Appendix D
Technical notes & recommendations: Part 3

Working in homes: The STEP field visits

Fieldworkers

Selecting fieldworkers: Community workers versus professionals

Non-professional fieldworkers with appropriate training and support are able to implement STEP effectively, but still require additional support. Rehabilitation professionals could play a complementary and supportive role to fieldworkers but should be trained in STEP before being required to do so. It is important to distinguish and articulate the roles of the fieldworker versus clinical rehabilitation within the STEP programme. These healthcare workers are different and meet niches in the healthcare system, but are complementary and if the roles of defined, can provide efficient and holistic care to CWDs and their families.

Selecting fieldworkers: Essential qualities of a fieldworker

The overarching characteristics of effective fieldworkers:

- Passion and motivation to work with CWDs
- Willingness to learn and develop their skills

Home visits

Caregivers' perspectives on home visits

- Home visits should be arranged in advance for a time convenient to the family.
- Frequency of visits should be guided by needs and circumstances.
- Telephonic follow-ups can substitute for visits at times when intensive input is not needed.

Community perspectives on home visits

Although mostly very positive, home visits may have unexpected negative consequences for families, especially when foreign visitors accompany fieldworkers. Visitors and their organisations need to be mindful of this, and to be guided by local staff in their choices and actions in the field.

STEP reasoning process

Assessment and identifying needs

The addition of other tools (possibly for professionals) such as the Manual Ability Classification Scale (MACS), Communication Function Classification Scale (CFCS) and the Eating and Drinking Assessment and Classification Scale (EDACS) may be beneficial too in shaping child-focussed interventions and aligning them with international assessment practice.

Goal setting

- Consider modifying or replacing SMART format, which is not realistic for this client and fieldworker group
- Address household as well as child-focused goal setting
- Equip fieldworkers to break larger goals into smaller steps, through understanding of developmental components and sequences
- Include training on the counselling dimension of goal setting with families

Intervention planning

- Ongoing training is needed to extend the range of intervention strategies available to fieldworkers

- Training should focus on family-centred strategies as well as child-focused ones
- Fieldworkers need coaching in the difficult conversations often arising with families, especially around needs they are unable to address

Most common interventions during STEP visits

Interventions with children

Motor skills: Positioning and moving

Fieldworkers taught positioning in lying, supported sitting or supported standing in more than half of the homes (55%). On evaluation of their practical skills, we did find that the position options were limited, and fieldworkers found it difficult to problem-solve alternative positioning strategies or adaptations on techniques when the need arose. Passive stretches were taught as a means of tone management in 42% of the cases; this was done with varying degrees of finesse and success. Some caregivers had been taught the appropriate technique matched with the child's need, but unfortunately others were still using an outdated approach for tone management. Almost 80% of caregivers had hands-on facilitation techniques demonstrated to them on how to guide movement patterns with their children, i.e. hand over hand facilitation.

Oromotor skills: Eating, drinking and communication

Feeding difficulties was raised as a common problem by two-thirds (66%) of the caregivers in the evaluation sample. Approximately 40% of the children had feeding addressed as part of their intervention plans. Fieldworkers relied mostly on positioning during feeding, i.e. manual hold, CP chair or wheelchair and on introducing alternative feeding methods to the caregivers. The use of upright positioning in CP chairs was seen to improve feeding practices and interaction, thereby improving function and quality of life in the relevant homes.

Only 26% had received recommendations on appropriate food types, textures and preparation. Of concern, was that no assessment of feeding safety was done in any of the children. Although a specialised area of expertise, without ascertaining safety, fieldworkers run the risk of giving advice poorly matched to the safety profile, putting the child at further risk of choking, aspiration or malnutrition. In addition, no preparatory oro-motor work had been done which would ease the transition into improving feeding, communication and drooling management.

Promoting communication was only evident in a fifth of the logbooks. Fieldworkers and caregivers shared that the intervention around communication had been limited to encouraging caregivers to talk to their child during the day or during activities.

Activities of daily living and play

Children with CP often struggle to engage in self-care activities due to difficulty with motor control as well as the cognitive planning and communication required to execute the tasks. Fieldworkers can provide strategies to ease the burden of ADL tasks for parents or demonstrate how they could include their child in these tasks that would promote mastery and participation over time, if not independence. However, providing intervention based on ADLs was limited in the sample group. Toileting, one the ADLs that gained priority status from the caregivers, was only addressed in 11% of the households.

Play was encouraged with a third of the children, higher than anticipated as play is correlated with culture and family priorities. In many African homes, play is deemed a luxury or unproductive as learning should be school-based or a child should be engaging in domestic tasks. The play encouraged thus far in STEP interventions has been suggesting playful interactions with other adults or siblings

and the use of basic toys for sensory stimulation. The interventions have therefore been more focussed on stimulation than play in the true sense of the concept.

Mobility and assistive devices

The issue and use of assistive devices were varied across countries, largely due to access to devices within country. Uganda had easier access to devices than Kenya and Cameroon. Cameroon relies heavily on donations of assistive devices, but it was encouraging to see them work alongside caregivers to design and make assistive devices out of locally available materials.

