STEP Newsletter October

LEARNING & BUILDING EXPERTISE

After the first training sessions in Uganda and Cameroon in May and June this year, most participants took off with new competences and renewed energy to work with caregivers and their children with neurological disabilities.

The one-year STEP pilot has since entered into a new phase of learning and building expertise, with fieldworkers applying lessons learned from the training to their work in their respective communities.

The coaching phase in Uganda, Tanzania and Kenya – from August onwards – was done by Kenneth Nangai and supported by Kees van den Broek. Coaching in Cameroon will take place from mid-November '18. The second training will be organised in Uganda from Oct. 22nd to Oct. 27th and in Cameroon from Dec. 2nd to Dec. 7th.

In general, findings during the coaching visit were positive, with the more specific observations as follows:

- The STEP-RPS (Rehabilitation Problem Solving) log-book was well used by most of the participants. Some critical feedback on missing aspects has been received and integrated. A revised version will be presented during the second training.


A child and her mother

- Almost all children with CP we have seen so far are moderately- to severely-disabled. Only a few children with mild CP are part of the STEP pilot. The more severe cases were almost inexistant in programmes until STEP started, while mild cases were often already benefiting from programmes.
- CP is sometimes confused with (severe) intellectual disabilities, Hydrocephalus or Spina Bifida.
- The two (Lake Region & Cameroon) WhatsApp groups are quite active, sharing and learning from each other's experiences and difficulties. Dialogue between trainees as well as with the experts is motivating and sometimes leads to creative solutions.

A child and his grandmother

Almost all communication in both WhatsApp groups are about interventions, especially about positioning and feeding. This is in line with the aim of the STEP pilot, which is to capacitate fieldworkers to acquire better practical rehabilitation skills and techniques, and build competences in coaching caregivers. Coaching caregivers, however, should go beyond these (important!) practical rehabilitation skills: it should also be about helping caregivers better understand their child and improve their daily living skills.

While some of the challenges identified during the coaching period (see following page) do not fall directly within the scope of the STEP pilot, they are certainly relevant in the work we do, and will be reflected upon during the first day of the next training.

A 'process design' is currently going on in Uganda, following 40 families with a child with CP more closely. The report on this study will be published during the second half of 2019. Based on the findings of the STEP pilot, the management of the Liliane Foundation will decide on whether and how to upscale the STEP approach.

CHALLENGES IDENTIFIED DURING THE COACHING PERIOD:

Poverty:

- The caregiver often indicates that she spends too much time on caregiving tasks and thus does not contribute to family income.
- Health-related costs for the child with CP are high and this places an additional burden on families.

The need for (day/home) care:

- Caregivers often feel isolated and 'like a prisoner in their own house'. Many caregivers indicate that they have an immediate need for relief care and this may be best organised with parent-support-groups and day care facilities.

(Mal)nutrition:

- The caregiver is confronted with feeding problems and the key question is how best to feed the child.
- Problems encountered with feeding often lead to malnutrition. This can be a result of not being able to give the child sufficient food, an unbalanced diet or parents not knowing what is the best food to give the child.
- More information on nutrition and local food is also available for download on the STEP portal!

Availability of appropriate assistive devices:

- There is usually either an absence of or lack in quality of tailor-made assistive devices for sitting, standing, mobility, eating and drinking.

Psychosocial issues:

- Caregivers experience a lot of stigma from society but also from themselves, including feelings of shame, depression, marital and sexual problems as fathers often blame their wives for giving birth to a child with a disability.
- Overprotection by parents resulting in so-called 'Queen/King syndrome' is noticed as well, however.

THE ROLE OF THE FIELDWORKER: MORE THAN A 'THERAPIST'

It is important to realise that the role of fieldworkers is not only about being better 'therapists' and solely improving functioning of the disabled child. The aim of capacity building is to increase fieldworkers' competences in analysing the broader context, taking into account all relevant aspects (e.g. economic, social, personal, educational, ...), as opposed to medical aspects only. This is why we emphasise WHO's ICF framework within STEP, to offer fieldworkers a broad, conceptual approach to reflect on their work. Doing so also requires fieldworkers to collaborate with a network of other stakeholders with expertise in other areas of work.

All this requires first and foremost commitment and a lot of critical thinking, with two important tools to accompany this work: a pair of ears to listen, ask, reflect, and a pair of eyes to observe. All senses are necessary to fully comprehend the situation, however. And just as there is no single treatment for anything in life, there is no 'one size fits all' approach to CP.


Kenneth and a fieldworker during a home visit

FROM THE INDIVIDUAL TO THE COMMUNITY: THE THREE LEVELS OF CP

The individual level: the caregiver and the child. It is on this level that fieldworkers apply interventions aimed at improving QoL and Participation and/or Inclusion. However, the central question to ask is: what are the functional goals as identified by the child and the caregiver(s)? Everything we do in any kind of 'therapy' should be directed at helping people achieve their own goals, rather than assuming that attention to the child's impairments alone will lead to better functioning. Activities should be meaningful and motivating in order to be integrated into daily life, especially in the absence of the fieldworker (which accounts for the majority of the time).

The family level: the role of other family members (e.g. the grandmother or the elder sister taking care of the child while the mother works). It is important to realise that rather than wanting caregivers to be their child's 'best therapists', we want them to be their child's 'best caregivers'. It is necessary to think developmentally and in terms of caregiving, seeing all that we do as being designed to support child- and family-development. Some of this will be about therapy and a lot of it about caregiving.

The community level: stigma, not only from people 'next door' but also from the local community, and from society at large (e.g. health professionals, religious/traditional leaders and the general public).

Strategies for an 'Enabling Environment' are also needed to reach the family and the community. Raising general awareness about disability and CP specifically, trying to change mindsets of (key) stakeholders in society, as well as advocating with and on behalf of children with disabilities and their caregivers with local government and traditional authorities are steps to consider.

There are a few issues that need to be further discussed during the next training:

- The conventional way of treating children with CP with passive stretching exercises to reduce contractures. Although always stemming from the best possible intention, we have seen too many examples during the past few months of children being 'tortured'. We strongly pledge to stop these practices and will discuss alternatives during the next training. There are still more 'exercises' to be discussed, such as routine passive 'range of motion' exercises, often applied without being functional.
- Yet another issue that needs more discussion is the prescription of wheelchairs: some therapists have a fear that providing wheelchairs to children (who need it) will make them 'lazier'.

SECOND STEP TRAINING:

- Training packages on measuring skills for devices, including seating devices and AFOs;
- The relation between the technician making the device(s) and the rehabilitation professional for instructions on adjustment of the device;
- Training package on balanced (local) nutrition;
- Coaching and counseling;
- Training on use of Rehapp CP;
- New version of STEP-RPS log-book, including development chart of 'normal' development and growth monitoring.

Kees van den Broek
STEP project leader
kvdbroek@lilianefonds.nl

Kenneth Nangai
STEP coordinator Africa
kennangai@yahoo.co.uk