



Evaluating the impact of a community –based parent training programme for children with Cerebral Palsy in Ghana



Project Team

International Centre for Evidence in Disability, LSHTM:

- PI: Ms Maria Zuurmond (Research Fellow) maria.zuurmond@lshtm.ac.uk
- Senior Lecturer: Sarah Polack Sarah.Polack@lshtm.ac.uk
- Research Assistant: David O'Banion
- MSc Students: Claudia Donkor, Alison McCracken, Jackie Lee

School of Biomedical and Allied Health Sciences, University of Ghana:

- Local investigator: Gifty Gyamah Nyante Dept. of physiotherapy (SBAHS) UG
- Project Coordinator: Sandra Asante (Physiotherapist, Korle-Bu Teaching Hospital)

CBM & Presbyterian Church of Ghana

- Marjolein Meande Baltussen (CBM Inclusive Child Development (ICD) West Africa Regional Advisor) marjoleinbaltussen@hotmail.com
- Jedidia Abanga (Coordinator Inclusive Child Development Program) jedidiaayoka@gmail.com

Advisory Group Members (Ghana): Lilian Bruce-Lyle (National Council on Persons with Disability (NCPD/GFD) Dr Isabella Sagoe-Moses (Ghana Health Service RCH Dept), Esi Amoafu (Ghana Health Service Nutrition Dept., FHD, Accra, Hannah Awadzi (Special Mothers Project / Journalist), Matilda Asante (Dept. Of Nutrition & Dietetics School (SBAHS) UG), Peter O. Ndaa (Dept. Of Occup. Therapy, School of Biomedical Allied Health Sciences, Mr. Sam Sarpong Appiah (Health Co-ordinator, PCG), Dr Eben Badoe (Neuro- Peadiatrcian Korle-Bu Teaching Hospital

Advisory Group Members (UK): Marko Kerac (Assistant Professor Public Health Nutrition, LSHTM), Dr Mel Adams (Director MAITS) , Dr Melissa Gladstone (Senior Lecturer in Paediatric Neurodisability, University of Liverpool), Dr Faith Martin, Dr Sarah Bernays (Assistant Professor Department of Social and Environmental Health Research, LSHTM)

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- Boadi, Ransford, PTA, Holy Family Hospital, Techiman (Techiman & Sunyani group), Brong-Ahafo region.
- Ayambiri William, CBR Sandema, CBR community officer, Sirigu, Upper East Region (UER)
- Luguzizing B. Joseph, CBR Sandema,PTA Sirigu and Bolga, UER
- Acuroa David , CBR Sandema, UER
- Frederick Nketiah Mensah, Nutrition Officer, Presbyterian Primary Health Care, Bolgatanga,UER
- Adama Johnson Abdulai , CBR Garu, CBR community field officer, Garu & Bawku,UER
- Issah Osman PTA, Bawku Presbyterian Hospital, Physiotherapy Unit, UER
- Anthony Adoboe, Special Education Officer,Ghana Education Services, Dodowa, Greater Accra
- Sandra Asante, Physiotherapist, Head of department, Korle-Bu Teaching Hospital, Accra, Dodowa-group, Greater Accra
- Abass Kabiru Mohammed, DCO, Agogo Presbyterian Primary Health Care, Agogo, Ashanti Region.
- Joseph Ken Adu Poku, PTA Agogo Presbyterian Hospital, Agogo, Ashanti Region



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1 Executive Summary

1.1 General

- Cerebral palsy is the most common cause of physical disability in children worldwide, and yet in most low resource settings there are few services available to support children with cerebral palsy or their families. Research is required to understand the effectiveness of community and/or home based programmes to address this gap. This 2-year study aimed to evaluate a participatory caregiver training programme called 'Getting to know cerebral palsy' in Ghana.
- The training programme consisted of a monthly half-day support group with training, and a home visit, delivered across eight sites in Ghana over 10 months. A total of 76 families and children were included at baseline and 64 families followed up one year later at endline. Children were aged between 18 months and 12 years with a mean of 3.8 years and a range of severity of cerebral palsy. Nearly all (97%) the caregivers were female and the father was absent in 51% of families.
- The study was a pre-post intervention design using mixed methods to evaluate the impact. A baseline and endline quantitative survey was conducted to assess caregiver quality of life (QoL) and knowledge about cerebral palsy and child feeding, health, and nutrition outcomes. Qualitative data was collected to explore the impact and experiences of the training programme in more depth.

1.2 Key findings

1.2.1 Impact on the caregiver

- 'Getting to know cerebral palsy', delivered through caregiver support groups and home visits, was associated with positive changes in the lives of caregivers. At baseline, caregiver QoL scores were low. At endline QoL had improved significantly; overall QoL scores improved by 30% and similar increases were seen across each of the eight domains measured. This improvement in caregiver QoL was evident across all levels of severity of cerebral palsy.
- There was a significant improvement in caregiver reported knowledge and confidence in taking care of their child with cerebral palsy at endline compare to baseline. **Caregiver attitudes** towards the children improved as understanding of the condition increased; this often resulted in greater patience in caregiving. The **self-esteem and dignity of caregivers** increased as they saw that their child and themselves were valued. Understanding that *'they were not on their own'* was key to affecting this change.
- The ability to combine working and economic activities with full time caregiving was a major challenge for most caregivers, especially when children are not in school, and childcare is unavailable.
- At the baseline 61 % of caregiver were unaware of the existence of the Disability Common Fund, and only one family had accessed the fund. At the end of the project awareness levels increased, but difficulties remained in accessing the Fund.
- At the family level, the impact of the training programme was more limited. There were some improvements in terms of improved family attitudes towards the child. However, this change was often small and sharing of knowledge and skills with other family members was sometimes limited. Many caregivers were socially excluded within their families and within the community.
- Stigma, discrimination, and exclusion towards children with cerebral palsy and their caregivers was a major issue. Some progress was made through the training programme, however, considerably more needs to be done to really change attitudes in families, in schools, in health centres and in communities towards children with disabilities.
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- The case studies illustrated the fluidity of family situations, and the intersectionality of poverty, disability, and the gendered nature of caregiving.

1.2.2 Impact on the child

- Child malnutrition and difficulties with feeding and drinking were identified as major issues at baseline.
 - The prevalence of malnutrition in this population was very high at baseline, with 70% of children malnourished, and this remained high at endline.
 - There was a significant improvement in child feeding and drinking scores from baseline to endline. Caregivers were less likely to report problems with eating and drinking and self-feeding at endline.
 - At endline, positioning at mealtime had improved, suitable utensils were used for feeding and a greater variety of nutritious food was offered. However, for children with severe cerebral palsy and with high tone, positioning could still be difficult.
 - The lack of time to prepare separate food, or for long mealtime durations, remained a challenge for poor families, especially when the primary caregiver is also working. Poverty limited the variety of nutritious food available
 - The level of inclusion, including follow up, from local nutritional and primary care services varied, but overall was poor.
- The caregiver's perception of their child's health improved from baseline to follow up. However, the actual frequency of reported serious illness over the last 12 months was high at both time points (> 65%). Episodes of illness in the past two weeks was high at baseline (64%) and decreased slightly at endline (50%)
- Epilepsy diagnosis was commonly not sought, despite convulsions being frequently reported. Access to medication remained inconsistent, even at endline.
- 56% of children were provided with an assistive device (AD) through the training programme, and this resulted in several benefits including improved social inclusion. However, a third of the ADs provided were no longer in use by the time of the follow-up survey and 40% of the main ADs needing repair.
- The standard mortality ratio was 14.61 for children 1-5 years ($P < 0.05$); this meant our children were nearly 15 times more likely to die than children compared to the standard population for developing countries. All the children who died had severe cerebral palsy, and most were severely malnourished.
- School attendance for children with cerebral palsy in this study was low at baseline (29%) and there was some improvement at endline (39% attendance). The main reason for non-attendance at school was that the caregiver assumed the child could not attend or the school refused them because of their disability and there was improvement on this at endline.

1.1.1 The role of the support group

- Overall there was an extremely positive response to the establishment of the support groups by the participating caregivers
- The support group can serve to reduce the sense of social isolation and exclusion of caregivers. It can offer a platform to provide psychosocial support to caregivers, and a safe place to share experiences.
- The collective sharing of experiences can help to address stigma, and facilitate opportunities for peer learning, encouragement, and hope for caregivers.
- The overall cost of the programme indicates that this is a model which is scalable, with some adaptations for rural and urban settings and a review of the role of facilitator.

2 Background

There are an estimated 150 million children globally that live with a disability, and they represent 1 in 20 children aged less than 14 years[1] The vast majority (80%) of these children live in resource poor settings, where rehabilitative services available are extremely limited [2].

Cerebral palsy is the most common cause of physical disability in children worldwide [3] At a recent expert meeting on cerebral palsy in Africa, a mapping of the children's services highlighted substantial gaps in services across 22 countries in Africa (including Ghana). It highlighted the poor availability of medical personal and services with expertise in managing cerebral palsy, and the limited access to health care facilities. For example, in Ghana there are currently only an estimated 150 practising physiotherapists ¹ and the country is now training its first batches of Occupational Therapists and Speech and Language therapists. These numbers are woefully inadequate in a country of over 27.9 million people [4]. Reviews have highlighted a dearth of evidence available for home and community-based programmes in low resource settings and the need for more research to help realise the rights of children with disabilities with suitable support for families[3, 5].

Responding to this need for home/family-based interventions, the International Centre for Evidence in Disability (ICED) developed a participatory community-based caregiver training package for children with cerebral palsy '*Getting to know cerebral palsy*' (GTKCP) [6], which aims to be "*empowering to parents/caregivers*" to improve care and support for children. The programme is a ten-month intervention which consists of a once a month caregiver support group training of approximately three hours, and a monthly home visit. It is a participatory training, and covers different aspects of care and support: (1) An introduction to cerebral palsy, (2) Evaluating your child (3) Positioning and carrying (4) Communication (5) Everyday activities (6) Eating and drinking (7) Play (8) Disability in your local community (9) Running your own parent support group (10) Assistive devices and resources. A key component of the training is promoting and strengthening linkages and referrals to local services.

Although this training manual has proved popular, and has been disseminated widely, no evaluation has been conducted to understand and measure its impact. Responding to this gap, this research aimed to evaluate the impact of the community-based programme '*Getting to know cerebral palsy*'² in Ghana on the caregiver and child, the mechanisms for change, as well as issues related to implementation of the training, so that the intervention can be improved and lessons learnt for scaling up.

2.1 Aims and objectives

The overall research aim was to evaluate the impact of the training programme GTKCP on children with cerebral palsy and their families.

2.1.1 Research Questions:

- What is the impact of the training programme on the QoL of the caregivers?
- What is the impact of the training programme on caregiver knowledge and awareness regarding caring for children with cerebral palsy?
- What is the impact of the training programme on the health, well-being, and nutritional status of the child?
- What are the pathways, barriers, and facilitators for change for caregivers and children who have participated in the training programme?
- What are the costs of the training programme?

¹ Data from the World Federation of Physical therapy at <http://www.wcpt.org/node/24012/cds>, accessed 22/11/2106

² This training material is free to download at <http://disabilitycentre.lshtm.ac.uk/2013/08/01/publication-of-getting-to-know-cerebral-palsy-manual/>;

2.2 Getting to know cerebral palsy in Ghana - implementation

2.2.1 Project location and groups

The programme was implemented across eight sites in Ghana: Four of the training groups were in the 'Upper East' region and four groups in Greater Accra, Brong Ahafo, and the Ashanti region. These sites were selected by CBM and their partner, the Presbyterian Church of Ghana, because they already ran programmes at these sites; in three sites, there was an existing community based rehabilitation (CBR) programme and in five sites an inclusive primary health care programme. Some staff at each site had received training 18 months previously on using appropriate paper based technology (APT) for the development of assistive devices. This is important, as it meant that in all sites there was the option of onward referrals for low cost assistive devices.

The GTKCP support groups are recommended to be run in a community setting rather than a clinical setting. In Ghana, the groups were run in a range of venues; a community hall, a church, a school classroom, and a room offered by a local NGO. The primary caregiver and child attended the training together.

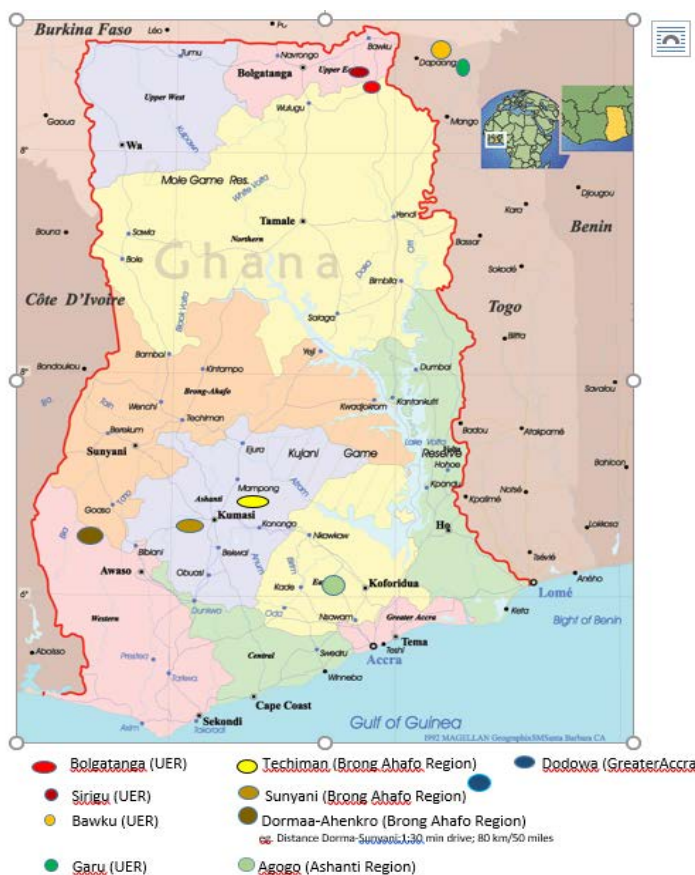


FIGURE 1 MAP OF PROJECT SITES

Caregivers were invited to attend 10 once-a-month participatory group training sessions each lasting of approximately three hours, and a monthly home visit. On average, there were eight parents per group³. Transport or transport costs were provided for all participants who attended. This was particularly important in the rural locations where distances to the support group meeting site were sometimes quite considerable. In addition, all families were visited once per month, for an average of 45 minutes. The purpose of the home visit was: (1) to provide follow up on the training session (2) to engage with the whole family (3) to provide counselling to parents.

2.2.2 Recruitment of children

Children and families were recruited through i) existing PCG- CBR screening programmes for cerebral palsy and ii) hospital physiotherapy department records of children diagnosed with cerebral palsy in the last 6 months, and who had only attended 2-3 physiotherapy sessions. In three sites, there was additional case finding in the target areas during April and May 2015.

Inclusion criteria included children of 18 months-12 years, with all levels of severity of cerebral palsy, and where caregivers were not members of an existing parent support group. This age range was selected because this is the target age group for the training programme, and diagnosis of cerebral palsy in children under 18 months can be

difficult. All children included in the study had a confirmed clinical diagnosis by a physiotherapist and paediatrician at baseline.

At the time of recruiting families, an initial sensitisation meeting was conducted in each home to ensure that the caregiver had family support to attend the meetings. An additional community sensitisation meeting was also organised for the home community to explain the purpose of the support groups. Although, as the women came from many different often dispersed communities, this was not feasible in every community setting.

2.2.3 Recruitment of facilitators

Pivotal to the programme is the role of the facilitators who lead the participatory training and home visits. For this study a pair of facilitators was recruited at each site: one community health worker (CHW) and one therapist (physiotherapist or physiotherapist assistant). The intention was to have a gender balance of facilitators, but in practice 11 of the 13⁴ facilitators were male. For this report, the CHWS and therapists are described throughout by the term 'facilitator'.

3 Methods

3.1 Ethical considerations

Ethics approval was obtained from the London School of Hygiene and Tropical Medicine and from the Noguchi Memorial Institute for Medical Research (NMIMR), University of Ghana. Informed written consent was obtained from all participating caregivers, with a signature or thumbprint as appropriate. Throughout this report all names have been changed to ensure confidentiality.

3.2 Research Design and overview

This study was a pre/post evaluation of the monthly training course for parents of children with cerebral palsy. The study used mixed methods with collection of quantitative, qualitative and monitoring data. Specifically, we conducted a quantitative survey before (baseline) and at the end (endline) of the training programme to measure the impact on caregiver quality of life and knowledge and understanding about cerebral palsy and child feeding, health, and nutrition outcomes. Qualitative data was collected at baseline, mid-line, and endline to explore the impact and experiences of the training programme in more depth.

