

EXECUTIVE SUMMARY

Cerebral Palsy Africa is a **Dutch Charitable Incorporated Organisation** working in countries throughout Africa to improve the lives of children with cerebral palsy. CPA works with all who strive to enable children with cerebral palsy to reach their potential. It is important to note that it appears a large number of children with neurodevelopmental disability (NDD) born in Low-and Middle-Income Countries such as Ghana and most countries in Africa and their parents/caregivers, are struggling to come to terms with the challenges of managing life (often from birth to adulthood).



Kiss and Huib facilitating the NDD Master Training Workshop



Cross section of the invited guests and participants

It is also evidence that most low middle-income countries especially Ghana lack needed qualified therapists and CBR practitioners to manage NDD conditions. It is against this backdrop CPA-AFRICA, Netherlands, The Salvation Army Ghana and Togo Territory as well as the University of Education, Winneba and two other partners – Multi-Kids Africa and Heart, Hands and Voice Foundation decided to convene a conference on “BUILDING A NETWORK OF AFRICAN MASTER TRAINERS IN NEURODEVELOPMENTAL DISABILITIES” which seeks to improve the competencies in the management of children with neurodevelopmental disabilities and their families in Ghana. This is in line with CPA’s main purpose which is to develop expertise and evidence of best practices on rehabilitation for children with NDD in low middle-income countries and also to provide training programs for fieldworkers to improve skills on identification and functional rehabilitation, including appropriate assistive devices, for children with NDD and their families. This current training held at Gloriaka Marquis hotel in Winneba, Ghana was connected with concrete and practical implementation in the field, with the focus on the participation of the child with NDD in family life and community Monitoring evidence is part of the planning process.



TC & Hon. Presiding Member in a pose during the opening session of NDD Training

INTRODUCTION

The Opening ceremony of the first training for Africa Masters in Neurodevelopmental Disability was hosted by The Salvation Army Ghana and Togo Territory in partnership with the University of Education, Winneba with support from Cerebral Palsy Africa was graced by the above-mentioned personalities. Participants are from Ghana, Uganda, Ethiopia, DR Congo and two additional facilitators from Netherlands, CPA-Africa.



The above picture shows Huib, David (Chairman) and Kees

The programme began with a prayer by Major Edward Kyei (Divisional Commander / a Priest / officer of The Salvation Army Ghana after which Mr Acheampong introduced the Chairman for the occasion in the person of Mr David Norden Botwey, Executive Director of SWEB Foundation a disability-focused non-

governmental organisation based in Accra.



Major Agatha in the middle together with Major E. Kyei & the new communication Secretary Capt. Kyle Maynor-USA

Major Agatha Essel delivered the welcome address, she said she has been observing from close quarters, children who are perpetually trapped at the back of their mothers from birth till age twelve and counting. Some are not able to ambulate no matter how hard the therapist's tries. She further stated that through the forty years journey of CBR services in The Salvation Army- Ghana no children with

Neurodevelopmental Disability has been cured. What is of extreme importance is to enhance the lives of the children through therapy and assistive technology on one hand and social interventions for mothers, on the other hand, to build their economic capacity to be able to support the needs of their children.

Colonel Dr Samuel Amponsah delivered the Introductory Speech, he said the current training is timely and underpinned the mission and vision of The Salvation Army. Despite a clarion call for inclusion, children, young adults and families with Neurodevelopmental disabilities still face the worse forms of rejection,



Colonel Amponsah presenting Certificate to a participant from Ghana while Huib looks on!



The above picture shows the Hon. Mayor of Winneba, Ghana, Chief Secretary and the 2nd in command of The Salvation Army Ghana Lt. Col. Ayanam Friday & wife Lt. Col. Glory Friday and the wife of the Territorial Commander Colonel Hagar Amponsah

stigmatization, discrimination, exclusion, lack of access to appropriate assistive technologies and more prominently, inadequate human resources to manage the NDD conditions not only in Ghana but Africa at large.

