STEP

pilot end evaluation report

for Liliane Fonds

June – September 2019

Acknowledgements

We extend our warmest thanks to all the organisations who hosted us during this evaluation. Our particular thanks to Mr Kenneth Nangai, Mr Timothy Fanfon and Mrs Glory Tsangue for their support, generosity and humour, and for their hard work in making our field visit possible under often challenging circumstances.

Thank you to the staff at the Liliane Fonds office in the Netherlands for their administrative support and sharing of STEP resources.

Thank you to each fieldworker who took the time to talk to us and share their work with us. We commend them for their hard work and courage in learning and trying something new within their communities.

And most importantly, thank you to each family who welcomed us into their homes and shared their stories and experiences with us. Families are the experts on their children, and we are grateful for the opportunity to share in and learn from your expertise.

Disclaimer

All findings here are drawn from observations and interviews with various stakeholders in each country but remain the opinions of the authors, not those of Liliane Fonds. Due to the relatively short time in the field, there are necessary limitations of the "snapshot" view. Please let us know of errors or serious omissions.

Extensive data was collected during this evaluation, more than could be presented in this report given the limitations in both time and space. We trust this report gives a comprehensive overview and sufficient data to justify the main findings and recommendations. Readers are more than welcome to contact us for further questions or discussion.

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Executive Summary

Introduction

The STEP intervention was piloted for a period of one year, by 14 organisations across four African countries. This external evaluation of the pilot covered a sample of nine of these organisations in three of the countries, namely Uganda, Kenya and Cameroon. The evaluation methodology involved both qualitative and quantitative data collection, including semi-structured interviews, observations, home visits, focus group discussions and document review. The field visit took place over six weeks during July and August 2019 and was carried out by two South African occupational therapists.

The aims of the evaluation were:
   (a) To evaluate the project methodology and gather lessons from the implementation process
   (b) To investigate and advise on the feasibility of upscaling the project and the approach to it in future

This included understanding both the appropriateness and fit of the designed intervention for the target beneficiaries, and the effectiveness of its implementation so far.

In evaluating interventions of this kind, it is essential to understand the context in which they are applied, as this shapes both implementation and outcomes. When transferring the intervention to new settings, the same contextual factors need to be investigated and considered in planning.

Context is also crucial to how children with neurological disabilities (ND's) develop and thrive. The family or household is the immediate developmental context and are therefore an important target for interventions aiming to support the child. Having a child with a disability also has serious consequences for family members; and their survival, health and well-being cannot be separated from that of the child. Families in turn live within a community context, which either includes and supports, or isolates and marginalises them. The community is situated within a regional and national context, and ultimately a global one. This multi-layered context for child development can be seen as a series of concentric circles *(see diagram)*, where each layer interacts with the others.
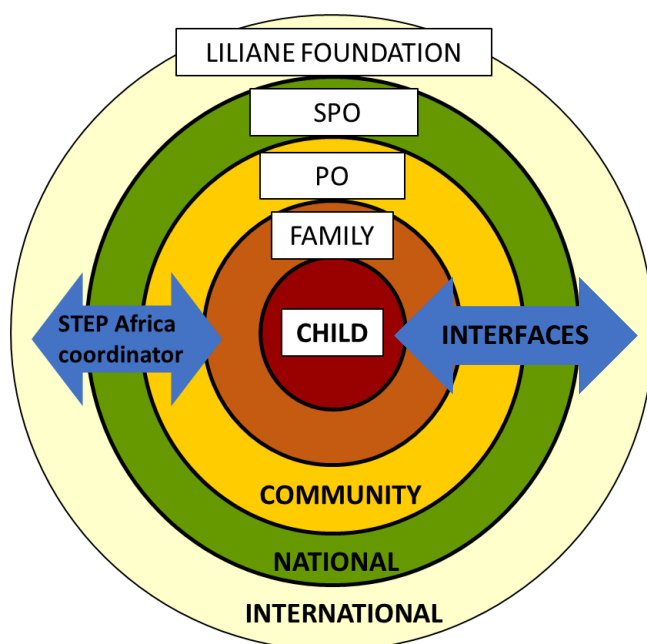
This evaluation used an integration of Bronfenbrenner's Ecological Systems Theory (Garbarino & Ganzel, 2000) and Long's Actor Oriented Analysis (Long, 2003) as a conceptual framework to guide the design of the study and analysis of data collected. Data was collected at each circle as well as at the interface between each circle to understand context, influences and interactions in each layer and interface.

Children with neurological disability in context

Disability is understood as the experiences which arise from the interactions between a person with an impairment and their environment (WHO, 2007). The nature of disability as experienced by children with ND's living in African countries is intrinsically shaped by the realities of daily life in their communities.

All four pilot countries are classified as low-income or developing countries. Resource and financial poverty levels are high, as is unemployment, and literacy is often low. For a number of reasons, children with ND's tend to be born into poorer families, often living in rural or peri-urban areas with subsistence farming and small informal businesses serving as the main forms of livelihood. In these communities, infrastructure tends to be poor, without piped household water, electricity or sanitation. Survival depends on time-consuming manual labour, in which all family members participate from a very young age. Extended family relationships are paramount, both for socio-economic and cultural and spiritual reasons.

A child with ND born into this context often has a catastrophic impact on the family. Many people believe that disability is caused by the sin of a parent (often the mother), and this often leads to the rejection of that parent together with the child. Marriage and relationship break-ups are common, with usually the father leaving the mother to raise the child (and any other children) alone. In-laws may disown the child, saying "we don't have children like this in our family". There is also a common belief that disability is the result of a witchdoctor's curse, at the instigation of a relative or neighbour. This creates different tensions, as the parents try to guess who may have caused the disability and why.

"We say it takes a village to raise a child, but when the child has a disability it is you alone"
(Fieldworker, Uganda)

Families of children with ND's often face heavy stigma and tend to be ostracised and isolated. This is worse where the child also has epilepsy, which is believed to be contagious. At the same time, the task of caring for a child with ND is physically strenuous and time-consuming, often taking away the resources needed for the family's livelihood (e.g. time to go to the farm to tend crops). The costs of the child's care (including access to healthcare and other services, nappies, special food and transport), together with lost opportunities for livelihood activities, pose a serious financial burden.

Caregiving is also stressful and emotionally draining, and caregivers of children with ND's are at very high risk of mental illness. So-called "mercy killings" of children with disabilities are common in these countries, as is child abandonment. Many children with ND's are left to the care of grandparents, who face the physical limitations of ageing while their grandchildren grow and become heavier to manage. The abilities and care requirements of children with ND's vary widely, but the STEP intervention focused on children with moderate to severe impairments. These children have difficulty moving around independently, communicating, using their hands and doing activities for themselves. Many children included in the pilot are completely dependent for all self-care, including toileting.

The STEP intervention

The STEP intervention pivoted around the role of fieldworkers to be the hands and feet of the project. Fieldworkers identify families of children with NDs and, through doing home visits, provide support tools to enable parents and caregivers. The aim is to improve the quality of life of the child and family and improve the coping and handling skills of the caregivers.

Training and tools

The STEP training has given a basic foundation to fieldworkers in working with children with ND's and their families and has empowered fieldworkers to transition from a role of assessment and referral in the field, to one of intervention. The STEP reasoning process (ICF and RPS) was found to be a positive strategy to provide a structure for thinking and action for the fieldworkers during planning and home visits. It encouraged a holistic view of the child and family, and to consider context and pressing needs. At times, this resulted in difficult issues and concerns being raised that are beyond the scope of the STEP project and thereby having to manage parent expectations.

Translating needs into realistic and collaborative goals was crucial in directly shaping interventions but also to temper parents' expectations for the STEP services. Goal setting, although a simple concept, is difficult to apply well without the underlying knowledge and experience to guide ones' goals. Intervention planning was often limited to common interventions, with the question 'what next?' arising.

Interventions most frequently used with caregivers were counselling and problem-solving strategies as well as advocating for medication compliance for epilepsy and linking families to healthcare and support services. Assisting families with their livelihoods through income-generating activities, although less frequent, was regarded as valuable by families.

Intervention selection for the children should be directly related to the primary needs identified by caregivers and through the ICF-based assessment conducted on the initial home visits. Intervention choices were influenced by retention of learning from the training workshops and the number of trainings attended as well as prior training and experience of the fieldworker. The most common interventions used with children are clustered into 4 groups: working on positioning and gross motor skills, oro-motor skills of eating and communication, activities of daily living and play, and assistive devices for positioning or mobility.

"When I first started working with children, we were seeing so many complex cases, I didn't really know what to do, but with this intervention, you see changes"

In addition to training, coaching was essential to build the confidence and skills of fieldworkers, including areas such as goal setting and intervention planning as well as managing family expectations. There is also a need to continue extending their knowledge to enrich their practice in homes and the use of context-friendly resources and tools.

Four tools were created to support the fieldworkers: a WhatsApp group, RehApp, logbook and an online portal. The WhatsApp group provided a measure of support to fieldworkers, although with some difficulties due to cellular networks. The logbook and App were used in guiding assessment, goal setting and intervention planning. No use was made of the online portal. Internet access, text-heavy design and dependence on English fluency were significant limitations in the use of the tools.

Families

Primary positive changes seen in children were improved feeding and therefore nutritional status, and access to anti-epileptic medication was improved and seizures were better managed. As general health improved, so too did functional outcomes, including sitting, mobility through the provision of assistive devices, communication and overall the ability of the child to participate within the home and community.

The STEP intervention has positively influenced most caregivers' perspectives on and view of their children, improved their mental health and allowed them to hope for change. Caregivers have grown

more confident in how to handle their children and has resulted in seeing changes in their child's abilities and potential. Fieldworkers have served as important sources of socio-emotional support particularly in communities where families are isolated.

"You are the only family I have" (Grandmother, Cameroon)

Small interventions have made significant changes in the function and quality of life of the children and as their children showed improvement, as well as with IGA support, caregivers were able to provide for their families again. A positive spinoff of home visits was a more inclusive and understanding response from the community.

Additionally, home visits reduced the financial output of the family, and many shared that the quality of services provided by the fieldworkers was better than those at the institutions as the interventions were linked to the home life and needs, and fieldworkers engaged more directly with caregivers.

Fieldworkers

By visiting in homes, fieldworkers developed a richer understanding of the challenges faced by the child and family within context and this resulted in the development of interventions that are responsive to family needs and context. Following the STEP training, fieldworkers felt more equipped to provide home-based intervention and to adopt the role of coaches to create and manage an empowering relationship with caregivers, so that they in turn can coach and empower their children to live their best lives. Adequate training as well as having a heart and concern for children with disabilities were valued by the families in this evaluation.

The organisational context for STEP

The STEP pilot was implemented within the multi-layered organisational context of LF's partnerships with a strategic partner organisations (SPO) in each country, who in turn liaises with a number of partner organisations (PO's) on the ground. This entails much inter-organisational communication and coordination. STEP is a far more complex intervention than previous work by LF in these countries, and therefore needs more investment in relationships and organisational capacity. The pilot highlighted numerous areas for development in this regard.

Partner organisations

While STEP was intended as a minimal-resource intervention, this proved unrealistic. STEP equipped fieldworkers to do far more with children with ND's and their families than was previously possible, and this meant a significant increase in time and resources spent on this client group. Costs of home visits (including transport, airtime and fieldworker salaried time), together with addressing the range of needs identified, resulted in a more resource-intensive intervention than anticipated.

Management support for STEP was critical to mobilise these resources, including negotiating fieldworker responsibilities to accommodate the larger caseload. Not all managers concerned were included in the training, and several did not have a community disability background, which made it more difficult for them to accept the organisational changes needed. Not all partner organisations had a strong community-based inclusive development mindset, and this proved a barrier to effective implementation.

Future STEP work needs to engage managers actively in planning for the intervention, including budgeting resources needed and planning how these will be mobilised. Some form of the training should be aimed at managers specifically.

Strategic partner organisations

SPO's did not have a very clear role in the pilot, so this varied considerably depending on the nature and capacity of the organisation. They were most effective in supporting PO's when they had practical disability expertise and hands-on experience in community-based rehabilitation work, which allowed them to offer coaching and practical support to PO fieldworkers. It was also important that they had national reach and capacity to advocate for the program with other stakeholders, build service and support networks and connect PO's with needed resources.

It is possible that existing SPO's may not be best placed to play this role, and perhaps other options in-country could be investigated. It will be important to define the roles of alternative STEP SPO's clearly in relation to existing SPO's to avoid tension and confusion.

STEP African coordinator

An African coordinator for the pilot, Mr Kenneth Nangai, was employed for a two-year period, and his role has been essential for the pilot's success, as attested by every organisation we met with. In Cameroon, a similar role has been played by Mr Timothy Fanfon, the national rehabilitation supervisor for the SPO (Cameroon Baptist Convention). Strong relational, organisational and problem-solving skills are crucial for developing STEP in each country, together with dedicated time and travel resources, amongst others. Realistically, a coordinator is needed for each country, particularly if they are responsible for all coaching.

Interfaces between organisations and contextual layers

This organisational model depends strongly on the relationships and interactions between the different partners. Two interfaces emerged as being of particular significance.

The interface between LF staff in the Netherlands and African SPO's (and sometimes PO's) was complicated by cultural differences and largely remote communication (e.g. email, Skype, written reports). Most communication relied on English, which for most was not a first language, and information conveyed in text, apart from human and relational context leaves much room for misunderstanding and uncertainty, especially for non-westerners. The further development of STEP will depend on strengthening interpersonal relationships through face-to-face time, building the trust needed for LF and its partners to work more collaboratively. This time should also allow LF staff needed in-depth exposure to the project context. With this basis in place, remote communication should become more effective.

The most critical interface was between the PO and the community (including the household), as this was the site of the STEP intervention itself. While PO's and especially fieldworkers were the "face" of STEP, what happened in the other layers often had an impact here. Relationships built by PO's with their communities and beneficiaries formed the basis for the intervention, and STEP could have both positive and negative effects on these relationships. Future decisions about implementation and how this unfolds must create space for fieldworkers and PO's on the ground to give input to decision-makers on likely impact at this level.

Recommendations

Recommendations reflect the gaps and challenges faced by STEP thus far and areas to strengthen the programme across levels and stakeholders reflected in the conceptual framework.

1. Take evaluation findings back to the pilot partners for feedback, reflection and planning
2. Rethink costing of STEP and make new resource plans
3. Build multi-level capacity at local and national levels to sustain STEP
4. Build strong networks between STEP implementers

5. Employ country coordinators
6. Train & coach for context
7. Include community development skills in fieldworker training
8. Assistive devices: develop local capacity for design, manufacture & repair
9. Review and revise support tools to be locally accessible and appropriate
10. Parent support groups

STEP is a complex intervention and will require ongoing development to best meet the needs of children with ND's in context. The preliminary, pilot-phase findings are positive and indicate that STEP is meeting a need and has potential for growth and expansion. There is however no 'lite' version of STEP, it will require a long-term commitment and investment in building capacity to ensure that it works over the lifespan of the children and families with whom it engages.

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List of abbreviations

AD	Assistive Device
ADL	Activities of Daily Living
AFO	Ankle-Foot Orthosis
CBC	Cameroon Baptist Convention, Cameroon
CBID	Community Based Inclusive Development
CBR	Community Based Rehabilitation
CDSK	Cheshire Disability Services, Kenya
CEP	Child Empowerment Programme
CP	Cerebral Palsy
CWD	Child(ren) with Disabilities
EDID	Empowerment and Disability Inclusive Development programme
FBO	Faith Based Organisation
GMFCS	Gross Motor Function Classification Scale
ICF	International Classification of Functioning, Disability and Health
IDP	Internally Displaced Person
IGA	Income Generation Activity
INGO	International Non-Governmental Organisation
KAFO	Knee-Ankle-Foot Orthosis
KCH	Katalemwa Cheshire Home, Uganda
LF	Liliane Fonds
LMIC	Low- and Middle-Income Countries
LVR	Lake Victoria Region
ND	Neurodevelopmental Disorder
NGO	Non-Governmental Organisation
OT	Occupational Therapist
PO	Partner Organisation
PT(A)	Physiotherapist (Assistant)
PWD	Person(s) with Disabilities
RPS	Rehabilitation Problem Solving
SEEPD	Socio-Economic Empowerment for Persons with Disabilities
SPO	Strategic Partner Organisation
STEP	Support Tools Enabling Parents
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WHO	World Health Organisation

Part 1
Introduction

STEP background and scope of evaluation

The STEP project, an acronym for 'Support Tools Enabling Parents', and initiative by the Liliane Fonds (LF), represents an important attempt to develop locally appropriate, high-quality rehabilitation and support for children with neurological conditions living in low-resource contexts. Neurodevelopmental disabilities impact not only the functioning of the child, but also the function and integration of the family into the community. STEP aims to provide community-based fieldworkers with skills on the assessment, planning and practice to aid their work with these children and families, and thereby promoting inclusive change in the communities. The STEP project was piloted for 1 year (May 2018 – July 2019) in four countries in Africa, Uganda, Kenya, Tanzania and Cameroon.

The terms of reference for this evaluation include analysis of both the process and outcome aspects of the pilot. The evaluation aims were therefore:
1. To evaluate the **project methodology** and gather lessons from the implementation process
2. To investigate the **feasibility of upscaling** the project and provide relevant recommendations

Literature review

15% of the global population have disabilities, with a higher prevalence in developing or low- and middle-income countries (LMIC) (WHO, 2011). An estimate calculated in 2005, suggests that 150 million children under the age of 18 years have disabilities, with a prevalence of disability in up to 12.7% of children in LMIC (WHO, 2011).

Within the field of childhood disability, neurodevelopmental disorders (NDs) are one of the many disabilities, is one of many neurodevelopmental disorders occurring, with cerebral palsy (CP) remaining the most common neurological condition, with a global occurrence of 1.8-2.3 per 1000 live births (Donald, Samia, Kakooza-Mwesige & Bearden, 2014; Kakooza-Mwesig et al., 2017). In Africa, the term 'cerebral palsy' is often used as an umbrella term for a variety of motor disabilities, including aetiologies of neonatal encephalopathy, infections and traumatic brain injury (Donald et al., 2014). As per the internationally accepted criteria, the sequelae of these conditions need to be apparent before the age of 2 years (Donald et al., 2014).

The prevalence of cerebral palsy and other neurodevelopmental disorders is higher in low- and middle-income countries (LMIC) than in high-income countries, with a distinctive contrast in the aetiology being apparent (Kakooza-Mwesige et al., 2017). Extracted from the limited African prevalence and aetiology studies available, the estimate of cerebral palsy in Africa is between 2.9-10 per 1000 live births (Donald, Samia, Kakooza-Mwesige & Beardon, 2014; Kakooza-Mwesige et al., 2017), with the majority being classified with lower levels of functioning according to the Gross Motor Function Classification Scale (GMFCS) (Donald, Samia, Kakooza-Mwesige & Beardon, 2014; Donald et al., 2014). An estimated 65% of children with cerebral palsy have GMFCS level IV or V (Kakooza-Mwesige et al., 2017).

In high-income countries, the primary cause of cerebral palsy is preterm birth, however in Africa, that is the leading cause of neonatal death. In Uganda it was estimated that 25% of children with CP is caused by neurological insults during the first 28 days after birth (Kakooza-Mwesige et al., 2017). These include obstetric complications, neonatal encephalopathy, cerebral infections, neonatal jaundice and head injuries (Donald et al., 2014; Kakooza-Mwesige et al., 2017). As maternal and neonatal care improves in LMICs, there may be an increase in the number of children with CP due to the improved neonatal mortality rates (Kakooza-Mwesige et al., 2017).

There remains a dearth of research on cerebral palsy and other neurodevelopmental disorders in Africa, including prevalence, screening and effective intervention strategies (Donald, Samia, Kakooza-Mwesige & Beardon, 2014) and the research that is available often has its cohorts drawn from hospitals and are thus not community or population-based (Donald et al., 2014). To date, research suggests the greatest benefits in management of NDs through community-based rehabilitation (CBR) programmes (Donald, Samia, Kakooza-Mwesige & Beardon, 2014) and self-help groups (Wickenden, Mulligan, Fefoame, & Katende, 2012).

Community-based rehabilitation is an approach that has been adopted over the last 3 decades and is now structured around five areas: health, education, livelihood, social participation and empowerment (Wickenden, Mulligan, Fefoame, & Katende, 2012). Despite the availability of guidelines on CBR as well as frameworks around the inclusion of people with disabilities; there remains a gap between the ideals and the realities of families living with children with NDs, particularly in rural communities within developing countries (Booyens, Van Pletzen & Lorenzo, 2015).

In addition to structural and resource limitations, discriminatory attitudes and stigmatic beliefs around disability present a challenging context in which to work with families (Booyens, Van Pletzen & Lorenzo, 2015; WHO 2011). It is within this context that the Liliane Fonds is aiming to position the STEP project, Support Tools Enabling Parents.

Conceptual framework

This evaluation is constructed around a conceptual framework that is a combination of two established models: Ecological Systems Theory by Bronfenbrenner (1986) and Actor Oriented Analysis by Long (2003). The project itself is framed within the International Classification of Functioning, Disability and Health (ICF) (WHO, 2007), which meshes readily with these two frameworks.

Ecological Systems Theory, developed by Bronfenbrenner, is a means to study the interplay between individuals and their environments (Garbarino & Ganzel, 2000). The environment is divided into several systems, which are viewed as interconnected and influencing one another (Bronfenbrenner, 1986; Garbarino & Ganzel, 2000). This model is used specifically to understand how a child's health and development are shaped by the multiple levels of context within which they are situated.

To the above model, concepts from **Actor Oriented Analysis** (Long, 2003) are added. Actor Oriented Analysis aims to understand development interventions in terms of the interface between a community or population and the development organisations which seek to serve them. This model starts from the understanding that development interventions may have different effects and outcomes in different settings, because people respond in very different ways to the same set of circumstances. The interface between an organisation and a community is made up of various interlocking spaces which feed into and influence each other. In these spaces, different cultures collide, giving rise to conflict, negotiation and creative reinterpretation.

Functioning and participation are important outcomes of rehabilitation, as highlighted by Liliane Fonds in the STEP project; and is associated with improved well-being and quality of life (Rainey et al., 2014). The **International Classification of Function, Disability and Health** (WHO, 2007) framework not only assists in classification, but also links to the other proposed conceptual frameworks by understanding the interaction between disability or limitations to function, participation and environmental factors in everyday life (Adolfsson et al., 2011). Additionally, the ICF assists in identifying needs and prioritising goals in rehabilitation and allowing these to change across diverse areas of function and environments (McDougall & Wright, 2009).

All three conceptual frameworks allow for analysis of individuals, functioning and participation as well as environmental factors – either within a system or the interface between them. To ascertain whether the STEP project's outcomes are being met, understanding and evaluating each system within the Ecological Systems Theory provides information on outcomes, the Actor Oriented Analysis looks at the interface of the interactions occurring between the systems providing insight into the process and the use of the ICF frames these in relation to disability, limitations, function and participation in an internationally consistent language.

