Evaluation of Home Based Rehabilitation project

Capacity Building of Persons with Disability in the Community Organization (CABDICO)

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Methodology

Between the 20th and 29th of August, I spent approximately 8 days traveling to visit CABDICO projects in Banteay Meanchey, Siem Reap and Kep. I interviewed 10 field staff and 13 families who received Home Based Rehabilitation (HBR) in Siem Reap and Kep. I also spoke to numerous Self Help Groups in Banteay Meanchey.

I tried to measure the approach and impact of the HBR project from both the perspective of staff and also the families of children with disabilities. In particular, I focused on caseload management, and whether or not there were exercise and communication materials.

I attempted to compare the existing HBR project with the World Health Organization (WHO) CBR guidelines, which talks about components that are necessary in a comprehensive rehabilitation project. The purpose of this was to see where the gaps were, while still allowing for plenty of room for qualitative questions that would discover more information.

As a result of this assessment, there are 33 recommendations that I have made. Recommendations follow one continuous list from 1 to 33 throughout this document. In Appendix 1 you will see the additional work plan that I have added in, which demonstrates when I intend to follow up with the recommendations listed. Appendices 2-4 show full responses from interviews.

Key findings

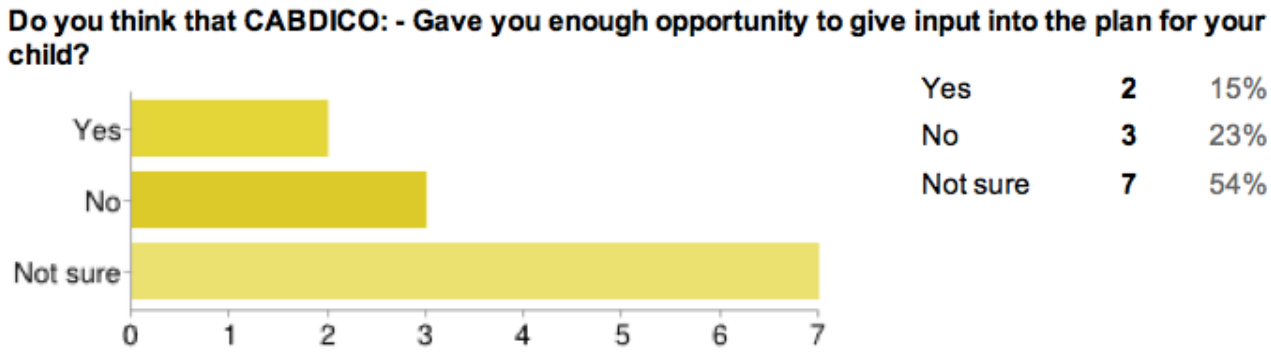
1) Problems with goal setting and ending treatment (discharge) are limiting the effectiveness of CABDICO's work.
2) Families demonstrate a clear understanding of "what" rehabilitation is, but not "why" it is being done. This relates to greater problems around goal setting. There is a lack of understanding about "why" CABDICO does what they do, which perhaps means that staff are not explaining this well enough or involving families in setting plans and goals.
3) The effectiveness of some of CABDICO's treatments needs to be reviewed by Mr Bun Eang and staff. See recommendations 9-13.
4) There are key areas that CABDICO can improve on, which will involve some input from myself (as a consultant in the next 12 months) and beyond - these include materials for exercises, information/materials on communication, working with moderate/severely impaired children and assistive devices. The parts that I can help with are indicated in Appendix 1.

Full findings

A) Plans and goals

The WHO recommends that rehabilitation should include individual treatment plans, with clear goals defined at time of assessment. Generally speaking, CABDICO did this throughout their projects. In terms of the purpose of rehabilitation and knowledge of what these goals are, many families didn't understand *why* their child was receiving treatment, but instead understood the *what* of treatment. Most families were unaware of what the goals of treatment were, written by the field staff in the Yellow Book.

This is a problem for two reasons. Firstly, it shows that there is a lack of ownership by families over the goals of each child. Only 2 families believed that they were given enough opportunity to have input into the plan for their child (see below). Secondly, it shows that the goals of the family and field worker may not be the same - which was often the case. When I asked families what their goal for the child was, it was often completely different to what was in the Yellow Book.



Recommendations:

1) CABDICO staff should ensure that goals set use the S.M.A.R.T. criteria (Specific, Measurable, Achievable, Realistic, Time-bound).
2) Goals should be given to the parents so that they are clear on what they are and have ownership over treatment and achievement of these goals.

