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**University of Gondar Community Based Rehabilitation program**

**Building a network of African master trainers in Neurodevelopmental Disabilities**

*Improving the competencies in the management of children with neurodevelopmental disabilities and their families*

**Submitted to: CPA-NL**
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1. **Executive summary**

Neuro Developmental Disorder (NDD) is the most common cause of neurological impairment in children and can be associated with a lifelong disability. Because of the functional limitations experienced, some children with NDD are dependent on others for assistance with daily activities, which leads to long-term caregiving that far exceeds the usual needs of typically developing children. Providing the high level of care required by a child with long-term functional limitations can become burdensome and may affect the caregiver's physical and psychological health. Poor nutritional status is also another common challenge for children with NDD, especially for children in low- and middle-income countries. Due to lack of access to a balanced diet or swallowing problems, children with NDD are exposed to malnutrition. This situation is worse in low-income countries. Children with NDD may also need nutritional support in order to prevent nutritional deficiencies. Caring for a child with a disability affects the role of both parents, but the daily lives of mothers are often more affected because they are usually the primary caregivers for the child. Improving these children's conditions requires coordinated efforts of professionals who have skills in managing NDD, parents, and community rehabilitation workers.

To this end, building the capacity of senior CBR workers, physical therapists, or occupational therapists in the handling of children with NDD is found to be very crucial. The proposed project is designed to enhance the skills of these professionals in NDD by providing focused and practical training on NDD with specific emphasis on their role in supporting and coaching parents and/or caregivers. The training will be conducted for 20 people whom we regard to become game changers and they are invited and known people involved in current CPA programme involvement in Ghana, Kenya, Zambia, Malawi, Uganda, and Ethiopia. In addition, some people from Rwanda and DRC will also be included. It is expected that up to 2 participants will be invited from each participant countries, and 6 participants will be expected from Ethiopia. The training will be conducted in the form of a training of trainers so that the 20 participants will become resource persons and trainers of others (mainly frontline rehabilitation workers) in and for their respective countries.

The training will be provided by highly experienced professionals in the area of NDD management. As stated, the training will be practical in nature and directed at the role of rehabilitation staff - notably frontline rehabilitation workers – in coaching and supporting parents of children with NDD. The training will be provided in Gondar and will be a joined initiative from the university of Gondar, Light for the World and Cerebral Palsy Africa and it is suggested that Cheshire Homes - the strategic partner organisation of the Liliane Foundation – may become part of this initiative as well as they already established a connection with CPA showing their interest in this development.

As the training is highly practical and where possible takes place in the community of Gondar, children with NDD and their parents living in Gondar and already part of the CBR programme run by the University of Gondar will be essential part of the training.

Trainees will be expected to already have sufficient skills and experience in the management of children with NDD. They are furthermore expected to work with frontline mid-level CBR workers, supervisors, and parents of NDD. The professional therapists are expected to assist and further build the capacity of mid-level CBR workers in assessment, goal setting and monitoring of results as part of their action/intervention plans.

This capacity building project which will run for one year although it is expected to have a longer project time up to 3 years in order to carefully monitor the outcomes of this project at the community level. It also is expected to review and discuss during this training the needs and opportunities to address the availability of assistive devices for children with NDD in the Gondar Zuria district of the Amhara Region, Ethiopia and find out if and how CPA - in collaboration with the mentioned partners - can play a role in addressing the large unmet needs that are related to assistive devices in Ethiopia as well.

The proposed training program fits within the broader CBR context and the ICF framework and as such will address issues such as: social support, awareness raising, creating support groups or parent groups, education of children with NDD and active participation parents. The master trainers are expected to support and supervise CBR frontline workers in working with children with NDD and their parents. CPA and the local Ethiopian partners will engage in the monitoring and evaluation of outcomes at the level of the child with NDD, parents and the community at large. Lessons will be shared among all partners and the broader field involved in working with children with NDD in low- and middle- income countries. The success of the program eventually will be measured against indicators such as improved empowerment of parents to support their children at home and improved quality of life of children with NDD and their parents.

1. **General Information**

1. **Organizational background**

The University of Gondar was established in 1954 to create an opportunity for those who lived with malaria through the provision of treatment service and building prevention and control on the local community and the country at large in terms of training skilled healthcare providers. Its vision of 2020 is “to be the leading societal problem-solving University in the country”. The University of Gondar is the only university that ‘owns’ a CBR Programme in Ethiopia. UoG CBR program was established in 2005 in partnership with Light for the World and *Save the Children* to alleviate different problems faced by people with disabilities due to lack of access to rehabilitation services and community awareness. By now, it is providing home to home rehabilitation services in 16 districts of the region to offer CBR services to people with disabilities. Currently UoG-CBR has a total number of 44 staffs that includes a program director, 2 coordinators, 7 office staffs, 6 supervisors, and 28 field workers. Amongst the international donors of the programme are: *Light for the World–Austria*, Save the Children, Austrian Development Agency, some Dutch physiotherapists and the *MasterCard Foundation*. In the midst of a recent programme evaluation, it was noticed and observed that children with NDD need further support regarding assistive devices and rehabilitation services. Therefore, it was recognized that a need exists for a more strong and focused action to improve services for children with NDD and to pilot a new initiative to enhance actions directed at the promotion of project interventions for children with NDs across the nation.