Although quantitative measures were employed to explore a range of measures, including quality of life, we recognised that understanding people's experience of their lives as a whole, is challenging, and the value of qualitative research in contributing to the deeper understanding of the context is well documented [7, 8]. The use of mixed methods and combining of multiple data sources for evaluation, is also in line with various guidelines for evaluating complex intervention [9]. The UK Medical Research Council (MRC) highlights the value of this approach for understanding a whole range of effects, such as how the impact of a health intervention may vary among recipients and across sites. These MRC guidelines also recommend the development of the theory of change [9].

3.2.1 Using longitudinal qualitative methods to explore quality of life

The primary outcome for this evaluation was the impact upon the QoL of the caregiver. The longitudinal collection of qualitative data over a one year period enabled a more in-depth understanding of change over time and of the multiplicity of factors (see table Figure 2) which impact on children, caregivers, and families. It allowed a fuller exploration of the household context and how it is shaped by the social context, including the economy and social norms [10]. This is important for understanding more fully the QoL of caregivers, in line with the World Health Organisation definition of QoL which states that:

⁴ Some facilitators worked across more than one site

Quality of life is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment, which includes the context of the culture and value systems in which they live [11].

The longitudinal design also facilitates the building up of trust and relationships between the researcher and caregivers and children, thus enabling a more in-depth exploration of often very sensitive issues [12].

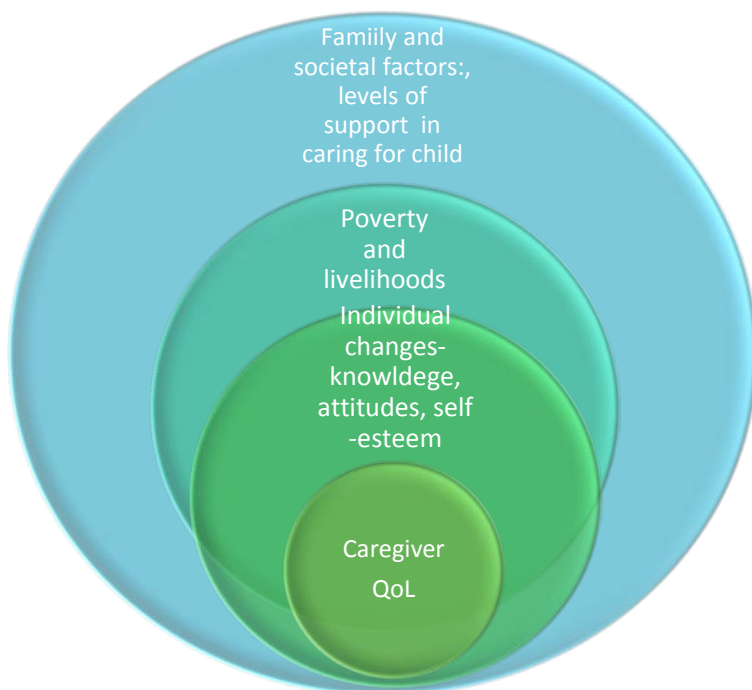


Figure 2 Layering of factors which impact upon QoL.

3.2.2 Theory of change

At the initial planning stage,

a draft theory of change (ToC) was developed to explain how and why this training programme was expected to work, assumptions made and relevant contextual factors. This ToC was informed by the caregiver literature, learning from participatory community-based women’s programmes [13], earlier work by our team in Bangladesh [14], and the adult learning theory which underpins the training approach. In summary, the theory of change considered outcomes and underlying change process at the level of: (1) the individual child and caregiver (2) within the family, (3) community and service level changes.

This ToC approach to evaluation can be particularly valuable for more complex health evaluations, defined as interventions that have several interacting components [9, 15]. The ToC can facilitate understanding of the active ingredients, and how they are exerting their effect, which is essential for ensuring that the design of the intervention is effective for scaling up.

3.2.3 Sub-Studies

In addition to the main study, two sub-studies were conducted: (1) Qualitative study on feeding experiences with malnourished children (2) Mixed methods study on Assistive devices. The results of both these studies are included in this report, but a more detailed thesis of each study is also available separately.

Table 1 Timeline of Research and monitoring Activities

Date	Methods/Activities
May -June 2015	<ul style="list-style-type: none"> • In-depth interview 14 families • Baseline Survey 76* families
June-July 2015	<ul style="list-style-type: none"> • Training groups start • Sub-study on malnutrition with 12 families in three sites

November 2015	<ul style="list-style-type: none"> • In-depth interview 12 families
January 2016	<ul style="list-style-type: none"> • Mid-term learning meeting with facilitators
April-May	<ul style="list-style-type: none"> • Training programme finished**
June 2016	<ul style="list-style-type: none"> • In-depth interviews with 14 families
July 2016	<ul style="list-style-type: none"> • Endline Survey 64 families • Sub-study on malnutrition with 15 families • Sub-study on the role of assistive devices
July 2015-April 2016	<ul style="list-style-type: none"> • Monthly monitoring forms from each group • What app messages collected
June-September	<ul style="list-style-type: none"> • Interviews with facilitators

*One child excluded as did not have correct diagnosis

3.3 Quality and adherence to training

Attendance at the group sessions was recorded. The quality and rigour of the implementation of 'Getting to know cerebral Palsy' was monitored with one monitoring visit per group by the research coordinator/ project manager. In addition, the facilitators established a social media 'What's app group', and this allowed for ongoing support from the project manager, supplemented with monthly phone calls to provide follow up support.

3.4 Quantitative survey

At baseline (June-July 2015) and endline (July 2015), all families participating in the training programme were interviewed, using a structured questionnaire, which collected data on the following:

- Socio-demographic characteristics of the child and caregiver*
- Child's education
- Child's Health
- Functioning of the child *⁵
- Understanding and knowledge about the child's condition
- Nutrition and feeding and drinking practices
- Rehabilitation
- Quality of Life
- Anthropometry
- Gross Motor Function Classification*
- A review of Goals achieved**
- Satisfaction with training**

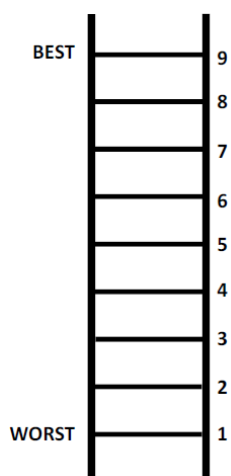
The questionnaires were pilot tested, adapted accordingly and translated into three languages (Twi, Gruni, and Kusaal).

At Baseline data were collected by a paediatrician (LSHTM) and a Ghanaian physiotherapist (University of Ghana) and the endline by one physiotherapist (UG) and one occupational therapist (LSHTM). Data was collected electronically using a tablet and Opendata kit software. The same respondent (primary caregiver) was interviewed at baseline and endline.

⁵ * Only asked at baseline, ** Only asked at endline

3.4.1 Quality of Life Measure

We used the PedsQL™ Family Impact Questionnaire Module as measure of caregiver quality of life [16]. This is a health-related quality of life questionnaire, designed to measure the impact of paediatric conditions on parents and the family. It measures parents' self-reported physical, emotional, social, and cognitive functioning, communication, and worry, as well as daily activities of the family, and family relationships. This 36-item questionnaire, with a 5-point response scale, was administered to the main caregiver.



Linguistic validation of the PedsQL tools was conducted, in line with the permission guidance for use of the tool. This consisted of forward and back translations by small teams of experts (two teams per language) to produce a final reconciled version of the questionnaire. A final phase involved one day of cognitive field testing with families in each of three community sites, to check understanding of the questions and terms, and to agree on a final agreed version in each language.

In addition, a simpler measure of QoL, the 'Ladder of Life', from the Young Lives longitudinal research project [12, 17], was included. The respondent is shown a card with the diagram of a ladder (Figure 3) and it is explained that the top is the best possible life for the caregiver, and the bottom represents the worst possible life (economic, health, social, personal). Respondents are asked to say where on the ladder they feel they are.

FIGURE 3 LADDER OF LIFE

3.4.2 Anthropometric assessment: Anthropometric measures were taken by two trained field workers following standardised protocols adapted for the field. The following measures were taken for each child:

- Weight
- Laying length (0-5 years)/standing height (5+ years)
- Knee height
- Middle Arm Circumference (MUAC)
- Tibia length
- Head circumference

Height/length measurements were obtained twice or more for agreement of <0.5cm and recorded to nearest 0.1cm. Recumbent lengths were taken for children < 5 years. Standing height, when possible depending on the child and environment, was recorded for children ≥5 years. Weight was recorded to the nearest 0.1kg. Children unable to stand were held by their carer, then the carer was weighed separately to calculate the child's weight.

3.4.3. Eating and drinking questions

Information on the child's feeding and drinking was collected using structured questions adapted, with input from the author, from a previous study of children with cerebral palsy in Bangladesh[18]. These eight questions asked about frequency of difficulties with child's feeding and drinking (e.g. How often is it a problem that your child coughs or chokes whilst eating or drinking?) rated on a five-point response scale from 'never' to 'always'.

3.4.3 Gross Motor Function Classification System.

The Gross Motor Function Classification System (GMFCS) is internationally recognised classification system for assessment of the level of severity of cerebral palsy which grades the level of severity of cerebral palsy from 1-5 [19]. It is also worth emphasising that many children had additional co-morbidities, such as epilepsy and learning and behavioural impairments which are not captured through this measure.

3.5 Qualitative Methods

3.5.1 Longitudinal research with families

The main study qualitative field work with families was conducted in May 2015, November 2015, and June 2016, over a 2-week period at each visit. One lead interviewer mainly conducted the interviews, with translation from English into four different languages. Two additional local interviewers conducted interviews in the local language. Every effort was made to interview caregivers on their own. In a small number of cases this was not possible within the cultural context, in extended family settings, where sometimes another family member was present in the compound.

All interviews were conducted in the homes and this enabled observation of the child and caregiver in their local context. On average an interview lasted 1 hour. At endline we used photo-elicitation with photos⁶ taken of the various groups and activities, including their own group activities, to help quickly re-establish rapport with the caregiver, and to stimulate more detailed discussions about the support groups. Photo-elicitation to provoke responses has been particularly useful for groups which lack verbal fluency and can be a good way to concretise issues [20, 21]. For example, we used photos of the group activities to prompt discussion about the other caregivers they knew in the group, how they worked together as a group, what activities the photos showed and their views on the activities.

In addition to the in-depth interviews, multiple data sources are drawn upon: observational field notes, background information on a child's progress from the local facilitator collected in advance of all interviews. All interviews were recorded and transcribed.



PHOTO: PHOTOS TAKEN BY CAREGIVERS IN THE UPPER EAST REGION

3.5.2 Sub-study on nutrition

In the sub-study on nutrition, semi-structured interviews were conducted with twelve caregivers at baseline, and eleven of the twelve caregivers were re-interviewed at endline in order to have a more in-depth understanding of feeding and drinking practices⁷. There were three components to the sub-study on nutrition: (1) in-depth interviews with the primary caregiver, (2) 24-hour dietary recalls, and (3) a short structured mealtime observation. These interviews were predominantly conducted at home. The sampling was purposeful to include caregivers of children who were moderately or severely malnourished at baseline per WHO child growth standards.

3.5.3 Sub-study on assistive devices

This was a mixed methods study conducted at endline only; additional questions on assistive devices were added to the quantitative questionnaire completed by all caregivers (n=64) and 20 caregivers were sampled purposively for short semi-structured interviews. Criteria for purposive sampling were: a range of geographical locations, a range of assistive devices provided and different severities of cerebral palsy.

⁶ All caregivers were given photos of their own group and themselves from previous interviews.

⁷ One of the children had died at endline

3.5.4 Qualitative Sampling

At baseline, the families selected for Case Studies were selected from three sites: one site in the South (Greater Accra) and two sites in the North of Ghana (Bolga and Sirigu). One site was a rural setting (Sirigu) and the other two sites were peri-urban settings (Bolga and Dodowa). In one site, the parent training programme was embedded within a community based rehabilitation (CBR) programme (Sirigu) and in the other sites the training was included as part of an inclusive primary health care programme. A fourth site was added at endline (Agogo).

In-depth interviews were conducted with a total of 21 caregivers; 14 caregivers at baseline (2 months before the training was initiated), 12 caregivers at mid-term (six month after training started), and 15 caregivers at end-line (one-two months after training completion). These interviews, combined with the survey data collected, formed our 'Case Study Families'. In total, seven caregivers were interviewed at three time points, five caregivers interviewed at two time points, and the remainder interviewed once. Additional short interviews were conducted with any secondary caregivers, if they were present at the time of the household interviews.

A mix of purposive and theoretical sampling was used for selection of families to ensure a geographic spread, gender balance, different age bands (18 month-5 years, 6-12 years), and different levels of severity of cerebral palsy. In order to better explore some of the emerging findings and enrich understanding of the ToC, theoretical sampling was used to select five additional families at mid-line, and a further two families at the end line. Theoretical sampling is a way of sampling where the choice of data to next collect is intended to help in further development of the theory, and in this case, we wanted to have a better understanding of the role of poverty. Additional families were added from the richest tertile (the richest third of the group) for us to better explore how poverty shapes the lives of the children and caregivers within the programme.

3.5.5 Training Programme Implementation lessons

At Endline, interviews were conducted with facilitators (one facilitator per site) to explore key issues related to implementation of the programme. In addition, a review of the use of the what's app group is underway, to explore its role in the implementation of the programme. This data will be reported on in a separate report.

3.6 Monitoring Data Collection

All facilitators completed monthly monitoring forms which included: attendance data, referral information, highlights of the monthly training, and challenges faced in delivery of the training and home visits. A mid-term learning meeting was also conducted with all facilitators and Most Significant Change stories (MSC stories) collected from facilitators. MSC stories are a commonly used evaluation tool, whereby personal accounts of change are collected, and discussions about why they are significant [22].

3.6.1 Mortality data

Following the death of a child, a home visit conducted by the local facilitator to ascertain cause of death and circumstances related to the death. A standard mortality ratio was calculated which is a measure of the 'excess' deaths compared to the standard population.

4 Analysis

4.1 Quantitative data analysis

The quantitative data were analysed using Stata 13. For the purposes of analysis, the 5 level GMFCS was reclassified into 3 groups: mild (levels I and II), moderate (levels III) and severe (levels IV and v).

PedsQL sub-scale and summary were calculated as the sum of all items divided by the number of items answered (ref). These scores were converted into scores out of 100 with 0 as the worst possible score and 100 as the best score.

We generated a composite feeding score comprised of the eight feeding/drinking questions which ranged from 0 (extreme difficulties) to 100 (no difficulties). To assess the internal consistency of this composite scale we calculated

that the Cronbach's alpha coefficients were >0.7 and item-total correlations were >0.3 as per recommended guidelines for reliability.

It was not possible to measure the standing height of 165(baseline) and 7 (endline) of the children aged ≥ 5 years and the laying length for 34(baseline) children <5 years. For these children knee height was used as a proxy measure. The line of best fit on a scatter graph of the relationship between laying length and knee height was used to predict the heights of those children for whom data were missing. This method was used because of a lack of validated published conversion formula available for this specific study population.

Weight for age (children <10years only), height for weight and weight for height (children ≤ 5 years only) z scores were calculated based on WHO growth standards using the Emergency Nutrition Assessment and WHO Anthroplus software. Children with Z scores between <2 and ≥ 3 were defined as stunted/wasted/underweight and those with z scores <-3 were defined as severe. For MUAC, wasted was defined as 115mm – 124mm and severe wasting as <115mm. Children with z-score values outside the recommended range (z-scores greater than 5 or 6/less than -5 or -6, depending on the measure) were excluded from the analysis. We calculated prevalence of stunting, wasting and underweight as well as the mean z-scores. These analyses were repeated excluding those children with imputed height data and results were essentially unchanged.

A socioeconomic status (SES) index was calculated from poverty indicators (household ownership of assets and building materials of the house) using principal components analysis. This index was divided into tertiles from poorest (lowest SES score) to least poor (highest SES score).

We used multivariate logistic regression to explore the association between child malnutrition with socio-demographic characteristics of child and caregiver, severity of cerebral palsy and socio-economic status at baseline.

Outcomes at baseline and endline were compared using the McNemars tests for binary data and the paired t-test (normally distributed data) or Wilcoxon sign rank test (if data were skewed) for continuous data. Analysis were restricted to respondents who were included at both baseline and endline.

4.2 Qualitative data analysis

The conceptual framework for the qualitative analysis was the Theory of Change (TOC) developed at the outset of the project by the lead researcher.

There were two stages of the analysis: (1) a thematic analysis using a-priori themes from the ToC, and an iterative process of developing more themes and sub-themes as interviews were compared, and (2) a biographical case study analysis of children and their caregivers over a 6 month- 1-year period.

