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**To cite this article:** Karen Bunning, Joseph K. Gona, Charles R. Newton & Sally Hartley (2014) Caregiver Perceptions of Children who have Complex Communication Needs Following a Home-based Intervention Using Augmentative and Alternative Communication in Rural Kenya: An Intervention Note, *Augmentative and Alternative Communication*, 30:4, 344-356, DOI: [10.3109/07434618.2014.970294](https://doi.org/10.3109/07434618.2014.970294)

**To link to this article:** <https://doi.org/10.3109/07434618.2014.970294>



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Published online: 07 Nov 2014.



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## INTERVENTION NOTE

# Caregiver Perceptions of Children who have Complex Communication Needs Following a Home-based Intervention Using Augmentative and Alternative Communication in Rural Kenya: An Intervention Note

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## Abstract

A high level of unmet communication need exists amongst children with developmental disabilities in sub-Saharan Africa. This study investigated preliminary evidence of the impact associated with a home-based, caregiver-implemented intervention employing AAC methods, with nine children in rural Kenya who have complex communication needs. The intervention used mainly locally-sourced low-tech materials, and was designed to make use of the child's strengths and the caregiver's natural expertise. A pretest-posttest design was used in the study. Data were gathered using an adapted version of the Communication Profile, which was based on the International Classification of Functioning, Disability, and Health (ICF) framework. The non-parametric Wilcoxon signed-rank test was applied to data from the first two sections of the Communication Profile-Adapted. Qualitative analysis was conducted on the final section. The data provided evidence of statistically significant positive changes in caregiver perceptions of communication at the levels of Body Structure and Function, and Activities for Communication. Also, analysis of the Participation for Communication section revealed some expansion to the children's social activities. The potential impact of the home-based intervention would benefit from investigation on a larger scale. Limitations of the study are discussed.

**Keywords:** *Low-income country; Developmental condition; Home-based intervention; Augmentative and alternative communication*

## Introduction

The World Report on Disability estimates the prevalence of disability worldwide is approximately 15%, with severe disabilities occurring in 2.2–3.8% of the population (World Health Organization and the World Bank, 2011; p. 29). However, representation of people with communication disability in international reports may be inadequate due to “the way disability is frequently conceptualized and measured” (Wylie, McAllister, Davidson, & Marshall, 2013, p. 1). The definitions used relate to underlying health conditions and are therefore disease-related, as covered by the International Statistical Classification of Diseases and Related Health Problems (ICD-10) (WHO, 2010a) and do not reflect the different dimensions of disability defined within the International Classification of Functioning, Disability

and Health (ICF) (WHO, 2001). Furthermore, individuals with complex communication needs are likely to come from a number of different conditions (e.g., cerebral palsy), or may not be associated with a specific disease (e.g., intellectual disability). However, severity of problem and extent of need is likely to be variable. The estimated figure of 15% of children with disabilities cited by the World Report on Disability (WHO and the World Bank, 2011) is likely to include individuals with mild to moderate disabilities. Those children with more complex communication needs are likely to fall in the 2.2–3.8% estimated prevalence for children with severe disability (WHO and the World Bank, 2011). Thus, overall, an estimated 1.1–1.9% of the population may have severe communication difficulties. Although some people with these difficulties will be adequately

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(Received 15 July 2013; revised 31 July 2014; accepted 30 August 2014)

supported by help from other people, such as teachers, caregivers, community workers, and family friends, there will be some who are underserved due to the scarcity of rehabilitation specialists in low-income countries (WHO and the World Bank, 2011). Wide variation in rehabilitation support was reported in 29 African countries and was characterized by poor coordination of delivery, limited access at community level, and a continuing need for development work (WHO, Disability & Rehabilitation Team, 2004).

Globally, speech and language therapists (SLTs) are recognized as the specialist workers who focus on helping and supporting people with communication difficulties. However, a lack of SLTs in sub-Saharan Africa is reported, with only 1 per 2–4 million people (Wylie, McAllister, Marshall, Wickenden, & Davidson, 2012). If 1.1–1.9% of the population has communication difficulties, then there would be only one therapist for every 22,000 people, a figure that represents the minimum of the estimated ranges cited, who would benefit from specialist assistance. SLT provision in East Africa (Burundi, Kenya, Rwanda, Tanzania, Uganda), with an estimated population of 141.8 million (World Bank and the World Bank, 2011), is mainly confined to urban areas (Jochmann, 2006) and is often restricted to private health care. Individuals who reside in rural and remote areas have difficulties in accessing support (Wylie et al., 2013). Barriers may be physical (e.g., poor transport system, Moisi et al., 2011), informational (e.g., ignorance of available support, Ensor & Cooper, 2004), or financial (e.g., insufficient funds for travel, Makinen et al., 2000; or to access private care).

Recent developments to combat the lack of support for communication include a speech and language therapy degree course at Makerere University, Uganda, from which two cohorts have graduated successfully so far ( $n = 18$ ), with destination posts in Uganda, Tanzania, Rwanda and Kenya. There are three more regional programs planned at East African universities (Staley, 2013). However, despite such developments, the level of help for individuals with complex communication needs, whether sourced by rehabilitation and education services, or provided by community workers, remains inadequate.