These were integrated to create a conceptual framework used to guide the design of the evaluation study and the data collection process *(see figure 1)*.
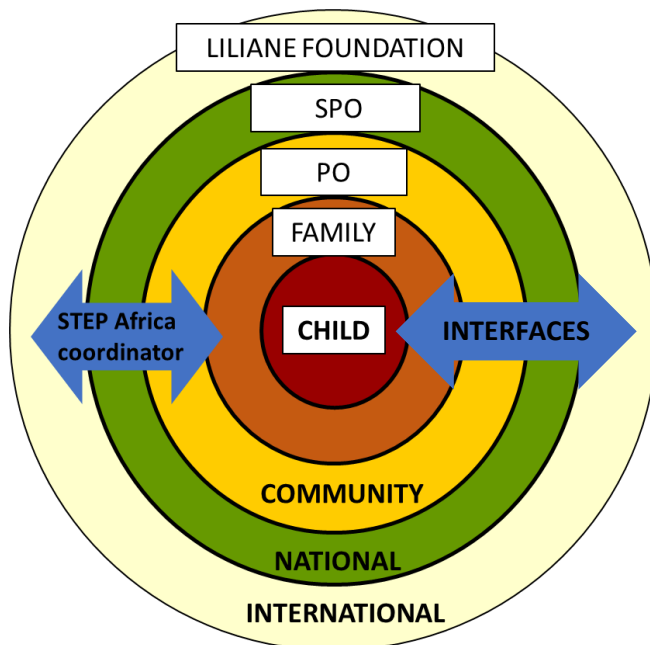
Figure 1: Conceptual framework used in the end evaluation

The child (red) and family (orange) layers represent the microsystem, the immediate setting that fosters development. Of significance here is the interface and interaction between the caregiver and the child.

The next layer (yellow), the mesosystem, consists of the community and members therein directly contributing to development of the child. This includes the partner organisations (POs), the fieldworkers and other community members. The interfaces of importance at this layer of the system were between the fieldworker and family, and the PO and fieldworker.

The green layer represents the exosystem, settings that have a bearing on the child but in which they do not participate. At this level, the strategic partner organisations (SPOs) and their functioning within national networks and policies were considered, as well as the interface with affiliated POs.

Finally, the macrosystem (cream) represents the international arena and their influence on the system, represented in the STEP project by Liliane Fonds. The interface between LF and SPOs was evaluated.

Methodology

Research design

This evaluation study made use of an embedded case study research design (Yin, 2009). Embedded case studies allow experiences of individuals or households (one level of 'case') to be understood in the context of the community or organisation within which they exist (another level of 'case'). This nested design corresponds well to the conceptual model described above.

For this evaluation, three partner organisations (POs) piloting the STEP project per country were selected as case studies. At each site, a sample of households were chosen as another level of case. This design allowed for the interpretation of findings at the level of the child, family and the quality of rehabilitation services in the light of the community, organisational and project context. This approach goes beyond outcome measures alone to understand why and how outcomes were achieved (or not), providing essential information for decision-makers going forward.

Sampling

Country and organisation sampling

Sampling had a multi-level orientation to align with the conceptual framework. Through discussion with Liliane Fonds representatives, it was decided to visit 3 of the 4 countries; Uganda, Kenya and Cameroon with the exclusion of Tanzania. Variation in practice and levels of support (high support versus low support) as well as contexts (East Africa versus Central Africa; politically stable versus volatile) was considered to achieve sample variation at a country level.

Each country is linked to Liliane Fonds by way of a Strategic Partner Organisation (SPO). The SPOs, in conjunction with the Africa STEP coordinator and Liliane Fonds, were responsible for selecting POs for the evaluation, based on criteria provided by the evaluators. Purposive and convenience sampling were used to select POs *(see table 1 and appendix A)*.

Name of organisation	Type of organisation	Location & catchment	Main services	Fieldworkers trained
UGANDA				
Katalemwa Cheshire Home (KCH)	NGO - Rehabilitation centre	Kampala (National)	Medical rehabilitation Assistive devices workshop National outreach Disability advocacy & awareness	1x therapy assistant (trained teacher) 1x OT
Namutamba Rehabilitation Centre (NRC)	NGO - Rehabilitation centre	Mityana (District/local)	Medical rehabilitation Referrals for surgery and assistive devices	1x parent of child with CP (volunteer)
Benedictine Eye Hospital	FBO – Specialist eye hospital	Tororo (Regional)	Eye care and surgery Community eye health CBR project: outpatient rehab, community services	1 x PT assistant
KENYA				
Cheshire Disability Services Kenya (CDSK)	NGO – Inclusive development organisation	Nairobi (National)	Community-based inclusive development (CBID) efforts at national level, especially in inclusive education	1 x project officer

			Advocacy and awareness Support for local disability centres Capacity-building for POs around the country	
Sisters of Mary St Joseph the Worker	FBO – Special school	Kakamega (District/local)	Boarding school for learners with disabilities	1 x OT
Franciscan Sisters of St Joseph Small Home	FBO – Special school	Sigomere (District/local)	Hostel for learners with disabilities attending inclusive school Special unit	1 x PT
CAMEROON				
Cameroon Baptist Convention (CBC)	FBO – Health services provider	Head office in Bamenda / Yaoundé (National)	Healthcare SEEPD EDID Training/education	1 x PT* 1 x disability services manager*
CBC Yaoundé	FBO – Primary healthcare centre	Yaoundé (District/local)	Primary healthcare services Facility-based physiotherapy CBR worker outreach	x PTA x CBR worker
CBC Bafoussam	FBO – Primary healthcare centre (PHC)	Bafoussam (district/local)	As above	x PTA x CBR worker
CBC Ngounso	FBO – PHC	Ngounso (District/local)	As above	x PTA x CBR worker

Table 1: Strategic- and Partner Organisation sample[1]

Due to in-country logistics and safety considerations in Cameroon, many decisions regarding sampling of fieldworkers and families were made by the SPO. As far as possible, the criteria were held in consideration. Samples of fieldworkers were limited as most POs only had 1 STEP-trained fieldworker however, variation was achieved with regards age, gender, level of previous training and prior experience. Families visited included those fieldworkers had experienced as successful cases and those with challenging children, caregivers or home situations.

Household and child sampling
A total of 37 families were visited; 15 in Uganda, 10 in Kenya and 12 in Cameroon. For maximum variability in the home visit sample, criteria regarding the household, child, fieldworker and access to rehabilitation were considered.
- Household: socioeconomic status, education or livelihood, dwelling area (rural vs. urban), primary caregiver
- Child: age, gender, level of impairment, functional status, potential
- Fieldworkers: level of training and experience
- Access to rehabilitation: prior medical rehabilitation vs. no access, quality

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[1] Marked by *: These staff were trained by the LF team, and they in turn trained fieldworkers from the other CBC sites. Unfortunately, the original trainees from other PO's were based in the crisis area (north-west province) and had mostly been forced to stop their work. Many CBC staff from Bamenda (also in the north west) were redeployed elsewhere in the country, including Bafoussam, Ngounso and Yaoundé. Many of the families we visited were internally displaced people (IDP's)

Most children were in early to middle childhood *(see figure 2)* with cerebral palsy being the most common of the neurodevelopmental disabilities represented, accounting for 91% of the sample *(see figure 3)*. Reflecting available research, 66% of the children in the sample had severe cerebral palsy of GMFCS (Palisano, Rosenbaum & Barlett, 2007) levels IV-V *(see figure 3)*. Of the sample, almost 70% presented with marked spasticity (muscle tightness) and almost half had malnutrition at the time of initial intake into the STEP pilot *(see figure 3)*.
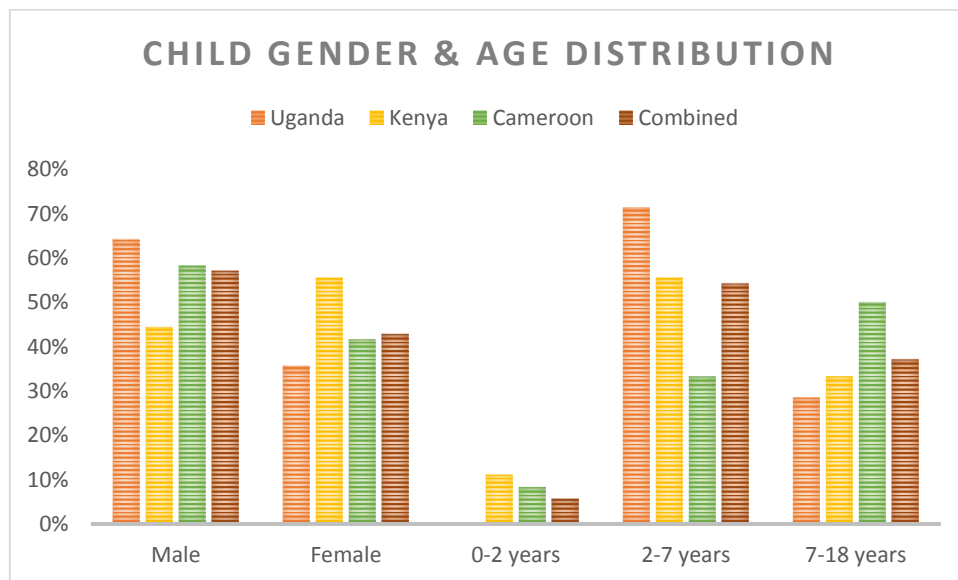
Figure 2: Child sample - gender and age distribution
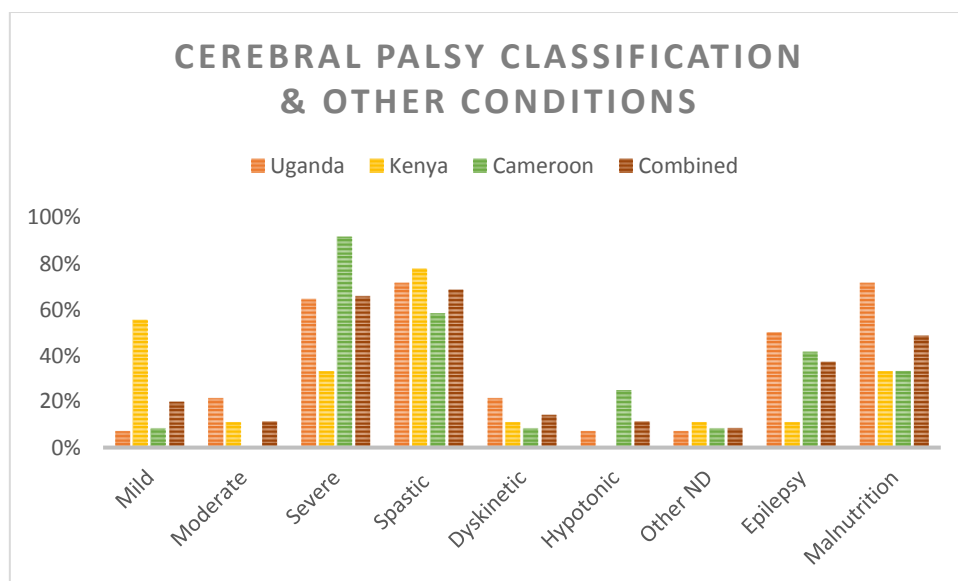
Figure 3: Cerebral palsy classification and other conditions/comorbidities

Data collection

The data collection was structured into two parts:

1. **Desk review**

The desk review phase was curtailed due to time constraints. The documents reviewed included:

- African literature on neurological disabilities, disability and poverty, caregiver burden and quality of life, current intervention practices

- Literature on country context, history, socioeconomics and politics
- Liliane Fonds reports
- Training timetables and notes
- WhatsApp conversations (June 2018 – May 2019)

2. Country and field visits

The field visits took place over 6 weeks in July-August 2019, with approximately 2 weeks in each country. Field visits included home visits to families of children with NDs, focus group discussions and interviews at various organisational levels. The visits into homes was done with the relevant fieldworker, a translator where necessary, and in Cameroon, with the addition of a physiotherapy assistant and CBC Communications department representative. The larger group for home visits in Cameroon may have affected the interactions with household members and therefore the data collected during the visits.

Data collection in the field used predominantly qualitative methods, although both qualitative and quantitative data was derived. Question guidelines were designed for use at each layer of the conceptual framework of the Ecological Systems Theory model as well as each interface needed for interactional analysis *(see figure 4)*. These guidelines were used to structure semi-structured interviews for the relevant stakeholders.

In the homes, the data collection included observations and clinical assessments of the children, observations of the caregiver and fieldworkers, and review of the logbooks (where available). Where logbooks were written in a local language, these were translated by the designated translator. Each visit took between one and two hours.

Semi-structured interviews were carried out with caregivers, fieldworkers, and PO and SPO representatives, as well as representatives from affiliated organisations. Interviews typically took 1-1.5 hours. A focus group discussion (FGD) was held with 11 caregivers in Uganda. Three FGD's with fieldworkers took place: one group in Uganda (3 fieldworkers), and two groups in Cameroon (5 and 6 fieldworkers respectively). Focus groups typically lasted approximately 2 hours.
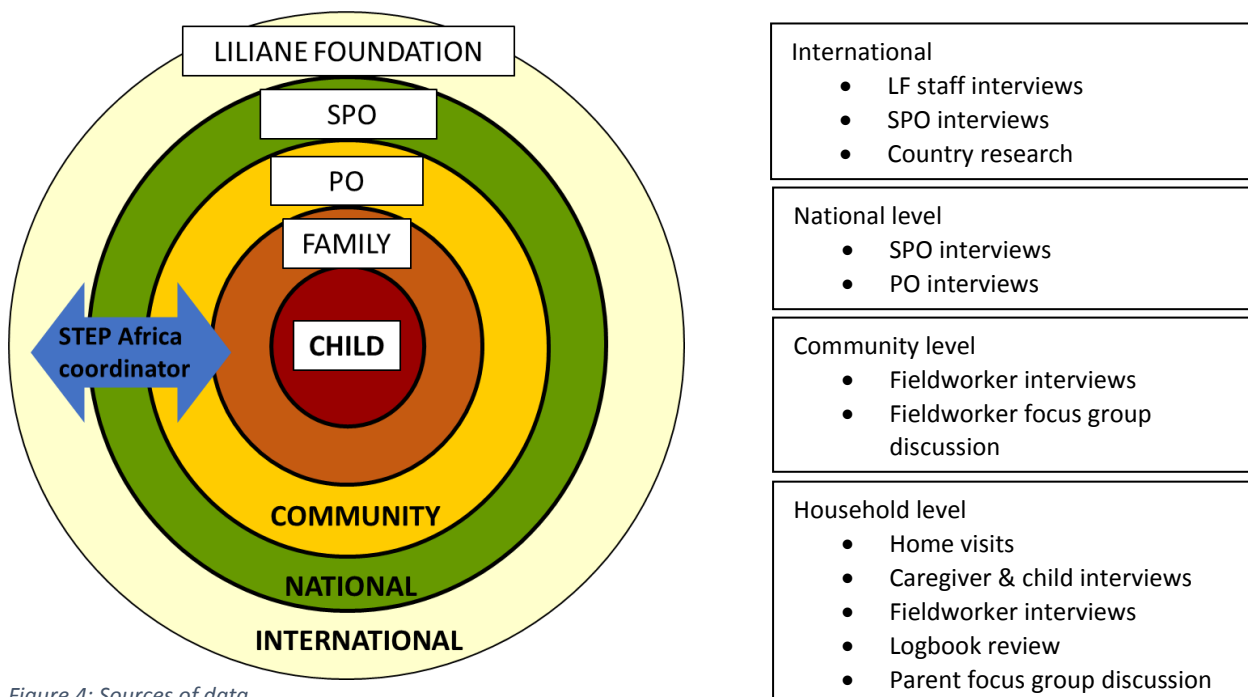
Figure 4: Sources of data

Data management

The two evaluators alternated interviewing and observation roles during home visits and interviews. Reflective discussion and comparison of observations was ongoing, and electronic data capture took place at the end of each day. Interpretations of the data were checked where necessary with key informants. Audio recordings of FGD's and certain interviews were transcribed thereafter. Photographs of logbooks, assistive devices and children were gathered with permission *(see Ethics).* All data was stored on password protected computers with back-up to the cloud and an external hard drive.

Data analysis

Preliminary analysis in the field consisted of discussion, constant comparison and triangulation as well as identification of preliminary themes. On our return from the field, data analysis continued with a period of data immersion and framework analysis based on the conceptual framework. Primary and secondary themes were elicited through this qualitative process, while descriptive statistics were produced from the quantitative data.

Data quality

Data quality was ensured through triangulation of data sources, peer debriefing and thick description of context to situate the findings.

Ethics

Informed consent was required from all participants, and participation was voluntary. We were guided in consent procedures by the hosting SPO's and PO's, and under their recommendations, permission for photographs of home, assistive devices and children was ascertained verbally. Although we had prepared written forms, we were advised that for cultural and locally specific reasons, being required to sign documents often caused distrust and unhappiness in families. All families enrolled in the STEP pilot had previously given consent for photographs for the extent of the pilot, including by external visitors. The purpose and use of photographs were explained to each caregiver.

All names and visits were coded in our data to ensure anonymity of the child, family members and fieldworkers. Consent for audio recording of interviews and focus group discussions was obtained in writing and/or verbally, depending on the participants. Once digitally captured, these recorded were destroyed.

All information shall be returned to the Liliane Fonds upon completion of the evaluation, including digital notes and photographs. Records in the possession of the evaluators shall be destroyed by the evaluators after an agreed waiting period.

Data referencing

Information throughout this document, unless otherwise referenced, has been obtained through analysis of the data collected from children, caregivers, fieldworkers or organisational representatives, by observation, interview or document review.

Conclusion to Part 1

The evaluation of the STEP pilot is framed within a systems approach and has been designed to reflect the embedded nature of the child within the family, community and country context as well as the interactions between the different stakeholders and the influence on the success of the STEP project.

Part 2
Neurological disabilities in context: The need for STEP

According to the ICF, disability results from the interaction of a person with an impairment, with their environment. The nature of the environment is pivotal to the lived experience of disability and its impact on both children and their families.

This section situates children with neurological disabilities in the pilot sites within their national, regional, community and family contexts, giving a picture of daily lives of these children and their households. This is crucial for understanding the needs STEP seeks to address, and also the setting in which it has been implemented so far. We go on to describe the impact of a neurological disability on both child and family, and to describe the needs and challenges identified by the households we visited.

Icons are used to locate each section within the multi-layered context framework.

National and regional context
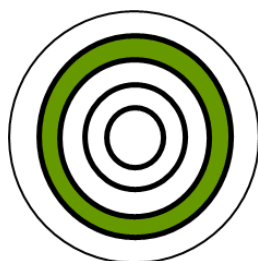
STEP was piloted in two regions of Africa: the Lake Victoria Region (LVR) of East Africa, and Cameroon (Central Africa).

The Lake Victoria Region (LVR) includes contiguous areas of Uganda, Kenya and Tanzania, which share many similarities of terrain, climate and other aspects of daily life. Tropical climate and generally fertile soil provide good conditions for agriculture, and subsistence farming was the most common form of livelihood among the families visited. All three countries are classified as low-income or developing, with widespread poverty and low levels of formal employment. Infrastructure is poorly developed, affecting transport and physical accessibility of the environment, as well as access to basic services (e.g. electricity, sanitation and running water). Politically this region is currently stable, although corruption is widespread.

Cameroon is geographically and socio-economically similar, but culturally and politically quite different. Its inclusion in the pilot resulted from a plea from the Cameroon Baptist Convention (CBC, the SPO in-country), who are deeply concerned about children with ND's in their context and were already searching for service solutions. Cameroon is made up of both francophone (80%) and anglophone (20%) populations, stemming from two different colonial legacies. For the past three years, it has been in the grip of a political crisis, arising from conflict between the francophone central government and leaders in the anglophone north-west and south-west regions. Increasing instability and mass internal displacement has had a particular impact on children with disabilities and their families, and on the implementation of STEP.

In all four pilot countries, government provision of services and social protection for people with disabilities is poor to non-existent. While the UN Convention on the Rights of Persons with Disabilities has been signed or ratified by each, implementation on the ground is minimal. Other development priorities, including universal health coverage, access to basic education and basic infrastructure development are being slowly addressed, but weak states, high corruption and lack of resources are significant barriers. There is therefore an ongoing need for non-governmental bodies (such as the Liliane Fonds and its partners) to serve children with neurological disabilities and their families, and this is likely to continue indefinitely.

Culture

Language & literacy

Each of the countries included in the pilot consists of a number of different tribal groups, speaking different languages and with different cultural practices (although with many similarities). Cameroon is possibly the most diverse, with more than 240 languages spoken within its borders. Although each country has at least one official common language (English in Uganda and Kenya, French and English in Cameroon), many of the families we visited did not speak it. Because of the link between childhood neurological conditions and poverty, levels of literacy are generally low.

Spirituality and beliefs

Spirituality is a powerful part of African world view and daily life, and traditional beliefs are freely combined with more formal religious practices. Christianity is the predominant religion in all three countries (70-85%), with Catholicism accounting for approximately 40% (World Population Review, 2019). Islam forms a large minority, (11-21%, outlier Tanzania with 35%); and people of different beliefs co-exist peacefully. Attendance of worship (across different faiths and denominations) is an important aspect of social participation in all communities, and a highly valued source of social support.

Religious beliefs are highly influential in daily life, including in how children with disabilities are treated. The Catholic church has a long history of supporting and caring for people with disabilities, and many disability organisations in the region are faith-based or began as mission organisations. The ethos has historically been one of respect for the life of every human being regardless of appearance or ability, beginning with the early homes and communities for people with leprosy in 1950s – 1960s (ILA, 2019). These roots have had a lasting impact on available disability services, which often retain an institutional focus and a charity mindset, although a strong move towards rights-based inclusion development has happened in some areas.

The newer Pentecostal churches, fast-growing in poor communities across the region, have brought a different attitude to disability, emphasising prayer and miraculous cure. Many parents of children with disabilities take them for prayer at these churches in preference to seeking healthcare or other services, resulting in significant delays before they access healthcare and other services.

Community and daily life

Family structures and relationships
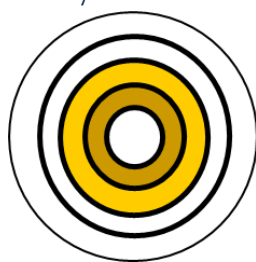
Family roles and relationships are paramount in African society, and the extended family is the most important source of practical, economic and social support. Families traditionally live close to one another, often in compounds housing several generations, where the household head and elder members (usually male) make decisions. Married women typically go to live in the homes of their husband's relatives, where their mothers-in-law have a strong influence on child-rearing and related practices.

Polygamy is relatively common in all three countries we visited, and men frequently have large numbers of children with different women. Fathering is focused on material provision for the family, and hands-on involvement in child-care is unusual. Childbearing is a central part of women's roles and social value, and childcare is almost exclusively female work. Care of babies and young children is usually shared by the extended family, including grandmothers, sisters and older children, freeing the mother up for other tasks as needed.

While these arrangements remain typical in small towns and rural areas, many adults of working age migrate to the larger towns and cities to find work. In urban neighbourhoods, neighbours are far less likely to be related or even to know each other, and social support may be far less.

Livelihood and meeting basic needs

The national and regional context described above shapes the daily life of families in the pilot areas: generally characterised by time-consuming manual labour, including housework, home maintenance and repair *(see figure 5)*, fetching fuel and water, and growing food. In most of the places we visited, household water is drawn from a borehole or village pump and must be fetched daily *(see figure 6)*. Few homes have piped water on site, and toilets are commonly pit latrines (if any). Only a few have any form of electricity, whether municipal or from solar panels. Cooking was mainly over charcoal stoves or open fires.