There was certainly some confusion over goal setting and how they affected treatment. The situation was different between Kep and Siem Reap.

Goal setting in Kep

Field staff in Kep reported that if the family decides to change the goals set on initial assessment, they are then able to the rewrite the goals in the yellow book. For example, goals can be added in, and treatment continued until the new goals are reached. He also indicated that he follows the rule of discharging the child after 3 years, or if the child has improved and the mother has gained enough knowledge to manage the child they can be discharged early.

There is no reason why children should be seen as long as 3 years in some cases, or should not be seen longer than 3 years in other cases. Furthermore, saying that the child has improved or the mother has gained knowledge on how to manage the child is both vague and difficult to measure.

Recommendations:

3) CABDICO should review the policy of not providing treatment to children for longer than 3 years. Whether the child should be discharged should be based on how much progress the child has made towards reaching goals. For example, goals could be reviewed every year, and if the child has not made significant progress towards goals, either the goals can be adjusted, or the child can be discharged.
4) Further recommendations below for Siem Reap also apply to Kep.

Goal setting in Siem Reap

CABDICO's Rehabilitation Guidelines indicate that rehabilitation should be guided by a specified closing date of activity and no case should be rehabilitated for more than 3 years. In practice, field staff have 2 criteria to cease treatment:

1) The child reaches the goals set at initial assessment or
2) The family is able to care for the child independently.

Field staff in Siem Reap indicated that there is the possibility for families to come up with new goals, in which case treatment can be extended. Even though the Rehabilitation Guidelines indicate that "each case should be re-evaluated every three months", goals are generally not changed once they are set at the start. There is no possibility to change the goals, because the goals that are set at initial assessment determine whether treatment is continued or not.

The problem with the way that CABDICO sets goals and then determines treatment is clear with the case of Veng Sokai, from Siem Reap. This 15 year old girl with Cerebral Palsy had been seen since 2009 by CABDICO staff. When the child was first seen, the family had very little idea about realistic expectations for the child, and the goals set were:

1) Walk independently with assistive device in the house,
2) Feed independently.

In 2009, *mobilization* was a key goal. However, the child is moderately to severely affected by cerebral palsy and as treatment continued, it became clear that these goals were not realistic. While speaking to the family during my visit, I asked them what their main goals for the child are now. They indicated that their main goal was to have the child sitting in front of the house, so that she did not spend most of her time lying down in the back of the house – in other words, *socialization* was their primary concern.

The current treatment of CABDICO was guided by the goals set in 2009. The field staff were trying to get the child to use a trike to mobilize around the house, however the family told me that the trike did not have enough support on it and needed heavy modifications. The problem was that the trike was the wrong piece of equipment, and it was being supplied with the 2009 goal in mind – *mobilization*. Because the family's expectations and hence goals had changed since then, the new goal of *socialization* would have better been achieved by a different piece of equipment – perhaps a chair with more support, rather than a trike.

Recommendations

5) CABDICO needs to rethink their criteria for ceasing treatment. Rather than simply saying that treatment ends when goals are achieved, there needs to be the possibility to change goals as expectations change. This means perhaps that treatment should be ended when the child stops making progress, for instance.
6) Goals that are set at initial assessment are often unrealistic and should be able to be reviewed at a set time afterwards (for example 6 months after initial assessment).
7) Goals should be able to be changed based upon the progress (or lack of) of the child.
8) Even though this does occur to a certain extent, CABDICO staff need to be able to set Long Term (~3 years), Medium Term (6 months to 1 year) and Short Term (1 to 3 months) goals for treatment, which can be changed as needed. Short Term and Medium Term goals are intermediate goals that can progress the child towards achieving Long Term Goals.

B) Treatment

In terms of CABDICO's actual treatment, the variation is quite large. As part of their HBR project, CABDICO offers the following to families of children with disabilities:

- Teaches exercises to families in order to improve the function of the child
- Teaches the family how to better care for the child, in terms of hygiene, feeding, communication and self care
- Provides assistive devices (such as wheelchairs, special seats, toys for fine motor skills, equipment for feeding etc)
- Modifies the home environment (for example, concrete modifications to an area and building bamboo rails)
- Provides emergency funding so that the family can accompany the child on hospital visits (see more on this later)
- Refers the family to other services
- Provides food assistance (for example, rice and milk powder)
- Provides equipment for school (such as pens and books)
- Talks to school authorities to help child attend school