Given these circumstances of limited support, responsibility for the child's development and welfare usually falls to the family. Caring for a child with developmental disability frequently demands extra physical and psychological resources (Geere et al., 2012; Hamzat & Mordi, 2007; Raina et al., 2005). While it is acknowledged that variation exists in caregiver adaptation to the situation, evidence suggests that lack of time and personal energy (Raina et al., 2004), the extra demands of care-giving tasks and inadequate social support systems (Ambikile & Outwater, 2012; Chang & McConkey, 2008), and the economic challenges of poverty (Ambikile & Outwater, 2012), all contribute to caregiver stress. External to the family situation is the social stigma of caring for a child with disabilities (Ambikile & Outwater, 2012; Hamzat

& Mordi, 2007; Raina et al., 2005), which may extend to the child's condition being viewed as the result of evil spirits (Gona, Mung'ala-Odera, Newton, & Hartley, 2010; Hamzat & Mordi, 2007). Not surprisingly, many caregivers in poor economic conditions have expressed the desire for a cure for their child's condition, both in rural areas (Gona, Newton, Hartley, & Bunning, 2013) and in urban slums (Sen & Goldbart, 2005).

### *Caregiver Involvement*

The active involvement of caregivers is considered critical to the success of an intervention (Granlund, Bjorck-Akesson, Wilder & Ylvén, 2008; Marshall & Goldbart, 2008; Sen & Goldbart, 2005). From their Cochrane review on speech and language therapy for children with cerebral palsy, Pennington, Miller, and Robson (2010) advocated targeting the familial context in order to increase interaction opportunities. The expectation is that gains will be seen, not only in the child, but also in the dynamics and interaction of the family unit (Granlund et al., 2008). Caregiver participation in child-focused interventions that are relationship-based and located in the home setting have been found to improve development in the child (Shin et al., 2009), to promote language growth (Roberts & Kaiser, 2012), to reduce negative parent-child interactions (McIntyre & Abbeduto, 2008), to lower levels of caregiver stress (Hastings & Johnson, 2001), and to improve family outcomes (Kim & Mahoney, 2005). Ronski et al. (2011) reported that parents viewed their children's language difficulties as less severe after an augmented communication intervention, although the children assigned to a speech-only condition were perceived as having more severe difficulties post-intervention. The authors suggest that focusing on a non-speech modality may reduce the pressure on parents to achieve some kind of success in their communication with their children. Psychological support is integral to the home-based intervention and interestingly, this was cited as the most important facilitative factor by parents implementing a behavioral intervention with young children with autistic spectrum conditions (Johnson & Hastings, 2002).

Some interventions involve parent-directed training whereby change is brought about to the child's communication skills through the parent acquiring information and adopting new ways of communicating with their children. For example, Kent-Walsh, Binger, and Hasham (2010) reported that mothers learned to use a partnership, interactional reading strategy with their children in a relatively short time, which appeared to be associated with increased turn-taking by the children and use of a wider range of meanings. Girolametto, Sussman, and Weitzman (2007) observed changes in maternal responsiveness towards their children with autistic spectrum condition, while Ferm, Andersson, Broberg, Liljegren, and Thunberg (2011) identified improvements in the parental experience of communicating with their children.

Despite the acknowledged relevance of natural contexts to positive intervention outcomes, there are few

AAC interventions reported that are fully based and implemented in the home setting (Granlund et al., 2008; Nunes & Hanline, 2007). Ferm, Ahlsén, and Björck-Åkesson (2012) reported a strong correspondence between activity-type and dyadic interaction in a single case study of a child with physical disabilities with caregiver, where the mealtime context affected conversation purposes and the use of devices such as pause towards goal attainment (e.g., intake of nutrition). Where there was deliberate consideration of the context for communication, reported gains have included an increase in eye gaze between mother and child (Wadnerkar, Pirinen, Haines-Bazrafshan, Rodgers, & James, 2011), improved expressive language and social closeness of children (Light & Drager, 2010), growth in initiations and responses by the people using the AAC and extension of communication strategies used by the caregiver (Nunes & Hanline, 2007).

### *AAC in Africa*

The World Health Organization's (WHO) World Report on Disability (WHO and the World Bank, 2011) considers technology to be appropriate if it "meets people's needs, uses local skills, tools, and materials, and is simple, effective, affordable, and acceptable to its users" (p. 301). In Africa, the majority of AAC research has emanated from South Africa focusing on cross-cultural readability of graphic symbols (Basson & Alant, 2005; Bornman, Alant, & Du Preez, 2009; Haupt & Alant, 2002); facilitation of language and literacy (Alant & Moolman, 2001); effects of visual characteristics on symbol usage (Alant, Kolatsis, & Lilienfeld, 2010); and use of communication boards to report crimes (Bornman, Nelson Bryen, Kershaw, & Ledwaba, 2011). Beyond South Africa, there have been reports of other initiatives. For example, AAC Market Cards have been developed in Ghana to support functional communication among young people with intellectual disability (Crowley & Baigorri, 2012). Cameron and Markowicz (2013) report on the local development of a communication board to meet the needs of a child in Tanzania. However, a need for information and training on AAC has also been acknowledged in other areas, including teachers in Botswana (Mukhopadhyay & Nwaogu, 2009), and speech therapists in Egypt (Wormnaes & Malek, 2004). The WHO's 2010b report, *Community-Based Rehabilitation Guidelines* (pp. 57–72) addresses some practical approaches in the area of assistive technology, of which AAC forms a part; however, there are no published outcomes on usage.

As in other high need, low resource areas, there are many possible reasons for the limited amount of AAC research in Africa. As noted earlier, there are only a small number of trained professionals, and the demands for services are great. Because of these service delivery challenges, it is often not possible to see children and families on a frequent basis, and family support measures (e.g., regular one-on-one trainings, frequent workshops,

parent groups) and data collection techniques (e.g., videotaping of interactions), that are often observed in high resource countries, are not economically feasible.

