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ORIGINAL RESEARCH

Thinking outside the cardboard box: insights from a course to train rural Kenyans to make postural support devices from appropriate paper-based technology (APT) for children with cerebral palsy

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ABSTRACT

Purpose: Suitable assistive devices for children with cerebral palsy (CP) in low-income countries are often unavailable. Devices made from APT are in use in several countries but are unevaluated.

Materials and methods: A 2-week training course focused on APT principles, measuring children and constructing postural support devices. Twenty-three Kenyans attended the course. The host organization identified four local children with CP who attended for assessment and measurement. Participants made the devices and children returned for fitting and necessary adjustment. Completion of post-course forms, action plans, visits after 14 months and contact 3 years later comprised the evaluation.

Results: All participants found the course beneficial and valued the networking opportunity provided. They appreciated the practicality and utility of locally manufactured cost effective devices. The trainees planned further implementation to provide assistive devices for children with CP in their localities. Follow-up visits revealed several challenges to local ongoing production.

Conclusions: Training people in low-income communities to make bespoke assistive devices for children with CP is straightforward, and the course was positively evaluated. However, maintaining device production is limited without local group support and stable leadership, ideally as part of an existing programme.

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Cerebral palsy; resource limited country; paper technology; assistive devices

➤ IMPLICATIONS FOR REHABILITATION

- Assistive devices are often unobtainable for children with cerebral palsy (CP) in low-income countries.
- APT is a cost effective way of fulfilling this need and it is relatively straightforward to train people who care for or work with those with CP to make devices using APT.
- Feedback from APT training suggests participants find the technique a practical way of producing assistive equipment for individuals with CP in their community.
- Maintaining device production requires support, leadership and increased public awareness of the use of APT at a local level.

Introduction

Children with cerebral palsy (CP) require postural support to enhance function, provide stability and improve participation in their social environment [1]. These devices help the child to maintain a comfortable, functional and energy efficient position in either sitting or standing. Provision of these pieces of equipment helps prevent contractures, spinal deformity and can improve digestion, bowel function and maintain skin integrity. The equipment also enables the child's interaction with their environment, play and communication with those around them.

The provision of adapted seating devices has been shown to increase both the amount and the quality of their participation in home activities, as well as increasing independence, communication and quality of life [2]. A review of studies looking at the use of adaptive seating systems in young people with CP suggested that although evidence for the use of such devices is diverse with regards to its reliability and methods, improvements in activity participation were consistent [3].

In high-income countries, postural support is provided routinely as part of standard multidisciplinary medical care [4]. The provision of equipment to meet the individual child's specific needs follows professional assessment and devices are maintained and adjusted regularly. Careful consideration to the environment the equipment is to be used in such as schools, playgroups or home is given.

In resource poor settings, these services are not readily available despite the overwhelming need. Kenya has a population of at least 50 million people with a median age of 19 years. [5]. The

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Supplemental data for this article can be accessed here.

incidence of CP is estimated at 2% per 1000 live births, though the proportion in Kenya may be higher and with an annual population growth rate of 2.5% [5] an estimated 2500 children with CP are born each year. Data from Botswana show that 41% of children with CP can be classified as functioning at GMFCS level V [6]. A significant proportion of children with disability in Kenya therefore qualify for supportive devices, a service rarely provided within the public health sector. Provision of donated equipment is unsustainable and the equipment may not provide ideal support for the child. Sitting and standing aids made from wood have previously been used in some settings but these are expensive and not always an environment-friendly intervention. Appropriate paper-based technology (APT) started in Zimbabwe in the 1970s [7]. APT is a way of making strong and useful items from waste materials including cardboard and newspaper. The devices are constructed using thick, corrugated cardboard. Three layers are 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. Reinforcement of the pieces 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, complete the structure. Decoration of the device to suit the interests of the child finalises the process.

A variety of supportive devices including seats, standing frames, corner seat and inserts for wheelchairs have been made from APT. Accessories for the devices are constructible such as headrests, communication boards, trays, ramps and sloping desks [8].