Livelihoods in most of the communities visited were based on subsistence farming *(see figure 7)*, with each home having a plot of land where they grow staples such as cassava, maize, beans, millet, sorghum, groundnuts and vegetables. Some had small informal businesses, for example selling fresh produce *(see figure 8)*, retailing household essentials (e.g. matches, washing powder, sugar, etc.) and others were seeking odd jobs.

Figure 5: Household water is often collected from village pumps
Figure 6: Traditional building methods mean homesteads require ongoing maintenance and repair

Figure 7: Subsistence farming in rural Uganda
Figure 8: A roadside stall supplements a single mother's livelihood

Labour-intensive survival means each household member must contribute, and there is powerful benefit in good relationships with extended family and neighbours. Children participate in household work from a very young age, including fetching water, caring for younger siblings and working in the garden. Most children in the areas we visited were however in school during the day, with the exception of the very poorest families, who could not afford school fees or uniforms.

Impact of child with ND in family & community context
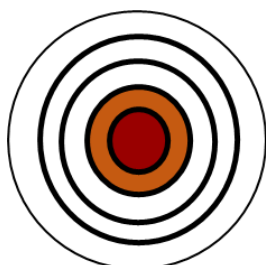
"We say it takes a village to raise a child, but when the child has a disability, it is you alone" (Ugandan fieldworker)

The birth of a child with a disability has far-reaching effects on the social, cultural and economic structures which help families survive and flourish. The following section outlines the impact of neurological disability on the family and child, drawing on home visits across the pilot sites, as well as focus group discussions and conversations with caregivers and fieldworkers.

Beliefs about disability & family breakdown

Beliefs about the cause of disability play a pivotal role in how a child with disability is received in the family. Although local cultures vary, there is a shared belief in the power of witches, wizards or witchdoctors to curse people, and disability is often seen as the result of being cursed by someone. Guessing which relative or neighbour is responsible for this curse can be a source of ongoing stress and fear, and families frequently take their children to traditional healers as well as to churches and healthcare services. In some areas, children with disabilities were themselves suspected of being witches, and they were feared and neglected for this reason.

Disability is also commonly blamed on the mother[2]. Sometimes she is accused of having done something wrong (e.g. had an affair), or the father's family simply claims that "we don't have children like that in our family" and disowns the child. This often results in the father leaving or sending mother and child back to the maternal family (if the parents were married). Without the father's support, the mother is left with the double burden of caring for the child physically and providing for the family financially.

Grandparents quite commonly become caregivers for children with NDs. Sometimes this is to free the parents to work and earn an income, at other times the child is abandoned with them. Four grandparents described rescuing their grandchildren from severe neglect or even from so-called 'mercy killings' (infanticide):

"Her mother left her with the [paternal] uncle and grandmother who wanted to throw her in the river to drown. I asked for her. Had [the child] stayed with them for just 3 weeks she would have been dead" (Kenyan grandmother)

Figure 9 shows the patterns of primary caregiving in our sample of 38 households.

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[2] In one unusual household in Cameroon, the mother's family had blamed the father for the child's disability and taken their daughter back from her husband's home. The paternal grandparents then became the main caregivers for the child.
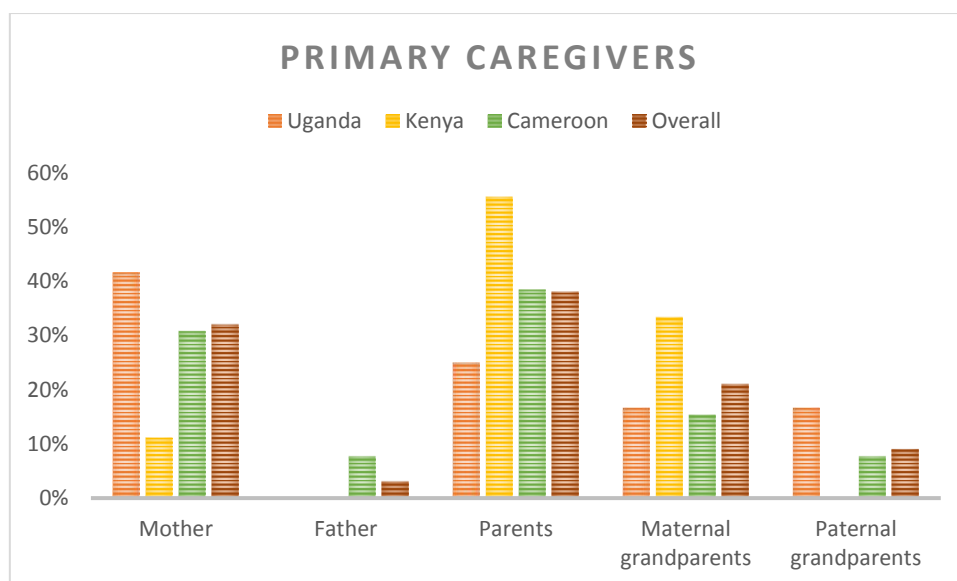
Figure 9: Primary caregivers

'Mercy killing' is the practice of allowing children with disabilities to die, on the basis that lifelong disability is suffering from which the child should be freed. The killing may be more passive (e.g. allowing the child to starve or denying them medical care), or more active (e.g. drowning the child in the river or dropping them from a height). Releasing the family from the burden of caring for the child is a common motive, particularly in the context of stigma and poverty (Tannock et al., 2018).

Burden of caregiving
"When a child with a disability is born, everything stops" *(Ugandan fieldworker)*

Physical cost
Caring for a child with a severe disability is a difficult, physically taxing and highly time-consuming task, especially in the absence of assistive devices (e.g. wheelchairs), day-care or assistance. Many of the children seen were unable to sit independently, and therefore were either carried on their mothers' backs or left lying on a bed or mat. They were completely dependent for all washing, dressing and self-care, and many could not even indicate when they needed the toilet. Two-thirds of the children had feeding difficulties, which meant they took a long time to eat and often needed special food prepared for them. As the children grew, they became more difficult to carry and to handle, especially for older caregivers. Increased tightness of limbs could make hygiene more difficult over time.

Economic cost
For these reasons, family members or neighbours were often unwilling to help with caring for the children, which meant the primary caregiver could seldom leave the child with someone else while she went to the market, the clinic or to work in the garden. This had a serious impact on family livelihoods, while the child's needs simultaneously increased household costs (e.g. buying special food, nappies, medication).

Some single mothers visited worked in small shops (e.g. hairdresser, electronics stall), and were able to take their children to work with them, although unable to give them much attention during the day. One mother made and sold potato chips on the side of the road but could not care for her daughter at the same time, so would leave her alone in the house while she went to work. Coming home to check on her and feed her during the day had an impact on her earnings, but she had no alternative assistance.

Social costs

The demands of caring for a child with ND also made it difficult for caregivers to care for other children, both practically and financially, and attend to other household and community roles. Being unable to leave their disabled children with someone else prevented caregivers from participating in social and community activities, such as visiting friends or going to church. Lack of appropriate wheelchairs or buggies meant children could not easily be taken out of the house, and social participation was further affected by the stigma around disability. As a result of all these factors, caregivers often became extremely isolated.

Relationship costs

Having a child with disability places extreme stress on the relationship between the parents. The burden of caregiving and the financial costs to the family play a role, as do the reactions of extended family and community members to the child. Several parents described their ongoing struggles to find medical help and advice for their children's condition, sometimes for the first few years of his/her life. Lack of knowledge among healthcare workers and a general dearth of disability services meant that this was often a costly and frustrating exercise, which took its toll on the family.

Acceptance of the child with ND by both parents was hampered by lack of information and understanding of the condition – both its causes and its long-term effects. Parents worried about the future of the child, and especially about whether any more children they might have would also have a similar disability. One mother expressed her fear that her husband, a taxi-driver working in the city some distance away, would look for another wife if he thought she could only bear disabled children.

Both parents could be vulnerable to the social isolation, worry and hopelessness developing in these conditions. At the same time, where this relationship was strong and supportive, it made an enormous difference to the primary caregiver's coping and the family's survival.

Emotional costs

All of these factors add up to extreme emotional stress, usually combined with a situation of reduced coping resources. Many caregivers shared that they were depressed when they looked at their child and the child's condition and saw that their child is different to other children. Mothers (and sometimes fathers) of children with NDs described the anxiety of not understanding their child's condition, as well as their fears about the future and a sense of hopelessness about their situation. Other risk factors for depression and mental illness included social isolation, physical exhaustion and financial stress, and it was not surprising that several caregivers reported suicidal thoughts.

Neglect, abandonment and 'mercy killings' of children with severe disability are predictable outcomes of this situation. A number of caregivers we met presented with signs and symptoms of mental health concerns, but there is little access or awareness of mental health services for them as caregivers.

"I have hope for change, but only a little. I have had to abandon many things over the years and despite trying everything I can think of, nothing with [my child] changes, so I have lost hope."
(Cameroonian mother)

Available services and support

In all three of the countries visited, national governments have either signed or ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), and even written policies domesticating the Convention in national legal frameworks. However, implementation of these good intentions was found to be almost non-existent on the ground.

Healthcare

All three countries have a state healthcare system, significantly supplemented by non-profit and private providers. In Cameroon, the SPO itself is a major provider of healthcare in the country. Very little healthcare was available for free, with a few minor exceptions (e.g. in Kenya, children with epilepsy could register on a treatment program and receive their medication for free – although in practice the medication was usually out of stock) *(see figure 10).*

Besides user fees, transport costs for children with disabilities accessing healthcare were considerable, and public transport was often difficult to access. Families also complained of long waiting times (especially at state services), and the lost earnings or household labour time from going to the clinic or hospital.

Healthcare workers seemed to have very little knowledge of childhood ND. Unhelpful responses from staff included blaming the mother for the child's condition (e.g. when a child with swallowing difficulties became malnourished), giving incorrect and even damaging information about the disability (e.g. telling parents the disability was caused by the use of contraception), and treating the child for a condition they did not have (e.g. neonatal tetanus treatment for a baby who sustained a head injury at birth because no midwife was on hand to catch him). These encounters created a great deal of frustration and eventually hopelessness among parents.

Figure 10: Government dispensary (Kenya)

Rehabilitation and disability support services

Medical rehabilitation services available to the families we visited were limited and almost entirely centre-based – either at government hospitals or through the POs themselves. Before STEP, CBR workers mainly visited homes to identify and refer children with disabilities, and rehabilitation by trained therapists was primarily passive exercises and sometimes assistive devices such as AFO's, KAFO's and callipers. These orthopaedic practices have little or no positive effect on children with cerebral palsy, and caregivers usually stopped taking their children to therapy after a short while, being unable to justify the time and transport costs of attending. Sometimes passive stretching could be extremely forceful, causing the child much pain and the caregiver considerable distress (this was highlighted especially in Cameroon, where children with cerebral palsy are often referred to massage therapists – some of whom pay commissions to doctors for recommending their services).

Assistive devices, such as wheelchairs, were scarce in all three countries, with only Uganda having an in-country manufacturing workshop for context-appropriate devices (*KCH)*. Imported second-hand wheelchairs were sometimes available, but usually not appropriate for the terrain or the child, and difficult to repair once broken. Families could almost never afford devices even when available, unless paid for by a Non-Governmental Organisation (NGO), Faith-Based Organisation (FBO) or 'well-wisher'.

Inclusive education

Inclusive education policies are written in the Ugandan and Kenyan context, but very little was still evident in practice. In Cameroon, inclusive education is being developed under the Empowerment and Disability Inclusive Development programme (EDID) project run by CBC.

Kenya has special needs units attached to mainstream schools and all countries do have designated schools for learners with special education needs, although these are usually disability specific, i.e. visual impairments, hearing impairments. There are insufficient schools for the number of children with disability, and they are often financially and geographically inaccessible.

Some mainstreaming of disability in the education sector is happening in all three countries, but this is highly variable. Children with severe and multiple disabilities such as the target group usually cannot be included in ordinary schools, and there are few if any inclusive day care facilities.

Social security

Almost none of the families received financial support from the government for their children. In Kenya, a disability card has been introduced which entitles registered children and adults with disabilities to monthly cash transfers. Unfortunately, the application process is convoluted and extremely slow, and only one family we encountered had succeeded in accessing this.

Social and community support

Social and community support is available, as described above, through family and religious structures. In addition, many communities have community savings groups or women's groups that can provide sources of support to caregivers of CWD. Access to such support is frequently blocked however by stigma and social isolation resulting from the disability.

The needs of children with NDs and their families

Through conversations with families and fieldworkers, home visit observations and review of the intervention logbooks for each child, a clear pattern of priority needs emerged. Figure 6 shows the incidence of primary problems described for the child across the sample, while Figure 7 reflects secondary challenges affecting both child and household.
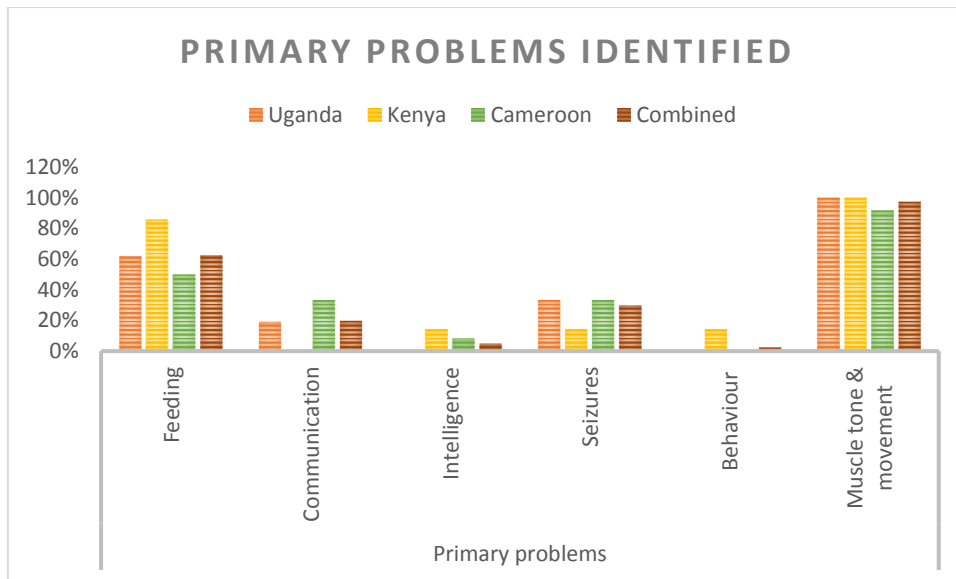
Figure 11: Primary problems identified by caregivers
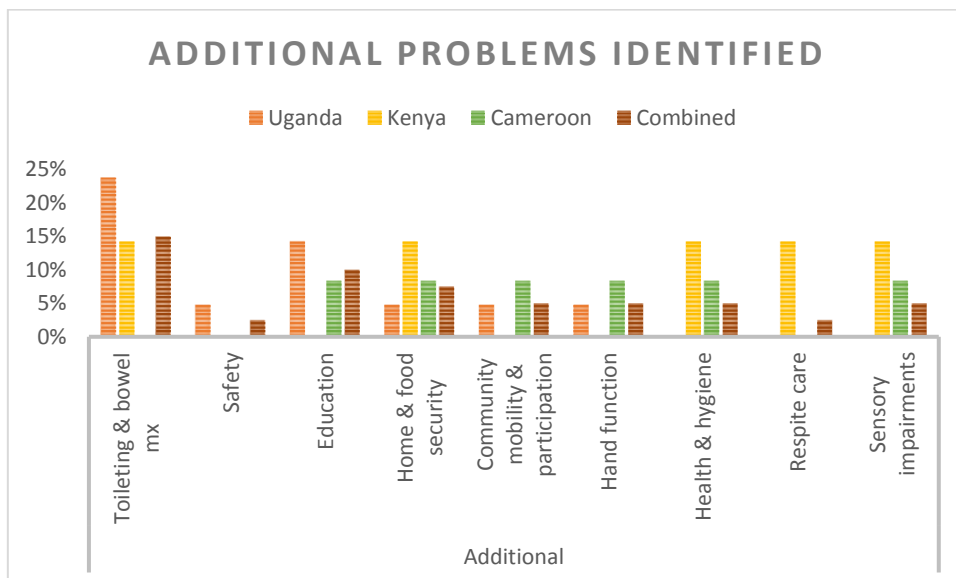
Figure 12: Additional problems identified by caregivers

Children with ND's in the moderate to severe range experience multiple impairments. While difficulties with muscle tone and movement are usually the most obvious, a large proportion also have cognitive impairment, visual and hearing problems and seizures (epilepsy). The nature and extent of these issues varies a great deal from child to child, which makes understanding and working with this group even more complex. The combination of impairments can have a serious impact on all aspects of functioning.

Most of the children visited (62%) experienced **difficulties with feeding**, because their ND affected the movements of the mouth, tongue and throat. This makes feeding difficult and often dangerous, as the child may choke or inhale food into the lungs, resulting in infection. Caregivers are faced with long and difficult feeding sessions that cause frustration and anxiety for both the caregiver and the child.

Malnutrition was unsurprisingly common, causing low energy and frequent illnesses in the children, which was costly and discouraging for families. Up to 80% of children with CP in African settings may

be malnourished (Donald, Samia, Kakooza-Mwesige & Bearden, 2014), and lung infections resulting from inhaled food are a leading cause of death for this group.

Communication is affected by both cognitive development and movement difficulties, and most of the children we saw were unable to speak. The lack of stimulation resulting from their environment was a compounding problem.

Almost a quarter of the children in the evaluation were diagnosed with **epilepsy**. In all three countries, access to anti-epileptic medication is expensive and the supply is often inconsistent. Repeated seizures result in further neurological impairment, reducing the overall functioning of the child. All three countries shared stigmatic beliefs around epilepsy, particularly that it was contagious, often leaving children with epilepsy and their families even further isolated and discriminated against.

Many of the children were unable to control their **bladder and bowel**, and some could not indicate when they needed to go to the toilet. Nappies/diapers were too expensive for most families, and this meant children often needed to be cleaned. Soiling, especially in older children, was given as a major reason why others were unwilling to look after them.

"It's not a joke, it's hard work" (Cameroonian grandmother)

All of these challenges emerged against a **backdrop of poverty**, which was almost always the primary problem identified by caregivers. While most were poor to begin with, having a child with a disability exacerbated this situation, and blocked many of the actions needed to support and care for the child. Lack of time and social support were often as much a barrier as lack of finances, and the three were closely interrelated. The needs of the child could not be considered in isolation from the needs of the family, and it was difficult for anyone to focus on 'rehabilitation goals' when basic needs were not being met. **Safety, home and food security and basic health** were challenges shared by both children and families, and the **lack of respite or day-care** facilities meant caregivers were seldom free to generate more income or look after their own health.

Introducing STEP

This is the context in which STEP has been developed and introduced. STEP stands for "Support Tools Enabling Parents" and aims to empower caregivers with the skills and supports to care for their children and enable their development at home. Trained fieldworkers visit families at home, overcoming the access barriers experienced with other services, and focus not just on the child but on the caregiver and household as well. This section has made clear how the well-being of child and family are inseparably intertwined, each affecting the other. By working holistically and directly in the child's context, STEP addresses the functional and practical problems faced by families, instead of only trying to make changes in the physical aspects of disability. While not a new approach in itself, STEP was the only such intervention we encountered in the communities visited.

Conclusion to Part 2

Not only do children with neurodevelopmental disabilities tend to be born in poorer families, but the dynamics around the condition can seriously affect family livelihoods and coping. This in turn creates an even less favourable environment for the child's growth and development, as well as for other members of the family.

Children with NDs require a great deal from their caregivers - physically, emotionally and financially. Families living in the conditions described here (typical of LMIC's where most children with NDs and CP live), however caring and motivated, have very limited resources for this care, and the caregiving system is highly vulnerable to collapse. Services and support for these families and children are few to non-existent.

These findings demonstrate clearly that the STEP approach fills an important gap in services/support for children with CP and their families in the context described. Understanding this context is essential for understanding how the intervention has unfolded and its outcomes in the pilot sites so far. The following chapter unpacks the intervention itself in more detail.

Part 3
Implementing STEP: Process and quality

The previous section established the need for STEP, and its potential in making significant differences for the target population.

In this section, we consider STEP's implementation so far, in order to understand:

1. Quality of the current implementation
2. Factors in project design and process which determine or influence quality

Working in homes: The STEP field visits
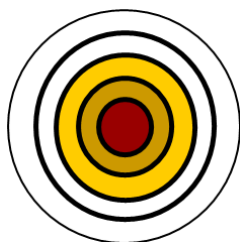
Fieldworkers

The role of fieldworkers is to be the hands and feet of the STEP project. They identify families of children with NDs and, through doing home visits, provide support tools to enable parents and caregivers. The aim is to improve the quality of life of the child and family and improve the coping and handling skills of the caregiver.

18 STEP fieldworkers were available during the evaluation process, some met on home visits and others formed part of fieldworker focus group discussions. The nature of the fieldworkers varied, including parents of CWD, CBR fieldworkers already employed within organisations, and physiotherapy assistants as well as professional physiotherapists and occupational therapists. STEP fieldworkers were selected by the PO's, usually one or two per organisation. Those who were employed as CBR workers were familiar with home visits, whereas the few trained therapists tended to be based at institutions and did not typically work in communities. The majority of STEP fieldworkers had prior exposure to CP in particular and already had some children with NDs as part of their caseload.

Selecting fieldworkers: Community workers versus professionals

A difference was noted between professional rehabilitation workers (occupational therapists, physiotherapists and physiotherapy assistants) and non-professional CBR workers (who included lay people, parents of children with disabilities and workers with other qualifications, e.g. teaching). Each group had its advantages and disadvantages in carrying out STEP.

Therapists trained as fieldworkers had the advantage of more background knowledge of ND's and health in general, but they struggled with the mental shift from clinical intervention to community-based, holistic intervention. They tended to approach home visits as therapy sessions, whereas the STEP intervention is intended to take a holistic and practical approach, focusing at the activity and participation levels of the ICF and on the environment. Non-professional fieldworkers proved better at adopting a family-centred approach and tended to be more function-focused in their goal setting. Although they generally required more coaching and support than their professional colleagues during the pilot, it was clear that the STEP approach can be successfully implemented by trained non-professionals.

Medical rehabilitation remains an important service for children with ND's, and forms part of comprehensive CBR (WHO, 2010) *(see appendix C)*. Professional rehabilitation workers are a valuable and scarce resource, and it may make more sense to retain them in their therapist roles rather than deploy them as STEP fieldworkers. They may play an important role as coaches and trainers, although this should not be expected without first training them in STEP. At present professional training in the region does not equip therapists very well for community-based work, although OT's tend to be better prepared for it, particularly in Uganda.

Figure 13: Fieldworker in action (Uganda)
Figure 14: Good relationships with both child and family are essential to fieldwork

Selecting fieldworkers: Essential qualities of a fieldworker

Internal and external factors influenced the success of the fieldworkers during the STEP pilot. Internal factors such as having passion and motivation to work with CWDs allowed them to build positive relationships with families. An appreciation for the need to develop their skills and knowledge and a willingness to learn, especially through peer learning, was found to combat stagnation of fieldworkers using limited STEP intervention strategies. External factors in their organisations and available resources affected the quality of intervention they were able to deliver *(see Part 4)*.