The aim of the project was to investigate preliminary evidence associated with a home-based, caregiver-implemented intervention employing AAC methods, with children who have complex communication needs in a rural part of Kenya. The focus was on children with little or no functional speech and their main caregivers as implementers of the intervention. The research question was: What is the reported impact associated with a home-based AAC intervention as measured by parents' reported changes for their child in three domains: (a) body structure and function, (b) activities for communication, and (c) participation in family and community events?

## **Method**

### *Design and Setting*

A within-group study was conducted to investigate the reported impact associated with a home-based, AAC intervention. A pretest-posttest study design was used to investigate changes in parents' perceptions following the implementation of a home-based AAC intervention. The study was carried out in the Kilifi area under surveillance of the Kenya Medical Research Institute (KEMRI). It is estimated that 8–10% of this population are children with moderate to severe disabilities (Mung'ala-Odera et al., 2006). Kilifi is situated on the Indian Ocean coast and is among the poorest areas in Kenya, with most of the rural population living as subsistence farmers. The majority of homes are of mud construction, consist of one or two rooms and are without power supply and running water. Per capita, the average income for a household (typically parents plus six children) is Ksh1,000 per month – less than \$10 USD (Kenya National Bureau for Statistics, 2005, 2006). The under-5 mortality rate is 41.0 per 1000 live births, with a lower life expectancy for adults in rural areas compared to urban (Scott et al., 2012). Some of the challenges associated with poverty include low levels of nutrition, inadequate control of infectious diseases, poor enrolment in schools and limited literacy amongst adults generally. The inhabitants are mainly from the Mijikenda groups (about 80%) and speak Giriama, Chonyi, and Kiswahili. English is the main language in Kenyan education schools and is spoken by those fortunate to be educated.

Available specialist rehabilitation services comprised occupational therapy, physiotherapy, and orthopaedic technology located at Kilifi District Hospital (KDH). Services were delivered through outpatient appointments with minimal outreach or community follow-up. There was no speech and language therapy, although what was referred to as "speech work" was carried out by the occupational therapists in KDH. The therapy mainly consists of manipulation of the facial muscles and oro-motor exercises, which was delivered to all



children referred regardless of presentation. Educational services were provided by two special schools and five special needs units on mainstream school sites. Some speech work was carried out by teachers in the residential school for the deaf, which was characterized by auditory discrimination, and sound and word production in rote learning tasks (Bunning, Gona, Buell, Newton, & Hartley, 2013).

### Participants

Sample recruitment focused on children with complex communication needs and their main caregivers. Identification of children was conducted via the register maintained by the Education Assessment Resource Centre (EARC), where the primary condition only was recorded for each entry. In the absence of more relevant information concerning function, activities and participation of individuals, as an initial stage in determining the sample, children with the four most common conditions recorded (cerebral palsy, autistic spectrum condition, intellectual disability, and hearing impairment), either as a single primary diagnosis or in combination, were identified. Hearing impairment was included at the behest of the EARC because of unmet need in the district. A second inclusion criterion was if the children were identified as having restricted speech and language, and/or severe intelligibility problems. The child also needed to live with the primary caregiver most of the time and the caregivers had expressed a willingness to commit time to the intervention.

The head of the Education Assessment Resource Centre (EARC) selected a total of 32 children out of the 2000 registered who met the inclusion criteria. Using a purposive-convenience sampling procedure, 12 children were identified, representing all four primary conditions and aged between 4 and 12 years, with 4-years-old being the age at which a typically developing child would usually be considered a competent communicator. There was a balanced ratio of males to females. Because of variable literacy levels, project information was communicated orally to the caregivers with a paper version also available, covering what the home-based intervention would involve, prospective time commitment to the intervention, assessments that would be conducted and the right to withdraw at any time. Caregiver consent was recorded on paper in the form of a signature, thumbprint or record of oral response as appropriate to the individual. Two caregivers declined to take part in the study due to family problems. The family of a third child (Participant 4) relocated and was subsequently withdrawn from the study. Table 1 provides a summary of the presenting characteristics of the nine children who took part in the study.

### Procedures

Because of the challenges associated with the use of measurement techniques such as direct observation and

video recording in this high-need low-resource area, we chose to collect information on the perceived impact of the intervention using parent report.

