/information materials are used or available for the groups. f) Challenges experienced in having the trainings. g) What have the organization, you and other individuals achieved from these trainings?

4. How are the children and young people with SBH involved in activities arranged by you or your organization?

Probe: a) How many youth are involved in these activities? b) Activities which they are involved in and in what way? For example: project design, planning phase, implementation, sensitisation, monitoring and evaluation etc.

Gender equality

1. What are the unique needs which females and males suffering from SBH have that need to be considered in service delivery?
Probe: How these unique needs are being addressed in the delivery of health services for these children

Networking and collaborations

1. Which local, regional and international institutions/NGOs, professional/health providers do you work or collaborate with?

   Probe: a) Reasons for networking. b) What they collaborate on, e.g. making referrals, having joint participation in planning of prevention etc. c) The form of collaboration (vertical/horizontal) and how the collaboration is organized. d) Advantages of networking. e) Provider’s experiences in collaborating with other professionals and organizations.

2. Which other significant people/actors in institutions and the community do you reach and how are they involved in your activities?

   Probe: a) The advantages/disadvantages of involving these actors. b) The activities they are involved in and in what way. For example: project design, planning phase, implementation phase, sensitization, monitoring and evaluation etc.

3. What challenges do you experience in collaborating with other professionals/health care providers or organizations?

   Probe: The challenges and how they are dealt with

Research, monitoring and evaluation

1. Are you involved in any research activities as an organisation, a partner organization or individual? YES/NO

   a) Probe: i) Activities. ii) The role which the provider plays. iii) The benefits. iv) The opinions he/she has about the importance of research and data collected etc.

   b) Probe: i) The methodology for data collection. ii) Who are the other actors involved in data collection and evaluation? iii) How often is the data collected? iv) Documentation. v) How the data collected is utilized etc.

Effectiveness or successes

1. What, in your view, has been the effect of the activities you have implemented over the past years on the lives of the target population?

   Probe: a) What makes him/her to think that the project is effective? b) Which project activities have been effective or successful? c) To which actors have these activities been effective and what impact have they created in their lives? d) Why have some activities been effective but not others? e) What perceptions do the stakeholders and other actors in different institutions and communities have about the effectiveness of these activities and what has been achieved from the project?

Challenges

1. What are the challenges which have affected the effectiveness and progress of your interventions and programme?

h) Lack of follow-up. i) Increased number of children and care providers who need different types of help. j) Poverty in the community. k) Cultural beliefs. l) Stigma and discrimination against the children with SBH and/or their parents within the family, institutions, and the community.

**Sustainability**

Considering the relevance, successes and challenges in the programme, what strategies can you suggest for its sustainability?

**Suggestions:** What specific personal and institutional suggestions/recommendations would you give for the future of this project?
Annex 5: Data Collection Guide for IDI-FGDs (Parents)

Personal Information
1. Name
2. Sex
3. Age (optional)
4. Present place of residence (district, sub-county, parish and village)
5. Education level
6. Marital status (single, married, divorced, widow/widower, co-habiting)
7. Number of children (biological, adopted)
8. Number of children with: a) spina bifida; b) hydrocephalus

Awareness and knowledge
1. What do you know about: a) spina bifida? b) Hydrocephalus?

Probe for local terms used to describe SBH and local understanding of SB and H
2. What is the magnitude (how widespread) of this condition in your family or community?
3. When and how did you come to know that your child/children are suffering from the following conditions: a) Spina bifida? b) Hydrocephalus?
4. How did you feel and react on understanding that your child/children have this or these conditions?
5. What do you perceive as the causes of these conditions: a) Spina bifida? b) Hydrocephalus?

Probe for: a) Socio-cultural perception of causes. b) Socio-cultural illness explanations (explanatory models of the illness/condition). c) Perceived religious causes/explanations of the illness. d) Biomedical causes/explanations for the illness/condition (spina bifida and hydrocephalus) etc.
6. How do people in your family/community perceive children and families having children affected by: a) spina bifida? b) hydrocephalus?
7. What are the needs of families and children affected by: a) spina bifida? b) hydrocephalus?
8. What challenges are experienced by families and children affected by: a) spina bifida b) hydrocephalus?
9. How do these families deal with these needs and challenges?

