



Aga Khan University

Sustainable seating and standing solutions for children with disabilities using appropriate paper-based technology

Catherine Barton [i,ii] Rachel Lindoewood [i,ii] Pauline Samia [iii.]

[i] Powys Teaching Health Board, Wales, UK. [ii] APT for Social Development, [iii] Department of Pediatrics and Child health, Aga Khan University, Nairobi, Kenya.

[i] cath.barton@wales.nhs.uk [i] rachel.lindoewood@wales.nhs.uk [iii] Pauline.samia@aku.edu

Children with Disabilities including Cerebral Palsy (CP) cannot access suitable, affordable seats or standing frames in many resource poor countries.

CP is the most common neurological condition and cause of physical disability in children worldwide, affecting about 1 in 500 live births with lasting impact [1]. Some countries in Africa have estimated it to be four times more common [2]. Approximately 40% of children with CP suffer from a severe non-ambulant form and are unable to sustain a sitting or standing posture [3] requiring therapy support services throughout life.

The World Health Organisation (WHO) has reported that assistive technology in low-middle income countries (LMICs) is only available for 5-15% of those requiring them [4]. These data concur with our team's experiences of working with children with cerebral palsy (CP) in Kenya, where assistive devices are rarely provided as part of routine care and families cannot access suitable, affordable seats or standing frames. Postural support devices including seating (Fig.1) and standing frames (Fig 2) are provided for children with CP as part of routine therapy in countries with well resourced health care services, like the UK [5,6].

Fig 1. Adaptive seat, UK

Fig 2. Standing frame, UK

They promote postural control, enhanced motor skills, safe feeding and social interaction while helping to prevent painful musculo-skeletal deformities and fractures [5,7-10]. These devices are often unobtainable for children with CP in LMICs. Efforts to resolve this challenge has included importing equipment but often the donated devices are unusable for a variety of reasons including; it is not customised to the child's ability, size or environment, or it is broken and neither personnel, training or components for adjustment and repair are available.[11,12]). Wooden seating and standing devices have been used in some settings but are expensive to produce locally, are difficult to adapt to the growing child and unaffordable for many families [13]. There is therefore a need to find ways to provide affordable seating and standing frames to promote the physical and social development of these disabled children [14,15].

Appropriate paper-based technology (APT)

APT is a way of making useful items from recycled materials including cardboard and newspaper [12,16]. Items are constructed using engineering principles and are both strong and light-weight. Three layers of thick corrugated cardboard are layered and glued together using a paste made from flour and water. After cutting, the cut pieces are slotted together and then tied with strips of used nylon tights. The structure is reinforced with strips and rods of thin cardboard, which are then covered with newspaper and glue and finally thick paper, such as those used as bags for flour or animal feed. Decoration of the device to suit the interests of the child completes the process. A variety of APT supportive devices have been designed for postural support of children with CP, including seats, standing frames, corner seats and inserts for wheelchairs. Accessories for the devices are constructible such as headrests, communication boards, trays, ramps and sloping desks [12]. APT is a low-cost, sustainable solution for bespoke postural supports for children with CP in resource poor settings.


Fig. 3 & 4 APT Seats in Kenya


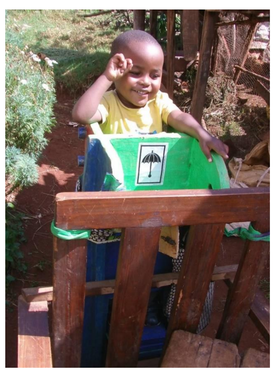

Fig. 4 & 5 APT Prone standing frames, Kenya

Efficacy of APT Postural supports

A recent pilot study evaluated the efficacy of APT devices for ten children with non-ambulant cerebral palsy in rural Kenya [17]. A convenience sample of children with CP and their families participated. Inclusion was based on the Gross Motor Function Classification System levels IV and V. APT seating or standing frames were provided for six months. A mixed methods impact of APT device on the children and families included the Family Impact Assistive Technology Scale for Adaptive Seating (FIATS-AS); the Child Engagement in Daily Life (CEDL) questionnaire; and a qualitative assessment from diary/log and semi-structured interviews.

Results: Ten children (median 3 years, range 9 months to 7 years). Baseline to follow-up median (IQR) FIATS-AS were: 22.7 (9.3) and 30.3 (10.2), respectively (p = 0.002). Similarly mean (SD) CEDL scores for "frequency" changed from 30.5 (13.2) to 42.08 (5.96) (p=0.021) and children's enjoyment from 2.23 (0.93) to 2.91 (0.79) (p = 0.019). CEDL for self-care was not useful; seven families scored zero at both baseline and 6 months. Qualitative interviews revealed three key findings where APT improved functional ability, participation in daily-life situations, and a reduced family burden of care.

In conclusion, the study found that the introduction of a bespoke APT seating or standing device had a meaningful positive effect on both the children's and their families' lives. The postural support devices were both valued and highly utilised by the children and families in this study. **APT is potentially a low cost and sustainable solution to make seating and standing devices for disabled children in Kenya.**

Practical Applications

Cerebral Palsy Africa, CPA, a charitable organisation, have been providing training in APT for many years. An APT manual of design, construction and training has now been published based on courses run in Africa [12]. Training people in low income communities to make APT assistive devices is straightforward and workshops can be established for sustainability [18].

In **Zambia**, a group of Disabled People known as APTers have been producing devices for 24 years and a second workshop has been running for eight years [12]. In **South Africa and Lesotho** several training courses have been run and the trainees have been linked to a therapy clinic at a hospital. They then start a business making APT chairs/equipment for the children with CP who attend these clinics. The therapists take the measurements of the child and pass this on to the APTer who then makes the equipment from home. The family of the child pay for the equipment. The cost differs from area to area. Working out costings and profit margins to set the cost of the device is important. Most of the people trained, who are linked with proactive therapists, get plenty of work.

In rural **Kenya** there have been several training courses in APT over the past decade. The most successful were linked to an established organisation working with disabled children in the Nyahururu community, St Martin Catholic Social Apostolate (CSA). In a three year period St Martin CSA produced over 100 APT devices. One recent course targeted five community based rehabilitation programmes from a wide area in Kenya, training individuals. These were more likely to have time capacity to make devices such as the disabled peoples organisations and community based volunteers rather than hospital based therapists. Participants reported the course to be beneficial and appreciated the practicality and utility of locally manufactured, cost effective devices [18]. However, on return to their local communities APT device production has been limited with various challenges. Maintaining device production requires ongoing support and stable leadership within the community organisation.

A sustainable way of supporting APT production in Kenya based on the model of south-to-south networking [19] is being developed with a central Kenyan hub, where an experienced APT trainer has a workshop for APT production and training, which will be developed to become a support and resource for other areas. Local therapists are being sought to link with the APT practitioners to assess and refer children and help in developing a business model. Making household items and other furniture for income generation to support the manufacture of affordable devices is anticipated, as in Zambia.

More courses on constructing APT devices are needed in the children's own communities, alongside the training of rehabilitation workers on the importance of postural support, prescription, accurate measurement of children and fitting of devices.

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