Families indicated that they have further needs that they would like CABDICO to provide, including:

- More assistance with speech therapy (both in terms of communication and feeding)
- Greater assistance in getting child to school
- Trike powered by feet – mostly for recreation rather than mobilization
- Build a new roof so that the child can sleep in a designated area in the house
- Money for clothes and food
- More information about nutrition for the child
- Money to send child to school
- Filling in a pond so that the child can play over it

It is important that CABDICO considers what their intervention is trying to achieve. Is CABDICO a comprehensive service that aims to assist families in all possible ways (eg

even nutrition and providing food assistance)? Or, does CABDICO specialize mostly in physical rehabilitation and integrating the child to school?

Can CABDICO provide financial assistance to help the families and if it does, is it enough? It's worth noting that when CABDICO provided funds for the family to accompany a child to go to hospital – it was **much** too little. For example, one family was given $2 to help send a mother to hospital, but she estimated that she needed at least $25 as she spent 4-5 nights with the child.

Clearly, families will ask for assistance in terms of a wide range of treatment areas, and it is up to CABDICO to determine whether they are able to sufficiently help in all the areas that are needed. It is also up to the organization to be aware of what other services exist to help in the area. If CABDICO aims to help in too many areas, then it runs the risk of being ineffective in any of the treatments provided, by trying to do too much.

Recommendations

9) CABDICO clearly defines, in their own policy documentation, what treatment they are able to provide to families and what they cannot provide, in which case they will refer on to someone else.
10) This information is effectively conveyed to families in writing or otherwise.
11) CABDICO reconsiders whether it should be giving grant money for hospitalization at all (considering that the amounts given are much too little). CABDICO can also consider increasing the amount that is given in these cases.
12) CABDICO raises money individually for certain cases – for example, seeks donors for specific pieces of equipment (such as the trike requested), certain amounts for food assistance, or certain amounts of money that can be given to families. I believe at present this is occurring - for example with the case of Nak Sota through a Dutch donor. However, this donor only donates to surgical cases. Setting this up more formally for other one off donations could be very effective for CABDICO.
13) CABDICO more effectively maps out services in the area (I believe Handicap International is already doing this in Siem Reap) so that they can see what services would be better provided by other organizations.

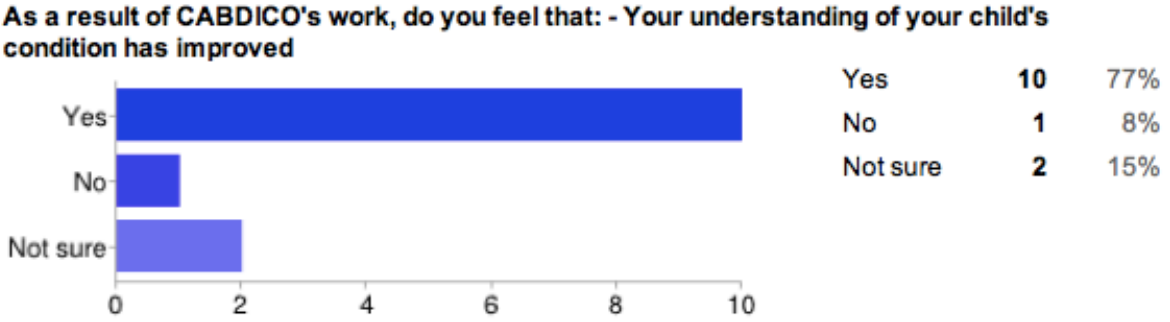
C) Caseload management

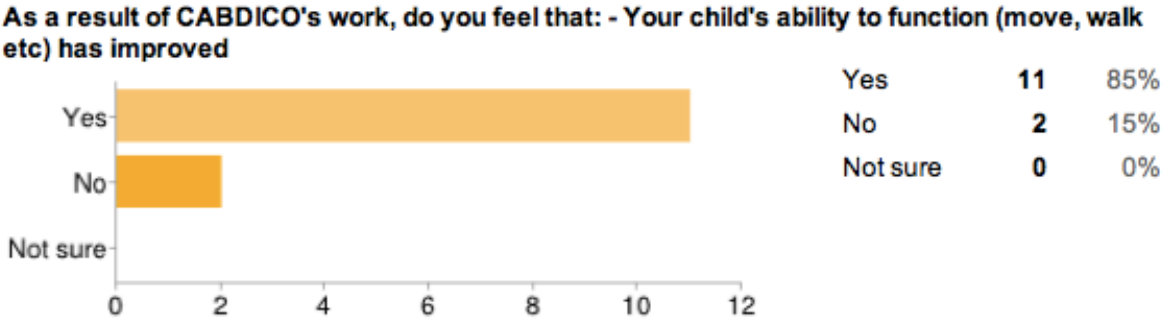
According to the Rehabilitation Guidelines, each field staff has the responsibility to rehabilitate 36 children at one time. This load is split up according to geographical locations in Siem Reap. Children are either referred to CABDICO through a volunteer who lives in the community, through teachers or through families that contact CABDICO directly.