He further added that a large number of children with neurodevelopmental disability (NDD) are born in Low-and Middle-Income Countries (LMICs), and their

parents/caregivers are struggling to come to terms with the challenges of managing life (often from birth to adulthood) (CPA-AFRICA Strategic Plan for 2021/2022).



The above flags represent the countries who attended the NDD Master Trainers Workshop in Ghana

While the needs of children with NDD and their parents are enormous and well documented, the tragedy is that LMICs resources (human and material) for appropriate services/interventions to these children and their parents are scarce. In practice, it means that there is a serious shortage of:

- competent rehabilitation professionals and field workers
- appropriate assistive technology as mentioned earlier on and others.

It is against this backdrop that The Salvation Army Ghana & Togo Territory through its Medical Social and Community Services and Rehabilitation Programs agreed to collaborate with its partners to host this maiden training program here in Ghana in order to change the narrative and to bring about the needed change we all desire to see.

The former Director of Liliane Fonds (Foundation) a Dutch-based disability organisation Mr Kees Van Den Broek stated that the purpose of the training was to adopt new ways of managing the condition. He said the old approach/ways that were used in the 80s to manage orthopaedic conditions such as club foot, polio etc. is the same approach being used to manage neurodevelopmental di



The former Director of Liliane Fondation – Kees van der Broek in a media briefing with JOY NEWS

added that this African Masters’ training in Neurodevelopmental disability is to adopt different ways/approaches to manage and help children with the condition and their families with a call on professionals to look for new effective ways to manage NDD.

He further reiterated “There is the need for a different approach in managing neurodevelopmental disabilities which focuses on the wellbeing of the child and the family and centres on the role of parents.

Mrs Hannah Awadzi, Executive Director of the Special Mothers Project, said it was important that therapists and rehabilitation professionals embrace a new way of engaging parents in their approach to managing cerebral palsy and other neurodevelopmental conditions.



Mrs Hannah Awadzi –Executive Director Special Mothers Project/Journalist & Mother with NDD child sharing her true life story and experiences with the delegates

Professor Sakina Acquah the Dean of Educational Studies of the University of Education, Winneba has urged parents with children born with a neurodevelopmental disability to take proper care of them to realise their full potential. According to her, there are institutions and Non-governmental organisations available to assist in caring for such children to grow up to be useful to society.



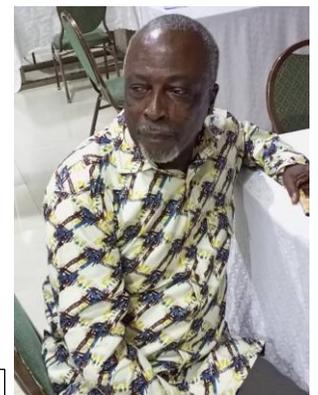
Professor Sakina Acquah the Dean of Educational Studies of the University of Education, Winneba

Hon. Captain Kwesi Eyi Acquah, Presiding Member of the Effutu Constituency represented the Member of Parliament for the area Mr Alexander Afenyo -Markin pledged the MP’s commitment and support towards children’s neurodevelopmental disabilities. He also stated the need for all to get on board to solicit support for children with NDD

and their families. Ms Annelove Prempeh, the Mother of an 18-year-old girl with cerebral palsy shared her experiences with the participants.

Narrating the experiences she has acquired as a primary caregiver to her daughter and was also grateful to professionals who supported her in this journey. A short video of her daughter’s rehabilitation was screened.

Mr David Norden Botwey, Executive Director of SWEB Foundation, a disability based non-governmental organization who chaired the opening ceremony said the training programme was innovative.



Mr David Norden Botwey, Executive Director of SWEB Foundation –Chairman for the ceremony.



Miss Annelove, the mother of Nabilla sharing her experiences with the participants and invited guest during the opening session of the conference.

The story of Nabilla was quite revealing and the delegates were touched as lots of lessons were learnt. Especially the role of mothers and importance of family support and how it plays a critical role in an NDD Child quality of life as part of treatment/therapy process.

PARTICIPATION:

Participants of the workshop were CBR field workers, occupational therapists, physical therapists, Speech therapists, University lecturers and many other dignitaries who attended the training.

