**Updated project plan**

**February 2018 – September 2019**

**[S]upport [T]ools [E]nabling [P]arents**

**for better rehabilitation and care of children with neurological disorders**



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| Liliane Foundation Havensingel 26 5211 TX 's-Hertogenbosch The Netherlands |  |

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1. **Background**

The STEP-pilot is in line with the changing role the Liliane Foundation is seeking to play in the field of childhood disability in low- and middle-income countries: a role whereby new methods and tools will be developed and used in order to ensure that the quality of life as well as the functioning of the child with disability will improve. The Liliane Foundation aims a facilitating role towards SPOs and next to be knowledgeable on specific issues within the international disability scene, with an added-value based on evidence.

STEP is focusing on the therapeutic/technical aspects (of neurological disorders (NDs) and mainly Cerebral Palsy) as well as on the caregivers’ and fieldworkers’ needs, aiming to have impact in a holistic manner, in line with the broader ICF framework.

1. **Goal and objectives**

The vision of the STEP project reflects particularly one of the outcomes of the current results framework of Liliane Foundation: children with neurological disorders participate to their potential at home, within their community, at school and on the (informal) labour market.

The goal of the STEP project is: to improve the quality of life and participation of children with neurological disorders.

The objectives are to:

1. Improve the quality of comprehensive intervention process by including all ICF domains to explore and describe main difficulties from the clients’ perspective, assessment, (SMART) goal setting, monitoring and evaluation of goals for children with NDs among fieldworkers.
2. Enable caregivers to feel confident in taking care of their child and supporting in daily life in what (s)he is capable of.
3. Ensure that fieldworkers are trained in a functional approach of rehabilitation and in so doing ensure that the quality of rehabilitation for children with NDs among fieldworkers and caregivers becomes relevant and meaningful.
4. Ensure that fieldworkers feel more confident after the STEP training in addressing main difficulties (in terms of knowledge, attitude, and practice) expressed by clients.
5. **Setting**

The pilot took off in May ’18 in the Lake Victoria region and in July ’18 in Cameroon. The project is implemented in close collaboration of POs in the four countries, and SPOs are also to be involved. The SPOs together with the Onsite Coordinator of the STEP project identified 21 participants for Lake Victoria Region and 8 for Cameroon.

1. **Methods**

The STEP project has been developed in such a way that the following outputs need to be achieved:

1. Have competent staff in place – e.g. professionals, fieldworkers and caregivers are equipped to optimally provide rehabilitation and care to (their) children with neurological disorders.
2. Relevant staff is trained in the use of assessment tools (e.g. COPM, GMFCS), in setting rehabilitation goals, and in developing appropriate interventions.
3. Available staff feels and is competent in providing necessary interventions to children with neurological disorders and capable of optimally involving caregivers.
4. Assistive devices and necessary medicine are available.
5. A resource centre is established in each participating country.
6. Caregivers are aware of and understand the prognosis, potential and limitations of their children with neurological disorders.
7. Caregivers of children with neurological disorders feel valued by members of their community.
8. Infrastructural barriers that hinder the child to participate in family- and community-life are reduced.
9. **Project phases**

The STEP project consists of **seven phases**, which are described as follows:

**Phase 1: Inventory (done)**

An inventory of what therapists, fieldworkers, and caregivers in each country and region need to improve in terms of quality of care and rehabilitation, including early referral and intervention, has been carried out. The outcome of this inventory was discussed by a team of experts – based on their expertise and experiences in African and/or Asian countries. In addition, a study using the Knowledge-Attitude-Practice (KAP) method with individual interviews and focus group discussions have further informed the inventory and the next phases. In this phase, training participants were also identified.

**Phase 2: Preparation of Training and Toolbox (done)**

Before training fieldworkers and starting other interventions, the STEP team gathered and critically evaluated existing and to be developed materials and information for the trainings, the RehApp CP, videos and/or posters and flashcards for caregivers. In this phase, experts were consulted for input and support. The training toolbox was drafted, and the trainers attended a workshop in the Netherlands to synthesise the training content and approaches.