Some field staff indicated that the 36 cases was about right, however some also indicated that they were only able to see the families once a month, because they didn't have the capacity to see them more often. 4 out of the 13 families indicated that CABDICO did not visit their child often enough.

Even more important than how often CABDICO visits is the effectiveness of these visits. Overwhelmingly, families indicated that as a result of CABDICO's work, their

understanding of the child's condition improved and their child was able to function better (see below).





Keeping in mind that there is no standardization of how often children are seen, there is also evidence that some children were being visited without clear gains or improvements. For example, one of the children with moderate to severe disabilities was seen 2-3 times a month, yet the progress of the child was minimal. Ideally, a child of this nature should/ could be seen less often, with more maintenance or monitoring than hands on treatment. This means that a child that has less potential to improve is being seen instead of a child with more potential to improve.

Of course, standardizing the number of times that a child should be seen is very much dependent on each organization and their local context. For example, factors like the time taken to travel to see a family, or the amount of time that the field worker needs to spend at meetings, all influence this aspect of treatment. Looking into what standards or guidelines exist, and then working with the field staff so that it is relevant for Siem Reap and Kep would be the best approach.

Recommendations:

14) Investigation into classification systems that other organizations use to standardize the number of visits that field workers do. This could be based on the potential of the child to improve or the level of impairment.

15) Work with the field workers so that this standard is contextualized in the areas that CABDICO works.

16) Put these recommendations into the Rehabilitation Guidelines so that CABDICO attempts to standardize the number of visits for different children.

D) Moderate to Severe Disabilities

At least one field staff member indicated that she does not treat GMFCS Level 5 (ie child severely affected by Cerebral Palsy) as a general rule. Out of all the families, it was the families with children who are most severely affected who seemed least satisfied with CABDICO's intervention. For example, the family of one 14 year old boy with severe Cerebral Palsy did not feel that their understanding of his condition, his ability to function, or their hope for the future had improved at all. The goals set for the child, and hence the treatment, were too unrealistic. As a result, the expectations of the family were too high and they were dissatisfied with the treatment.

All in all, this seems to indicate that field staff are not as confident treating children with moderate to severe impairments.

Recommendations:

17) Further training to staff on appropriate treatment of moderate to severely impaired children with disabilities.
18) Setting aside a time every week where staff can work through case studies of "problematic" children as a group with other staff members and site supervisor.
19) Ability for field staff to communicate with a technical "expert" regularly to brainstorm through problematic cases (I am happy to play this role for the remaining months of my consultancy, though I do not profess to be an expert).
20) Better use of assistive devices for children of this nature - eg an appropriate chair with stretches may be the only appropriate treatment for children like this.
21) CABDICO staff should be more forceful in setting realistic goals for children with moderate to severe disabilities.
22) Discourage not treating children simply because "they are too severely disabled" - but rather encourage appropriate treatment and follow up.

E) Referrals

According to the WHO, identifying and providing information on referral services in health and rehabilitation should be an important component of a HBR project. Following up after the referral is made is also very important. In the cases where CABDICO staff referred a child to another service, followup was made afterwards. Sometimes the referrals were ineffective in achieving anything, whereas other times the referrals did help.

Field staff indicated that there was no list of places to refer children to for various reasons. This meant that referrals tended to occur simply by asking the supervisor where the child should go to. For newer staff, there is no list of places that they can refer to.

Recommendations:

23) CABDICO creates a list of organizations to refer children to for various services - including contact details and what services these organizations provide.
24) This list is given to new staff so that they are aware of what services are available.
25) This list is available to family members so that they can follow up if necessary.

F) Exercises

One of the key objectives of the field visits was to identify what materials CABDICO provides to families to help them do exercises with the children. In general, there are three different responses by field staff:

1) Nothing written was given to the family,
2) A poster with generic exercises was given, but not tailored to individual needs,
3) Photocopied pages from a book with relevant exercises were given.