All interviews were transcribed from the local language into English, and one researcher (MZ) lead on the analysis. Key themes and sub-themes were discussed the local Ghanaian PI, and the data was managed using NVIVO 12 software.

For the purposes of this report we have presented the quantitative and qualitative findings together.

5 Results

5.1 Quality and adherence to training

Attendance at the training group sessions was high: ranging from 78%-100% of parents, with an 92% average attendance across all sessions. The quality and rigour of the implementation of 'Getting to know cerebral Palsy' was monitored with one monitoring visit per group by the local research coordinator/ project manager. Overall adherence to the manual was rated as 'good' from these observations, although home visits varied in quality across sites in the time spent and quality of the follow up.

5.2 Study population

5.2.1 Baseline survey sample

At baseline, data were collected on a total of 76 out of the 77 children who were invited to participate. Most children in the sample were under 5 years (72%). The mean age of the children was 3.8 years (95% CI 3.2- 4.5). There were slightly fewer females (47%) than males (53%) in the study sample (Table 2). Just over half (53%) of the children were from the Northern region and 47% were from the Southern Region. There number of children included from each of the 8 districts was similar (between 8 and 11 children per district).

TABLE 2 STUDY POPULATION AT BASELINE

	N	%
Sex		
Male	41	53%
Female	35	46%
Age Group		
18months-2 years	31	41%
3-4 years	23	31%
5+ years	21	28%
Region		
North	40	53%
South	36	47%



All caregivers interviewed lived in same household as the child. Nearly all the caregivers were female (97%) and the clear majority were mothers (80%) or grandparents (15%) (Table 3). Most caregivers (61%) reported not having worked in the past month and 'household or childcare' duties were the most common reason given for not working. Among caregivers 43% reported never having attended school, 24% completed primary school and 33% completed junior high school or above.

Most caregivers were married (70%). However, half of the biological fathers of the child with cerebral palsy did not live at the same household as the child. Half of the children saw their biological fathers daily, 4% monthly and 40% less than monthly.

TABLE 3 SOCIO-DEMOGRAPHIC CHARACTERISTICS OF THE CAREGIVERS OF STUDY CHILDREN

	N	%
Age group		
15-20	4	5%
21-25	9	12%
26-30	10	13%
30-40	34	45%
40-60	15	20%
60+	4	5%
Relationship to child		
Mother	61	80%
Father	1	1%
Grandparent	11	15%
Other	3	4%
Worked in last month		
No	46	61%
Yes	30	39%
Reason not working in past month		
Student	4	9%
Childcare/duties/work inside house	30	65%
Incapable of working, physical	1	2%
Other 'no money'	5	11%
Other	6	13%
Marital status		

Married/living together	53	70%
Divorced/separated	6	8%
Widowed	6	8%
Single	11	14%
Ever attended school		
No	33	43%
Yes	43	57%
Highest level completed		
None	33	43%
Primary	18	24%
Junior High	13	17%
Senior High	9	12%
Tertiary	3	4%
Where does child's biologic father live*		
Not in household	38	50%
In household	35	46%
Not known	2	3%
How often has father seen child in past 6 months		
Daily	37	49%
Monthly	3	4%
< monthly	11	14%
Not seen	20	26%
Not known	2	3%

*Excluding fathers who had died (n=2)

5.2.2 Study area

Significantly more of the households in the Northern region were in the poorest Socio-Economic Status (SES) tertile (56%) compared to households in the Southern region (17% $p < 0.001$) indicating the northern region is poorer than the south (Figure 4 The socio-economic distribution of households in the north and south region).

Overall, the level of poverty was low for all households, with indicators such as only 30% of households owning a bicycle, and 86% living in a house made from unbaked bricks or mud. This may reflect the areas where the Presbyterian Church of Ghana target their programmes in the North in rural settings and focus on working with the poor.

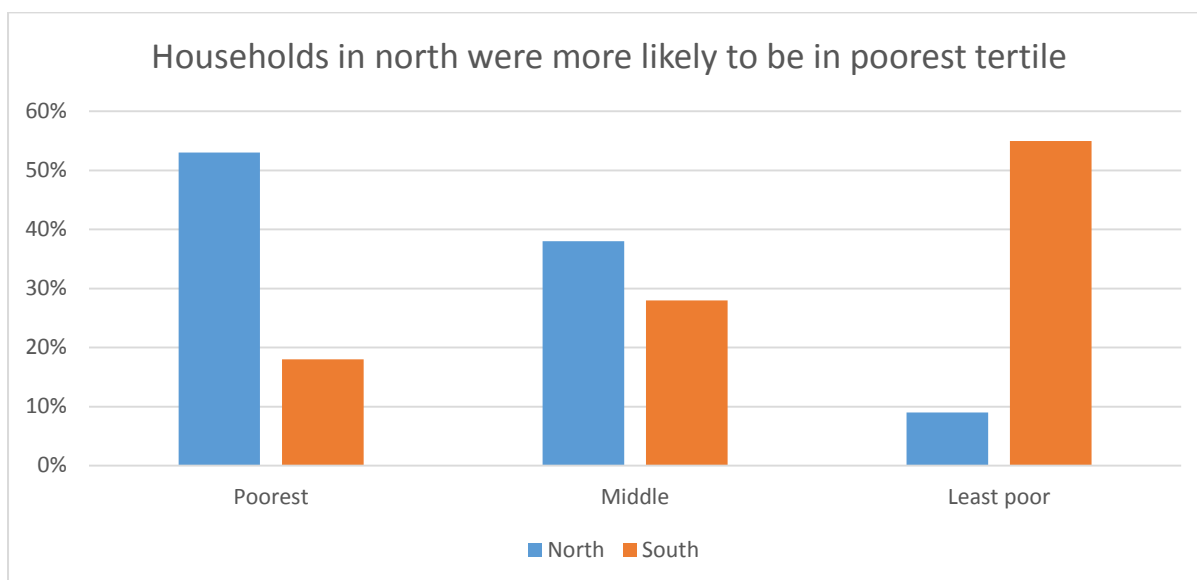


FIGURE 4 THE SOCIO-ECONOMIC DISTRIBUTION OF HOUSEHOLDS IN THE NORTH AND SOUTH REGION

5.2.3 Endline survey sample

At endline, data were collected on a total of 64 of the 76 children (84%). Of those lost to follow up eight had died, three did not complete the training programme (attended <3 sessions), and one was excluded because of a misdiagnosis of cerebral palsy.

There were few socio-demographic differences between study participants included and lost to follow. The exception was that girls were more likely to be lost to follow up compared to boys (p=0.03). (see Table 8 **Characteristics of Endline study total population and those lost to follow up** in Appendix 2).

5.3 Qualitative sample - Case Study Families

Detailed data was collected on 18 families; seven families were visited three times over a one year period, five families were visited twice, and six families visited once.⁸

Children were a range of ages, with an average age of 5 years (at Endline), eight girls and ten boys, nine were diagnosed with severe cerebral palsy, seven with moderate and two with mild. In terms of the caregivers, we interviewed three grandmothers, one male relative and the remainder were mothers (see 15.3 Appendix 3 Table Case Study Family Details). The grandmothers had been left to look after the child and the mother never returned after leaving the child (1), had died (1), or lived nearby (1). Two of the mothers had paid employment (midwife and health administrator) but the majority were traders or ran small businesses.

In almost every case the father was absent from the house; 14 fathers were not living in the house, and even when the father was present, it became apparent over the 1-year period that they often worked regularly away from home, for several months at a time. Over the course of the year, two husbands moved out of the living accommodation with the mother and child.

	Baseline Median score (SD)	Endline Median score (SD)	P-value*	Mean change (95%CI)
Summary scores				
Total	12.5 (18.6)	51.4 (23.6)	P<0.001	31.3 (25.6-37.0)
Parent	13.8 (19.7)	47.5 (25.6)	P<0.001	28.9 (22.9-34.9)
Family	14.1 (27.4)	57.8 (30.0)	P<0.001	31.9 (23.5-40.3)
Sub-scale scores				
Physical functioning	16.7 (21.0)	50.0 (30.2)	P<0.001	26.7 (19.2-34.3)
Emotional functioning	10.0 (17.8)	47.5 (28.9)	P<0.001	33.4 (26.1-40.8)
Social functioning	6.3 (25.4)	37.5 (33.4)	P<0.001	25.9 (17.8-34.1)
Cognitive functioning	10.0 (26.5)	50.0 (27.5)	P<0.001	29.2 (21.8-36.6)
Communication functioning	8.3 (18.4)	66.6 (26.7)	P<0.001	45.4 (37.5-53.4)
Worry	10.0 (19.7)	50.0 (26.7)	P<0.001	31.7 (24.4-39.1)
Daily activities	0 (25.2)	50 (31.7)	P<0.001	32.3 (23.2-41.4)
Family relationships	5.0 (63.4)	62.5 (37.1)	P<0.001	31.6 (21.1-42.2)
*Wilcoxon Sign Rank test comparing baseline and endline scores; NB: We calculated median scores and used a non-parametric statistical test because baseline and endline QoL data were skewed. Change scores were normally distributed.				

6 Impact of programme on the caregiver

6.1 Caregiver Quality of life

The primary outcome measure for the programme was the quality of life of the caregiver. We assessed change in QoL pre-and post-training programme using two standardised quantitative measures (PedsQL™ Family Impact

⁸ 2 families added at Endline and 3 families' child died before the mid-term, and one child dropped out. A further 3 families were interviewed in our baseline qualitative but not included in the survey.

Questionnaire and Ladder of Life). In addition, our qualitative research with case study families explored the multiple layers that interact to shape the quality of life within families, [11], and how they were impacted by the support groups and home visits.

Table 4 : Baseline and endline caregiver QoL scores and mean change between the two-time points

At baseline, median caregiver QoL scores were low (<17 for each subscale). At endline, QoL scores had improved significantly across all three summary scales (parent, family, and combined) and the eight domains of physical, emotional, social, cognitive, communication functioning, worry, daily relationships and family relationships ($p < 0.0001$, Table 4). The average total QoL score increased from 12.5 (SD 18.6) to 51.4 (SD 23.6).

To find out if this improvement was seen across each of the cerebral palsy severity levels we compared QoL for caregivers with children who had mild, moderate, and severe cerebral palsy separately. The significant increase in QoL was observed at each of these three cerebral palsy severity levels.

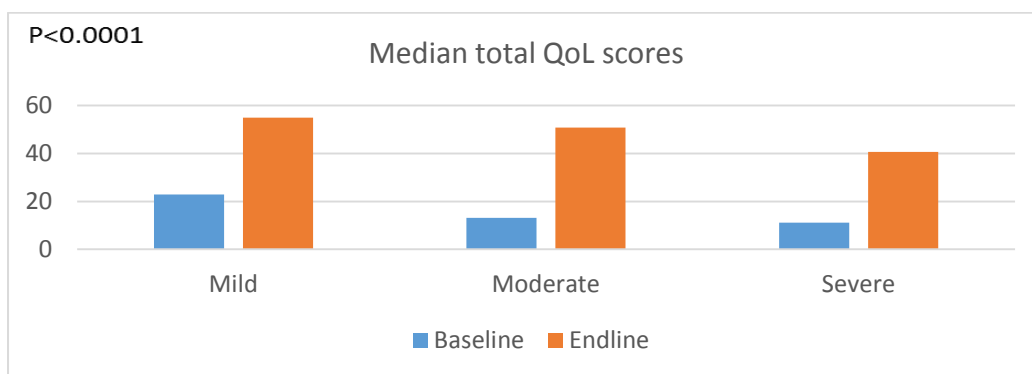
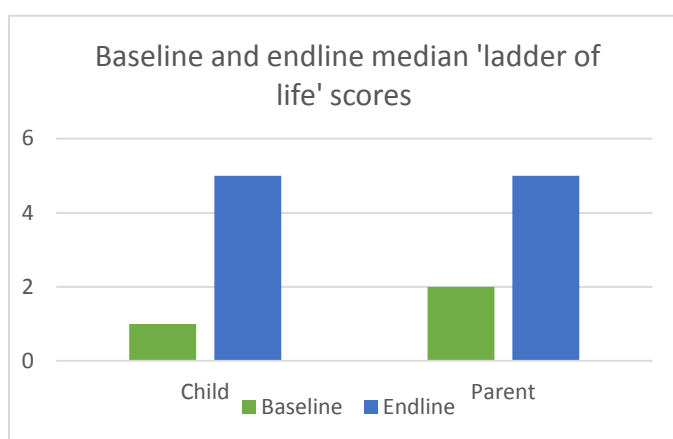


FIGURE 5 QUALITY OF LIFE CHANGE AND CEREBRAL PALSY SEVERITY (GMFCS 1-5)



The improvement in quality of life was also significant for caregivers of children with each of the different levels of severity of cerebral palsy (Figure 5)

As a 'simpler' measure of quality of life caregivers were also asked to report on where they felt (a) their child and (b) themselves as caregivers, were on a scale of 1-9 on a 'Ladder of life'. One is the 'worst' possible life and nine is the 'best' possible life. As shown in Figure 6, there was a significant increase in the ladder of life scores from

FIGURE 6 LADDER OF LIFE QOL SCORES

baseline (child: median 1.0, SD 1.6; parents 2.0 SD 2.2 to endline (child 5.0 SD 2.3; parent: 5.0 SD 2.5, $p < 0.0001$).

These QoL results are supported by the qualitative data, which also showed that aspects of life improved for children and caregivers over the course of the training programme. As illustrated below, the caregiver lives were complex and fluid and multiple factors impacted upon the quality of their lives in caring for their child, which is detailed below.

6.2 Caregiver knowledge and attitudes about their child's condition

Overall levels of diagnosis of cerebral palsy were very poor: 49% of cases caregivers claimed they had never received a diagnosis from the hospitals, only 15% stated they had been told it was something related to the brain, and 21% were offered a diagnosis provided by a traditional healer (See Figure 9). The most common 'other' diagnosis given was convulsions. The lack of appropriate information from health professionals was evident from the qualitative interviews:

They did not tell me what was wrong

The Doctor said there was nothing wrong with her, she is only fat

I did not ask the nurses and the doctors what was wrong with the child, I only go when the child is very warm and they tell me how to give her drugs.

The doctors did not tell me anything but traditional healers said someone has given him Asram

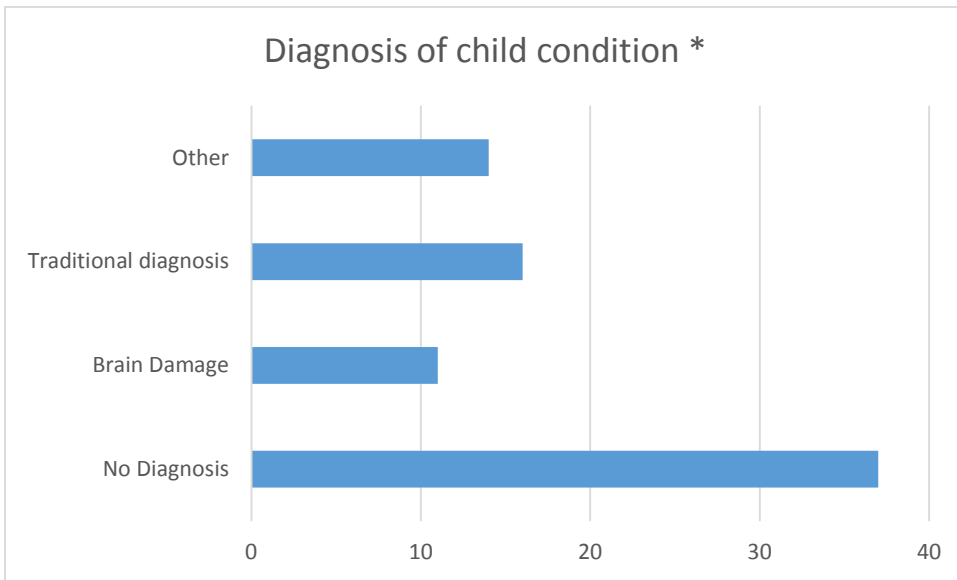


FIGURE 7 PARENT REPORT OF DIAGNOSIS OF CHILD’S CONDITION AT BASELINE

6.2.1 Knowledge and confidence with taking care of child

As shown in figure 2, at baseline the clear majority of caregivers (84%) reported having no/low levels of knowledge about their child’s condition and only 6% reported good or lots of confidence. By the endline, reported knowledge significantly improved so that 73% reported good or lots of knowledge ($p < 0.001$). In terms of confidence in caring for the child, the proportion reporting good/lots of confidence increased substantially from 36% at baseline to 89% endline ($P < 0.001$).