Caregivers were asked to describe the kind of person they would like to see as fieldworkers, and responded as follows:
- Someone with a heart and concern for children with disabilities
- Someone with training and knowledge that can teach families
- Someone with experience with CWD and their families, such as a parent of a CWD
- Someone who is trustworthy and comes prepared.

These points were echoed in what fieldworkers said themselves, and what we observed as key success factors in the home visits we made.

Non-professionals, i.e. CBR workers and parents of CWD, were seen throughout the evaluation to have the capability to provide effective STEP services provided they had the right attitude, suitable personal attributes as well as adequate support and coaching.

Summary
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.

Home visits

Home visits have been included in CBR literature as a useful means of effecting change, an approach that also facilitates insight into and scope for reaching out to the needs of families at risk as they are faced with challenges of poverty, disability and limited access to support and resources (Dworkin, 2000).

Caregivers' perspectives on home visits

Many caregivers responded positively when asked about their preference for home visits or institution-based services. Receiving home visits as opposed to travelling to a centre made a significant difference in terms of cost and accessibility, particularly for children with limited mobility. Home visits therefore reduced the financial output of the family, and many shared that the quality of services provided by the fieldworkers was better than those at the institutions as the interventions were linked to the home life and needs, and fieldworkers engaged more directly with caregivers.

For many it was more convenient to receive assistance at home, although they reflected it would be beneficial for fieldworkers to make appointments so that visits do not clash with other activities. Agricultural practices change seasonally, and this influenced whether home visits were deemed a burden; for example, during the busy farm season in Cameroon caregivers preferred being visited early morning or late afternoon, resulting in long days for fieldworkers.

Given the predominant lower GMFCS levels of CP seen *(see figure 3 in Part 1)*, changes within the child and family are slow. It was seen that it was not necessary to visit on a weekly basis as suggested by the STEP project. Fieldworkers could visit with more intensity and frequency over some periods, and then wean off for others. Telephonic follow up was also given as an option by families.

Fieldworkers' perspectives on home visits

Although resource intensive, i.e. time, transport and staff, home visits allow fieldworkers to design and embed interventions within context, thereby making them relevant and practical. Home visits has also shaped the way professionals view families by giving them an appreciation for the context from where the families come from.

"In the hospital you see the child dressed and clean. When you go to the house you see how things are. Like [child] – the first time I went there, I said what kind of thing is this? This house is almost falling down, if a strong wind can come it can fall down on these people. It's not like when they come to hospital and the mother puts the nice dresses, you see the reality of life" *(Cameroonian fieldworker focus group discussion)*

Figure 15: Home visits allow fieldworkers to see the child in context

Several fieldworkers expressed frustration of finding themselves in the position in home visits with the perceived need to 'bring something to offer'. Particularly with children with low GMFCS levels, change was slow and when intervention options were limited, both fieldworkers and caregivers ran the risk of becoming irritated with one another. Another point of frustration for fieldworkers was if expectations were created and if the fieldworkers were unable to meet these expectations, they had to deal with negative reactions from families.

Community perspectives on home visits

Home visits have bearing not only on the household but also in the community, again reflecting the ripple effect through the layers of the Ecological Systems Theory, both positive and negative.

Families feel like they are no longer alone and express that the feel they are aligned with powerful support. By seeing fieldworkers care for and support CWD, community members become more willing to engage with these families and support them. Home visits can therefore be 'humanising' towards the children and their caregivers. In some instances, having visitors has changed community perception of the child and household to the extent of adding value onto the child who brings the visitors. In Cameroon, it was shared that the fieldworkers going into the communities increases the visibility of the POs and as a result has boosted trust between communities and POs.

***"South Africa** [external visitors] **is here, other countries are here, fieldworkers are here, all because of [the adolescent]. It has made him a great man"** (Cameroonian community pastor)*

Figure 16: Home visits usually take place in the open, and foreign visitors are highly visible

International visitors linked to STEP also have an influence when doing field visits, particularly as they are a different nationality and often Caucasian. When INGO visitors go into homes, reactions from community members are much stronger than towards local fieldworkers. This needs to be borne in mind and home visits need to be done with sensitivity so that families have the opportunities to maintain positive relationships with their communities, especially if these relationships are already fragile.

Figure 17: Neighbourhood children crowd round a fieldworker and the little girl he is visiting (Uganda)

A perception is held in many communities that white people bring money which can cause jealousy between neighbours. In one case, the father of a child in Uganda withheld financial support as he believed that the child and mother were being paid a monthly stipend by the fieldworkers and backing organisation.

Ethics around confidentiality and privacy may need to be adjusted during INGO visits to keep an 'open door' appearance, reducing the risk of rumours. Visitors may otherwise find themselves unwittingly as the cause of family or community conflict (i.e. co-wives come to spy on the mother during a visit). Such visits can either strengthen and support families or render them incredibly vulnerable. However, INGO visits can also be perceived as positive, where communities perceive an added strength to the fieldworkers and that the programme represented is one taken seriously.

"To me they feel good [when visitors come], because like my best child, – when [LF] came, they added some skills to what we were doing, doing together with family – so they feel happy that there are people who come to supervise us and help us do the work better" *(Cameroonian fieldworker focus group discussion)*

Summary
The use of STEP fieldworkers visiting children and families in their homes improved access to services that are otherwise difficult for children with disabilities. By visiting in homes, fieldworkers developed a richer understanding of the challenges faced by the child and family within context and this resulted in the development of interventions that are responsive to family needs and context. A positive spinoff of home visits was a positive and more inclusive response from the community.

STEP reasoning process

The rehabilitation problem solving (RPS) process introduced to STEP fieldworkers starts with understanding the body structures and functions of the child, the activities and participation as well as the context in which they live, from the perspective of the caregiver and that of the fieldworker. Thereafter, priority needs are identified by both parties and synthesised into a single goal list with proposed action or intervention plans.

"Even if you don't know that child before, you go through the logbook and RPS process, assess them, set goals, make plans – step by step. Before we didn't really know – you go to visit, but you don't do very much, just there to check on them" *(Ugandan fieldworker focus group discussion)*

By following a structured approach, fieldworkers shared that they felt more confident when approaching families and doing initial assessments. However, within this process several challenges were raised by fieldworkers and was evident in the logbooks; these are detailed below.

ICF and STEP approach

"In the past we were not evaluating the family... Now you look at the family, how they are able to care for the child, how is their income… before we weren't going into those details" (Cameroonian fieldworker focus group discussion)

STEP introduced a different way of thinking about children, families and disability to the fieldworkers. This approach is embedded in the International Classification of Function, Disability and Health (ICF) model. The ICF does have a Child and Youth version (ICF-CY) and it is uncertain as to why this was not selected as the STEP project focuses predominantly on children and youth with neurodevelopmental disabilities. The ICF approach is laid out in the logbook as a structure to guide more holistic thinking, looking beyond the child to consider her context, including more pressing needs such as extreme poverty, acute illness and malnutrition. This approach was well received and effectively used by most fieldworkers and informed how goals were.

Assessment and identifying needs

Fieldworkers felt more equipped by their training to identify NDs, particularly CP, as distinct from other childhood disabilities, as well as to use the internationally recognised Gross Motor Function Classification Scale (GMFCS) to classify the level of impairment. However, the simplified version of the GMFCS taught to them did not afford fieldworkers the full benefit of this system, which includes predicting functional prognosis (although in broad terms). This could be extremely useful when counselling of families on expectations for the future, and to guide realistic goal setting and selection of assistive devices.

The assessment and needs identification approach as practiced by the fieldworkers we observed remained focused on the individual child, rather than being fully family centred. Few used the developmental charts provided in the training to identify developmental difficulties, set goals or plan interventions. The ICF and assessment opens the discussion for families to raise various needs, some concerning the child and others on the household. It may need to be considered how the fieldworker frames their role in order to contain the concerns and needs and manage caregiver expectations within the scope of the STEP project.

Goal setting

"The difficulty is you might see what you think the goal should be, the parents come with something else – it is difficult then to agree. Maybe the child isn't yet sitting, but the mom wants them to walk. It needs a lot of patience, and you visit maybe once a month, the mother is with the child 24/24 – if she doesn't accept or agree with you, you are wasting time. The most difficult thing is getting the parent to understand what is needed first" (Cameroonian fieldworker focus group discussion)

Translating needs into reasonable goals is crucial in directly shaping interventions but also to temper parents' expectations for the STEP services. Goal setting is a nuanced skill and most fieldworkers expressed difficulty in developing goals, particularly in the SMART (Specific, Measurable, Acceptable/Appropriate, Realistic and Timebound) format as well as in a collaborative way with caregivers. Fieldworkers highlighted the importance of caregiver buy-in and alignment of functional and household goals. This was often difficult to achieve due to different levels of understanding or acceptance around disability, and relied heavily on astute counselling skills of fieldworkers, a skill that takes time and experience to hone.

In addition, they shared that SMART goals are not only difficulty to write, but often also difficult to achieve. In the context of STEP work, factors such as time frames may be difficult to work within and will require frequent readjusting due to factors often beyond the control of families or fieldworkers. Other challenges in goal setting were also apparent. Fieldworkers (including therapists) who have little experience working with this client group find it difficult to gauge what progress can reasonably be expected for a given child, which makes it difficult to set realistic goals and timeframes. They also experienced difficulty in breaking up a major goal (e.g. sitting independently) into smaller sub-goals (e.g. maintaining upright head position, sitting with decreasing amounts of support). Finally, many fieldworkers did not know how to counsel caregivers through the process of selecting appropriate goals. Setting of unrealistic goals and then seeing no change on periodic evaluation leads to dissatisfaction and frustration on both the part of the fieldworkers and the caregivers.

Linking goal setting for the child's progress more directly to the GMFCS may assist in selecting appropriate goals and counselling caregivers through the process of choice of priority areas. The training did target two sets of goal areas, namely core caregiving skills and functional goals, which was a useful structure. It would also be helpful to address how to set goals for household interventions, (e.g. livelihood activities). Finally, the SMART format should be reviewed, and alternative approaches considered. Understanding the different steps to achieving particular developmental and functional goals would be more helpful, and assist with meaningful and realistic goal-setting with families.

Intervention planning

"When I first started working with children, we were seeing so many complex cases, I didn't really know what to do, but with this intervention, you see changes" *(Ugandan fieldworker focus group discussion)*

STEP has empowered fieldworkers to transition from a role of assessment and referral in the field, to one of intervention. As setting goals was an ongoing challenge, intervention planning also presented challenges as a result. Upon evaluation, it was evident that grading existing plans and developing future plans became difficult once the fieldworkers had exhausted the intervention strategies that they felt most comfortable with.

Examining the training workshop outlines, different intervention styles were included but mostly related to the child and less inclusive of family focus, i.e. restoring, training, adapting and coaching. This perhaps limited the scope presented in intervention planning. Additionally, support may be needed during the training or coaching in helping fieldworkers deal with the challenge of being faced with issues that are beyond their scope to manage and how to have these difficult conversations. It must be noted that, even when fieldworkers considered themselves out of their depth, the small interventions they did implement in challenging circumstances made significant differences in the lives of the children and caregivers.

Evaluation

Fieldworkers across all 3 countries were not using managing to use the evaluation sections purposefully. In some cases, the evaluations would be left out entirely, the evaluation would not be linked back to the relevant goals or one goal would be evaluated three times over on the same evaluation sheet. Only a handful of more experienced fieldworkers managed to use this as an opportunity to reflect and set new goals collaboratively with caregivers.

In Cameroon, a few fieldworkers used the Ladder of Life was used as a way of drawing out pertinent issues for the caregiver and as a way to encourage caregivers to reflect on their progress and see if there is improvement as a family, not just on a particular goal. This could be a useful strategy, as frequent, monthly evaluation of goals may be disheartening due to slow changes seen in children with

CP. By and large, the Ladder of Life was not used by most fieldworkers in Uganda, Kenya and Cameroon as numerical scales are conceptual rather than practical and are often difficult for caregivers to understand.

Summary

The STEP reasoning process (ICF and RPS) was found to be a positive strategy to provide a structure for thinking and action for the fieldworkers during planning and home visits. It encouraged a holistic view of the child and family but has resulted in difficult issues and concerns being raised that are beyond the scope of the STEP project and thereby having to manage parent expectations. Goal setting, although a simple concept, is difficult to apply well without the underlying knowledge and experience to guide ones' goals. Intervention planning was often limited to common interventions, with the question 'what next?' arising; however, it was seen that small interventions made a big difference in households. Overall, the ICF and RPS are good starting points to shape clinical reasoning and problem-solving for STEP fieldworkers.

Most common interventions during STEP visits

Frequency of interventions used by fieldworkers during home visits was extrapolated from the logbooks. A limitation to this is that not all the fieldworkers documented accurately in the logbook and therefore the intervention frequencies may differ in practice.

Interventions with caregivers
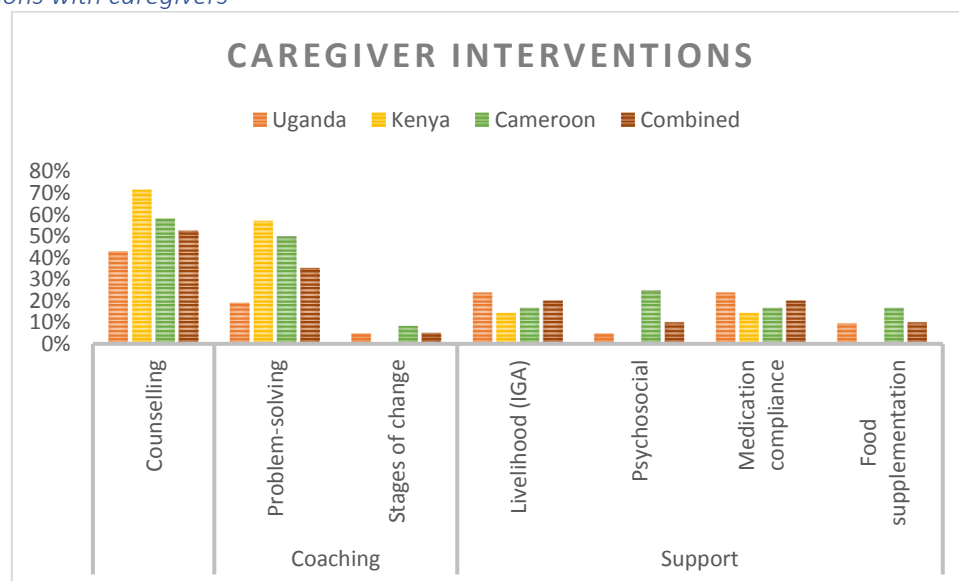
Figure 18: Common interventions with caregivers

Interventions most frequently used with caregivers were counselling (53%) and problem-solving strategies (35%). Fieldworkers also worked equally (average 20%) on medication compliance for epilepsy and livelihoods *(see figure 18)*.

Counselling tended to involve conversations with caregivers around understanding their child's diagnosis and its causes, and discussions on how that interfaces with traditional health beliefs. Some cases included conversations around difficulties faced in the family and community, such as poverty or discrimination. Fieldworkers did express that they did not feel equipped to manage these difficult conversations around stigma, traditional health beliefs and when needs exceeded their scope of practice.

Problem-solving was intended to be a collaborative process between caregivers and fieldworkers. This would involve identifying a need or problem and collaborating on exploring a solution or identifying other sources to assist in the problem. This collaboration was seen in Cameroon regarding the design and fabrication of assistive devices, where fieldworkers, caregivers and local carpenters would collaborate on creating CP chairs for positioning. The highest percentage of problem-solving was seen in Kenya (almost 60%), however this was not collaborative but rather the therapists having to problem-solve solutions to their own challenges faced on home visits.

Counselling, stages of change and psychosocial support are intimately linked and essential in developing a partnership with the family; this may require strengthening in order to become more widely used and with greater quality. Strengthening collaborative problem-solving will enable families to decrease their reliance on fieldworkers over time as they generate their own skills in personal empowerment, which would be especially important in the area of livelihood generation and its sustainability.
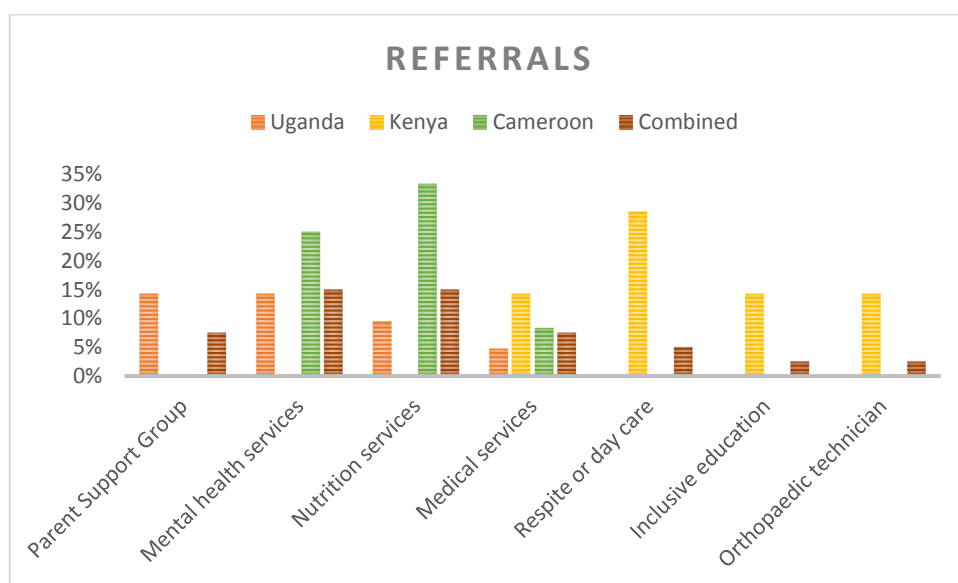
Figure 19: Common referral pathways (cf to Part 4)

Linking families to healthcare and support services is an important and familiar part of the fieldworkers' roles. Many employed as CBR workers were already assessing needs and referring to appropriate services, despite this rate of referral was generally low, at maximum 15% *(see figure 19)*. Referral sources during the STEP pilot were primarily formal supports within the healthcare (nutritional and mental health services) or education sector. However, referral need not only be to formal services. Personal, associational and community-based sources of support contribute to the overall support system and solution base of caregivers and families (Wolery, 2000).

Uganda included referrals to parent support groups, where available, as a means of assisting families to access informal and community-based support. The Kenyan sample included 'referral' to day care services although these were not readily available within the communities. Identifying different levels of sources of support as well as community-based resource mapping may be useful techniques to employ in order to shape a more comprehensive formal and informal support referral system (Wolery, 2000).

Interventions with children
Intervention selection should be directly related to the primary needs identified by caregivers and through the ICF-based assessment conducted on the initial home visits. Intervention choices are also

influenced by retention of learning from the training workshops and the number of trainings attended as well as prior training and experience of the fieldworker.

The interventions with children, although limited in range and selection of intervention strategies, largely met the primary needs highlighted by caregivers. The interventions were often reflective of what the fieldworkers retained from the training as well as what they felt confident in sharing in the homes. At times the application was generic, with difficulty in adapting intervention plans or strategies to specific or complex needs arising.

The interventions can be clustered into 4 groups: working on positioning and gross motor skills, oro-motor skills of eating and communication, activities of daily living and play, and assistive devices for positioning or mobility *(see figures 20-23)*. Once fieldworkers had exhausted the skillset, they felt confident in, the question of 'what next?' arose for both caregivers and fieldworkers.

For motor skills, passive stretches were still widely taught (40%), particularly by therapists in Kenya (71%), with varying degrees of skill and appropriateness *(see figure 20)*. Three-quarters of caregivers were taught how to facilitate movement patterns with their children, i.e. manual sitting support, guiding standing and balance and as positively, over 50% were taught how to position their children; the high rates reflecting the need of 98% of children needing tone and motor assistance *(see figure 11 in Part 2)*. These strategies alone make a significant difference in promoting function as well as reducing the risk of secondary musculoskeletal complications.

Feeding was a major concern raised by caregivers, with 63% of the children experiencing feeding difficulties *(see figure 11 in Part 2)*. Manual or device-based positioning as well as modifying feeding techniques was addressed in 40% of the children *(see figure 21)* as well as linking to referrals made for nutritional support *(see figure 19 above)*.

Toileting was raised as a concern by parents in 15% of the sample, with it addressed in 10% upon home visits *(see figure 22)*. This is an area that requires further strengthening as the methods suggested to families were not always appropriate to the level of functioning. Play was introduced in a third of the families, this includes encouragement of caregivers to promote interaction with peers and other adults.

