

## **Abstract: Evaluating the impact of a training programme to empower parents of children with cerebral palsy. Baseline Results.**

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### **Background**

Cerebral palsy the most common cause of physical disability in children worldwide[1], and the majority of these live in poor resource settings [2]. Yet recent reviews [1, 3] highlight the huge gaps in services for these children, and the need for research into effective home based programmes of care and support.

This study aims to evaluate the impact a participatory community based parent training programme which is being implemented across 5 districts in Ghana over a one-year period. This consists of monthly parent meetings. Here we present the results from the baseline study.

### **Aims**

The overall aim is to understand the impact on children with cerebral palsy and their caregivers from participating in the community based training programme 'Getting to know cerebral palsy.

### **Methods**

This is a mixed methods study. At baseline a survey was conducted with 76 children (18 months – 2 years) with cerebral palsy and their primary caregivers across 8 sites in Ghana. Children were recruited through the primary health or CBR programmes. Using a structured questionnaire data were collected on the child (e.g. difficulties with child feeding, functioning, health), the caregiver (e.g. quality of life using *PedsQL™Family Impact module [4]* and household socio-economic status). Anthropometric measures were taken: standing height (>5 years), laying length (<5years), weight, middle upper arm circumference (MUAC)). If standing height could not be measured, knee height was used as a proxy. We explored the association between socio-demographic and economic characteristics and severity of cerebral palsy and i) Caregiver QoL, ii) Feeding score iii) malnutrition using multivariate regression analysis. The qualitative component comprised 12 family case studies, with a longitudinal design over 12 months.

### **Results at Baseline**

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Key results at baseline show that caregivers report very low quality of life (PedsQL™Family Impact). There is a limited support at household level for caregiving, a lack of any community social safety and levels of stigma and discrimination are very high. In 50% of households the father is absent. 84% of caregivers reported poor understanding of their child's condition, and their narratives highlight the emotional stress and physical exhaustion of caregiving, and the negative impact on livelihoods. PedsQL™Family Impact was lowest in the poorest families, and significantly poorer for children with moderate or severe feeding difficulties. Overall 70% of children were underweight, stunted or wasted.

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2. World Health Organization and World Bank. *World report on disability 2011* [cited 2013 19/12]; Available from: [http://www.who.int/disabilities/world\\_report/2011/en/index.html](http://www.who.int/disabilities/world_report/2011/en/index.html).
3. Allan Colver, C.F., Peter O D Pharoah, *Cerebral Palsy Published online November 20, 2013* [http://dx.doi.org/10.1016/S0140-6736\(13\)61835-8](http://dx.doi.org/10.1016/S0140-6736(13)61835-8). The Lancet, 2013.
4. Varni, J.W., et al., *The PedsQL™ family impact module: preliminary reliability and validity*. Health and quality of life outcomes, 2004. 2(1): p. 55.