Probe for positive and ‘negative’ ways of dealing with these conditions (knowledge and awareness of service delivery agencies and their interventions)
10. Can you please tell me if there are any organizations (public, NGOs or private sector) that offer services to families and children affected by this condition?
11. What kinds of services are offered by these organizations?

a) Probe: Prevention (advocacy, awareness creation, information dissemination, community mobilization, nutrition, folic acid etc.)
b) Response (health, CIC, surgery, psycho-social support, economic support, material support, security/shelter, training and capacity-building)

12. How do the organizations mentioned deliver the services you have outlined above? Thus, how do they reach out to your families, children and communities?

Probe for: Strategies and methods used to engage the parents, children, families and communities, e.g. radio talk shows, community outreach, parent support groups, home visits)

Health-seeking behaviour/treatment

Can you please tell me how you go about seeking treatment and care for children affected by the following conditions;

a) Children with hydrocephalus

1. What kind of treatment and care (formal-biomedical and informal/traditional) is available for these children?

Probe for: a) Formal and informal or indigenous care-seeking practices – where do they go to seek care and treatment and why? How is the decision on where to seek care decided upon? Who makes the decisions about health- or care-seeking and what informs these decisions?

b) Probe for public and private: What kind of treatment and care is available? Why do people seek treatment from there? What about traditional healers (if not already mentioned). .

2. What are the factors affecting and/or enabling access to and utilisation of these services?

a) Probe for: Distance, affordability, lack of health commodities and supplies, attitude of health workers, perceived efficacy of treatment etc.

b) Probe for: Enablers of and barriers to accessing and services.

3. Quality of care: Are you satisfied with the care received from the health care providers

(probe for level of satisfaction and attitude towards either from the formal health care facilities [public and private/NGO facilities] and informal/indigenous/traditional providers).

4. Are you aware of the shunt devices? YES/NO


5. Have you ever seen or used a shunt leaflet? YES/NO

If YES, probe for how it is used to sensitize parents/the community.

b) Children with spina bifida

1. What kind of treatment and care (formal-biomedical and informal/traditional) is available for these children?

2. Are these services accessible and used by all children affected by this condition? YES/NO (please explain your answer).

3. What are the factors affecting access to and utilization of services by these children?
Probe for distance, affordability, lack of health commodities and supplies (stock-outs), attitude of health workers, perceived efficacy of treatment, enablers of and barriers to accessing and utilizing services.

4. Are you aware of the shunt devices? YES/NO

If YES, probe for: a) How they came to know about it. b) Availability c) Accessibility d) Utilization. e) Experience of using it.

5. Have you ever seen or used a shunt leaflet? YES/NO

If YES, probe for: How it is used to sensitize parents/the community.

6. Are you satisfied with the care received from the health care providers? YES/NO

a) If YES, probe for: 1) How and why they are satisfied.

b) If NO, explain.

**Continence Management**

1) Are you aware of any procedure for continence management?

If YES, probe for: **How it is done at home, at a health facility and during outreach.**

2) What is your experience with continence management?

**Probe for:** a) **Bio-medical and indigenous mechanisms.**

b) What are the things you like about the biomedical ways of continence management?

c) What are the things you do not like about the biomedical ways of continence management?

d) What are the things you like about the indigenous ways of continence management?

e) What are the things you do not like about the indigenous ways of continence management?

3) Have you been involved in continence management training?

**Probe for:** a) **How training in continence management is organized for parents, children, youth and other participants, including the number of participants and dates if possible.** b) If new training materials have been provided to the parents and children. c) How useful the continence management training was. D) What would you suggest about the improvement of the continence management programme?

**Experience with outreaches**

1. Do organizations working on SBH organize outreach clinics for children with SBH? YES/NO

If YES, probe: **How they are organized and how often? If NO, why not?**

2. How satisfied are you with the way these outreach clinics are organized?

**Probe for:** What do you like most and what do you like least? What aspects of outreach clinics would you like to have, why and how?
3. Have you been visited in your homes by health workers or organisations dealing with SBH? YES/NO

If YES, probe: How are they organized and how often do they visit? If NO, why not?