*The Communication Profile-Adapted.* To assess caregiver perception of the child's abilities and activities for communication, and participation in family and community events, an adapted version of The Communication Profile (Baker & Hartley, 1999) was administered pre- and post-intervention. Developed as an outcome measure in neighbouring Uganda (Baker & Hartley, 1998), it was selected for its cultural relevance, use of non-technical vocabulary, translatability into the local languages and relative ease of administration (i.e., no prior formal training was required to administer it). The tool needed to capture changes to the caregiver's view of the child's abilities and difficulties, which should not be restricted to functional domains of communication, but include aspects of the child's health condition. The conceptual framework of the Communication Profile-Adapted (CP-A) is based on the Communication Disability Model, described by Hartley (1997), and Hartley and Wirz (2002), researching the needs of people with communication disabilities in Nigeria and Uganda. It was linked to the then-draft form of the International Classification of Functioning, Disability and Health (ICIDH-2) (WHO, 1999). Profile terminology was revised to correspond to the most recent version of the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001). The profile was designed to recognize the personal knowledge and experiences of caregivers in their role as daily supporters of the child and is divided into three sections. There were three sections, which served as the three dependent variables: (a) Body Structure and Function, (b) Activities for Communication, and (c) Participation in Communication. The first two dependent variables were summative scores for the sections 1 and 2. The third dependent variable represented qualitative data from section 3. Section 1 addressed body structure and function for communication through the biomedical classification of the body's organs. There were 10 questions covering seeing, hearing, moving, dribbling, drinking and eating, paying attention, sitting still, learning, understanding, and epileptic seizures (fits). The caregiver was asked whether the child had any difficulty in each aspect and to indicate the degree of severity using a rating scale portrayed as a pictorial ladder. The bottom of the ladder was labelled *very severe* = 0. The rungs in between were for: 2 = *severe*, 4 = *moderate* and 6 = *mild*. The top of the ladder was labelled *none* or *not a problem* = 8. Thus the more severe the problem, the lower the score, with the higher scores indicating greater perceived competence in the particular area. Section 1 scores yielded a summative score for each participant. Section 2 focused on communication activities and consisted of six subsections: (a) Communicative modes, (b) Communicative functions – expressive, (c) Communicative functions – social, (d) Communicative functions – receptive, (e) Communicative effectiveness, and (f) Personal factors.

Table I. Participant Characteristics.

Participant	Sex	Age (years; months)	Health condition	Activities and participation for communication			
				Motor skills	Comprehension & expression	Awareness of environment	Education
1	M	11;0	Cerebral palsy (quadriplegic) and profound intellectual disability; visual impairment	Unable to walk or sit unsupported; limited voluntary control of head and eye movements	No evidence of verbal comprehension; limited vocal, body, hand and facial gesture	Recognition of familiar persons and objects	Does not attend school
2	F	3;7	Global developmental delay of unknown aetiology; parental report of skills loss and regression in social behaviour post first 12 months of typical development	Some crawling behaviour and sits on floor unsupported; voluntary control of head, eye and hand-arm movements	No evidence of verbal comprehension; limited vocal, body, hand and facial gesture	Limited recognition of familiar persons and objects	Does not attend school
3	M	6;0	Cerebral palsy (quadriplegic); epilepsy	Unable to walk, bottom shuffles on floor; some voluntary control of eye-hand-arm movements for grabbing objects	Verbal comprehension at 2–3 word level; some vocal, body, hand and facial gestures; attempts speech	Good recognition of people, objects and pictures; good awareness of environment	Attends special needs unit attached to school
5	F	6;0	Intellectual disability, poor attention and hyperactivity	Able to walk. Reasonable voluntary control of hand-arm movements	Limited verbal comprehension. Some vocal, body, hand and facial gesture	Limited recognition of familiar people and objects	Does not attend school
6	F	6;0	Moderate hearing impairment (currently no hearing aids)	Fully mobile; motor skills are unimpaired.	Verbal comprehension at the 2 word level; attempts speech; uses vocal, body, hand and facial gestures	Good recognition of people, objects and pictures; good awareness of environment	Does not attend school
7	M	5;6	Cerebral palsy (quadriplegic), intellectual disability	Unable to walk or move independently; some voluntary control eye-hand-arm movements	Basic verbal comprehension; uses vocal, body, hand and facial gesture. Attempts speech	Good recognition of people and objects	Does not attend school
8	M	12;0	Autistic spectrum disorder	Fully mobile; motor skills are unimpaired	Verbal comprehension at 4 + word level; restricted use of vocal, body, hand and facial gesture	Some recognition of people with good recognition of objects and pictures	Attends special needs unit attached to school
9	F	6;0	Severe intellectual disability – Down syndrome	Fully mobile; good voluntary control of eye-hand-arm movements	Verbal comprehension at the 1–2 word level; good use of vocal, body, hand and facial gesture. Attempts speech	Good awareness of people, objects and pictures	Does not attend school
10	F	6;0	Cerebral palsy (quadriplegic), global developmental delay, nystagmus noted-vision queried	Unable to walk Limited voluntary control of eye-hand -arm movement on right side	Limited verbal comprehension; restricted use of vocal, body, hand and facial gesture	Limited recognition of people and objects	Does not attend school

*Note.* Participant 4 withdrew from study.

Adaptations to this section included amalgamation of questions that had similar content, resulting in a reduction in the overall number of questions. The original version used two rating scales: A 5-point rating scale denoting frequency of activities used in a similar way to the scoring ladder in Section 1; and a 3-point rating scale to determine the extent of the problem, where the response options were presented orally for the respondent's selection: *not a problem* = 2, *a bit of a problem* = 1, *a big problem* = 0. Thus the more severe the problem, the lower the score, with higher scores indicating greater perceived competence in communication. In order to reduce administration time, it was decided to use the latter scale for its brevity and to omit the more time-consuming ladder scale. Again, Section 2 yielded a summative score for each participant. Section 3 collected descriptive data on the range of community events in which a child could participate (e.g., going to the well, attending church).

The CP-A was translated from English and back-translated into the main local languages of the district (Kiswahili, Giriama, and Chonyi). Its administration followed a structured interview format with the main caregiver at the homestead, with the child present. It was conducted by the second author, a native user of the local languages who had previously worked as a teacher of the deaf. He was unknown to the participants and their families. During the pre-intervention interview, an SLT engaged the child in interaction to investigate the child's communication performance. Opportunities for interaction were provided by the speech and language therapist using mainly non-verbal communication (facial, vocal, body, and hand gestures) supplemented by key words from the local language supplied by the caregiver and second author. This involved a range of interactive, playful initiations from therapist to child (e.g., showing household objects to the child, presenting a pencil and paper for use), initiating non-verbal games (e.g., covering objects and face for the child to rediscover) or following the child's lead. Observations were recorded in note form detailing the child's use of communicative modalities, vocabulary and pragmatics as well as their contribution to the discourse. The local assets of the homestead were identified using a standard format that was completed with the caregiver and supplemented by observations. This information yielded information about the interests of the child, activities and occupations of family members, the availability of key family members for communication, the facilities in the home and other people in the neighbourhood. This informed the development of intervention activities, and especially the identification of vocabulary to be used in intervention activities, with respect to people, objects, events, and activities.