OPENING CEREMONY: 4TH OCTOBER, 2021

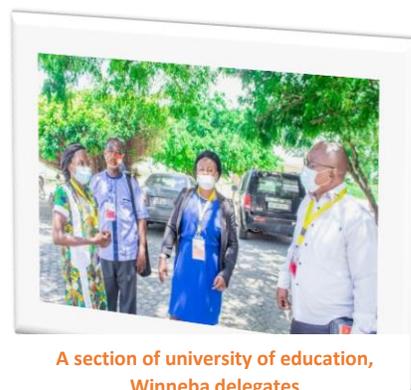
IN ATTENDANCE:

- Col. Dr Samuel Amponsah - Territorial Commander, The Salvation Army Ghana & Togo
- Col. Hagan Amponsah - The Salvation Army, Womens' Ministry
- Lt. Col. Ayanam Friday - Chief Secretary, The Salvation Army
- Major Agatha Essel - Director, Medical, Social and Community Services
- Hon. Alexander A. Markin - Member of Parliament and Deputy Majority Leader



Kees and other delegates visited a family as part of training fieldwork

- Prof. Dr Sakina Acquah - Dean, Faculty of Educational Studies, UEW
- Hon. Dr Robert Ghanney- Head, Department of Special Education, UEW
- Dr Yaw Nyadu Offei - Senior Audiologist, UEW
- Dr Samuel A. Gyimah - Senior Lecturer Deafness Studies,
- Dr Daniel S. Dogbe - Senior Lecturer & former HOD SPED, UEW
- Mrs Joyce Tsatsu - Administrator, SPED UEW



A section of university of education, Winneba delegates

DAY ONE:

The afternoon session saw the start of the training where the goals and objectives of the training were stated as below:

GOAL:

OBJECTIVE 1

To build the capacity of rehabilitation professionals to impact new thinking and improve their knowledge of NDD children and their families from X no. of African countries and bridge the competency gap in the area of neurodevelopmental management.

OBJECTIVE 2

Define results/reflections which we like to achieve 'on the ground' considering the following:

- The functionality of the child
- Quality of life of the child.
- Parents involvement in the child's life and wellbeing 'if the parents do well, the children will do likewise

OBJECTIVE 3:

Learn, share and internalize practical skills and tools for adopting a new approach aiming for better results ‘on the ground’

OBJECTIVE 4:

Draw an action plan for implementation

- Baseline
- Monitoring
- Learn and share and be a catalyst.



One of the facilitators of the training Mr Kenneth joining and supporting one of the group during presentations

GROUP WORK 1 – ROLES AND RESPONSIBILITIES

In groups, delegates were tasked to outline the role of professionals, parents and CBR workers.

Professionals	CBR Workers	Parents
<ul style="list-style-type: none"> • Assessment and Diagnosis • Intervention 	<ul style="list-style-type: none"> • Awareness creation Advocacy • Skills/knowledge transfer to parents • Facilitate social inclusion • Give information to parents • Identification • Setting goals with other • Monitor • Co-ordinate Parents Support Groups • Counselling • Create enabling environment • Community mobilization • Formation of PSG's 	<ul style="list-style-type: none"> Primary caregiver / TLC Monitoring of the child’s development/progress Advocate for their children Basic knowledge of the Condition Assist the child in ADLs Co-operate with professionals/child support Groups Accept child’s condition Seeking professional advice Compliance with professionals Financial support Vital information to professionals and field workers Role model to the child Educating children at home

In a plenary delegates were tasked to select four (4) most important roles of the professionals, parents and CBR workers

Professionals	CBR Workers	Parents
<ul style="list-style-type: none"> • Assessment & Diagnosis • Intervention & Rehabilitation plan • Training of CBR workers (capacity building) • Research for evidence 	<ul style="list-style-type: none"> • Advocacy /awareness/ + social inclusion • Skills & knowledge Transfer • Identification and Referrals to different Institutions • Formation & co-ordination Of PSGs 	<ul style="list-style-type: none"> • Primary caregiver TLC • Monitor child's Developmental progress • Assist in ADLs • Co-operate with Professionals/PSGs

DAY TWO (2)

INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH (ICF)

ICF is the WHO framework for the classification of health and health-related domains as the functioning and disability of an individual, ICF also includes a list of environmental factors.