In terms of assistive- and mobility devices, almost 40% of the children were assisted with specialised chairs that accommodated their difficulties with postural control *(see figure 23)*. In Cameroon these were not supplied by the fieldworkers, but they advised families on the design. In Kenya and Uganda, chairs were manufactured at in-country workshops and then given to families. A third of children received wheelchairs which greatly assisted with community mobility and participation as will be explored shortly in the 'changes in the children' section. The provision of assistive devices will be discussed in more detail in Part 4. There was still a high prevalence, particularly in Kenya, of using orthopaedic devices to attempt to remediate neurological conditions *(see figure 23)*. How the intervention set can be developed further, refer to Part 3: Training and Support Tools. For further details on the child-specific interventions, refer to supplementary technical document *(see appendix D)*.
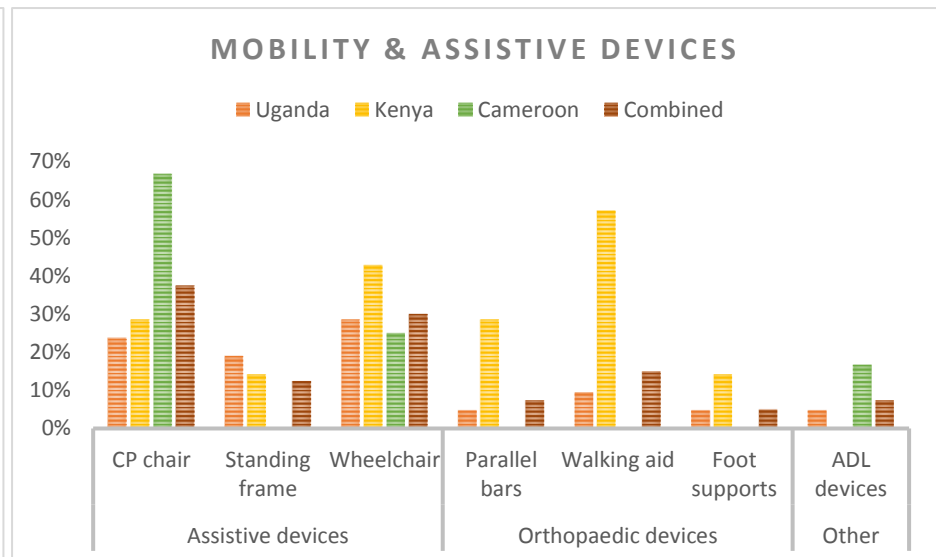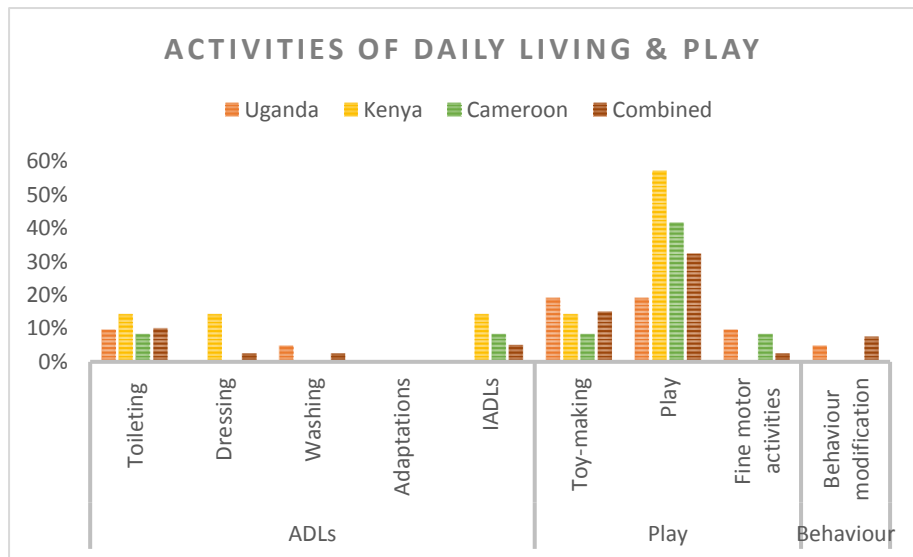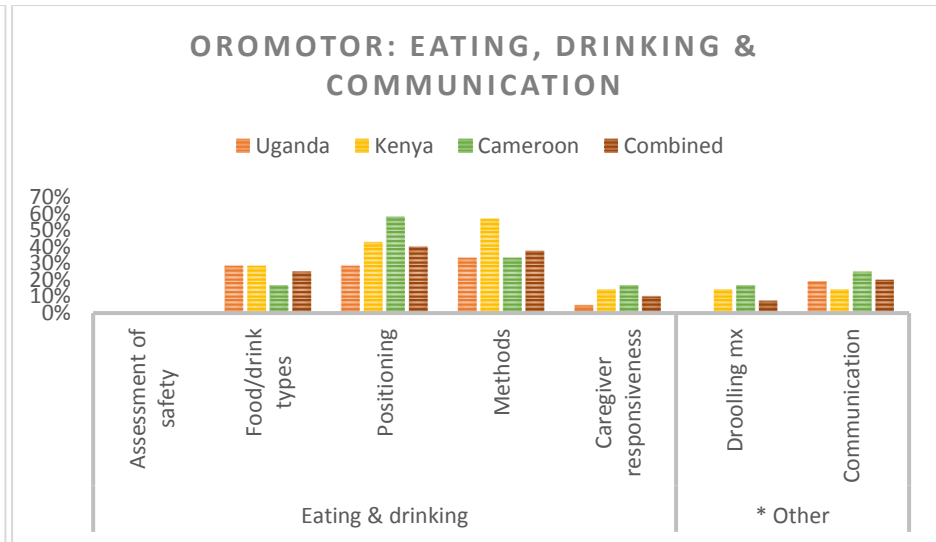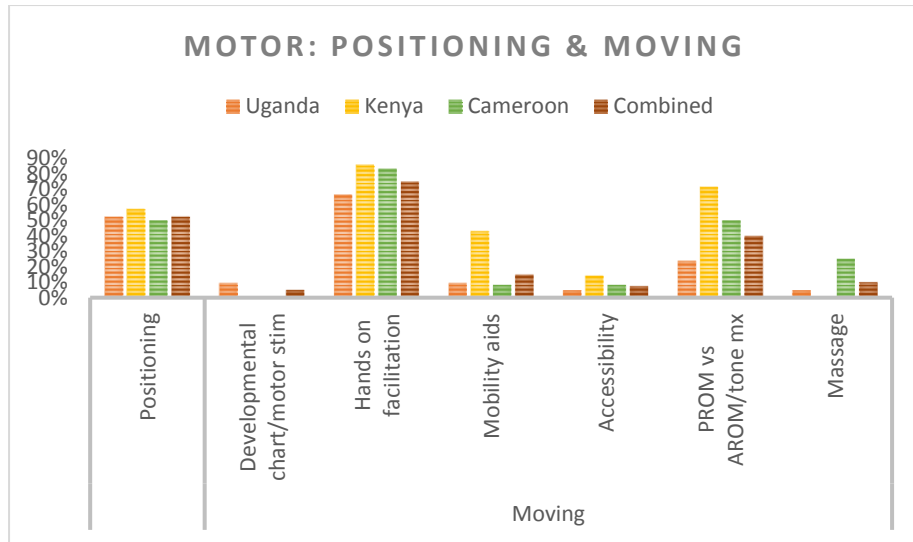
Figure 20-23: Common interventions with children

Changes in the child that are important for family
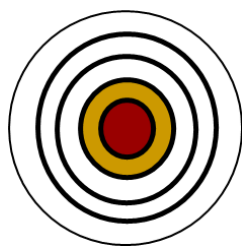
Even without significant increase in independence or physical function in the child, small changes could make a big difference to the family. Against a backdrop of almost no previous input or support, we saw often quite dramatic results with small interventions.

Feeding & nutrition

Improved positioning, feeding techniques, food types and dietary adjustments made big differences in this area. Changes varied from a child becoming independent in feeding herself, to improved speed and reduced choking. These changes not only impact the health and wellbeing of the child, but allows the time usually spent on feeding to be utilised in other ways in the home.

Nutrition was also addressed, with education to caregivers on providing balanced diet using local foodstuffs, even for children who could only manage soft food (e.g. mashed bananas, maize porridge, silver fish). Some families received short-term nutritional supplementation in the form of local foodstuffs they could not otherwise afford to buy, usually while IGAs were being established. Severely malnourished children were referred to nutrition services, and some placed on medical supplementation programs. Along with feeding, some fieldworkers addressed household and cooking hygiene which reduced the rate of illness in the children and family members in the cases seen.

Seizure management & access to medication
"Now that the seizures are more controlled, life is positive" *(Ugandan grandmother)*

Through the STEP pilot, caregivers expressed an increased awareness and understanding of epilepsy, assistance in accessing medication and as a result reduced discrimination and improved engagement and functioning of their child. Many families found the cost of epilepsy medication a barrier, and assistance with procuring or paying for the drugs (e.g. through CEP) was hugely helpful.

Some children needed referral to a doctor or nurse as they had either never been diagnosed, or not successfully medicated yet. Finding the right drug and dosage for a child, with minimal side-effects, can take time and persistence, and caregivers need information and encouragement (and sometimes financial support) to follow through with this process.

When seizures were controlled, there was often dramatic improvement in the child's posture, alertness, communication and interaction. This gave parents more hope. Stigmatic treatment of both child and family reduced significantly when the child was no longer fitting frequently.

Sitting
"Now he is able to sit outside in his chair, other children come and play with him and I am free to do other things during the day" *(Ugandan mother)*

Most children not sitting independently (GMFCS IV-V), were most often either carried on the caregivers' back or lain on a mat or bed. Wanting their child to sit was one of the most common goals expressed by caregivers, and fieldworkers helped with strategies for supported sitting using available materials (e.g. chair cushions, jerry-cans), and where possible with a wooden chair designed for children with CP.

Figure 214: In this communal compound yard, this chair allows a little boy to be part of the neighbourhood while his mother does chores

Proper positioning helps with the development of trunk and neck control, which are the foundation for vision, communication, use of the hands and almost all functional activity and participation. Being upright rather than lying down also allows a child to be viewed as a child and not 'a lump' or 'baby', and she/he therefore gets treated differently by family members.

Mobility

Assistive devices, particularly mobility devices such as wheelchairs, improve the opportunity and ease for household and community mobility. The wheelchair allows children to be pushed out in the community, interact with different environments and people and leave the confines of the home. Whilst the child is in the wheelchair, the caregiver is also freed up to take on other activities.

"Before STEP I had to carry the child, when I was tired I had to put him down; but now with a wheelchair I am able to move him easily and it gives me the chance to do other things in the day" (Ugandan grandmother)

One adolescent with cerebral palsy (GMFCS V) expressed that having a wheelchair has allowed him to control his arms and hands more and allowed him to join in at church and visit friends in his neighbourhood more easily. He is assisted by his 'driver' (a younger boy from his family) who ensures he is seated correctly and pushes his wheelchair for him. Personal mobility through an assistive device has greatly improved his postural control and participation within the community.

Communication

"He is more responsive and 'communicates' more with me now" (Ugandan mother)

Children with a GMFCS level IV and V often present with difficulties in expressive and receptive communication, with familiar and unfamiliar communication partners. Difficulties in facial-, oral- and gross-motor control reduces the use of facial expressions, gestures and sounds or words as means of communication. Most children use only crying as a means of communication. For many caregivers, the limited communication is a source of frustration in not being able to understand if their child is in pain, is affectionate or has a particular need.

Through simple intervention strategies, such as positioning in sitting, directed communication and increased opportunities for interaction, improvements in communication with familiar partners was noted. This was a huge source of encouragement for caregivers, strengthening their relationship with the child and stimulating other family members to engage more with him/her as well.

Ability to participate

The combined effect of these different changes was to increase participation of the children in their households and sometimes in the surrounding community. When caregivers' mental health and confidence improved, they were also more willing to take their children out (where this was possible), instead of leaving them inside the house. In some cases, this had an effect over time of reducing caregiver isolation and increasing acceptance and support from the surrounding community. Where this virtuous cycle was set in motion, it promised lasting improvements in quality of life for both the child and the family.

The most significant change shared by the caregivers, was that of participation. This aligns with the one of the original aims of STEP to focus on shaping the 'activities' and 'participation' areas within the ICF (Liliane Fonds, 2018). The use of assistive devices such as specialised chairs, wheelchairs and improvement in motor function resulted in the ability of their children to participate more actively within the home and community environment.

"[Child] enjoys going to church now, particularly the singing" *(Kenyan mother)*

Using positioning and mobility devices, children have the opportunity to participate in a wider number of contexts. The grandmother at a home in Kenya shared that her granddaughter likes her wheelchair and now other children can wheel her around, she feeds better in the chair and she can now go with the grandmother to the market, to fetch water or to support group meetings.

Upright posture together with increased interaction with others may contribute to an improvement in neurological and functional abilities. The child at a home in Cameroon gained functional use of her hands as her trunk and legs were stabilised in a CP chair. She is now able to participate in activities, such as washing her legs, feeding herself and helping to prepare vegetables. Another caregiver shared how her daughter is now able to help sweep the yard and wash dishes, even though the quality is not as good*.*

Changes in the caregivers
Socio-emotional support
"You are the only family I have" *(Cameroonian mother)*

Socio-emotional support for caregivers of CWD is often limited, reinforced by isolation and discrimination. Caregivers share their experiences of accessing support through STEP fieldworkers as well as the parent support groups (where available). Fieldworkers helped caregivers feel cared for and listened to, feel like they have not been abandoned and that they and their children are accepted as they are*.*

Understanding and acceptance of the child
"[Child] was initially taken to witchdoctors as they believed that witchcraft had caused her disability. Now they 'got the light'" *(Ugandan fieldworker)*

Through repeated education and counselling, caregivers come to a more accurate understanding of NDs, and as a result, attitudes and practices towards their child change. In some cases, there was a shift from a traditional health belief, i.e. witchcraft to a biological perspective which influenced the access to healthcare. A different understanding on the condition allows caregivers to realise that a disability is not a punishment and is not their fault, which reduces feelings of guilt, self-blame and in turn impacts caregiver mental health (also found in research by Zuurdam et al., 2019).

"We see change in how families treat their children, impact on the whole family. As the child changes, even small things, they are treated differently [more positively]" (Ugandan fieldworker focus group discussion)

Sensitisation in households and communities also encouraged caregivers to acknowledge their CWD and started to reduce the practice of 'hiding' CWDs. This is the start of improving inclusion in the home and community context (Booyens, Van Pletzen & Lorenzo, 2015).

Increased ability to provide for family

High levels of income and resource poverty was common amongst many families visited. Through STEP, some families were able to access resources for income generation activities (IGAs) through which they could generate an independent source of income to support themselves and their families. Caregiver stories are telling: one Ugandan mother shared how she used to have to wait for her husband to find odd jobs and bring food home, now having a small business (brewing local beer), she is able to provide for her child. This sentiment was echoed by numerous families and the impact of IGAs on families included changes in overall nutritional status of CWD as well as ripple effects within the family, such as being able to afford the school fees of other siblings in the home.

Confidence and skills in caregiving

Empowering caregivers with skills to care for their child was valued, fostering their own ability to 'help'. Caregivers expressed their appreciation at being provided the skills with which to help their children themselves. The impact of providing for their child's special needs has improved the child's condition (e.g. less crying, feeling better) as well as caregivers' wellbeing (e.g. getting more sleep). This change is central to the concept of STEP and creating sustainable change in homes through empowered caregivers.

Changes in the community
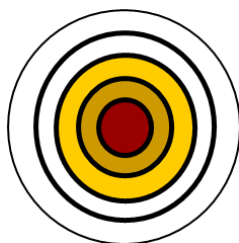
"And when you go to field you get to meet other children – people will tell you, there is another child here…" (Cameroonian fieldworker focus group discussion)

As a result of STEP, there has been an increased awareness and acceptance of CWD and their families in various communities. Community members observe home visitors going to the homes, and now see that children with NDs are valued and cared for. As a result, attitudes have changed from isolating families to promoting inclusion. This was commonly seen in rural communities, where people within compounds and villages would know one another. In urban areas, people lived in more isolation and neighbours often did not know one another well. Over time, in all 3 countries, it was seen that communities and families would start identifying other CWDs for fieldworkers to connect with.

Figure 225: Caregivers share experiences at a focus group discussion

Summary

Overall, the STEP intervention has positively influenced most caregivers' perspectives on and view of their children, improved their mental health and allowed them to hope for change. Caregivers have grown more confident in how to handle their children and has resulted in seeing changes in their child's abilities and potential. Small interventions have made significant changes in the function and quality of life of the children. And there has been a positive spinoff effect in some communities.

Fieldworkers feel more equipped to provide home-based intervention although still require support to deal with goal setting and having difficult conversations around scope of practice and managing family expectations. There is a need to continue extending their knowledge to enrich their practice in homes.

Gaps and challenges in fieldworker practice

Gaps in fieldworker practice was identified by the fieldworkers themselves as well as observation of unmet needs. Areas that raised questions or difficulties during home visits were also considered. Five main challenges to fieldworker practice emerged:

1. Having difficult conversations
2. What next?
3. 'Giving' versus 'doing'
4. Barriers to an empowering relationship
5. Supporting parents: beyond the fieldworker

Having difficult conversations

At times, expectations from caregivers or needs arising during assessment, are greater than those that can be managed by the fieldworker. Many did not feel equipped to manage these situations or how to set out boundaries of their scope of practice. Additionally, high risk situations arising, such as risk of mercy killing or suicide, would require delicate conversation from fieldworkers. Being empowered with counselling skills on how to navigate these situations would allow fieldworkers to intervene in a meaningful way, be it referrals or engaging in more directed collaborative problem-solving.

What next?

"The problem of the severely disabled child [...] – you've given assistive devices, addressed feeding, now what? Not even sure what to do when you visit – you feel stupid, mothers start to realise you don't know what to do. You find you don't want to go back there. You ask the mother, what does he like? She says yoghurt, milk – so you end up taking him food, because you don't know what else to offer." (Ugandan fieldworker focus group discussion)

The question of *"what next?"* was raised by fieldworkers in all 3 countries. Change is evident through the course of the logbooks in how caregivers' hopes, and expectations evolve, gradually becoming more realistic, and more subtle. However, fieldworkers reflected that they felt 'stuck' or limited in knowing what to do after they had covered the basic interventions in a home. On occasion they feel forced to continue frequent visits when it may be a waste of time for both parties when they do not know what else to bring to guide caregivers. This highlights the importance of coaching, but also perhaps assistance in more 'concrete' progression of goal setting, i.e. level 1 (feeding, positioning), level 2 (play, dressing).

'Giving' versus 'doing'

The concept of 'giving' was seen commonly in the STEP home visits; such as nutritional support, epilepsy medication, assistive devices as well as IGA or economic assistance. It appeared as a means to 'fix a problem' even on occasion where it was not warranted but the fieldworker may not have known what else to do. 'Giving' was relied on as opposed to coaching and collaboration with

caregivers. Although there were significant gains in many of these households as a result of the products, it should be complementary to the main STEP activities and not the main activity.

'Giving' leads to a change in relationship and dynamics between families and the donors (represented by fieldworkers and POs). The expectation of receiving may shift responsibility onto the fieldworker or organisation and may result in caregiver passivity. The idea of STEP is to shape empowered caregivers that can play an active role in their child's care and development. Without this aspect of empowerment, fieldworkers become benefactors which is problematic.

"Parents may be willing to take what's given but do nothing themselves – they shift responsibility for the child onto NGO's – YOU must do something, it's YOUR child now" (Ugandan PO manager)

'Giving' also changed expectations in some settings, at one site, caregivers were assisted with medication for epilepsy, but then also wanted it delivered to their homes. Thereafter more families became *"demanding and dependent" (Ugandan PO manager)* as they deemed solutions to be being given resources, rather than changes they can make themselves.

The impact on the relationship between the fieldworker and family can be disrupted when resources or IGA interventions are delayed, leading to frustration and mistrust. In some organisations, the rationale behind distribution of financial resources per family was unclear. Rather than a budgeted, equitable approach towards financing, there was ad hoc responses to family in need. This resulted in inequitable expenditure of allocated resources and rapid depletion of the funds. Criterion on which to base 'giving' may also benefit from being clearer, i.e. *who* qualifies for nutritional supplementation and for *how long*; *who* qualifies for IGA support and to *what* degree.

Barriers to an empowering relationship

Lack of confidence in the material learned during the training, and limited reference material to support them to recall additional learning, at times lead fieldworkers to feel like they were unable to do quality work in the homes. Supporting their continued learning through references resources and coaching would be beneficial. Building an empowering relationship between a coach and fieldworker could serve as a model of what is to be shaped within a home visit.

Supporting caregivers: beyond the fieldworker

"I often felt like I was the only person to carry this burden of a child with a disability, but through the group I now realise that there are other mothers like me too" (Cameroonian mother).

A few of the organisations were running or piloting parent support groups *(see table 2)*. Through the evaluation, it was noted that the parent support groups had significant value, most importantly in the area of the mental health of those attending. Caregivers in a Ugandan parent support group reflected on positive changes in their mental health through being able to support one another and reducing their sense of isolation, to share their stories and feel heard, share experiences and problem-solve parenting challenges and as a space to learn (also found as results in Zuurdam et al., 2019). There was an overall expression of improved mental health from states of depression and suicidality to acceptance, hope and action.

The other useful focus of the support groups, highlighted in particular in Kenya, is that of income generation support and a communal savings group. Some groups were evidence that financial empowerment happens in this group, and that it can be a means of counteracting the 'handout' practice.

EXISTING PARENT SUPPORT GROUPS			
	Facility	**Organised by**	**Focus**
Uganda	UNAC	UNAC	Education
	NRC	STEP fieldworker	Disability & livelihood
Kenya	Sisters of Mary	Sisters of Mary	Parenting
	Ywaya group, Sigomere	Teacher with a disability	Livelihood
Cameroon	CBC Yaounde	STEP fieldworker *Started before STEP	Education & livelihood
	CBC Ngounso	STEP fieldworker	Pilot stage

Table 2: Existing parent support groups per country

However, establishing, running and developing leadership within a parent support group requires skills in group handling, community advocacy and others. Fieldworkers expressed a desire to gain basic skills to enable them to establish and run parent support groups as they recognised the inherent value for parents.

"...[T]hey just want us to be doing things for them. It's very challenging, I need help with how to do that" *(Cameroonian fieldworker focus group discussion).*

Some challenges of parent support groups presented were that an expectation of being given resources had been established in some areas and fieldworkers found this a challenging attitude to navigate. Numerous caregivers expressed the idea of training people from the parent support group to run a day care that would be inclusive of their CWDs.

Summary
The role of the fieldworker to create and manage an empowering relationship with caregivers, so that they in turn can coach and empower their children to live their best lives. Barriers to developing empowering relationships should be addressed to support fieldworkers in the work they do.

Training & support tools: Building fieldworkers' capacity

STEP Training
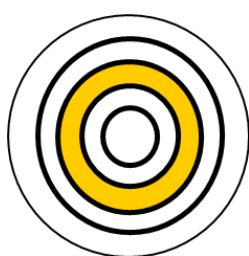
Training overview
Three regional training sessions were conducted over the period of a year, with each structured around training timetables that are available, with lectures interspersed with practical lessons. Children with CP and their caregivers were brought in during the training to serve as case studies. The lack of trainer or participant manual made it difficult to determine the content of the training in order to accurately compare with the practice of the fieldworkers post-training.

The content of the first 5-day training covered the STEP approach and its tools, material to promote an understanding of neurodevelopmental disorders, the ICF and the process of assessment, goal setting, intervention planning as well as practical intervention strategies on communication and mobility (positioning and moving). Additional support skills were also added into the training which would enhance the participants' work with children and their families, such as counselling and coaching. The training was grounded in the ICF approach but was not integrated into the CBR matrix which is the role of many of the fieldworkers. It was difficult to ascertain the exact content of each module as most sessions said, 'session not ready yet'.

The second 5-day training included a number of master classes covering additional skills around eating and drinking, the 4 steps of the rehabilitation cycle, and the measurement of assistive devices. Shorter sessions on nutrition, epilepsy, challenging behaviour and meaningful activities were included.

The final training workshop, only 2 days, reinforced concepts around assessment, classification and goal setting as well as explored more about counselling, functional activities, adaptation of assistive devices and epilepsy management. Those relating directly to identified needs have been highlighted in the table below. The logbook and STEP tools will be discussed further.

INTERVENTION MODALITIES			
	Training workshop 1	**Training workshop 2**	**Training workshop 3**
1	Understanding NDs		
2	ICF model of disability		Identify, assess & classify
3	Home visits	Sharing experiences	Way forward
4	Counselling & coaching	Counselling	Counselling
5	RPS	4 steps of rehab cycle	Priorities, goal setting
6	Communication		
7	Mobility: positioning & moving		
8	Psychosocial needs	Challenging behaviour	Hyperactivity & cognitive development
9	Health & wellbeing	Nutrition, epilepsy	Epilepsy management
10	Play & leisure	Play & meaningful activities	
11	Eating & drinking	Eating & drinking masterclass	
12	Self-care		Functional activities
13	Tools: RehApp, Portal		Tools: Logbook
14	Carer2Carer PSG		

Table 3: Intervention modalities outlined in training programme

Due to the political crisis and instability in Cameroon, those whom had been trained in the western region, had to relocate services out of that area and in so doing had to train a new cohort of CBR workers and physiotherapy assistants to initiate STEP in a new region. Those who had attended the original training, were able to run a similar workshop and transfer the skills and knowledge to the new cohort with good outcomes and a similar quality STEP fieldworker emerged.

Integration and application of training
During fieldworker focus group discussions, review of the logbooks and observations during home visits, the most commonly used and remembered aspects from the training workshops were detailed. The emerging needs following the application of training can be clustered around four main themes:
1. Training over time
2. Contextual problem-solving
3. Andragogy or adult learning
4. Working with communities

Training over time
The basic syllabus provided a foundation for fieldworkers from which to work, which was supported through coaching. In Cameroon, success was noted in responsive training thereafter, with short workshops offered to address emerging needs.

