

STEP Newsletter

June

STEP: SUPPORT TOOLS ENABLING PARENTS



We are glad to share with you the first STEP newsletter, which has a double purpose: (1) to update the core group of participants on the first round of training in Uganda and Cameroon, and (2) to keep a network of interested professionals informed on the progress of this one-year, mid '18 – mid '19, pilot programme from the Liliane Foundation.

STEP has been initiated for a number of reasons, as outlined in STEP documentation (soft copies available, please contact Lea Guignard – STEP project team: lguignard@lilianefonds.nl). One of the reasons being the high prevalence of central neurological disorders (CNDs) in childhood disability, with a recent study from the London School of Tropical Medicine and Hygiene (LSTMH) reporting up to 70% of Cerebral Palsy (CP) in childhood disability in Asia. The STEP initiative fits within Liliane Foundation's Multi-Annual Strategic Plan 2018–2020: to develop expertise on specific disability domains and to generate viable evidence about results on the ground, on impact with regards to 'quality of life' and on 'participation' of children with a disability in various domains of life.

Many of our partners worldwide struggle to implement meaningful services for children with CP and their parents. Moreover, there is a growing tendency to exclude children with CP from Community-Based Rehabilitation (CBR) programmes, as it is felt extremely difficult to provide tangible results, which is nowadays an important requirement from donors. All of us need to realise that CP is a condition that can't be 'fixed', although much can be done to help children as well as parents to cope with it in a better way. Another concern is the fact that worldwide, many existing rehabilitation programmes still follow a strategy that was popular in the last century for managing post-polio paralyses. However, conditions like CP require different approaches e.g. more comprehensive approaches such as CBR and **functional rehabilitation**, with more than attention for the medical condition only. Within CBR, parents should be motivated and trained to offer experiences in their child's life routine that contribute to their development. Attention should be given to e.g. posture and positioning; to nutrition and feeding; and results should be measured with small steps of progress.

The needs of children with neurological disorders don't require long-term admissions in rehabilitation centers, receiving frequent routine physiotherapy with endless passive stretching exercises, completed with calipers that are hardly useful (except in some conditions the relevance for Ankle Foot Orthosis).

"IT CAN BE DONE DIFFERENTLY, WITH BETTER RESULTS"

With limited skills from fieldworkers and rehabilitation professionals, the need to invest in practical training on CP is obvious. Apart from skills training primarily focusing on fieldworkers, evidence building is also an important aspect of the STEP pilot. Within STEP, we propose a new way of working with CNDs and realise that our services 'could be done differently, with better results'. While we are convinced that this is true, we owe it to ourselves, our donors, as well as the children we serve that this assumption holds true!

- A baseline study has been completed
- A total number of around 200 families with a



- child with CP will be monitored during the pilot
- An action research will be conducted in Uganda studying 50 families
- Articles will be published (main contributors: Huib Cornielje & Angelique Kester – Enablement, senior advisors for STEP)
- A publication with results will be presented during an end-conference

Based on the results of this pilot, decisions will be made by the management of the Liliane Foundation on up-scaling the STEP project.

ADDED VALUE

The key concept of STEP is to transfer skills from fieldworkers to caregivers. Ideally, professionals will make an assessment and set goals together with the caregivers. However, it may very well be that there are no professionals available. In that case, the fieldworker should have the skills to make an assessment and set short-term rehabilitation goals together with the caregivers. The caregivers will be coached in their own homes by the fieldworkers to translate (their) goals into daily functional activities.

The following tools were developed in support of this:

- logbook for caregivers (translated into their own language and for them to keep)
- a CP-App to help fieldworkers make a simple but comprehensive assessment
- an **online portal**, with training material, frequently asked questions, and a forum for trainees to share specific cases or questions, as well as video clips and photographs (which currently happens via a Whatsapp group).

For training, existing and high-quality materials have been used, such as the "Getting to Know CP" manual from LSTMH and MAITS' training manual on feeding.



The STEP project was initially launched during the first week of training in Kampala (May 28 to June 1), with 12 partner organisations (19 trainees) from Uganda, Tanzania and Kenya. The launch in Cameroon took place from June 18 to 22 in Bafut, with 6 partner organisations (12 trainees). During both training weeks, a few 'expert moms/dads' (mothers or fathers who are active in their local community an/or parent support groups) were invited with their CP child.

The first training in Uganda and Cameroon was primarily meant to build a solid foundation addressing the 'WHY' and 'WHAT' questions, and were dealt with by highly professional trainers – Sue Fry (Motivation, South Africa), Mel Adams (MAITS, UK), and Marian Fransen (the Netherlands).

Within the broader context of CBR, the ICF framework, as well as functionality and activities of daily living (ADLs), specific areas such as stigma were discussed. STEP trainees identified the following topics as key priorities requiring specific attention:

- Cultural beliefs
- Sensitisation (of medical staff, midwives but also the general public)
- Lobby about early detection and registration
- Initiation and/or support of Parent Support Groups
- Day care facilities and education as an important element of the 'total package' that is offered

After the first training, all participants will do fieldwork, with each partner organisation being responsible for the follow-up of 10–15 families with a CP child (maximum age of 10 approximately). The STEP tools will be used in practice and data will be collected throughout the project.

The project leader and coordinator Africa will be in the field starting August 7 to visit participating organisations; coach trainees in the field; do a context analysis; and liaise with other relevant (including government-) organisations and training institutes/universities in order to ensure that this development won't be an isolated initiative but will become part of a sustainable development in the four pilot countries.

The coaching period for Uganda, Tanzania, and Kenya will take place from August 7 until the second round of training, October 22 to 27 in Kampala.

As from November 21, Kenneth (until December 20) and Kees (until mid-January '19) will be in Cameroon to visit and coach the trainees. The second round of training in Cameroon will be held from December 3 until 7 in Bafut.

As with the first training, the second round will be facilitated by highly professional trainers and will focus more on the 'HOW' of working with children with CP. There will be a specific focus on handling techniques and this will almost exclusively be done in practical sessions with children with CP.

THE NEXT STEP NEWSLETTER WILL BE CIRCULATED EARLY OCTOBER '18. ANY FEEDBACK OR SUGGESTION ARE MOST WELCOME AND APPRECIATED. PLEASE HELP US MAKE STEP WORK AND ENSURE THAT WE SEE BETTER RESULTS ON THE GROUND!

FIRST TRAINING FOCUS

Transferring practical skills to fieldworkers with regards to interventions for ADLs was key, in order for them to coach and transfer these skills to caregivers of children with CP. The following key components were addressed:

- Importance of positioning as basis for ADLs
- Introduction of various assistive devices for proper seating and trunk control
- Tailor-made and common-sense attitude along with 'clinical reasoning' (observation and listening) skills

As stated earlier, a WhatsApp group was also formed to stimulate learning and sharing.



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