Levels of disability:

Severe - Fully dependent and cannot use an assistive device

Moderate - Able to use an assistive device, partially dependent,

Mild - Independent.



Another group session / presentations

REHABILITATION FOLLOW UP LOGBOOK

It's a logbook used in assessing children with NDD taking into consideration the following:

In the logbook is the **ladder of life** where field workers and primary caregivers can discuss the level of the child's condition about capabilities and through negotiation come up with an individual rehabilitation plan to help the child move up the ladder with improved condition.

- **Body functions and structures:** has to do with the anatomical and physical functions which are how the body system works e.g. mental functions and nervous system

- **Activities and participation** are activities/adaptions a child does with others e.g. activities of daily living, learning, schooling and playing etc.
- **Personal factors:** information about personal preferences e.g. age, gender etc.
- **Environmental factors:** information about the family and community e.g. built/physical environment (buildings), socio-economic etc.
- **Individual Rehabilitation Plan:** in drawing the IRP caregiver and fieldworker can have different priorities. Negotiation and advice will lead to a compromise with a well thought out plan where the caregiver and the fieldworker are on the same page.

Notable points:

- Huib and Kees will meet with the University of Education, Winneba leadership to help develop a new module for training students
- The therapist should and must work with CBR workers and vice versa.
- Professionals to coach CBR workers to use Logbook correctly.
- What structures your organisation has to support CBR workers.
- Environmental factors are key in setting a plan. Do not set nice rehabilitation plans that do not work instead small plans which are achievable and workable must be considered,
- Intervention monitoring helps caregivers/parents better



Another group sessions during NDD Master Trainers Training

RECAP:

Participants did a recap of the previous day topics i.e. Goal, Objective, Roles of Professionals, Parents and Caregivers, ICF and the logbook. During the recap, it came to light how important the role of the caregiver is important as they are the primary caregivers to do the monitoring and co-operate with the professionals and the field workers.



Group Sessions /Presentations

Appropriate Assistive Technology and Educational Toys:

- Align posture as follows: head, trunk and pelvic. Adaptations like the use of sandbags and cushions to support children, always think outside the box.

- Assistive technology enables children with NDD to achieve independence in mobility and ADL activities. It improves children's participation and activity significantly
- The positioning includes feeding, equipment, feeding materials/tools, the texture of food, nutritional value, feeding place and quantity/frequency
- Communication is very important for a child to understand language and gestures.
- Goals must not be set focusing on the child alone.

Participants were taken through the logbook with special attention to the rehabilitation problem-solving form. These discussions were centred on the caring of NDD children i.e. child positioning for feeding, drinking and activities of daily living including playing and communication. Huib introduced several rehabilitation books and advised fieldworkers to use tools/manuals, including information technology in training, coaching and their actual work.

He listed the following books to use as references: Disabled Village, Getting to know Cerebral Palsy, and The RehApp and flashcards provided in the tools box. He further stated that the Tips Sheets were funded by Light of the World during the COVID 19 pandemic. After lunch discussions centred on the use of Appropriate Assistive Technology and Educational toys. A video was shown about a girl walking with homemade assistive devices but the fieldworker prescribed to aid her mobility. This sparked a huge debate between participants and facilitators. Others felt she is better off with the assistive device (walker) whilst others thought using her homemade stick for support whilst walking is the best. Ken stated that with a new way of rehabilitation we should not try to make the children "perfect" instead we should help enhance the positives/abilities of the children and allow them to do what they can do better and not restrict them with assistive devices which impede their progress. Groups prepared for the next day fieldwork.

DAY THREE (3):

Recap of the previous day's activities was discussed i.e. use of appropriate technology and devices, rehabilitation plans, posture alignment, communication etc.

GROUP WORK 2

Participants in six (6) groups departed for home visits to use the Logbook. Two groups did their presentation which generated a lot of discussions. Rose of Uganda, herself a primary caregiver shared her experiences. She further added that a logbook is a good tool as it allows the caregiver to express his/her feelings.