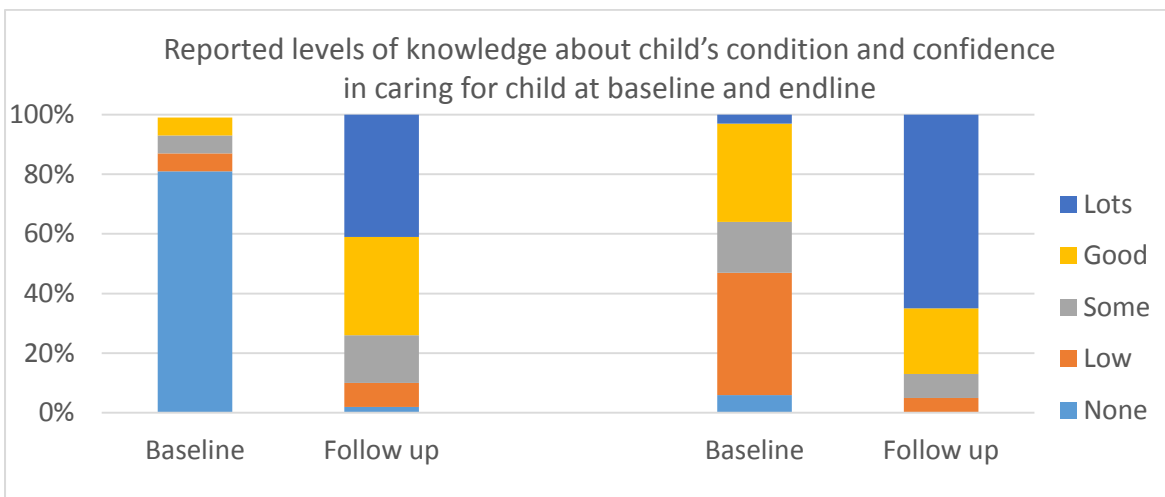


FIGURE 8 REPORTED LEVELS OF KNOWLEDGE ABOUT CHILD’S CONDITION AND CONFIDENCE IN CARING FOR A CHILD AT BASELINE AND ENDLINE

6.2.2 Case studies: knowledge and attitudes change because of the training

Our case study families similarly highlighted the lack of knowledge, and understanding about their child’s condition at baseline. Most of the caregivers, and other family members, held strong traditional beliefs about the child’s condition. Very few had been given any formal diagnosis about the condition despite multiple visits to a hospital. In at least two cases the child had received expensive CT scans, that could be ill afforded. One consequence of this was that the families often spent considerable time and resources constantly seeking a ‘cure’ for their child, or

discontinued outpatient physiotherapy, as described by one grandmother who was caring for her granddaughter following the death of the mother:

I first took her to the hospital; the doctor said she was lazy because of her weight. We were then referred to the physiotherapy unit and we were given some days to attend. We were made to buy some ointment and we attended for a while. I got sick of going to the hospital every day.

A mother of a four-year-old son describes her continued efforts to get a diagnosis. She finally received a diagnosis from the regional health director personally but it was only through the training course that she explains that she *'really understood'* her child's condition.

At 1.5 years, I was taking him to the regional hospital they were not giving me any information. I then had to find out what is wrong. Whenever I went to the hospital they never tested, they never did anything until he was 2 years. At 2 years, they did a test and they asked me if I take my injections for polio and I say yes. I asked them what the problem is, but they didn't tell me anything.

By the end of the programme, the in-depth interviews showed there was a very substantial improvement in **caregiver knowledge** and understanding about their child's condition but also a real shift in the caregiver **attitude** towards the child.

The change in knowledge and attitudes contributed to some extremely important outcomes for caregivers:

(1) the caregiver themselves were **emotionally happier** about their child and with themselves, in some cases with the recognition that the **child was 'human'** and not a 'spirit child' (2) a **greater acceptance** of their child's condition (3) having **more patience** with the child because of their improved understanding of the condition (4) multiple examples of **improved care practices** (5) **greater resilience** of the caregivers in the face of prejudice and discrimination. Facilitators also commented on the increase in caregiver's patience with looking after their child. Many of these outcomes are summarised by one single mum of a three-year boy, with severe cerebral palsy:

Mother: I have a better life now because first when I take my child to weighing, people used to talk a lot about him. They say, *'see how this lady has given birth to an abnormal child'*, and this made me weep so much. From the meetings, and their advice, my life is better now.

Interviewer: What did they explain to you that has changed your life?

Mother: I used not to know what is wrong with my child but they have taught me all that.

Interviewer: In your group meetings, what is very useful to you and that has helped you?

Mother: Well the good thing that I have seen is that when he used to eat, while crying, I used to beat him and when he was eating and turning here and there I didn't know how to take my time and feed him I just kept on feeding him. But when we went for the meeting they said whenever the child turns itself or is refusing to eat, we shouldn't do anything. (Code 3344)

The case studies reflected a gradual process over the year of a **fuller and deeper acceptance of the condition, and** learning collectively from other parents. A greater understanding and acceptance of the child's condition was closely linked to the appreciation that they are *'not the only one'* and *'not on their own'*. The value of the group shared experience was repeatedly highlighted:

At first my mum (grandmother) and I used to weep. *I thought I was the only one with this problem* but when I saw my colleague women with similar problems, I realized that I wasn't the only one. [And how does that help you knowing the other women?] I now know that there are other women like me with the same situation, so I have other mothers that I can share my problems with each time I go for meetings. (Case 9916)



First, I did not know. I thought she wasn't a human being but after we came to [the training] we saw so many mothers with the same problem and we realized *we were not the only people in that situation*. I now know it's sickness that has caused her situation. (Code 9920)

The '**humanisation**' of the child because of this training is an important impact of the training in a context of very strong and embedded traditional beliefs towards disability and family misfortune in Ghana.

M: You know some of us when we delivered we used to think they are 'spirit' children and not real children. But they trained us and enlightened us and we now know how to care for these little children. (Case 9921)

M: Oh, it has helped us. Some felt the children are *water children* (*usuo ba*).....but we got to know that it is caused by a brain injury (*adwen mu yare- brain sickens*) or when there is prolonged delivery (Case 1104)

The issue of **hope** also emerges as an important element of the support group, and being able to observe changes in other children, as well as their own.

M: I am already a health worker, but being in a group has helped me a lot because sometimes you see children with the same problem and it gives you hope and to see other children recovering..... and I've seen so many changes (5560,).

6.2.3 Knowledge of services

In addition to evaluating caregivers' understanding of cerebral palsy, the survey also measured their awareness of local services and government provision. For example, at baseline, knowledge of the Ghanaian Disability Common Fund was very low with only 39% of families aware of the fund, and only one family had received this, despite this being one of the main sources of social protection for families.

By the endline, 90% of families had heard of the fund, but there were only a further 3 families who had received funding. There remained some confusion around the process of application; 38% said they did not know where to access the service, and 30% offered other reasons for not accessing the fund, which was mainly confusion about the application process. In some cases the parent was told the child was not eligible, and/or that funding was currently unavailable.

6.2.4 Improvement in self-esteem and self-worth of the caregiver

In addition to demonstrating improved knowledge and attitudes, the case studies illustrated how the programme resulted in caregivers having **a sense of being valued** and of their child being valued, which, in turn, linked into improved quality of life. Something as simple as a home visits facilitated a sense of self-worth and dignity amongst caregivers who are frequently socially excluded:

Mother: I feel that we are also human beings and that is why people have come to visit us. Their coming makes me happy.

I: Was it different before the training?

Mother: No one was coming to us. It has always been the two of us here alone, my mum and I and we were always crying. Now, from the meetings, we have all learnt a lot and this happens no more.

This **increase in the resilience** of caregivers in the face of stigma towards their child is commonly reflected upon by many of the parents:

Mother: Before they used words like 'Dwarf' or 'spiritual child', and now when they use these words it doesn't hurt me because I know what is wrong with my child. When before when they said it, it hurt me. (CASE 3340)

6.2.5 Caregiver behaviour change

Caregivers reported a wide variety of positive changes in caregiving. The changes in caregiving practice varied across families, reflecting the wide diversity of needs in children with cerebral palsy. Simple changes in changes positioning, and understanding how to communicate with their child were two common themes frequently commented on by caregivers.



PHOTO: BEFORE AND AFTER TRAINING – LEARNING TO POSITION CHILD

Additionally, an increase in **patience in caring** for their child because of improved understanding about their condition was a frequently reported outcome; as one parent explained she no-longer *'beats the child'* whilst feeding him. This extremely important shift in caregiving practice was also emphasised by facilitators in the monitoring data and Most Significant Change (MSC) stories.

Key findings: Impact on the Caregiver

- At the end of the parent training programme, caregiver quality of life scores had increased substantially, with an improvement of approximately 30% in overall QoL scores at endline compared to baseline
- This increase in caregiver quality of life was evident across each cerebral palsy severity level.
- There was also a significant increase in the parent and child 'ladder of life' scores from baseline to endline
- Qualitative data highlighted that the Quality of life of the caregiver is impacted positively by a layering of different factors
 - caregivers reported having good levels of **knowledge and the confidence** in caring for their child with cerebral palsy after compared to before the training programme.
 - **Attitudes** towards their children improved as understanding of the condition increased; this often resulted in greater acceptance of the child and more **patience** in caregiving.
 - The **self-esteem and dignity of caregivers** increased as they felt that their child and themselves were valued. The understanding that 'they were not on their own' was key to affecting this change in the group setting. They reported being emotionally happier.

7 Impact on the family

Our theory of change for the programme reflected the important role of the family in child-rearing, and that in the Ghana context (as in many contexts) the QoL of a caregiver is closely tied to family relationships and their support for the child, and the role of other family members as gatekeepers in decision making about health care. It was anticipated that caregivers would share information and resources (e.g. handouts) from the training within the family and would demonstrate lessons learnt. In addition, the home visits would facilitate engagement with other family members.

One component of the PedsQL Family Impact measure showed significant positive change in terms of measures of improved communication within the family. In the case studies, there were several examples of positive change in attitudes in the family towards the child over the 1-year period, and examples of mothers who actively engaged with the other family members, or even a case of taking the information to their workplace:

Before, I could not go to any place and leave the child behind. Anytime I went out, it was difficult for my mother to feed him. He used to vomit everything you feed him, but after the training, I also educated my mother and anywhere I go I come back to see him good fed. (Code 9916)

Yes – I share with my husband and I also take to my workplace (health clinic). And when there are clients I give them a talk on it. When they come, I give them a health talk on it. I educate the women (Case 3340 who plans to establish her own group)



However, in general, the case studies highlighted a very complex picture of family life. Sadly, many of the mothers did not feel supported in caring for their child, with often little change in family attitudes over time for caregivers living with their husband's family, where blame for bringing a disability into the family was attributed to the mother. This is illustrated in the case study below (Case 3344):

7.1.1 Case 3344 Case Study: Making Change within a difficult family context

Case Study: Making Change within a difficult family context

When we first meet Monica she lives with her husband and his family, and cares for their 3-year-old son who has severe cerebral palsy, and is severely malnourished. Over the time that she participates in the support group she reflects on various positive changes; she no-longer beats him through frustration, his feeding has improved and thus her son no-longer cries through the night, she positions him correctly rather than just lying him on the floor and learning about communication has been key:

M: The part that has touched my heart is how we communicate with him.

So how do you communicate with him?

M: Laughs loudly.....like his sitting. If I want to talk to him I will turn his face towards me and play, but when he bends down I will turn him this way while I throw him up and down and he laughs.

Although Monica reflects on all these positive improvements, her own home situation deteriorates over the year. Her husband moves out of their room in the house and she is left on her own with the child. The mother-in-law is looking for a new wife for her son. His increasing lack of support means that she also now struggles financially to pay for health care for the child, such a follow up hearing test, because the husband is no-longer willing to contribute to this. The difficult family situation also means that Monica is not motivated to share the resources from the training within other family members: *They give us papers [parent handouts] and teach us. [And do you explain it to the people of this house] We are not united so I do not do that.*

The main reasons given by caregivers for not sharing their knowledge and understanding and handouts within the family include (1) **a lack of time** (2) the **husband would not be interested** and/or It is **not the role of the husband** to care for the child (3) the **husband works away** from home (4) the caregiver is not willing to discuss their child because of the **stigma and discrimination** experienced- '*some people just won't listen*'. Many of the women are living on their own, having been left by their father of the child, and so opportunities for sharing with family members are limited.

Yes, I do explain it to them but now everybody is busy so I don't get time to continue that. (Case 3342, husband works away from home)

I am not on good talking terms with my family members because of a problem and I am not close to the neighbours around, because of the child's condition too, I do not draw near to them. (Case 5558)

7.2 Lack of male engagement in caregiving

In 51% of all families at baseline, the father of the child was reported to not be living at home and visited infrequently or not at all. In our qualitative case studies, the father of the child was present in only four families, and in three of these cases the husband worked regularly away from home. Although in some settings seasonal working was common, a common reason given for a father's departure, was due to the child's disability. Sadly, over the course of the training, two additional husbands moved away from the family accommodation; in one case the mother and child moved out of the shared rental accommodation, and in a second case the mother-in-law was engaged in finding a second wife for her son, reflecting the persistent and pervasive negative attitudes towards children with a disability, and the blame on the mother

7.3 Poverty, livelihoods and caregiving



At baseline, a key factor identified by many caregivers, which would improve quality of life, was having a more secure livelihood.

The longitudinal research over the year illustrates the cycle of poverty, livelihoods and caregiving, and how household poverty shapes the caregiver's ability to implement change in caregiving. For example, poverty was the key barrier identified for being unable to improve nutritional meal for the child.

This is not about the children alone. Most of the parents are going through psychological problems and financially most of them are handicapped. Most of them

psychologically impaired, they are going through so many emotional issues- you must feed that child morning, afternoon, and evening, and not only that but with a balanced diet but they cannot even offer them three square meals. (Code 5560 talking about other mothers in her group).

Many of the mothers sought to squeeze some economic activities around the child-caring, but without additional family support it can be challenging. The impact of poverty is far reaching and impacts negatively upon family decisions to access health care.

Case study (9916): **The impact of caregiving on livelihoods**

Jamilla has two children and the youngest 'G', 2 years old, has severe cerebral palsy and is severely malnourished at the start of the project. She lives with her mother (who also has a disability) and a younger sister who is at school.

The child, 'G', has severe cerebral palsy and it's difficult to leave him down to work. The father of the child visits briefly on two occasions in one year, but the support is minimal:

I: Does he [husband] support you in any way?

Mother: No, ... but when he is coming (once every few months) he can buy soap for me to use to wash the child's clothes.

It is difficult for Jamilla to weave hats when she is always holding G, and he often cries when he is put down.

I: How are you able to do your work when you are holding G?

M: I put him down to lie.

I: OK. And how easy is that?

Mother: He always cries. When you put him down he doesn't lie, he cries.

Seven months later, Jamilla is very positive about the small changes that she has seen in her son. However, the family have run out of the raw materials for hat weaving, and getting food on the table for the whole family is a major challenge: *Sometimes I wake up and can't even put food in my mouth.* The grandmother explains: *She [my daughter] is the only person who supports the family. If this child were healthy and strong, Jamilla would have been able to go out to work and to get money to support us, but because of the child, she can do just nothing.she used to go to K to help transplant tomatoes and to harvest her stalks for the weaving. In a month's time, she comes back with money and stalks, and she buys food stuffs and ingredients for the house, Because of the child, [my daughter] can no-longer do that again.*

When we visit her at the end of the year she is making hats again, and has a new sitting chair for G which has helped as she can leave him whilst she does chores. His feeding has also improved over time so that he is not always crying, and sometimes she can leave him with the grandmother. At first, she was turned away from the local nutrition services, and told that her son will not benefit from nutritional supplements. However, the programme staff work closely with the local health staff, and thus, Jamilla now takes G regularly for weighing and nutritional support. However, she explains that having work would improve her life.

Understanding the role of the community

The GTCP training programme is designed as a community based training programme, with parents trained in support groups close to their communities. Within the theory of change, there was an expectation that the caregiver, or their group, would engage with the wider community on issues related to disability.

At baseline pervasive stigma and discrimination was experienced in the family and community, and the social exclusion of children, and caregivers impacted upon the quality of their lives in a variety of ways.

7.3.1 Stigma and discrimination

Stigma and discrimination are addressed here in the community section, but in practice they are cross-cutting issues across almost every theme and sub-theme of the case studies. The impact of this stigma is multi-faceted; a common reason given for fathers to leave, why other family members are unwilling to care for the child, and exclusion of the child and caregiver. At baseline, across all sites, the levels of stigma and discrimination were extremely high, closely interlinked with prevalent traditional beliefs about the cause of disability, and this manifested in a wide variety of ways.



Mother: They call her a 'dwarf' (meaning a child from the spiritual world).

Interviewer: What does that mean?

Mother: That the way she is, her body is dead. She is not a human being.

Interviewer: And how does that make you feel?

Mother: It's normal.