### *Intervention*

The design and content of each participant's intervention focused on the developing child in the natural context

(Granlund et al., 2008; Simeonsson, Björck-Åkesson, & Lollar, 2012). The completed CP-A recorded observations of the child and assets of the homestead informed the content of the intervention. Individual goals were tailored to each child's activities and participation as determined by the CP-A. The preferred modalities of communication and any materials to be used were identified, and information was provided on targeted lexical content and communicative functions. The main caregiver was viewed as the agent for change, occupying a pivotal role in the implementation of the intervention.

Based on Nakajima's (1985) three maxims, cited by Alant (2005), the intervention needed to be (a) technically valid such that it was amenable to caregiver implementation in the home context, (b) economically feasible (only low-technology options were used that required neither power supply, nor technical expertise for use and maintenance), and (c) socially and culturally acceptable (the content of the intervention was negotiated with the main caregiver and locally sourced materials were used).

Five main approaches were identified for implementation with the participants. Each approach was tailored to the individual in context. Objects of reference, defined as objects to which particular meanings have been assigned (Ockleford, 1994; Park, 1997), were used by four participants (Participants 1, 5, 7 and 10). Participants 7 and 10 used an object board, that is, a carpet-covered board to which the objects of reference were attached with loop fasteners. Participants 1 and 5 used freestanding objects that were stored in a box. Two participants (Participants 6 and 9) were introduced to total communication, a communication approach that is commonly used with children with hearing impairment (Mayer & Lowenbraun, 1990), and that emphasizes the flexible use of communication across modalities. Participant 3 used two communication boards displaying pictorial representations of important people, things and activities. The first board showed photographs of important people in Participant 3's life. The second displayed picture communication symbols representing core vocabulary (e.g., subject pronouns, verbs, adjectives) that could be used in combination with fringe items (e.g., food items) (see Latham, 2005). It was devised using the software package Boardmaker™ (Mayer-Johnson, 1981–2008). Participant 8 was introduced to the Picture Exchange Communication System (PECS) (Bondy & Frost, 1994) using pictures cut out of the packaging of food items purchased at the local supermarket. He was trained to exchange these pictures for things he wanted through repeated opportunities. Participant 2 and her caregivers were introduced to a sensory approach based on the principles of Intensive Interaction (Nind & Hewett, 1994). Sensory materials were chosen for their interest value to the child, for use in interactive play (e.g., a fan for wafting air, cream to rub into hands and feet). The caregiver was taught to follow the child's behavioral lead, shap-

ing their responses into interactional sequences. The intervention plans for each participant are summarized in Table II.

The AAC materials were supplied to each caregiver during a home visit that lasted approximately 60–90 min and which included a demonstration of how to use the materials with the child, supported by a verbal explanation. The caregiver was encouraged to try communicating with the child in a similar way. Feedback on the positive aspects of the resultant interaction was given. The intervention was carried out for a period of 6 months. Caregivers were advised to practise communication with the child many times a day or as their individual circumstances permitted. In order to track progress and to reassert the intervention principles, monthly monitoring visits were carried out, each lasting between 40 and 60 minutes. Each visit followed a similar structure. The main caregiver was asked a series of questions and their responses were recorded in note form:

- (1) How have you been communicating with (child's name)?
- (2) How has (child's name) been communicating with you and other members of the family?
- (3) What things have changed with (child's name) communication since the last visit?
- (4) What things continue to be difficult since the last visit?
- (6). Are there any new things you want to try communicating about?

Based on the caregiver responses, adjustments were made to the individual therapy plan.

Topics raised by caregivers at the monitoring visits included their observations of what the child could do communicatively, particularly any new behaviors of note, activities engaged in and personal requests for new items for communication.

### Analyses

We provide information on the scores obtained using our modified version of the CP-A with the understanding that at present there is only limited information available on its reliability and validity as a tool for measuring change in parent perceptions. However, we share this information in the belief that reporting data such as that described here makes an important contribution to the refinement of existing tools and the development of new ones.

The scores for each Section and sub-section of the CP-A were entered into a prepared spreadsheet. Using the Statistical Package for the Social Sciences (SPSS-18), the non-parametric Wilcoxon's signed-rank test was applied to Sections 1 (Body Structure and Function) and 2 (Activities) only. The results of Section 3 (Participation) were recorded in text that was entered into an Excel spreadsheet as qualitative data. New evidence of participation at post-intervention assessment was compared with pre-intervention data.

### Results

Parent ratings for the child's reported competence in Body Structure and Function was significantly higher at post-intervention assessment ( $Mdn = 69$ ) than at baseline ( $Mdn = 44$ ),  $Z = -2.316$ ,  $p = <.02$ ,  $r = -.5$ . Parent perception of the child's degree of problem in Activities for communication was significantly higher post the intervention period ( $Mdn = 50$ ) than at baseline ( $Mdn = 30$ ),  $Z = -2.547$ ,  $p = <.008$ ,  $r = -.6$ . Pre- and post-assessment of Sections 1 and 2 revealed large effects ( $r$ ) accounting for 25% of the variance. Table III shows the parent ratings for individual participants on Sections 1 and 2 of the CP-A. While variance in individual scores and the degree of reported change pre- to post-intervention is noted; there is evidence of a positive change in parental perceptions of each child, with the exceptions of Participant 10 in Section 1 and Participant 2 in Section 2.