**Phase 3: Baseline Study (done)**

Baseline measures were obtained through:

* the Canadian Occupational Performance Measure (COPM);
* a caregiver survey with components on demographics, household information, child’s education, disability knowledge, child’s general health information, classifications (GMFCS, MACS, CFCS, and EDACS), rehabilitation questions, fieldworker interaction, and young lives ladder; and
* a pre- and post-training questionnaire (based on the KAP survey model).

The baseline data was initially to be collected for 40 children, however due to data collection issues, only 10 case studies (10 children and their respective caregiver(s) and fieldworker) in Uganda were complete enough to be used.

**Phase 4: Interventions (ongoing)**

To meet the objectives, the following **interventions** are taking place:

* 1. **Training + RehApp CP**

The training pays attention to issues such as observation and assessment skills, (clinical) reasoning, goal setting and decision-making about appropriate interventions. Each training session takes place over the course of 5 days, and involves two rounds of training for both LVR and Cameroon.

Specific intervention topics included in the pilot version of the app will be:

* Mobility
* Eating and drinking
* Communication
* Self-care
* Health and well-being
* Psychosocial

The information and tools used in the training can also be found in the RehApp CP, which fieldworkers can use as a resource, but also as a tool helping them to better observe, assess, interview, set goals, develop interventions and record progress.

**ii. Portal: a communication tool for major stakeholders**

In order to support fieldworkers as well as caregivers a Portal was created on LF’s new online platform. This allows fieldworkers, staff of POs, as well as caregivers to find information related to both specific training content as well as neurological disorders more generally. Moreover, based on the types of questions received throughout 2019, a decision will be made in regards to whether experts of Dutch Rehabilitation centres should be involved as well.

**iii. Empowerment of parents**

All the caregivers in the project are being trained to be empowered in such a way that they better understand their child’s condition and feel confident in taking care of and supporting their child in daily life and in what the child is capable of. This is also done within POs’ Child Empowerment programme, which aims to ensure caregivers know the child’s conditions, potential and limitations. As such, the goal is for caregivers to engage more in their children’s rehabilitation plan but also to help manage their (sometimes) high expectations. The development of parent support groups and self-help groups will continue to be stimulated as these are ways for caregivers to share experiences and support each other. Finally, day-care initiatives are felt to be a priority by most parents and linking with relevant stakeholder (both implementing and funding) will be enhanced.

**iv. Create more (public) awareness.**

POs already support basic infrastructural adjustments at home and in the community to lessen barriers that limit the participation of children with NDs. Caregivers – through parent support groups – are supported to have a voice on matters regarding development and treatment of their children in the community. This component aims to change attitudes about children with NDs specifically. Increasing awareness has been identified as one of the main lessons from the pilot’s first phase and will lead to further recommendations for upscaling after the pilot.

**Phase 5: End Line Study – Evaluation research**

This evaluation research will focus on measuring improvements in quality of life of children with ND as well as their caregivers as an outcome of the STEP project in Uganda. This will be done by comparing data collected during the baseline in phase 3, with the data to be collected and analysed in this phase. For this end line collection, the same measures as those used for the baseline (COPMs, caregiver surveys, as well as post-training questionnaires) will be repeated, using the same 10 case studies.

**Phase 6: Project End-Evaluation**

The objective of this project end-evaluation will be two-fold:

(1) To get insights into the outcomes of the STEP approach in regards to fieldworkers’ competencies as well as quality of life of children with ND and their caregivers, and

(2) To reflect on the shortcomings of the initial research plan and evaluate the project-design as a whole.

The end-evaluation will be carried out by an external third party. The Terms of Reference for this end-evaluation – namely whether data from the evaluation research, field reports, and accounts from project team members will be sufficient or whether visit to the field is necessary – still needs to be decided upon.

**Phase 7: Debriefing workshop – Scaling Up**

During this phase, a final workshop will be held with:

* Fieldworkers, to do a final review of practices and upgrade the remaining lacking stills
* The aforementioned group as well as programme staff of participating (S)POs, to discuss the STEP strategy as an approach, and to map out ideas for possible upscaling.

In addition, the STEP training will be revised based on the evaluation of the pilot period. Depending on the decision by the Liliane Foundation management structures, the project will be rolled out to other countries in Africa and Asia.