A link has existed between Powys Teaching Health Board and Molo, Kenya since 2008. The link works with the sub-county public health team in training and capacity building. Between 2009 and 2011, Powys Teaching Health Board and Kenyan trainers conducted two community based rehabilitation (CBR) short courses in Kenya. These sought to focus on enhancing the quality of life for people with disabilities and their families; meeting their basic needs; and ensuring inclusion and participation. CBR is a multisectoral strategy that empowers persons with disabilities to access and benefit from education, employment, health and social services. "CBR is implemented through the combined efforts of people with disabilities, their families and communities, and relevant government and non-government health, education, vocational, social and other services" [9].

There is limited published research into the efficacy of assistive devices; made either conventionally or by APT in resource poor settings – most focusing on adults or prosthetic limbs and only one from South America describing the local production of supportive seating. [10]. A study into nutrition of children with CP in Bangladesh [11] mentions APT devices. Powys Molo Link introduced APT in Molo in 2012 as described by the authors [12]. A manual has since been published describing the technique, by the lead APT trainer on our course, which includes the templates and other resources used on this and previous APT courses run in Africa [8]. Very recently, different sized standardized supportive chairs made from APT have passed British standard tests of stability, strength and durability [13].

Materials and methods

A two-week long APT training course took place in January and February 2015 at Tabor Hill Spirituality Centre in Nyahururu, Kenya with invitations sent to five CBR programmes to send teams of up to five with capacity to make APT assistive devices for disabled children. There were four UK facilitators: two occupational therapists a physiotherapist and an APT trainer who volunteers for cerebral palsy Africa (CPA). Two Kenyans experienced in making many APT devices and in training others were part of the training team. A consultant paediatrician assisted for parts of the training, and also travelled to Nairobi to meet with a paediatric neurologist to discuss future research collaboration and who suggested evaluating the course.

The workshop consisted of practical sessions where the participants divided into four groups, each with a facilitator. There were also classroom based sessions introducing APT to participants including how to construct devices. The importance of good positioning for children with CP was emphasized and participants learnt how to measure a child for a device.

The participants learnt how to make a basic stool in the first few days of the course. Then at the end of the first week, four children with bilateral spastic cerebral palsy (GMFCS level IV or V) from the local community came to the workshop with their parents. They were aged between 2 and 6 years old – the three youngest (two boys and a girl) were unable to sit unsupported and had never had an assistive device, the oldest boy could sit but not stand and had a supportive seat he had outgrown. Workshop participants took detailed measurements of the children in lying and sitting positions to enable bespoke construction. Allowance for expected growth was included in the measurements by making simple inserts that could easily be removed.

In the second week, the participants made sitting and standing aids for each of the children (Figures 1 and 2). The children then returned towards the end of the second week for fitting into their almost complete devices (Figures 3 and 4). Children were reassessed in their device and adjustments made to ensure an appropriate fit for each child. The host organization received the devices and arranged delivery of the equipment to each families home and the local team positioned the child, made any final adjustments and instructed the caregiver on how to do this.

Participant groups from different communities formulated action plans to guide introduction of APT into their communities or increase its productivity. Each community participant group received a simple tool kit, the stools they had made and a sample device made by UK based volunteers to enable them to get started. They received letters, requesting support from sponsors of each participant as well as completion certificates. Participants completed evaluation forms about the two-week workshop. Evaluation forms were in English with a Kiswahili translation provided for participants who required it for better understanding. Participants completed the forms anonymously but included their sex and their age. The questions and answers are shown in Table 1.

A follow-up visit took place in April 2016 by the lead trainer (JW) who had ongoing links with the host community and a disability community worker (PL) who had helped establish two of the community projects and was involved in the course preparation including a 2014 visit. They visited all five centres and made an additional visit to a satellite centre close to another, which was the base of one of the trainees. Further training and a workshop had been set up with support from another UK charity at the latter centre.

Results

Twenty-three participants aged between 22 and 60 years of age attended from five communities, in counties as in Table 2 which also summarizes the progress made in device production at each

Figure 1. Participants learning APT technique.

