



# STEP Symposium 2019

Closing report

The STEP Symposium was organized by the Liliane Foundation on the 26<sup>th</sup> of September in Den Bosch in the Verkadefabriek. The morning session consisted of a number of presentations from participants directly involved in the implementation of the STEP project. The afternoon session took place in the office of the Liliane Foundation (LF) in Den Bosch. It was an interactive session in which participants gave their ideas on what the Liliane Foundation needs to take into consideration if it wants to further upscale the project. The reflections from the presentations of the morning session and the discussion points of the afternoon session are presented in this report which the Liliane Foundation will share with all the guests and people who were on the guest list but did not manage to join Symposium.

The Symposium was facilitated by Erik Heijdelberg, Chairman of the Board of Partners for Youth from the Netherlands and William Schrikkergroep.

## What is STEP?

STEP was a pilot project that aimed to improve the quality of life and participation of children with neurological disorders such as Cerebral Palsy (CP). It was a one-year project, implemented in the Lake Victoria Region (Uganda, Tanzania and Kenya), as well as Cameroon. The pilot phase was finalized in September 2019. The project focused on training fieldworkers and caregivers in particular competencies to improve care and basic rehabilitation services for children with neurological disorders and their families. STEP was a training package consisting of face to face training sessions with coaching in between and tools such as: a Whatsapp group for intervision, a log-book which basically is a proper client record that helps the fieldworker together with the caregivers to systematically record assessment, setting goals, designing strategies and monitoring progress of the child, the RehApp-CP, a smartphone App that can be used as a vital resource and the Liliane Foundation's *Connect online platform* where all training materials and resources can be found. More project information you can find on this link:

<https://connect.lilianefonds.org/step/project+information/1199054.aspx?t=General+Setup>.

## Morning session

### 1. Keynote speech:

The morning session of the STEP Symposium started with a keynote speech by Jetta Klijnsma, a Dutch politician of the Labour Party. She is the King's Commissioner of the province of Drenthe since 1 December 2017. Jetta is also an ambassador of the Liliane Foundation. In her speech she reflected on her own childhood and what it meant for her to have a disability. She also shared her impressions on STEP during one of her field visits in Uganda earlier this year.

### 2. Presentation on the urgency for STEP:

Kenneth Nangai, the STEP coordinator reflected on the urgency in the four countries to have STEP and its comprehensively designed package for improving the attitude, the knowledge and the skills of

fieldworkers so that they in return will help improve the coping skills of parents who have children with neurodevelopmental disabilities. He presented a number of photos and a short video of children who were part of the project, explaining the outdated practice of a fieldworker and another one showing what was improved in the quality of the life of a child with CP since STEP was implemented.

### **3. Presentation on the STEP outcomes:**

Angelique Kester, CBR advisor from LF reflected on the STEP outcomes from her evaluation research done in Uganda. Her research question was: *What are the outcomes of the STEP pilot on the lives of children with neurological disorders, their caregivers and fieldworkers involved with the family?*

Some of the outcomes from STEP are following:

- Most of the caregivers have reported change in the functioning of their children: use of hands, being more active, saying words, eating by themselves, swallowing better, sitting with better head control, moving in the house, naming objects, indicating needs, etc.
- Most caregivers have gained more knowledge about their child's condition and the possibilities for improving their functioning. They understood the causes and the symptoms of neurological disorders, which enable them to face the challenges of daily care for their children in a more effective way. Further, their coping skills improved, and they have grown more confident in how to handle their children, resulting in changes in their child's abilities and potential. Small interventions have made significant changes in the functioning and quality of life of the children. And there has been a positive spinoff effect in some communities.
- The crucial factors required for fieldworker efficacy in the STEP project are access to support, regular coaching and resources, i.e. assistive devices as well as a passion and positive interest towards children with disabilities and their families.

The report was shared as a hardcopy with all participants in the Symposium and it is also available as PDF: <https://connect.lilianefonds.org/step/project+information/1447803.aspx?t=Reports>

### **4. Presentation on the end evaluation of STEP:**

Lyndal J. Alexander, independent consultant and occupational therapist from South Africa, presented the results from the end evaluation of STEP. The executive Summary was shared as a hardcopy with all participants in the Symposium and the full report is also available as PDF:

<https://connect.lilianefonds.org/step/project+information/1447803.aspx?t=Reports>

### **5. Reflections and moving forward:**

Maria Zuurmond from the London School of Hygiene and Tropical Medicine (LSHTM) shared some of her reflections about the STEP outcomes with the audience and invited everybody to think forward on how STEP can be implemented further. The important role of the fieldworkers was discussed in relation to the empowerment of the caregivers. Further, participants discussed possible strategies for preventing a turnover of fieldworkers by providing some professional development and career paths.

### **6. End notes:**

Steven Berdenis van Berlekom, the Liliane Foundation's Director reflected on the importance of STEP for the organization and setting it up in the context of the Rehabilitation-2030 agenda of the World Health Organisation (WHO).

Kees van den Broek, the STEP project leader and the Liliane Foundation former Director made the final conclusion reflecting that development is a functional match between what the environment can afford and what the actor can and wants to do. In that line the STEP approach has managed in shifting mindsets of people from *fixing the disability* towards *coping with disability*. He expressed his hopes for the project to be scaled and the lessons learned from the pilot to be used for creating more effective implementation strategies in the countries where upscaling will take place.

## Afternoon session

In the afternoon session the participants joined 4 different tables in which they discussed different key topics for upscaling and contributed with their thoughts to each topic. The session was organized as a World Café assignment. The topics and the discussion points from the 4 tables are presented below.