Table IV summarizes the caregiver responses about the child's participation in relation to the number of outings per week, the places visited and the people seen. Frequency of opportunities was reported to have increased for four of the participants, with no difference in the remainder ( $n = 5$ ). Among this latter group, however, three caregivers identified new places to visit with the children on a weekly basis. Extrinsic factors focused on time availability, information needs and support. Time was viewed as a critical factor in the child's participation with four caregivers stating that they had enough time to support their child post-intervention.

### Discussion

The results appear to provide some initial evidence that the parents viewed their children differently (as reflected in parent ratings and interview data) following the intervention. Why did the caregivers view their children differently post-intervention? Correspondence is made to the qualitative aspect of the study reported by Gona et al. (2013), which focused on pre- and post-intervention interviews with the caregivers. It is unlikely, with regard to Section 1 of the Communication Profile, that actual change to the child's Body structure and function in areas such as hearing or seeing took place. However, there appears to be some evidence that caregiver perception of the child was altered, such that identified deficits were perceived as less severe and communication activities were viewed as more prevalent. Belief in the power of the intervention may be a factor. The expectation was for the child to improve, which may have influenced higher ratings of the child's abilities and communication skills by the caregiver. Gona et al. (2013) describe another aspect of the intervention reported in this manuscript, and provided detailed information on the caregiver's experiences. In that paper, it was reported that more than one caregiver attributed change in the child's condition to the intervention described here. Their use of affirmative



Table II. Intervention Devised for each Participant.

Participant	Approach	Goal(s) for child attainment	Communication opportunities	Targeted vocabulary (corresponding objects/items as appropriate)	Materials to be used
1	Objects of reference	To request the thing he wants by responding to a yes/no choice when offered either one or a pair of real life objects	Use of eye gaze (L-R) to identify preferred object held up by Mother, which mother then uses with him	Drink/no drink (cup), food/no food (bowl), comb hair/no comb hair (comb), wipe face/no wipe face (face cloth), play/no play (shaker)	Box containing everyday objects
2	Intensive interaction using multi-sensory stimulation	To engage in socially interactive play with mother, father and familiar others at home	Playful interactions between child and parents using multi-sensory material accompanied by babble play approximating "Mama" and "Baba"; parents watch naturally occurring behaviours of child and imitate them	Babble play: Mama (mum) and Baba (dad)	Multi-sensory objects (e.g., cloth, mirror, body lotion, fan) to use in interactions
3	Pictorial communication board(s)	To communicate basic needs and to tell his family about things that have happened or people he has seen	Use of gestural point to pictures displayed. Mother points to items and looks at P3 with questioning gaze to see if he can relate it to the environment (e.g., persons present/absent, or to an event)	Vocabulary used (Mama, Baba, family members, drink, food, sleep, happy, sad, me, want, like, go, no, yes, school, bed, food, drink, fruit, shop, neighbours)	Two communication boards: (a) photographs of Participant 3 and all the familiar people in his life, and (b) line drawings for vocabulary using board maker
5	Objects of reference	To communicate basic needs and to engage in socially interactive play with familiar people	Use of eye gaze and giving/receiving objects during basic exploration activity of objects in box (e.g., use of face cloth, making sound with shaker); selection of appropriate object by mother to indicate daily event (e.g., time for a drink)	Drink (cup), food (bowl), comb, bathe (face cloth), play (shaker toy), look (mirror)	Box containing everyday objects
6	Total communication	To expand communicative vocabulary and to use a range of expressive functions	Imitation of spoken and signed naming of objects, people and actions in the environment by mother followed by focal practice of items with mirror.	Vocabulary used in daily routines (e.g., duck, dog, chicken, goat, cow, water, bicycle, house, washing, food, drink, mobile phone)	Large mirror to provide visual feedback in speech practice. Signs drawn from Kenyan Sign Language
7	Objects of reference	To communicate basic needs and simple choices	Use of hands to remove items (attached with loop fasteners) and give to "Mama"	Drink (cup), food (bowl), comb, face cloth (bathe), play (shaker toy), look (small mirror)	Every day object board covered in carpet and displaying items attached with loop fasteners
8	Picture Exchange Communication System	To communicate basic needs	Selects and gives picture item to receive the desired item from Mama (e.g., pieces of sliced mango). Trial is repeated several times.	Vocabulary used (drink, juice, milk, crisps, biscuits, banana, apple, mango, biscuit)	Picture tokens of items
9	Total communication	To build functional vocabulary to support expressive language	Family members in the homestead use signs with speech to label items, actions and events in the homestead and to support a range of communicative functions	Vocabulary relevant to homestead (e.g., food, writing, goat, cow, duck, chicken, water, bicycle, coconut, house, bed, drink)	Kenyan sign language core vocabulary of everyday objects, actions and events
10	Objects of reference	To communicate basic needs and to interact socially	Use of arm-hand to remove items from the object board and give to "Mama"	Drink (cup), food (bowl), comb, bathe (face cloth), play (shaker toy), play/look (mirror)	Every day object board covered in carpet and displaying items attached with loop fasteners

Note. Participant 4 withdrew from study.