Contextual problem-solving

The introduction of the ICF and RPS provided structure to the thinking of fieldworkers during home visits, however, the abilities to reason, adapt and apply in vivo still needed strengthening, much of which will occur over time. Developing critical and contextual problem further would be best facilitated through facilitated peer networks and coaching from those familiar with the context.

Andragogy or adult learning

Many fieldworkers found the transition from training and theory to going into the field to apply the learning a daunting endeavour. Adapting the training programme to provide opportunities for supported practice, observing others in action and consistent coaching may alleviate this stress and improve confidence. Shaping learning around andragogical or adult learning principles and multimodal methods of learning may enhance integration and application.

Working with communities

Adopting a holistic, ICF-based approach to STEP training has allowed fieldworkers to consider the child as part of the family system. In order to adequately support families, one also needs to consider than families are embedded within communities. Actively training fieldworkers in community skills, such as community advocacy, resource mobilisation and accessing community-based resources will assist in addressing family needs within a larger network.

As an example, in a village in Cameroon, the fieldworker together with the caregiver had approached the community's church leader about wheelchair accessibility. The church leader had negotiated with church members to widen the doorway of the church to allow wheelchair access and had asked the village to build mud ramps at their doorways ensuring one of the adolescents part of the STEP project could participate in church and visit his neighbours with greater ease.

This needs to be a more conscious part of training that will inevitably link with advocacy and barrier removal for families. Some problems facing families can be addressed by using the community to drive change.

Recommendations for training

Training design and andragogy

Training programmes need to be designed to promote learning of content across a wide variety of learning styles and prior knowledge held by adult learners. Training packages need to reflect both content and adult learning pedagogy.

The design of the training needs to bear in mind the worldview in which the fieldworkers and families are embedded. This would require the training to be mouldable around the contextual understanding of disability and other traditional health beliefs. African cultures, in broad strokes, tend to adopt a different time orientation and approach to human agency than Western cultures, as well as often relying more heavily on narrative approaches to situations than analytical or principle-based approaches.

Additionally, practical considerations to bear in mind when developing the training include the language, level of literacy and orientation to written documents as well as the daily life demands, such as time, resources and competing demands that may influence the fieldworkers in the STEP programme.

At a point of considering up-scaling, training manuals (both trainer and participant) would be beneficial in ensuring a 'standardised' approach and quality to the STEP training methodology and content, yet that can still be adapted for contextual fit.

Many of the fieldworkers retained and used only a small selection of the training workshop content *(see above)*. It was shared that a series of workshops to upgrade skills for STEP would be beneficial so that participants could learn, practice in the field, assimilate, reflect on and integrate each skill set. Adult learning principles proposes that it is useful to build on existing mental frameworks and schemas (Collins, 2004). Layering and structuring the training as a series, could also serve as a way of gradually upgrading the fieldworkers' skills that can spill over into the homes and address their concern for "what next?".

Recognition of training and learning promotes confidence and allows fieldworkers, where necessary, to use the recognition, i.e. certificate with transcript of basic learning outcomes, to apply for work elsewhere.

"What I would love to happen – if they can empower us – certificate that reflects what we are doing, to present what we've learnt, been trained in" *(Cameroonian fieldworker focus group discussion)*

Different levels of training
Consideration to structure the training at different levels was touched on by different sources, from caregivers to managers. By tailoring training to different layers of role players within the conceptual framework, the STEP training could be more user specific and targeted, thus improving uptake and retention of information. Different levels to consider:
- Parent support group
- Fieldworkers: multiple short courses
- Coaches or therapists
- Organisational level

Further discussion on orientation of training at each level is available in the supplementary technical document *(see appendix D)*.

Trainer selection and development
Trainer selection is critical to the process of translating information and skills into the worldview, cultural and overall context that the fieldworkers will be working in as well as pitching the training to different levels of expertise and experience. The STEP programme should ideally consider a 'trainer-of-trainers' (TOT) approach to encourage the development of locally based skills and in-country retention of skills, supporting "Africans training Africans for Africa" (Donald et al., 2014: 7). This will promote strengthening of countries as well as provide LF a way of potentially having a more support-only role in future. The advantage of locally based trainers, apart from skills retention, is that they should have a richer understanding of local context, challenges faced and how to work with local partners.

Strengthening content
The training programme already contains a good range of approaches, theory and practical skills. Through the evaluation process, it became evident that some of those areas may gradually require strengthening, either in the existing training programmes or in future, iterative workshops. Examples of some areas are highlighted below, but for a full discussion on areas to be strengthened, please refer to the supplementary technical document *(see appendix D)*.

Stigma and traditional health beliefs

Fieldworkers expressed that working around stigma, discrimination and traditional health beliefs posed a challenge to their efficacy within households. Equipping fieldworkers to understand the beliefs and perceptions held by caregiver's will enable them to select their approach on counselling and intervention in the household (Patel et al., 2017). Incorporating therapeutic education strategies could empower fieldworkers to negotiate complex issues around stigma and beliefs, within their own belief set and those of the families they work with. The Health Belief Model is a framework developed to understand and explain beliefs and behaviours linked to health conditions (Patel et al., 2017); although with critical conversations around cultural sensitivity and relativism, could empower fieldworkers with strategies to think about and navigate the complexities of health beliefs.

Caregiver mental health and high-risk social situations

Without caring for and supporting the mental health of caregivers, it is difficult for them to provide care and support for their children with disabilities. Almost 78% of caregivers of CWD in the African context struggle with depression and anxiety (Zuurmond et al., 2019). Fieldworkers, as initial contact healthcare workers, serve as the front line in the identification of mental health concerns in caregivers of CWD, including risk of abuse, suicide or mercy killing. Offering immediate support in those situations is vital, such as counselling or managing internal and external psychosocial stressors, but above all, having the resources to link caregivers to appropriate referral and follow up services.

Caregiver coaching

Coaching caregivers is essential in building and maintaining an empowering relationship between fieldworker and parent and to ensure that they are given the skills to help or support their own children. Coaching strategies taught in the training were used in part by the fieldworkers but may need to consider narrative approaches in addition to the more psychotherapeutic approaches used.

Community mapping and referral

Giving fieldworkers the skills to map their local community to better understand local, informal referral sources will allow them to reduce the burden of what they have to provide through linking families to other support sources (Sharpe, Greaney, Lee & Royce, 2000). These informal sources could include religious leaders, senior community members, tribal chiefs, experienced mothers, etc.

Supplementary content

It is recognised that some of the STEP fieldworkers were previously trained as CBR workers and have therefore obtained basic training in primary healthcare identification and referral. However, the STEP pilot has included therapists and laymen as fieldworkers, and if it is considering using fieldworkers with no prior training in healthcare or CBR, it would be beneficial to add these facets into the STEP package as they have direct bearing on the health and wellbeing of children with NDs.

Topics such as hygiene or basic health education could even be linked to established programmes, for example the WHO Integrated Management of Childhood Illnesses (IMCI) and the corresponding WHO IMCI Household and community component. Additional training content can be found in the supplementary technical document *(see appendix D)*.

Continuous and responsive training and learning

It remains crucial for fieldworkers to continue to build their skills and encourage a practice of lifelong learning. Many fieldworkers were eager for more skills and knowledge and reflected on the benefit of continuous learning opportunities. Determining human resources within POs and SPOs to host training workshops or provide input on various topics will be useful to promote the "Africans training Africans for Africa" (Donald et al., 2014) philosophy and strengthen locally based skills.

Summary
The STEP training has given a basic foundation to fieldworkers in working with children with NDs and their families. It was difficult to evaluate the training comprehensively as no formal manual was available. The practical nature of the workshops was useful, but addition of reference material to refer back to whilst in the field would be beneficial. Training may benefit from being restructured towards a more adult learning pedagogical approach and trainers and content need to be contextually relevant and adaptable. Iterative and ongoing training, structured to meet the needs of stakeholders at different levels, would transfer knowledge and skills in tailored ways to each unique audience.

Other support tools

Despite STEP being named Support Tool Enabling Parents, the primary package of 'tools' provided were for fieldworkers and not parents. These tools included a logbook, an application designed by Enablement for smart mobile phones, RehApp, a portal on the Liliane Fonds website as well as a WhatsApp group per region.

Logbook

The STEP logbook has been through several design iterations, but essentially serves as a means for fieldworkers to frame and record assessment and intervention with a child and caregiver during the STEP process. The logbook is retained by the caregivers, a method that reinforces the responsibility of the caregiver for their child's health (Dworkin, 2000). In Cameroon, this practice is widely used for all healthcare records and therefore STEP fits in to the existing culture of parent-held records. An added benefit of keeping the logbooks in the home, is that it may prevent repetition of services particularly in geographic areas where fieldworkers' service domains may overlap.

It was found that caregivers seldom read the logbook, rather store it safely and retrieve it only at the following visit. This was due to the varying literacy levels, unfamiliarity with different languages and time.

"It's not in our culture, mothers don't have time to read. If you give them a booklet, they will put it there [in the suitcase, on the shelf] – then when you come back again it will be in the same place, they will show you they still have it but never used" (Ugandan fieldworker focus group discussion)

A negative reflection from the fieldworkers on logbooks being left in the homes, is that in order for them to do future planning or reporting, notes that are written into the logbook have to be rewritten into their own notebooks during the home visit, a time-consuming practice.

The logbook was reported to be useful in creating a structure to follow during the home visit, to link assessment, goal setting and intervention planning to the ICF.

"Every time you go, start with evaluation from the previous visit, helps you to focussed on the plan or goal, so you are following things up and seeing them attained" (Cameroonian fieldworker focus group discussion)

The evaluation section of the logbook was not used to its full potential and was either skipped out or evaluations poorly related to goals was written. As progress is slow, evaluations on a monthly basis is not feasible and the use of Likert-style faces was not always easily understood by caregivers.

RehApp

See: http://www.enablement.nl/index.php/176/RehApp_a_tool_for_fieldworkers_who_work_with.html

LF proposed the creation of 2 apps, one assessment app and one intervention app (Liliane Fonds, 2018). To date, only 1 app is available. RehApp is a tool that can be used by fieldworkers and professionals to guide thinking and provide some information pertaining to cerebral palsy. The app gained mixed reactions from fieldworkers; but they agreed that it was a tool to be used by fieldworkers and that not user friendly for caregivers. This was primarily due to the app being text heavy and with few pictures. Available in English only, the language may present a problem if fieldworkers are not literate or have a low literacy in English.

In Cameroon, the app has assisted in goal setting and intervention planning, particularly for more complicated cases and is therefore assumed to have been designed to serve as both assessment and intervention app. An advantage was that it is available offline, however it does require a smart mobile phone that not all fieldworkers have access to. Feedback from fieldworkers also included that it is difficult to navigate and therefore difficult to access solutions or ideas quickly in the field, as a result, those who do use the app, use it mainly for planning prior to visits or only use one section of the app (What can you do? > Action > Attention points).

STEP Portal

See: https://connect.lilianefonds.org/step/default.aspx

The STEP portal was designed to make resources available to fieldworkers and organisations implementing STEP as well as be a means for the former plus caregivers to access professionals and 4 Dutch rehabilitation centres (Liliane Fonds, 2018). None of the fieldworkers (nor caregivers) in the 3 countries evaluated made use of the portal. They reported a number of limitations:
- Limited internet expensive due to network
- Limited access to smartphones or computers
- Internet data is expensive
- Portal was too complicated
- Not aware of its existence

For caregivers in rural areas the above limitations apply to an even greater degree. Use would also be limited by lower rates in literacy – English language, reading and writing, and computer literacy.

WhatsApp

Each region (Lake Victoria Region and Cameroon) established a WhatsApp group following the first training workshop. The fieldworkers, representatives from POs, African coordinator and training mentors had group membership. Through fieldworker interviews and an analysis of a year's worth of WhatsApp conversation history, it was found that the two regions utilised this tool rather differently.

Lake Victoria group: April 2018 – May 2019, 13 pages
Cameroon group: June 2018 – May 2019, 44 pages

Lake Victoria Region

The expensive data and high taxes for data use in the Lake Victoria Region (LVR) reduced the use of WhatsApp amongst fieldworkers – ***"to hell with WhatsApp!"*** *(Ugandan fieldworker focus group discussion).* The network is unreliable, particularly away from urban centres and WhatsApp can only be operated on smart mobile phones, which are not always available or break easily. The LVR group expressed frustration at the slow and inconsistent responses from the WhatsApp group members and instead found it easier and more reliable to contact individual members directly with specific queries.

Finding a common language can be a problem on groups, as some fieldworkers may have lower literacy, particularly in a second language.

On analysis of the WhatsApp conversation history, the LVR group tended to offer superficial support with only 2 incidents of requests for input on cases. When questions were raised, the mentors on the group would respond on the same day and it was a means of sharing additional resources from Liliane Fonds members, although there may be limited downloading of resources due to data restrictions.

[18/03/2019 12:10:07] Kenneth Nangai: Everyone is so quiet on this group can you please share on this platform on your successes challenges with a picture story or video? Thanks in advance

Cameroon

The Cameroonian group was more active in their discussions, both case-related and social support. This was reiterated in the Cameroon fieldworker focus group discussions, that the WhatsApp group was well-used and a good way of connecting one another and sharing ideas. In a country experiencing instability, the group served to check in with one another and provide encouragement in a difficult context.

[29/01/2019 21:07:14] +237 6 70 51 57 8: Dear step team thanks for the contributions that is going on, at this moment we cannot take part in the contributions or giving our on views due to our situation now. Please pray for us.

The group would frequently have focussed case discussions supported by photographs and video clips. Responses and input were offered from both mentors and other fieldworkers, with succinct and practical advice being shared along with own experiences. Very often fieldworkers would connect their case questions to function and the ICF. They would routinely upload updates on previous cases to show progress and serve as encouragement to the group.

[07/02/2019 21:57:51] +23773300711: [Fieldworker], identified [Adolescent], 19 yrs with severe CP, can not seat upright, only sleeping, can eat by using two left fingers, can move by rolling, find difficult to draw up the goals, can the group help to bring out the goals,
[07/02/2019 21:58:00] +23773300711: <attached: 00000417-VIDEO-2019-02-07-21-58-00.mp4>
[07/02/2019 21:58:25] +23773300711: A field worker is having this challenge, can someone advise?
-
[11/02/2019 17:34:21] +31 6 24573000: They will when father is around. Now his brother could ask him if he was in pain. But today the whole community was standing there, so no privacy. But he seemd to like sitting up and drinking water went a lot better as well.
[11/02/2019 17:35:40] +23777475757: Thanks for the feedback Dr Petra. I am just wondering aloud. If he comes to sitting already and a you say, he relaxed a bit more. Could we not also try to put him more in sitting and see how it goes before thinking of a mobility device in prone lying?
-
[12/02/2019 05:43:28] +23780702110: Greetings to everyone. What a great work done with Peter. So inspiring.

Additional tools for fieldworkers

Through focus group discussions with fieldworkers, 2 recommendations for additional tools were suggested: a resource booklet for fieldworkers and a flipchart of pictures for use with families and as home programmes.

Resource booklet for fieldworkers

It was difficult to determine whether a participant manual was provided for the training workshops; it appeared that the fieldworkers had to rely largely on memory, the RehApp, other people and David Werner's book, Disabled Village Children (where available). A training timetable and an incoherent collection of notes served as trainee reader, available on the LF STEP portal, but it is questioned whether these were distributed to participants. As not all fieldworkers have access to smart mobile phones or internet, it has been difficult for many to access RehApp or the portal to obtain notes; therefore a comprehensive, collated participant manual from each training would be preferable so that fieldworkers have a resource to refer to during STEP activities. This would encourage standardisation of the content and quality taught in workshops if they are coordinated by different trainers.

Flipchart of pictures

Fieldworkers shared the difficulty of trying to explain or illustrate concepts to caregivers without graphic aids. Although a series of flashcards is available, it is similar content and format to the RehApp tool and the same feedback applies; that they are text heavy and not appropriate for caregivers. It would be useful to have a series of illustrated charts each covering a major topic or skill that can be photocopied and left with caregivers when necessary to serve as home programmes.

"Pictures speak many more words; you see it and it reminds you straight away" *(Ugandan fieldworker focus group discussion)*

The collection of illustrations can be bound together for use as a teaching tool by the fieldworkers during home visits. Suggested illustrated charts include, positioning in different postures, positioning during feeding, feeding techniques, play and stimulation ideas, adaptations for ADLs. In this way, information can be spread to other members within the home.

Summary

In practice, there is not a strong transfer of new written knowledge into practice. Written resources therefore have to serve as a prompt to support familiar, already learnt material. Support through coaching or contact ideally needs to come from those with knowledge of the context and experience in application and adaption within context. Heavy reliance on technology has significant limitations in developing contexts. Support tools need to be tied into the training to ensure they are used during and familiar by the end of the training programme.

Coaching and support

Coaching was designed into the original STEP model as a way of providing in-field, one-on-one support to fieldworkers. This would include accompanying them on field visits to build their skills and confidence, assisting in managing challenging cases and modelling practice in the field as well as providing learning opportunities that are informal and responsive. There has been a very positive response around the need for coaching with the view of it is complementary to the training.

Need for coaching and support

As explained in previous sections, fieldworkers required ongoing coaching, supervision and support in carrying out their role. The complex needs and range of issues affecting households of children with

ND's make them a notoriously challenging group to work with, even for rehabilitation professionals. Fieldworkers needed to be able to discuss cases with others, both for advice and for their own emotional support.

Fieldworkers voiced the need for ongoing coaching and support; and those that fared best were those with ready access to this kind of input. Few of the organisations had the necessary expertise in their existing staff to offer this kind of support. The exceptions were KCH (with a strong team of occupational therapists) and CBC, through the role of Mr Fanfon as Physiotherapy coordinator. Mr Nangai, the STEP coordinator, played a vital coaching role, but this meant an enormous amount of travelling and he was unable to provide nearly what the fieldworkers felt they needed. A common recommendation from PO's and fieldworkers was for *"more Kenneth's"*!

Coaching and support could be offered through the WhatsApp group and telephonic contact, and was of some use, but in less accessible in some areas than others *(cf Support Tools: WhatsApp).*

The focus group discussions with fieldworkers clearly showed the value of peer support in their work. Although this was not the intention of the groups, the conversations allowed them to express their challenges in a supportive environment, reflect on their work and gain encouragement from this process. Since most of the organisations have only one fieldworker trained, the groups provided an unusual opportunity for fieldworkers to be with peers, and they voiced their appreciation for this.

There is also a need for a 'critical mass' of fieldworkers within regions to provide support to one another and to cultivate and strengthen positive regional relationships. A collective of fieldworkers would encourage peer support and accountability as well as the possibility to share the workload in times of crisis, i.e. fieldworker is sick *(case in Kenya)*, family problems *(case in Uganda)*, left the organisation *(case in Cameroon)*. A peer support network would also be a space for fieldworkers to share their challenges and work towards constructive solutions for difficult cases. This network has been initiated in part by means of the WhatsApp group, although there are some difficulties experienced with this forum.

Coaching also provides coordinators the opportunity to gain information on the performance and efficacy of the fieldworkers, challenges and issues they are facing on the ground and where additional training or support may be needed.

Selection and roles of coaches
Professional rehabilitation therapists in the staff of the PO were of some support, although this depended very much on their training and experience working with children with NDs and in the community with families. Most of these therapists had not been trained in the STEP approach, and this made it difficult for them to support the fieldworkers as they did not share a common perspective on NDs. Their clinical training was usually focused on the child, with a strong impairment focus, rather than on the family; and the coaching approach for supporting parents was unfamiliar. Being required to support and supervise fieldworkers in a therapeutic approach in which they did not feel comfortable could be stressful, and at times resulted in conflict between what fieldworkers had been taught and what therapists felt to be the correct approach. In these situations, fieldworkers would often forfeit their opinion and approach as they felt obliged to follow the recommendations of a professional. Training all parties involved in the STEP approach would be beneficial to upskill everyone, and coaches experience application the field before coaching would aide in all speaking a common language around NDs and STEP.

The clear need for Occupational Therapy support and supervision was highlighted, as they are trained with a more functional approach, as well as a more holistic view on child development, families and

communities; mental health; assistive devices, etc. Therapists would also need the time to go on field visits with fieldworkers to provide in vivo technical support and coaching when necessary. Time constraints and workload also limited possibilities for therapists from one organisation to support fieldworkers in another, although where possible this may be a resource-saving approach. Facilitating case study discussion meetings may be a way to gain coaching on complex cases and reducing the frequency of field visits required by therapist/coaches.

As a source of clinical and more technical expertise, therapists may need further professional development in the field of paediatric neurology to provide that level of support and advice that may be needed. As professional rehabilitation workers are scarce and valuable, they may therefore be best suited to coaching roles as they may not have the time available due to high workloads to do home visits themselves.

An additional role that may be needed by therapists or coaches is that of reflexive supervision and a listening role. The work in the field with families and children with NDs is emotionally draining and fieldworkers may end up having difficult conversations and facing challenging situations whilst in the field. Aside from a peer network, having a coach to sit down with a get support and guidance from and encourages reflective practice and learning, will strengthen their skill and coping strategies as fieldworkers. This form of support may be more needed at the beginning of practice and taper off with time as fieldworkers learn to cope with more situations and shape their thinking.

Intensive coaching may be necessary initially as the fieldworker builds their reasoning, skills and confidence. As they become more comfortable with their skillset and managing increasingly complex cases, the intensity and frequency can taper off. Coaching can also be a form of career pathing for fieldworkers; as they become more experienced, they may have the opportunity of upgrading their training to become coaches to other novice fieldworkers.

Multi-layer training on support and coaching
Again, referencing the conceptual framework, at each layer of the system, a degree of coaching and support is needed: children are coached by parents, parents are coached by fieldworkers, fieldworkers are coached by therapists in the PO, the PO is supported by the SPO and the SPO is supported by LF. Therefore, the training programme ideally needs to provide different coaching skills at each level.

Fieldworkers need to have skills to coach and counsel parents; this was included in the training timetables as discussed previously, but with limited formal reference made to it by fieldworkers. When challenging cases arise, fieldworkers need to have access to a network of therapists to provide support and coaching, knowing when and whom to ask for assistance.

Therapists in the POs need to be trained not only in the STEP approach, but also in skills to coach and provide reflexive supervision. Therapists in Uganda reflected on the value of including a different level of coaching and in a learning space where they do not feel pressured to be 'experts'; i.e. when being trained with fieldworkers, they felt like they needed to know more. Questions to be considered are also whether local therapists are available and whether they are equipped to provide a supervision, support and coaching role.

It is also important to include links to other professionals, to prepare them for referrals and to ascertain appropriate referral networks, i.e. nutritionists, social workers.

Summary
Fieldworkers need supervision, coaching and peer support to develop their problem-solving and intervention practice. The coaching already available was seen to be extremely valuable and furthered

Changes in fieldworkers and their practice

Pride and respect

"When people see those changes, they call you doctor!" (Cameroonian fieldworker)

Fieldworkers were proud to be able to provide intervention in homes where previously they have only been able to identify and refer. They expressed feeling more satisfied with their work and identified the importance of being respected by families and colleagues for their skills.