Folic acid (FA)
1) Is folic acid available for women? YES/NO
   a) If YES, probe: Which women are provided with FA (target group and frequency).
2) What are the factors affecting and/or enabling access to and utilization of FA?
   Probe: Enablers of and barriers to accessing and utilizing FA.
3) Are you provided leaflets and other educational materials on FA? YES/NO
   Probe: a) The experiences of using these leaflets and other educational materials. b) To what extent are the leaflets and other educational materials useful to these women etc.?

Feedback on treatment and follow-up
1. How would you describe the interactions you have with health providers?
   Probe: a) What the parent likes or does not like about these interactions. b) Does the parent get medical feedback on the provided medical treatment/material?

Support Groups
1. Are there any support groups for parents/children affected by SBH?
2. What support groups are you aware of?
   Probe: a) The composition of these support groups in terms of gender, age and social categories. b) Do you belong to any parent/children’s support groups? c) Their functions. c) Their capacity-building initiatives etc.
3. Do you hold meetings with these groups and do you have minutes of the meetings? YES/NO
   a) If YES, probe: i) Objectives of these meetings. ii) What is often discussed in these meetings. iii) How often the meetings are held. iv) Participation in these meetings. v) Added value/benefits of these meetings to individuals/children and the families.
   b) If NO, explain.
4. Are there trainings or capacity building for; parents, children, youth and/or other members in the support groups? YES/NO
   a) If YES, probe: i) Who is targeted. ii) What kind of training is being conducted? iii) What topics are covered during the training? iv) What benefits do you get out of the trainings? 5) What changes would you want to see in the current type of training (for example the methods of delivery, focus of the training etc).

Involvement of parents in programme activities
1. How are you involved in the project’s various activities?
Probe: a) The activities they are involved in such as providing care/treatment, making referrals, participation in planning, prevention, sensitization, advocacy etc., and in what way they are involved. b) What are the parents’ opinions about their current level of involvement in the activities?

3. Are their parents/youth advocacy committees? YES/NO
   a) If YES, probe: i) The composition of these committees. ii) The activities of the committees. iii) Their activities and challenges.
   b) If NO, explain why.

**Gender equality**

1. How are the unique issues about the relationship between men and women addressed in the project and support groups?

2. What are the unique needs and challenges of male and female children affected by SBH?

**Effectiveness/successes**

1. In your experience with the programme, what do you consider to be its successes?

Probe: a) What makes the participant to think that the project is successful? b) Which project activities have been successful?. c) What has been the positive impact of the project activities on the lives of the children and families affected by SBH?

**Challenges**

1. What are the challenges that have affected service delivery for SBH-affected children?

Probe: a) Financial, limited skilled personnel, awareness creation, lack of knowledge about the disease, lack of care and treatment, poverty in the community, cultural beliefs, stigma and discrimination against the children with SBH and/or their parents within the family, institutions, and the community.

2. What strategies do you use to address the above challenges?

**Suggestions**

What suggestions/recommendations would you give for the improvement of programmes that prevent and respond to SBH?
Annex 6: Data Collection Guide for IDI (Children and Youth)

**Personal Information**

1. Name
2. Sex
3. Age
4. Present place of residence (district, sub-county, parish and village)
5. Education level
6. Marital status
7. Number of children in the family (biological, adopted)
8. Type of condition child is experiencing: a) Spina bifida; b) Hydrocephalus

**Knowledge and experiences regarding SBH**

1. When and how did you come to know that you are suffering from the conditions above: a) Spina bifida; b) Hydrocephalus?
2. How did you feel and react on understanding that you have this or these conditions?
3. What do you perceive as the causes of these conditions: a) Spina bifida; b) Hydrocephalus?
   - Probe for: a) Socio-cultural perception of causes. b) Socio-cultural illness explanations (explanatory models of the illness/condition). c) Perceived religious causes/explanations for the illness. d) Biomedical causes/explanations for the illness/condition (spina bifida and hydrocephalus).
4. Can you tell your experiences with either a) spina bifida, or b) hydrocephalus? (Instructions: Please ascertain the condition the child or youth is experiencing. It may be SB or HC or both SBH)
5. How do people in your family/community perceive children and families having children that are affected by: a) spina bifida; b) hydrocephalus?
6. What challenges/needs are experienced by you and your families as a result of: a) spina bifida; b) hydrocephalus? (probe depending on the condition).
7. How do you and your family deal with these needs and challenges?
   - Probe for positive and ‘negative’ ways of dealing with these conditions.