Often posters were kept outside and then broke because of the wind, or children played with them. Individual sheets and books were sometimes lost or torn up by the children.

All families surveyed identified that there is at least one family member who is able to read, although the main carer for the child with a disability may not be able to read themselves.

4 of the 13 families interviewed stated that they did the exercises “almost never”, for various reasons. For example, some of them were too busy with farming work to do them with the child. Keeping this in mind, exercises that can be done with minimal or no supervision from the family are likely to be most useful for some children.

Recommendations:

26) Develop, in consultation with field staff, a collection of exercises that can be given to the families as needed. These exercises should be on individual pages and (preferably) laminated or otherwise protected from weather or children.
27) These exercises must contain large pictures and information about how often they should be done and for how long. There should be minimal writing, but some writing is acceptable.
28) The list should include some exercises that can be done with minimal or no supervision from the family.

G) Communication

Out of the 13 families interviewed, 12 stated that their child had some problem with communication.

In terms of what CABDICO currently provides to families to help them with communication with the children, the common response was that nothing written was provided by field staff. Instead, fairly general advice was given to the families - for example, telling the parents to stand in front of the child when communicating with them.

Some families were provided with a very small and simple communication board from the Blue Book, however this board is not comprehensive in any way.

Almost every field staff member indicated that they did not have enough training or resources in improving the families’ ability to communicate with the child.

Recommendations:

29) Develop or adapt a very simple training package on Speech Therapy resources for all staff (it is possible that CABDICO can look into joining an existing training program in this area is necessary).

30) Develop/adapt a simple communication board that families can be trained to use, to improve communication with children with communication difficulties.

H) Assistive devices

Every family interviewed was supplied with an assistive device of some description. These devices varied from items such as wheelchairs, special seats, pillows, bicycles, parallel bars, trike, fine motor toys, and special cups for feeding.

In Kep, a carpenter is responsible for making them. CABDICO pays 15 dollars for materials and labour, for a simple chair. The field worker gives the carpenter a drawing with measurements from the child. In total, even though the carpenter makes only 2 or 3 a year, the field worker thinks it would be useful to have a model of assistive device which is easier to make in the community.

In Siem Reap, generally, it seemed that the families or those in the community were responsible for actually making the assistive devices. CABDICO provided the materials or the funds to purchase the materials. For more complex devices, the Provincial Rehabilitation Centre (PRC) would provide them.

Recommendations:

31) There doesn't appear to be any set design for assistive devices that are supplied by CABDICO. Over the long term, this is probably desirable.

32) There should be set methods of construction, both for how the design looks, but also what the process of construction is (Who designs the items? Who builds them? Who prescribes them?).

33) In reality this is a huge task and something that is probably not within the scope of my current consultancy (however, given my background working with an NGO that provided assistive devices for 3 years, I would be very capable of helping in the future).

Appendix 1

Additional Work plan

In addition to responsibilities outlined in my TOR, I am willing to help CABDICO with some of the recommendations in my report following field visits in August/September 2012. Of course, I cannot take on responsibility to oversee every recommendation, particularly in the time period of my contract. However, I'm happy to help wherever possible.

Recommendation	Implementation Period (July 2012 to June 2013)									
	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun
1-2 hour training to staff on how to take photos of children										
1) - 8) Revise (with Mr Bun Eang) how CABDICO sets goals and discharges clients										
1) - 8) 1-2 hour training on appropriate S.M.A.R.T goal setting and how CABDICO will now set goals										
14) - 16) Investigate whether CABDICO can standardise the number of visits that should occur + work with staff to contextualise this and implement										
17) Discuss with staff possibility of getting further training on mod/ severe disabilities from other organizations + budget to do so with Mr Bun Eang.										
19) Be available to discuss "problem cases" with staff.										

23) - 25) Encourage site supervisors in Siem Reap and Kep to build a list of places to refer to (and then leave it with them to complete)										
26) - 28) Develop information materials with staff on exercises and communication (Output 5)										
29) - 30) Develop simple training package on Speech Therapy resources and communication board (Output 5)										
31) - 33) Assistive devices: work with the site supervisors on ideas to standardise assistive devices (this is the kind of work I could complete thoroughly if contract is extended)										

By viewing the above you will see that recommendations 9-13, 18, 20-22 will require following up by someone else apart from myself (Mr Bun Eang can decide), and that 31-33 is not within the scope of this contract.