Grandmother: I usually say it's God who created her. She wasn't created by human beings. (CODE:5562

Mother daughter of 3 years with severe cerebral palsy)

Grandmother: What is most difficult is that people call her a spirit, so my prayer is that, one day, she will rise and walk, and those who call her a dwarf will be put to shame and stop calling her a dwarf again. (Grandmother, child of 991b)

One year on, it is evident that there is change in the beliefs of the caregivers towards their children; the support groups offer a *safe place* to caregiver to discuss their experiences, and that sharing and learning between caregivers helps to promote the understanding that '*they are not the only one*' {with a child with a disability}, and this has contributed to changing caregiver attitudes about themselves (self-stigma) and towards their child.

That said, it is evident that everyday stigma and discrimination in the family and community is still commonplace. In the extreme, it can result in neglect of the child within the family, and child protection and safeguarding were also a cause for concern in some cases, where the child was at risk from other family members. This is illustrated in the case study below of a child who died early in the programme.

In terms of the caregivers engaging with the 'community' and/or mobilising with other parents to engage with the community on issues related to their child's disability, we found only some evidence of this type of activity. This is perhaps not surprising given the time scale of the project. After the endline data collection there were a range of collective advocacy activities as part of the celebration on World cerebral palsy day, but it is not captured in this report⁹.



Case study -Traditional beliefs, stigma and neglect

Matilda is 5 years old and was left by her mother into the care of her grandmother when she was 3 years old. It is an extremely poor household. At the time of the first visit Matilda was severely malnourished and unwell. Her grandmother did not have an up to date health insurance card for Matilda and so was not taking her for any treatment. There was very little understanding about her condition, but very strong traditional beliefs that the child was a 'spirit child' as opposed to a human child, and there was regular ongoing consultation with local fetish priests:

We thought she was a "child" but when she finally came, she was like this, almost five years now. I don't know. This problem did not start here for me to say what exactly happened. But when we took her, we are Frafra¹⁰ people; it is our duty to consult the gods and do traditional treatment of the condition.

From observation at the time of the assessment*, the child appeared neglected, was covered in flies, and was roughly handled by the grandmother. Commonly Matilda is left for several hours a day lying on the floor on her own, in one corner of the house, whilst the grandmother goes to tend the cattle or to do to the market. Sadly, very shortly after the start of the training, Matilda died. During contact with the family over a three- month period, it became more apparent that although poverty played a role, the traditional beliefs of the grandparents were a main reason for the severe neglect of the child. *[Following the child's assessment referrals were made to the local nutrition team]

⁹ The endline Data collection was conducted in July 2016, and in October 2016 there were a number of group advocacy activities focussed around World Cerebral Palsy Day, however they are not captured here.

¹⁰ Belief in a supreme creator being is central to Frafra beliefs. A shrine to this god occupies the center of every village. Each extended family maintains its own hut, in which the lineage magical objects are kept. The objects allow the family to maintain contact with the vital forces of nature. These objects are inherited by the ancestors and are the communal property of the lineage, providing protection and social cohesion among all members of the family (Wiki-pedia retrieved Oct 2015)

Key Findings: Impact on the family

- There were some reported improvements in family attitudes towards the child. However, this change was often small, and sharing of knowledge and skills with other family members was sometimes limited.
- Many caregivers were socially excluded within their families, and within the community. Fathers were absent in half of the families and even when present there was limited involvement in caregiving.
- Stigma towards, discrimination, and exclusion towards children with cerebral palsy and their caregivers was a major issue. Some caregivers reported some improvements through the training programme.
- The ability to combine working and economic activities with full time caregiving was a major challenge for most caregivers, especially when children are not in school, and childcare is unavailable.

8 Impact on the child

8.1 Reported Limitations with Child's Functioning

At baseline, caregivers were asked to rate difficulty experienced by their child in different aspects of functioning (Figure 9). Nearly all children experience at least some difficulty with walking (94%) and 71% cannot walk at all. Difficulties with hearing or seeing were less common (<20%). Difficulties being understood, with learning and with behaviour were reported for more than 70% of children. These questions highlight the very wide range of functional limitations in the children in our sample which the training is aiming to address with the caregivers.

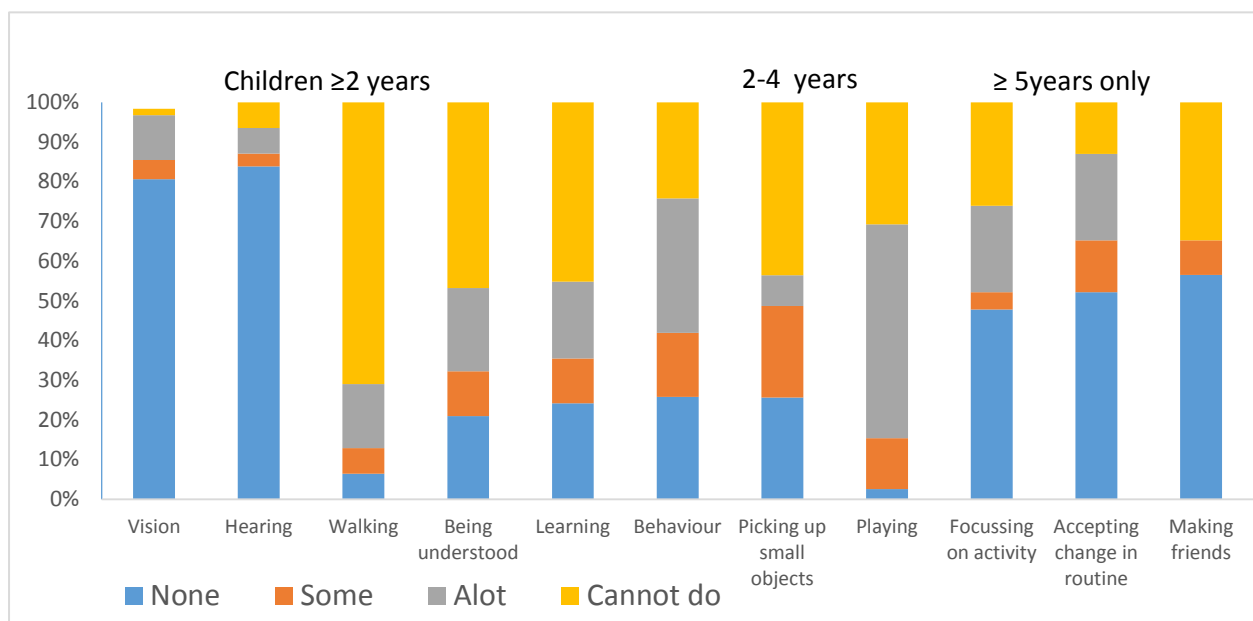


FIGURE 9 RESPONSE DISTRIBUTIONS TO UNICEF QUESTIONS ON REPORTED FUNCTIONAL LIMITATIONS OF THE CHILD

8.2.1 Malnutrition

The prevalence of malnutrition was high at both time points (Table 5 Prevalence of malnutrition among children at baseline and endline).

At baseline, 64% of children were classified as underweight and this remained similar at endline (p=0.5). At baseline 54% were stunted and this was 64% at endline (p=0.06). Wasting was evident in 60% of children (< 4 years only) and baseline and this was 45% at endline as wasted (p=0.01). At both time points, the proportion classified as being

wasted according to the MUAC measurement was considerably lower (<25%) than the weight for height measure (>45%).

We compared the baseline and endline malnutrition for each level of CP severity separately and found the trends were similar to that for the full population at each level of severity of cerebral palsy.

These levels of malnutrition are very high, in comparison to 2014 Ghana DHS survey which reported overall improvements in malnutrition since the last survey, with 5% of children wasted, <1 % severely wasted, 11% underweight, with 2% severely underweight, and 19% stunted and 5% severely stunted. Of course, with regional variation[23].

Factors associated with malnutrition at baseline

At baseline, the risk of being underweight was significantly higher among children with the greatest feeding difficulties (OR 16.0 95% CI 3.4-75.3). There was also a borderline trend of increasing proportion of malnutrition with increasing severity of cerebral palsy (mild 43%, moderate 67%, severe 72%, $p=0.07$) and worsening levels of poverty (least poor 54%, medium 63%, Poorest 78%, $p=0.08$)

TABLE 5 PREVALENCE OF MALNUTRITION AMONG CHILDREN AT BASELINE AND ENDLINE

	All ages				Children < 5years (at baseline)			
	N	Baseline % (95% CI)	N	Endline % (95% CI)	N	Baseline % (95% CI)	N	Endline % (95% CI)
Weight for Age**								
'Normal'	21	36.8% *(25.1-50.3)	20	34.5% (23.1-48.8)	15	34.9 (21.7-50.7)	15	34.1 (21.3-49.7)
Underweight	14	24.5% (14.8-37.7)	10	17.2% (10.4-29.6)	12	27.9 (16.2-43.6)	9	20.5 (10.7-35.5)
Severely underweight	22	38.5% (28.5-52.6)	28	48.2% (35.4-61.3)	16	37.2 (23.7-53.0)	20	45.5 (31.0-60.7)
Mean z-score (95% CI)		-2.6 (-2.9- -2.2)		-2.8 (-3.1- -2.3)		-2.6 (-2.9- -2.1)		-2.7 (-3.2- -2.3)
p-value (z scores)*				P=0.08				P=0.06
Height for Age								
'Normal'	29	46.0% (33.9-58.6)	23	35.9% (24.9-48.7)	24	52.2 (37.4-66.6)	18	39.1 (25.8-54.3)
Stunted	17	26.9% (17.3-39.5)	16	25.0% (15.7-37.4)	10	21.7 (11.8-36.5)	12	26.1 (15.1-41.1)
Severely stunted	17	26.9% (17.3-39.5)	25	39.1% (27.7-51.8)	12	26.1 (15.1-41.1)	16	34.8 (22.1-50.0)
Mean z-score (95% CI)		-2.3 (-2.6- -1.9)		-2.7 (-3.0- -2.4)		-2.2 (-2.6- -1.8)		-2.6 (-3.0- -2.2)
p-value (z scores)*				P=0.003				P=0.002
Weight for height***								
'Normal'					12	40.0 (23.4-59.1)	17	54.8 (36.5-71.9)
Wasted					12	40.0 (23.4-59.1)	4	12.9 (4.6-31.6)
Severely wasted					16	20.0 (8.8-39.2)	10	32.3 (17.7-51.4)
Mean z-score (95% CI)						-2.1 (-2.5- -1.6)		-1.9 (-2.5- -1.3)
p-value (z scores)*								P=0.24
Middle Arm Circumference								
'Normal' (>=125mm)					43	84.7 (70.7-92.7))	36 ^c	78.3 (63.5-88.1)
Wasted (115-124mm)					10	15.2 (7.2-29.2)	6	13.0 (0.6-26.8)
Severely wasted (<115mm)					0	0	4	8.7 (3.1-21.7)
Mean MUAC (95% CI)						144.8 (139.3-150.4)		144.4 (137.9-150.8)
p-value (mean MUAC)*								P=0.8

*P-VALUES COMPARING Z SCORES AT BASELINE AND ENDLINE. NB DATA WERE EXCLUDED IF Z SCORES <-6/>6 FOR WEIGHT FOR AGE AND HEIGHT FOR AGE AND Z SCORES <-5/>5 FOR WEIGHT FOR HEIGHT WHICH EXPLAINS THE SMALL DIFFERENCE IN 'N' AT BASELINE/ENDLINE. **WEIGHT FOR AGE CALCULATED FOR <10YEARS ONLY; ***WEIGHT FOR HEIGHT NOT CALCULATED FOR CHILDREN AGED ≥5 YEARS, THEREFORE THESE ANALYSIS WERE RESTRICTED TO CHILDREN AGED <4 YEARS AT BASELINE SO SAME COHORT COULD BE COMPARED

8.3 Feeding and drinking

At baseline, at least 45% of caregivers reported problems often/always with the eight different domains shown in Figure 10. At endline, there was a significant reduction in the proportion of parents who reported problems often/always in the following domains (figure 5): ‘How often child has problems eating and drinking’, ‘How often does child have problems feeding themselves’, ‘how often does child need help feeding’ and ‘how often do you worry about these problems’. Responses to the other domains (choking, eating the same as others, being unhappy during mealtimes, whether the child is eating enough) remained similar between baseline and follow up.

We developed a composite score from the eight feeding questions which ranged from 0 (extreme difficulties) to 100 (no difficulties). There was a significant improvement in the median summary score from 29.7 (SD 31.4) at baseline to 51.6 (29.8) at endline ($p < 0.001$).

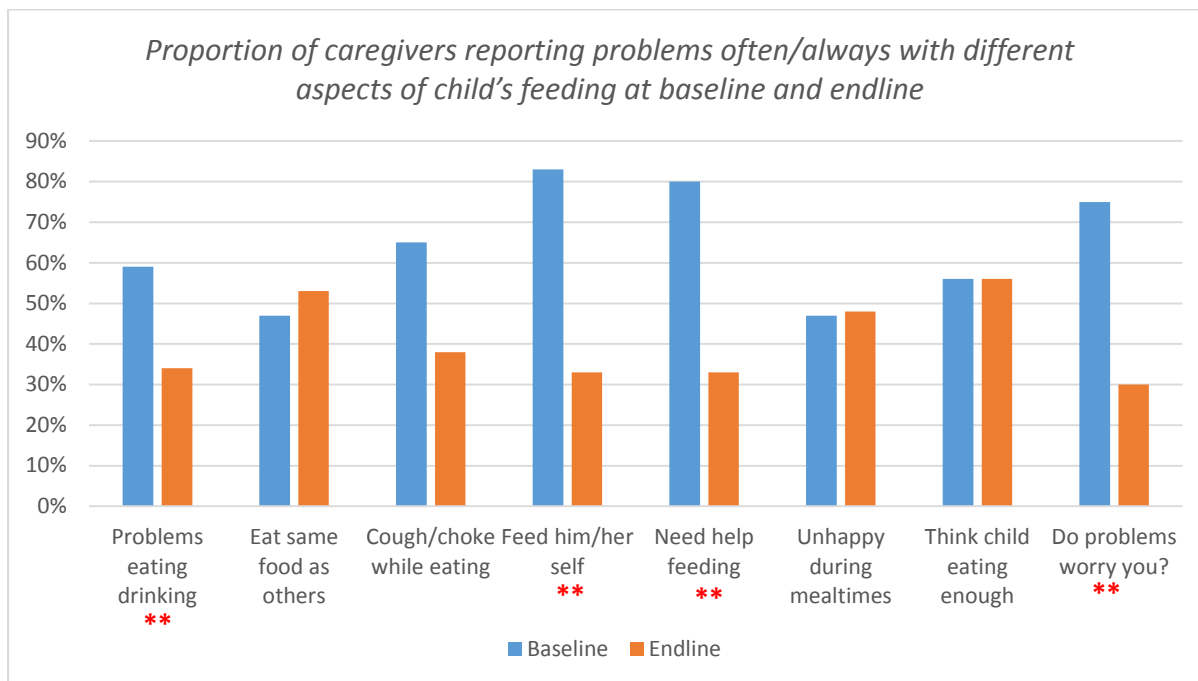


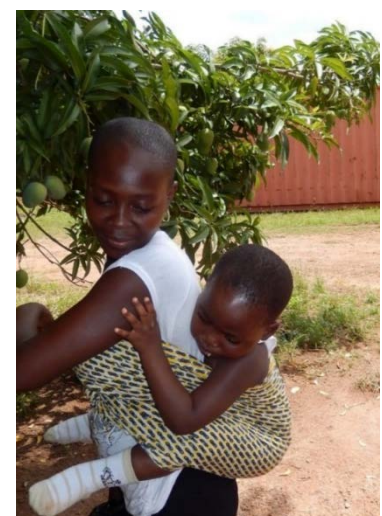
FIGURE 10 PROPORTION OF CAREGIVERS REPORTING FEEDING PROBLEMS AT BASELINE AND ENDLINE

**** Significant ($p < 0.05$) reduction in proportion reporting often/always at endline compared to baseline**

The findings from the sub-study on mealtime challenges mirrored these findings from quantitative survey. At endline in the malnutrition sub-study, observations and interviews showed that:

- mealtime experiences reported by caregivers had improved,
- Caregivers were less stressed about mealtimes
- there was some improved nutritional content
- positioning of the child was much improved.

However, challenges remained which may go some way to explain the ongoing malnutrition. Although positioning at mealtimes had improved, for example parents were not feeding a child lying down, there remained some observed difficulties for children with more severe cerebral palsy and with high tone, and it could still be very difficult for the caregiver to support the child in an upright position. Additionally, caregivers reported ongoing difficulties with other family members positioning their child incorrectly. For these children with cerebral palsy, coughing, choking or having difficulties breathing were still evident.



Despite improvements in mealtimes, most caregivers reported still experiencing some mealtime challenges, and ongoing worry, unhappiness and frustration.

