

# APPROPRIATE PAPER-BASED TECHNOLOGY (APT) ASSISTIVE DEVICES FOR YOUNG CHILDREN WITH CEREBRAL PALSY IN RURAL KENYA

## PRELIMINARY FINDINGS FROM A FEASIBILITY STUDY

Lindoewood R<sup>i</sup>, Samia P<sup>ii</sup>, Barton C<sup>i</sup>, Chege D<sup>iii</sup>, Johnson C<sup>i</sup>, Kiragu T<sup>iii</sup>, Westmacott J<sup>iv</sup>

<sup>i</sup> Powys Teaching Health Board Wales, UK. <sup>ii</sup> Aga Khan University, Nairobi, Kenya <sup>iii</sup> St Martin Disability Programme, Nyahururu, Kenya, <sup>iv</sup> Cerebral Palsy Africa, UK

### Introduction

The World Health Organisation<sup>1</sup> notes a lack of assistive devices for disabled people in Africa particularly children with Cerebral Palsy. APT using cardboard to make bespoke chairs and standing frames has been introduced in several African countries. Such device production is potentially sustainable as the materials are cheap and available although production is labour intensive requiring training<sup>2</sup>. In Zambia, a group of Disabled People known as APTers have been producing devices for 23 years and a second workshop has been running for 7 years<sup>2</sup>. A number of centres have begun production in Kenya after training courses supported by Cerebral Palsy Africa between 2009 and 2015<sup>3,4</sup>. Informal follow up and reports from recipients of APT devices, their carers and service providers has suggested benefits to their posture and participation but these have not been formerly evaluated or published in the scientific literature.

### Methods

One centre in Kenya with the most experience of APT device production was chosen and 6 children registered at the centre and meeting the eligibility criteria (see Table 1) were invited to participate in the study. Following informed consent by their caregivers and identification of needs by the caregiver and rehabilitation worker, the children were assessed for Gross Motor Function Classification System (GMFCS) Level, posture and range of movement, care needs and their participation. They were measured for either a supportive chair or standing frame, issued with the device and advised how to position the child and complete a daily logbook of time using the device.

#### Inclusion criteria

- Child Aged 1-6 years with a diagnosis of bilateral Cerebral Palsy. The preschool group are targeted as it may be that neural plasticity is at its greatest at this time and there would be the least disruption to their education.
  - GMFCS level IV or V.
  - Caregiver able to bring child to Workshop for assessment and APT device(s) fitting
  - Caregiver able to record daily device usage on paper.
  - If child is attending school, caregiver is able to transport the APT device to and from school.
  - Child able to tolerate and cooperate with detailed assessments
  - Child can be brought or visited a week after fitting and then regularly by research assistant to monitor usage of device(s), positive and any negative effects.
- Exclusion criteria.
- Child with hemiplegic Cerebral Palsy (only one side of the body affected.)
  - Child with a progressive neuro-muscular disorder
  - Child with severe uncontrolled epilepsy
  - Child already using a postural support device

Figure. 1 Eligibility criteria.

Regular visits by a rehabilitation worker took place to check the continued suitability and correct use of the device and completion of the log book. Reassessments of range of movement, ability to maintain posture, care needs and participation were made after five months of device usage and interviews with caregivers recorded to provide qualitative data. A further six children have been recruited to be reassessed in six months time



Figure 2. Therapist assessing posture



Figure 3. Child measured for APT assistive device.



Fig. 4 Adjustments agreed for partially constructed chair by rehab. worker and caregiver

