

# Spina Bifida and Hydrocephalus Interdisciplinary Program



# The need

## **Mbale study**

Where CBR is available, the mortality in SB/H children is the same as in the normal population

If not the mortality is extremely high

CBR and lifelong follow up is as life saving as surgery

Surgery is opening the door to a  
decent life!

But after that door a full house with many  
rooms need our attention.

Till now we mainly focussed on surgery, now we  
want to look in all aspects of long life care

# Care starts even before surgery

- diagnose
- will surgery be possible/needed?
- referral conditions
- information transfer to other professionals

Then:

Hospitalization and surgery

Post-operative care – during and after hospitalization

Lifelong care

Parent groups

Adult involvement

# Development of a concept

Concept note prepared by expert group:

- Surgeon
- Parent
- Paediatrician
- Nurse
- CBR expert
- Adult was missing



# Draft concept note

Two day workshop in Nov 2011 Kampala, Uganda

Concept and tools further developed after input

Try-out of the concept for one year

Next year evaluate and plan the future

# What is S.H.I.P.

**A coordinated, multidisciplinary approach  
towards an individualized care program**

*Coordinated* = SHIP coordinator(s) to ensure communication between stakeholders

*Multidisciplinary* = covering medical and lifelong care

*Individualized* = according to needs of the child

# What is S.H.I.P.

Objective: to **involve** all stakeholders and to improve **collaboration** in order to ensure continuity and quality of care.

*Short term:* create efficiencies within current activities  
(& current budget)

*Long term:* expand activities



# Stakeholders

- Who?
  - Surgical hospital
  - CBR centre
  - Outreach clinic locations
  - Parent & peer support group
  - But also: other hospitals, health centres, government?
- Role?
  - Different roles during different phases
  - Ownership for activities
  - SHIP Coordinators as key communication

# SHIP Coordinator

- At each main SHIP location
- Coordinates multidisciplinary team work
  - Team meetings
  - Info dissemination / knowledge transfer
- Communicates with:
  - Team members
  - Other SHIP locations
  - Support group
- Data collection & reporting

# Current vs. future

	Current situation	Future S.H.I.P.
<b>Stakeholders</b>	Who are involved	Who should be involved
	Current level of involvement	Ideal level of involvement
	Achievements	SHIP Coordinator & Team
		Challenges
<b>Activity domains</b>	Which domains covered	Which should be covered?
	Why (not)?	Why (not)?
		Challenges
<b>Standardization</b>	Protocols & tools used	Current tools to be improved?
		How to integrate new tools?
		Challenges

**The needs for your country specific S.H.I.P.**



# Implementation Plan

- Needs for your country specific S.H.I.P.
- Next steps
- Planning 1st year
- Follow up: Monitoring & evaluation

# S.H.I.P. Framework & tools

- Framework
- SHIP Coordinator
- Passports
- Standardized information
  - Medical protocols
  - Leaflets & brochures

# S.H.I.P. Framework

	CBR centre/Health institution	Surgical hospital	Parent support group
Initial Assessment	1st assessment		Identification
	Referral		
Surgical Care		Pre-op Op Post-op Discharge	Link parents to support group
Follow-up	Outreach		Parent/youth meetings & trainings
	Home visits		Home visits

# S.H.I.P. Passport

- Overview of most important data
- Tool for parents and specialists
- Does not replace hospital/CBR files
- Not meant to duplicate
- Stays with child
- Boys / Girls
- To add locally:
  - Vaccination card
  - Leaflets

# S.H.I.P. Protocols & leaflets

## Protocols

Spina Bifida  
Hydrocephalus  
Operative care  
Contenance mng  
Skin care  
Folic Acid  
Follow-up  
Transition (Youth)

## Leaflets

Spina Bifida  
Hydrocephalus  
Contenance mng  
Skin care  
Folic Acid  
Education  
Transition (Youth)  
Parent & Youth Support Groups  
Family Planning