Oromotor dysfunction (OMD), such as drooling, coughing, choking, vomiting, spewing and bringing up food, was still frequently identified as remaining mealtime challenge by over half the caregivers, and was interpreted by some caregivers as the child's dislike of the food or being full. These difficulties occurred more often in children with moderate and severe cerebral palsy. These children also required food modifications which required additional time for food preparation, which was not always available, and parental knowledge was low about the need to change the consistency.

The issue of **feeding duration** was perceived as a challenge more commonly by caregivers who had to work, as well as the difficulty of having time available for additional food preparation. Linked to this, was the little evidence of additional support from family members for feeding, and that knowledge learnt in the training was not easily transferred to other family members. Some of these complexities are illustrated in the case study below.

Case Study - Improvements in meal times and remaining challenges

A three-year-seven-month-old boy with severe CP is severely wasted for his age. He is non-mobile, non-verbal, and is completely dependent on his family to care for him. At baseline, his food was softened and broken into smaller pieces. The variety of foods he was given was very limited and his caregiver felt he could not be given 'heavy' or 'thick' foods made of cassava and yam. His mother was observed to have difficulty positioning her son and force-fed him large pieces of a local bean cake (kose), and giving him water with a syringe!

In contrast, at endline, the mother was observed to seat her son upright on the floor and supported his head. He was given water slowly in a small cup, was reportedly given a greater variety of foods. Ongoing challenges were present, such as coughing, choking and vomiting, although these were reported to be less often than at baseline. Despite these reported and observed improvements, there was little change in the boy's anthropometric measures and he remains severely wasted. The parents also explain that it is now the grandmother who predominantly feeds the boy, and he has now moved to live with her in northern Ghana as his parents work full-time. The father reflected on the limited knowledge transference to the grandmother,

When [the grandmother's] feeding him, it's always different. So, I think because of that, he is having difficulty in swallowing the food, than [with] the mother." Case 7785

8.4 Nutrition Referrals

A key theme, from both individual case studies, and from monitoring data, was the variation the quality of the referrals for additional nutritional support, and a lack of clarity related to the follow up required and/or lack of inclusion from the local nutrition teams. This may go some way to also explain the malnutrition findings, and is illustrated by one of several mothers in the Upper East Region who was initially turned away by the local nutritionist:

M: I met one of the health workers here who is working in the nutrition center and I told him about it and gave the weighing card to him. He read it, and said that the child has eaten those foods before but there haven't been changes, and what shows that if he takes this food this time around there will be changes? (Case 9921)

In this case, fortunately, the situation improved after 6 months, following intervention by the facilitator with the local nutrition and primary health staff at the CHPs compound. However, there was variation across sites in the strength of linkages made with local nutritional support. In two sites in the North extra emphasis was placed on engagement with the local nutritional services, with visits and awareness raising discussions with health staff, which did result in changes in the inclusion of families. Parents themselves, in most cases, had judged that there were some improvements in feeding, as illustrated by the case below.



Case Study: Improvements in Nutrition

When we first meet 2-year-old 'Rebecca she is seated in an upturned stool in the corner of her house. She has moderate cerebral palsy, and her head is slumped forward and she has nothing to play with. She is severely malnourished (across all the measures). Velma gave birth to Rebecca at one of the large hospitals in Accra, and the baby was described as 'tired', and treated for 'Asram' (a traditional illness). They then returned to Northern Ghana, and continued to seek traditional treatment. The mother is devoted to the care of her daughter but is living with the husband's family (whilst the husband works away in Accra) and she feels unsupported.

We meet Velma at 6 months and she is very positive about R's changes: *'She used to be weak but now she is a bit strong.'* Rebecca can feed herself and there have been other small improvements. However, she is struggling to buy the nutritious food because she cannot work and has little financial support from her husband who works away from home.

After one year Rebecca is making good progress and her eating and sitting had improved. A new standing frame, made from APT (appropriate paper technology), allows her to engage with play, and to be left whilst the mother is cooking/conducting household chores.

Velma now receives some nutritional support for her daughter and has borrowed money from her own parents so that she can sell rice and oil at the market. She appears happier that she is economically more independent and she uses this money to buy food for her daughter. She also explains that she shares information in the market: *"I always tell them that she was not like that (as a baby), but it is because sickness caused that. And they shouldn't say 'she is not a child'.*

The **family dynamics and support** remain complex, and the husband has only visited twice for very short periods in the last year. The intervention of the facilitator at home visits appears to have helped change attitudes within the family, but tension with the elderly mother-in-law remains, and Velma does not share her learning within the family: *"When I came back my mother-in-law told me that the child that I went and delivered, they don't need it. (.....in tears). there is improvement but I just keep quiet and always go to [to the training]"*.

8.4.1 Poverty as a barrier to nutrition:

Our in-depth interviews highlighted the role that poverty frequently plays in limiting access to nutritious foods. This is often interlinked with the challenge of combining work with a full-time e caregiving role, which necessarily limited the time for patiently feeding a child, or taking the extra time to prepare a meal. This is illustrated in the case study below.

Case: Poverty and nutrition

When we first meet Ella she has been sick for several months with fever and diarrhoea, and the main reason given for not accessing treatment was the lack of an up to date health insurance card (HIC). By the end of the project the family has been supported to get a HIC, treatment had been sought, and Ella's overall health had improved.

The mother is also the main caregiver for husband's ailing and elderly parents, and struggles to manage livelihood activities.

M: Harvesting groundnut and millet is what we've been doing.

I: So, you are always busy?

M: Yes, but because of the child my work is slow. I quickly go to work when she is sleeping She likes me to be changing her diets and if she eats a food for a while, she will not eat it again. Because there is no money to change her diet,

For the last seven months, her husband has been working in Kumasi and living with a second wife. (Code 9920).

Key messages: Feeding, Drinking and Malnutrition

- The prevalence of malnutrition in this population was very high at baseline, with 70% of children malnourished, and remained high at endline.
- There was a significant improvement in overall composite child feeding and drinking scores from baseline to endline. Caregivers were less likely to report problems with eating and drinking and self-feeding at endline.
- Several improvements in feeding were observed by endline including improved positioning at mealtime, use of suitable utensils for feeding and a greater variety of nutritious food offered. However, for children with severe cerebral palsy, and with high tone, positioning could still be difficult.
- The lack of time to prepare separate food or long mealtime durations, remained a challenge for poor families, especially when the primary caregiver was also working. Poverty limits the variety of nutritious food available.
- The level of inclusion from local nutritional services varied, but overall was poor.
- Poverty is a major barrier to improved nutrition for many of these families

8.5 Child's health and wellbeing

8.5.1 Caregiver perception of child's health

At endline, compared to baseline, caregivers were more likely to rate as good, very good, or excellent their child's physical health (73% versus 34%, $p < 0.001$) or the child's emotional health (64% versus 36%, $p < 0.001$) (Figure 6).

Most children had experienced a serious health problem (i.e. a problem the caregiver felt required treatment) in the last 12 months at both baseline (70%) and follow up (67%). At both time points, the most commonly reported primary place attended for advice or treatment was hospital (baseline: 80%, endline 63%) followed by health centre (baseline 13%, endline 32%). At baseline four people (9%) reported seeking advice or treatment from a traditional healer, while no-one reported attending traditional healer at endline (Table 6).

Illness in the last two weeks was common in this study population. At baseline 64% had been ill in the past two weeks with at least one of the following: fever (38%), Cough/breathing difficulties (39%) diarrhoea (13%). At endline this was lower with 50% ($p = 0.05$) reporting illness in the past two weeks: (fever: 25%, Cough/breathing difficulties: 25%; diarrhoea: 18%)

Our monitoring data showed that at baseline only one family had an up to date Health Insurance Card for their child, which was a major impediment to access health services. By the end of the year many families had been supported to re-register the card for their child.

TABLE 6 DETAILS OF HEALTH PROBLEMS EXPERIENCED IN THE PAST YEAR AND PAST TWO WEEKS

	Baseline		Endline	
	N	%		
Child had serious health problem in past year				
No	19	30%	21	33%
Yes	45	70%	43	67%
Where sought advice (All responses)				

Hospital	36	80%	27	63%
Pharmacy	4	9%	4	9%
Mobile clinic	1	2%	0	0%
Private doctor	4	9%	1	2%
Health Centre	6	13%	14	32%
Traditional healer	4	9%	0	0%
Primary place sought advice				
Hospital	34	76%	25	58%
Pharmacy	2	4%	4	9%
Mobile clinic	0	0%	0	0%
Private doctor	3	7%	1	2%
Health centre	5	11%	12	28%
Traditional healer	1	2%	0	0%
Illness in past 2 weeks				
Diarrhoea	8	13%	12	18%
Fever	24	38%	16	25%
Cough / Difficulty breathing	25	39%	16	25%
Any of above*	41	64%	32	50%

*Calculated as percentage out of the children who sought advice; *Significant change from endline to baseline (p<0.05)

8.6 Epilepsy

At baseline 19 (38%) children had more than three seizures in the past year, suggesting a possible diagnosis of epilepsy. However, many families did not have a confirmed diagnosis. At endline, only three families reported having a confirmed diagnosis of epilepsy from a healthcare facility. The case studies highlighted several children who experienced fits. In one case the child had still not received a diagnosis, but was on medication, provided by a private chemical seller. Private prescriptions to purchase drugs at pharmacies was a common because of frequent drug stock-outs at the government clinics, and this could result in discontinuation of treatment by the mother.

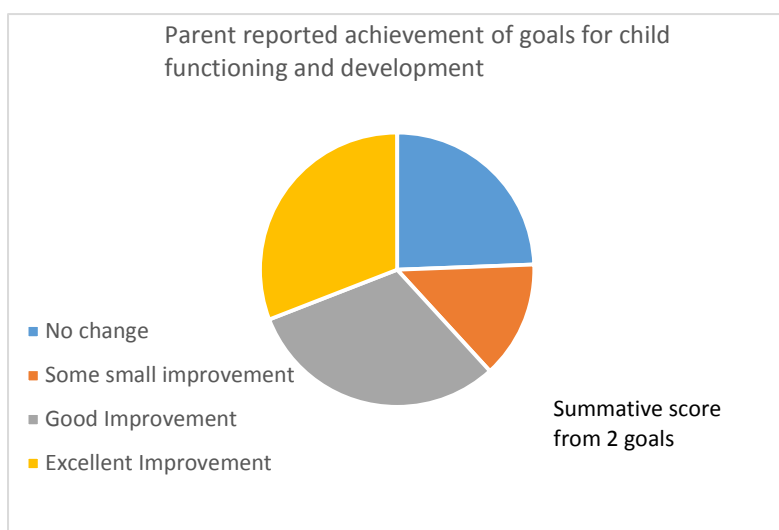
8.7 Goal-setting for children

Within the first two months of the training caregivers were asked to set goals for their child, in relation to the child's functioning and priorities for their child's development. These were to be identified by the caregiver with support from the facilitator, and were intended to be SMART¹¹ Goals which could cover aspects of the child's functioning, or aspects of participation and inclusion. At Endline, caregivers were asked to reflect on the changes in their child and progress made in the goals set, and their satisfaction with changes. As shown in Table 7, on average across two goals, 60% reported good to excellent improvement in their goals and 62% reported being satisfied or very satisfied. Around a quarter of caregivers reported no change in goals, and not being satisfied with change.

TABLE 7 PARENT REPORTED IMPROVEMENT IN CHILD GOALS AND LEVELS OF SATISFACTION

	Goal 1	Goal 2
Goal change		
No change	14 (22%)	16 (26%)
Some small improvement	2 (6%)	15 (24%)
Good Improvement	23 (37%)	15 (24%)
Excellent Improvement	22 (35%)	16 (26%)
Satisfaction with change		
Not satisfied	11 (18%)	18 (29%)
Satisfied	10 (16%)	7 (11%)
Satisfied	17 (27%)	19 (31%)
Very Satisfied	25 (40%)	18(29%)

¹¹ The SMART goal setting is an activity in Module2 of the training manual



The parent-identified goals for improvement in the child's functioning were sometimes very ambitious given the level of severity of the child's condition, and yet, every parent in our **case studies** commented on a variety of changes that they have seen in their child. Overall there was a tendency for parents to comment on observed physical or functional changes which could be clearly observed, but they were also able to reflect on small changes that some felt gave them hope that the child was developing in the right direction.

FIGURE 11 GOAL IMPROVEMENT IN CHILD FUNCTIONING

8.8 Child Mortality

In total, eight children died over the 12-month study period: 6 girls and 2 boys. The standard mortality ratio is 14.61 for children 1-5 years ($P < 0.05$). This means that the study children of 1-5 years are 14.61 times more likely to die than children in the standard population for developing countries, calculated with data from standard UN child model life tables¹².

For the wider age range of children (1-12 years) the standard mortality ratio is 5.88 ($P < 0.05$), using life table data from Ghana¹³, which means that children of 1-12 years with cerebral palsy are 5.88 times likely to die than children in the standard Ghana population without cerebral palsy. The difference in these mortality ratios highlights the particular vulnerability of children with cerebral palsy under five years.

Five children died in the very early stages of the programme intervention, within the first 3 months of the training. Three further children died between the 5th and 7th month of the programme. All eight children had severe cerebral palsy and five children were severely malnourished (on both measures of underweight and wasting). In terms of their home context; seven out of the eight were in middle or poorest tertile for socio-economic status, four families scored zero on the family QoL score, highlighting very poor communication and support within the family. In terms of cause of death there was some sensitivity in discussions with parents with a fear of 'blame' for the child's death, which meant that information offered was often limited. A confirmed diagnosis for death was not provided for any child. All children identified at baseline as moderately or severely malnourished were referred by the local facilitators to enrol in local nutrition programmes, with varying degrees of follow up and adherence.

In at least four of the children who died our data illustrated that stigma and traditional beliefs appeared to play a pivotal role in care of the child and as a barrier to seeking treatment. In one case the child was taken to a spiritualist because the mother felt that the husband's family was bewitching the son (the father lived abroad), and the son sadly died shortly after being given a local 'concoction'. In a second case, a girl of 5 years had been left with the grandparents who also believed the child was a 'spirit child' and had been bewitched.

¹² Child model life tables for developing countries at http://www.un.org/esa/population/publications/Model_Life_Tables/Model_Life_Tables.htm

¹³ Ghana WHO life table (updated 2016) at <http://apps.who.int/gho/data/?theme=main&vid=60630>

<http://apps.who.int/gho/data/?theme=main&vid=60630>

Key messages: Child health

- The caregiver's perception of their child's health improved from baseline to follow up
- Actual frequency of reported serious illness over the last 12 months was high at both time points (> 65%)
- Frequency of illness in the past two weeks was high at baseline (64%) and decreased at endline (50%, $p=0.05$)
- Epilepsy diagnosis was not sought by all families, despite convulsions being frequently reported. Access to medication remained inconsistent, even at endline
- The standard mortality ration for children of 1-5 years is 14.61, which means that the study children with are 14.61 times more likely to die than children in the standard population for developing countries. The high standard mortality ratio for children of 1-5 years highlights the particular vulnerability of children with cerebral palsy under five years and the importance of early intervention.

9 Access to education

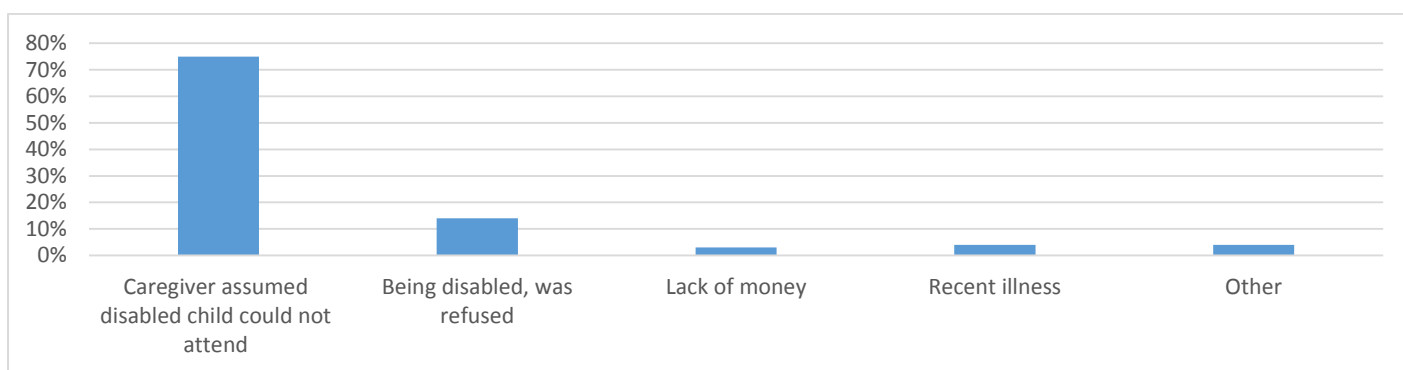
For the following analysis, the data are restricted to the children who were of school going age (4+ years) at baseline i.e. the same cohort who were then 5+ years at endline. At baseline 9 out of 31 (29%) children of school going age were attending school. The main reason given for not currently attending school was that the caregiver *'assumed the child could not attend because of their disability'* (75%) or that the *'child was refused by the school because of their disability'* (14%) (Figure 14).