Table III. Parent Ratings for the Child's Reported Competence: Section 1, Body Structure and Function, and Section 2, Activities.

Participants	Section 1 <sup>a</sup>			Section 2 <sup>b</sup>		
	Pre	Post	Difference <sup>c</sup>	Pre	Post	Difference <sup>c</sup>
P1	38	56	+ 8	18	28	+ 10
P2	34	42	+ 8	14	10	- 4
P3	34	74	+ 40	52	63	+ 11
P5	44	68	+ 24	5	34	+ 29
P6	78	79	+ 1	59	64	+ 5
P7	61	69	+ 8	25	51	+ 26
P8	40	76	+ 36	36	44	+ 8
P9	80	80	0	33	64	+ 31
P10	48	47	- 1	10	16	+ 6
Mean	50.8	65.7	13.8	28	22	13.6
Min	34	42	- 1	5	10	- 4
Max	80	80	+ 40	59	64	+ 31
SD	18	14	12.2	18.7	20.8	15.6

Note. Participant 4 withdrew from study

<sup>a</sup>The higher the score, the greater the perceived competence. <sup>b</sup>The higher the score, the less the perceived problem. <sup>c</sup>Pre- to post-intervention difference in parent reported ratings: + = a perceived gain; - = a perceived decrease. SD, standard deviation.

language to describe their children post-intervention provides further evidence of this more positive view of the child.

The intervention built on the caregiver's relationship with the child, invoking their natural expertise as primary caregiver. Whilst their insight into the child was evident in the pre-intervention interviews reported by Gona et al. (2013), it was frequently accompanied by their descriptions of personal struggle. It is possible that the intervention served both to increase parent skills, as well as increase parent confidence in their existing skills. The caregivers were instrumental in facilitating the child's strengths through the individually tailored AAC intervention. Indeed, current ways of communicating with the child as reported by the caregiver formed the foundations of the intervention. Thus it is possible that this provided a social and technical validation of role enactment by the caregiver as suggested by Granlund et al. (2008). There was also the opportunity for them to develop their skills and acquire new techniques for communicating with the child, thereby exposing what the child could do communicatively. This may have influenced a more positive parental experience similar to the findings reported by Ferm et al. (2011).

Each visit to the homestead, whether for pre- and post-intervention measure or for intervention monitoring, offered an occasion where caregivers were listened to, information was provided and helping the child was the main focus. For example, the caregiver of Participant 9 was unaware that her child had Down syndrome and early conversations served to inform, to clarify observations and to answer questions. Thus, the ongoing support afforded by the intervention process may have been a factor in how the caregivers perceived the child, which resonates with findings reported by Johnson and Hastings (2002). Certainly, a sense of well being was

expressed by the majority of the caregivers in the post-intervention interviews reported by Gona et al. (2013). This may even explain the post-intervention report by Participant 1's caregiver of greater, community acceptance of her child and greater number of people with whom to communicate.

By locating the intervention in the homestead, the natural context of child and caregiver, costs to the caregiver were kept at a minimum. Barriers commonly associated with accessing more usual urban-based facilities, for example time away from the homestead, a poor transport system and financial contribution to therapy services, were effectively averted. Interventions that make deliberate consideration of socio-economic factors have been found to have a more dramatic effect than any specific interventions (e.g., Shin et al., 2009). The home-based intervention was low-cost and immediately available in the current caregiver's role in relation to the child, with any materials for the AAC supplied. Thus active participation in an intervention that was amenable to the circumstances of the homestead may have affected caregiver well being and enabled viewing the child more positively.

The strengths of the child were the starting point of the intervention. Determined by pre-intervention observations and exploratory interactions, each child's intervention sought to extend already established communication skills to which most of the caregivers were already responding, albeit in a limited way. The intervention period invited caregivers to draw on their experience of communicating with the child, to learn some new techniques and to use particular AAC materials. Thus the intervention provided validation, not only of the caregiver as the expert and parent, but also of the child's available skills. The participants had been recruited to the project because they had no or severely limited speech, associated with four common developmental conditions, including cerebral palsy, intellectual disability, autism spectrum disorder, and hearing impairment. The introduction of communicative forms that were compatible with the child's abilities meant that success, at least in the short term, was enhanced. Consistent with Ronski et al. (2011), the use of communication modalities other than speech may have reduced pressure on caregivers simply by providing alternatives to speech. This resonates the caregivers' experiences reported by Gona et al. (2013), where the desire for "normality" (p. 35) and even a cure – exemplified by the child's ability to walk and talk – was evident at pre-intervention assessment. While the desire for normality did not disappear post-intervention, expectations appeared to be more based on reality with many caregivers referring to an "opening up" (p. 35) of their child's communication. This hypothesis is further supported by the increase in outings reported for six of the participants, with new places and additional contacts with other people being identified. The AAC materials created the relevant conditions for revealing what the child could do from the very first visit, when the imple-

Table IV. Parent Report on Section 3: Opportunities for Child's Participation and Extrinsic Factors.