Holistic approach to children and families

"Before, you might see a child today and never see them again – [...] – no plan, no continuity. Now you feel it's actually constructive" (Ugandan fieldworker)

A more holistic approach to children and families allowed fieldworkers to embed interventions into context and appreciate the context in which people lived (acknowledged particularly by therapists). This allowed their interventions to be better received and changes to more evident.

Positive relationships

"I have so many friends now! All the parents – we have good relationships, enjoy being together, work becomes 'stress free'" (Ugandan fieldworker)

Fieldworkers shared that through STEP they had developed positive relationships with other colleagues (coming together for training) as well as with the caregivers and children they visited. The communication strategies in the training was reported as beneficial in assisting in transforming these relationships and the knowledge that people feel listened to.

"The children are so happy to see us, even when they just see the car, when you are going back they are crying" (Cameroonian fieldworker)

Conclusion to Part 3

STEP is a complex intervention and will require ongoing development to best meet the needs of children with neurodevelopmental disabilities in context. The preliminary, pilot-phase findings are positive and indicate that STEP is meeting a need and has potential for growth and expansion. There is however no 'lite' version of STEP, it will require a long-term commitment and investment in building capacity to ensure that it works over the lifespan of the children and families with whom it engages.

Part 4
Organisational context: The supporting framework for implementing STEP

The interventions described in the previous chapter are supported by a multi-layered organisational framework. Understanding the organisational dimensions of STEP is essential to understanding the process of implementation during the pilot, as well as for planning scale-up and building sustainability. This chapter draws on interviews, focus group discussions, observations and document review to describe this organisational context and extract lessons for the implementation process going forward.

STEP is housed within the Liliane Fonds's model of working through in-country strategic partner organisations (SPO's) and partner organisation's (PO's) to reach children with disabilities. Figure 4 shows these layers as concentric circles, centring once again on the child and family, reflecting the Liliane Fonds's focus on making a difference directly in the lives of individual children. The organisational layers correspond more or less to the contextual layers described in the previous sections, and in the same way, each has an effect on the others.
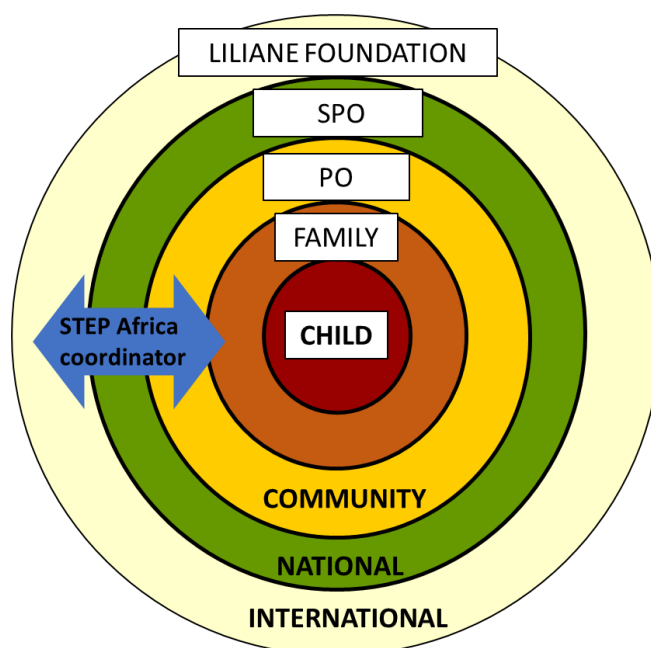
Figure 25: Organisational context for STEP

Coordination of STEP pilot

To this existing structure was added a STEP regional coordinator for Africa, who was seconded to LF from the Ugandan SPO (KCH) for a two-year period. Mr Kenneth Nangai is a Ugandan occupational therapist who has worked with LF for a number of years as program head for the Child Empowerment Program (CEP) at KCH. He was joined in-country for part of the pilot by the LF STEP project coordinator, Mr Kees Van Den Broek. Together, they were responsible for the overall implementation of the pilot, from screening and engaging participating PO's and organising the trainings, to visiting PO's during the pilot for fieldworker coaching and support. They were the also main liaison between LF in the Netherlands and the STEP implementing partners.

Partner organisations in the STEP pilot
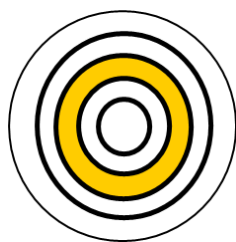
The implementing organisations for the STEP pilot were selected from among existing PO's, using the following criteria:

1) PO should be willing to cooperate on this project and allocate a contact person who is motivated and having assigned time for this project;
2) PO with broad CBR interventions for children with disabilities that include children with central neurological conditions such as cerebral palsy among other conditions;
3) PO with a visible Community Based Rehabilitation (CBR) program making use of so-called field workers, community or CBR workers;
4) POs that are within the Lake Victoria zone, except for Cameroon.

(*Source: project planning documents*)

The Lake Victoria region (LVR) was chosen as the pilot site based on the existing network of CBR practitioners supported by Liliane Fonds in this area. It was also felt that the setting was sufficiently similar (although across three countries), to provide a reasonably equal context for testing the concept. Cameroon's addition to the pilot was explained in Part 2.

A total of 18 organisations participated in the pilot: 4 in Uganda, 4 in Kenya, 4 in Tanzania and 6 in Cameroon. This included the 4 SPO's, of which 3 were also direct implementers of STEP. The organisations differed significantly in their size, type, overall focus and activities. The sample described in Part 1 offers a reasonable representation of their range *(see Table 1)*.

The pilot organisations were selected based on perceived fit between the STEP approach and their existing work. This included both practical fit (i.e. STEP can be easily integrated into existing activities) and conceptual fit (i.e. STEP aligns with organisational focus and intentions). In practice, this fit was not always as expected, and this had a significant impact on implementation.

Practical fit: Resource requirements

STEP was conceptualised not as a new set of activities, but as a means to strengthen and improve existing work being done with children with ND's. For this reason, STEP was not expected to require additional financial resources for the PO's, since fieldworkers and a home visit program were taken to be already in place. In practice, STEP required significant shifts in PO's work, and these came with resource requirements. When this became apparent, LF allocated an additional US$2000 for each PO, to use at their discretion. Each of the PO's expressed that this was helpful but not adequate, and resource constraints placed considerable strain on the pilot work.

Time

For all the PO's, STEP increased the amount of time being spent on the target group. Prior to the training, staff didn't know what to do with children with severe ND's, and therefore intervention with this group was minimal. STEP changed this, and the ten children enrolled by each PO for the pilot were an addition to their existing caseloads. The original project plan expected weekly visits to these ten children, which could easily take up two or more days of the week, depending on travel times (in practice, almost all PO's reduced visiting to monthly or less).

The STEP intervention proved more time-consuming than previous home visits, which were largely focused on identification and referral of children with disabilities. Time spent educating and counselling parents, discussing household challenges and addressing functional difficulties resulted in much lengthier visits than would otherwise have been made, and therefore fewer home visits could

be done in a day. Such visits are mentally and emotionally demanding, and while most of the fieldworkers enjoyed the work, they also found it draining.

STEP's time requirements brought it into competition with other aspects of organisations' work, creating various tensions. All the fieldworkers had other responsibilities in their organisations, with the exception of the volunteer parent at NRC, who had a child with CP to care for and a family to support. Physiotherapy staff at CBC expressed conflict between being available at their health centres for in- and outpatient clinical work, and the need to be in the field for STEP. Managers were often resistant to them leaving the hospital for fieldwork, especially where there was only one PTA to provide both centre-based services and community-based services.

A fieldworker from another PO expressed conflict she experienced between STEP duties and other project work, because STEP made no contribution to her salary. Other projects paid according to the hours she worked on them, so that in order to make up her monthly salary, she had to make sure those hours were covered. This meant STEP work was only done after this had been achieved each month.

Only one fieldworker was working as a volunteer, and she was the mother of a child with CP. Although she was able to leave her child with family members some of the time while making her visits, this was not a consistent or sustainable arrangement. She was also a breadwinner and ran a small food stall to support herself and her child. Although her lived experience as a parent was invaluable in her work, volunteering her time for STEP was clearly not a viable long-term prospect.

It was abundantly clear that secure salaries for fieldworkers are non-negotiable for the sustainability of the project. While there may well be roles for volunteers in the STEP work in some settings, the realities of household survival described in Part 2 make it unreasonable to expect anyone in similar settings to carry out the fieldworker role without payment.

Transport & other visit costs
Access to transport was a further challenge. Some organisations had vehicles for outreach, but these were usually shared with other programs and organisational needs, so weren't always available. Public transport was often not feasible, because it was too time-consuming to use, or (more frequently) too unsafe.

Airtime was another significant cost of home visits. Fieldworkers needed to contact families to arrange visits, make calls to colleagues for advice or information while on the road, and call families to follow up between visits. Airtime and data costs varied in the different countries. In Uganda, internet access is taxed, making WhatsApp (among other online resources) too expensive to use without further subsidy.

Fieldworkers also reported making small incidental purchases to support their work with families, for example buying a baby feeding spoon for a child with feeding difficulties. Sometimes this was for the purposes of demonstration, at others it was because families could not themselves afford even these minor things. Some fieldworkers would use their own money for this.

Finally, fieldworkers unanimously expressed the need for money to buy food for themselves when they are in the field all day – usually small snacks or street food, as well as cooldrinks or bottled water. This seemed usual practice at all the PO's we visited and was seen as both a necessity (since they cannot cook lunch while on the road) and a small motivation for the physical, mental and emotional demands of home visits.

Some PO's paid their fieldworkers "facilitation" for STEP visits, an amount which was intended to cover the above costs. This seemed to be sourced in part from the PO's own funds, and in part from the additional US$2000, but it was often felt to be inadequate by both managers and fieldworkers.

Resources to address identified child and family needs

Not only did STEP add new children to PO's caseloads, but STEP's holistic approach raised a broader range of needs than was being dealt with by most PO's. Some PO's already had partnerships or activities which could address these, while others needed to problem-solve new approaches. The most common needs identified were:
- Assistive devices
- Epilepsy treatment
- Nutrition support
- Income generating activities (IGA's)

Assistive devices

Many of the children were unable to sit alone and spent most of their time either carried by a caregiver or lying down (usually on a mat or mattress indoors). Sitting up is essential for developing interaction and communication with others (including looking, listening and non-verbal responses), as well as eating (safe swallowing). The right supported sitting position stimulates the development of head control and postural muscles, particularly in children with ND's who may not follow the usual developmental stages of rolling, crawling, etc. Lying down indoors meant that children weren't participating in the life of the household and could be ignored by others who saw them as passive "babies". Carrying the children placed a heavy physical strain on caregivers and made it difficult to take them out of the house, e.g. to go to the clinic or to the market. This further increased the children's isolation. Caregivers also reported that carrying the children around made it very difficult for them to get other things done.

For these reasons, most of the children seen were recommended a basic 'CP chair' (usually a fitted wooden seat with cushions, support straps and a tray table). These can be made by a local carpenter, given the appropriate design and measurements, although in Uganda and Kenya they came mainly from central workshops. In Cameroon, families made chairs themselves with what they had available, under advice from the fieldworker.

Wheelchairs were identified as a need for a number of the children but were difficult to access. Only Uganda had a local producer of wheelchairs (in KCH), while other countries relied on imported devices (often second-hand), which were often not suited to the terrain and difficult to repair once broken. KCH's wheelchairs have the advantage of being sturdy enough for the generally rough terrain and are made from stainless steel tubing and bicycle parts, which are easy to repair or replace locally.

The cost of purchasing even locally made devices was usually not affordable for the families, and funding had to be found by the PO for these. However, where available, they often made a very significant difference for both child and family *(see Part 3)*. Further technical discussion and detailed recommendations are available in appendix F.

Epilepsy treatment

As mentioned previously, a high proportion of children with neurological disorders have epilepsy, and access to medication is a considerable challenge. Initiating epilepsy treatment can take time, as the type and dosage of medication needed to control seizures with minimal side effects is different for each child. This may require several visits to a prescribing clinician, with periodic follow-up once the right treatment is established. Even where treatment is theoretically provided for free by state health services (e.g. in Kenya), the drugs are often out of stock and families then need to purchase them from

private retail pharmacies. The cost of treatment also includes transport cost, which can be significant, especially in rural areas.

Some PO's offered epilepsy treatment themselves as part of clinical services; others were able to link families with local services (both NGO and government). The majority of services still required some payment for the medication itself, and PO's mostly tried to cover this using CEP funding.

Nutritional support

"Previously you would try to do therapy, work on other things, but if the child is hungry and malnourished, you gain nothing" (Fieldworker, Uganda)

In some cases, families were unable to afford even the basic foods recommended to improve the nutritional status of the child. Where there are feeding difficulties, children may not be able to eat the same diet as the rest of the family and may need slightly more expensive alternatives (e.g. buying yoghurt because the child can't manage the stew and stiff maize porridge eaten by others). Until diet is addressed, other interventions may be useless, and therefore some of the PO's chose to fund extra food for certain children (e.g. paying a local farmer to deliver a cup of fresh milk daily).

Some children's feeding problems and nutritional status were serious enough to need clinical nutrition services. The CBC fieldworkers in Cameroon were able to link with the nutritionists at their health centres, while other PO's sometimes had contacts through local health services.

Livelihood interventions

The overwhelming realities of poverty for STEP families meant that most PO's tried where possible to fund IGA's (income generating activities) for caregivers. Examples included brewing local beer, cooking food to sell and running small roadside stalls. IGA funding usually provided the initial cash to buy basic equipment and supplies, so that the business could start. Some families needed help to re-start a business that had stopped because of a crisis, for example a storm destroying a stall structure. We witnessed a number of successful micro-enterprises begun like this, and many other parents expressed the need for help of this kind. Additional funds to scale up a small business to make it more profitable were also requested. One example was a grandmother who sold cooldrinks and other small items outside her home. She had to go to the market often to buy stock, because she could only afford a small amount at a time. With extra cash, she could have bought in bulk and less often, reducing her overall costs and increasing profitability, as well as saving her time away from her child.

Funding additional services and needs

Many of the items needing funding (e.g. assistive devices) fitted within the remit of the CEP, but STEP was introduced after the annual plans and budgets were already finalised for the year. Sometimes PO's were able to reallocate funds within their CEP plans, and the extra US$2000 STEP money was also drawn upon. In other cases, families had to wait months (or indefinitely) for funds to be sourced.

PO's made slightly different choices about what they funded, and not all seemed to have clear systems for how such decisions were made. As the STEP approach elicited needs from families which the organisations might not previously have addressed, they had to work out how (and whether) to respond to them. At the same time, the levels of severe poverty in STEP households often meant that without this kind of support, major barriers to child and family well-being remained.

The flexibility allowed by the CEP was hugely beneficial in giving PO staff the freedom to respond to particular household needs. At the same time, there may be a need for organisations to reflect on how they do this and set boundaries which allow them to be consistent and realistic in the support

they offer. Clear guidelines in some instances would support the fieldworkers in clarifying expectations with families and reducing misunderstandings and disappointments.

Management support for STEP

In order to leverage these resources for STEP work, management support for the project was imperative. Although all managers had in theory agreed to participate in the pilot, this varied considerably across organisations. It proved a strong disadvantage that most managers were not included in STEP training, and there was need for ongoing negotiation and advocacy through the pilot period, especially as demands for resources (described above) arose.

Two of the pilot sites were situated within medical services (BEH and CBC health centres), and therefore fell under more senior managers that were not disability- or rehabilitation-focused. This posed challenges for fieldworkers, especially where home visits and community-based work were not prioritised by the organisation as a whole, and rehabilitation itself was not well understood.

For some organisations, offering free services at people's homes did not sit well. Many non-profit service providers (especially in healthcare) rely on fees paid for services for some of their funding, and STEP was sometimes perceived as taking away from this source of income. In practice though, families of children with severe ND's were almost never using available rehab services, because of the time and transport costs and the lack of change observed. One rehabilitation centre generated much of its income from issuing callipers to most of the children seen there, and the STEP training, by deeming these devices unhelpful, threatened to reduce this source of funds.

Despite these challenges, almost all managers observed the positive effects of STEP over time and appreciated its achievements. Seeing change in a group of children for whom this was thought to be impossible proved a huge boost to rehabilitation services in many places, and even strengthened management support for rehab programs as a whole. One health centre manager (CBC) observed how the positive impact of STEP strengthened community trust in the health centre itself, increasing uptake of their services. For managers with no rehab background, the examples of families included in STEP gave them a far clearer understanding of disability and what rehabilitation is intended to achieve.

Negotiating management support for STEP was a key task for the STEP Africa coordinator, especially in the LVR region. Since most of the STEP trainees were fieldworkers in operational and often quite junior roles, it was difficult for them to advocate for the program to their superiors. External and more senior support in this was sometimes essential for the pilot to continue.

The situation in Cameroon was somewhat different. The drive for the pilot came from CBC itself, as described, and was championed by the national head of CBC's disability program (EDID). STEP was implemented within the rehabilitation services based at some of their own health centres, as well as through outside PO's. Although health centre managers were at first doubtful about their PT staff leaving the hospital for field visits, the EDID head was able to negotiate permission and support for this to happen from the national office level through the correct channels, and this negotiation was followed up by the national supervisor of PT services (Timothy), during his support visits to each centre. This removed the pressure for negotiation from the fieldworkers, which was hugely helpful.

Conceptual fit: CBR/CBID

A strong determinant of management support for STEP was the conceptual fit between this approach and the organisation's existing work. While almost all had an existing "CBR" program, which included fieldworkers conducting home visits, the underlying mindset and approach to this work was often quite different. Most CBR workers visited homes in order to identify children with disabilities and refer them to available services. Such services were mainly medical rehabilitation, including centre-based

therapy offered by physiotherapists and/or occupational therapists, corrective surgery and sometimes assistive devices. The approach therefore was primarily medical and impairment-focused, although parallel programs within some of the organisations also addressed other areas (e.g. inclusive education).

Most of the organisations had begun as centres for children with disabilities in the 1980's or before, with an historically institutional approach which was adapted to a greater or lesser extent over time. The underlying ethos of each organisation was strongly determined by its history and organisational affiliations. The perceived roles of rehabilitation professionals and of parents were also shaped by these organisational contexts. The STEP approach of coaching parents to stimulate their own children's development was new to almost everyone, although some PO's were already working with parents through support groups and livelihood interventions. Rehabilitation professionals tended to occupy a very specific therapist role, confined to "doing therapy" with the child even in a home visit situation, and this could be difficult for them to change. This was more successful however where the larger context supported the shift, for example in Uganda (and especially in KCH), where a rights-based inclusive development approach is relatively well established, compared to Kenya where the medical model still predominates. Some managers (particularly those at the two Kenyan PO's visited) still preferred their therapist staff to use STEP home visits for direct therapy, not feeling that skills transfer to parents or non-professional fieldworkers was really viable.

Many of the organisations had components to their work in areas of the CBR matrix *(see appendix C)* other than health. A focus on inclusive education was common, as was some form of livelihoods intervention. Table 4 below charts the activities of the different PO's (excluding/prior to STEP) for comparison. The nature of these activities varied considerably, as did their scale and success.

Note: Green blocks indicate activities by the organisation itself, yellow blocks indicate referral to another organisation

CBR activities	UGANDA			KENYA		CAMEROON
	KCH	NRC	BEH	SMK	SHS	CBC
HEALTH						
Promotion						
Prevention						
Curative healthcare	MH clinic & epilepsy meds Refer for surgery	Epilepsy meds Refer for surgery	Epilepsy meds Refer for surgery	Epilepsy meds	Epilepsy meds	Epilepsy meds
Health rehabilitation	OT, PT, O & P	PT	OT, CBR	OT	PT	PT/A
Assistive devices						
EDUCATION						
Education ECD						
Primary			Facilitate inclusion in local schools	Special school	Hostel for inclusion in local school	
Secondary and higher						
Non-formal *Day centre or special unit*	Day centre	Holiday basic skills program		Special school	Special unit	

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Lifelong learning						
LIVELIHOODS						
Livelihoods: Skills dev		Arrange internship				
Self-employment	IGA's	IGA's	IGA's	?	?	IGA's
Wage employment						
Financial services	VSLA groups				PSG revolving loan	
Social protection					Help getting disability card	
SOCIAL						
Social and Family: Personal assistance						
Relationships, marriage and family						
Culture and arts						
Recreation, leisure & sports						
Justice						
EMPOWERMENT						
Empowerment Advocacy & communication						
Community mobilisation						
Political participation						
Self help groups	PSG	PSG				PSG

Table 4: PO activities mapped according to the CBR matrix

It was clear from the STEP pilot that families of children with ND's had seldom been included in such activities, because of the multiple barriers posed by complex needs, severe stigma and isolation of families. Once PO staff were equipped to engage these families through STEP, it also became possible to include them in other services. The marginalisation of children (and adults) with CP and other ND's *within* the disability sector was highlighted by UNAC, the national association for CP in Uganda. This points to a potentially serious weakness in generic CBID work, and to the ongoing importance of technical disability knowledge and training if inclusion work is truly to be effective. The STEP approach represents one possible bridge between the two.

Changes stimulated within organisations

While the conceptual orientation of the implementing organisation was crucial to the effective integration of STEP into their work, STEP itself had a significant effect on the organisations over time.

Change in attitude to children with ND's and their families

As mentioned, families of children with ND's were often excluded from services, especially where children were being hidden. This meant that prior to STEP, the needs and the number of these families were unknown and therefore not attended to.

Fieldworkers described their previous sense of helplessness when faced with children with ND's. They lacked knowledge and skills to address their needs and were often frustrated by the minimal changes any therapy was able to make. Some mentioned actively avoiding these families because of this. Once they had received training and began to feel more confident, this attitude changed dramatically. As they began to apply the approach and see changes in the children and families, the interactions with families could become very positive and rewarding. This was highly motivating for fieldworkers who experienced it, and added hope and energy to their work, even where this had become more demanding due to STEP.

More holistic and context-appropriate approaches to practice

The STEP approach had a fundamental impact on broader work with families, through holistic assessment which broadened its focus. Fieldworkers began to understand how household and caregiver factors influenced the child's life (and vice versa), and to broaden their own scope. This was often challenging, and management and coaching support were needed to guide them in navigating new areas of intervention. This change in perspective had a ripple effect on organisations, and how they conceptualised their own roles in relation to the needs of the families of children with disabilities. The result could be a more holistic and multi-sectoral approach, shifting from individual impairment focus to a more inclusive developmental approach.

These effects were felt beyond the STEP work itself. Therapists commented on the impact of home visits and family-centred practice on their other work, even in the medical outpatient setting. They were far more aware of their clients' home contexts, and this changed their treatment:

"I have a different touch, I see [my patients] differently now" *(Cameroonian therapist)*

Summary
The fit of STEP within each partner organisation had both practical and conceptual components. Practical fit included availability of the resources required for the intervention, which were beyond what was anticipated in the planning of the pilot. Conceptual fit was about a match between the ethos of the organisation and the STEP approach, particularly concerning the empowering of parents to facilitate their own children's development, instead of depending on professionals. Management support for the pilot involved ongoing negotiation, which could be challenging for fieldworkers. At the same time, the STEP experience had a visibly positive effect on the organisations themselves, both relating to and beyond their work with children with ND's and their families.