Figure 2. Participants put finishing touches onto standing frame.

centre. The communities were identified during a prior visit in June 2014. Most participants had experience working with people with disabilities and six of them had a physical disability. The others included an occupational therapist, two orthopaedic technologists, a social worker, workshop assistants and chairpersons of local disability groups or local non-governmental organization,

a community health extension worker, community volunteers, parents and carers. There were nine women and 14 men.

One participant moved from a faith based CBR programme to work in a more deprived government facility without an established CBR programme but was hoping to start APT there. His initial enthusiasm, including seeking advice on devices for specific children and sending photos of devices he had made, was not sustained due to his more challenging work situation and lack of others locally trained in APT to help. The programme he left had only sent two participants to the APT course so the remaining one was unable to commence production alone.

The lead team member from the project that sent the most people to the course, moved from one government public health

Figure 3. Trainer checks measurements with child positioned in partially constructed chair.

Figure 4. Young boy with cerebral palsy tries out his standing frame.

Table 1. Summary of responses by course participants on their evaluation forms.

Question	Responses	
Did the course meet your objectives?	All 23 said yes to this question.	
What did you like about the course?	Enjoyed working together with people from other communities …. .. Liked making new friends.	Learning new skills to make useful items for the children using cheap, locally available materials …. liked that APT as a technique that was easy to learn and will benefit my community
What didn't you like about the course?	Some thought the course was too short and they had needed to work over time to complete the devices. Others would have liked more time to improve their skills further and would have liked to receive a timetable.	One of the participants with a physical disability commented that they had found the travelling to and from the course challenging as their community was a good distance from the workshop venue.
Is there anything you would change about the course?	More communities to have attended so that the participants covered the whole of Kenya. …. would have liked more time to work on their skills and a printed timetable that they could refer to.	The possibility of a refresher course in the future was mentioned as well as the opportunity to spend more time with the children with CP and their parents
What will you do with your APT skills when you return home?	Most participants said that they would share their knowledge with others.	All planned to start putting their skills into practice making APT devices especially for children with CP in their area

Table 2. Short and Medium term follow up regarding subsequent APT device production by course participants.

Area	Nakuru County	Kibwezi, Makueni County	Embu County	Meru County	Nyahururu, Laikipia County
No. of trainees on 2015 course	6	5	5	3	4
Original participants still working on APT in 2016	None	2 disabled technicians in established workshop linked to CBR programme with social worker support. 2 others work in other parts of the community	1 parent working with other parents (3 others too far away from each other and, 1 too ill to work)	1 health worker in new workshop supported by UK charity. 1 health worker made 6 items before he was moved to a remote area (Mandera county) 1 disabled person unable to work alone in faith based centre.	2 technicians in established faith based workshop, assisted by 2 residents with intellectual disability. 1 has returned to driving and 1 is too busy with other work in same programme.
No. of items made by April 2016	0	24	2	9 (and several smaller APT items)	38 items including 12 for research study.
Additional trainings	May 2017 2 weeks in nearby Elburgon	None	None	June 2015. 2 attended Molo Course,in May 2017	Informal during research study
No. of items made between April 2016 and February 2018	1 in Elburgon 7 in Molo (email 28/2/18)	11 WhatsApp (12/2/18)	Not Known	4 in faith based centre (WhatsApp 1/3/18) 2 in Mandera (13/2/18 Messenger) Unknown in other Meru workshop	11 (WhatsApp 4/2/18)

service to another – also hoping to start production in the new area but leaving gaps in the original area and delaying progress. Another from this group went away to university; one got a full time job leaving two people only who lived in different towns and were unable to start production until a year later when further training of additional people was requested and delivered. There was a 6th person from this group who actually lived and worked in a different town who had also not started production after a year but had applied for a grant from an international funder to establish a workshop under a community based drop in centre. The community worker who had moved was unable to develop APT production in her new post on her own although she did access some parent education facilitator training and has made progress in rolling this out to a group of parents of children with CP.

The oldest CBR programme, now led by a disabled peoples organisations (DPOs) – did not communicate their progress until one of the authors specifically requested an update and they then sent photographs of devices made but not yet issued to children. The follow-up visit confirmed that they had made and distributed 24 items but they had challenges in sourcing raw materials and funding their work.