**Knowledge and awareness of service delivery agencies/organizations**

1. Can you please tell me if there are any organisations (public, NGOs or private sector) that offer services to you and your family to deal with this condition?
2. What kinds of services are offered by these organisations?
   - a) Probe: Prevention (advocacy, awareness creation, information dissemination, community mobilization, nutrition, folic acid etc). Probe for: What do you think about these services? How helpful have they been in dealing with your situation?
   - b) Response (health, CIC, surgery, psycho-social support, economic support, material support, security/shelter, training and capacity-building)
3. How do the organizations mentioned deliver the services you have mentioned above? Thus, how do they reach out to you and your family?

Probe for, e.g. radio talk shows, community outreach, parent support groups, home visits, supporting income-generating activities.

**Health-seeking behaviour/treatment**

**Treatment**

1. Can you please tell how you and your parents go about seeking treatment and care for the condition that you are having? **Probe for formal and informal or indigenous care-seeking practices:** Where do they go to seek care and treatment and why? How is the decision on where to seek care made? Who makes the decisions about health- or care-seeking and what informs these decisions?

   **a) Children with hydrocephalus**

   1. What kind of treatment and care (formal-biomedical and informal/traditional) is available for you and children with this condition?

   2. How do you get access to these services? Please explain what you mean by your answer.

   3. Please can you tell me if these services are accessible?

   **Probe for:** Distance, affordability, availability of health commodities and supplies, availability of health workers etc.

   4. Do you use these services? Yes/No. If YES or No, please explain your answer.

   5. What are the factors affecting the utilization of services by these children? **Probe:** Are there things that make it easy for you to use the services? If YES, please explain.

   6. **Quality of care:** Are you satisfied with the care received from the health care providers? Yes/No: a) **Probe for care level of satisfaction and attitude towards either from the formal health care facilities (public and private/NGO facilities) and informal/indigenous/traditional providers.** b) **Probe for:** Regularity of services, issues related to stock-outs of medicines and other health supplies, availability and perceived competences of health workers, waiting time, and positive attitude of health workers.

   7. Have you ever heard about the shunt device? YES/NO. If YES, how did you come to learn about it?

   8. Is the shunt leaflet used to give you and your parents/guardians some information and guidelines? YES/NO

   **If YES, probe how they are used; and if NO, find out why.**

   **b) Children with spina bifida**

   1. What kind of treatment and care (formal-biomedical and informal/traditional) is available for you and or other children with the same condition?

   2. Are these services accessible and used by you and other children affected by this condition? YES/NO (please explain your answer).
3. Are there things that make it easy for you to access the services you need or that you have mentioned above?

Probe for: Distance, affordability, availability of health commodities and supplies, availability of health workers etc.

4. Are there things that make it difficult for you and other children to use these services? If YES, please explain.

Probe for: Distance, affordability, lack of health commodities and supplies (stock-outs), attitude of health workers, perceived efficacy of treatment, stigma, discrimination etc.

5. Are you satisfied with the care you receive from the health care providers? YES/NO

If YES:

a) Probe how and why they are satisfied; and if NO, find out why.

b) Probe for quality of care: regularity of services, issues related to stock-outs of medicines and other health supplies, availability and perceived competences of health workers, waiting time, and positive attitude of health workers.

Continence management programme

1. Have you ever had any challenges with passing out urine (bladder) or moving the bowel or with other related bodily fluids? Yes/NO. If YES, what are these problems?

2. How do you deal with these problems when they arise? How is continence management done (problems with the bladder and bowel – passing out urine and other fluids)?

3. Describe the procedure(s) being used to implement the continence management programme under the project for children with spina bifida at home and at the facility.