Strategic Partner Organisations in the STEP pilot
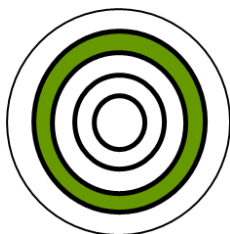
The formal role of the SPO did not seem to be clearly defined in the project planning, although it included administering the additional funds allocated for STEP within the CEP and incorporating STEP activities in their consolidated reports. The SPO's in the three pilot countries visited vary considerably in their nature, scope, capacities and services, and this influenced the role they played in STEP. Representatives from all SPO's were included in the STEP training.

Uganda

KCH is a regional rehab centre with a strong referral network among disability organisations and services across the country, including the Ugandan PO's. Because staff at the SPO and PO's communicated frequently as part of their work, there were already relationships on which to base the STEP implementation.

KCH had solid rehabilitation expertise which fieldworkers knew they could draw on, and it also offered a number of the key services and resources needed by STEP households, including an assistive devices workshop and an epilepsy clinic (although costs still needed to be covered through CEP or other means).

KCH was also itself a STEP pilot site, which meant the organisation had first-hand experience implementing the program. [Kenneth] being based at KCH was also significant, although he was officially seconded to LF at the time, rather than a direct employee.

Kenya

CDSK is a well-known disability organisation with a national reach, focusing on CBID and particularly inclusive education. Unlike the other two SPO's, it is not a direct service provider, although it supports several service centres around the country. Based in its national office in Nairobi, CDSK played a mainly administrative role in the STEP pilot. One staff member was trained in STEP, giving sufficient background for him to support the four PO's in managing the allocated funds and completing the necessary reports. He conducted support visits to the sites and assisted with mobilising additional resources when needed.

More technical and practical support for fieldworkers (including coaching) was provided by the STEP Africa coordinator, although this was seriously limited by the overall demands of his role.

Cameroon

CBC is a large national FBO, and one of the main providers of healthcare in the country. It runs five large hospitals and over 40 health centres, concentrated in the central and western regions of the country. Rehabilitation services are offered at 11 of its health centres, mainly by CBC-trained physiotherapy assistants (PTA's).

CBC was able to integrate STEP within the PT services at several health centres, using existing CBR fieldworkers, transport resources and clinical support from PTA's. Mr Fanfon played a strong coordinating and coaching role in the program, which dovetailed with his existing activities as national PT supervisor.

CBC has the potential for national strategic action to support and expand STEP, both through their service provision network and their influence with the national Ministry of Health. They are currently concluding an agreement to establish Ponseti club foot management, already rolled out through in their own centres, as national standard treatment. Similar action may be possible in future for STEP. CBC also has an accredited training institute, which offers a one-month training for CBR workers and a two-year program for PTA's. They have already begun using STEP training materials in the latter, and plan to integrate it formally into their programs going forward.

Key findings on SPO roles

It was clear how the level of enthusiasm and initiative by the SPO could have a defining impact on implementation in-country, both at a broader strategic level and in providing essential resources, coaching and support to fieldworkers at PO level.

These three very different examples indicated the possible roles of SPO's in STEP. SPO's with national reach may be in a strong position to coordinate the development of STEP across a region. This includes organisation-level support for PO's, and the development of resource networks and partnerships (e.g. for the production of assistive devices). Organisations with a high profile and political influence may be able to effect change in national/regional programs and structures, including training of health and

rehabilitation workers. Such work is vital in developing local capacity which will maximise STEP's impact and sustain its work into the future.

It's possible that existing SPO's working with Liliane may not be best placed to play this role, but that other in-country organisations may be found which are better suited. Such an organisation should have rehabilitation expertise, staff with time and resources allocated for the work, and a passion for the project.

Whichever organisation is identified as national coordinator for STEP, it is important for its role to be clearly defined. Where this is not the existing SPO, the SPO's role in STEP must also be defined, including the lines of communication and authority between the two and with the PO's. Coordination is crucial to avoid confusion and conflict among partners.

Local and regional support networks
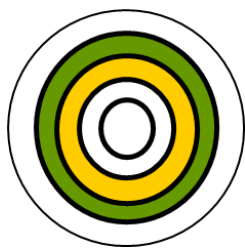
As explained, the success of STEP relied on networks between various stakeholders at local, regional and national levels. Some of these relationships were already existing, but many needed to be built. This required conscious planning and effort and is an ongoing process.

At local level, PO's needed to link with other services and organisations to address the various needs of children and families. Some of these relationships were already in place, while others needed to be developed. A community mapping exercise during the training was helpful to fieldworkers in identifying potential partners and strategizing how to build networks of support, including local leaders, schools, healthcare services, churches and others.

Within regions, networks of STEP staff themselves were developed, through the training and sometimes the WhatsApp groups *(see above)*. Building these relationships and channels for communication is important for developing the in-country capacity to sustain STEP. There is huge potential for shared learning and problem-solving between implementing organisations, where there are opportunities (i.e. space and time) for this to happen.

Interfaces between stakeholders

The multi-layered organisational context for STEP means that its successful implementation relies on the interfaces between numerous partners: between LF and the SPO, the SPO and the PO, and the PO (through the fieldworker) with families and communities. Such interfaces are made up of all the spaces, situations and tasks in which the two (or more) parties interact (Long 2003), and are influenced by many contextual factors, both related and unrelated to the work itself. Understanding what happens in these interfaces is essential for understanding STEP's implementation.
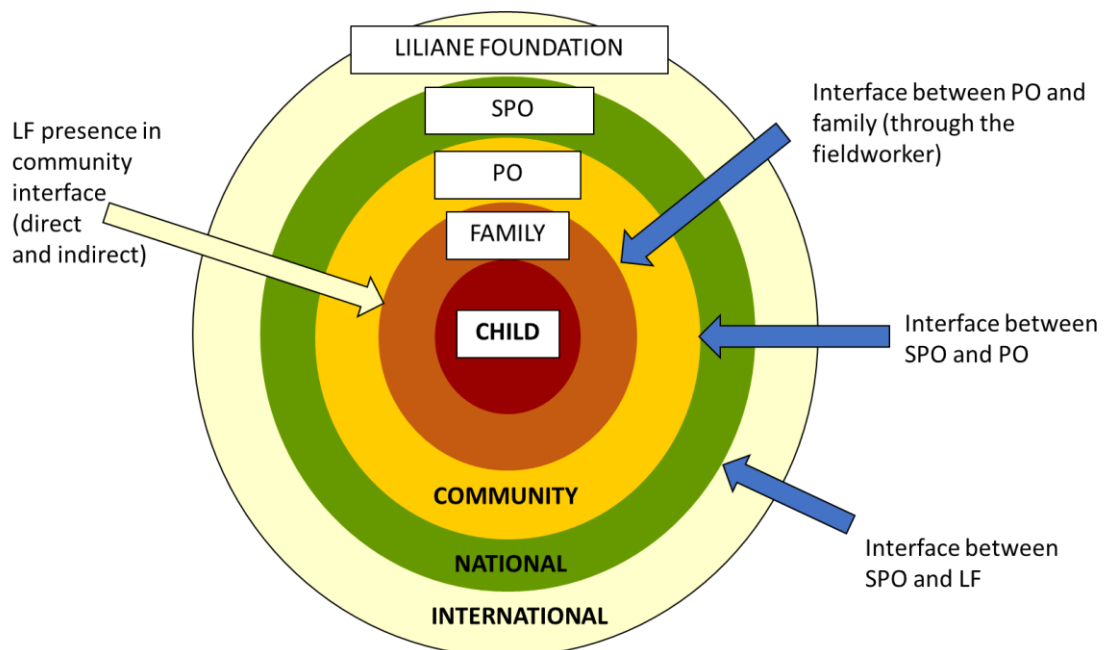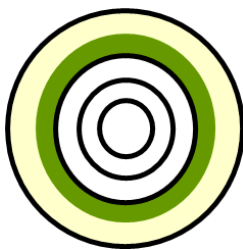
Figure 26: Interfaces between organisations involved in STEP

Interface between LF and SPOs

National organisations, made up of local staff and firmly grounded in context, are well placed to implement LF's positive intentions in a locally appropriate and effective manner in the partner countries. LF has worked in this manner for several years, and the benefit of the system was visible during the evaluation. SPO's are often able to bring their expertise and influence to bear for the benefit of the PO's, e.g. linking them with other funding opportunities, and connecting organisations whose work is related or complementary. The relationships built between local and regional organisations have the potential to decrease fragmentation and duplication of services, build support networks and allow for coordinated strategic action at local and national level. The investments made in building SPO capacity, including their capacity to build capacity in the PO's, are a further positive contribution to sustainability.

One challenge in the system lies in the interface between LF and the SPO's. Removed from one another geographically, culturally and socio-economically, the Dutch and African partners face a number of communication and relational barriers. Dutch staff are frequently unfamiliar with the realities of the African context, and decision-making and planning may therefore be based on incorrect assumptions about what is feasible and appropriate. The same is true in reverse, with African staff at times struggling to understand Dutch decisions and communications without understanding the European context. For a fairly straightforward and structured intervention such as CEP, these gaps may be less significant. STEP is a far more complex undertaking, and the pilot phase required a great deal of interaction, planning, problem-solving and communication.

Understandably, face-to-face interaction between LF and SPO staff is very limited, because it is expensive and difficult to arrange. This interface is therefore largely made up of remote communication: emails, telephone or Skype calls, and the structured process of proposals and reporting. These types of communication rely on written language (usually not the first language of either party), removed from the human context. While westerners are fairly comfortable relying on text, other cultures generally are not: context, specifically relational context, is as important (if not more so) than information alone. This can give rise to communication blocks and misunderstandings

which both sides find hard to understand and resolve. This was observed during the process of doing the evaluation (specifically in LF's interactions with our host organisations around planning and logistics), as well as described by various stakeholders during interviews.

Interface between SPOs and POs
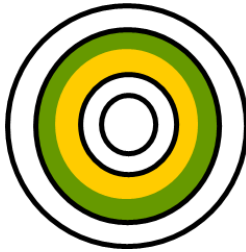
From what we observed, LF generally has little contact with the PO's, as most action and communication is via the SPO. This places considerable responsibility on the SPO to mediate between the funder on the one hand and the local organisations on the other. It also means that PO's (and their beneficiaries) may have limited understanding of LF: its contribution, approach and decisions/actions.

LF has a general policy of not promoting itself to its beneficiaries, being happy to remain in the background. This is in many ways laudable. The result of this approach is that its decisions and actions may be identified as those of the SPO (from the PO's perspective), or of the PO (from the community/beneficiary perspective). This can be both positive and negative, depending on how those actions affect those involved.

For the purposes of STEP, the role of the SPO was not very clear, as explained above, but the project coordinators played a primary role in mediating between different organisational "layers".

Role of the project coordinators
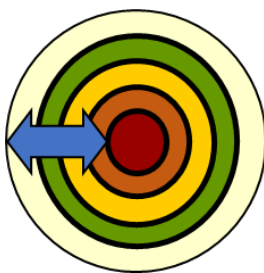
The two project coordinators played a pivotal role in mediating between LF and the African organisations. The time spent by Mr Van Den Broek (himself the recently retired director of LF) in Uganda and the other pilot countries was very positive in strengthening relationships and shared contextual understanding. Mr Nangai also visited the Netherlands at the beginning of the pilot, gaining a better understanding of LF's own context. Between them they formed the main channel of communication between LF and the implementing organisations, which was often a complex undertaking.

Building and maintaining relationships with a diverse array of stakeholders was an important success factor for the African coordinator's role in particular. Visits to the different partner organisations and time spent with both management and fieldwork staff provided opportunities for building these relationships, and for understanding how the different organisations worked. It was clear how face-to-face interactions formed the strongest basis for other communication during the pilot. This helped make sense of how remote communication between LF staff and African staff who had never met one another could at times be so challenging: there was no personal relational basis for the messages passing between them, which gave neither side the context to interpret such messages. Mr Nangai's role often included mediating and interpreting between the two, smoothing over potential misunderstandings.

A challenge for the project coordinator was the lack of formal authority he held over STEP activities and fieldworkers in the implementing organisations. His role existed outside formal management structures, and he often had to negotiate very carefully with managers and field staff when conveying instructions or requests from LF. The relation of the STEP coordinator to the coordinating role of SPO's was also not well articulated, which caused tension at times. Again, excellent relational and communication skills were essential for this role.

Interfaces between POs and communities
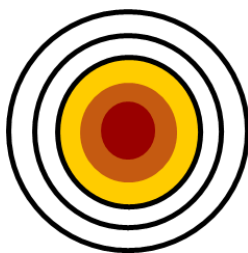
LF's ultimate goal is to make a difference to the lives of individual children and their families. This makes the interface between its implementing partners (SPO's and PO's) and the community and families the most critical of all. While PO's often have a good degree of freedom in how they go about LF-funded work, there are times when what happens in other layers of the system inescapably impacts on this interface. Such impacts may be difficult or impossible to anticipate from a distance but can have lasting and serious effects.

For community members, the staff of partner organisations are the "face" of LF's work, with LF itself choosing to remain in the background. This is often positive, as PO's are empowered to respond to the needs of children and families, and to build and maintain the relationships on which their work depends. At the same time, staff are held responsible by communities for all they do or don't do, including for things beyond their control. For example, fieldworkers described how families who had been promised assistive devices or an IGA could become frustrated with them personally when these things were delayed. In some cases, family members even suspected fieldworkers of keeping "their" money for themselves, because they couldn't conceptualise the organisational processes which delayed or restricted funds (even when these were explained to them).

At a higher level, SPO and project staff expressed a similar dynamic between themselves and partner organisations. One stated:

"People have agreed to STEP because they know me, they know who I am and they trust me. If this thing [STEP] doesn't work, they will not trust me again. Next time I come to them with something, even if has nothing to do with LF, is something else entirely, they will say no, the last thing you did with us failed, we don't want anything from you now" *(Ugandan fieldworker focus group discussion)*

This shows that while LF's work depends on the relationships and good standing of its implementing partners, its actions can also place those things at risk. With this in mind, it is absolutely essential that the organisational framework for STEP makes room for PO's to interact with decision-makers, and for all planning to bear in mind dynamics and potential impact in the community interface. This is best achieved by creating opportunities for personal interactions between partners at different "layers" in the framework and giving LF staff opportunities to spend time in the community context. There is also a crucial role for trusted in-country coordinators, who are able to guide decision-making with cultural and contextual insight.

Conclusion to Part 4

STEP was implemented within the organisational framework already existing for Liliane Fonds's Child Empowerment Project but was a decidedly more complex intervention. The experiences of the pilot have yielded important lessons about the organisational requirements and challenges of STEP, which are vital considerations for the future.

Part 5
Moving forward with STEP

This report has outlined key elements emerging as necessary for the success of STEP in the pilot sites visited. Future implementation should take careful account of these factors in selecting, planning, preparing and supporting new sites. Additionally, the following points should be considered in discussions about scaling up STEP.

What exactly should be scaled up?

"Scaling up" could happen on a number of different levels. It could mean increasing the number of families seen by each fieldworker, the number of fieldworkers trained in each PO, the number of PO's in a country or region, or the number of countries or regions in which the program is implemented. LF and its partners need to decide what "scaling up" means at this point in the project.

How will costs be covered?

The pilot has demonstrated clearly that the costs of implementing STEP were significantly underestimated. Even where fieldworkers were already working with families of children with disabilities in their homes, STEP considerably expanded the size of caseload and time needed in the community and raised needs in the households which required further resources to address.

Whether or not Liliane Fonds and its donors choose to cover such costs, planning at each intervention site needs to consider how these costs will be covered, preferably *before* services are initiated and expectations created.

What next for the pilot sites?

STEP has made a positive beginning in most of the pilot sites, but without further investment, training and development, these initiatives are unlikely to sustain the gains made. At the same time, the pilot has opened up possibilities for families and created a demand for the intervention and stopping it at this point could have a very negative impact on the relationships between communities and PO's.

The STEP intervention clearly requires considerable investment in local and national capacities for its implementation. Ongoing training and coaching of fieldworkers, upskilling of professionals and development of coaching capacity and training of local/regional trainers are all needed if the existing pilot sites are to succeed and sustain their work.

Timelines & exit strategy

As with any development intervention, planning is needed around the period and type of investment needed to build sustainable local capacity. International development support is always finite, and it is essential to include thoughtful strategies for withdrawal and exit in the planning.

Conclusion

The 'minimum viable investment' to build an effective and lastingly positive intervention is an important consideration. Anything below this level will be at best unhelpful, and at worst, damaging to the communities and organisations where it happens. Scaling up needs to first consider building local capacity before expansion, and thereafter consider a stepped approach – in organisation, in country and cross country.

Recommendations

The previous chapters have suggested a number of technical recommendations for different aspects of STEP, and these can be found summarised in appendices D and E. The following are ten key strategic recommendations.

1. Take evaluation findings back to the pilot partners for feedback, reflection and planning

The organisations, fieldworkers and families who have piloted STEP are waiting on Liliane Fonds' responses to their input presented in this report, and to know how the donors plan to go forward. Simply sharing the written evaluation report from a distance would be an entirely inadequate response, both relationally and informationally (not least because the parents who have asked for feedback are unlikely to read an English document).

This is a critical moment for all stakeholders to come together to reflect on the project and make decisions and plan for the future. Each organisation needs to consider how STEP fits within their mission and activities, and if or how they may continue with it. It is likely that some organisations will wish to adapt their work in the post-pilot phase, and most will need to consider how resources are used and whether they can continue to be covered. Bringing different organisations together will give opportunities to share ideas, celebrate successes and problem-solve for the future.

If this is timeously arranged and well facilitated, the gains made during the pilot can be consolidated towards strong local ownership and more positive and trusting relationships between stakeholders. This intra- and inter-organisational basis is essential for the future of the project.

It was clear during our field visits that skipping this crucial step will have extremely negative consequences for LF's relationships with partners (including families) and therefore for the future of STEP.

2. Rethink costing of STEP and make new resource plans

The pilot made it clear that STEP is not a minimal-resource intervention. This report has outlined various cost implications in the pilot, and the next step will be to re-cost the project based on this experience, with decisions to be made on what LF will be able to fund and what will need to come from other sources. 'Minimal viable investment' needs to be borne in mind, so that under-resourced implementation does not actually cause damage to local relationships and PO effectiveness.

Each participating organisation should carry out a facilitated costing exercise as part of their reflections and planning post-pilot. With clear information about what LF is able to contribute, this should allow them to make decisions about continuing the project. Resource-mapping at local, regional and national levels can be done by organisations working together to share ideas and find solutions.

3. Build multi-level capacity at local and national levels to sustain STEP

Implementing countries need to develop the local capacity to train, coach and support their own fieldworkers. Rehabilitation therapists need upskilling to be able to manage more complex needs and support fieldworkers using the STEP approach. Versions of training are also needed for parents and caregivers, managers and possibly others. The following are recommended:
- A multi-level training package, including content appropriate for parents, novice and advanced fieldworkers, rehabilitation therapists and managers
- A training-of-trainers program
- Supporting selected therapists to attend context-appropriate advanced training in paediatric neurology rehabilitation (e.g. the South African basic paediatric neurodevelopmental therapy course, which applies latest evidence-based practice to low-resource contexts and meshes

well with STEP's functional goal-directed focus). This expertise is vital to ensure appropriate training and a basis for developing effective intervention strategies, especially for more complex children.

4. Build strong networks between STEP implementers

Organisations implementing STEP in similar settings can learn from each other, support each other and find solutions to challenges together. Creating ongoing opportunities for fieldworkers and managers to meet together will support the development of strong local networks, and reinforce the actions outlined in number 3 above.

5. Employ country coordinators

The roles played by the Africa STEP coordinator (Mr Nangai) and CBC's senior staff (Ms Tsangue and Mr Fanfon) in Cameroon were invaluable to the STEP pilot. This demonstrated the need for STEP "champions" in each country or region: people with excellent organisational and relational skills, strategic ability and the influence needed to build the project from the 'top down', and hands-on coaching and fieldwork experience needed to build it from the 'bottom up'. Where such people are identified, ideally one per country, it must be ensured that they have the time and resources to carry out these roles.

A great deal of work is needed by such leaders in working STEP into their context: engaging the right stakeholders, mobilising resources, and supporting PO's and fieldworkers. They form a vital liaison between the Liliane Fonds in the Netherlands and the project countries and are able to advise and guide LF in terms of the local impact of its actions and decisions. As LF engages in more complex community interventions (such as STEP), trusted local partners of this kind are essential to ensure that the Foundation realises its positive intentions, and avoids unintended negative impacts.

6. Train & coach for context

Ultimately, training and coaching should aim for "Africans training Africans for Africa" (Donald et al., 2014: 7). As a holistic, family-centred approach, STEP depends for its success on detailed contextual knowledge and application. Trainers need experience in the same or similar settings to those of trainees for their training to be effective. This is a strong supporting argument for Recommendation 3 above.

7. Include community development skills in fieldworker training

Fieldworkers need specific training in aspects such as establishing and running parent support groups, conducting awareness campaigns, working with schools for inclusive education and implementing livelihood activities. These form a critical part of their role and cannot be assumed to be 'common sense'.

Rehabilitation therapists are not always trained in these areas and may also need upskilling if expected to coach and supervise CBR workers.

8. Assistive devices: develop local capacity for design, manufacture & repair

Assistive devices can make significant difference for children and families, and local design, manufacture and repair are key to ensure they are appropriate, effective and affordable. The following actions are needed:

- Train fieldworkers in essential design and problem-solving skills for positioning devices
- Support development of local workshops for device manufacture and repair, to reduce costs and increase likely usefulness of devices

- Where needed, work with existing workshops to further develop appropriate devices for children with CP

9. Review and revise support tools to be locally accessible and appropriate

The STEP tools hold considerable potential but need adaptation before they can be used by those for whom they are intended (see Part 3 and technical recommendations).

10. Parent support groups

Support groups for caregivers have proved invaluable in creating local social support, learning opportunities and capacity to address shared concerns at community level. They are also critical for supporting caregiver mental health and sustaining care structures for children with ND's. As per number 7 above, the skills of establishing and facilitating such groups usually need to be taught, and fieldworkers should be equipped and supported in this area. Caregivers and other community members form part of the multi-layered capacity described in number 3 above, and importantly, they remain even when fieldworkers and PO's change.

Conclusion to Part 5

Recommendations reflect the gaps and challenges faced by STEP thus far and areas to strengthen the programme across levels and stakeholders reflected in the conceptual framework.

Conclusion

The situation of children with disabilities, particularly neurodevelopmental disabilities, and their families remains dire in the African context. The need for a community-based, family-centred intervention such as STEP has been made abundantly clear. This evaluation has revealed very promising early results from the pilot, and caregivers, fieldworkers and organisations were unanimous about the need to continue the program. The STEP approach has great potential to drive change from child and household level all the way "outwards" to communities and even countries, but a great deal more work is needed.

This is an important moment for Liliane Foundation and all its implementing partners to come together and reflect on the experiences of STEP so far. Successes should be celebrated, ideas shared and plans discussed and worked out for the next part of the journey. The participation of all those involved - caregivers, children with ND's, fieldworkers and organisation staff – is vital if the potential of STEP is to be realised.

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Appendices

A. Map of pilot sites
B. Terms of reference for evaluation
C. CBR Matrix
D. Technical recommendations: Part 3
E. Technical recommendations: Part 4
F. Assistive devices