Overall, 39% of children received CP chairs, 32% wheelchairs and 13% standing frames. Caregivers shared that standing frames were used less frequently as they were uncomfortable. Many of the chairs and wheelchairs unfortunately were not the ideal fit for children and would require adaptation. Most fieldworkers were able to identify the need for adaptation but would not be able to analyse what or how to make the adaptations within the home.

Training & support tools: Building fieldworkers' capacity

Training overview

What is CP?

"If they don't understand it is very difficult for them to accept, even what we are doing...So even though there is a lot of improvement in the child, she can't accept it" *(Cameroonian focus group discussion)*

Fieldworkers reflected on the value of having a better understanding of NDs as this is the first obstacle to work on with caregivers. Due to the prevalent traditional health beliefs and stigma around disabilities, as well as often limited or inaccurate explanations at healthcare facilities; counselling and education are used as a first step towards understanding and accepting the condition, the child and the fieldworkers' intervention.

Feeding

Feeding and swallowing problems were common, and fieldworkers experienced the most significant success and change in feeding practices through teaching positioning techniques, with manual or with assistive devices. Skills also used were discussing frequency of feeds, consistency and food selection.

Other skills that may be useful in future master classes could include working on generic oro-motor strategies to promote feeding, lip closure, drooling and support communication. Reinforcing learning on independent finger-feeding, lateral feeding and cup feeding could provide fieldworkers with more options to assist with feeding difficulties. Looking at options around assistive devices, such as bottles, cups, spoons may also be useful. Links need to be made with families regarding the connection of feeding to communication and speech as well as dental hygiene.

Epilepsy management

Current intervention relied on referral only to mental health services, psychiatrist or psychiatric nurse. Other skills to add could include how to recognise seizures and educate families on the impact of seizures, how to communicate about seizures to other healthcare workers and mapping the best options to access local services for the management of epilepsy.

Nutrition

People tend to eat 3 meals in the day, if they can afford it, with long breaks between (e.g. breakfast at 07h00 or earlier, lunch at 13h00, dinner at 21h00), but because children with ND's take in very little at once, they need to eat more often in the day – therefore caregivers need be educated about

frequency and adaptation in daily routines to accommodate more frequent feeds. Increasing the frequency will decrease the risk of volume-related malnutrition.

Decision on whether food supplementation is going to be made available through STEP needs to be made, and then also the criteria for whom qualifies, type of supplementation and the duration. Linking to nutritional advisors or UNICEF's Infant and Young Child Feeding (IYCF) programme/training may result in lessening of supplementation by rather educating on food diversification and adaptation for feeding difficulties.

Assistive devices

Toilet seats or commodes

Many children are incontinent and particularly the paid carers or extended family did not want to deal with toileting and mess. Many wanted to either leave their jobs or family members no longer visited or helped out. Additionally, children have physical limitations impacting toileting, such as difficulty squatting or sitting on a bucket. Issuing of commodes allowed for easier toileting for caregivers, less mess, more socially acceptable.

Standing frames

- Problematic design promoting knee flexion and sliding down
- Minimal use in homes of the standing frames provided
- Do fieldworkers feel confident doing the positioning and activities in standing frames?

CP chairs and seating

Fieldworkers were able to recognise problems with seating but did not know how to correct it in the field, so were sending chairs and children back to central sites which is costly and time-consuming. Teaching simple seating principles and adaptation techniques could allow fieldworkers to address these challenges within the homes or during coaching visits. Also need coaches who understand the principles of seating and seating adaptation. Consider adaptations in design: adjustable, tilt in space, IT blocks, adductor blocks (overuse seen...know when it is needed!), tray tables. The most essential component in seating of stabilising the pelvis was not considered in most of the seating cases seen, no use of pelvic straps, IT blocks of understanding of pelvic positioning.

Splinting and orthotics

Almost no use of splints, even by occupational therapists. May benefit from simple wrist extension splints, thumb abduction splints, soft splints, etc. to promote functional use, promote hygiene and minimise deformities. In-country occupational therapists may need additional training in static and soft splinting, making use of local resources.

Alternative assistive devices and toys

Large focus on positioning devices only, consider others such as built up grips, cutaway cups, drinking aids and recycled, low cost toys. Limited uptake or recall from current training, consider what was done and mode? Also explore culture of play in children in context.

Activities of daily living

Assessment of ADLs was a helpful approach as it helped the fieldworkers and family understand what the child can and can't do – can he wash his hands, dress… They could explain what ADLs are and encourage caregivers to allow the child to try, they relied on positioning and common sense or prior training, not much from the STEP training. Many had difficulty adapting ADLs for increased participation. Interest in using activities and toys to foster learning, may benefit from toy-making workshops and understanding developmental stages and matching appropriate activities.

Recommendations for training

Training design and andragogy

Andragogy refers to specific techniques to maximise adult learning; based on the premise and principles of adult learning, the STEP training could enhance the retention and integration of learning. One of the key principles in adult learning is to build on existing mental frameworks and schemas.
The first training could thus provide a general introduction and provide sufficient foundational information and skills for fieldworkers to go out and start. They do home visits for 3-4 weeks whilst keeping case studies and their own logbook. This period can be used to develop their confidence and modes of peer discussions as well as to encourage reflection on practice.