1. **Problem and Rationale of the Project**

Providing early rehabilitation intervention for children with NDD helps to reduce secondary complications. Lack of early stimulation and appropriate interventions leads the child to get into complications and end up with for instance (severe) joint contractures, limited movement, and even not being able to perform the basic activities of daily living. A lack of appropriate assistive devices is also another top challenge that often contributes to poor physical functioning of children with NDD. In support of this, the need assessment conducted by the joint review committee of CBR revealed that there is poor access to assistive devices and a lack of knowledge and skill among CBR frontline workers to provide appropriate rehabilitation intervention to children with NDD at an early stage of their development. Due to the nature of the disability which often requires long-term interventions, children with NDD and their families live in a challenging situation. Therefore, it is within this background that this project is designed. UoG – CBR program has been supporting a total of 795 (F 417) people with disabilities in Gondar; of these 156 (84 girls and 72 boys) are children with NDD. These children in general and children with cerebral palsy, in particular, have been left behind, and major gaps have been observed in their development as a result of limited practical training in the management of NDD, limited support and supervision and the absence of a specialized resource centre and trained individuals in making assistive devices. We believe children with NDD in Uganda, Kenya, Malawi, DRC, and other African counties experience the same kinds of challenges as the children in Gondar area. We anticipate that this new project with UoG-CBR program would bridge these gaps by building knowledge and skills and ultimately improving the life quality of children with NDD as well as their parents.

1. **Project goal, objectives and strategies**

**Overall goal:**

To establish a network of African master trainers in NDD

**General objectives:**

To improve the quality of life of children with NDD (and parents) by providing a highly practical TOT training for professionals in the area of neuro developmental rehabilitation; and

To further establish the importance of assistive devices and develop a proposal that will lead to a situation whereby such devices become more easily available in Ethiopia and other African countries with NDD-Master Trainers.

**Specific objectives:**

* To build the capacity of maximum 20 rehabilitation professionals from a number of African countries and bridge the competency gap in the area of NDD management by the end of year 2021.
* To improve the living condition of 80 children with NDD in Gondar Zuria district through deploying better planning and management of NDD by September 2022.
* To have a robust proposal focusing on the establishment of a local supply of the most essential assistive devices to be submitted to potential donor agencies.
1. **Activities**
2. Recruit participants from seven African countries to participate in the TOT training and communicate with participants about details of the training and all travel related information.
3. Send invitation letters to international participants and ensure all get a visa and other requirements to enter Ethiopia.
4. In collaboration with CPA and LftW, recruit experienced trainers and sign a MoU.
5. Organize ten days of practical TOT training. Participants will be from different African counties, and 6 will be from Ethiopia. The UoG CBR program (including the community of Gondar) will be used as a practicum site for the training.
6. Cascade the training in each of the countries mentioned to (a still unknown number of) mid-level CBR field workers so that they can become a coach in CBR programs working with or parents to better help their children in their development.
7. Conduct in close collaboration with the University of Gondar a baseline assessment, post-training assessments, monitoring and evaluation of outcomes and sharing/disseminating best practices.
8. **Indicators**

**Outcome indicator**

* 1. Families of children with NDD equipped with basic rehabilitation skills and able to support their children with NDD
	2. Physical well-being of children with NDD improved
	3. Quality of life of children with NDD and their families improved

**Output Indicator**

1. Trainees are better equipped to pay a tangible and significant role in training frontline CBR workers to offer good quality services to children with NDD and their families.
2. Parents of children with NDD receive adequate mentorship in the development, parenting and rehabilitation of their children with NDD.
3. Following the training a robust proposal has been developed in the field of the provision of assistive devices in Ethiopia.
4. **Project Sustainability**

This training is designed to provide TOT training for selected professionals who commit themselves to serving their respective countries as training staff and resource persons in the management of children with NDD. Trainees will be expected to provide training for the CBR frontline workers and other therapists in the countries they belong.

A post-training monitoring and evaluation will be carried out and best practices collected, described and shared with CBR programs in order to share a model of care/rehabilitation that is realistic, appropriate, effective and efficient and can be replicated throughout countries in Africa.

An inventory of the most essential assistive devices will be made; a proposal will be written for the establishment of a production line in Gondar, and which will support and is much needed for children with NDD.

1. **Project monitoring and evaluation**

The project will have periodic monitoring and evaluation to ensure whether the project develops as planned or not. UoG-CBR program will conduct a baseline assessment to be used as a scale for measuring the programme's outcome. End-line surveys will also be conducted to assess the programme's progress and results, and the assessment will be documented and disseminated to relevant stakeholders for learning and scaling up of best practices.

By the end of the training, there will be an evaluation to assess how the training was conducted, what went well, and what went not so well, and the assessment results will be documented as a learning for future training. After six months of the training, evaluation questions will be sent out to trainees to assess how the training helps them and children with disabilities and will evaluate their actual engagements in improving services for children with NDD in their countries. Bi-annual project reports, both narrative and financial, will be submitted to CPA to check the proper project implementation. A final evaluation directed at outcomes of the training will be done at the end of the project period, in the Gondar region and will be jointly prepared and executed by the UoG-CBR programme and CPA and reports will be communicated to the CPA. UoG-CBR will collaborate with the CPA to develop a programmatic approach that has the potential to be upscaled to other regions in Ethiopia or countries.