The most successful group were the host organization who were already part of an established organization working in the community with disabled children. New people were trained and able to increase their production, including at two intensive periods as part of the research pilot study since developed by the authors. Even this area have faced challenges with changes of personnel and it took time to gain accurate information about APT device production in the second year, apart from the 12 devices made for the research study. The most productive worker, who was one of the trainers (TK) has since left the organization in order to focus on APT device production in his home area and beyond having identified 200 more children in need of devices.

Discussion

The participants clearly valued the course and could appreciate the potential for APT production and use in their areas. They

were from a wide area in Kenya and represented quite different types of CBR programme. Several felt they needed longer to learn the techniques and would have liked to spend more time with the children. This may be a reflection of the fact that some had not had much experience working with children with CP, and if they had, their training and support in their home community was limited. The lack of a timetable was an omission by the trainers, now addressed in subsequent training courses, although this would have been difficult to draw up accurately prior to getting to know the participants. Some participants needed additional support to learn how to take the measurements accurately having had little formal education, including for example the use of a ruler. By having a flexible approach to the timetable, the course was tailored to the needs of the participants.

Only two groups had access to established workshops, and the range of professional and lived experience of disability was great. Mixing health professionals with parents and disabled people on the same course had the advantage of shared experience and insights into the issues faced by those trying to meet the needs of disabled children in Kenya, but made establishing the pace of teaching more challenging for the facilitators. The latter is likely to be a reason why some participants felt they needed more time to practice APT techniques although another reason was that each group decided the child they assessed would benefit from both a chair and a standing frame – doubling the amount of construction needed in the second week.

The participant who found travelling to the course a challenge had a physical disability and needed to board several vehicles in order to reach the venue. This reflects one of the many challenges disabled people in Kenya face. The organization or community the participant was working for were asked to be provide for transport costs as a form of cost sharing and a step towards sustainability. However, some sending organizations were less established and able to support their participants. Choosing a venue that could provide space for making devices as well as affordable and adequate accommodation is always a challenge, and simplifying access arrangements particularly for those participants with disabilities needs consideration. However, limitations of the budget and limited choice of facilities made it difficult to be more inclusive. The centre chosen to host the workshop had experience in making APT devices and in running a previous APT course, rather than its accessibility to the other communities sending participants.

The action plans from all groups were ambitious (Supplementary Appendix 1). We were expecting them to meet challenges in their daily lives that would conflict with the passion for making APT devices they shared at the end of the course – so support from their colleagues, sponsors and managers was key. Despite targeting groups who were more likely to have time capacity to make devices, e.g., DPO and community based volunteers rather than hospital based therapists, an established programme and/or cross-sectorial partnerships appear to be more important for sustainable APT production. The follow-up visits by the lead facilitator and a disability consultant a year after the course identified the need for more ongoing training and support (Supplementary Appendix 2). This has more recently emerged as a WhatsApp group, offering mutual support and encouragement in their work including APT device production but also in other areas of supporting parents of children with disabilities such as elements of a parent education programme called getting to know cerebral palsy [14] who's manual [15] features APT devices in its section on assistive devices, and surgical and educational opportunities for children with disabilities.

This was a one-off small scale training, from chosen known communities. On its own, it was not expected to meet local demands but more to test the feasibility of this approach and justification for broader collaborations and seeking funding for scale up. Nor did we expect to discover how effective APT devices were in rehabilitation of the children who got them as there was no resource for follow up (although preliminary findings of the subsequent pilot study suggest positive impact [16]). We demonstrated that such training was feasible and led to community members enabled to produce devices for children in their local area. However, a sustainable way of supporting APT production needs further consideration, as not all the programmes or communities participants came from had the capacity to support them with ongoing production. The benefit of south-to-south networking in development work is well recognized [17] and this is the model being considered with a central Kenyan hub, where one of our trainers (TK) is now based, acting as a support and resource for other areas. Ultimately, once the research this course sowed the seeds for is completed and disseminated, this will raise the profile of APT assistive devices as a way of meeting the needs of children with disabilities. Subsequent mobilization of people and resources to produce more APT devices will then improve their quality of life and participation.

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Disclosure statement

No potential conflict of interest was reported by the authors.

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