Of the 11 children who had ever attended school:

- Six (55%) had started at the age the caregiver wanted them too. The two reasons given for not starting at the desired time were *'being disabled they were refused'* or *'caregiver assumed the child could not attend because of their disability'*.
- Three (27%) had repeated a class
- Six (55%) had missed days of school in the last month, of which 4 missed ≥ 10 days

Figure 12 parent reported reasons for children of school going age not attending school





At endline, an additional 3 children (total n=12, 39% p=0.08) were attending school. For all these children, it was reported that the training programme had played a role in this, and reasons given were the 'Caregiver understands the child is capable', 'facilitator helped me or my child' and 'other'.

A similar proportion of school going children (56% and 58%) reportedly missed days of school in the past month at baseline and endline respectively. The average number of days missed was halved at endline (from 16 days to 7

KEY MESSAGES: Education

- School attendance for children with cerebral palsy in this study was low at baseline (29%) and there was some improvement at endline (39% attendance)
- The main reason for non-attendance at school was that the caregiver assumed the child could not attend or the school refused them because of their disability, and this changed at endline
- Training of teachers and peers is required to facilitate inclusion
- An assistive device can facilitate access to school

days). Our qualitative and monitoring data illustrated **that access to an assistive device facilitated access to school**, and that training the class teacher in GTCP also facilitated inclusion. However, the child was also likely face exclusion within the classroom or to drop out of school unless there was support and understanding from peers and teachers. For example, one child dropped out because of exclusion related to dribbling, and another child with severe cerebral palsy and intellectual impairment was excluded within the classroom, set aside on a table on their own, with the elder sister being brought in to change and feed him.

9.1 The complexity and fluidity of family lives

The case studies throughout this report highlight the extreme vulnerability of many of extremely poor families included in the study, and that although there were many positive changes from their participation in the programme, the research highlights that progress was not always linear; families were not always resilient to shocks, such as the loss of a job, a husband leaving, or a child becoming ill. The case studies highlighted the fragility of the lives of the caregivers and particularly how socially excluded they felt, even when living within extended family. Of course, all these factors impact upon perceptions of quality of life.

Throughout the findings, case studies illustrate the fluidity of family situations, the intersectionality (*how things interlink*) of poverty, disability, and the gendered nature of caregiving, and how layers of different themes and sub-themes are interwoven.

9.1.1 Case Study 5558 – Vulnerability and complexity of caregiver lives

Case Study: Vulnerability and complexity of caregiver lives

B has two children and is living on her own in one small rented room on the outskirts of Accra). Her older daughter is 6 years and is at school and her son is 4 years old and has severe cerebral palsy, epilepsy and additional

behavioural and intellectual challenges. Her husband left after the birth of their son, and does not visit nor provide any support the family: *"When I gave birth to M, the mother [the mother-in-law] said that in their family they do not give birth to children like this, and then he said the same thing."*

When we meet B for the first time she explains that her own mother has died and she has no family support from other family members:

[When you are feeling sad, or you have a problem, who are you going to for help?] I don't go anywhere I'm just in my room.

M has regular seizures but she doesn't give him medication *"because it makes him weak"*, and she is also unable to pay for the medication. She rates her quality of life as very low with multiple challenges: *Because M [my son] cannot walk, he cannot do anything for himself. And because of him I can't even work, and his father has rejected us. My family members too are not taking care of me. And I have so many problems in the world and it is very hard and difficult."*

At 6 months B is very happy that she has secured a job in a small tailoring business. She is a seamstress, but had not been able to work whilst looking after M. Her son is now making some progress, and her main concern is how to get M into a local school; he has already been turned away from one school.

One year on she explains how she has changed her care for M, especially around communication, encourages M to stand, and is giving him regular treatment medication, and M is also finally in school. She feels that teachers treat him well, but toileting is a problem, and he can be left all day in soiled clothing, or they will call the older sister to come and clean him and feed him, thus missing her own lessons. When M is observed in school he is sitting on *his own* and the teacher explains this is *'to protect the other children'*. Sadly, one month later M has dropped out of school.

By the time of the endline, B feels that her quality of life has 'regressed'. She has her job as a seamstress, and in the 6 months she has tried various trades, has borrowed money as which has put her further into debt and she struggles to put food on the table; at least her daughter receives a school meal as part of a feeding programme but otherwise they can often go to bed hungry.

Oh, there are days that when I struggle to get something to eat, I sleep on empty stomach. It wasn't just once. And I don't want to be a burden on the people I live in the house with too, to seem as if every day give me this or that. I feel it is getting too much, so the little I have I give it to the children. Even if there is a little left, I reserve it for the following morning for them to eat before they go to school.

Social exclusion is also a key recurring theme in the first 6 months, but by the end of the year she reflects on the support group as a 'family' and valuable psycho-social support which it offers. One of the main difficulties is that the women come from large distances, so meeting up directly outside of meeting is limited:

At first I wasn't doing that [sharing problems] but now I have realized we are one family. So, each time we meet, we discuss our challenges.....I don't like discussing much of my challenges with just anyone because I may not know the person.but I have realized most people have problems like me so when we meet, we share our challenges. There is one of them who attends my church,, I can discuss a lot of issues with her. She took my number on the last day we met so she calls and we chat on the phone.

* After this interview, B is linked up with a local charity which provide her with a sewing machine so that she can work from home.

10 Understanding the impact of assistive devices

Through the programme 50 assistive devices (ADs) were provided to 36 (56%) of the children, with some children receiving more than one AD (figure 1). Standing frames (n=16) and static seats (n=20) were the most commonly provided ADs. Distribution of ADs was associated with geographical region and severity of cerebral palsy.

Caregivers reported that ADs enhanced their ability to work and reduced their tiredness. Caregivers perceived ADs as facilitating social inclusion for their children, including in play, school, and social interactions with their family and local community. Caregivers also felt that ADs promoted child development by improving mobility or trunk strength. However, Caregivers reported generally high levels of satisfaction with ADs during qualitative interviews, with reported dissatisfaction being linked to sizing and durability.

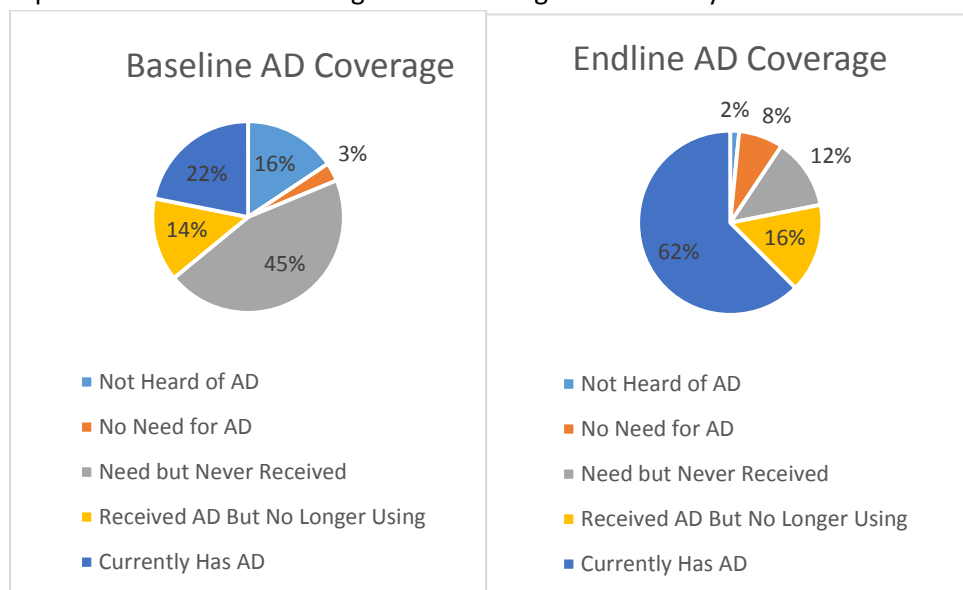


Figure 13 AD Coverage at Baseline and Endline

What happened was, before she had the chair, I would have to carry her most of the time, but after that, because of the chair, she is able to sit and play. She can sit, and eat. And, now she doesn't lie down most of the time, do you get it? [7778, Grandmother]

Challenges identified included issues of limited durability and abandonment of ADs, with a third of the ADs provided no longer in use by the time of the follow-up survey and 40% of the main ADs needing repair. There were challenges in providing suitable ADs for children with complex postural needs, including limited use of tilt in standing or seating devices and limited use of pelvic belts. ADs also caused discomfort and pain for some children, particularly where ADs were an inappropriate size for the child.



11 Understanding and evaluating the role of the support group

A cornerstone of the ToC is the role of the support group); it was proposed that the caregivers would offer valuable peer support both inside and outside of the group, offer shared strategies for caregiving, and that the group support would be pivotal in helping to address issues of stigma and discrimination.



In practice the group support was found to offer a wide range of benefits as hypothesised

All the caregivers included in the endline survey reported that they recommend the training to other families, and 86% stated they found *all* aspects of the training useful. In terms of the qualitative data, consistently across every case study interview there was overwhelming positive feedback about the support groups. The groups served a multitude of functions, but most notably a common recurring theme was the parent's realisation that they were '**not on their own**'.

What do you like most about the meeting?

GM: A lot. I thought it was only my child who had these 'disabilities' but now I know it's everywhere. We go there and they teach us how to feed the children, handle them, have patience for them and love them. They said these disabilities are from the brain. I learn a lot when I go there. (Case 3335)

So, tell me about the group. How do you see the group?

M: It was good, and there was so much happiness. When we go, we realize that each of us is not the only person with that challenge.....When we go too we don't only look at our child alone but help others too. (Case 1194)

M: In Accra, they used to talk and I was sad with the child, but I don't listen to them [now] because when I came here and saw the other mothers ... I know that I am not the only one who gave birth like that. (Case 9990)

Other positive outcomes of joining the group included forging new **friendships**, or as it was quite commonly explained that the group was like '**a family**'. This seemed to be a particularly important role, given the level of isolation that many of the caregivers' experience. In two sites the groups visited mothers following the death of a child, and one mother continued to attend the group for support, even though her own child had died. However, the large distances between some members in rural areas precluded the opportunity to meet outside of the sessions.

M: When I was in the house, I did not know what was wrong with my child but after I joined the group, I was told what is wrong with him and I'm fine now. I have also made friends from the group. (Case 9921)

M: The group was good because there was unity among us.....Hum! I am alone sitting; I have no one to share my problem with..... I know that I can share with them what my worry is, and there is understanding so they can support me. (Case 3342)

Sharing and learning from each other was valued; caregivers realised that they also had something to offer other parents, in turn, improving their own self-esteem. The groups also offered an opportunity to reinforce learning through peer-to-peer learning, especially as most of the parents were not literate, and many had not attended

school. Ghana has also multiple local languages and some of the mothers translated for individuals whose first language was not the medium for the training.

M: Yes, I have something to tell the group when we meet next time. The way my child is improving from the meeting, they should have patience for their children and continue with the training because they will also get improvement with their children.

I: That's very important. Did you realize you have something you can share with the group?

M: I did not have this in mind, but I realized that today when you came. (3342)

I: Well I don't know how to read but when I attend the meeting and forget about something after the meeting but I want to recall what I have learnt I will give it to B [another mother who is very active] and she will tell me. (3344)

Giving hope from seeing the improvements of others, was also reflected on, and for some mothers, seeing that their child could do more activities than other children was also comforting (CODE 3335)

M: Yes, I am already a health worker, but being in a group has helped me a lot because sometimes you see children with the same problem and it gives you hope that one day..... And to see other children recovering and I've see so many changes. (Case 5560)

The group sessions also afforded the opportunity for **encouragement** and reinforcement of good practice to their peers:

Maybe there is something I know which the other person doesn't know, so we share ideas. When we meet, we become happy and encouraged by the things we are taught. (Case 5577)



Another benefit of the support groups was a **safe space to share experiences**, especially on sensitive subjects, and especially given that for many the home environment was unsupportive. The space allows for psycho-social support. This is illustrated by one of the caregivers who explained how her group supported one of the other mothers whose husband wanted the child to be removed from the house. The example below also illustrates child protection issues which, from the wider monitoring data collected, remain an ongoing priority, and require further attention.

M: There is one woman who lives with her husband, but he says he doesn't like the child so she should send the child away.

I: She should send the child where?

M: She should give the child to anyone interested in him even if it means throwing the child away, he doesn't care. So, when we heard about the issue, we went to her place and advised her not to mind the man, but continue taking care of the child. As God can help the child to become a better person in future.

Notably, some of these positive reflections on the role of the group emerged towards the end of the ten-month period

Key lessons: Understanding the mechanism of the support group

- reducing the sense of social isolation and exclusion of caregivers
- offering a platform to provide psychosocial support to caregivers
- providing a safe place to share experiences
- collective sharing of experiences can help to address stigma
- through shared learning there are opportunities for peer learning, encouragement, and hope
- Large distances reduce opportunities in rural areas for meeting up outside of the group

reflecting the time needed for group formation and identity with the group.

11.1 The role of the home visits

Within the ToC, the home visits were intended to offer an opportunity of reinforcing learning from the groups, for counselling the parents, and to be able to engage with the wider family.

Overall home visits lasted on average 45 minutes. Although most caregivers stated that they valued the home visits, the main purpose of home visits was perceived to be a way for the facilitator to 'check' that they were implementing lessons learnt from the group session. They were also seen as useful for reminding caregivers what they had forgotten, and for discussing individual follow up around referrals. However, the counselling element anticipated from the home visits, did not emerge as a key theme reported by caregivers or facilitators. The extent to which other family members were involved in home visits appeared to vary considerably, but was generally quite limited.

The participatory mid-term review-meeting with all facilitators concluded that home visits provided privacy to discuss certain issues one-to-one. Facilitators did identify that home-visits help in family and community sensitization, however, stigma was also seen as a hindrance to community involvement. There was lack of support from some family members and misinformation from opinion leaders, such as pastors and spiritualists, also played a role. Challenges to delivering home visits included a lack of transport, climate conditions (the rainy season) and language barriers [24].

12 Programme Costs

A full economic evaluation of the project was not conducted, but costs were collected to evaluate: (1) How cost varied across sites, including urban/rural differences (2) A cost break-down of the different components of the intervention.

On average, the cost of running **each monthly parent** session per site (including a home visit) was: \$246 (GHS 981, £195)¹⁴ ¹⁵which was based on an average of 10 parents attending¹⁶. This covered all programme costs including transport, facilitation costs, refreshments, support for onward referrals, airtime, community sensitisation, and general administration, and provision of assistive devices.

The overall programme cost, per site, for a 10-month programme, was \$2970 (GHS, 11,830, £2410). The largest proportion of expenses was for facilitation fees (20%), and overall transport costs (32%); this covered costs for parents to attend the training (15%) and for facilitators to conduct home visits (17%). For a detailed breakdown see Appendix 4– Average cost of different programme components for a total of 10 sessions over 10 months.

¹⁴ This was based on data collected for running 9 sessions at time of data collection & needs readjustment when final budget available

¹⁵ Exchange rate \$3.99= \$1 , £= GHC 5.02 (11th November 2016)

¹⁶ This was an average group size because in addition to the parents included for the study, additional parents joined the group.

We did not find a difference in costs in running the programme between the urban and rural sites, which is surprising perhaps, however transport costs were covered in both contexts. The overall cost for the provision of assistive devices was low at only 6%, and it was anticipated that this would be considerably higher. However, in most cases the children were referred for locally made assistive devices using APT (Appropriate paper technology) where costs were very low for materials.

13 Conclusion and recommendations

13.1 Conclusion

Children with disabilities have a right to health care, education and social participation as enshrined in the 2006 UN Convention on the Rights of Persons with Disabilities [25] and in the UN convention on the rights of the child [26]. Cerebral palsy is the most common condition associated with childhood disability and yet there are few services available to support these children and their families in low and middle income settings, and there is a need for home and community based approaches which have a good evidence base.

This research project has shown that it is feasible and acceptable to implement the participatory community based parent support groups programme in different settings across Ghana, and that caregivers highly valued the training and would recommend to other parents. Caregivers provided very positive feedback on the training, and in particular, valued the support from other caregivers attending the training including which helped them understand that they are *not on their own*, and offered an important social support network in communities where they often felt socially excluded.