The second training could then be scheduled to build onto the schema or framework already in place are the first training and practical experience. Reflection on learning and challenges shape this workshop, with the focus on building on the reasoning and planning skills.

Different levels of training

Parent support group

- How to start one, how to develop leadership within group, group handling, group growth, developing a vision and goals for the group
- Training of caregivers on STEP programme as a collective group
- Training caregivers to become future STEP fieldworkers or day care facilitators

Fieldworkers: multiple short courses

- Adult learning approach
- Responsive workshops to their needs and challenges
- Peer learning or cross-organisational skills

Coaches or therapists

- Training on how to do reflexive supervision and coaching
- Support versus doing

Organisational level

- How to integrate STEP into overall organisation and adequately support it
- Budgeting and allocation of funding – systematic and sustainable approach

Strengthening content

Areas identified for additional strengthening within the existing training programme included:

Rehabilitation Problem-Solving (RPS)

Topic	Recommendations
Identifying risks High risk social situations	Caregiver mental health status Risk of mercy killings Acute social problems
Goal setting	See more detailed comments in section
Intervention planning	
What next?	Selection and grading of new goals and interventions

Child intervention strategies

Topic	Recommendations
Multiple disabilities	***"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"*** *(Ugandan fieldworker)* Approach to sensory impairments Handling of NDs with little prospect of change
Challenging behaviour	Discipline strategies

Communication	Communication & interaction for low-functioning children Strategies beyond talking to the child during daily activities AAC boards?
Hand and fine motor function	Preparation for ADL or play participation Strategies to improve hand function
Activities of daily living	
Dental hygiene	Caries, pain, thrush, poor hygiene, bite reflex
Toilet training	Stages of awareness Training routine & techniques Using pictures and related tools Adaptations for poor postural control, seating options, commodes
Drooling management	Oro-motor stimulation strategies, compensatory techniques
Sleep	Calming strategies, routine
Play, stimulation and learning	
Play and stimulation	Building blocks of child development Developmentally appropriate play skills & training Developmentally appropriate toy-making with local materials Cognitive development and stimulation
Home-based education	Activities where school isn't an option
School inclusion	Who can be included at school Working with teachers and principals

Caregiver intervention strategies

Topic	Recommendations
Caregiver coaching	NIVEA, OMA, LSD, motivation interviewing (psychotherapeutic technique) described in training, not seen/spoken about https://www.onderwijsmaakjesamen.nl/actueel/downloads-oma-oen-dik-nivea-en-anna/
Counselling strategies	How to have difficult conversations Setting boundaries on scope of work with STEP – at the initial visit, first frame what step can offer/is about before opening can of worms needs Young woman to counsel older caregiver, outside personal scope...
Parent support groups	How to start a group Training group leadership Group handling strategies
Family empowerment	Collaborative livelihood problem solving

Supplementary content

Hygiene

Poor domestic and personal hygiene results in higher frequency of illness for caregivers and all children in the home, thereby increasing the cost of healthcare to the family. By assisting in developing healthy hygiene practices, some common health conditions can be reduced. Some fieldworkers already incorporate hygiene practices into their home visits, as was evidenced at *BEH5* where an emphasis on hygiene has impacted the general health and wellbeing of the family.

Basic health education

Many families may have limited access to primary healthcare, particularly accessing these services with a CWD. Common health concerns can be addressed within the home as an initial step where

access to healthcare may be difficult. This could include basic knowledge on identification and home-based management of simple conditions that are prevalent in children with NDs.

Condition	Basic health education options
Urinary tract infections	Hygiene, circumcision, bicarb/citric soda
Pressure care and wound management	Positioning, cleaning, dressings
Importance of basic child healthcare even for CWD	Vaccinations, deworming
Skin conditions	Scabies, tinea, impetigo, hygiene
Constipation	Massage, diet, activity
Gastroenteritis	Oral rehydration solution
Respiratory conditions	Identifying aspiration pneumonia, TB

These 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.

Other support tools

Logbook

Shared language has important implications for projects such as STEP which are both community-based and spread across countries and regions. Language differences and varying degrees of reading literacy should be considered, use of simple language and images/diagrams as visual aids to support text in logbooks. Generic language may be beneficial as many terms cannot be translated and are hosted in the English at the workshops. Fieldworkers can then write in whatever language they are comfortable with.

Coaching and support

Selection and roles of coaches

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. Need to weigh up the benefit of therapist-lead home visits versus therapist-lead support and coaching. Clinical rehabilitation has a place within STEP but is not the whole focus. Therapists can use their clinical knowledge to develop the critical thinking and intervention skills of the fieldworkers. Training of therapists in STEP so they have the same background and updated approach to ND's and then providing skills on how to coach which stands them in good stead both with fieldworkers and their colleagues or students they may have to supervise thereby strengthening the rehabilitation sector internally. Promoting mental wellbeing by providing tailored and skilled supervision and reflection times.