Points for consideration:

- Need for professionals, caregivers and CBR workers to work together as one cannot do it alone.
- A lot of common sense must be applied, CBR workers should think outside the box.
- If need be parents/caregivers must be separated to allow free flow of information.

- The logbook is more useful to children with NDD with levels 3, 4 & 5.
- Expectations of parents should be managed and not be given false hopes.
- Professionals and CBR workers should look at other abilities of children with NDD.
- Community education and sensitization are key.
- Parents/caregivers should be counselled.
- Offer psychosocial support for caregivers.
- CBR workers should not have a 'stiff back', they should interact more, listen and observe.
- **Certificate distribution to training participants**
- Certificate distribution ceremony to the successful participants of the training workshop.

DAY FOUR (4)

The four remaining groups did their presentations of the children they visited.

Lessons Learnt - ICF

- The ICF model presents a holistic approach to rehabilitation.
- Professionals and field workers need an intersection for a holistic approach to rehabilitation.
- The target/focus of intervention should be on the child and the family.
- The Parents Support Group (PSG) could be useful in counselling.
- The new approach has come with a lot of flexibility, caregiver focused and encourages the social model.

Lessons Learnt - Assessment:

- Assessment should be multisectoral.
- Communication is a vital role.
- Consider sustainability, affordability and more informal procedures,
- Focus on abilities of child and caregivers must be directly involved.
- Consider the emotional, socio-economic aspects.
- Use the holistic approach.

Lessons Learnt - Ladder of (LOL)

- Caregivers are key stakeholders.
- Observe child's abilities and build on them,
- Goals should be negotiated with caregivers
- Employ a multi-disciplinary approach.

- Find an appropriate time convenient to both parties.

A Network of implementing organisations working with children with NDD was formed. Zelalem from Ethiopia was selected as the moderator and Martin as vice moderator.

DAY FIVE (5)

Recap of previous day's topics and discussions.

Groups departed for home visits (fieldwork), followed by group presentations. A beautiful closing ceremony was held and this was attended by the leadership of The Salvation Army, signatories from the University of Education (Winneba) and participants.

DAY SIX (6)

Recap of the previous day's discussions.

Lessons Learnt: Action Planning

- Actions plans should be **specific, achievable, short/medium/long term and time-bound**.
- Caregiver involvement is very key.
- Use and build on workable existing resources.
- Frequent monitoring/follow-ups.
- Tailored to the needs of child and family.
- Involvement of multi-disciplinary teams.
- Regular feedback/reporting.

What did we miss?

- Practical interventions after assessment.
- Basic counselling skills.
- Linking ICF to CBR.
- How to engage children with NDD without being told what to do.
- How to deal with overprotective parents.
- What happens to children with NDD below participatory ages.



The Leaders of The Sal. Army Ghana & Togo in a pose with the conference leaders

CONCLUSION:

Overall, the training introduced the participants to the new approach of managing children with NDDs that goes beyond "fixing" impairments to promoting activity and involvement in the home, school, and their communities. It was a very successful training and Master Trainers will train and coach their field/CBR workers to improve the lives of the children and their families.

Finally, participants were asked to prepare and present their action plans for consideration as it is expected that all the countries and institutions represented were encouraged to start a pilot NDD programs/projects within their communities beginning with smaller number of children. The training ended on a good note and delegates promised to implement and inculcate the knowledge gained in their daily therapy activities.



Pots of flowers were presented to the local coordinating team and Mr. Kenneth, a facilitator from Uganda as a token of appreciation for their various roles in the success of the training.



HUIB-DIRECTOR OF ENABLEMENT AND CHAIRMAN OF CPA-AFRICA, NETHERLANDS ALSO ONE OF THE FACILITATORS OF THE NDD MASTER TRAINERS WORKSHOP WAS QUITE EXCITING AND CREATED POSITIVE HUMOUR WHICH IMPACTED POSITIVELY ON ALL DELEGATES – THANK U
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