There was a significant improvement in caregiver QoL measures after the training programme. This is one of the only studies of home based programmes for children with cerebral palsy targeted at LMIC, to demonstrate this positive impact of the programme on a child and the caregiver, recognising the central role of the caregiver. An earlier study in Bangladesh had highlighted the low QoL measures of families with a child with cerebral palsy but had not evaluated the impact of the training programme [14]. Caregivers reported positively about even small changes in their child's development, and felt this gave them hope. We found that the knowledge about the child's condition improved significantly, which was particularly important given that most had never received any diagnosis about their child's condition. Caregivers also reported a significant increase confidence in caring for their child, and importantly also greater patience and understanding in caring for their child. There were also caregiver-reported improvements in the child's functioning, reflected in the positive reported progress in the individual goal-setting for each child.

There was a mixed picture of outcomes in relation to feeding, drinking and malnutrition. The mealtime experience improved, with the caregivers reporting significantly less stress at mealtimes and more patience with their child. However, some of the challenges with feeding their child remained. The overall levels of malnutrition remained very high, although at least did not deteriorate further. The referral and inclusion with local nutrition services varied across the sites, but was generally poor, and this is therefore an important area for follow up.

There was some small improvement in access to education, but children were also likely to drop out of school unless they had support and understanding from peers and teachers. For a child with severe cerebral palsy our research highlighted the challenges of meaningful inclusion in the classroom, and that other models of community support need to be explored.

The in-depth research with families also highlighted that although there were very many positive examples of change, their lives were also extremely fragile and fluid, and not resilient to shocks, such as the loss of their livelihoods. In most of our case study families there was no support from the father of the child, many of whom were absent from the household. Linked to this is the high levels of poverty which shaped the lives of many caregivers was exacerbated by not being able to combine work with full time caregiving. Although there were home visits and

family based activities as a component of the training, there was generally little change in the level of family support, and a way to engage with the family and particularly engage with fathers, is a priority going forward.

This intervention focusses on caregivers within a community setting, and although there is a small component of training on disability in the community and on disability rights, it is a relatively small component of the overall training¹⁷. However, this research emphasises the extremely high levels of stigma and discrimination towards children with cerebral palsy, and in many cases to their caregivers, which is a major barrier to accessing services and wider community support, and for which there is an urgent need to address. Given the gendered nature of caregiving, the interplay of gender, poverty and disability needs further consideration.

13.1.1 Study strengths and limitations

The strength of this study was the mixed methods design. The longitudinal qualitative research facilitated the building of trust and relationships between the researcher and caregivers and children, thus enabling a more in-depth exploration of often very sensitive issues. It allowed improved interpretation of the quantitative data collected, and for an exploration of the underlying mechanisms of change.

The numbers were relatively small, but were still substantial for a disability study, given the prevalence of cerebral palsy. The target families were identified in areas supported by the Presbyterian Church of Ghana, who typically work in areas of greater deprivation, and therefore our sample was likely to be considerably poorer than the general population. This may have influenced the outcomes, especially given the central role that poverty appears to play in influencing the ability of caregivers to influence change

¹⁷ 3 months after the endline data collection, in October 2016, each site conducted a range of community focussed advocacy activities which are not captured in this study.

14 Key recommendations

These recommendations are informed by the 2- year research findings, and from the research dissemination meeting with key stakeholders in Ghana, held on 24th November 2016 at the Presbyterian Church of Ghana (Headquarters).

1.2 National level

- 1.2.1 Children with cerebral palsy have wide-ranging needs and therefore a multidisciplinary approach is required to support children and their families
- 1.2.2 Conduct a review of national nutrition guidelines and identify and strengthen opportunities for inclusion of children with disabilities (including the specific needs of children with cerebral palsy).
- 1.2.3 Advocate and plan for training of health professionals, including nutritionists and at the primary health care level, on disability. More specifically on early diagnosis, strengthening referrals, and improved communication and support for families. This should include the review of training curricula and continuous professional development programmes for health professionals.
- 1.2.4 Strengthen partnership working with the Ministry of Education and the department of special education.
- 1.2.5 Advocate for more effective mainstreaming and inclusion of disability within social protection and livelihoods programmes. This needs to include the specific needs of children with disabilities and their caregivers.
- 1.2.6 Strengthen linkages with organisations working on mental health. Identify opportunities to effectively monitor anti-epileptic drug stock-outs at community level, and strengthen follow up at community level. Also, highlight the mental health needs of caregivers, and how these can be addressed.
- 1.2.7 Collaborate with the Ministry of Gender, Children, and Social Protection to identify opportunities to address the specific needs of caregivers as well as children with disabilities. This should include how to address child protection and safeguarding issues most effectively, and how to support the mental health needs of caregivers.
- 1.2.8 Explore opportunities and further develop approaches to early detection and early intervention for children with disabilities, and specifically for children with cerebral palsy.
- 1.2.9 Use the 'Getting to Know cerebral palsy training' to spearhead the development of caregiver/parent support groups and networks.
- 1.2.10 Utilise the research to inform a national advocacy campaign to address key issues such as disability-related stigma. Engage with the faith-based organisations and networks, and the media, to maximise engagement on issues of stigma, discrimination, and exclusion of families with children with disabilities.
- 1.2.11 Facilitate disability inclusive national strategy, policy, and data collection. Engage policy makers to pass the legislature (L1) for Ghana's Disability Act which came into effect in 2006.

1.3 Programming level

- 1.3.1 Establish caregiver/parent support groups at community level using 'Getting to know cerebral palsy'. Therapeutic services should support the running of the groups and provide technical assistance, as required.

- 1.3.2 Identify opportunities to effectively engage with family members, and the wider community, on disability and specifically the needs and rights of children with disability and their caregivers. Utilise traditional structures (such as Durbars¹⁸ and traditional healers), faith based organisations, and the village health committees as key stakeholders in fighting stigmatization and encouraging inclusion.
- 1.3.3 Identify opportunities to engage with fathers to maximise their participation within the training. This can include, for example, the use of male role models and male disability ‘champions’ within the community.
- 1.3.4 Plan for local training of health professionals, including nutritionists and at the primary health care level, on disability. More specifically strengthen options for early diagnosis, strengthening referrals, and improved communication and support for families.
- 1.3.5 Facilitate access for the most vulnerable families for re-registration for the National Health Insurance Card Scheme (NHCS).
- 1.3.6 Strengthen referral processes to all local services for children with disabilities and their caregivers.
- 1.3.7 Access to education for children with cerebral palsy must include training/awareness raising of staff and of peers.
- 1.3.8 Identify opportunities for the mainstreaming of disability into local livelihoods programmes, including micro-financing. Any livelihood opportunity also needs to be gender sensitive, given the gendered nature of caregiving.
- 1.3.9 Child protection and safeguarding issues must be planned for, with clear processes and referrals and aligned with the social welfare services.
- 1.3.10 Explore approaches to engaging with traditional healers

1.4 Assistive devices

- 1.4.1 Align the planned work on assistive devices/technologies with the new programme on Global Cooperation on Assistive Technology (GATE).
- 1.4.2 Ensure that Ads are of sufficient quality and durability to be used by children within their everyday lives. Caregivers and children should be involved in decision-making processes about ADs and receive appropriate training in their use. Encourage information sharing on locally sourced low-cost ADs.
- 1.4.3 Explore options for building capacity of local craftsmen (carpenters and welders) to produce ADs from local materials and including training on ADs in local vocational training schools.
- 1.4.4 Strengthen the training to caregivers on ADs, and ensure robust follow up with families, which also includes monitoring of pain or discomfort and adjustment of the ADs as the child develops.
- 1.4.5 Future training programmes for AD provision should focus on postural management strategies and increasing durability of ADs.

¹⁸ Durbars are large community gatherings in Ghana used for information sharing

1.5 Recommendations for the Manual 'Getting to know cerebral palsy'

- 1.5.1 Explore opportunities for the use of 'expert mothers' (mothers who themselves have a child with cerebral palsy) instead of therapists in the delivery of the training, and for home visits. This would then free up time for more targeted use of therapists to complement the training. This should be accompanied by research and robust monitoring and evaluation to evaluate their impact.
- 1.5.2 Provide further training on participatory approaches in the delivery of the training.
- 1.5.3 Review and strengthen the nutrition module and the approach to nutritional support and referrals, for children who are severely and moderately malnourished.
- 1.5.4 Identify the most vulnerable families and agree on closer and more frequent follow up to these families, which includes strengthened referrals to local services needed.
- 1.5.5 Build in additional components to the training manual on early intervention for children < 2 years
- 1.5.6 Child protection and safeguarding needs to be included in the manual as a topic.
- 1.5.7 Further strengthen how to address stigma and discrimination as a cross cutting issue.

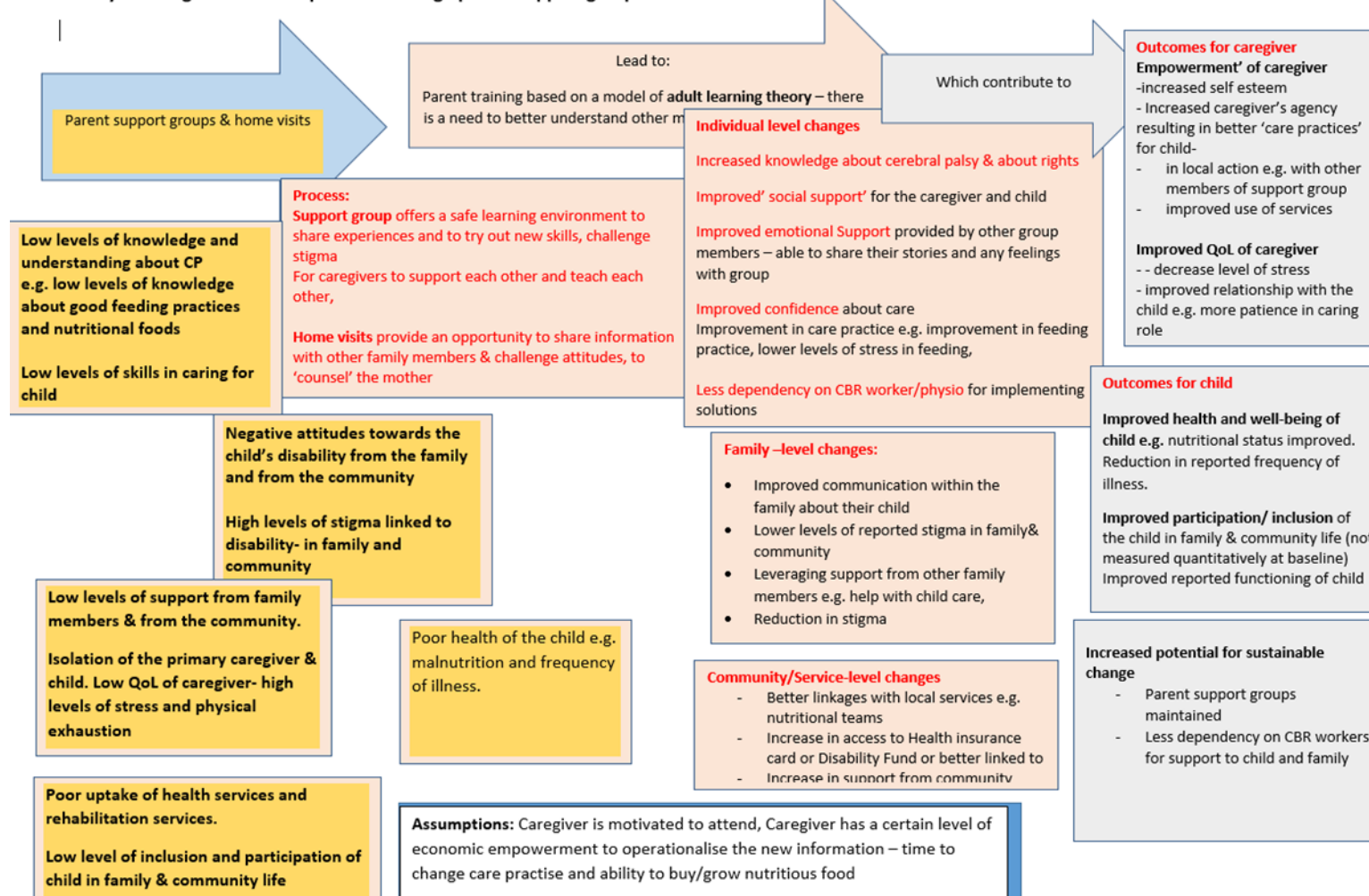
1.6 Research

- 1.6.1 Conduct follow up research on nutrition and disability, which includes a more in-depth understanding of the supply-side barriers to inclusion within primary health care.
- 1.6.2 Conduct research into the use of expert mothers in the delivery of the support group training. How can expert mothers be most effectively utilised to improve outcomes for children, caregivers, and families? An RCT which compares the use of expert mothers and therapists in the delivery of training and home visits is one possible option
- 1.6.3 Evaluate the use of the manual for early intervention programmes.

15 Appendices

Appendix 3 Theory of change

Theory of change: Parents empowered through parent support groups- REVISED JANUARY 2016



15.1 Appendix 2: Characteristics of Endline study total population and those lost to follow up

TABLE 8 CHARACTERISTICS OF ENDLINE STUDY TOTAL POPULATION AND THOSE LOST TO FOLLOW UP

	Included in End-line		Lost to follow up		P-value
	N	%	N	%	
Child characteristics					
Sex					
Male	38	59%	3	25%	0.03
Female	26	41%	9	75%	
Age Group					
18months-2 years	25	39%	6	55%	0.54
3-4 years	21	33%	2	18%	
5+ years	18	28%	3	27%	
Cerebral Palsy severity					
Mild	15	23%	2	17%	0.57
Moderate	17	27%	2	17%	
Severe	32	50%	8	66%	
Caregiver characteristics					
Age group					
<30	19	30%	4	33%	0.96
30-40	29	45%	5	42%	
>40	16	25%	3	25%	
Ever attended school					
No	28	44%	5	42%	0.89
Yes	36	56%	7	58%	
Household characteristics					
Region					
South	36	56%	4	33%	0.15
North	28	44%	8	66%	
SES group					
Poorest	21	33%	4	33%	0.30
Middle	19	30%	6	50%	
Least poor	23	37%	2	17%	

15.2 Appendix 3 Table Case Study Family Details

Child Age* (years)	Gender	Relation. M= Mother, GM= GM	occupation	M= married/living together, W=widow/div, S=single	Father in house N= No Y=Yes	Enrolled in school	Socio-economic status (Tertiles) 1=Poorest 3+=richest	GMFCS (level of severity of CP) 1=mild 4/5=severe
1.5	F	M	Trader	M	N	N	3	2
3	M	M	Trader	M	N- father moved out – visit daily	N	3	3
2	F	GM	Manual work	W	N	N	2	2
4	M	M	Health worker	M	Y- away at endline	Y	2	3
12	F	M	housewife	M	Y- works away from home regularly	Y	1	1
3	M	M	Learning Hairdressing	M	N- living separately in compound	0	2	4
4	M	M	Seamstresses	D	N	Y- then dropped out	2	4
2	M	M	Midwife	m	N	N	3	3
3	M	GM	Sells alcohol at home	m	N	N	3	5

11	M	M	Trader	s	N	Y	2	4
2	M	M	Farming	s	N	N	1	5
2	F	M	Farmer	d	Y – but polygamous marriage – absent for 7 months	N	1	4
1.5	M	M	Dressmaker	M	Y- works away from home regularly	N	2	3
2	F	M	apprentice dress making	M	N	N	1	3
5	F	M	Manual work	W	Dead	N	3	5
6	F	GM	Trader	M	N	N	2	4
1.5	F	M	Farmer	m	N	N	2	4
11	F	Cousin	Farmer	M	N	N	2	1

15.3 Appendix 4– Average cost of different programme components for a total of 10 sessions over 10 months

TABLE 9 AVERAGE COST OF DIFFERENT PROGRAMME COMPONENTS PER GROUP BASED ON AN AVERAGE OF 9 SESSIONS AT TIME OF DATA COLLECTION

	Community Sensitization	Sensitization for CHW and Volunteers	Transport Cost (for 12 parents)	Airtime & Stationery (12 Home Visits)	Admin (printing materials)	Toys and Accessories	Refreshments (Parents & Children), volunteers, staff	Facilitation Fee	Transport (Home Visits)	Assistive Devices	Other Health Costs NHICs., referrals	Average Cost per site
GHS	212.44	368.29	1,453.22	241.67	189.66	428.37	1404.46	1,971.73	1,693.24	597.78	1254.28	9815.14
\$ *	53.24	92.30	364.21	60.59	47.53	107.36	351.99	494.16	424.37	149.81	314.35	2459

*Exchange rate \$3.99= \$1 , £= GHC 5.02 (11th November 2016)

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