Participant	Pre/post	Participation opportunities			Extrinsic factors		
		Frequency per week	Places	People	Time	Information	Community support & acceptance
1	Pre-	1–2 outings	Nothing reported	Contact with parents, siblings, neighbours, non-disabled children, family members	Not enough	Limited	Not enough people to communicate with, no acceptance of child
	Post-	No change	Goes to shop, church, market, hospital	Additional contact with teacher	Not enough	No change	Enough people to communicate with and acceptance of child
2	Pre-	6–10 outings	Goes to shop, church, visiting relatives; market, well, school, neighbours, out with children, community events, hospital	Contact with parents, siblings, neighbours, disabled children, relatives	Not enough	Enough	Enough people to communicate with, acceptance of child
3	Post-	11 + outings	No change	No change	No change	No change	No change
	Pre-	6–10 outings	Goes to shop, church, market, well, visiting neighbours, hospital	Contact with parents, siblings, neighbours, children	Limited	Enough	Enough people to communicate with, acceptance of child
5	Post-	11 + outings	No change	No change	Enough	No change	No change
	Pre-	6–10 outings	Goes to church sometimes, visiting relatives	Contact with parents, brother and sister, relatives	Limited	Enough	Enough people to communicate with, acceptance of child
6	Post-	11 + outings	In addition goes to shops, market, well, out with children, hospital	Additional contact with neighbours, non disabled children	Enough	No change	No change
	Pre-	6–10 outings	Goes to shops, church sometimes, visiting relatives, market, well; out with children, hospital	Contact with parents, brother and sister, neighbours, non disabled children, relatives	Limited	Enough	Enough people to communicate with, acceptance of child
7	Post-	11 + outings	No change	No change	Enough	No change	No change
	Pre-	0	None reported	Contact with parents, few neighbours' non disabled children, family members	Limited	Enough	Enough people to communicate with, acceptance of child
8	Post-	No change	No change	No change	Enough	No change	No change
	Pre-	6–10 outings	Goes to shop, church, visiting relatives, market, well, out with children, hospital	Contact with parents, brother and sister, neighbours, non disabled children, relatives	Limited	Enough	Enough people to communicate with, acceptance of child
9	Post-	11 + outings	No change	No change	Enough	No change	No change
	Pre-	11 + outings	Goes to shop, church, visiting relatives, market, well, out with children, hospital	Contact with parents, brother and sister, neighbours, non disabled children, relatives	Limited	Enough	Enough people to communicate with, acceptance of child
10	Post-	No change	No change	No change	Enough	No change	No change
	Pre-	0	Goes to hospital	Nothing reported	Enough	Limited	Enough people to communicate with, no acceptance of child
	Post-	No change	No change	No change		No change	No change

Note. Participant 4 withdrew from the study.

mentation was demonstrated to the caregiver and the child. It is also possible that the novelty of the materials presented an attractive focus for interactions with the child, particularly in low-income homes where material possessions were minimal.

Finally, consideration must be given to the social impact of the study. The extra attention given to the caregiver and child, brought by the initial assessment and monitoring visits, may have been a factor in the caregiver ratings of the child's communication skills post-intervention.

### Limitations

This was a pilot study with a small sample and therefore the findings cannot be generalized to the wider population with complex communication needs. The sample comprised participants who had expressed a willingness to commit time to carrying out the intervention. They were therefore motivated towards changing the existing situation from the start. Thus, any difficulties that might have arisen from this type of intervention (e.g., non-compliance), were circumscribed to a certain extent.

The CP-A was a useful tool for capturing positive transformations to the caregiver's perceptions of the child; however, it did not yield information about the child's actual communication skills in use. Observation and analysis of caregiver-child interactions would provide a more objective and direct measure of the child's communication, to be used in conjunction with caregiver ratings. The 30–40 min for administering the tool may have been affected by the repeated verbal support required by caregivers using the Ladder rating scales. Enhanced visual definition of the scale at the upper and lower ends, for example a picture representing *NONE* and *VERY SEVERE* may support improved usage by the respondent.

The AAC materials were sourced mainly through local businesses, and included labels cut out of food packaging purchased from the supermarket, communication object boards made to specification by a carpenter and objects of reference supplied by stalls in Kilifi market. However, Participant 3 required a picture-based communication board. Due to time and financial constraints the picture display had to be devised using office-based computer software and laminated for durability. This flouted the principle of using local resources. It would be preferable for any future research project to utilize a local artist to provide culturally relevant visual materials for individuals requiring graphic symbols as part of their communication intervention.

The monitoring visits were essential to maintaining the intervention process and providing ongoing support to the caregivers; however, they could have fulfilled an important recording function as well. For example, data on dosage – how much time the caregivers reported spending on the intervention with the child – could have been collected.

Finally, sustainability was not planned for in the small-scale study. This needs to be addressed strategically in any future development work.

### Conclusion and Implications

The preliminary evidence from this study suggests that a home-based intervention using AAC techniques may be associated with some positive transformations to caregivers' perceptions of children with complex communication needs and developmental disability. However, it is not possible to attribute this change to the intervention as no control group was involved. Building on assets of the homestead, the child's available skills and the caregiver's natural expertise, using relevant and locally sourced AAC materials, and focusing on home-based implementation were all key components. The intervention would benefit from further investigation, as its simplicity and potential effectiveness could form part of the skill set for community-based rehabilitation workers. The use of this strategy by community workers would mean that appropriate supports could be made available to parents and families throughout low-income countries.

### Acknowledgements

We would like to thank the Director of Kenya Medical Research Institute for permission to publish the data. We would also like to thank the Educational Assessment and Resource team in Kilifi. Most importantly we would like to express our appreciation for the involvement of the mothers, their children and other family members who participated in this study.

**Declaration of interest:** The authors report no conflict of interest. The authors alone are responsible for the content and writing of this paper.

This work was supported by the C.P. Trust (UK) and the KEMRI/Wellcome Trust research programme. Charles R. Newton is supported by Wellcome Trust, UK.

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