Training in continence management

i) Have you had any training in continence management? If YES, please describe the training, contents covered and how they were delivered?

ii) Were you provided with any training materials? If YES, can you describe the materials provided? Are they useful; if YES, how?

iii) Was the training useful in improving your managing CIC? If YES or NO, please explain.

iv) Are you aware of any traditional or indigenous ways of handling continence? If YES, please describe the procedures.

v) Have you used any of these procedures or practices in continence management? If YES, what was your experience (positive/negative)?

Probe: What are the things you like about the indigenous ways of continence management?

Probe: What are the things you do not like about the indigenous ways of continence management?

vi) Are there other aspects in which you would like to be trained? If YES, please indicate them and why.
vii) What would you suggest regarding improvement of the continence management programme?

**Outreach**

1. Do organizations working on SBH organize outreach clinics for children with SBH? YES/NO.

2. Have you ever been attended to through mobile outreach clinics?

   If YES, what was your experience?

3. What services were provided? Can you please tell your experience with mobile outreach clinics?

4. How satisfied are you with the way these outreach clinics are organised?

   **Probe for what you like most and what do you like least.**

5. What aspects of outreach clinics would you like to change, why and how?

4. Have you been visited in your homes by health workers or organisations dealing with SBH? YES/NO

   **If YES, probe: How they are organized and how often? If NO, why not?**

6. How satisfied are you with the way these home visits are organised?

   **Probe for what you like most and what do you like least.**

7. What aspects of home visits would you like to change, why and how?

**Folic acid**

(Ask only youth above 18 or emancipated minors who are below 18 but are already parents or pregnant/married)

1. Is folic acid available for women? (YES/NO)  If YES, which women are provided with FA?  **(Probe: Target group)**

2. What are the factors affecting access to and utilization of FA?

3. Do you provide leaflets/teaching materials on FA to women? YES/NO.

   **Probe: a) The difficulties these women face in understanding these leaflets. b) To what extent are the leaflets useful to these women etc.?**

4. What would you suggest for the improvement of availability, access to and use of folic acid?

**Feedback on Treatment and Follow-up**

1. How would you describe the interactions you have with health providers?

   **Probe: What do you like about these interactions? What do you not like? Do you get medical feedback on the provided medical treatment/material?**
2. What kind of feedback do you get and from who?

**Support Groups/Associations**

1. Are there support groups for children with SBH? YES/NO.

2. Are you a member of any of these support groups? YES/NO. If YES, what is your experience with these groups? What is done in these groups and how do you participate in these groups’ activities, e.g. training etc?

   **Probe:** a) Objectives for training them. b) How often is the training conducted? d) What training/information materials are used or available for the groups? e) Any benefits/or no benefits from the training.

   If you are not a member of the support groups, explain why.

3. What other support groups do you know about?

4. How do you describe the contributions of any of these groups to you in coping with your condition?

   **Probe:** Added value/benefits of these meetings to individuals/children and the families.

**Participatory involvement of various actors and stakeholders in programme activities**

1. How are you involved as a child or a young person in the project’s various activities?

   **Probe:** a) Which activities are you involved in and in what ways are you involved?

**Gender equality**

1. What unique gender issues affect boys and girls or how are male and female youth affected by this condition (SBH)?

   i. How are issues related to gender equality addressed in the project?
   ii. What sexual and reproductive health issues do you deal with as an adolescent or young person?
   iii. How do you deal with these issues?
   iv. How have the project/health workers helped you to respond to these sexual and reproductive health issues?
   v. What suggestions do you have to improve response to sexual and reproductive health issues for you and other children affected by this condition?

**Effectiveness /successes**

1. In view of the project for SBH, do you think that the project activities have been beneficial to you or effective? YES/NO

   **Probe:** a) What makes you think that the project is successful? b) Which project activities have been successful? c) Which of these activities have been effective?

   What, if any, has been the impact of the project activities on your life and other people experiencing this condition?
Challenges

1. What are the challenges that have affected service delivery for SBH-affected children?

Probe: a) financial, limited skilled human resources, awareness creation, lack of knowledge about the disease, lack of care and treatment, poverty in the community, cultural beliefs; stigma and discrimination against the children with SBH and/or their parents within the family, institutions and community.

Suggestions

What specific suggestions/recommendations would you give for the future of programmes that prevent and respond to SBH?