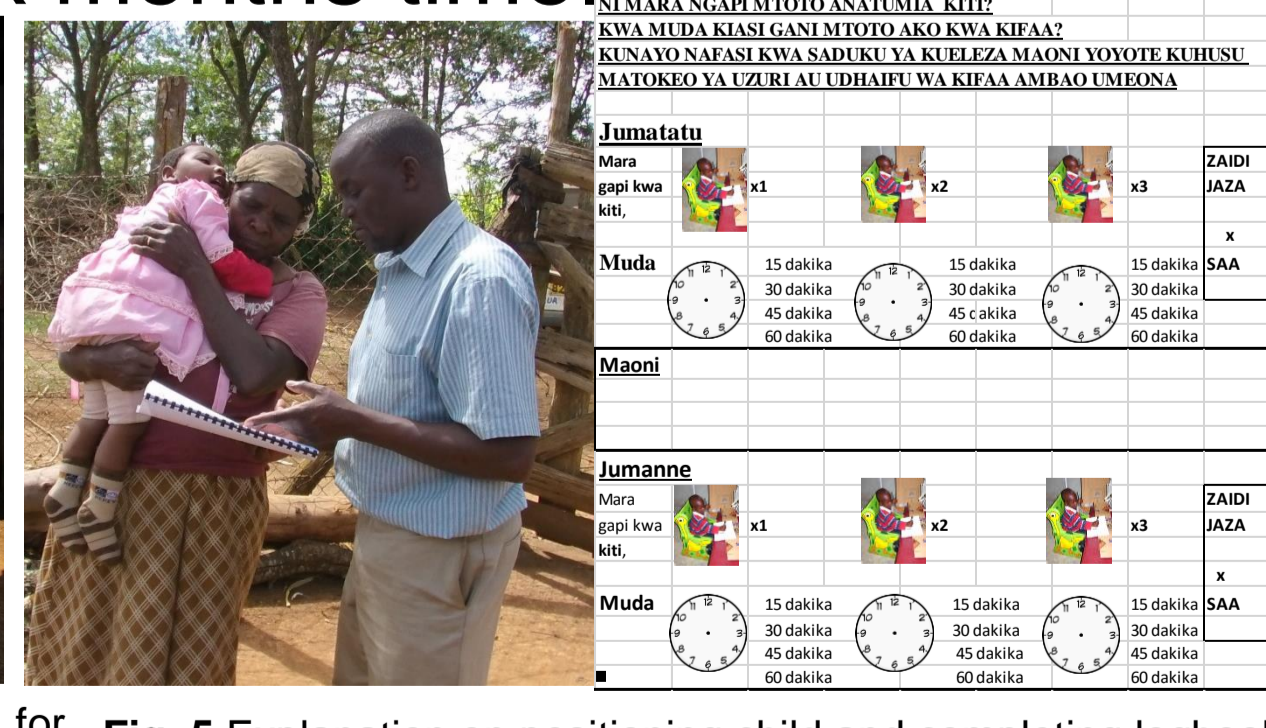


Fig. 5 Explanation on positioning child and completing logbook (example page right) given to caregiver by rehabilitation worker.

### References

- 1 Assistive devices/technologies: what WHO is doing—World Health Organisation 2014 <http://www.who.int/disabilities/technology/activities/en/>
- 2 Assistive Cardboard Equipment using Appropriate Paper-based Technology. Westmacott J. Cerebral palsy Africa 2016,2a p185,chapter by K.Habaalu
- 3 Introducing appropriate paper-based technology (APT) assistive devices for young children with cerebral palsy in rural Kenya. Lindoewood R, Johnson C, Kanaris K. Welsh Paed J 2015;42:6-8
- 4 Introducing local production and use of postural support devices made from Appropriate Paper-based Technology (APT) for young children with Cerebral Palsy through Kenyan Community Based Rehabilitation (CBR) Programmes. Poster presented at International Symposium on Disability in the SDGs: Forming Alliances and Building Evidence for the 2030 Agenda 18th-19th February 2016, London School of Hygiene and Tropical Medicine

### Results

Three supportive chairs and three standing frames were issued to six children aged 1-6 years, and five chairs and one standing frame are almost ready to be supplied to six newly assessed children, all GMFCS level V aged 9 months to 7 years. One child in the initial group moved away to a distant province soon after issue of the device and the father of another child declined further follow up after receiving his child's device. The remaining four children (two GMFCS level IV and two GMFCS level V) had been visited twice by rehabilitation workers and on the reassessment visit found to be using their devices on a daily basis, although one standing frame recipient was also found to be using a supportive chair provided by another centre.



Figures 5-7—Three children using their standing frames 5 months after issue. Note three different methods of supporting the device. Figures 8-9—Youngest child in her chair—material wedged to right in Fig 9 to improve posture. Curved insert and head support to be added.

One standing frame and one chair required adjustments for better posture. Three caregivers had completed their logbooks well with gaps only when the child and caregiver were away from home and when another child had started residential school towards the end of the study period with a plan to take the device to the school for the new term. All children in the initial group had a full range of movement at baseline and reassessment visits when an additional trunk stability measure was added. Improvement in participation was seen and acceptability of the devices was high, although further analysis of the participation and care needs questionnaires and of the interview transcripts is awaited.

Five of the additional children had a full range of movement at recruitment with the oldest child having a dislocated hip and some restriction of hip and knee movements – a reclining chair has been made for him to maximise posture and comfort.(figure 14). A wheelchair was observed on visiting his home which needed adaptation.



Figures 10-14 APT devices being made and then taken to the study children for adjustments 3-4 days after measurement

### Conclusions

Young children with Cerebral Palsy benefit from locally made bespoke APT devices, although numbers in the initial stage of the study were small with 2 out of 6 not completing the study period and fewer follow up visits than planned due to limited staff availability. Six more participants have been recruited with the possibility of 10 completing the study, and a plan to reassess the original four after 12 months adding further data. Although two children were slightly outside the proposed age eligibility and one from each group had alternative assistive devices for different uses- they were included to increase study numbers, with a possible change in eligibility criteria for future studies. A full range of movement and lack of deformity in the group recruited suggests that detailed postural assessment is not required but a simpler measure of trunk stability pre and post device use may be a better outcome measure. Postural support remains essential to prevent deformity and maximise participation. Having demonstrated feasibility of the study, a larger multicentre study is envisaged to establish long term benefits, sustainability and acceptability of APT devices for children with cerebral palsy in Africa