### **1. How poverty influences the project and what we can do to tackle the poverty issues?**

- a. Mapping local stakeholders and get them on board for upscaling.
- b. Create adequate day care facilities, both in urban and rural areas.
- c. Create/facilitate development of parent support groups that can contribute in a day care
- d. Use the parents support group for starting up income generating projects.
- e. Tap into existing Micro Financing Institutions and lobby for them to become more inclusive towards families of children with disabilities.
- f. Tap into existing government social care schemes and lobby for their disability inclusiveness.
- g. Connect to existing poverty reduction services and lobby for them to become disability inclusive.
- h. Should STEP be only limited to provide support for poor families? STEP can serve parents who have low or middle income, so that they can help each other and address joint issues that they are facing such as stigma and exclusion.
- i. Address properly the topic of prevention of disability and early identification.
- j. Empowering parents economically to pay for the services.
- k. Create household vulnerability assessment and plan for each family what are the most important steps for tackling their child's disability.

### **2. What is the capacity of people to address the coping in an effective way?**

- a. Create parents support groups exclusively with fathers, as they connect with each other differently.
- b. Address adequately mental health issues of caregivers that come as consequence of their life situation and coping style and provide psychological support through parent support groups.
- c. Embed the project in CBR structure, do not create parallel systems and structures, but integrate in an existing one.
- d. Work on children peer support groups.
- e. Invest in coaches with local/context specific experience.
- f. Create moments/structures where caregivers can have some relief from the daily care by involving the community.
- g. Invest in regional centers for expertise and Training of Trainers provision.
- h. Pair health community worker and physiotherapist/occupational therapist with caregivers for creation of a tailored plan for the child.
- i. Have in mind that the process of rehabilitation is time-consuming for the caregivers and provide support whenever necessary.

### **3. What is the minimum viable investment?**

- a. Link it with Rehab 2030 and the existing Cerebral Palsy Network. Entry point can be the World Health Organisation (WHO) agenda and it's the possibility to have some influence there. Ideal package would be to have skills transfer at the community level.
- b. Create an evidence-based package with clear exit strategy for the children in the programme and clear length of rehabilitation time.
- c. Work on behavioral change in caregivers and community members.
- d. Promote and facilitate a transition for rehabilitation (centers/ programs) to focus more on neurological disorders and complex needs of children and to build expertise/ impact

evidence on that; this would require also a new business model for sustaining the organization and to be ready/ strong for a new future role.

- e. Create a clear minimum package addressing the following questions:
  - How many visits per family and how long?
  - Better define the roles of the fieldworkers and caregivers in the rehabilitation process.
  - Family collaboration and creating coping strategies for each family.
  - Groups' assessment and rehabilitation vs. home visits.
  - What is needed as a minimum requirement in each visit?
  - Make sure that adequate assistive devices are being produced.
  - Focus on proper nutrition and medications.
  - Link with Gross Motor Functioning Classification System.
- f. Invest in integration of the project in existing structures and create local ownership
  - Integration into existing programs of Liliane Foundation's partners.
  - Ownership by communities.
  - Link to existing service providers.
  - Comprehensive access by building strong networks or local CBR oriented organisations.
- g. Staff retention
  - Keep your knowledge investment free from "brain drain".
  - Try to give some structural incentives (better payments) for fieldworkers to stay and to learn and improve.
  - Use locally empowered staff with high passion and motivation.
  - Provide some career development trajectories.
  - Provide some support and prevention from burn out.
- h. Multi-layer competencies
  - Engage both with physiotherapists and fieldworkers and stimulate structural collaboration.
  - Local knowledge with insights from caregivers' experiences.
- i. Align the project with existing initiative of other INGOs.
  - Check similar initiatives in the context where the upscaling will take place.
  - Educate back donors on importance of having STEP in the field.
- j. Increase the awareness on the importance of projects as STEP.
  - Focus on the different layers: starting from the child up to the community and country level.
- k. Financial issues
  - Fieldworkers costs: salary and transport.

#### **4. How do we know the existing framework is strong enough?**

- a. Start building it from the child and caregivers needs.
- b. Prepare local/regional stakeholder's analysis.
- c. Link with other organizations that are doing the same/similar initiatives.
- d. Ensure adequate assistive devices production, maintenance and use.
- e. Tap into existing resources.
- f. Link with Neurological Disorders services at local level.
- g. Use the Community Based Rehabilitation (CBR) and International Classification of Functioning (ICF) as frameworks.
- h. Create explicit position on primary prevention and early identification.
- i. Link with primary health care services.

At the end, the facilitator asked all participants to come up with the most important first step for upscaling of STEP. Many of the participants had same points which became priority steps for upscaling, such as:

1. Align with existing initiatives of other stakeholders: NGOs (SPOs and POs), government, community organizations, service providers/hospitals, DPOs, caregivers, etc. and create joint programme that will be tailored to diverse contexts and realities of families.
2. Map the stakeholders, who do you need to join in order to create more effective upscaling.
3. Learn from this symposium and create professional coaching group that will work on the upscaling of the next STEP.
4. Ensure that you do not lose the existing fieldworkers.
5. Strengthen local relationships first. Organize feedback and reflection with the African partners before you upscale. They should give their insights and experiences of the whole process of implementation. Organize workshop/symposium in the countries where STEP is implemented and build/maintain the trust and the relationships with the partners. Link the lessons learned with other countries where this kind of developments are a bit more advanced such as countries from Latin America.
6. Lobby for the STEP needs on the Government and WHO level.